



Responses and Expectations of Parents with Children Experiencing Emergencies due to Terminal Illnesses: A Phenomenological Study

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ABSTRACT

Background: Terminal illnesses can happen to anyone, and children are no exception. This kind of illness is very close to an emergency. The role of the family is significant, primarily if the disease occurs in a child. This terminal disease is fatal, so an emergency approach can be taken. An *emergency* is related to a disease or other condition that can threaten life.

Study Design: Qualitative research was conducted using a phenomenological approach to discover parents' perceptions when caring for children suffering from terminal illnesses. Terminal illness suffered by children with emergency conditions is the focus of the research. The research was conducted on 10 participants from patients suffering from terminal illnesses in the Pediatric Ward of Dr. Kariadi Hospital.

Results: In-depth interviews with participants found three main themes: 1) parents' response when their child was diagnosed with cancer; 2) the spiritual response of parents caring for children with cancer; and 3) the hope of parents for healing. Parents' expectations are a parent's "fuel" for children with terminal illnesses. Parents' expectations have a negative correlation with all parental psychological pressures. The higher the parents' expectations, the more psychological pressure they will feel.

Conclusion: The role of parents is very important in the lives of children, especially in children who suffer from terminal illnesses and experience emergencies. The closeness and support of parents help children get through difficult circumstances.

KEYWORDS *Terminal Illness; Parents; Children Experiencing Emergencies*



INTRODUCTION

Terminal disease means that the patient does not have the opportunity to recover. This process, in theory, reduces the patient's physical performance and the psychosocial and spiritual changes experienced by the patient or family (Ministry of Health of the Republic of Indonesia, 2022). This disease requires a comprehensive palliative approach to treat patients and families holistically¹. The role of the family is significant, primarily if the disease occurs in a child. This terminal disease is fatal, so an emergency approach can be taken.

The physical problems experienced by children diagnosed with cancer include paleness, bruises on the body, nosebleeds, bone pain, painless lumps, white and protruding eyes causing swelling or enlargement in the stomach, and even emergency conditions. In contrast, the psychological symptoms experienced are stress and changes to the child's daily activities and the social system, such as health care, school, friendship, and family relationships². Children with terminal illnesses often experience problems such as severe pain. This can directly traumatize the child³.

Adverse circumstances leading to emergencies can arise for children with terminal illnesses. Emergency care is a concept of an approach that must be taken as quickly as possible to prevent death or permanent disability^{4,5}. Although the concept of emergency is often contradicted by the concept of terminal illness, in reality, emergencies often occur in patients with terminal illnesses. Nurses need to provide emergency services to patients with terminal illnesses to provide a sense of comfort or according to their wishes. Beneficence, nonmaleficence, and autonomy are the basic ethics that nurses always hold in providing care for terminal patients in the emergency department⁶. One of the impacts of the high mortality rate due to pediatric cancer, which reaches 50–60 percent, is that patients arrive late or are already in an advanced stage due to cancer symptoms that are difficult to detect⁷.

Children with terminal illnesses in emergencies require high levels of treatment and complexity. Children's cultural approach and emotional responses often create a disconnect with the concept of emergency care by nurses⁸. These differences, directly or indirectly, will lead to different experiences, especially for parents. Mothers will experience fear, loss, and even depression. Parents feel very responsible for the child's entire condition, whether there is social support or not. Parents of children with terminal illnesses will experience emotional pressure. Plus, children are approaching an emergency, adding to the psychological pressure on parents⁹. Not only mothers, but fathers, when they find out that their children have been diagnosed with a terminal illness, have a variety of responses. Fathers will see the event



differently when compared to mothers. Fathers feel that the world has turned around, the father's negative response because his child will die, and the desire to play a role in the healing process of his child ¹⁰.

For parents, their children are their future, which must be preserved. When a child has a terminal illness, confusion and psychosocial stress are very high. Parents of children with terminal illnesses frequently experience anxiety about losing their children, sadness, and uncertain situations ¹¹. Many previous studies have reviewed the psychological aspects of parents who have children with terminal illnesses, but not many studies have examined the experiences of parents of children with terminal illnesses in emergencies. However, there is still no research that reviews the experience of parents in emergency care with children suffering from terminal illnesses. The purpose of this study is to explore parents' responses to emergency care for children with terminal illnesses.

METHODOLOGY

Design

We conducted qualitative research using a phenomenological approach to understand parents' perceptions of children with terminal illnesses, particularly during emergencies. In more detail, this study was conducted to explore parents' experiences, parents' feelings, obstacles in caring for their child, and parents' hopes in caring for a child with a terminal illness during an emergency situation. The study employed in-depth interviews as the data collection method, and the Colaizzi method was used for data analysis.

Research question

What is the parent's perception regarding a child's emergency with a terminal illness?

Samples and settings

The research was conducted in the pediatric disease ward on the ground floor and 1st floor of Dr. Kariadi Semarang hospital between March and August 2023. Participants were parents with inclusion criteria, namely as parents of children with terminal illnesses, children aged 0–15 years; participant children had experienced and dealt with emergencies. The exclusion criterion in this study was that participants experienced communication barriers. The research has undergone ethical testing at the Ethics Commission of Dr. Kariadi Hospital with ethics letter number 1449/EC/KEPK-RSDK/2023.



Instruments

In qualitative research, the researcher himself is the main instrument. Researchers must have independence, so it is necessary to do bracketing within the researcher to prevent the mixing of the researcher's assumptions with the participants' answers when conducting interviews (Prihanto et al., 2018). Researchers develop interview guidelines as a reference when conducting in-depth interviews with participants. The researchers used data triangulation by utilizing various data sources to verify the findings. The data used includes interview transcripts from the patients' parents. The researcher also confirmed the data directly with the patient and with the nurse who treated the patient. The data analysis also used additional data, such as treatment history records, as supplementary information.

Data Collection

Data collection began with participants visiting the children's ward at Dr. Kariadi Hospital to coordinate with the nurses. Researchers discussed with nurses the appropriate participants in the research. The nurse recommended, and the researcher will meet with potential participants to explain the research objectives and get consent to participate in this study. Researchers prepared a conducive and supportive environment and interview tools such as recorders, filed notes, and documentation. Researchers asked opening questions such as "How are you?" "How is today?" and others. After that, the researcher asked open questions according to the core topic of the interview to be studied. The researcher asked questions using an interview guide according to the question point. The questions did not come from the interview topics or guidelines; the researcher recorded all verbal and non-verbal responses.

Analysis data

Data analysis uses the Colaizzi method as follows: 1) Have a clear picture of the phenomenon to be studied; 2) The results were recorded after interviewing the participants and perform transcriptions by changing the recorded dialogue into written form verbatim. The transcription was carried out after the interview with one participant was completed and before starting the interview with another participant. 3) Read the transcripts repeatedly from all participants so that the researcher better understands the participants' questions; 4) Read the transcript to obtain critical words from each participant's statement, which are then underlined on the essential statements so that they can be grouped; 5) Determine the meaning of each important statement from all participants; 6) Grouping data into various categories and determining the main themes that emerge 7) Researchers integrate the overall results into



narrative form; 8) The researcher returns to the participants to clarify the data from the interviews and provides an opportunity to add information that has not been obtained from the participants at the time of the interview or that does not want to be published in the research; 9) Refine the analysis results with data obtained during the validation process.

Ethical Considerations

Qualitative research conducts in-depth interviews without carrying out any intervention with the participants. Each potential participant will be informed about the form of research and given consent. Participants were free to accept or refuse to participate in this research. The disadvantage that participants will experience is a delay of 30–60 minutes during the interview process. The researcher gave a memento as a gratitude for agreeing to participate in this research.

RESULTS

The research was conducted on 10 participants, namely parents of patients suffering from terminal illnesses in the Children's Ward at Dr. Kariadi Hospital. In-depth interviews with participants found three main themes: 1) parents' response when their child was diagnosed with cancer; 2) the spiritual response of parents caring for children with cancer; and 3) the hope of parents for healing. These three research themes are divided into several sub-themes, as follows:

Parents' Responses When Children Are Diagnosed with Cancer

This theme has three sub-themes, namely:

Deep sadness when a child gets a cancer diagnosis;

Feeling sad when a child is diagnosed with cancer with the following participant statements:

"Feeling completely shattered, I don't know..."(P1)

Participants stated that they felt devastated after learning that their child had been diagnosed with cancer. Apart from that, participant 4 expressed his painful feelings as follows:

"yes, it hurts emotionally..."(P4)

Some participants expressed deep sadness, and the 3rd participant had mixed feelings as follows.:

"My feelings are all mixed up and chaotic...." (P3)

Feelings of compassion as a parent

The feelings of compassion for parents to see their child have cancer as stated by participant 4 are as follows:



“...At the beginning, it was hard to bear, wondering why such a small child was given a disease like this.”(P4)

Did not think his son had cancer

Parents never think their child will get cancer, as stated by 6th participant as follows:

“As if his life was being taken away because he never thought about it...(P6)

Participants who stated that they never thought negatively about children's health, as stated by 8th participant, were as follows:

“No, we initially didn't have any negative thoughts about it (Leukemia). Well, as parents, we don't think that way....”(P2)

Spiritual responses of parents caring for children with cancer

The second theme is the spiritual response of parents in caring for children with cancer, which has two sub-themes as follows:

Surrender to God for help

One of the spiritual responses of the participants was by praying and surrendering to the creator as stated by 9th participant as follows:

“Struggle together between parents and children, don't forget to pray.” The rest, I leave to the Creator...”(P9)

Participants believe that God will certainly provide help as stated by 10th participant as follows:

“Even though it's tough, my wife and I are sure that God will not give us a trial beyond our ability...”(P10)

Sincerity and Endeavor

Parents try to be sincere and try to find the best treatment as said by 2nd participant as follows:

“From there, we are sincere and make more effort according to the treatment....”(P2)

Parents hope is healing

The third theme in this research is parents' hope for recovery and has two sub-themes as follows:

The parents' hope is that the child gets the best treatment, so they can be together again

Parents have a strong hope that they will recover quickly, as stated by 1st participant as follows:

“...so thank God I found the right person (doctor) to guide me, hopefully with quick assistance the chance of recovery will be greater” (p1)



Parents hope that their child can recover as before, as stated by 4th participant as follows:

"My feeling is that I hope to recover quickly to how I was before..." (p4)

Participants also have hope to get good treatment and recover quickly as stated by 6th participant as follows:

"Our hope here is to receive good treatment according to procedures and protocols that will result in my child being completely healed..." (P6)

Parents have hope that they can recover and gather with their families, as stated by 8th participant as follows:

"I want to get better, basically to get better and be able to gather with family.." (P3)

Cancer patients hope to be cured

Participants have the wish that their children recover and be able to achieve their goals as stated by 5th participant as follows:

"want to get better (the participant's child)_ if he gets better when he grows up, he wants to become a police officer..." (P5)

DISCUSSIONS

As parents, when they found out that their child has been diagnosed with a terminal illness, they will have a variety of responses. Children suffering from terminal illnesses will depend more on adults, including caregiving, monitoring, and providing health care ¹². The participating children and parents must respond optimistically to their child's illness ¹³. Parental responses with positive thinking can be achieved by paying close attention to the child and prioritizing the child's communication. Parents also need to motivate children to increase their self-confidence as a form of positive reinforcement ¹⁴.

The complex response is when parents learn that their child has a terminal illness. They often find themselves trapped in difficult situations such as sadness, empathy, anger, and feelings of guilt. Parents often find themselves caught in moments of gratitude and deep understanding of their child's situation. The negative traits that parents possess, such as identity crises, often emerge in parents in such situations ^{15,16}.

The responses of parents of patients with terminal illnesses are quite diverse, such as feelings of surrender to God. Sincerity and sincerity in supporting their children spiritually are also practiced by parents. Parents always carry out continuous spiritual support during emergencies. As a very religious country, spiritual approaches during emergencies are always taken by participants to support the child's recovery. Spirituality provides important support



for parents, helping them cope with this devastating experience by providing hope and assisting in the search for meaning and purpose in life. On the other hand, spirituality helps parents accept their inability to protect their child from life-threatening illness, provides guidance, and supports emotional decompression^{17,18}.

Parents often experience an initial reaction in the form of shock, anxiety, or rejection when they learn that their child has a terminal illness. However, sooner or later, parents accept circumstances as something that must be passed on. This circumstance is a parental learning process in psychological maturity¹⁹. Parents who discover their child has cancer tend to increase emotional-focused coping pressure and seek excellent social support²⁰.

Patients with terminal illnesses require palliative care to provide comfort and improve their quality of life. Providing palliative care is carried out by reviewing various scientific disciplines to provide services that are physical, biological, psychological, spiritual, and even cultural²¹. Emergency care in palliative care is contradictory because the focus of emergency care is to save lives, whereas, in palliative care, it is to provide comfort without prolonging life. So, the focus of emergency services in the palliative sector is to provide services according to the wishes of participants and patients, who always adhere to the principles of beneficence, nonmaleficence, and autonomy.

Emergency care for children does require a different approach. Parents, as the main person in charge, must be involved to provide comfort for the child. Because it is essential to remember that terminal illnesses children suffer require long-term treatment, involving parents is very important for treatment^{22,23}.

For Indonesians, the spiritual dimension is significant. Parents who know that their child is suffering from a terminal illness will improve their spirituality coping system by praying²⁴. Most children seek God and/or a higher power by praying to a higher being to feel better, get out of the hospital, and care for family and friends²⁵.

Parents' expectations are a parent's "fuel" for children with terminal illnesses. Parents' expectations have a negative correlation with all parental psychological pressures. The higher the parents' expectations, the more psychological pressure they will feel²⁶.

CONCLUSION

For children with terminal illnesses, parental support is very important for the patient. The child greatly needs physical, emotional, and spiritual support to get through difficult times. Moreover, during an emergency situation, parents play a very important role in helping their



children get through it. As parents, it is very important to accompany children in difficult situations during the treatment process. Nurses need to provide space for parents accompanying children undergoing terminal illness treatment. Providing space for closeness between parents and children also requires the support of the family and community.



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