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Barriers and Supports in Empowering Parents Care for Children with Cancer

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Abstract

Cancer that occurs in children does not only affect children, but also parents. Parents experience anxiety, stress, fear of losing their children, and helplessness in caring for their children, so that parents are less than optimal in caring for their children. Parent empowerment can increase parents' knowledge, confidence, and ability to care for their children. Previous research found several obstacles to parent empowerment carried out by nurses so that parent empowerment was not optimal in its implementation. Knowing barriers and supports in implementation of parent empowerment in caring for children with cancer can support implementation of parent empowerment to be more optimal. The purpose of this study was to explore barriers and supports in parent empowerment in caring for children with cancer based on the nurse's perception. The design of this study was qualitative research design with a phenomenological approach. The data was collected by in-depth interview method using semi-structured interview guidelines on six nurses who were selected by purposive sampling technique. The data analysis was carried out by thematic analysis with the analysis stage according to Colaizzi. The results of this study were resulted in four themes, namely parental attitudes, parental characteristics, attitudes of nurses, availability of nurses and facilities. This study concluded that implementation of empowering parents to care for children with cancer became more optimal by knowing the barrier and supports in empowering parents care for children with cancer and nurses could make more effective planning in caring for children with cancer.

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INTRODUCTION

Cancer is a disease with a high mortality rate. Every year there are 12 million people worldwide suffer from cancer and 7.6 million of them die (International Union Against Cancer, 2009). Each year about 150,000 children are diagnosed with cancer. Cancer cases in children are found to be increasing every year and 20% of them die (World Health Organization, 2014). In 2015, the United States estimated 10,380 new cases of cancer in children aged 0-14 years (National Cancer Intitute., 2015).

Children with cancer will be hospitalized and require a long treatment. Hospital care is a stressor for children because children have to adapt to unfamiliar environments, medical equipment, and painful treatment procedures (Hockenberry & Wilson, 2011). Cancer does not only affect children, but also parents. Parents experience anxiety, stress, fear of lossing their children, and helplessness in caring for children, so that parents are less than optimal in caring for their children (Da Silva & Jacob, 2010)

Parent are the closest people to children. Parent are also a source of strength and support for a sick child. Parents as a service center in a child nursing approach will help the nursing service process during hospitalization (MacKay and Gregory, 2011). Parent-focused care (PBB) is the main concept in implementing child nursing practice because the existence of children cannot be separated from the parents (Paliadelis et al., 2005). In the application of parent empowerment, parents also receive nursing care and are encouraged to participate actively in the process of care and decision making (Abraham and Moretz, 2012). One of the basic concepts of family centre care is empowerment. Parental empowerment is an effort to improve parental abilities by increasing parental knowledge and skills.

Attaros (2004) *cit* Panicker (2013) stated that nurses do not only treat children with cancer, but also improve parents 'ability to increase parents' knowledge, skills, and confidence in meeting children's needs and helping children overcome their problems urses who are involved in day-to-day child care play a role in empowering parents by providing opportunities for parents to participate and be involved in child care activities, increase parental skills and confidence to determine the best choice of child treatment (Pacniker, 2013).

Parent empowerment is effectively used to increase knowledge, self-confidence, and the ability of parents to care for children, so that parents will be better prepared to care for children after returning from the hospital (Borhani, et al., 2011). Parental empowerment can increase parental satisfaction with health services (Wacharasin, Phaktoop, Sananreangsak, 2015). The results of research conducted by Hulme (1999) *cit* Panicker (2013) on the empowerment of parents who have children with chronic pain show that parental empowerment can reduce anxiety, fear, fulfill children's needs, and reduce child care costs. This is supported by the research of (Ghazavi, Minooei, Abdeyazdan, 2015) concerning the effect of parent empowerment programs on improving the quality of life of children with chronic kidney failure show that parent empowerment can improve the quality of life of children, both physically and psychologically. Research conducted by (Gonya et al., 2015) on the effect of parental empowerment programs on length of stay and re-care for premature babies in intensive neonatal care units (NICU) showed that parental empowerment in the NICU can reduce length of stay and re-hospitalization for preterm infants who are in the NICU, parent become confident , is able to care for her baby at home and make decisions about her baby's care.

Several previous studies stated that implementation of parent empowerment still experiences various obstacles so that implementation is not optimal. One of them in research conducted by (Panicker, 2013), nurses revealed difficulties in parental empowerment, namely limited time for nurses, lack of skills of nurses, and lack of facilitating parents to be involved in caring for children.Knowing barriers and supports implementation of parent empowerment in caring for children with cancer can support implementation of parent empowerment to be more optimal. Qualitative research with a phenomenological approach was chosen by researchers to explore more deeply about the barriers and support for parent empowerment in caring for children with cancer based on the nurse's perception.

METHOD

The design of the sudy was a qualitative study with a phenomenological approach. The method was used because this study was to understand the

meaning of a phenomenon in depth, explore phenomena directly and describe the phenomena of a number of individuals with their various life experiences related to concepts or phenomena (Cresswell, 2014).

The research participants were nurses in the Kartika II room Dr. Sardjito Yogyakarta. The technique of taking the participants was by using 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 being studied (Cresswell, 2014). The participant of this study was nurses who were selected with certain criteria. Inclusion criteria of nurse, they are nurses who served for three years or more in the Kartika II room Dr. Sardjito Yogyakarta, minimum education level of diploma nursing, was willing to be a participant in the interview.

Researchers used interview guidelines with open-ended questions and semistructured MP4 voice recording devices to record interviews between researchers and participants during the interview. Interviews were conducted 1-2 times. Interviews were conducted for 45-60 minutes. Interviews were conducted with nurses when changing nurse shifts in the nurse's room.

The ethical principle carried out in this study was that the researcher provides an explanation of the research then the researcher asks the participants' willingness to participate in this study and gives the participants the freedom to choose the place and time of the interview (respect for human dignity), the participants are involved in this study of their own accord Without an element of coercion (autonomy), participants were given the opportunity to share their experiences of empowering parents in caring for children with cancer (beneficience), maintaining the confidentiality of participant identities and information provided by participants (respect for privacy).

Qualitative research data analysis was carried out at the time the data collection took place and the data collection was completed within a certain period. The data analysis process in this study uses data analysis steps based on Colaizzi (cit. Holloway, 2008) including:1) 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 researcher reread the transcript repeatedly to get meaningful words about the perceptions of parents and nurses about parental empowerment in caring for children with cancer; 3) The researcher described the meanings of the participant's statements to formulate the meaning of the statement, so that categories emerge; 4) The researcher read all the categories then classifies the same categories into sub-themes and themes; 5) Researchers combined the results of the themes obtained to describe the phenomenon of nurses' perceptions of barriers and support for parental empowerment in caring for children with cancer completely; 6) The researcher turned a deep explanation of the phenomenon under study into a statement with a complete description or identifies the essence of the nurse's experience; 7) Asked the participants again regarding the findings for the final validation stage.

RESULT

The number of participants was six nurses who served in the child care room with cancer at Dr. Sardjito Hospital Yogyakarta. All participants are women. The last nurse education is DIII (Diploma) to S1 (Sarjana-Ners). There are five nurses at the DIII (Diploma) education level and one undergraduate level. The ages of nurses varied from 31 years to 50 years. Four of the nurses were 31-40 years old and two were 41-50 years old. The position of nurse varies from associate nurse (PA), there are three people, nurse in charge of duty (PJTJ) has one person, and primary nurse (PN) has two people. The nurse participants had clinical work experience varying from four years to 28 years. There are five nurses who have work experience for more than five to ten years, more than ten years there is one person. The characteristics of nurse participants can be seen in Table 1.

This research produces a theme, namely parental attitudes, parental characteristics, nurse attitudes, availability of nurses and facilities. themes, categories, and participant statements can be seen in Table 2.

The nurse revealed the various barriers and supports experienced by nurses in empowering parents, the first is the parent's attitude, namely the positive and negative attitude of the parents. The positive attitude of parents, namely the attitude of parents who are cooperative and care about their

Table 1. Characteristics of nurse participants

Participants	P1	P2	P3	P4	P5	P6
Age	39 years old	37 years	50 years	31 years	31 years	41 years
Gender	Women	Women	Women	Women	Women	Women
last education	S1 (Ners)	DIII	DIII	DIII	DIII	DIII
Position	Associate Nurse (PA)	Associate Nurse (PA)	Primary nurse (PN)	Associate Nurse (PA)	Nurse in charge of duty (PJTJ)	Primary nurse (PN)
Length of work	4 years	9 years	28 years	6 years	10 years	8 years

Table 2. Themes, categories, participant statements

Theme	Category	Statement
Attitude of parents	Positive attitude	P1: "So far, when parents are cooperative, the handling is usually smoother, so if we look at it, nurses, when parents are cooperative, it is comfortable to care for children ... if those who care for their children know, read the protocols and they will ask tomorrow what medication their child is taking"
	Negative attitude	P1: "Being invited to chat is also uncomfortable .... His face is flat, I don't ask anything after being asked if someone wants to be asked again instead asking when he will recover when he can come home" P3: There are those who don't dare, once they are taught, they can't"" Sometimes parents are annoying, for example putting on a nebulizer, sometimes we talk about it, the parents will let go by themselves, their children are fussy, and the parents will take them off by themselves. "P2: "Not cooperative, the problem is waiting, visiting, someone will cough"P5: "Education for watchers is usually someone who is fussy both of them"P4: "There are parents who don't have the heart"P6: "In the past, children were still tracking, according to him, the BMP was engineered by doctors and nurses ... Sometimes parents were doubtful if they were educated.the science of nurses and doctors whether the nurses, doctors have the correct knowledge... if the infusion is put on later, the mother will choose, I want the same. The nurse's job is also a lot, it doesn't have to be the same, which is usually us "P1: "There are also those who refuse chemotherapy ... There are also some who want to seek other alternative treatments.. There are also those who are still denial "
Parental characteristics	Level of education	P3: "For those with higher education, they will understand quickly, if they are taught directly"P1: "Parents' knowledge is lacking" "There are one and three, maybe not easy, so we will understand that later we willP5: I will tell the children who can understand there too"
	Age	P3: "In terms of age, how many times did the grandmother teach it?"
Attitude of nurses	Positive attitude	P6: "They talk more with them so they trust us more "
	Negative attitude	P3: "But it's better if we don't have parents ... Yes, we feel better if the parents' actions are waiting outside"

Availability of nurses and facilities	Number of nurses	P2: "We have a lack of energy ... we work a little separately, so we need supervision, lots of action, so we focus our minds on the bad ones."
	Educational provision facilities	P1: "There will be nutrition, from the hospital, we will make it with the team"P6: "There is a guide from the hospital... discharge planning ... sheet on patient education about going home, map review "

children, making it easier for nurses to involve parents in caring for children. Negative attitudes, namely parents who are afraid, parents are also not cooperative in caring for children and obeying the rules of patient watchdogs, the attitude of parents who doubt the science and ability of nurses. The second obstacle and support experienced by nurses in parental empowerment is the characteristics of nurses such as parental education level and parental age. The low level of parental education makes it difficult for nurses to provide education to care for children, while the high level of parental education is easier to understand the information provided by the nurse. Furthermore, the elderly parents when accompanying children in the hospital make it difficult for nurses to provide child care education.

The third barriers and supports experienced by nurses in parent empowerment is the attitude of the nurse. Nurses' positive attitudes such as attention and more frequent communication with parents so as to create a trusting relationship between nurses and parents and make it easier for nurses to work together with parents in caring for children. The negative attitude of nurses, namely nurses feel more comfortable if parents are not involved in child care actions such as infusion. Anxiety and the attitude of parents who do not have the heart when nurses take action make nurses uncomfortable at work.

The fourth barriers and supports experienced by nurses in parent empowerment is the availability of nurses and facilities. The number of nurses is limited, so nurses cannot monitor parental activities. In addition, educational provision facilities such as the use of media and guidelines in providing education. Media used are discharge planning, leaflets, educational sheets, map reviews, guidelines from hospitals such as standard operational procedure to assist nurses in educating parents and patients so that parent find it easier to understand and remember the information provided by nurses.

DISCUSSION

Barriers and supports in parent empowerment are parent attitudes, parental characteristics. The nurse revealed that the attitude of parents who were not cooperative, was the attitude of parents who did not dare to take care, denial, doubted the knowledge of nurses and doctors. The nurse revealed that at the initial diagnosis of treatment, it was difficult for parents to cooperate with nurses in providing care because the condition of the parents still did not believe in the child's disease and even some parents did not believe in the treatment that would be carried out on the child (MacKay and Gregory, 2011).

The nurse also mentioned that the attitude of parents who do not trust doctors and nurses is an obstacle in working with parents in caring for their children. This is in accordance with research conducted by Dunloop (2008) which states that parents are often not ready when they find out the diagnosis of a child's disease, this causes conflict for nurses to work with parents. Nurses experience stress and confusion when working with parents in the early stages of diagnosing a child's illness. The attitude of parents who have not accepted their child's illness makes it difficult for parents to convey information and cooperate with parents in child care. This is consistent with research conducted by (Gibbins and Steinhardt, 2012) .

The nurse also revealed that parents did not dare to take care of their children such as feeding them through NGT, after the nurse gave education by giving examples to parents and assisting parents in taking care actions, so the nurse did it. The results of this study are also supported by research conducted by Panicker (2013) which reveals that parental empowerment will not be carried out if parents are not ready to care for children, so parents cannot follow the process of child care, cannot care for children properly, and ignore suggestions from staff. Health.

The results of this study are in accordance with research conducted by Bedells and Bevan (2015) which states that parents do not dare to treat children because parents do not have sufficient knowledge. This is also supported by research conducted by (Fisher et al., 2011) which states that the lack of parental participation in caring for children is because parents do not get information from nurses. The attitude of cooperative parents is a supporter of empowering parents to care for children with cancer. The nurse revealed that the attitude of parents who pay attention to children, respect doctors and nurses, can accept the child's disease conditions, make it easier for nurses to work together with parents in caring for children while in the hospital.

Furthermore, barriers and supporters in empowering parents are parental characteristics such as education level and parental age. The nurse revealed that the low level of parental education made it difficult for nurses to educate parents. **Mazor et al. (2013)** stated that the adequacy of information provided to patients and parents is influenced by cognitive, patient education level, parents and the duration of time provided by health workers. The results of the study are also supported by research conducted by Panicker (2013) whisch states that one of the obstacles to parental empowerment is the low level of education, so parents find it difficult to participate in caring for children.

Meanwhile, a high level of parental education is a supporter of parental empowerment. A high level of parental education makes it easier to provide education. Some nurses revealed that it was easier to provide education to parents with higher education because parents could more easily understand the information conveyed by the nurses. Hulme (1999) *cit*. Panicker (2013) stated that the factors that influence the stage of parental participation are the level of education, occupation, socioeconomic status, the condition of the child's severity, and the mental status of the parents. According to (Quinn et al., 2015) providing information with a focus on client education is a way to increase knowledge and promote positive attitudes.

Furthermore, barriers and supports in empowering parents is the age of the parents. Advanced parental age. The nurse revealed that when a child is accompanied by an elderly parent it makes it difficult for the nurse to educate the parents, so the nurse often repeats the information provided. The results of this study are supported by research conducted by Wigert et al. (2014) states that parental participation in caring for children is influenced by parental characteristics, including gender, age, and previous experiences of parents when caring for children. The results of this study are also supported by research conducted by (Arumsari, Emaliyawati, Sriati, 2016) which states that age is one of the factors that influence communication.

Barriers and supports of parent empowerment are the attitudes of nurses, such as the attitudes of nurses who are more attentive, often communicating with parents and patients. The nurse revealed that nurses who communicate more frequently with parents and patients make parents not afraid to convey their needs in caring for children. Bedells & Bevan (2015) state that effective communication can help parents to obtain information about child care plans, so that parents are sure of the information conveyed. Research conducted by King & Hoppe (2013) stated that communication can build a trusting relationship between parents and staff by sharing duties and responsibilities with parents, so that parents understand their role in child care. Furthermore, the attitude of the nurse feels uncomfortable when parents are involved in caring for children. The results of this study, nurses revealed that nurses felt more comfortable if parents were not involved in invasive treatment measures such as infusion, NGT insertion, and intrathecal chemotherapy because according to nurses when parents accompany their children, their children are often fussy and parents are often anxious, afraid when the child is done. invasive action, so that the nurse feels less focused when taking action. This is in accordance with the statement of Abraham and Moretz (2012) which explains that the presence of parents in the room is feared to disturb patients and nurses are less flexible in nursing actions. This is in accordance with research conducted by Boztepe (2012) which states that 62, 8% of nurses do not want parents to accompany children during invasive action, 77, 1% of nurses reveal that children's anxiety increases when parents accompany children, 60% of nurses reveal that the level of anxiety of health workers increases which has an impact on the success of the procedure. Furthermore, barriers and supporters of parental empowerment are communication between nurses and parents and patients.

Barriers and supports in parent empowerment are the availability of nurses and facilities such as a limited number of nurses, and educational facilities. The results of this study revealed that the number of nurses was limited and not proportional to the number of patients, causing nurses to work individually and have to monitor patients with various conditions. The results of this study are consistent with research conducted by Coyne et al. (2013) which states that one of the obstacles to parental empowerment is the limited number of staff. This is also supported by MacKay and Gregory (2011) study of parent-centered care based on the perception of child oncology nurses who found the same results which stated that the barrier to parental-focused care was the limited number of nurses. The increasing number of patients does not match the number of nurses, so this causes a high workload for nurses and nurses only focus on completing tasks. This is also supported by research conducted by [a]ener and Karaca (2017) which states that nurses know the expectations of parents, but nurses cannot meet the needs and expectations of parents because of the high workload. Furthermore, the obstacle and support in empowering parents to care for children with cancer are educational facilities. Educational facilities such as leaflets and discharge planning helped nurses educate parents. The use of media in providing education to patients and parents can increase patient and parent knowledge. The results of research conducted by (Hesham et al., (2016) who noted that the use of media has been shown to save time, increase knowledge, attitudes, reduce parental anxiety, and facilitate interaction with staff.

CONCLUSION

Barriers and supports for parent empowerment, among others, are parent attitudes, parent characteristics, nurse attitudes, availability of nurses and facilities. However, barriers to parental empowerment can be overcome by the presence of several supporters so that parental empowerment can be carried out optimally, including cooperative parental attitudes, nurse therapeutic communication, parental education level that affects the provision of education, and the existence of supports facilities in providing education.

SUGGESTION

Based on the results of this study, it is hoped that nurses can carry out parental empowerment more optimally by paying attention to various inhibiting and supports factors in empowering parents to care for children with cancer. Future research can examine the barriers and supporters of parental empowerment from the parent perception.

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