
Original Articles: Qualitative Research

**INFORMATION GIVING BY NURSES IN EMPOWERING PARENTS TO CARE
FOR CHILDREN WITH CANCER**

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Email: dinarasmita@usu.ac.id**Keywords:***Parents, Empowerment, Nurse.***Page Number:** 64-73**Abstract**

Background: Parents empowerment involves accessing information, support, resources, and opportunities for parents to optimize the health of the children with cancer, feel meaningful, determine themselves, become competent, and impact their lives. Nurses play a crucial role in educating and training parents to care for their children.

Objective: The purpose of the study was to explore the provision of information by nurses to parents in empowering parents to care for children with cancer based on parents' perspectives.

Methods: The participants involved in this study were six nurses who served in the treatment room for children with cancer selected by purposive sampling technique. Data collection was carried out by in-depth interview method using semi-structured interview guidelines. Data analysis with stages of analysis according to Colaizzi.

Result: The results of this study found four themes about the provision of information by nurses in empowering parents, namely information provided by nurses, how to provide information, sources of information, and family responses after being given information. providing information nurses to parents, namely information about room rules and facilities, child care while in the hospital and at home, how to provide information that is often provided by nurses, namely verbally, demonstrations, and media, parents' information sources are nurses, doctors, media, and fellow parents with cancer, and parents' responses after being given information are sad and happy.

Conclusion: Nurses need to pay attention to the right time, and the right method, and assess the readiness of parents when providing information so that the information given to parents can be received and understood by parents well.

INTRODUCTION

Children with cancer will undergo hospitalization and require prolonged treatment. Hospitalization is a stressor for children as they must adapt to unfamiliar surroundings, medical equipment, and painful treatment procedures. Cancer not only affects the child but also the parents. Parents experience anxiety, stress, fear of losing their children, and helplessness in caring for their children, so parents become less than optimal in caring for their children (Jackson et al., 2007 cit. Rodgers et al., 2016).

Parents are a source of strength and support for sick children. Parents as the center of care in the pediatric nursing approach will help the nursing care process during hospitalization (Ashcraft et al., 2019). Family Centered Care (FCC) is a key concept in pediatric nursing practice because children cannot be separated from their parents (Paliadelis, 2005 cit. (Hill et al., 2018)). One of the basic concepts of FCC is empowerment. Parental empowerment is an effort to improve parents' abilities by increasing parents' knowledge and skills, so that parents are able to decide the best choices for their children's needs, and the best care for children, and increase parents' confidence in caring for children (Dunst and Trivette, 1996 cit. (Wacharasin et al., 2015)).

Nurses not only care for children with cancer but enhance parents' ability to increase their knowledge, skills, and confidence in meeting their child's needs and helping their child cope with their problems. Nurses involved in the day-to-day care of children play a role in empowering parents by providing opportunities for parents to participate and be involved in childcare activities, increasing their skills and confidence to make the best choices for their child's treatment (Panicker, 2013)

Parent empowerment is a way to gain access to information, support, resources, and opportunities to learn and grow so that parents are able to optimize their health status, feel the meaningfulness of life, be able to determine themselves, become competent, and have an impact on life (Ashcraft et al., 2019). This is in accordance with research conducted by Panicker (2013) which states that one of the roles of nurses in empowering parents is to educate and train parents to care for children, thereby increasing parents' confidence in caring for their children. Perry et al. (2014) Perry et al., (2014) explain one of the most important nursing interventions, is to provide information to families about the disease, its treatment, prognosis and home care. Information can improve parental coping, and decision-making, and assist parents in the transition process (Kelly & Porrock, 2005 cit. (Rodgers et al., 2016)).

Based on interviews conducted with parents in the Kartika I room of Dr. Sardjito Hospital Yogyakarta, it was stated that the empowerment of parents carried out by nurses was to provide education to parents such as infection prevention, involving parents in fulfilling basic needs. Parents also revealed that the information provided by nurses was not clear enough and the lack of communication between nurses and parents. Therefore, qualitative research with a phenomenological approach was chosen by the researcher to explore more deeply the provision of information by nurses to parents in empowering parents to care for children with cancer based on the parent's perspective.

METHODS

Study Design

The research design is qualitative research with a phenomenological approach. The qualitative research method with a phenomenological approach was chosen because this research is to understand the meaning of a phenomenon in depth, explore the phenomenon directly and describe the phenomenon

of a number of individuals on their various life experiences related to concepts or phenomena (Cresswell, 2014).

Settings

This study was conducted in the Kartika Room of Dr. Sardjito Hospital, Yogyakarta on 2023.

Research subject

The participants of this study were father or mother has a child aged 1-19 years old with a medical diagnosis of cancer who were treated in the Kartika room of Dr Sardjito Hospital, Yogyakarta, father or mother who accompanied their child during treatment, do not have speech impairment and can speak Indonesian, and are willing to be a participant in the interview.

Instruments

The researcher used an interview guideline with open-ended and semi structured questions. An MP4 voice recorder was used to record interviews between researchers and participants during the interview. The interview was conducted for 45-60 minutes. Interviews were conducted with nurses during nurse shift changes in the nurse's room. Data saturation was achieved at the sixth participant interview.

Data collection

The data collected is data from the results of direct interviews with respondents using the questionnaires. Before potential respondents filled out the questionnaire, the researchers asked for their willingness to become respondents in this study. After the research data was collected, the researchers tabulated the data and coded it so that it could be analyzed using statistical applications.

Data Analysis

Qualitative research data analysis is carried out during data collection and after data collection within a certain period. The data analysis process in this study used data analysis steps based on Colaizzi (Cresswell, 2014) including: 1) Researchers read all transcripts obtained from interviews with parents and nurses to find out the perceptions of parents and nurses about parental empowerment in caring for children with cancer; 2) Researchers reread the transcripts many times to get meaningful words about the provision of information by nurses to parents in empowering parents to care for children with cancer based on parents' perspectives; 3) Researchers deciphered the meanings of participants' statements to formulate the meaning of the statements, so that categories emerged; 4) The researcher read through the categories and then grouped similar categories into sub-themes and themes; 5) The researcher combined the results of the themes obtained to fully describe the phenomenon of nurses' perceptions of the activities and roles of nurses in empowering parents to care for children with cancer; 6) The researcher turned the in-depth explanation of the phenomenon under study into a statement with a complete description or identified the essence of parent experience; 7) Re-questioned the participants regarding the findings for the final validation stage.

Trustworthiness

Trustworthiness in this study used method triangulation. Method triangulation was carried out by means of non-participation and undercover observation of nurses with observation guidelines. Observation of nurses by observing the provision of information of parents and children.

Ethical Consideration

This research has been ethically approved by committee ethic with ethical number KE/FK/957/EC. The ethical principles carried out in this study are that the researcher provides an explanation of the research then the researcher asks the participant's willingness to participate in this study and gives the participant the freedom to choose the place and time of the interview (respect for human dignity), participants are involved in this study of their own accord without coercion (autonomy), participants are given the opportunity to tell experiences about the provision of information by nurses to parents in empowering parents to care for children with cancer (beneficence), maintaining the confidentiality of the participant's identity and the information provided by the participant (respect for privacy).

RESULTS

Most of the parent participants are mothers' patients because the parent who is more often waiting is the mother, so the researcher assumes that the one who interacts more with nurses is the mother. Researchers assume that those who interact more often with nurses are mothers. The age of the participants varied from 20 years old to 50 years old, between 20-30 years old there were two people, between 30-40 years old there were three people. Between 20-30 years old there were two people, between 30-40 years old there were three people, and between 40-50 years old there was one person. 50 years old there was one person. The participants' educational backgrounds varied from elementary to high school, with two people having elementary school education, two people having junior high school education, and two people having junior high school education. Two people, junior high school education level two people, high school education level two people. The occupations of the participants were farmers and housewives. There was one participant who worked as a farmer, and one participant who worked as a housewife, as housewives (IRT) there were five people. The age of the children being cared for varied from 3-17 years old. Two were aged 1-3 years, three were aged 6-12 years, and three were aged 13-18 years. Three people, and one person aged 13-18 years.

Table 1. Demographic Characteristics Participants.

Participant/Description	P1	P2	P3	P4	P5	P6
Age	26 years old	36 years old	37 years old	50 years old	40 years old	21 years old
Relation with patients	Mother	Mother	Mother	Mother	Mother	Mother
Job	Farmer	Housewife	Housewife	Housewife	Housewife	Housewife

Education	Primary school	Senior high school	Senior high school	Junior high school	Primary school	Junior high school
Age of Children	7 years old	3 years old	6 years old	17 years old	10 years old	3 years old
Diagnose	Acute Lymphoblastic Leukemia	Neuroblastoma	Acute Lymphoblastic Leukemia	Acute Lymphoblastic Leukemia	Ewings sarcoma	Neuroektodermal
Therapy week	12	24	17	17	12	12

This study produced themes related to the provision of information by nurses in empowering parents caring for children with cancer, namely information provided by nurses, ways of providing information, source of information, and family response after being given information by the nurse.

Theme 1: Information provided by nurses

Information provided by nurses to parents included information about child care in the hospital and home care as well as room rules and facilities. Parents stated that nurses provide information about child care in the hospital such as drug side effects, fever treatment in children, prevention of fall risk, care after invasive measures, oral care, how to feed through NGT (Nasogastric tube) and care after chemotherapy. The following is a parent's statement:

"Yes, it was explained to me, right, if a child is given chemo drugs, sometimes the child becomes fierce, wants to ask for anything, then when the drug is entered, if vomiting, itching, fever, you have to report it" (K1).

"I was told by the nurse to apply compresses, drink a lot, drink warm water" (K3).

"...if you want to leave this (while pointing to the bed divider) must be closed so that the child does not fall" (K6).

"Just put a warm compress on it, mum, so that it's deflated so that the blood circulation flows again" (K2).

"Use gauze to enter, give betadine to gargle...the nurse taught me" (K6)".

"Later, a little bit of thick porridge will be inserted and then cleaned with water after the food is inserted" (K3).

"The nurse told me not to wake up for six hours, not to eat until I wake up" (K4).

Parents were informed by the nurse about information on room rules and room facilities during the initial patient orientation. The information provided is the rules for waiting and visitors, as well as how to dispose of rubbish. The following is a parent's statement:

"Wash hands, if there are many, the immune system is weak, so there should be no infections, coughing and colds are also not allowed...There is a nurse's correlation, it must be sterile....wash your hands, wear a mask, wear clothes for one person waiting for you."(K2).

"The way to dispose of garbage should not be mixed, some can be disposed of here, some can be disposed of outside" (K5).

Parents were informed by the nurse about home care. The information provided by the nurse included signs and symptoms that the child should be taken to the hospital immediately, control schedules, and maintaining food. The following is the parent's statement:

"If the fever is 38.0C, they are immediately taken to the hospital" (K3).

"The nurse also told me, don't forget, don't ignore, the control schedule must be followed, the food must be maintained, don't drink ice and preserved food" (K4).

Theme 2: Ways of providing information

According to parents, the way information is provided by nurses is by giving examples, verbally, using media, and information is given after parents ask. Information was provided by giving examples such as how to wash hands and feed children through NGT (Nasogastric tube). Information is delivered verbally about treatment based on patient complaints. Information provided with media, namely information about medication and child care. Information is provided after the family asks, such as information about examination results and the child's condition. The following is a parent's statement:

"The nurse will first give me an example and then I will do it" (K4).

"They don't just tell me, they don't teach me how to do it." (K1).

"I was given this paper to read, no one told me" (K6).

"Later there will be given to see the CD" (K3).

"No, if you don't ask, I won't tell you unless the results are bad, then I'll tell you" (K3).

Theme 3: Sources of information

Parents' sources of information about their child's illness, treatment, and care were not only nurses but also doctors and fellow parents who had children with cancer. Information obtained by parents from doctors is about the disease, treatment, rules for waiting and visitors, and hospital facilities. Information about halfway house facilities from teachers and foundation administrators. One parent participant revealed getting information about how to wash hands from a student who was doing research. The following is the parent's statement:

"The doctor here said it was blood cancer, leukemia" (K1).

"Later, due to chemo like this, nausea, vomiting, diarrhea, for the first two chemo is healthy, then the next one drops...

the doctor said the effect of the chemo was diarrhea" (K2).

"They were taught how to wash their hands, how to cough, and that you can't wait together" (K6).

Parents also get information from fellow parents with cancer. The following is a parent's statement:

"Yes, if the first protocol I was confused, I asked others how to do it, what other treatment, I found out myself" (K2).

"Yes, sometimes there are mothers whose children have zero leucocytes too, try eating duck eggs" (K3).

Theme 4: Family response after being given information by the nurse

Parents' responses after being given information were confused and happy. Parents' responses were confused after being given information because parents still did not believe, and were surprised to learn about their child's illness when the information was given at the beginning of the cancer diagnosis. Information about the child's treatment and care was given at the same time as the doctor and nurse told them about the child's illness. Parents also forgot the treatment information and treatment that had been delivered at that time. The following is a parent's statement:

"Yes, thank you, I'm confused, I don't remember what the doctor said because I was still panicking when I found out my child had cancer" (K1).

"At the beginning, I was still confused when I was told ... I just found out that my child has cancer ... I was confused" (K6).

DISCUSSION

One of the roles of nurses in empowering parents is to educate and train parents to care for their children, thus increasing parents' confidence in caring for their children (Panicker, 2013). Perry, et al. (2014) explain one of the most important nursing interventions is to provide information to families about the disease, its treatment, prognosis, and home care.

Information provided by nurses to parents is information about child care in hospitals such as information about performing oral hygiene on children, care after chemotherapy, food restrictions, information about room rules and facilities such as how to wash hands, and dispose of garbage, and information about child care at home such as control schedules, signs and symptoms of children should be taken to the hospital immediately. The results of the study are research conducted by (Narayanan, Rath, Mahapatra, 2023) parents want information about cancer, disease management and self-care, communication and information interaction of medical team, consultation services, information sharing and exchange, access to health services, and hospital's facilities and equipment. The results of this study are supported by research conducted by Gibbins et al. (2012) which states that providing information according to the needs of parents makes parents able to deal with the situations they experience and strengthens parents in dealing with various situations and conditions that may occur to their children in the hospital. Information provided can reduce anxiety, and fear, help improve coping and help parents in decision-making.

The information provided by nurses to parents includes verbal, giving examples, using media, and after the family asks. The results of this study are supported by research conducted by Marcus (2014) that several methods commonly applied by nurses to increase knowledge and teach skills to the patient's family include handouts, classes, video, and online information, demonstration, and verbal education. The results of this study are also supported by Rodgers et al. (2016) who states that the approach that can be taken by health workers to help parents learn is to hold discussions with parents, provide information in writing, and tell important things about care child information, repeating the information provided, allowing parents to ask questions, providing information consistently, providing information to parents using posters, demonstrating, and counseling. Nurses can provide information according to the needs of parents, use methods that are easier for parents to understand, and repeat the information provided at a certain time. The results of the study are research conducted by Aburn & Goat (2014) that parents want information about their child's illness and treatment to be provided regularly, clearly, accurately, completely, and using simple sentences so that parents can understand the information provided and reduce parental anxiety about the development of their child's condition.

Information obtained by parents about their child's treatment and care Apart from nurses, parents get information from doctors, and fellow parents of cancer patients. This is by research conducted by Kilicarslan-Torune & Akgun-Citak (2013) which states that parents obtain information first from doctors and nurses, while other sources of information are from the internet, friends, and fellow parents who have children with cancer.

Parents' responses after being given information were confused and happy. The feeling of confusion experienced by parents when given information about the disease, treatment, and care of children at the beginning of a cancer diagnosis. Parents expressed sadness, disbelief when they found out about their child's illness, so parents did not focus on the information presented, did not parents did not focus on the information provided, did not understand the information provided, and did not even remember the information provided because at that time parents were still panicking when they heard about their child's cancer and the information was given once during the initial diagnosis of the disease. The results of this study are supported by Rodgers et al. (2016) parents revealed that they understood little information and did not remember the information delivered by the doctor when the child was first diagnosed with cancer. Parents received some information about the disease and the treatment plan, but parents were unprepared and still surprised to hear about their child's illness and the communication at that time was one-way. The results of this study showed that parents also revealed that they were happy after being given information because they knew how to care for their children. This is by research conducted by Aburn & Goat. (2014) that in providing education it is necessary to pay attention to the officer who provides education, the right time to provide education, the values adopted by the family, and how to provide education to the family.

LIMITATION

Maximum variation was not obtained in the participants because all participants were mothers. All mothers, thus underrepresenting the various perspectives from the parent participants (fathers) towards the provision of information by nurses in treating children with cancer.

CONCLUSION

The provision of information by nurses to parents is information about room rules and facilities, child care while in the hospital and at home. This information is needed by parents. Nurses need to pay attention to the right time, and the right method, and assess the readiness of parents when providing information, so that the information provided to parents can be received and understood by parents properly.

AUTHOR CONTRIBUTION

Dina Rasmita: Literature review, conceptualization, methodology, investigation, resources, project administration, and manuscript drafting.

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CONFLICT OF INTEREST

There is no conflict of interest in this study.

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