Parent empowerment program in caring for children with leukemia

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KEYWORDS
Leukemia; Parent; Empowerment

Abstract
Objective: The purpose of this study was to analyze family behavior in caring for children with leukemia through the parent empowerment program.
Method: Using a pre/posttest design and pre-experimental research design. The population in this study were 50 families with children suffering from leukemia who underwent treatment in the Dr. Soetomo Surabaya and currently living in the halfway house of the Indonesian Child Cancer Care Foundation (YPKAI) Surabaya.
Results: There was an effect of the application of the parent empowerment program on family behavior in caring for children with leukemia with significance values for knowledge (p = 0.000), attitude (p = 0.000), and action (p = 0.000).
Conclusion: Family behavior in treating children with leukemia consists of indicators of knowledge, attitudes, and actions. Nurses can facilitate families through the implementation of the parent empowerment program to collaborate with doctors in treating children with leukemia.

Introduction
Cancer is one of the chronic diseases in children. Caregivers or families who have children with chronic conditions are faced with demands, challenges, emotional and cognitive problems, as well as changing roles in family and society. Families of children with chronic health conditions often feel helpless in meeting their child’s healthcare needs and in sustaining their family lives.

In addition, accompanying children undergoing cancer treatment will have the impact of severe and prolonged stress on parents, especially mothers. Parents will find it difficult to understand the feelings and conditions experienced by their children. Ignorance of children’s financial needs and care as well as social life also affect psychologists and physical parents, especially mothers,

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in caring for children with leukemia. A study by Knafl and colleagues found that parents whose children had acute lymphoblastic leukemia experienced anxiety, especially mothers.

Cancer prevention in an integrated and holistic way should involve all components of the family because the needs of cancer patients are very complex, the need to be pain-free, the need to be cared for, and the need for psychological support. Family-centered care emphasizes the importance of family involvement and empowerment to provide care for children. The study shows that the application of family-centered care in practice treats families attentively, communicates information to families so that they understand the conditions and care of their children, involves family participation in decision-making and child care, and cooperation between families and nurse. Through family empowerment, it is expected to help families so that they can make changes. The parent empowerment program (PEP) is expected as an effort to improve family behavior in caring for children with leukemia.

**Method**

This study uses pre/posttest design and pre-experimental research design. The population in this study was 50 families with children suffering from leukemia who underwent treatment in the Dr. Soetomo Surabaya and currently living in the halfway house of the Indonesian Child Cancer Care Foundation (YPKAI) Surabaya. Fifty respondents were selected using purposive sampling technique. The independent variable in this study is the family empowerment program, and the dependent variable is family behavior in treating children with leukemia as measured by knowledge, attitudes, and actions.

**Results**

The results in this study indicate that showing the value of knowledge in families with cancer patients before being given treatment has an average value of knowledge of 9.00 and is increased after being given treatment with an average value of 12.00. Statistical analysis of family knowledge in treating children with leukemia shows a significance level of $p=0.000 (<0.05)$ (Table 1).

Family attitudes in treating children with leukemia before intervention were mostly in the negative category of 28 people (56%) with an average attitude score of 23.36. Family attitudes in caring for children with leukemia after being given intervention were mostly in the category of positive with 36 people (72%) with the average value of attitude of 25.04. Statistical analysis of family attitudes in caring for children with leukemia shows a significance level of $p=0.000$ (Table 2).

| Table 2 | Family attitude about family care with family members suffering from cancer. |
|---|---|---|
| No | Pretest (family attitude) | Posttest (family attitude) | Wilcoxon |
| Mean | SD | Mean | SD |
| 23.36 | 3.199 | 25.04 | 1.106 |

| Table 3 | Family action about family care with family members suffering from cancer. |
|---|---|---|
| No | Pretest (family action) | Posttest (family action) | Wilcoxon |
| Mean | SD | Mean | SD |
| 15.24 | 2.568 | 17.34 | 2.228 |

Family actions in treating children with leukemia prior to intervention are in the category of action as many as 34 people (68%) with an average value of action of 15.24. Family actions in caring for children with leukemia after being given an intervention experienced an increase with an average value of 17.34, with most being in the good category of as many as 32 people (64%). Statistical analysis of family actions in treating children with leukemia shows a significance level of $p=0.000$ (Table 3).

**Discussion**

Strategies that emphasize knowledge and deepening knowledge are academic change strategies that provide primary influence. A parent empowerment program is an intervention approach to the family in an effort to improve the ability of families to care for children with leukemia. Family empowerment is an intervention that nurses can use to help families. Family-centered empowerment can improve the family ability to care for children with leukemia. These interactive interventions are designed to help families through the empowerment process, which consists of several stages and which can increase trust and family decision-making to work with health professionals. Activities are based on the assumption that everyone has the strength, ability, and capacity to grow and become more competent. Family empowerment is influenced by several factors, such as care demands, family factors, patient factors and healthcare factors, in this case, nurses. The constituent attributes of family empowerment can be assessed from self-efficacy, motivation, acceptance of threats, responsibility, respect, and care. The expected results for families with such empowerment are the ability to negotiate with health professionals, minimize the effects of chronic conditions on children and siblings, reorganize family roles and responsibilities, meet child healthcare needs, and reduce healthcare use and costs. Knowledge of caring for cancer patients will enable patients and families to understand so that they are motivated to try to overcome the recurrences that occur due to cancer. The knowledge that increases after
the intervention is theoretically linked to education. The higher one’s education, the easier it will be to accept or adjust to new things. Education influences one’s learning process, so someone with higher education will tend to get more information easily. Knowledge about the care of families who suffer from cancer is given to the family through the parent empowerment program, to optimize family functions in the field of health; otherwise, it will have an impact on the degree of recurrence of the patient and affect the activity.

Attitude is the response of someone who is still closed to a stimulus or object. The component of attitude consists of trust (belief), ideas and concepts of an object, emotional life or emotional evaluation of an object and tendency to act. According to Wright, trust is a sub-category of assessment, which is something that underlies ideas, opinions, and assumptions that are owned by individuals and families. Changes in the knowledge domain are intermediaries for changing attitudes and behavior. In this affective domain, the family is facilitated to share the experiences of children suffering from leukemia and provide family support. Knowledge and attitude also play a role as predisposing factors. Knowledge of cancer treatment that has been good will bring about a response in the respondents in the form of a positive attitude. A positive attitude will be reflected in the individual’s behavior in applying cancer treatment. The act of care for families with cancer in the family is in line with the concept of cybernetics, which is the ability to organize themselves in the family process through the feedback process. Intrapersonal systems are primarily families that can be seen from feedback that occurs due to the behavior of a person that influences and is influenced by the behavior of others.

A study stated that, through learning, people are able to change behavior from previous behaviors and display their abilities according to needs. Calgary intervention in the cognitive domain is one of the enabling factors for the formation of behavior. Knowledge and attitude also play a role as predisposing factors. Knowledge of cancer care that has been good will bring a response in the respondent in the form of a positive attitude. A positive attitude will be reflected in the behavior of individuals in applying cancer care. The Calgary family study model approach in the parent empowerment program can improve knowledge, attitudes, and care actions for families with cancer patients. Nurses in the field of nursing science of children in the community can use the Calgary family intervention model approach in the care of cancer patients in optimizing the role of families. Families can collaborate with the health team in monitoring the development of the condition of children suffering from leukemia. In this research, the authors declare that they have no conflict of interest.

Conflict of interests

The authors declare no conflict of interest.

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References