"Hope Amidst Uncertainty"- Parents' Experiences During Their Children Stayed in Pediatric Intensive Care Unit with Respiratory Failure: A Qualitative Phenomenology Study

Nisachon Sangsuk[1]*, Watcharawan Wongkruasorn[1], Kanokwan Pethsuwan[2], Jidapa Poogpan[1]

[1] Faculty of Nursing, Mahasarakham University, Thailand
[2] Mahasarakham Hospital, Thailand

Abstract

Background: The hope of parents was vital, especially in the context of children's high risk of mortality due to respiratory failure.
Purpose: To discover how parents hoped with children who had respiratory failure in pediatric intensive care unit of a general hospital located in northeastern, Thailand.
Methods: This qualitative research method was based on Heideggerian hermeneutic phenomenology. Participants were purposively chosen. A semi-structured interview guide was used to keep focus during the interviews. The 12 participants were recruited by the principle of data saturation. Lifeworld's approach of van Manen concept used for data analysis. Lincoln and Guba's criteria were used in approaching trustworthiness.
Results: This study found 8 main themes: Lived body: 1) Blaming my lateness, hopefully recovery. 2) Comforting myself, come to terms with the truth (Tum jai). Lived space: 3) Floating in the dark, death was imminent, hopefully hospital discharge. Lived Time: 4) Waiting was torturous, every second counts. Lived relation: 5) Requiring humanized care. 6) Hoping holy things help my child heal. Lived things: 7) Enduring excruciating pain with life-saving devices. 8) Keeping a phone close at hand but not wanting to hear its call.
Conclusion: Parents depended on hope as the way to cope with uncertainty and the possibility of death. Nurses should support parents in coping with guilt, uncertainty, and despair by fostering holistic approaches, humanized care, enhanced communication, effective pain management and promoting family centered care.

Keywords: coping; guilt; hope; pain; stress; uncertainty

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Corresponding author

Nisachon Sangsuk*
Faculty of Nursing, Mahasarakham University, Khamriang Sub-District, Kantarawichai District, Mahasarakham Province, Thailand; Postal code: 44150:
Mobile phone: +66819075853,
E-mail: nisachon.c@msu.ac.th

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Introduction

In positive outcomes for individuals in good health or those suffering from severe and chronic illnesses (Paramos et al., 2023). Hope could improve the well-being of children, adolescents, and adults across all age group (Murphy, 2023). Children dealing with chronic illness gained both emotional and physical benefits from hope (Piasai et al., 2024). Conversely, hopelessness was associated with depression in children and adolescents (Liu et al., 2021). In critical illness conditions, children face higher risks of physical and functional impairment, increased invasive interventions, and symptoms of acute stress. Children who were admitted to the pediatric intensive care unit (PICU) experienced significant psychological effects. They had more emotional and behavioral problems along with poorer memory (Ko et al., 2022). During the first week of PICU admission, their family members experienced depression and would exhibit signs of post-traumatic stress disorder (Chaiyakulsil et al., 2020). Most families had disruption in their physical and mental well-being, family cohesion, and financial stability (O'Meara et al., 2022). The

worsening more the severity of children's illness conditions, the parental stress levels also increasing kept rising (Upadhyay & Parashar, 2022). Parents' greatest stressor was their children's dependence on the ventilator for breathing (Debelić et al., 2022).

In Thailand, the incidence of PICU patients using a ventilator for more than 14 days was as high as 10.9 %. Consequently, tracheostomy rates, ventilator associated pneumonia, and mortality rate by disease were 63.5%, 98%, and 34.6% (Chongcharoenyanon et al., 2023). For critically ill patients, acute respiratory failure and acute kidney injury were associated with a higher risk of hospital death (Kulvichit et al., 2022). Mortality among PICU patients was linked to vancomycin treatment and had been on mechanical ventilators and renal replacement therapy (Khangtragool et al., 2022). Extended stays in intensive care units longer than seven days were associated with social, cognitive, and physical dysfunction (Tippayawong & Chaiyakulsil, 2022). The worse serious problems their children got, the more uncertainty the parents felt. (Maneekunwong et al., 2022).

When children experienced respiratory failure in PICU, patients and their families needed hope. Despite the fact that, Thai nurses could measure hope using the Hope scale. (Inyoo & Polsook, 2021), there were notable gaps in our knowledge of parents' experiences of hope in Thai northeastern context. This research aimed to understand how parents hope with children who faced respiratory failure in PICU of a general hospital located in northeastern, Thailand. It would be useful in nursing practice to improve positive outcomes for pediatric patients and their families.

Materials and Methods

Sensitive to lifeworld exploration, the Heideggerian hermeneutic phenomenological qualitative research approach was conducted (Suddick et al., 2020). To provide insights from parents' lived experiences, this study focused on the importance of meaning, thoughts, emotion, feelings of parents when their children had respiratory failure and were on ventilators in pediatric intensive care unit.

Design

According to Van Manen's concept of lifeworld's' approach, corporeality (lived body), spatiality (lived space), temporality (lived time), relationality (lived relation) and lived things dimension were reflected the meanings of parents' live experiences of hope in study phenomena (Mac Ginty, 2024).

Participants and setting

A purposive sampling technique was used. We utilized the small samples that were adequate to address the research question of this study (Bartholomew et al., 2021). Parents who were the primary caregivers of the children with respiratory failure admitted in PICU of a general hospital in the northeastern part of Thailand served as the key informants. After obtaining permission from the hospital, researchers secured participants' consent for interviews in a private room to collect data in a relaxed setting. Participants had to be emotionally stable, willing to share their own experiences of hopes, and willing to have conversation recorded to meet the study's inclusion criteria. In accordance with exclusion criteria, they were free to leave the study at any time. The code of participants was done during the information presentation to secure their identities. The 12 participants were recruited by the principle of data saturation and none of them withdrew from the study (Table 1).

Ethical consideration

This research has been reviewed and approved by the ethics committee for research involving human subjects of Mahasarakham University, Thailand. The approval number 215-233/2024. The Helsinki declaration was used by the hospital's ethics committee to approve this study. The hospital approval number COA No. 67/042, MSKH_REC 67-02-044.

Data collection

Data was collected between April 2024 and September 2024. Using face to face in-depth interviewing technique, the researchers asked parents in the Issan and Thai dialects with open ended questions to share their experiences, feelings, and hopes in caring for children admitted in PICU with respiratory failure. Additionally, they were asked to talk about the troubles and problem-solving techniques they used when caring for children in critical conditions. Each interview lasted between 45 – 60 minutes, using a semi-structured interview guide to ensure focus (Adeoye-Olatunde & Olenik, 2021). The questions were: "When your child admitted in PICU with respiratory failure, can you describe how did you feel and what hope did you have?" Further inquiries were made based on the participants' answers and reactions during interview, including, "Could you elaborate on that?" "How did that make you feel?" "What is your viewpoint on that? "How was your experience?" "Please provide some examples of the events that occurred." "What was your involvement in that situation?". During the interviews, parents' feelings and emotions were respected by the researchers. Verbal and non-verbal responses were recorded to reveal hidden information. They were no consequences, if they wish to pause providing information. Data saturation occurred when there were no new issues in data collection from interviews and data were repeated.

Data analysis

Researchers considered the key informants' background and context as well as their real-life experiences to formulate interview questions. Following the interviewing process, researchers

Table 1. Participant’s characteristics data

Person	Sex	Age (yrs.)	Education	Occupation	Patients Relationship	patient’s age (yrs.)	Diagnosis
1	Female	40	Grade 6	Farmer	Grandmother	4	Asthma with respiratory failure
2	Female	23	Grade 9	Factory worker	Mother	4	Pneumonia with respiratory failure
3	Female	34	Grade 12	Merchant	Mother	10	Pneumonia, Duchene muscular dystrophy, post cardiac arrest
4	Female	53	Grade 4	Farmer	Grandmother	6	Pneumonia with respiratory failure, Epilepsy
5	Female	29	Grade 12	Nurse aid	Mother	7	Pneumonia with respiratory failure, Head injury
6	Female	32	Bachelor’s degree	Teacher	Mother	2 mo.	Pneumonia with diarrhea, born with meconium aspiration syndrome
7	Female	28	Grade 12	Goods truck driver	Mother	4	Pneumonia with severe asthmatic attack
8	Female	37	Grad 6	Labor	Mother	2	Pneumonia with respiratory failure
9	Female	31	Bachelor’s degree	Teacher	Mother	8 mo.	Pneumonia with respiratory failure, born preterm 25 weeks birth weight 780 gram. Bronchopulmonary dysplasia
10	Female	39	Grade 9	Housewife	Mother	5	Pneumonia with respiratory failure
11	Male	49	Grade 6	School Janitor	Grandfather	2	Pneumonia with respiratory failure
12	Female	56	Grade 4	Stay at home, raising grandchildren	Grandmother	4	Pneumonia with respiratory failure, diarrhea, born with meconium aspiration syndrome

Table 2. Themes of parents’ lived experiences

Lived existential Theme	Themes
Lived body	1. Blaming my lateness, hopefully recovery
	2. Comforting myself and coming to terms with the truth (Tum jai).
Lived space	3. Floating in the dark, death was imminent, hopefully hospital discharge
Lived Time	4. Waiting was torturous, every second counts
Lived relation	5. Requiring humanized care.
	6. Hoping holy things help my child heal.
Lived things	7. Enduring excruciating pain with life-saving devices.
	8. Keeping a phone close at hand but not wanting to hear its call.

listened to the recordings, transcribed the interviews verbatim, and read the transcripts to ensure understanding. All transcriptions were confirmed to be accurate in Thai by first and second authors. To perform qualitative analysis, several codes were allowed for the interpretation of data. The data was analyzed, reduction, reflection, interpretation, and categorized for each the van Manen's domain by research team (Monaro et al., 2022) . The key issues that came up were identified and synthesized the words and sentences that reflect the meaning as themes. Significant themes were interpreted to understand the lived experiences of parents of the study phenomena. The study phenomena findings were examined by an experienced qualitative researcher to reduce bias for validity and consistency. (Hemming et al., 2021). Finally, English translation was carried out after the discovered of every quote explaining the themes.

Trustworthiness

The researchers used Lincoln and Guba's criteria in approaching trustworthiness (Stahl & King, 2020). For creditability, the third author, who is a PICU senior nurse researchers established rapport and trust with participants prior to interviews. The first and third authors Researchers prolonged engagement and persistent observations in the research context. During the interviews, the accuracy of information was verified by using reverse questions to determine whether the informants and the researchers share the same understanding and summarizing throughout the conversation. Data was systematically recorded and verbatim transcribed. Transcripts and field notes were clearly recorded, coded and references checkable for confirmability by the research team. For dependability, peer debriefing and member checking were designed to guarantee data accuracy. To reduce the bias, the first and fourth authors, who had experiences in qualitative research, examined the study phenomena findings for validity and consistency. For transferability, researchers realistically explored the parents' experiences when their children were admitted in PICU with respiratory failure whether the research findings can be applied to similar context.

Results

The participants included mothers, grandmothers, and just one grandfather. They served as main caregivers for the children admitted to PICU with respiratory failure in the study context. Table 1 presents their characteristics. According to the experiences of parents, the findings were grouped into 8 themes presented in table 2.

Lived body

Parents reflected the meaning of their own world about their mind, body, emotions and spirit on their experiences when their children were admitted to PICU due to respiratory failure as follows:

Theme 1: Blaming my lateness, hopefully recovery.

The parents addressed their own feelings of inadequacy in caring for children. They were guilty of arriving at the hospital too late, which led to the children using the endotracheal tube with ventilators. They hope for their children to recover as shown in the following statement:

"I blamed myself. Why didn't I bring my child to see the doctor earlier? My child felt like a chest tight, but I didn't know the disease. I didn't know how to do. I didn't want her to be like this. I very worried about serious condition, but on the other hand I hope for my child's recovery." (Person 1)

"(Cry) I feel disheartened and blame myself, I am not good at caring. Why did I wait until the illness was serious? I blame myself. I should have noticed that something was wrong with my child. The endotracheal tube was not used if I hurried 2 days earlier. My husband said it was fine; our child would heal. Hopefully, the doctor will remove the respiratory tube tomorrow." (Person 8)

Theme 2: Comforting myself, come to terms with the truth (Tum jai)

Parents comforted themselves that their children must recover from the critical illness, even though they were terrified that they wouldn't. They gradually come to terms with the fact that their children's condition was serious, the procedures were painful, and the death was a possibility. They used Thai words "Tum Jai" or tried to accept truth and comforted themselves that their children were under the care of doctors and nurses. Things would improve. The statements were examples below:

"I cried and couldn't sleep. I considered my son's illness and gradually came to terms with the truth (Tum jai) that on a day in the future his heart will not beat. I told the nurses not to resuscitate. He may be in pain and suffering. It's tormented. Eventually all that lives must die. I feel tight in my chest. Look in my eyes. When that day comes, I still need my child to be alive. (Person 3)

"I've already come to terms with it (Tum jai or try to accept it). Since she was the size of a bottle, my little girl has been struggling to survive. I must be here alongside to help her." (Person 9)

"I'm anxious, but I must come to terms with the treatment. If I'm afraid of suffering, my child won't be cured. I must accept. It's the doctor's treatment plan. It's necessary for my child's recovery. I talk to myself that things will improve." (Person 10)

Lived space

Parents reflected their own world to space when their children were admitted to PICU due to respiratory failure as follows.

Theme 3: Floating in the dark, death was imminent, hopefully hospital discharge

Parents felt floating in the dark. They worried about the imminent death of their children who had life-

threatening illness housed in an intensive care unit. They hope their children to exit the intensive care unit soon and eventually be discharged from the hospital. Example of statements as follows:

“I never imagined that my child would need a breathing tube with a ventilator and be admitted to the intensive care unit. I didn’t see that coming. This visit to the ICU is the second time. I feel more depressed than last time. I feel like I’m floating. My tears are uncontrollable. All I hope for at this moment is my child’s recovery, discharge from ICU, and eventual hospital discharge.” (Person 6)

“When doctor said he must take my child to ICU, oh ICU stands for waiting to die. I feel sorrow. Noting death, will my child pass away?” (Person 12)

Lived Time

Parents expressed their emotions about time regarding their children’s admission to the pediatric intensive care unit as the following manner.

Theme 4: Waiting was torturous, every second counts.

Parents felt that every second mattered to them. Waiting was so torturous. The only thing to do was to wait, including waiting for a visit to children in the intensive care unit, waiting for the patients’ symptoms and indications to improve, waiting for the nurses and doctors to provide the information and waiting for the day to return home. The statements were shown below:

“Nurses allow parents to visit patients twice a day at noon and in the evening. I will wait to visit at noon after arriving here at 9 o’clock and I’m longing for my child while waiting outside. The time to visit my child is too brief. I worry that if he wakes up, he will feel alone.” (Person 5)

“Time is mattered to me. Every second counts, I eagerly wait for the opportunity to see my child whether it’s five minutes, an hour, or short time. It’s okay. I would like him to know mom and dad are here with him. I want to know whether he’s feeling less tired and how he’s doing. He is on my mind. I’m waiting for an ICU visit, just waiting patiently. I’m hoping he will get off the endotracheal tube, but it will take time. If my child improves, we should be able to go home in a few days.” (Person 7)

Lived relation

Parents reflected their feelings towards those around them including doctors and nurses, and supernatural beings when their children admitted in PICU with respiratory failure, as follows:

Theme 5: Requiring humanized care

Parents put their hope into nurses and doctors. They need nursing with quality care. They need not only physically support to help their children recover but also need humanized care. The statements were follows:

“I put my hope in nurses and doctors. They will help my child recover, but I couldn’t. What mom hoped would happen was that the nurses would be able to provide my child with the best care possible. In the intensive care unit, nurses look after my child instead of me. I hope they do all the same as I used to do such as comforting when she cries and save my child’s life.” (Person 6)

“I didn’t know what’s wrong with my child, but the nurses and doctors knew. My child had more secretion, they must know how to remove. They cared for and treated so many patients. My child was in the hands of nurses and doctors. If they can’t treat, then in this life, my child probably had only made this much merit.” (Person 11)

Theme 6: Hoping holy things help my child heal

For supernatural beings, parents hoped the holy objects to help their children’s recovery. They prayed and kept the deceased parents in mind to ensure their children’s safety and recover from critical illness as the statement shown below.

“I must sit cross legged down on the floor. I prayed and thought of my deceased parents. Mom and dad please support me, helping my child recover. I will provide merit. I told my brother to light incense at the Don Phi Pu Ta shrine in my home village to pray for my child’s survival. I called the spirit of my child to return and hope her to stay with me. Please don’t pass away.” (Person 4)

“I close my eyes, meditate and repeat saying “Budho” for helping my child recover from critical illness. The only things that will help me were meditation and requesting my child healing. I need my child to get better so we can return home.” (Person 12)

Lived things

Parents felt to things when their children suffered respiratory failure and were admitted to the PICU as outlined below.

Theme 7: Enduring excruciating pain with life-saving devices.

Although parents knew that inserting endotracheal tube, ventilator, and lines were the life -saving for critical ill children. They need their normal well-being children. They did not want their children to be intubated and inserted lines. They worried that the children would not survive, enduring excruciating pain.

“My heart was broken. (cry) I can’t do anything. I feel sorry for my child to be like this. Just seeing my child get bitten by ants, it hurts me. In this condition, she had the tube with respirator and full of lines on her body. It hurts me more. I want to pain instead of my child.” (Person 2)

“All I did was cry. I’m afraid my child won’t wake up. I knew that the placement of tube, ventilator and lines could save lives. But I worry that my child would be in severe pain.” (Person 5)

Theme 8: Keeping a phone close at hand but not wanting to hear its call.

Parents reflected that they must carry the phone with them all the time. They worried about hearing from the intensive care unit that their children were getting worse. They didn't want to hear the hospital calls from. If they received a call, they would head to the intensive care unit as quickly as possible.

"The phone is with me. I worry that I might miss the hospital call in the event of an emergency. My worst fear is that the phone rings at night while I'm asleep. I'm afraid of hearing from ICU that my child is dying. I get anxious about the phone ringing every day. Before he passes away, I must arrive in time for the final moment." (Person 3)

Discussion

According to the findings, we found the parent's bereavement. They reflected their grief started when their children diagnosed a life-threatening condition and moved to PICU with respiratory failure. Grief might be considered a form of learning that required time and experiential feedback (O'connor & Seeley, 2022) They cried and felt disheartened. They placed the blame on themselves, which was like their guilt. Guilt was associated with posttraumatic stress symptoms (Shi et al., 2021). Parents were guilty about not being good parents in raising their children because they felt stressed, anxious, and fearful about losing their children. When individuals had moral injury and moral distress but were not at fault, they felt guilty, self- blaming and powerlessness (Čartolovni et al., 2021). They started the questions with "Why I didn't…". These sentences demonstrated that their guilts were focused on solving problems rather than hurting themselves. If nurses allow parents to feel guilty without communicating with them, depression which had been connected to guilt may result (Luck & Luck-Sikorski, 2021) .

When individuals expected the impending loss of a loved one's death, they may feel uncertainty, fear, and sadness. Uncertainty served as a necessary source of fear and hope that were interconnected (Han et al., 2021). Hope encompassed the awareness that the desired result might not be realized. We might hope for a positive outcome while still feeling anxious that things might not turn out as we desire (Vazard, 2024). In this study context, parents comforted themselves with the hope that their children might recover from critical illness. They used positive self-talk that things would improve. They used the Thai words "Tum Jai", which signifies coming to terms with the truth or attempting to accept the treatment in PICU despite experiencing pain and suffer. They felt like floating in the dark because death was imminent when their child had respiratory failure. Floating in the dark symbolized various emotions experienced by parents of children admitted to PICU such as feeling lost, distress, hopelessness, and helplessness (Kichu et al., 2024).

In the study context, waiting was so torturous and every second counts for parents. Waiting frequently had a negative impact on them and resulted in their distress. While waiting could not be completely avoided, family centered care, together with the warm and comforting hospital environment, could help ease the stress for family members of patients in PICU. They needed humanized care for their children and wished for nurses to deliver exceptional nursing care to critically ill children by employing a holistic approach such as comforting children when they cried, just like their mothers did. In addition, they needed nurses and physicians to assist their children in healing. When caring for critical ill children in the PICU, nurses typically prioritized clinical outcomes, patient safety, and basic care requirements (Danielis et al., 2021). Nurses should be sensitive to parents' perceived level of satisfaction, either. Parental satisfaction would increase due to care and cure, communication and parental involvement (Cintra et al., 2022). Communication posed a significant challenge for nurses in supporting patients and their families and reducing stressors during difficult life experiences (Tager et al., 2024).

In this research, parents hope for holy objects to protect their children and help in healing. Offering spiritual support to families was essential in critical care environment (Stevens et al., 2024). Spirituality and beliefs in religion were vital when coping and making decision (Nageswaran et al., 2022). The research participants utilized meditation as a mindfulness technique, allowing them to concentrate on the present rather than worry about the stressors. Mindfulness practices helped individuals cope with stress by reducing biological and behavioral responses to stress and by lessening emotional reactions to stressors (Grossman, 2022).

Parents sensed their children suffered from tubes, lines, ventilators, and life-saving devices. Severe pain was the most frequent occurrence in critically ill patients. Even though they required pain management for their children, they were worried about their children's unconsciousness. Thus effective assessment and management of pain not only benefited the child by symptom relief and improving quality of life, but also enhance well-being of the families that nurses should concerned (Grunauer et al., 2021).

In the end, parents kept the mobile phone close at their hands but did not want to hear its call. They were anxious about the phone call from PICU informing them that their children were either nearing death or facing worsening conditions. They hoped to be with their children in PICU as soon as they got a call. For patients and their families, hope is essential. It had a favorable impact on their body-mind and emotions. Nurse should increase patient's hope by encouraging their inner resources, pleasant experiences, and emotional support (Piasai et al., 2024). For parents, hope was the way to cope with the situation linked to the possibility of death, an unpredictable situation. Hope was related to the

survival of children in any way, irrespective of the experts’ statements and the reality they face. Nurses should support families in facing these situations (Cabeça & Melo, 2020).

Limitation of the study

The limitation of from this study was that it focused on the parent’s hope only during the time their children stayed in PICU may have limited its ability to capture how hope changed over time following recovery and discharge, necessitating a longitudinal approach.

Conclusion

When parents witnessed, their children being admitted to PICU due to respiratory failure, they experienced feeling grief, stress, anxiety, and fear of losing their children, which made them felt guilty. Uncertainty arose when they were afraid of losing. Despair and powerlessness were their feelings drifting in the darkness. The wait was incredibly agonizing for them. Parents relied on hope as a mean to handle uncertain situations and the prospect of death. Mindful practice, faith and spirituality assisted them in managing with stress. When supporting patients and their families, nurses should adopt a safe space to express their feelings without judgement, use deep listening techniques and build trusting relationships, help them to express their needs and concerns, provide information and promote shared decision-making, and encourage positive coping mechanism.

Declaration of Interest

The authors confirm that there was no conflict of interest, and no competing financial interest could have influenced any of the work mentioned in this article.

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Data Availability

The data that originated from the participants’ explanation during the interviews can be provided by the corresponding author.

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