



## Analysis of Home Care Needs in Children with Leukemia

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### ABSTRACT

Children with leukemia often experience physical and psychological problems caused by the disease or side effects of treatment. In addition to care the child is in the hospital while at home, the child also needs treatment related to the problems faced. The need for care at home in children with leukemia to be known so that health workers are able to meet the needs of care while the child is at home and able to improve the ability of parents to meet the needs of care at home. This study aims to analyze the need for home care in children with leukemia. The design of this study used a qualitative method with a descriptive phenomenological approach. This research is a form of formative research that uses certain techniques to get answers about what the target audience thinks and feels. In this study, researchers need to understand the need for home care in children with leukemia. The study was conducted on parents and children with leukemia living in a halfway house in Semarang. Data collection was carried out by interviews and focus group discussions on participants. The data that had been obtained was carried out. Analysis was carried out to determine the theme included physical care needs, nutritional needs, emotional needs, and social needs.

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### Kata kunci:

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### ABSTRAK

Anak dengan leukemia sering mengalami masalah fisik maupun psikologis yang disebabkan dari penyakit maupun efek samping pengobatan. Selain perawatan selama anak di rumah sakit, saat di rumah anak juga membutuhkan perawatan berkaitan dengan masalah yang dihadapi. Kebutuhan perawatan di rumah pada anak leukemia perlu diketahui agar tenaga kesehatan mampu memenuhi kebutuhan perawatan selama anak di rumah dan mampu meningkatkan kemampuan orang tua dalam memenuhi kebutuhan perawatan di rumah. Penelitian ini bertujuan untuk menganalisis kebutuhan perawatan di rumah pada anak leukemia. Rancangan penelitian ini menggunakan metode kualitatif dengan pendekatan fenomenologi deskriptif. Penelitian ini merupakan salah satu bentuk penelitian formatif yang menggunakan teknik-teknik tertentu untuk mendapatkan jawaban tentang apa yang dipikirkan dan dirasakan oleh khalayak sasaran. Pada penelitian ini peneliti perlu memahami kebutuhan perawatan di rumah pada anak leukemia. Penelitian dilakukan pada orang tua dan anak leukemia yang tinggal di rumah singgah Semarang. Pengambilan data dilakukan dengan wawancara dan focus group discussion pada partisipan. Data yang sudah didapatkan dilakukan analisis untuk menentukan tema. Hasil penelitian ini menunjukkan kebutuhan perawatan di rumah pada anak leukemia meliputi kebutuhan perawatan fisik, kebutuhan nutrisi, kebutuhan emosional dan kebutuhan sosial.

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## INTRODUCTION

Cancer can affect all age ranges. Cancer can also occur in children. The prevalence of cancer in children aged 0 to 14 years is 0.42/1000 (Badan Penelitian dan Pengembangan Kesehatan Kementerian Kesehatan Republik Indonesia, 2018).. Type of cancer that most often occurs in children is leukemia around 30-40% type of cancer that occurs in children (Siegel et al., 2021).

Leukemia is a malignancy of blood cells originating from the bone marrow which is characterized by the proliferation of white blood cells that are irregular and uncontrolled (O'Brien et al., 2018)(Hunger & Mullighan, 2015). Proliferating cells suppress the production of blood elements formed in the bone marrow. Children with leukemia often develop anemia, infections, joint and bone pain, hepatosplenomegaly, and increased intracranial pressure (Hockenberry et al., 2016).

Some therapies used for leukemia include surgery, radiotherapy and chemotherapy. Chemotherapy can be the first treatment or additional treatment for surgery or radiotherapy. In general, chemotherapy agents work by interfering with the function or production of deoxyribonucleic acid nucleic acids (DNA) or ribonucleic acid (RNA). Side effects of chemotherapy agents are very important in order to be able to provide nursing care to children (Hockenberry et al., 2016). Physical problems that often arise in children with cancer are anemia, fatigue, infection, and pain (Rahmatina et al., 2021) (Riegel et al., 2019). Some of the side effects of chemotherapy experienced by children include fatigue pain or fatigue, mucositis, nutritional, distress, nausea and vomiting.

Children with leukemia undergo treatment for a long time children have to go through continuous and repeated hospitalizations with physical and psychological problems experienced by children in going through illness and the treatment that must be undergone requires children to continue to fight (Nuraini & Mariyam, 2020). In addition to treatment at the hospital, children with leukemia also need treatment at home. Symptoms or problems experienced at the hospital may also be experienced at home. Parents play a very important role in treating children with leukemia (Maria et al., 2014).

Families with children with leukemia are required to have the ability to care for children. Families are required to carry out health care functions both in the hospital and at home (El-sawy et al., 2013). Some parents experience anxiety when caring for children with leukemia (Mulyani et al., 2019). Parents have difficulty understanding the feelings and conditions experienced by children. Ignorance of needs will affect the psychological and physical aspects of parents in caring for children with leukemia. Parental involvement is defined as things parents do to take part in their children's lives are included in helping children to develop positive behavior, determining rules and discipline for children, and helping children in learning. Parental involvement as a source of cognitive intellectual behavior and personal relationships that parents give to their children in certain situations. The purpose of this study was to analyze the need for home care in children with leukemia.

## METHOD

The purpose of this study was to determine the need for home care in children with leukemia. The study design was a qualitative study with a descriptive phenomenological

approach. Descriptive phenomenology involves direct exploration, analysis and description of certain symptoms as free as possible from untested conjectures towards the maximum presentation of intuition. Descriptive phenomenology stimulates our perception of life experiences emphasizing the perfection, breadth, and depth of the experience. The research was conducted on parents and children with leukemia living in a halfway house in Semarang. The selection of participants used a purposive sampling approach with the criteria of mothers with children with leukemia undergoing chemotherapy treatment at home. stopover Semarang is willing to be a participant and able to communicate well. The research ethical test was carried out at the committee Fikkes Universitas Muhammadiyah Semarang with the number 0150/KEPK/VII/2022.

The researcher surveyed the research location and arranged for a research permit. Before the research was carried out pre-research activities to equalize perceptions between the research team. Identified participants who fit the researcher's criteria. The researcher explained the purpose of the benefits of the research, procedure to participants and asked participants who were willing to sign a consent letter. Data collection was carried out through interviews based on interview guidelines that had been prepared previously. Interviews were conducted by asking open-ended and non-rigid questions because the questions could be developed according to the needs of the researcher. The goal is for researchers to get extensive information from participants. Information submitted by participants should be free from the influence of others.

the researcher offers the participants about a time and place that is suitable and comfortable for the participants with the aim of establishing a trusting relationship. During the interview the participants received open-ended questions and were able to express freely about experiences related to the need for home care in children with leukemia. The interview lasted about 45 to 60 minutes and was then recorded using a recorder with the consent of the participants and then a verbatim transcript was made in the textual description after making the transcript of the recording immediately deleted. explanations given by the participants.

In addition to the interview, the researcher also made field notes containing a description of the date, time and basic information about the situation during the interview, such as the social interaction environment and activities that took place during the interview. For the convenience of the participants, field notes were made during the interview process for each participant.

The researcher integrates the overall results into the form of an in-depth narrative description of the phenomenon under study. The researcher can clarify the data to the participants through discussions to re-ensure whether what the participants submitted is appropriate or whether there are additions or reductions according to the participants' perceptions. Testing the validity of this study by testing the credibility or internal validity and transferability or external validity. Testing the credibility using triangulation of data sources from case managers who participated in the care of children with leukemia.

## RESULTS AND DISCUSSION

All participants were mothers of leukemia children undergoing chemotherapy. The characteristics of the participants can be seen in Table 1.

**Table 1. Characteristics of the participants**

Partisipants	Age of participants (year)	Job	Age of children (year)
P1	31	Housewife	3
P2	46	Housewife	13
P3	48	Housewife	12
P4	47	Housewife	13
P5	44	Housewife	15
P6	38	Housewife	4

Children with Leukemia undergoing chemotherapy often experience problems, both physical, psychological and social. These problems are also experienced by children while at home. An analysis of the needs for home care for children with leukemia based on what was conveyed by the participants included physical care needs, nutritional needs, emotional needs and social needs.

**1. Physical care needs**

Leukemia children with chemotherapy treatment mostly experienced physical complaints. Participants said that after undergoing chemotherapy treatment there were several physical complaints experienced by children.

“after chemotherapy, my child often experiences weakness and fatigue” (P1)

“last night his head felt throbbing his legs hurt all night after chemotherapy, sometimes the throat hurts the same as canker sores” (P3)

“my child still get frequent nosebleeds after several weeks of chemotherapy” (P4)

“during the first to eight cycle, you have to have a transfusion, you also had a drop of nausea and diarrhea, now it's better” (P5)

**2. Nutritional needs**

Adequate nutrition is really needed by children while undergoing leukemia treatment, but leukemia treatment or chemotherapy also has an impact on the emergence of nutritional problems in children. Some participants said that children experienced problems related to nutritional needs.

“when at home many children of the same age eat snacks, my child want to eat snacks like other children” (P1)

“if a child gets 6 MP it's very difficult to eat, want chicken to be cooked, only eat a little, want potatoes already cooked, only eat a little, don't want to eat and want to vomit” (P2)

“if he takes Dexamethasone he says his appetite increases so his body feels heavy, if he gets 6 MP it's hard to eat but his body is light, if you change medicine your appetite will change” (P3)

“my child gets bored easily with steamed food and often asks for fried food, my child has a hard time eating vegetables” (P6)

**3. Emotional needs**

Several participants said that after a child was diagnosed with leukemia, there were emotional or psychological changes.

“my child will be angry when asked to take a nap or sleep at night, I don't know what to talk about, Moreover, I'm confused about what to do” (P3)

‘after chemotherapy 2 or 3 days later the child becomes more irritable’ (P4)

“my child is now more sensitive, I'm confused why my child becomes more emotional, I have to be careful every time if I talk to my child, my child have said it's better to just die and bang the head against the wall want to end everything” (P5)

“their children tend to be quiet when they are angry or sad they don't want to talk, I as a parent are confused about what to do” (P5)

**4. Social needs**

The diagnosis of leukemia and the high need for care in children with leukemia has an impact on the social needs of children. Hospitalization has the effect of breaking off the social needs of the child. The participants conveyed a number of things related to the social needs of the child.

“I limit children's play activities so that children don't get tired” (P1)

“I limit children's play activities but the child refuses when I limit it” (P4)

“While playing with his friends and see friends eating snacks, my child always wants to be like his friends” (P4)

“my child might be jealous of seeing his friends go to school and go camping so that my child becomes more easily offended”

“if my child is being treated at a children's hospital, my child rarely interact, my child don't want to sunbathe outside, my child just want to play with gadget”

Children with leukemia during chemotherapy treatment experience progress in health conditions, but there are several problems that arise, including physical, emotional, nutritional and social problems. In children with leukemia there is a major disturbance in the bone marrow, namely normal elements are replaced with abnormal white blood cells (Chapla, 2015). Some of the symptoms that arise due to leukemia experienced by children include fever, malaise, anorexia, fatigue, bone pain, bruising and bleeding (Riegel et al., 2019). In this study, all children with leukemia were treated with chemotherapy. Some of the physical problems experienced by children included weakness, sore throat, sore throat, mouth sores and nosebleeds.

Fatigue in children with leukemia can come from disease therapy or psychological stress. The prevalence of children who experience fatigue shows 98% that the average fatigue score experienced is more than 6. Fatigue can be experienced by children before during and after chemotherapy (Fernandes, 2020). Planning periods of rest and activity as well as support for psychological stress is needed to overcome fatigue experienced by children. Pain also experienced by children in this study. Pain in children can be experienced before diagnosis and during treatment. Pain during treatment can result from complications due to chemotherapy (Coluzzi et al., 2020). Leukemia drug agents have an effect in the form of gastrointestinal disorders in the form of mild anorexia, nausea, vomiting, diarrhea which can cause a decrease in the nutritional status. Children with leukemia cannot be separated from the attention of parents, especially a mother (Maria et al., 2014). Chemotherapy in children with leukemia also results in oral manifestations including high physical caries and mucositis (Ponce-Torres et al., 2010).

Parents will experience a transitional period in caring for children at home after the child has undergone treatment at

the hospital. Parents are fully responsible for caring for children at home, so they need to adapt to new and complex care. Parents need confidence in caring for children while at home. Discharge planning is needed to prepare parents after coming home from the hospital. Discharge planning can be in the form of guidelines related to preventive medication, environmental prophylaxis, diet and other general care. Parents need to get information on how to handle emergencies related to illnesses such as fever and risk of infection. Family education is very necessary to provide parents with an understanding of their responsibilities while at home. Professional support is needed so that parents can get through this transition period well (Silva-Rodrigues et al., 2019).

Assessment of nutritional status and monitoring of signs of hematological toxicity is urgently needed to prevent adverse effects from chemotherapy treatment in children with leukemia. The toxic effects experienced by each child during chemotherapy are different, including leukopenia, thrombocytopenia and anemia. and bleeding that can affect the continuation of the chemotherapy treatment being undertaken. Changes in nutritional status in children undergoing chemotherapy are influenced by several factors, including factors related to disease or malignancy, factors related to patients and factors related to nursing care. The nurse can develop a comprehensive treatment plan based on emerging nursing diagnoses and collaborate with other health professionals to prevent nutritional deficits (Puspita et al., 2018).

The diagnosis of leukemia experienced by the child and the chemotherapy that the child must undergo is a state of crisis which has an impact on the psychology of the child. Children with leukemia have a fairly heavy psychological burden children experience decreased positive mood and decreased self-esteem have behavioral problems and increased difficulty sleeping poor mood and low acceptance. This psychological impact is also experienced by parents. The psychological burden is quite large with the presence of a child who has leukemia caused by stress from medical procedures in the hospital environment and difficulties in transitioning family social life (Sherief et al., 2015). Psychological problems experienced by children certainly require the mother's role in providing care to children.

Mother's behavior in fulfilling the basic needs of caring for and caring for a child with leukemia can be formed from the mother's characteristics, sources of self-efficacy and self-efficacy of parents. Self-efficacy of parents can be increased, especially by improving the coupling mechanism and experience of parents (Praba Diyan Rachmawati, 2014). In addition, health workers must communicate with parents and children to understand what information needs are needed in child care (Yamaji et al., 2022)

#### LIMITATION OF THE STUDY

The chemotherapy phases of leukemia children in this study were not the same, thus affecting the parents' experience in caring for them at home

#### CONCLUSIONS AND SUGGESTIONS

Children with leukemia undergoing chemotherapy often experience problems both physical, psychological and social. These problems are also experienced by children while at

home. An analysis of the number of care needs in children with leukemia based on what was conveyed by the participants included physical care needs, nutritional needs, emotional needs and social needs. Future researchers can take the same participants in the chemotherapy phase of children

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#### Conflict of Interest

No conflicts of interest.

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