

# SOCIAL SUPPORT OF PARENTS OF CHILDREN WITH LEUKEMIA

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**ORIGINAL RESEARCH**

**SOCIAL SUPPORT OF PARENTS OF CHILDREN WITH LEUKEMIA**

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**Abstract**

**Background:** Leukemia in children is not only a stressor for children but also all family members, especially for parents. Caring for children with leukemia relies on the importance of social support to overcome various crises caused by the disease and its treatment. However, parents' perception of social support can be affected by several factors. Thus, assessment of factors that impact social support of parents of children with leukemia is needed.

**Objective:** This study aimed to analyze the social support perceived by parents of children with leukemia and examine the relationship between perceived social support and characteristics of parents and children.

**Methods:** A quantitative study with cross-sectional approach in 104 parents of children with leukemia aged 3-18 years. Social support was measured using Multidimensional Scale of Perceived Social Support (MSPSS) questionnaire. Data were analyzed using univariate analysis, Mann-Whitney U test, Kruskal-Wallis, and Spearman Test.

**Results:** Total scale score of the Multidimensional Scale of Perceived Social Support (MSPSS) of parents of children with leukemia was  $5.74 \pm 0.48$ . The highest subscale score was on family support ( $6.06 \pm 0.46$ ). There were statistically significant differences in MSPSS total scores based on parental education and family income ( $p < 0.05$ ).

**Conclusion:** Nurses play an important role to provide support for parents who have children with leukemia, especially in risky families. Support that nurses can provide among parents of children with leukemia is by giving information about disease and care, empowering the family, and finding support outside the family, such as the source of financial support related to treatment, utilization of cancer foundations, and supporting group and others.

**KEYWORDS**

children with leukemia; parent; social support

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**INTRODUCTION**

Leukemia is the most common form of childhood cancer. It is more common in boys and white, with a peak incidence between 2-5 years of age (Hockenberry & Wilson, 2013). Leukemia accounts for 29% of all childhood cancers (Siegel et al., 2017). In general, leukemia is classified based on how quickly the diseases progresses; acute leukemia, and chronic leukemia. Acute Lymphoblastic Leukemia (ALL) is the most common type of leukemia found in children (American Cancer Society, 2016).

In Indonesia, it is estimated that there are 4,100 new cases of cancer in children every year. Based on the Child Cancer Register Data, Department of Childhood Cancer, Dharmais Hospital Cancer Indonesia, cases of child cancer tend to increase from 2006 to 2014. Over the past 9 years, leukemia is the most common

type of child cancer (Ministry of Health of the Republic of Indonesia, 2015). West Java is one of the provinces in Indonesia with the largest population. The incidence of childhood cancer in West Java is classified as high. In 2017, according to data from the Referral Hospital in West Java, there were 2.102 children hospitalized in that hospital (Hastuti, 2019).

Meanwhile, based on the preliminary research results done by the researcher in 2 hospitals in Bandung, which is the capital city of West Java Province, the number of incidence of children with leukemia in Bandung increases every year. There were 291 children with leukemia who had to undergo treatment in both hospitals in 2017.

Leukemia is one of chronic diseases that require long treatment. For parents of children with chronic diseases, the presence of disease itself can be a greater stressor in care when compared to healthy children. Parents are required to manage disease and care of their children. They also need to continue doing the household chores, balancing work activities, and meeting the physical, social, and emotional needs of other family members. Caring for children with chronic conditions has more energy, time and financial demands (Cousino & Hazen, 2013; Kaakinen et al., 2010). Caring for children with chronic diseases relies on the importance of social support. Social support is one of the effected factors in family coping in the management of cancer children (Fletcher et al., 2010). Social support is reported to have a statistically significant relationship with hopelessness and depression in parents of children with cancer. The more social support, the less hopelessness, and depression suffered by the parents (Bayat et al., 2008).

Social support has been defined as a resource provided by other persons (Altay et al., 2014). Social support is described as a "meta-construct" consisting of several sub-constructs. In some cases, social support includes two constructs, namely received social support and perceived social support (Haber et al., 2007). Measurements of received social support are designed to assess supportive behaviors that are provided to the recipients by their support networks. While measurements of perceived social support are designed to assess recipient's perceptions concerning the general availability of support and/or global satisfaction with support provided (Haber et al., 2007). Social support proposed in this study is perceived social support based on considerations that not all resources given to someone are perceived as social support by that person.

Parents whose children suffer from cancer describe the importance of support to ease their burden at the beginning of the diagnosis, during treatment, end of treatment, even after completing treatment. Adequate support can help families cope with various crises caused by the disease and its treatment (Björk et al., 2011; Björk et al., 2009; Earle et al., 2007; Sundler et al., 2013). Family, friends and significant others are the sources of support perceived by parents who have children with cancer (Altay et al., 2014). The kind of support chosen by parents of children with cancer was emotional support provided by partners and other family members, good communication with doctors, psychologists, nurses, other parents with similar situation, and other support groups. Parents also state the need to contact friends, relatives and other closest people (Kisić et al., 2012).

The Multidimensional Scale of Perceived Social Support (MSPSS) was designed to measure the adequacy of support from three resources: family, friends and significant others (Zimet et al., 1988). The MSPSS questionnaire was widely used in several studies to examine how families who care for sick family members perceive the social support from their family, friends and closest people (Altay et al., 2014; Bayat et al., 2008; Larsen et al., 2013; Winahyu et al., 2015). Furthermore, the questionnaire was used to assess social support perceived by parents of the three sources.

Parents' perceptions of social support can be affected by several factors. The most important factors are family income and education level (Larsen et al., 2013). A study conducted by Altay et al. (2014) showed that the shorter the duration of the disease, the higher the total social support scores of parents who had cancer children. The study results also showed that a lower mean total scale score was found in parents who stated that their expenditure was higher than their income. Another study conducted by Rosenberg-Yunger et al. (2013) stated that single parents need social-emotional, practical and financial support to assist them in taking care their children.

Nurses are health care provider who has the longest interaction with children's families. Nurses can be a consultant on the difficulties of social support of the parents of children with leukemia. It is important for nurses to identify the social support perceived by parents to support children's and family health. Nurses also need to examine the factors at risk in parents who have low social support so that interventions can be carried out to provide adequate social support to parents. This study aims to examine the perceptions of social support perceived by parents of children with leukemia using the MSPSS. This study also focuses on examining the relationship between the total scale scores of perceived social support and the characteristics of parents and children.

## METHODS

### Study design

This was a quantitative study with cross-sectional design approach.

### Setting

This study was conducted in the nursing children ward and polyclinic of two general hospitals in Bandung from 18 April 2018 to 1 June 2018. The hospital is a referral hospital which has sufficient resources to provide treatment for children with cancer.

### Sample

The number of samples were calculated using a cross-sectional study sample calculation formula  $n = \frac{N \times Z\alpha^2 \times p \times q}{d^2 \times (N-1) \times Z\alpha^2 \times p \times q}$  (Nursalam, 2013) with  $p=50\%$  (unknown),  $q=1-p$  (100 %- $p$ ),  $Z\alpha 0.05 = 1.96$ ,  $d = 0.1$ ,  $N = 291$ . Based on the calculation, the minimum samples were 100 respondents. One hundred and four parents joining this research were chosen by purposive sampling technique. The inclusion criteria of this study were: mother or father of more than 18 years old, having leukemia children 3-18 years aged, the main caregivers in the family, living with their children, and was able to read and write. The exclusion criteria were: mother or father having more than one child with chronic disease, and having children with leukemia accompanied by developmental delay.

### Instrument

This study used two instruments, namely demographic questionnaire and the Multidimensional Scale of Perceived Social Support (MSPSS). Questions about demographic characteristics included characteristics of children (age, sex, length of time

diagnosed) and characteristics of parents (age, sex, education level, parents' employment status, family income, and marital status).

The MSPSS consisted of 12 items assessing perceived social support of the parents from significant others (items 1, 2, 5, and 10), family (items 3, 4, 8, and 11) and friends (items 6, 7, 9, and 12) (Zimet et al., 1988). Each item was graded from 1 to 7. The participant could give a minimum of 1 point which means he/she does not agree, and a maximum of 7 points which means he/she agrees. To calculate mean scores, significant other subscale: sum across items 1, 2, 5, & 10, then divided by 4; family subscale: sum across items 3, 4, 8, & 11, then divided by 4; friend subscale: sum across items 6, 7, 9, & 12, then divided by 4. Total Scale: sum across all 12 items, then divided by 12. The range of scores was 1-7. A high score means a high level of perceived social support (Zimet).

The use of the MSPSS instrument in this study was an adaptation of the Indonesian version from the research of Winahyu et al. (2015) with permission. The Cronbach's alpha reliability coefficient was 0.903 and the correlation coefficient (r) was 0.489-0.781. Validity and reliability tests were conducted on 30 respondents before data collection.

#### Ethical consideration

Before collecting data, the researcher conducted ethical clearance from the Research Ethics Committee of Padjadjaran University Bandung on 29 March 2018 number: 253 / UN6.KEP / EC / 2018. The respondents who met the inclusion criteria were offered to be the participants of the study. The participation was voluntary. The respondents were asked to fill out a questionnaire provided by the researcher. For the confidentiality purpose, the researcher did not display information about identity, both name and address of the respondent in the questionnaire. The researchers used initials or identification numbers as a substitute for the identity of the respondents. The study was conducted after obtaining permission

from the head of two general hospitals. The author confirmed that all respondents have been well informed regarding the procedure of the study and have provided consent to participate in this study.

#### Data analysis

Descriptive analysis was carried out to the mean and standard deviation for continuous variables, and frequency and percentage for categorical variables. Normality test used was Kolmogorov-Smirnov. The results of the normality test showed that the dependent variable (social support) is not normally distributed. The bivariate analysis used were Mann-Whitney U, Kruskal-Wallis and Spearman test. Mann-Whitney U is used to compare scores of dependent variables that are not normally distributed with ordinal 2 groups independent variables. Meanwhile, Kruskal-Wallis is used if there were 3 groups. Spearman Test was used to examine correlation between dependent variables that were not normally distributed with independent variables.

## RESULTS

Table 1 showed the characteristics of children and parents. The age of the children in this study ranged from 3 to 16.4 years, with the mean of age of 8 years. There were slightly more boys (51%) than girls (49%). The length of time after diagnosis ranged from 3 to 60 months, with the mean time of 15.5 months. The age of parents ranged from 21 to 58 years, with the mean age of 37.9. The majority of respondents were women (83.7%) or mothers of the children. Nevertheless, there were also some males or fathers acted as the primary caregivers of children (16.3). Most parents did not work (64.4%) as they were housewives. The majority of parents had primary education level (60.6%) with income less than Rp. 1,500,000 every month. The majority of parents are married (86.5%), and only a small percentage of parents were single parents (13.5%).

Table 1 Descriptive Characteristic of Children and Parents (n=104)

Characteristics	n(%)	M±SD (Min-Max)
Child's Age (year)		8±4.2 (3 – 16.4)
Parent's Age (year)		37.9±7.4(21-58)
Length of time diagnosis (month)		15.5±13.2 (3 – 60)
<b>Child's Sex</b>		
Male	53(51)	
Female	51(49)	
<b>Parents' Sex</b>		
Male	17(16.3%)	
Female	87(83.7%)	
<b>Parents Education</b>		
Primary Education	63(60.6)	
Secondary Education	33(31.7)	
High Education	8(7.7)	
<b>Parent's Employment Status</b>		
Unemployed	67(64.4)	
Employed	37(35.6)	

Characteristics	n(%)	M±SD (Min-Max)
<b>Family Income</b>		
< Rp 1.500.000	48(46.2)	
Rp 1.500.000 – 2.500.000	15(14.4)	
Rp 2.500.000 – 3.500.000	21(20.2)	
> Rp 3.500.000	20(19.2)	
<b>Parent's Marital Status</b>		
Divorced/Single Parent	14 (13.5)	
Married	90(86.5)	

Description: n = number, % = percentage, M = mean, SD = standard deviation

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**Table 2** Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents (n= 104)

Variable	Mean	SD	Range <sup>a</sup>	Range <sup>b</sup>
<b>Subscales:</b>				
Significant Others	5.96	0.45	4.50-7	1-7
Family	6.06	0.46	5.00-7	1-7
Friend	5.20	1.02	2.00-7	1-7
<b>3</b> <b>Total Scale</b>	5.74	0.48	4.33-7	1-7

Range <sup>a</sup>= Range of score based on sample's responses | Range <sup>b</sup>= Range of score based on the questionnaires

The total scale score as shown in **Table 2** is 5.74 ± 0.48 (min 4.33 – max 7). The family sub-scale score is the highest in comparison to the scores of sub-scale significant other and friends. While **Table 3** showed the MSPSS total scale scores based on the child's

**20** the parent's age, and length of time of diagnosis of leukemia. There was no statistically significant correlation between the MSPSS total scale scores with child's and parent's age and length time of diagnosis ( $p > 0.05$ ).

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**Table 3** Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents and Child's Age, Parent's Age and Length of Time of Diagnosis (n= 104)

Characteristics	Perceived Social Support	
	r	p value
Child's Age	-0.050	0.611
Length of Time of Diagnosis	0.080	0.417
Parent's Age	0.017	0.862

Note: analysis using Spearman test

**1**

**Table 4** Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents and Child's Sex, Parent's Sex, Parent's Employment, and Parent's Marital Status (n= 104)

Characteristics	Perceived Social Support			
	n	M±SD	U	p value
<b>Child's Sex</b>			1245.000	0.486
Male	53	5.80±0.49		
Female	51	5.67±0.46		
<b>Parent's Sex</b>			564.000	0.120
Male	17	5.55±0.57		
Female	87	5.78±0.45		
<b>Parent's Employment Status</b>			1048.500	0.192
Employed	37	5.67±0.41		
Unemployed	67	5.67±0.50		
<b>Parent's Marital Status</b>			438.500	0.066
Married	90	5.77±0.49		
Divorced/Single Parents	14	5.57±0.38		

Note: analysis using Mann-Whitney U

**2**



Based on **Table 4** above, there were no statistically significant differences in MSPSS total scale scores of parents based on child's and parent's sex, parent's employment status, and parent's marital status ( $p > 0.05$ ). And **Table 5** shows that there were

significant differences in MSPSS total scale scores of parent based on parent's education and family income ( $p < 0.05$ ). The higher education and income of parents, the higher social support perceived by the parents.

**Table 5** Multidimensional Scale of Perceived Social Support (MSPSS) Scores of Parents and Parent's Education and Family Income (n= 104)

Characteristics	Perceived Social Support			
	n	M±SD	K-W	p value
<b>Parents Education</b>				
Primary Education	63	5.68±0.42	9.539	0.008
Secondary Education	33	5.73±.054		
High Education	8	6.23±.043		
<b>Family Income</b>				
< Rp 1.500.000	48	5.66 ±0.45	11.175	0.011
Rp 1.500.000 – 2.500.000	15	5.85±0.40		
Rp 2.500.000 – 3.500.000	21	5.63±0.59		
>Rp 3.500.000	20	5.97±0.42		

Note: analysis using Kruskal-Wallis

## DISCUSSION

This study showed the total scale score of social support of parents of children with leukemia measured by the Multidimensional Scale of Perceived Social Support (MSPSS)  $5.74 \pm 0.48$  (min 1, max 7). Zimet classified the mean scores of 5.1 to 7 as high support. The highest subscale score was on family support ( $6.06 \pm 0.46$ ). The results in the study were different from previous studies conducted by Altay et al. (2014) in Turkey which showed that the score of parents of children with cancer was  $51.18 \pm 25.30$  (min. 12, max. 84) and the highest subscale score was significant other support ( $19.97 \pm 10.56$ ) (min. 4, max. 28). The perceived social support of parents classified moderate support.

The high social support perceived by parents in this study is probably related to the socio-cultural conditions. Glazer (2006) showed that perceptions of social support can differ from one culture to another. There is indeed a different culture between Bandung and another region in West Country. Based on the characteristics of Indonesian culture in general, communities in Indonesia have high cooperation and family culture, which resulted on high support perceived by parents.

Parent's education and family income were other factors affecting parents' perceptions of social support in this study. The total subscale score of perceived social support in parents with a low educational level was lower in comparison to parents who were middle and high educated. Statistically, this study found the value was significant ( $p < 0.05$ ). Most of the respondents in this study had completed formal education up to elementary and junior high school (60.6%). Parental education influences in health-seeking behavior (Rabbani & Alexander, 2009). Health professionals can be a source of social support needed by parents. One of supports needed by parents of children with cancer was emotional support provided by health professionals such as doctors, psychologists,

nurses and support groups from the parent with the same experience (Kisić et al., 2012).

There was a statistically significant difference between the total scale score of perceived social support of parents with low income (<Rp.1.500.000) and the level of income above it ( $p < 0.05$ ). The higher family income, the more social supports perceived by parents. The results of this study were supported by previous studies conducted by Altay et al. (2014) that the family income was a risk factor of parent social support. The total score of social support perceived by parents was lower in parents who reported more expenses than income. Low family income levels, receiving support, and educational level were risk factors affecting access to care (Larsen et al., 2013).

Child's and parent's age in this study were not statistically significant to the total scale of perceived social support of parents with leukemia ( $p > 0.05$ ). These results were supported by the research conducted by Altay et al. (2014) showed there was no significant difference between social support and age. The length of diagnosis in this study was not statistically significant to the perceived social support of parents with leukemia ( $p > 0.05$ ). The results of these studies were not supported by the research conducted by Altay et al. (2014) which showed that perceived social support was negatively correlated with the duration of illness and statistically significant correlation ( $r = -0.272, p = 0.01$ ). The total scale score increased as the duration of the disease got shorter (Altay et al., 2014).

The child's and parent's sex, parent's employment, and parent's marital status were not statistically significant to the total scale scores of parent's perceived social support ( $p > 0.05$ ). This was supported by the research conducted by Altay et al. (2014) that showed that there was no difference in social support scores based on sex. Although there were differences in scores between perceived social support of single parents and married parents,

but it was not statistically significant ( $p=0.06$ ). Previous research showed that single parents had difficulty in managing their child's disease. It was caused by a lack of emotional and financial support as they are looking after their ill children (Crosier et al., 2007; Mullins et al., 2010; Wiener et al., 2013).

There is surely a limitation in conducting this study. As it was conducted at two hospitals in Bandung, the result of this study could not be generalized. Meanwhile, the strongest aspect of this study is that it is the first study in Indonesia, especially in Bandung that identifies perceived social support from family, friends and significant other parents of children with leukemia. This study shows that support from family was the most perceived by parents. Culturally, the family system in Indonesia is very close. If a child gets sick, all of the family will take care of the child. Grandmothers, grandfathers, uncles, aunts, and other siblings help parents taking care their sick children. Future studies are recommended to add larger samples and are conducted in different cultures.

## CONCLUSION

This study has shown that support from the family is the greatest support perceived by parents. The family has an important role in helping parents dealing with their child's illness. Nurses need to emphasize the role of the family in providing support for the parent by utilizing family support in dealing with childhood leukemia. Parent's education and income are factors that affected perceived social support. Nurses play an important role in risky groups by providing information for the family, empowering families to take advantage of the support they have and look for support outside the family such as sources of family financial support related to treatment, utilization of cancer foundations, support groups and others.

### Declaration of Conflicting Interest

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