Original Research

The Description of Parents with Children Suffering from Cancer during Encountering Emergency: A Qualitative Descriptive Study

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Article Info

Abstract

Introduction: Cancer is a chronic disease caused by abnormal cell growth in the body and can affect all ages, including children. Children with cancer are very vulnerable because they experience growth and development, so they need special attention, especially in emergencies, to avoid death and complications. This study aimed to describe parents’ perceptions of having children with cancer when the child is in a crisis.

Methods: This research design used a qualitative descriptive approach. This study's population was parents with cancer children with sampling using purposive sampling. Data collection through in-depth interview techniques (in-depth interview) using a recorder, field notes, and interview guidelines. Research data in conversation transcripts were analyzed using Colaizzi's method.

Results: Five themes developed, including 1) the participant's understanding of the emergency in pediatric cancer, 2) efforts made by participants in caring for children with cancer, 3) participants' experience in managing and treating children with cancer, 4) challenges in treatment, and 5) participants' expectations in the treatment carried out by their children. The experience obtained by participants is a feeling of fear of worsening the situation and negative thoughts that arise & impact the participants' psychology. In addition, the challenges experienced by participants are the cost of traveling the distance between health facilities and residence. Behind it all, participants hope their children will recover from cancer.

Conclusion: There is a lack of understanding of parents regarding emergencies in cancer; behind that, there are efforts made, such as efforts to treat children with cancer, struggles to care for children with cancer, and spiritual aspects.

Keywords: neoplasms, emergency, parent, child

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INTRODUCTION

Cancer is a chronic disease caused by abnormal cell growth in the human body. Malignant tumors can affect people of all ages, including children. About 10% of these diseases in children are caused by genetic mutations; the other causes are unknown with certainty [1]. Cancer is the leading cause of death for children and adolescents worldwide. Patients with cancer experience various physical and psychological problems that will impact the quality of life of patients, especially pediatric patients [2]. Pediatric cancer tends to be different from adult cancer and is more complex; cancer in children tends to be more challenging to detect because children generally cannot express their feelings [3].

According to WHO, the definition of a child is the age limit between 0-19 years. Childhood is when an individual's personality is formed to determine their growth and development. Mc Cance & Huether 2018 said children, adults, and older adults could have cancer. Children with cancer will experience physical development because sufferers, especially children, will be much different from healthy children physically, psychologically, biologically, socially, and spiritually. It can be seen that the definition of cancer itself is one of the chronic diseases caused by the growth of abnormal cells of body tissues that turn into cancer cells [4]. Most childhood cancers occur without specific signs and symptoms, making it slow to detect cancer. This triggers cancer in children to be seen at an advanced stage. Cancer in children is a diagnosis for the whole family, especially parents. Because parents must feel sad, anxious, and confused about their child's condition. Parents also say they do not fully understand the cancer experienced by their children. That is why the child needs the role of parents [5].

Children are at a very vulnerable stage of individual life because they experience growth and development, so they require special attention, especially in emergencies, to avoid death and complications that hamper independence in daily activities. Handling pediatric emergencies involves coordination between various departments and professions, rapid and responsive response, traceable systems, and adequate resources [6]. A child diagnosed with cancer undergoes several long and painful procedures. During a cancer hospital stay, children and parents may experience various events, especially medical emergencies or interventions that studies have found to be highly traumatic and disruptive experiences [5].

According to the World Health Organization (2018), about 300,000 children aged 0 to 19 years have cancer yearly, and about 90,000 children die from cancer [2]. Based on the Cancer Registration System in Indonesia (SriKanDi) in 2005-2007, the assumed incidence of cancer in children 0-17 years is 9 per 100,000 children, or among 100,000 children, there are nine who have cancer. In children aged 0-5 years, the incidence rate is higher at 18 per 100,000, while in children aged 5-14 years, it is 10 per 100,000 [7]. According to a pediatrician from the Hematology-Oncology division of Dr. Kariadi Hospital, Semarang, Ariawan said that children with suspicious physical symptoms
should not be ignored. It could be an early symptom of cancer in children [8].

A person who has cancer, especially a child, must face not only physical problems but psychological and social problems as well. Therefore, parents’ role is vital and not accessible because parents also experience these impacts when the baby is diagnosed with cancer. Physical issues experienced by children diagnosed with cancer include pallor, bruising on the body, nosebleeds, bone pain, painless lumps, white and prominent eyes so that swelling or enlargement in the abdomen, and even emergencies. In contrast, the psychological symptoms experienced are stress and changes in daily activities carried out by the child and for social systems such as health care, school or friendship, and family relationships [4]. The mortality rate of pediatric cancer reaches 50-60 percent because patients generally come late or are already in an advanced stage due to cancer symptoms that are difficult to detect [7]. According to the second vice chairman of the Central Java Province PKK TPK, Indah Sumarno, cancer in children is a reasonably complex problem because children still need other people to fulfill their daily needs [8].

Cancer patients are often distressed, and the first person to play a role in saving them is the family. The family’s knowledge and speed greatly influence patient safety in handling. Prahmawati (2021) explains that time is important for patient safety; the golden period is a priority in first aid, and appropriate action at that time tends to get good results [9]. Parents who care for children with cancer will provide the best for their children. Indeed, parents must recognize emergencies that children may experience because the crisis is potentially life-threatening. Emergencies experienced by children will have a negative psychological impact on parents. The negative impact can be reduced by proper psychological preparation. However, people in Indonesia often make these problems not the main issue. Therefore, parents must understand the principles and strategies to deal with the situation [10]. The purpose of this study is to explore the perceptions of parents with children with cancer when the child is in an emergency.

METHODS

This study used a qualitative and descriptive approach to explore the meaning and perceptions of parents who have children with cancer when the child is in an emergency condition. Participants in this study are parents who care for children with palliative diseases such as cancer. This study describes the family support system in caring for children with cancer, the obstacles faced in caring for children with cancer, the expectations families have of health services in caring for children with cancer, and the significance of family experiences in caring for children with cancer.

Specifically, this study describes the understanding of emergencies in children with cancer, efforts made in caring for children with cancer, experiences in managing and caring for children with cancer, challenges in care, and expectations in the care undertaken. Data were collected using a purposive sampling technique with inclusion criteria: 1) Participants are parents with children with cancer at Dr. Moewardi
Hospital, and 2) Participants cooperatively participated in this study. As well as exclusion criteria: Participants were not willing to be interviewed. Continued with data collection using in-depth interview techniques to obtain external data but not off-topic. The researcher is the main instrument in qualitative research, so he interviews all participants.

Data analysis was done by transcribing the recordings obtained in the field; then, researchers used Colaizzi's data analysis technique [11]. The transcripts were searched for significant statements and grouped into sub-themes and themes. Then, the pieces were interpreted into descriptive form and validated by participants. After the data is tested for validity, the researcher reads the results of the data analysis to the expert to ensure that the data obtained is mature.

Credibility was established through the process of reconvening with participants and analyzing the recorded data transcripts. Transferability was achieved through the comprehensive documentation of the study’s methodologies. Dependability was achieved through the proper and systematic execution of research, thorough examination of relevant literature, and meticulous analysis in accordance with the study’s objectives, ensuring that the produced results accurately reflect the true reality. Confirmability was achieved through consultation with experienced researchers, including the second and third authors. The findings were discussed, conclusions were drawn, and literature reviews were conducted to enhance data correctness.

This study was approved by the Research Ethics Committee at Dr. Moewardi Surakarta with number 893 / 5.299 / 2023. Participant information includes both the objectives and the advantages of the research. It was possible for participants to exit the study. Anonymization and protection of their data would be provided. In conclusion, the participants read the consent document on their own volition and signed it.

RESULTS

Based on Table 1, it is known that there were five female participants and one male participant. The study was conducted on parents with children suffering from cancer in the Flamboyan 9 inpatient room at Dr. Moewardi Surakarta Hospital.

Theme 1: Participants’ understanding of pediatric cancer emergencies

Parents caring for patients with cancer say several times the patient must have experienced an emergency or his condition decreased. When facing this situation, the family is confused or does not know what to do because the state of cancer patients often changes, and several times, it is usually found in life-threatening conditions where families need to understand and learn how to care for clients in life-threatening situations [12]. The first category was obtained from several participants’ statements when asked about the definition and dangers of pediatric cancer, the following statements from participants:

“I knew it was blood cancer, that’s all.”

(P3)
“At first I didn’t know, but I was diagnosed with leukemia, blood cancer, so I knew, we learned from the protocol from the doctor, and then we knew this…” (P2)

“….. is dangerous because according to what I read, the disease is not only in this lump, it can spread everywhere, it can be everywhere.” (P8)

“Can cause what? You know, if left untreated, it will lead to death, so yes, if you are rich like that, you don’t use your heart, the name is leukemia, it’s already a dangerous disease, so what is the solution, you have to be treated quickly, follow the doctor what the solution is, whether you want chemo, it’s okay, the important thing is to find the best way and finally, thank God, it’s getting better now.” (P5)

“It is said to be treated, yes, from the beginning, actually from this child there was no swelling, I already had treatment, from the beginning I took it seriously because every night he whimpered…” (P1)

“Must be ready to accompany, both at home and at the hospital, always on standby.” (P9)

“Well, frankly, I am the hardest for amputation; if I can still make other efforts, I ask for others first, and I ask again if it can’t be chemotherapy again, for chemotherapy you chat with Mr. Riza, then I meet Mr. Riza, the following week.” (P1)

Theme 2: Efforts made by participants in caring for children with cancer

The second category obtained three sub-themes, including efforts in treatment, caring for children with cancer, and efforts in spiritual terms. The following is the participant’s statement: used in Table 4.1, it is known that there were five female participants and one male participant. The study was conducted on parents with children suffering from cancer in the Flamboyan 9 inpatient room at Dr. Moewardi Surakarta Hospital.

“...treated, yes, from the beginning, actually from this child there was no swelling, I already had treatment, from the beginning I took it seriously because every night he whimpered…” (P1)

“Must be ready to accompany, both at home and at the hospital, always on standby.” (P9)

“Well, frankly, I am the hardest for amputation; if I can still make other efforts, I ask for others first, and I ask again if it can’t be chemotherapy again, for chemotherapy you chat with Mr. Riza, then I meet Mr. Riza, the following week.” (P1)

Theme 3: Participants’ experiences in caring for and treating children with cancer

The third category obtained three sub-themes: negative thoughts felt in the treatment process, feelings of fear of worsening the situation, and psychics in caring for children with cancer. Participants’ statements can be seen from the following words:

“I don’t have a heart, it’s like I don’t have a heart, only tears, crying, if you can exchange it, it’s just me, it’s just my illness.” (P5)

“The problem is that I like to be afraid, so if, for example, I find out more about it, then I will be anxious, so instead I think about it everywhere” (P3)
“Mentally, just prepare mentally so I can be strong to face everything. The worst possibility...” (P3)

Anyway, the point is to want to recover, I want the best.” (P7)

“Yes, I hope that doctors can achieve what high-tech medical science can help my child. I don’t expect much. At least he will recover, and the tumor will not grow anymore.” (P1)

“Hopefully, as a parent, my child must recover, be enthusiastic, I encourage him to try to recover anyway” (P2).

**Theme 4: Participants’ expectations for their child’s treatment**

The last category is the participant’s expectations of their child’s treatment. The following is the participant’s statement:

“The first hope is definitely to get well, to recover as before fully, but what yes.

Table 1

<table>
<thead>
<tr>
<th>Description</th>
<th>Gender</th>
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<tbody>
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<tr>
<td>Female</td>
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<td>Total</td>
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**DISCUSSIONS**

Cancer or malignant tumor is the uncontrolled growth of cells or tissues that continues to grow and increase and is immortal or cannot die. Unlike cancer in adults, cancer in children is more difficult to recognize because children are generally unable to express what they feel. Therefore, it is essential to recognize the signs and symptoms of cancer in children so that immediate treatment can occur and the cure rate improves. [7]. Palliative or cancer patients often experience severe or critical conditions; the first person who plays the most role in saving them is the family. A lack of family understanding of care management compromises patient safety because it is influenced by time. The golden period is the priority of first aid. Appropriate action at that time tends to get good results [9].
Parents' lack of knowledge about cancer affects their child's life. This lack of knowledge makes caregivers late to save or take their children to the hospital [13]. Participants' statements regarding ignorance about cancer are in line with Stefan and Harif's statement in a study entitled Early warning signs and diagnostic approach in childhood, which said that parents' ignorance resulted in delayed detection of cancer in children, resulting in further harm to the body because if detected quickly it can increase the survival of cancer patients [14].

An emergency is a patient's clinical condition that requires immediate medical action to save life and prevent disability [15]. Handling pediatric emergencies requires good coordination from various disciplines and professions, rapid and responsive response, and adequate facilities. The condition of children with troubles can be assessed quickly using scoring systems such as Assessment Triangle (PAT), Pediatric Early Warning System (PEWS), Pediatric Logistic Organ Dysfunction Score (PELOD)-2, and Pediatric Logistic Organ Assessment (pSOFA). To reduce pediatric mortality, an evaluation of the existing emergency system is required [6]. The hypothesis expressed by Megan et al. was that children with cancer presented to the ED with more than one chief complaint, with fever being the most common and most associated with cancer [16].

Parents have an essential role in paying attention to children's health; they must be more sensitive to children's growth and development. If there is anything unusual about the child's health, it can be immediately checked at the nearest health facility so that it can be detected and followed up. Currently, cancer is a severe disease that threatens children's health in the world [17]. Parents play a role in providing support to the child. The support includes accompanying the child while undergoing the treatment process, etc. As a result of chronic illnesses, children will need treatment and experience physical and psychological changes [18]. Parents who are caring for children with cancer must strive for their children to recover; from parents' ignorance about the disease suffered by their children, they inevitably have to learn about the condition, learn medical terms, know and understand treatment protocols, manage complicated drugs and support children to face the side effects of treatment and do not forget the never-ending prayers. Children with cancer require daily care, such as continuous chemotherapy treatment and complementary medicine. Complementary therapies are traditional treatments that have been recognized and can be used to complement conventional medical therapies [19].

Parents need support from family and the environment; positive social support can help parents go through all the processes while caring for and accompanying children undergoing cancer treatment. Every parent...
who finds their child sick will try to provide the best treatment according to their ability to cure their beloved baby. The role of parents for children with cancer is vital because parents are required to accompany and face children physically and psychologically [20].

Every parent who finds their child sick will try to provide the best treatment according to their ability to cure their beloved baby because a cancer diagnosis in children is a life-threatening event and stops the usual way of life of all family members. When a child is sick, especially when diagnosed with cancer, parents try all means and ask God for prayers [21].

Participants' experience in caring for and treating children with cancer

The presence of a healthy and normal child is the hope of all parents; cancer is an extraordinary disappointment and sadness for parents, so sometimes parents, especially mothers, cannot accept this fact [22]. As caregivers of children with cancer, parents are vulnerable to physical, social, and psychological health problems because parents require a lot of energy, time, and sacrifice. Emotional symptoms such as depression, guilt, anger, and anxiety become psychological disorders for parents. Pediatric cancer is a chronic disease affecting not only the child but also the family [19].

Parents generally feel guilty or anxious because they feel responsible for what happened to the child, or in their grief, they wish they could replace the child to bear the leukemia disease [23]. Parents are the most stressed after learning of their child's cancer diagnosis and treatment, whether physical, psychological, social, or economic stress. Problems experienced by families can be described objectively, such as financial and work needs [19]. The sudden and intensive demands of caring for a child with cancer will lead to feelings of uncertainty. They can cause symptoms of anxiety and depression, impaired cognition, and sleep disturbances [19]. Parents need support from family and the environment; positive social support can help parents go through all the processes while caring for and accompanying children undergoing cancer treatment.

Challenges in treatment

Being a caregiver for a child with cancer, parents provide the best care for children in health and illness. Caring for cancer parents is a sacrifice; the treatment takes a long time, and the child's unstable condition requires more energy to accompany the child, so sometimes the mother does not have much time for herself [19]. Chairperson of the Hematology-Oncology Coordinating Unit of the Indonesian Pediatric Association (IDAI), Dr. Teny Tjira Sari, SpA (K), revealed that pediatric cancer treatment in Indonesia is still facing several challenges, mainly in terms of the number of health workers and health facilities [24]. The challenges faced in caring for children with cancer parents sometimes face several challenges in the form of difficulties that must be met in the form of economic challenges and long distances to the treatment process. The research results in Zambia, Africa, said the challenges were a lack
of finances to meet medical and transportation costs and a lengthy hospitalization period [13].

**Participants’ expectations for their child’s treatment**

Pediatric cancer is a complex problem disease because care and treatment take a long time and require active involvement from the health team and family, especially parents. High expectations owned by parents can provide a positive force to support the treatment process of children with cancer. This hope is what makes parents able to survive for their children. With the amount of hope that parents have, it will be directly proportional to the recovery the children will achieve. Besides, the level of resignation in interpreting an event is also a driving force for someone to be enthusiastic and recover [22].

Research conducted by Pusmaika in 2020 revealed that parents with cancer have hopes, including good chemotherapy, children recovery, and, of course, if the children recovers, the children will always be healthy like other children [17].

**LIMITATION**

A limitation of the study was that the emergency events experienced by the participants' children were often too far away, so the participants' experiences were often different. On the other hand, if, during an emergency, the researcher interviewed the participant, it would be unethical.

**NURSING IMPLICATION**

The research aims to give nurses a comprehensive understanding of handling psychological issues in families with children experiencing emergencies. Furthermore, parents find themselves in a challenging situation when their future children suffer from a disease that remains incurable. For parents and families, a psychological approach is essential.

**CONFLICT OF INTEREST**

This study has no conflict of interest during the research process, from planning to submitting research results.

**CONCLUSION**

From the results of research that has been described previously about the Overview of Perceptions of Parents with Children with Cancer when Facing Emergencies, the conclusion of this study is the lack of understanding of parents regarding emergencies in cancer; behind that, there are efforts made such as efforts to treat children with cancer, struggles to care for children with cancer and spiritual aspects. The experience that participants get is a feeling of fear of worsening the situation and negative thoughts that arise & have an impact on the psychic participants. In addition, the challenges experienced by participants are the cost of commuting and the distance between health facilities and residence. Behind it all, participants hope their children will recover from cancer.
ACKNOWLEDGEMENTS

The researcher would like to thank all participants (Parents who are caring for children with cancer) in the Flamboyan 9 room of Dr. Moewardi Surakarta Hospital who have been willing to become participants in this study, as well as Dr. Moewardi Surakarta Hospital and Telogorejo school of health science Semarang for providing assistance and permission in the process of this research.

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