Activities and Nurses' Role in Empowering Parents on Treating Children with Cancer

Dina Rasmita

Fakultas Keperawatan, Universitas Sumatera Utara

Article Info

Article history:
Received 11 January 2021
Accepted 21 March 2021
Published 25 June 2021

Keyword:
Role of Nurse
Children with Cancer
Empowerment

Abstract

Children with cancer will hospitalize for a long time, so it takes the role of the family as an integral part that cannot be separated from the child. Family are partner in childcare. Family centered care is an important part of childcare because parent are source of strength and supportive child. The point of family centered care is empowering families in childcare. Empowerment is the most important part of caring for nurses, families, and patients. Nurses are not only involved in daily childcare, but also nurse play a role in empowering parents in caring for children with cancer. The study aim to explore the activities and roles of nurses in empowering parents to care for children with cancer based on the nurse perception. The research design was a qualitative design with a phenomenological approach. Participants involved in this study were six nurses who served in the childcare room with cancer selected by purposive sampling technique. Data were collected by in-depth interview method using semi-structured interview guidelines. Data analysis with the analysis stage according to Colaizzi. The results of this study found four themes about the activities and roles of nurses in empowering parents in caring for children with cancer, including providing education, providing support, involving parents in caring for children, involving parents in decision making. Nurses can provide support according to the needs of parents and increase collaboration with parents in caring for children.

Keyword:
Role of Nurse
Children with Cancer
Empowerment

Aktivitas dan Peran Perawat dalam Pemberdayaan Orangtua Merawat Anak dengan Kanker

Abstrak

Anak dengan kanker akan menjalani hospitalisasi dalam jangka waktu yang lama, sehingga dibutuhkan peran keluarga sebagai bagian integral yang tidak terpisahkan dari anak. Keluarga adalah mitra dalam perawatan anak. Perawatan berfokus pada keluarga adalah bagian penting dalam perawatan anak karena orangtua merupakan kekuatan dan dukungan utama bagi anak. Inti dari perawatan berfokus pada keluarga (PBK) adalah memberdayakan keluarga dalam perawatan anak. Pemberdayaan merupakan bagian terpenting dalam perawatan baik untuk perawat, keluarga, dan pasien. Perawat tidak hanya terlibat dalam perawatan anak sehari-hari, tetapi perawat juga berperan dalam melakukan pemberdayaan orangtua dalam merawat anak dengan kanker. Penelitian ini bertujuan mengamati aktivitas dan peran perawat dalam pemberdayaan orangtua merawat anak dengan kanker berdasarkan sudut pandang perawat. Desain penelitian ini adalah desain kualitatif dengan pendekatan fenomenologi. Partisipan yang terlibat dalam penelitian ini adalah enam orang perawat yang bertugas di ruang perawatan anak dengan kanker di luhur dengan teknik purposive sampling. Pengambilan data dilakukan dengan metode wawancara mendalam menggunakan pedoman wawancara semi terstruktur. Analisis data dengan tahapan analisis menurut Colaizzi. Hasil penelitian ini menemukan empat tema tentang aktivitas dan peran perawat dalam...
INTRODUCTION

Children with cancer will undergo treatment in the hospital and require a long treatment. Hospitalization was a stressor for children because children have to adapt to a foreign environment, medical equipment, treatment procedures that cause pain (Hockenberry and Wilson, 2011). Cancer did not only affect children, but also parents. Parents experience anxiety, stress, fear of losing their children, and powerlessness in caring for children, so parents become less than optimal in caring for their children (Da Silva, Jacob, and Nascimento, 2010).

The parent is a source of strength and support for a sick child. Parents as service centers in the child nursing approach will assist the nursing service process during hospitalization (MacKay and Gregory, 2011). Family-Centered Care (FCC) was the main concept in implementing child nursing practice because the existence of children cannot be separated from their parents (Paliadelis, 2005). One of the basic concepts of FCC is empowerment. Parental empowerment was an effort to improve parents' abilities by increasing parental knowledge and skills, so the parents are able to make the best choices for their children's needs, the best care for their children, and increase parents' confidence in caring for their children (Dunst and Trivette, 1996 cit. Wacharasin, Phakroop, Sananeangsak, 2015).

Nurses do not only care for children with cancer, but also increase the ability of parents to increase their knowledge, skills, and confidence in fulfilling their children's needs and helping children overcome their problems (Attaros, 2004). Nurses who are involved in daily child care play a role in empowering parents by providing opportunities for parents to participate and be involved in child care activities, increase parents' skills and confidence to determine the best choice for child treatment (Pacniker, 2013).

Parental empowerment was effectively used to increase the knowledge, confidence, and ability of parents to care for their children so, the parents will be better prepared to care for their children after returning from the hospital (Loghani, et al., 2011). Parental empowerment can increase parental satisfaction with health services (Wacharasin, Phakroop and Sananeangsak, 2015). The results of research conducted by Hulme (1999) on the empowerment of parents who have children with chronic pain indicate that parental empowerment can reduce anxiety, fear, fulfill children's needs, and reduce children's care costs. This is supported by the research of Ghazavi et al. (2014) on the effect of parental empowerment programs on improving the quality of life of children with chronic kidney failure showed that parental empowerment can improve children’s life quality, both physically and psychologically.

Several previous studies stated that the implementation of parental empowerment was not optimal. One of them is a study conducted by Pacniker (2013), nurses revealed difficulties in empowering parents, namely limited time for nurses, lack of nurse skills, and lack of facilitating parents to be involved in caring for children. Based on interviews conducted with nurses and parents in the room of Kartika I at 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 and there was a lack of communication between nurses and parents. Therefore, qualitative research with a phenomenological approach was chosen by researchers to explore more deeply about the activities and roles of nurses in empowering parents to care for children with cancer from the nurse's point of view.

METHOD

The research design is qualitative research with a phenomenological approach. The qualitative research method with a phenomenological approach was chosen because this research was to understand the meaning of a phenomenon in-depth, explore the phenomenon directly and describe the phenomenon of a number of individuals against their various life experiences related to the concept or phenomenon (Creswell, 2014).

The participants of this study were nurses in the room of Kartika II at Dr. Sardjito Yogyakarta. The sampling of the participant was used by the purposive sampling technique, the sample was selected according to the criteria determined by the researcher and the determination of participants who have strong information about the facts or phenomena studied (Cresswell, 2014). The participants of this study were nurses who were selected with certain criteria. The inclusion criteria for nurses, namely nurses who served for three years or more in the room of Kartika II at Dr. Sardjito Yogyakarta, with a minimum education level of DIII Nursing, willing to be a participant in the interview.

The researcher used an interview guide with open questions and a semi-structured. The MP4 voice recorder is used to record interviews between researchers and participants during the interview. Interviews were conducted for 45-60 minutes. Interviews were conducted on nurses during the shift change of nurses in the nurse’s room. The data saturation was achieved at the sixth participant interview.

The ethical principle carried out in this study is that the researcher provides a research explanation then the researcher asks the participants' willingness to participate in this study and gives freedom to the participants to choose the place and time of the interview (respect for human dignity), participants are involved in this study of their own accord without any element of coercion (autonomy), participants are given the opportunity to tell their experiences about empowering parents in caring for children with cancer (beneficience), maintaining the confidentiality of participants’ identities and information provided by participants (respect for privacy).
Analysis of qualitative research data is carried out at the time of data collection and completion of data collection within a certain period. The process of data analysis in this study used data analysis steps based on Colaizzi (cit. Holloway, 2008) including: 1) The researchers read all transcripts obtained from interviews with parents and nurses to determine the perceptions of parents and nurses about parental empowerment in caring for children with cancer; 2) The researchers re-read the transcript many times to get meaningful words about the perceptions of parents and nurses about parental empowerment in caring for children with cancer; 3) The researchers describe the meanings of the participant's statements to formulate the meaning of the statement so, the categories emerge; 4) The researchers read all categories and then group the same categories into sub-themes and themes; 5) The researchers combine the results of the themes obtained to describe the phenomenon of nurses' perceptions about the activities and roles of nurses in empowering parents to take care of children with cancer completely; 6) The researchers turn an in-depth explanation of the phenomenon under study into a statement with a complete description or identifying the essence of the nurse's experience; 7) Asking participants again about the findings for the final validation stage.

RESULT AND DISCUSSION

The number of participants was six nurses who served in the pediatric care room with cancer at Dr Sardjito Hospital Yogyakarta. All participants were women. The last education of nurses is DIII (Diploma) to S1 (Bachelor-Ners). The education level of DIII (Diploma) is five nurses and the education level of S1 (Bachelor) is one person. The age of nurses varied from 31 years to 50 years. There are four nurses aged 31-40 years and two people aged 41-50 years. The positions of nurses vary from association nurse, there are three people, the nurse in charge of duty is one person, and primary nurse is two people. Nurses have clinical work experience varying from four years to 28 years. There are five nurses who have work experience of more than five to ten years, and one person for more than ten years. The characteristics of nurse participants can be seen in table 1.

Table 1
Demographic characteristics of nurse participants

| Participant/ Description | P1     | P2     | P3     | P4     | P5     | P6     |
|--------------------------|--------|--------|--------|--------|--------|--------|
| Age                      | 39 years | 37 years | 50 years | 31 years | 31 years | 41 years |
| Gender                   | Female | Female | Female | Female | Female | Female |
| Last Education           | S1 (Ners) | DIII   | DIII   | DIII   | DIII   | DIII   |
| Position                 | Associate nurse | Associate nurse | Primary Nurse | Associate nurse | Nurse in charge | Primary Nurse |
| Length of work           | 4 years | 9 years | 28 years | 6 years | 10 years | 8 years |

Theme Analysis Results

This study resulted in themes related to the activities and roles of nurses in empowering parents to care for children with cancer, namely providing education, providing support, involving parents in caring for children, involving parents in decision making.

Theme 1: Giving Education

The activities and nurses' role involve parents in the first care, which is to provide education in the course of the disease. The types of education provided by nurses include early admission education, child care education in the hospital, education when returning home. The education provided by the nurse at the time of initial admission is the right and obligation of the patient. This was stated by the nurse as follows:

"The first is about the patient's rights while here, what are they?" (P1)

In addition, the education provided by the nurse at the beginning of admission to the parents was an education about the duration of treatment and the treatment protocol if the diagnosis of the disease was established. This was stated by the nurse as follows:

"How long does the treatment take, we inform what should the family do, we hope that the treatment journey will go smoothly, but on the way, it doesn't go smoothly, maybe an infection, Hb drops, bleeding, we explain to the family... At the beginning of chemotherapy, we educate the treatment protocol," (P5)

Parents are also educated on waiting and visitor rules and infection prevention. This was stated by the nurse, as follows:

"As the rules at Estella, we are different from the others unlike other children's wards, we emphasize to them that at Estella specifically for children with blood disorders, blood cancer, patients receiving chemotherapy, their endurance often drops, so the one waiting has to be one, then the waiting one have to wear a mask, if the parents are waiting for your change, you have to wash your hands by using the hand rub that has been provided in the room, then we teach how to wash their hands because to prevent infection of washing hands" (P6)

Nurses also provide initial education to parents about room facilities. These facilities that can be used by all patients and parents who waiting for patients include bathroom facilities and medical and non-medical waste disposal facilities. This was stated by all nurse participants as below:

"Environmental orientation, which room is this, where is the toilet, there are five kinds of orientation for the trash can and telling about medical waste" (P3)

Nurses also provide information about treatment coverage when the initial patient is admitted. This was stated by the nurse as follows:

"We tell the family what procedures must be done, there must be a guarantee for BPJS, the delivery of drugs, the management of family insurance must go to the guarantee, the pharmaceutical satellite for the invoice, after the invoice we get a receipt paper for copying" (P5)
In addition to providing education to parents when they first entered, nurses provided education about hospital care. Hospital care education is in line with daily hospital care and based on patient complaints, is about nutrition, personal hygiene such as oral care. Here is the nurse's statement:

"All foods that are allowed or not are allowed. At a glance, the nurse should tell that food with preservatives is not allowed. If the platelets are low, it is said that you can't eat chocolate milk, which is brown, because if one's have black bowel movements, use it to disguise bleeding... to see that the food is hygienic, it will better to buy closed food to minimize the number of germs... Oral hygiene care, prevention of how to do oral care" (P5)

“We are told to eat little by little, avoid spicy food... We recommend not eating hard food because it triggers bleeding”(P6)

Nurses also provide education about children's activities while in the hospital. Education about activity limitations to prevent bleeding in children when the child's platelets are low. Here is the nurse's statement:

"I educate patients with thrombocytopenia, don't act too much, move a lot, do a lot of activity, if it's children, their parents don't know there's bleeding, then their children will run around, ride in a toy car, they'll be bleeding”(P6)

When the nurse will give chemotherapy drugs, the nurse informs about the side effects of treatment and repeats the information conveyed by the doctor about the side effects of treatment and ensures that parents have been educated by the doctor about the side effects of treatment. This was stated by the nurse as follows:

"If it’s hot, we recommend compressing even though sometimes it can’t reduce the heat with a child's condition like this"(P1)

"If we, the nurses, know the best about eating and drinking and isolation protection, so if the leukocytes are low”(P4)

“We educate that everything is because of the side effects of chemotherapy to maintain it with adequate intake if leukopenia patients are very susceptible to infection, so we educate those who wait for patient one”(P6)

Next, the nurse informs parents about preventing the risk of falling. The nurse advises the family to increase safety so, the child does not fall. Here is the nurse's statement:

“We educate for the safe sleeping position, so don’t leave it behind, so we always remind that if you leave it anywhere, the safety must be raised so, the child doesn’t fall.”

In addition to providing early admission education, child care in the hospital, nurses also provide education to parents about care at home. The education given to parents is about the control schedule, explanations about the drugs given at home, and chemotherapy drugs that will be given for the next treatment. Here is the nurse's statement:

“Yes, that is for any medicine that is brought home including the dose, the rules for the medicine, control..." (P1)

the date, where... That is what must be brought during any control, yes for this control letter it is valid as a reference, yes, when the control is brought”(P3)

“We will tell them when they have to come back, we will see the protocol on what date the child should be here... the signs and symptoms of when the child should be immediately taken to the hospital”(P5)

Nurses also provide education about the signs and symptoms of the child should be immediately taken to the hospital. This was stated by the nurse as follows:

“If the fever occurred, taken to the hospital immediately, come home later with paracetamol, if there are signs of bleeding, taken to the hospital immediately”(P4)

Then, the nurse tells the parents to maintain personal hygiene, food, and infection prevention. Here is the nurse's statement:

"Care at home, take care of yourself, don't playing out first, don't be visited by many people, wear a mask when going out”(P4)

"House cleanliness, so don't have too many things in the patient’s room, for social interaction, as much as possible, don't be close to children who have a cold cough because children with this kind of disease have different endurance with healthy children... food nutrition is kept clean, it is recommended that parents provide support to their children."child”(P5)

The nurse recommends that when children are at home, always encouraged to comply with treatment and do not differentiate from other children. This was stated by the nurse as follows:

"We give families understanding to continue supporting their children so, their children are enthusiastic about undergoing treatment. Other family members are asked to support their children so that children feel cared for”(P5)

The provision of education carried out by nurses, is by orally, using media such as flipcharts, patient education sheets, and demonstrated. Here is the nurse's statement:

"I explain immediately, didn’t use leaflets like this how to wash hands, how to cough”(P2)

"Yes, if I teach, I just use orally”(P3)

Nurses provide early entry education using media such as flipcharts, educational sheets. This was stated by the nurse as follows:

“Early education using flipcharts from the time visits, family rights”(P5)

“The educational sheet was brought home so, they could read it so they could go home and read it” (P6)

In addition to the education provided by the nurse orally, and using the media, the nurse also gave an example in educating parents, such as how to wash hands, feed through sonde. Here is the nurse's statement:

"I educate them, sit together, I’ll bring a handrub later, I’ll ask if she already knows...First, the nurse will teach first, then the parents”(P2)

"We practice it, we demonstrate it to the family”(P4)

"We demonstrate the procedures from initial education that need to be demonstrated, we also teach patients who have grown up to their families, then we are asked to do it until the family is able to do it... for the first when using sonde, we monitor it like checking residues on how to use sonde we will wait for it”(P5)

The provision of education by nurses to families is carried out repeatedly if parents do not understand and cannot do as told by nurses. Here is the nurse's statement:
The nurse also asked parents to repeat the education that had been given and asked verbally to evaluate the education that had been given. Here’s what the parents said:

"Sometimes we’ll review again later, if it’s free time, let’s see how to wash your hands, usually look at the conditions too" (P5)

"We want to check, Mrs. So-and-so is going to have a sonde. I have put it in Ma’am ... later on I will ask, have you washed her hands? okay, at a glance, the information is just not detailed" (P2)

"We asked, did you understand what was said, later we told him to do what we meant earlier, so knowing what he caught, if the demonstration is clear, we can see it directly, oh, this mother has done it correctly, it means that her mother can do it already" (P5)

Early education, doctors and nurses sit together to provide education to parents or families. The nurse stated that they would complete the doctor's explanation that was still lacking, which was stated by the nurse as follows:

"This is the beginning of the patient’s admission, it is clearly diagnosed, when educating process there are nurses and doctors there, so we educate there, not here, doctors do not, so we sit together, so all the patient’s families receive all information" (P5)

"Nurses will add if from the doctors are not enough" (P3)

Theme 2: Giving Support

The activity and nurses' role in empowering parents is to provide support to parents. The first support provided by the nurse is informational support. Informational support provided by nurses to families is an explanation of information provided by nurses to parents about care actions taken for children and the purpose of conducted care.

"We’ll tell you what drugs are taken" (P1)

"Actions are given" (P6)

The second support provided by nurses is emotional support for parents. Emotional support is an expression of empathy, motivation, caring, and concern for parents. Here is the nurse’s statement:

"We motivate them, give the education for the families so, they are more excited to take care of their children" (P1)

"We just give motivation, we’ll explain the support education. If they want to share with their friends, we’ll find some good friends...we tell them to be patient" (P2)

"Yes, the family will usually be embraced, talked about, by giving a touch ... told to pray" (P3)

"Mmm, from the nurses, most of us are giving the motivation to be patient, enthusiasm, there are many friends here, all of use are trying" (P4)

"We give psychologically support, we will be that sharing place, we serve wholeheartedly with a smile, they are happy, we listen later, we ask what the complaint is, for example, vomiting does not go away, we don’t leave them and go but we have a chat first" (P6)

Furthermore, the third support is instrument support. Instrumental support is support in the form of material assistance for poor parents. Here is the nurse’s statement:

"There is also material support provided by nurses in class III, many of which are poor patients" (P6)

Theme 3: Involve parents in caring for children

The activity and the nurses' role in empowering parents are to involve parents in caring for children. Nurses involve parents to fulfil basic needs such as self-care and oral care for children to be carried out on patients twice a day because children with cancer have low immune systems, making them more susceptible to infection and mucositis after chemotherapy treatment. Here is the nurse’s statement:

"If a child has cancer, it will be easy for him to have a fever and sprue so, we involve them for oral hygiene and we continue to teach the to do it in the morning and evening" (P1)

"If taking a bath, we take the parents with us, sometimes there are some parents who help, help tilt it, work together...help us with ADL, we can't cover everything, we’ll help ADL later, yes, but we’ll check, if the sonde, yes we do" (P2)

"Families are involved for nutrition, feeding patients" (P5)

The nurse also includes the family to help with some care measures such as monitoring intravenous fluids. This was stated by the nurse:

"Mmm, yes, the infusion monitor is involved, if it's finished, please report it." (P2)

Parents are also involved by nurses to watch for signs of bleeding. This was stated by the nurse:

"Yes, they are monitoring, we ask for help, if the lab results are like this, if there are signs of bleeding, we will involve them so we don't have to wait 24 hours, so if there are signs of bleeding, report it immediately" (P1)

Furthermore, when children receive chemotherapy treatment, parents are involved to monitor the side effects of treatment, monitor the child’s position after chemotherapy, fluid intake and output. Here is the nurse’s statement:

"We will involve the family, we must pay attention to the accuracy of the IV line, if the children feel pain in the stabbed or swollen area, report it immediately and we will monitor it there. If the child is nauseated or vomiting, please confirm with us that you need antiemetics, monitor the medicine to run out to the neck of the infusion so it doesn’t happen fluid loss will be reported to the nurse...to report whether the medicine has had an effect...the family is educated so, the child does not wake up for 5-6 hours so, the medicine enters the brain barrier, during that time it is not allowed to wake up, it can’t be tilted, the children are fed until they are well aware that if the family is still in doubt, the family is asked to communicate with the staff at the front, can the child eat or not...The family is told to write down how much the child drinks milk or eats, then every six hours it will be calculated later after six hours it usually plays calculate fluid balance" (P5)

Parents were involved by nurses during invasive procedures such as infusion if the nurse was not accompanied by another nurse. Here is the nurse’s statement:
"If there are a lot of guards this morning, if the child has a lot of movements, fussy, we have some friends, if there are no friends, we have to ask parents for help anyway, when injecting we need the parents’ help, sometimes the child has traces, so, the parents help to hold it for NGT” (P6)

Parents are also involved to measure vital signs such as temperature. Here is the nurse’s statement:

“If the patient has their own thermometer, we ask them to measure their own temperature” (P5)

Parents are also involved in sampling for examinations such as urine samples. This was stated by the following nurse:

“If HDpTest, they hydrate first, then their parents will take a urine sample and evaluate it for us later by using a urine stick for pH” (P2)

The nurse revealed that parents were excluded from some invasive procedures such as intrathecal chemotherapy, and BMP (Bone marrow puncture) treatment. Parents only accompany the child when the child is given anaesthesia. Here is the nurse’s statement:

“Psychologically involved because the child feels anxious, from there, the family is sought to accompany the child before falling asleep. Family assistance is in the action room until the child falls asleep, after that the family leaves, so in the child’s imagination the family is there because it is impossible to act like the patient’s family waiting inside” (P5)

Invasive measures such as parental infusion are sometimes not involved by nurses. Parents are involved in infusion in certain situations and conditions.

“The mothers were asked to help hold them if we put the infusion, we don’t involve it, we have friends, if we are in a hurry, we will involve it” (P2)

Furthermore, nurses also did not involve parents of new patients for feeding children with NGT. Here is the nurse’s statement:

“Parents are also not involved in feeding through the sonde in newly admitted patients” (P5)

Theme 4: Involve parents in decision making

The activities and the nurses’ role in empowering parents are that parents are involved in making decisions about child care. Parents involvement in decision making such as consent to the action. This was stated by the nurse as follows:

“Everything comes back to family approval” (P1)

The nurse revealed that the invasive procedure, insertion of the NGT, the nurse asked for approval of the action using informed consent. This was stated by the nurse as follows:

“NGT uses informed consent” (P2)

Nurses revealed that the parents’ involvement in decision making, nurses gave detailed explanations about these actions to parents. This was stated by the nurse:

“Usually we explain first the child’s condition, why the action needs to be taken by the patient’s family, at least they understand with this condition, with an action like this, the patient’s family thinks positively, so we first give an understanding of the reason for what action to take... later if something goes wrong, families are asked to report, usually we educate first, later we will ask the doctor, have the doctor educated them yet if we have included them, if not we will not include them” (P5)

DISCUSSION

The activities and nurses’ role in empowering parents expressed by nurses are educating parents, providing support to parents, involving parents in child care and making decisions on medical and treatment actions. The nurse revealed that one of the activities and nurses’ role in empowering parents is to provide education to parents. This is in accordance with research conducted by Pacniker (2013) which stated that one of the roles of nurses in empowering parents is to provide education and train parents to care for children, thereby increasing parents’ confidence in caring for their children. Perry et al., (2014) explained that one of the most important nursing interventions, is to provide information to families about the disease, its treatment, prognosis and nurses at home.

The nurse revealed that the education provided by nurses to parents included early entry education such as patient rights, treatment protocols, room regulations and facilities, treatment administration, daily care education such as oral care, food abstinence, chemotherapy side effects, care after chemotherapy, as well as education when going home such as control schedules, signs and symptoms of children should be immediately taken to the hospital. The nurse also revealed that the education nurses gave to parents is education about infection prevention such as maintaining personal hygiene in children such as oral care, washing hands, the number of waiting patients because children with cancer with low immune systems are susceptible to infection. Infection prevention was important because infections that occur in patients with cancer can reduce the life quality to cause death (Biswal and Godnaik, 2013).

The nurse revealed that the education provided by the nurse was orally, gave examples, with the media, and evaluated the education that had been given. The results of this study are supported by research conducted by Wulanladi (2013) that several methods commonly applied by nurses in an effort to increase knowledge and teach skills to patients’ families include discussing, explaining, giving examples, and providing experiences to families. Most nurses revealed that education such as hand washing, feeding children through the NGT was done by demonstrating directly to parents so, the parents could practice directly, while information based on patient complaints was mostly delivered orally. The nurse also revealed that nurses were helped by educational media such as leaflets about home care, so parents could read them. The results of research conducted by Rodgers (2016) stated that the approach that can be taken by health workers to help parents learn is to have discussions with parents, provide written information, tell important things about children and care, repeat the information provided, provide opportunities parents ask questions, provide information consistently, provide information to parents by posters media, demonstrations, and counseling.

Nurses reveal that the activities and the nurses’ role in empowering parents is to provide support to parents, including emotional support, information support, spiritual support, and instrumental support. Providing support can increase cooperation between children, parents and nurses as well as increase parental participation in child care and provide a sense of calm for parents and children so, they can form positive coping by reducing anxiety and fear that occurs due to hospitalization (Fincher et al., 2012) . Nurses reveal that the emotional support given to parents is to motivate parents, listen to complaints, and give touch. This is
supported by the statement of Sanjari (2009) which stated that emotional support includes providing touch, listening, showing caring behavior, empathy. In addition to emotional support, parents also receive spiritual support from nurses such as nurses encouraging parents to pray, while spiritual support provided by nurses to parents in addition to encouraging parents to pray, nurses also facilitate clergy so, the parents can accept children's illnesses. Kamper et al. (2010) stated that spirituality is a source of peace and hope in someone when there is stress. In addition to providing emotional and spiritual support, nurses also provide informational support by informing the child about the actions taken. The results of the study are in accordance with the research conducted by Berube et al. (2014) which stated that nurses provide information to clarify the actions taken. This is reinforced by research conducted by Sener and Karaca (2017) which stated that parents want nurses to explain the actions taken to children and receive information about the child’s condition. The nurse also revealed that the nurse provided instrumental support to parents who could not afford it because most of the parents of cancer patients in the room of Kartika II were classified as underprivileged, so the instrumental support provided by nurses was material assistance. The results of research conducted by Nastiti (2012) one of the nurses in parents in caring for children with cancer was financial needs.

The nurse also revealed that the activities and the nurses’ role in empowering parents are to involve parents in caring for children in fulfilling basic needs such as oral hygiene, nutrition, bathing children, and assisting ADL (activity daily living), and assisting certain care actions. Nurses revealed that nurses involve parents more to assist nurses in meeting basic needs, except for patients with total dependence and new patients to fulfill nutritional needs if the patient is fitted with an NGT. Parents are also involved by nurses to carry out certain treatments for children such as monitoring the child’s condition after chemotherapy, measuring vital signs, recording fluids that come in and out after chemotherapy treatment, accompanying children during invasive procedures such as infusions, taking blood, caring for children when they have a fever, reduce pain in children.

The results of this study are supported by research conducted by Abdulbaki et al. (2011) which showed that there are two forms of parental participation in child care, namely helping physical and psychosocial needs. Physical needs that should be fulfilled by parents include nutrition, self-care, and being involved in nursing actions such as taking temperature and monitoring the child when receiving intravenous fluids and psychosocial needs by reading storybooks, playing with children, and activities that show the closeness of children and mothers. The results of this study are almost the same as the research conducted by Kastel and Enskar (2013) which showed that family participation in caring for children with cancer was related to fulfilling basic needs such as feeding and assisting with oral care in children except feeding with a tube and administering medication by injection.

The nurse also revealed that nurses feel comfortable if parents do not accompany children when invasive procedures are performed because parents experience anxiety when they see children in pain and cry when invasive procedures are performed, thus making nurses uncomfortable in performing these actions. The results of this study are supported by Sener and Karaca (2017) which stated that nurses did not allow parents to accompany children during invasive procedures because the anxiety experienced by parents during the action has a negative impact on children, nurses, and the success of the procedure. Nurses reveal that nurses involve parents in decision making. Decision making is done by giving an explanation to parents at the beginning. This is in accordance with what was expressed by nurses that nurses have a role in involving parents in making decisions about child care and providing information support to parents when making decisions. Decision-making on the children treatment is carried out by means of an informed consent sheet which has been previously explained by the doctor responsible for the child. Parents are given information support about the explanation of the actions to be taken for their children, including the objectives, benefits, and risks of the actions taken. Rodgers (2005) explained that parental empowerment was influenced by negotiations between nurses and parents and involves parents in decision making, thereby increasing parents’ ability to overcome problems and the decision-making process. This is in accordance with research conducted by Kuo (2012) which stated that the decision-making process for parents was by conducting discussions, supporting parents in decision-making, and giving parents choices. The results of this study are also supported by research conducted by Mack et al. (2011) which showed that some parents want to be together with doctors while making decisions related to the treatment of their children. Parents revealed that involving parents in decision making can reduce the level of parental anxiety related to their child’s treatment. The results of this study are also supported by research conducted by Watt et al. (2013) who examined family-focused care in the care of children with cancer stated that health workers have respected families in making decisions about their child’s care. The nurse also revealed that the decision from the parents would be accepted as long as it was agreed upon by the health worker and did not conflict with the treatment and care of the patient. This is in accordance with the research conducted by Palliadelis et al. (2005), Coyne and Cowley (2007) which stated that the decision to involve and include parents in child care and the setting of boundaries for care responsibilities rests entirely with nurses and health workers.

Limitations of the Research

When conducting interviews with nurses, other nurses often enter the action room and invite nurse participants to talk so that the interview often stops. In addition, the researcher had difficulty understanding some of the Javanese language used by the participants when answering the interview questions, so the researcher only confirmed some of the participants’ answers to be explained in Indonesian.

CONCLUSION AND SUGGESTION

The activities and the nurses' role in empowering parents have been carried out well, but the implementation of parental empowerment is still fully under the control of nurses. Nurses are the main parties who set the boundaries of the duties and roles of parents in child care. Nurses can provide support according to the needs of parents and increase collaboration with parents in caring for children.

Nurses should provide education about the duties and roles of parents in caring for children when they first visit the hospital so, the parents understand their duties and roles...
in child care and the benefits of parents' roles in the child's healing process.

**Conflict of Interest statement**

The author declares that there is no potential conflict of interest in relation to the authorship and publication of this article.

**REFERENCE**

Abdulbaki, M. A., Abd, Y., Gaafar, E., & Waziry, O. G. 2011. Maternal Versus Pediatric Nurses Attitudes Regarding Mothers’ Participation in the Care of Their Hospitalized Children. Journal of American Science, 7(9). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4020022/

Beddells, E., Bevan,A. 2015. Roles of nurse and parents caring for hospitalised children. Journal Nursing Children and Young People, 28(2), 24-28. https://doi.org/10.1077/jncyp.28.2.24-22

Berube, K.M., Fothergill-Bourbonnais, F., Thomas, M., Moreau, D. 2014. Parents’ Experience of the Transition with their Child from a Pediatric Intensive Care Unit (PICU) to the Hospital Ward: Searching for Comfort Across Transitions. Journal of Pediatric Nursing, 29, 586-595. https://doi.org/10.1016/j.pedin.2014.06.001

Borhani, F., Najafi, M.K., Rabori, E.D., Sabzevari, S. 2011. The Effect of Family Centered Empowerment Model on Quality of Life of School Aged Children 171172 with Thalassemia Major Life of School-Aged Children with Thalassemia Major. Iran Journal Nursing Midwifery, 16(4): 292-298. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3583099/

Cresswell, J.W. 2014. Penelitian Kualitatif & Desain Riset. Pustaka Ilmu Kesehatan, Yogyakarta.

Coyne, I., Murphy, M., Costello, T., O’Neill, C., Donnellan, C. 2013. A Survey of Nurses’ Practices and Perceptions of Family-Centered Care in Ireland. Journal of Family Nursing, 19(4), 469-488. https://doi.org/10.1177%2F01074840713508224

Coyne, I. 2008. Disruption of parent participation: Nurse’s strategies to manage parents on children’s wards. Journal of Clinical Nursing. 17, 3150–3158. doi: 10.1111/j.1365-2702.2006.01928.x

Da Silva, F.M., Jacob, E., Nascimento, L.C. 2010. Impact of Childhood Cancer on Parents Realitionship: an Integrative Review. Journal Nursing Scholarship. 42(3):250-61. doi: 10.1111/j.1547-5069.2010.01360.x

Foster, M., Whitehead, L., Maybee, P. 2010. Parents’ and Health Professionals’ Perceptions of Family Centred Care for Children in Hospital, in Developed and Developing Countries: A Review of the literature. International Journal of Nursing Studies, 47: 1184–1193. DOI: 10.1016/j.ijnurstu.2010.05.005

Ghazavi, Z., Minooei, M.S., Abdeyazdan, Z., Gheissari, A. 2014. Effect of Family Empowerment Model on Quality of Life in Children with Chronic Kidney Diseases. Iran Journal Nursing Midwifery, 19(4), 371-375. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4145491/

Gonya, J., Martin, E., McClead, R., Nelin, L., Shepherd, E. 2014. Empowerment Programme for Parents of Extremely Premature Infants Significantly Reduced Length of Stay and Readmission Rates. Acta Pediatractica, 727–731. doi: 10.1111/apa.12669.

Hesham, M.S., Mansi, Y., Abdelhamid, T.A., Saleh, R.M. 2016. Impact of a health education tool on enhancing communication between health providers and parents of neonates in intensive care in Egypt. Journal of the Chinese Medical Association, 79, 394-399. doi: 10.1016/j.jcma.2016.01.018.

Hockenberry, M.J., Wilson, D. 2011. Wong’s Nursing Care of Infants and Children, 9 th edition. Mosby Elsevier: Philadelphia.

Hulme, P.A. 1999. Family Empowerment: A Nursing Intervention with Suggested Outcomes for Families of Children with a Chronic Health Condition. Journal of Family Nursing, 5(1), 33–50. https://doi.org/10.1177%2F107484079900500103

Kastel, A., Enska, K. 2013. Family Participation in Childhood Cancer Care. Journal of Nursing Education and Practice, 4(3),112–124. https://doi.org/10.5430/jnep.v4n3p112

Laschinger, H.K.S., Gilbert, S., Smith, L., & Leslie, K. 2010. Towards A Comprehensive Theory of Nurse/Patient Empowerment: Applying Kanter’s Empowerment Theory to Patient Care. Journal Nursing Management, 18, 4– 13.175. doi: 10.1111/j.1365-2834.2009.01046.x.

Loghmani, L., Borhani, F., & Abbaszadeh, A. 2014. Factors Affecting The NursePatient’s Family Communication In Intensive Care Unit Of Kerman: Qualitative Study. Journal of Caring Sciences, 67-82. https://doi.org/10.5681%2Fjcs.2014.008

MacKay, L.J. & Gregory, D. 2011. Exploring Family-Centered Care Among Pediatric Oncology Nurses. Journal of Pediatric Oncology Nursing, 28,43– 52. doi: 10.1177/1043454210377179.

McKenna, K., Collier, J., Hewitt, M., Blake, H. 2010. Parental Involvement in Paediatric Cancer Treatment Decisions. European Journal of Cancer Care, 19(5), 621–30. https://dx.doi.org/10.1111%2Fj.1365-2354.2009.01116.x

Miaanei, S.J., Karahroudy, E.A., Rassouli, A., Tafreshi, M.C. 2014. The effect of Creating Opportunities for Parent Empowerment program on maternal stress, anxiety, and participation in NICU wards in Iran. Iranian Journal of Nursing and Midwifery Research, 19 (1). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4201207/

Palliadellis, P., Crucshank, M., Wainohu, D., Winskill, R., Stevens, H. 2005. Implementing family centered care: an exploration of the beliefs and practices of pediatric nurses. Journal Australian Advance Nursing, 23(1), 31- 6. https://pubmed.ncbi.nlm.nih.gov/16496815/

Perry, S. E., Hockenberry, M. J., Lowdermilk, D.L., Wilson, D. 2014. Maternal Child Nursing Care. Fifth Edition. Elsevier: Canada.

Panicker, L. 2013. Nurses’ Perceptions of Parent Empowerment in Chronic Illness. Journal Contemporary Nurse, 45(2), 210–219. doi: 10.5172/conu.2013.45.2.210.

Rodgers, C.C., Stegenga, K., Sachse, K., Kelly, K.P. 2016. Processing Information After a Child’s Cancer Diagnosis—How Parents Learn: A 177 Report From the Children’s Oncology Group. Journal of Pediatric Oncology Nursing, 33(6) 447–459. doi: 10.1111/j.1740-8745.2016.01128.x

Salmani, N., Hasanvand, S., Bagheri, I., Mandegari, Z., 2017. Nursing care behaviours perceived by parents of hospitalized children: qualitative study. International Journal Pediatric, 5(7), 5379-5389. https://dx.doi.org/10.22038/jip.2017.23123.1940
Activities and Nurses' Role in Empowering Parents on Treating Children with Cancer

Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J., Pascoe, E. 2012. Family centered care for hospitalised children aged 0-12 years. Cochrane Databased of Systematic Review, 17;10. doi: 10.1002/14651858.CD004811.pub3.

Toruner, E.K., Citak, E.A. 2013. Information-seeking behaviours and decisionmaking process of parents of children with cancer. European Journal of Oncology Nursing, 17, 176-183. doi: 10.1016/j.ejon.2012.03.001.

Vasli, P. & Salsali, M. 2014. Parents’ Participation in Taking Care of Hospitalized Children: A Concept Analysis with Hybrid Model. Iranian Journal of Nursing and Midwifery Research, 19(2).178. https://pubmed.ncbi.nlm.nih.gov/24834082/

Wong, P., Liamputtong, P., Koch, S. & Rawson, H. 2015. Families’ Experiences of Their Interactions with Staff In an Australian Intensive Care Unit (ICU): A Qualitative Study. Intensive & Critical Care Nursing. The official journal of the British Association of Critical Care Nurses, 31(1): 51–63. doi: 10.1016/j.iccn.2014.06.005

Wulandari, A. 2011. Persepsi Perawat Terhadap Pelibatan Keluarga Dalam Perawatan Anak di Rumah Sakit PMI Bogor. Tesis. Fakultas Keperawatan Universitas Indonesia, Jakarta