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The Effectiveness of Parent Education in Discharge-Symptom Management (PED-SM) on Parental Readiness to Care for Children with Cancer

Ruriwinta[1], Agni Laili Perdani[2], Nyayu Nina Calisanie[3,4], Nyimas Heny P[1]

[1]Muhammadiyah University of Jakarta, Jakarta, Indonesia
[2]Department of Pediatric Nursing, STIKep PPNI Jawa Barat, Indonesia
[3]Department of Emergency and Critical Care, STIKep PPNI Jawa Barat, Indonesia
[4]Department of Nursing, Lincoln University of College, Malaysia

***Corresponding email:** ruriwinita94@yahoo.com

A B S T R A C T

Introduction: Cancer in children is a life-threatening disease that has been steadily increasing over the past few decades. Parents are concerned about how to appropriately care for children due to the physical symptoms experienced by children with cancer. **Objective:** The purpose of this study was to determine the effect of Parent Education in Discharge Symptom Management (PED-SM) on parental readiness to care for children with cancer. **Methods:** This research utilized a quasi-experimental design with intervention and control groups, measured using a pre-post test design. Respondents in this study were parents of children aged 3 to 12 years newly diagnosed with cancer. A convenience sampling method was employed. The instrument used in this study was the I-PCS (Preparedness of Caregiving Scale-Indonesian) with a Cronbach's alpha of 0.73-0.78, where a Pearson's r > 0.320 indicates validity. **Results:** A total of 58 respondents agreed to participate in this study. The mean age of parents was higher in the control group (39.48), while the mean age of children was lower (7.38). More than half of the children were boys with ALL/AML cancer types. Parents mostly worked full time, had education up to junior or senior high school, and had a monthly income of 4.9 million. There was a statistically significant difference after the intervention in both groups, with a p-value < 0.005. However, the mean score after intervention (45.76 ± 5.81) was higher compared to the control group (32.34 ± 4.41). Employment showed a significant contribution of 6.52 to parental readiness among parents of children with cancer (β: 1.87, 95% CI: 1.29 – 32.97, p-value: 0.02). The intervention of PED-SM can be implemented by pediatric nurses in cancer units as one of educational tool aimed at reducing readmissions and enhancing the quality of life for children. **Conclusion:** The PED-SM module can serve as a reference for educating families of children newly diagnosed with cancer.

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1. INTRODUCTION

The cases of cancer among children have continued to increase over the past few decades and become a burden to caregivers (Chaghazardi, M., Janatolmakan, M., Rezaeian, S., & Khatony, A. (2022). In the United States, cancer is the second cause of death in children aged 1-14 years, and in 2024, a total of 9620 children will be diagnosed with cancer (Siegel, R. L., Giaquinto, A. N., & Jemal, A. (2024). Based on national data there were more than 4000 children with cancer in Indonesia (Agustina, J., Sinulingga, D. T., Suzanna, E., Tehuteru, E., Ramadhan, R., & Kadir, A, 2018) and Acute Lymphoblastic Leukemia (ALL) is the most frequent type of cases (Perdana, A. B., Saputra, F., & Aisyi, M. (2020). More than 50% of cancer cases in children who come to health facilities are already in an advanced stage.

The lack of parental education and knowledge about cancer is a contributing factor to children presenting with advanced stages of the disease. Childhood cancer is a life-threatening illness that presents significant challenges to parents and families (Schoors et al., 2019). Anxiety among patients and their families escalates concerning procedures, treatments, and pain during the initial year of treatment. According to Dupuis et al. (2016), nausea symptoms were notably severe on average in the month following diagnosis compared to subsequent evaluations.

Not all parents understand all the phases of disease and cancer treatment. Parental readiness in caring for cancer children is a vital part because contributes to the entire process of cancer management. The main factors influencing caregiver readiness are chemotherapy duration, disease complications, family economic situation, cancer knowledge, and support (Lu, F., Zhang, G., Zhao, X., & Luo, B. (2022). Previous studies explained the difficulty experienced by caregivers/families with caring for children with cancer at home was moderate to severe problems (Huang, R. Y et al, 2022). There was an 86.9% increase in unplanned readmissions from previous encounters in children with cancer due to symptoms after chemotherapy (Hoenk, et al, 2021).

Discharge education for children with cancer increases the effectiveness of the transition from hospital to home. Readmission can be avoided by equipping parents regarding handling their child's cancer at home. Parents often report difficulties with the complexity of information, especially regarding the physical care needed at home for their child (Withycombe, J. et al. 2016). To increase understanding of early discharge education strategies for parents of children with cancer, the *Parent Education Discharge Symptoms Management* (PED-SM) study needs to be developed and implemented (Hockenberry, et al., 2021). PED-SM proved that changes in parents' perceptions of readiness to care revealed a significant increase in parents' readiness from (time 1) to 2 months later (time 3) (Hockenberry, et al., 2021). PED-SM is an intervention aimed at educating families on managing a child's cancer symptoms post-treatment, encompassing knowledge, attitudes, and skills such as deep breathing techniques, distraction techniques, and dietary management (Hockenberry et al., 2021). This intervention different from others because completed approach and fulfill parental needs.

Providing education to parents of children newly diagnosed with cancer is a core responsibility for pediatric cancer nurses (Landier, et al. 2016). Education regarding cancer for parents of children who have just been diagnosed with cancer is very important and has an impact on parents' readiness to care for children with cancer at home, while research results related to this

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have not been found much in Indonesia, therefore researchers want to examine the effect of PED-SM on parental readiness to caring children with cancer.

2. METHODS

Research Design

The research is a quantitative study of a quasi-experimental approach with two groups control and intervention and used measured pre-test and post-test design.

Population and Sample

This study used a convenience sampling method. This study was conducted in one of the biggest military hospitals in Indonesia providing cancer centers in Indonesia during one one-month period of June-July 2023. The population in the study was parents with cancer children aged 3-12 years old, able to read and write, and as primary caregivers of patients. A total of 58 respondents agreed to participate in this study was divided into groups intervention and control with computer application

Instrument

This research used instruments of I-PCS (Preparedness of Caregiving Scale-Indonesian) developed by Sari, I. W. W., & Nirmalasari, N. (2021) with a total of 18 questions using a five Likert scale ranging from 0 (not ready at all) to 4 (very ready). A higher the score indicated a higher readiness score and vice versa. The validity result of Cronbach α was 0.73- 0.78 indicating good reliability and Pearson-r more than 0.320 indicates that the item is valid. I-PCS was proven to be valid and reliable for measuring caregiver preparedness.

Research Procedure

A total of 59 respondents were divided into two groups and intervention was delivered among those groups either PED-SM or regular health education test schedule. At first, informed consent was given to each respondent to fulfill their data. Researchers conducted a pretest using I-PCS before treatment. The intervention of PED-SM was given by researchers t using educational media, health education was given for 80 minutes. The intervention is structured into 5 minutes of opening, 15 minutes of presentation, 15 minutes of demonstration, followed by 20 minutes of re-demonstration, 15 minutes allocated for questions and answers, and concludes with 10 minutes for summary and closing. Meanwhile, the control group was only given basic education using leaflets that have been implemented in hospitals. In the end, researchers conducted a post-test on the intervention and control groups on the day the patient was scheduled to go home, to assess the readiness of mothers to care for children with cancer after treatment.

Data Analysis

The normality test of Shapiro-wilk is carried and the results indicate a normality value $\leq$ 0.05, so it can be concluded that the data used is data with normal distribution, therefore data was analyzed using a parametric test of Independent T-Test and Multivariate Regression.

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Ethical Clearance

This study gained ethical permission from the Ethic Committee- University of Muhammadiyah Jakarta Number 0765/F.9-UMJ/VI/2023 on June 9th, 2023, and therefore this study able to be conducted because no human rights violation or harm to respondents should be taken into consideration from this study.

3. RESULTS

Table 1. Demographic Characteristics among Parents and Children with Cancer (n=58)

Variables	Intervention (N=29)	Control (N=29)	p-value
Age (mean)			
Parents	37.62	39.48	0.93
Children	9.17	7.38	0.95
Gender Children (n, %)			0.69
Boys	19 (65.6)	16 (55.2)	
Girls	10 (34.5)	13 (44.8)	
Latest Parents Education			0.59
Elementary	1 (3.4)	1 (3.4)	
Junior High School	10 (34.5)	6 (20.7)	
Senior High School	10 (34.5)	17 (58.6)	
Higher Education	8 (22.6)	5 (17.2)	
Employment Parent Status			0.26
Full-time worker	16 (55.2)	15 (51.7)	
Unemployment	13 (44.8)	14 (48.3)	
Monthly Income			0.94
≥ 4.9 million IDR	7 (24.1)	6 (20.7)	
< 4.9 million IDR	22 (75.9)	23 (79.3)	
Cancer Types			
ALL/AML	14 (48.2)	17 (58.6)	0.71
Wilms Tumor	4 (13.8)	5 (17.2)	
Osteosarcoma	5 (17.2)	5 (17.2)	
Others (Lymphoma, Ovarium, Retinoblastoma)	10 (20.8)	2 (7)	

Table 2. The Analysis of Effect Intervention among Groups Intervention and Control (n=58)

Variables	Mean ± SD	Mean Difference	SE	p-value
Intervention		26.42		0.00*
Before PED-SM	19.34 ± 2.87		0.53	
After PED-SM	45.76 ± 5.81		0.94	
Control		12.89		0.00*
Before Education	19.45 ± 2.28		0.42	
After Education	32.34 ± 4.41		0.82	

*p-value is significant <0.05

Table 3. Factors Contributing of Readiness among Parents with Cancer Children

Variables	β	SE	OR	95% CI	p-value
Age	0.12	0.08	1.13	0.96 – 1.33	0.13
Employment Status	1.87	0.83	6.52	1.29 – 32.97	0.02*
Latest Education	1.38	0.81	3.95	0.79 – 19.49	0.09

*p-value is significant <0.05

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From Table 1 it can be seen that there is no statistically significant difference in both groups of intervention and control therefore those two groups shared similarities in demographic characteristics. The mean age for parents is higher in the control (39.48) but the mean children is lower (7.38) compared to the intervention group (37.62, 7.38). More than half children are boys. More than 50 % of parents worked full time, the latest education is junior or senior high school, and above 70% of them had 4.9 million monthly income. The majority type of cancer is ALL/AML in both group intervention (n: 14, 48.2%) and control (n: 17; 58.6%)

Based on data from Table 2, there is a statistically significant difference after intervention among both groups with a p-value <0.005. However, the mean after intervention (45.76 ± 5.81) is higher compared to the control group (32.34 ± 4.41) and also the mean difference is higher in the intervention group (26.42) rather than in the control group (12.89). The researcher analyzed all factors in the first model of regression and found that age, employment status, and education were significant to the readiness for hospital discharge but a second model of Logistic Regression was applied it can be concluded from Table 3 that employment showed a significant contribution of 6.52 to readiness among parents with cancer children (β: 1.87, 95% CI: 1.29 – 32.97. p-value: 0.02).

4. DISCUSSION

This research finding prove that PED-SM effectively increase parental readiness and supported by previous study that found the same as the average for children undergoing chemotherapy is 8 years old (Silva-Rodrigues, F. M et al, 2021). A significant effect of providing PED-SM on parents' readiness to care for children with cancer after treatment in the intervention group, compared to providing basic education in the form of leaflets in the control group. Parental readiness increased in both the intervention and control groups compared to before the intervention, attributed to the educational material provided using the Socratic method, which engages both students and educators actively in two-way dialogue.

The incidence of cancer in children aged 5-14 years is 10 per 100,000 children and at the phase of school-age. (Kemenkes. (2018). In general, parents who care for children with cancer are aged 31-40 years and similar to this study (Nurhidayah, I., Hendrawati, S., Mediani, H.S., Adistie, F., (2016). Boys have a higher risk of developing ALL than girls, but it is still unclear why cases of ALL occur more frequently in boys than girls (Tarigan, et al., 2019). This is also supported by several previous studies which say that the majority of children who suffer from cancer are male (Arania, et al., 2021; Nurhidayah, et al., 2016; Innasimuthu, et al., 2022). The research results show that the majority of cancer types are blood cancer types of ALL/AML. The results of this research are supported by Ortiz-Uribe, V.L (2022) which states that leukemia is the most common type of cancer in children at 92.9%.

In this study, parents generally work, where working respondents have better knowledge than respondents who don't work because they can get sources of information from the internet, books, magazines, and friends at work. This is in line with research by Ortiz-Uribe, V.L (2022) where the majority of parents' status is working. Almost all parent's income in this study was above standard. Socioeconomic status can influence behavior in meeting daily family needs. This is in line with Ariska et, al., (2020) who stated that the majority of caregivers' income is < 3.1

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million/month or income below the minimum wage. Caregivers who have full-time work are usually in middle to upper economic status and will have more readiness. The lower a person's income, the lower the opportunity to obtain information about health status and the limited costs of reaching health facilities in the community (Zahra, 2016).

Health promotion can be influenced by method factors, material factors delivered, officers who provide health education, and the tools/media used. PED-SM is a secondary prevention effort or action given after symptoms appear as a result of the stressor experienced (Alligood, 2017). This is in line with research by Desvita, et al., (2022), the average readiness of parents after being given education has increased.

The advantage of PED-SM is that it is a method of discharge education for children with cancer which includes management of chemotherapy symptoms, where by implementing PED-SM it is hoped that parents will be able to manage their children's cancer symptoms independently at home. This is not found in basic education in the form of leaflets, the leaflets only mention the definition of cancer, types, causes, symptoms, and treatment, not including attitudes and skills. Parents' skills in caring for cancer symptoms in children after treatment can reduce symptom scores and improve the child's quality of life.

The PED-SM worksheet provides detailed information and specific actions to assist parents in managing certain physical symptoms. Compared to the strategic approach of the PEDSS (Pediatric Educational Discharge Support) worksheet, the PED-SM worksheet is more concrete, potentially enhancing parental satisfaction with this educational method (Hockenberry et al., 2021).

Successful discharge of children with cancer often hinges on parents' belief that their child is healthy enough to leave the hospital and their understanding of managing the child's cancer symptoms at home (Hockenberry et al., 2020). Post-discharge care remains crucial, particularly for children at high risk of readmission due to complex illnesses. Parents in the intervention group exhibited greater knowledge and more positive attitudes towards caring for children with leukemia undergoing chemotherapy compared to the control group.

5. CONCLUSION

The results of this research and the PED-SM module can be used as a reference for students in providing education to the families of children who have just been diagnosed with cancer. The results of this research show that there are many benefits for families and patients, where families are prepared to treat children's cancer symptoms at home after planning to go home. This PED-SM module can be used as an educational medium by nurses in pediatric cancer units, this can reduce readmissions. and improve children's quality of life.

Child health services are family-centered, so involving the family in care, especially at home, is something that must be done. As a health service unit, it is hoped that health workers can facilitate families in getting the information they need, in order to prevent readmissions, decreased quality of life, and death outside the hospital. The recommendation for future researchers is to examine experience factors on parents' readiness to care for children with cancer at home.

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6. CONFLICT OF INTEREST

The authors state no conflict of interest.

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