

Family-Centered Empowerment in Caring Children with Leukemia

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Keywords: Family Empowerment, Family's Ability, Leukemia.

Abstract: Families of children with chronic illness often feel helpless in meeting their child's health care needs and they are faced with demands, challenges, and emotional and cognitive problems. Powerlessness experienced by the family affects the ability of families to provide care for their children. This study aims to analyze the influence of family empowerment on the family's ability to care for children with leukemia. An explanatory survey research design is used with a population of 140 families with children suffering from leukemia in Surabaya. Independent and dependent variables in this research are the family-centered empowerment model and the family's ability to care for children with leukemia, respectively. The results of this study indicated that the influence of family centered empowerment on a family's ability to care for children with leukemia is equal to $T = 3.9159$. The application of family-centered empowerment, based on the improvement of family filial value, will affect the family's ability to care for children with leukemia. More research is needed on such family-centered empowerment models. Factors that affect family empowerment in caring for children leukemia can be considered when providing nursing intervention, especially nurses empowering parents caring for children with leukemia.

1 BACKGROUND

Child with chronic illnesses, such as leukemia, grow and develop in a unique family and cultural environment with many variations. Meeting the health needs of children with chronic illnesses and sustaining family life are two major challenges faced by families (Deatrick & Knafl, 1990; Dunst, 2011; Wuest & Stern, 1991).

Families of children with chronic health conditions often feel helpless in meeting their child's healthcare needs and sustaining family life (Popp, Conway, & Pantaleao, 2015). Based on the results of interviews with mothers whose children were treated for leukemia, it is clear that much daily healthcare advice is time-consuming, unpleasant, and even burdensome. Research into the quality of parental care in the pediatric ward at Soetomo Hospital indicates that 50% of parents make insufficient effort to stimulate the development of their children; parents rarely play with their children and they choose games that are not in accordance with the child's developmental needs (Rachmawati, Ranuh, & Arief, 2016b).

Family empowerment is an intervention that nurses can use to help families (Wright & Leahey, 2000). These interactive interventions are designed to help the family through a process of empowerment, consisting of several stages that can increase trust and family decision making when working with health professionals (Johansson, 2006). Activities are based on assumptions that everyone has the power, ability, and capacity to grow and become more competent. Family empowerment is influenced by several factors, such as demands of care, family factors, patient factors, and healthcare factors, in this case, the nurse (Jones, Winslow, Lee, Burns, & Zhang, 2011). The constituent attributes of family empowerment can be assessed from self-efficacy, motivation, acceptance of threats, responsibility, respect, and care. The expected outcomes for families with such empowerment are to demonstrate the ability to negotiate with health professionals, minimizing the effects of chronic conditions on children and siblings, rearranging family roles and responsibilities, satisfying child healthcare needs, and reducing the need to use healthcare and related costs (Chiu, Wei, Lee, Choovanichvong, & Wong, 2013). Integrated

and holistic cancer prevention should involve all the components of the family because the needs of pediatric patients with cancer are complex; the need to be pain-free, the need for attention, and the need for psychological support (Elcigil & Conk, 2010). To help people with cancer thoroughly takes serious effort and the family's role is very important. Therefore, it is important to determine whether the Family Centered Empowerment Model can improve the family's ability to treat children with leukemia.

2 METHODS

An explanatory survey design was used for this research. An explanation is a way of exploring new things and reporting the relationship between different aspects of a phenomenon. This was then followed by a descriptive study to gain knowledge of the topic and finally, the research findings were explained (Rowley, 2009). Due to the data retrieval time, a cross-sectional design was used, with which the cause and effect of variables were studied and measured at the same time; all measured variables form latent variables. The first phase of this study explored the gap between the findings/facts with theories relating to factors that can realize family-centered empowerment. At this stage, factors that could affect family-centered empowerment were explored, comprising family factors, factors of patients, and factors of nurses. The samples in this study were 140 respondents from families who had children suffering from leukemia in Surabaya. A consecutive method was used for the sampling technique based on inclusion criteria. To discover families' ability to care for children with leukemia in this study, the instruments used were: the Health Status Questionnaire (HSQ-12), Personal Growth Initiative Scales (PGIS), and the Spiritual Well-being Scale (SWBS). This research has obtained the approval of ethical conduct from the Soetomo Hospital's ethical committee of Surabaya with the reference number 385/Panke.KKE/V/2017.

3 RESULTS

In this research, it was determined that there is an influence of the family-centered empowerment model equal to $T: 3.91$. The value is greater than the standard t value of 1.96, meaning centered family empowerment in caring for children with leukemia has a significant impact. Indicators of family-centered empowerment are family filial values, comprising of

responsibility, respect, and care. While dimensions of a family's ability consist of perceived health, personal growth, and existential well-being. For each indicator, it is clear that most family-centered empowerment is in the moderate category.

Table 2 indicates that the family's ability needs to comprise of perceived health, personal growth, and existential well-being. Most of the indicators that exist in the family's ability to care for children with leukemia are in the moderate category.

Table 1: Characteristic indicators of family-centered empowerment in the Pediatric Ward RSUD, Dr Soetomo, Surabaya, 2017.

Family-centered empowerment		category	N	%
Indicator	Range			
Responsibility	< 15,48	low	21	15.0
	15,48 < X < 22,35	moderate	96	68.6
	> 22,35	high	23	16.4
Respect	< 15,78	low	12	8.6
	15,78 < X < 22,11	moderate	111	79.3
	> 22,11	high	17	12.1
Care	< 26,24	low	25	17.9
	26,24 < X < 34,21	moderate	93	66.4
	> 34,21	high	22	15.7

Table 2: Characteristic family's ability in caring for children with leukemia in the Pediatric Ward RSUD, Dr Soetomo, Surabaya, 2017.

Family's ability	range	category	N	%
Indicator				
Perceived Health	< 36,66	low	23	16.4
	36,66 < X < 46,82	moderate	103	73.6
	> 46,82	high	23	16.4
Personal Growth	< 28,04	low	20	14.3
	28,04 < X < 38,75	moderate	101	72.1
	> 38,75	high	19	13.6
Existential Well-Being	< 34,14	low	24	17.1
	34,14 < X < 52,07	moderate	101	72.1
	> 52,07	high	15	10.7

Table 3: Influence of family-centered empowerment on family’s ability to caring children with leukemia in pediatric ward RSUD, Dr Soetomo, Surabaya 2017.

Relationship between variables	Original Sample (O)	T Statistics ((O/STERR))
Family-centered Empowerment → family’s ability	0.3401	3.9159

4 DISCUSSION

Family-centered empowerment influencing a family’s ability to care for a child with leukemia comprises of responsibility, respect, and care (Jones et al., 2011). In this research, it was determined that the mean indicator of family-centered empowerment is moderate. Family-centered empowerment is fostered by developing basic family values consisting of responsibility, respect, and care. This is supported by the level of family education mainly in the high school category (73.4%). Pradono (2013) explains that higher levels of an individual’s education provides mature understanding to enable the individual to choose or decide something. The role of family is very important to the family's empowerment in caring for children with leukemia. The higher the motivation, the more empowered families feel in providing that care.

Indicators of a family’s ability to care for a child with leukemia comprises of perceived health, personal growth, and existential well-being. These three indicators are positive care outcomes expected in families treating childhood leukemia. Jones et al. (2011) explains that to cultivate a good family experience in caring for sick family members, there is a need to increase existential well-being, personal growth, and the family’s well-being in terms of both physical and mental health. A family’s ability to care for a child with leukemia can be enhanced through family empowerment (Rachmawati, Ranuh, & Arief, 2016a).

Empowerment embodies various outcomes and well-being and is a necessary condition but is not the main thing. Zimmerman (2000) defines a process whereby people who have been denied the ability to make choices acquire those abilities.

The family provides an assessment of how the health worker, in this case nurses, provides strength, facilitates, and provides support to the family in treating childhood leukemia (Friedman & Marylin, 2003). Families who have received information from

health workers are expected to have good knowledge in healthcare, so they can form a strong responsibility and commitment with the patient to achieve the care goals (American Academy of Pediatrics [AAP], 2003, 2012).

Increased family-based health promotes improved family strength and ability to use coping mechanisms; the role of nurses is to encourage families to provide support in child healthcare and encourage cooperation between nurses and families (Newton, 2007). The role of the family is very important in the stages of health care, from stages of health promotion, prevention, treatment, to rehabilitation (Friedman & Marylin, 2010).

Family empowerment includes a capacity building paradigm (Dunst, 2011) that emphasizes family strength and focuses on family units, not just sick children. Family empowerment provides an opportunity for families to better understand the reality of the family and acquire knowledge and skills to make wise decisions relating to children and families: getting to know the problems/needs, managing childcare effectively, and confidently mastering family challenges (Dunst, 2011).

5 CONCLUSIONS

Empowerment is an ongoing process that develops people's ability and independence and improves their standard of living; this can only be achieved by generating their empowerment, to improve their lives using their own strength (Fotoukian, Mohammadi Shahboulaghi, Fallahi Khoshknab, & Mohammadi, 2014). Factors affecting family empowerment should be considered when providing empowerment interventions, because these factors are a determinant of the success of nursing interventions providing treatment in children with leukemia. Further research is needed specifically to observe other influential variables, such as empowerment intervention by applying the factors influencing the process of empowerment to families.

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