

## ORIGINAL PAPER

## REDUCING ACUTE STRESS DISORDERS IN MOTHERS OF LEUKEMIC CHILDREN BY MEANS OF THE FAMILY CENTERED EMPOWERMENT MODULE (FACE)

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**Abstract**

**Aim:** To analyze the effect of a parenting empowerment module, with the aim of reducing the stress experienced by the mothers of children suffering from leukemia. **Design:** The study used a quasi-experimental pre-test/post-test control group. **Methods:** The sample consisted of 60 mothers of leukemic children hospitalized in a pediatric oncology ward who met the inclusion criteria. The independent variable was the Family Centered Empowerment Module (FACE), which includes instruction on meeting nutritional needs, preventing infection, and preventing bleeding. The dependent variable was the stress experienced by mothers due to the hospitalization of their children. The instrument used for measuring stress of hospitalization was the DASS-21 questionnaire. The statistical tests used were Wilcoxon's signed rank test, and the Mann Whitney U Test (significance level  $\alpha = 0.05$ ). **Results:** There was a decrease in levels of stress in the intervention group ( $p = 0.001$ ). In the control group there were differences in levels of stress both before and after treatment ( $p = 0.042$ ). The results of the Mann Whitney U test indicated  $p = 0.017$ . **Conclusion:** Cognitive empowerment can improve the understanding of parents caring for leukemic children, and reduces the levels of stress associated with child hospitalization.

**Keywords:** acute lymphoblastic leukemia, acute stress disorder, empowerment, module, parents.

**Introduction**

The incidence of cancer in children is increasing every year, with the rate currently as high as approximately 130 cases per million children per year. Eighty percent of childhood cancer cases occur in developing countries. Indonesia has a child cancer incidence rate of 11,000 cases per year (Indonesian Childhood Cancer Foundation, 2017). The most common type of cancer in children is Acute Lymphoblastic Leukemia (ALL), accounting for up to 35.5% of cases (Gandhi et al., 2017), and a study by Krisnana (2013) ranked ALL as the most prevalent form of cancer documented in children. Based on the data from the children's oncology and hematology division of Soetomo General Hospital, the number of new leukemia cases in children in 2015 was 106. In 2016, 108 children were diagnosed, and in 2017, in the January–October period alone, 101 children had been diagnosed.

Parents who have children diagnosed with cancer experience higher levels of stress than parents who do not (Masa'Deh, Collier, Hall, 2012). The results of the study by Krisnana (2013) indicate that 56.7% of parents of children with cancer experience stress ranging from mild to severe. The diagnosis of cancer in children can have an impact on levels of stress of parents, especially mothers (Patiño-Fernández et al., 2008). Education for parents brings several benefits to both parents and children, including a reduction in levels of stress (McCall et al., 2017), and parents should be provided with information sufficient to help restore a sense of control over the state of the child's illness (Nair et al., 2017).

The role of parents in daily childcare is increasing (Aburn, Gott, 2011). Family-Centered Care (FCC) has long been recognized as a philosophy in child nursing (Dennis et al., 2017). The application of the family-centered care principle to nursing care provides a positive experience for parents (Arabiat et al., 2018). The application of knowledge modules to parents can increase their knowledge and reduce stress (Patra, Arun Chavan, 2015). The parent empowerment

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module is a module that can be given to mothers who actively care for children with chronic diseases, such as leukemia, in hospitals, as this media is designed systematically and attractively in order to achieve the desired competencies. There has been no previous research into the use of empowerment modules to reduce the stress of hospitalization, much less any research focusing specifically on the stress experienced by parents of hospitalized children.

## **Aim**

The aim of this study was to analyze the effect of a parenting empowerment module, with the aim of reducing the stress experienced by mothers of children suffering from leukemia.

## **Methods**

### **Design**

The design of this study was quasi-experimental.

### **Sample**

The study population consisted of mothers of leukemic children receiving treatment in the inpatient ward of the oncology department at Soetomo General Hospital, Surabaya, in December 2017 (a total of 60 parents). The sample of this study was determined based on the following inclusion criteria: 1) mothers of children hospitalized with leukemia, who were either new patients or established patients in the pediatric ward; and 2) mothers of patients who had received chemotherapy. Subjects who met the inclusion criteria were randomly assigned to either the control group or intervention group. The independent variable in this study was the provision of empowerment modules to the mothers of patients with leukemic children. The dependent variable in this study was the level of stress experienced by mothers during the period of hospitalization.

### **Data collection**

#### *Selection of respondents*

The initial process of data collection was completed by selecting candidates according to the inclusion criteria. The subjects in this study were mothers of children diagnosed with leukemia (both old and new diagnoses). New patients were those who had recently entered the inpatient oncology ward for the first time (five patients). The total number of leukemia patients from January 2017 to May 2017 was 300 children, with the average number of leukemia cases per month being 60 children. The sample formula consisted of 30 samples in the control group and 30 samples in the intervention group.

### *Pre-intervention*

Prior to the intervention, a researcher explained the purpose and benefits of the study, and asked prospective research respondents to complete and sign a consent form. The intervention and control groups were randomly selected. In the next stage questionnaires were distributed to respondents, the results of which were used as pre-test data. The researcher guaranteed the anonymity of the respondents, and gave assurances regarding the confidentiality of their data.

### *Instruments*

The empowerment module for the parents in this study contained information designed to improve the cognitive abilities of the mothers of leukemic children in an active caring role. The module used was a modification of the FACE Module/Family Centered Empowerment Module. Cognitive empowerment includes instruction on how to care for children by meeting their nutritional needs, preventing infection, and preventing bleeding. The modules were presented twice a week in the intervention group, followed by an observation over the following two weeks for both the intervention and the control groups. The questionnaire used was the Depression Anxiety Stress Scale 21 (DASS), as used in a study by Lovibond and Lovibond (1995), translated by Damanik (2011). It was used to determine the mothers' physical and psychological responses. The validity test results obtained 21 valid items with a reliability value of  $r = 0.9483$ . The questionnaire consisted of questions about the condition of the mothers, who could choose from the following responses: "0: never; 1: sometimes; 2: often; and 3: very often". The level of stress was determined by the following scores: normal: 0–14, mild: 15–18, moderate: 19–25, severe: 26–33, and very severe > 34.

### *Module FACE intervention*

The intervention was presented in two sessions during one week and was led directly by a researcher, and carried out in groups so that training was more effective and participatory, reducing dropout. The contents of the module, i.e. the cognitive aspects of caring for children with leukemia, were explained for about 30 minutes, and the second meeting focused on the same material. The control group received the standard hospital counseling intervention from health workers, in the form of a leaflet about caring for leukemic children.

### *Post intervention*

The final stage of data collection was the completion of the second stage of the questionnaire following the intervention. The results of the questionnaire from the

second data collection are referred to as post-test data and were preceded by a period of internalization or “settling”.

### Data analysis

A homogeneity test was carried out on the pre-test scores between the treatment group and the control group. The homogeneity test used statistical data, and had a significance level of  $p > 0.05$ . The statistics were tested using the Wilcoxon signed rank test and the Mann Whitney U test ( $\alpha = 0.05$ ).

## Results

The age distribution of the majority of the control group was 31–40 years old (16 respondents; 53.33%), and in the intervention group the majority were also 31–40 years old (18 people; 60%). The majority of the control group had completed high school education or the equivalent level of vocational education (13 respondents; 43.33%). In the intervention group, there was an even split between respondents with high school / vocational-equivalent education (11 respondents; 36.67%) and those with a lower level of education. Regarding occupation of mothers in the control group, the majority were housewives

**Table 1** The demographic data of respondents (n = 60)

Characteristics	Indicators	Control group		Intervention group	
		Frequency	%	Frequency	%
Age (years)	≤ 30	8	26.67	5	16.67
	31–40	16	53.33	18	60.00
	41–50	6	20.00	6	20.00
	> 50	0	0.00	1	3.33
	total	30	100.00	30	100.00
Education level	elementary school	3	10.00	5	16.67
	junior high school	5	16.67	6	20.00
	senior high school	13	43.33	11	36.67
	bachelor	9	30.00	8	26.67
	total	30	100.00	30	100.00
Occupation	housewives	23	76.67	13	43.33
	farmers	0	0.00	1	3.33
	employers	2	6.67	9	30.00
	entrepreneurs	4	13.33	7	23.33
	civil servants	1	3.33	0	0.00
	total	30	100.00	30	100.00
Length of work per day	8 hours	6	20.00	12	40.00
	>8 hours	23	76.67	7	23.33
	Part time	1	3.33	8	26.67
	Shifting time	0	0.00	3	10.00
	total	30	100.00	30	100.00
Income/ month	< Rp 500,000	1	3.33	3	10.00
	Rp 500,000 s/d Rp 1,500,000	8	26.67	5	16.67
	Rp 1,500,000 s/d Rp 2,500,000	9	30.00	5	16.67
	> Rp 2,500,000	7	23.33	11	36.67
	minimum salary based on east java province	5	16.67	6	20.00
	total	30	100.00	30	100.00
Funding	self-funding	0	0.00	0	0.00
	national insurance	30	100.00	30	100.00
	total	30	100.00	30	100.00
Length of stay (month)	< 1	12	40.00	2	6.67
	1 s/d < 2	7	23.33	16	53.33
	2 s/d < 3	3	10.00	10	33.33
	3 s/d 4	5	16.67	2	6.67
	> 4	3	10.00	0	0.00
	total	30	100.00	30	100.00

(23 respondents; 76.67%). The majority of the intervention group were also housewives (13 respondents; 43.33%). The distribution based on the working pattern of the mothers in the control group indicated that as many as 23 respondents (76.67%) worked more than eight hours, while in the intervention group a majority of 12 respondents (40%) worked according to the usual average of 7–8 working hours. Regarding the distribution of family income, nine respondents (30%) in the control group earned between Rp. 1,500,000 and Rp. 2,500,000 per month, while in the intervention group the majority earned > Rp. 2,500,000 (11 respondents; 36.67%). All 30 respondents (100%) relied on national insurance to fund treatment. The distribution of the length of the stay of the control group revealed that the majority had been in hospital for less than a month (12 respondents; 40%), while the majority of the intervention group had been in hospital for between one and two months (16 respondents; 53.33%) (see Table 1).

The homogeneity test results were  $p = 0.49$ , i.e.,  $p > 0.05$ , indicating that the intervention group and the

control group had a homogeneous pre-test value. Average levels of stress were in the normal range (12.27). The highest score in the intervention group before presentation of the FACE module indicated severe stress, while in the control group the average levels of stress indicated a moderate stress level. After one week of the FACE module, the average levels of stress of parents in the intervention group decreased to a score of 8.33 – lower than before the intervention module. The control group also experienced a decrease in mean score to 12.80, indicating a normal level of stress. The results of statistical analysis, using the Wilcoxon signed rank test, indicated that there were significant differences in levels of stress before and after the FACE module intervention, with a value of  $p = 0.001$ . The control group also experienced a significant difference in stress levels, with a value of  $p = 0.042$  ( $p < 0.05$ ). The results of statistical analysis using the Mann Whitney test indicated that application of the FACE module had an effect on the stress levels of parents of hospitalized leukemic children, with a value of  $p = 0.017$  (see Table 2).

**Table 2** The statistical test influence of the FACE module on the stress of hospitalization experienced by the parents of children with leukemia

	mean	min-max	SD	p*
Intervention group				0.017
Post-test	8.33	0-22	6.434	
Control group				
Post-test	12.80	4-38	7.117	

\*Mann Whitney test significance  $p < 0.05$

## Discussion

The results showed that the majority of the respondents had normal, mild, and moderate stress levels. Stress levels in the intervention group before receiving the FACE module intervention were in the normal range, with a mean score of 12.27. After the FACE module intervention, the mean intervention group score decreased to 8.33. This result might have been affected by the length of time that children were admitted to the hospital for. Mothers are preoccupied with waiting for their children to leave hospital, so the number of opportunities to relax are limited and the pattern of working and taking care of the household is disrupted (Krisnana, 2013). Most mothers who have children with leukemia are in a state of denial regarding their children's disease (Krisnana, Kurnia, Purweni, 2018). Clinical symptoms of distress are experienced by parents in the first year of the disease (Katz et al., 2018).

Parents should be provided with the right information when their child has cancer (Karst et al., 2018). Parents must be provided with adequate information

and the skills necessary for their child's cancer care (Rodgers et al., 2018). Parental levels of stress before the module was presented [the Family Centered Empowerment (FACE) module] indicated an average level of stress, but there were also respondents who experienced severe stress levels, with a score of 28. After the presentation of the FACE module, the stress level of the respondents decreased, with the average score falling to 8.33. The highest score for level of stress following the intervention was 22, a moderate level of stress, indicating that the FACE module can reduce parental stress levels (the results of the statistical test being  $p = 0.001$ ).

The FACE module intervention was presented to the groups of parents in such a way as to enable a degree of interaction between the respondents and the researchers. The interactions were in the form of questions, with parents providing information about the condition of their children. Information about childcare and cancer was well received by the respondents, aided by the education level of the

majority of parents, who had a high school level of education. Level of education was the strongest factor in shaping alertness and preventive behavior (Padovese et al., 2018). In addition, some mothers were housewives, and so had sufficient time to care for their children using the new information.

The results of the statistical test in the control group indicated that there was a decrease in the mean score during the seven days of treatment, from a mild stress level down to a normal level of stress. Regarding the highest scores in the control group, there were still respondents who experienced severe levels of stress. The results of the statistical tests using the Mann Whitney U test indicated that the FACE Module can cause a decrease in parental stress levels ( $p = 0.017$ ). Some of the previous research on the use of modules has indicated that they can increase knowledge (Jones, McEwen, 2015; Xu et al., 2018). Adequate knowledge about the disease, the diagnostic tests involved, and cancer treatment can reduce parental stress and anxiety, which can, in turn, increase the level of cooperation from parents in relation to care and treatment (Nair et al., 2017).

#### Limitation of study

This study used a small sample of 30 respondents in the intervention group and 30 respondents in the control group.

#### Conclusion

The FACE module can reduce stress levels in parents of children with leukemia. Information about nutritional needs, prevention of infection, and prevention of bleeding can increase parental knowledge, giving parents the confidence to care for their own children. Adequate knowledge about child care can reduce parental stress.

#### Ethical aspects and conflict of interest

There were no potential conflicts of interest. All respondents in this study received an explanation of the research before completing and signing an informed consent form. The respondents' anonymity was protected, and the study satisfied the ethical clearance standards of the Health and Research Ethics Commission (certificate number 760/XX.XX.X/2018).

#### Acknowledgement

We would like to thank the mothers and children, and the head nurse, and all nurses and physicians in the pediatric ward.

#### Author contribution

Collection of data and administration of ethical clearance procedures in the hospital (HS). Writing of the manuscript and analysis (IK, IDK). Checking of the manuscript and translation (PDR). Compilation of the FACE Module (YSA).

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