



Social support for parents of children with leukemia

Putri Carolin¹, Umi Hanik Fetriyah¹, Adriana Palimbo^{2*}, Rifa'atul Mahmudah¹

¹Department of Nursing, Faculty of Health, Sari Mulia University, Banjarmasin, Indonesia

²Department of Midwifery, Faculty of Health, Sari Mulia University, Banjarmasin, Indonesia

*Corresponding author: palimboadriana00@gmail.com

ARTICLE INFO

Article history:

Received 11 October 2024

Accepted 13 January 2024

Published 28 February 2024

Keywords:

Social support

Parents

Children with leukemia

Emotional support

Instrumental support

ABSTRACT

Background: The prevalence of children with leukemia tends to increase. Leukemia treatment requires a long period of time which has physical, psychological and social impacts on children and parents which affect their quality of life. Social support obtained protects parents in facing times of stress.

Objective: To determine social support for parents who have children with leukemia.

Method: Quantitative research type. The research sample consisted of 30 respondents taken using convenient sampling techniques. Data collection instrument using a questionnaire. Data were analysed with descriptive statistics.

Results: The majority of parents who have children with leukemia are over 35 years old (73.3%), have elementary education (43.3%), work as housewives (53.3%), and most parental category is mothers (80.0%). Mean value of social support (66.43), highest social support category (76.7%). Social support questionnaire items are highest in the family dimension of form of emotional support and lowest form of emotional support. Friend dimension is lowest form of instrumental support and highest form of emotional support. The dimension of closest person is the highest form of emotional support and lowest is the form of instrumental support.

Conclusion: Social support from family, friends, and close people is needed for parents who have children with leukemia. Because it can provide positive energy for parents and children, the attention, security, and comfort provided can increase their confidence. Recommendations for friends and parents to provide instrumental support in form of being ready to help parents who have children with leukemia when experiencing difficulties both facilities and material.

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1. Introduction

Cancer is a disease that profoundly impacts global public health, particularly among children. In the United States alone, an estimated 14,910 children and adolescents aged 0–19



years were diagnosed with cancer in 2024, resulting in 1,590 deaths (National Cancer Institute [NCI], 2021). In Indonesia, the prevalence of childhood cancer among children aged 0–14 years has reached 16,291 cases, with projections indicating a steady annual increase (Mahayaty et al., 2022). Among the various types of cancer, Acute Lymphoblastic Leukemia (ALL) is the most common form affecting children, accounting for 68.9% of all pediatric leukemia cases (Putri et al., 2023). Leukemia, as a chronic illness, necessitates prolonged treatment, significantly diminishing the quality of life for affected children and imposing considerable psychological and emotional stress on their parents, who often bear the primary caregiving responsibility (Kartika, 2021).

Social support plays a crucial role in alleviating stress for parents of children with leukemia. It includes emotional, instrumental, and informational support that assists parents in managing their caregiving responsibilities (Nathalia et al., 2024; Sakinah, 2018). Family and friends provide essential emotional support, fostering feelings of security, love, and confidence for both parents and children. This support also helps parents cope with the psychological challenges associated with their child's treatment (Gise & Cohen, 2022). Previous research has demonstrated that parents who receive adequate social support are better equipped to handle the difficulties of caring for children with cancer (Rusmiati & Maria, 2023).

A preliminary study conducted at Rumah Kita highlighted that social support can significantly help parents in supporting their children during treatment. However, it also revealed a case where social support was less effective due to a parent choosing to internalize their struggles. Based on this phenomenon, this research aims to determine the level and forms of social support received by parents who have children with leukemia.

2. Method

Research design

The research to be conducted is a quantitative research type. Quantitative research is a type of research that is systematically specified, planned, and clearly structured from beginning to the creation of research design (Siyoto and Sodik, 2015). Research design in this study that will be conducted is a descriptive study. Descriptive statistics are statistics used in analyzing data by describing the data that has been collected as it is without intending to make conclusions that apply to public or generalization (Sugiyono, 2016).



Respondent

The sample size was determined using the World Health Organization (WHO) guidelines for calculating sample sizes for non-communicable disease studies (WHO, 2021). The Sample Size Calculator 2.0 was employed to estimate the required sample size. With a prevalence rate of less than 5% (1.6% [NCI, 2021]), a margin of error of 10%, and a 95% confidence interval, the minimum required sample size was calculated to be 19 respondents.

To accommodate potential variations and ensure adequate representation, a convenient sampling method was utilized. This approach involved selecting participants who were readily accessible and willing to participate. As a result, a total of 30 respondents were included in the study, exceeding the minimum required sample size to enhance the reliability and robustness of the findings.

Data collection

Data collection instrument used was interview method with questionnaire. The questionnaire was Multidimensional Scale of Perceived Social Support (MSPSS) which consists of 3 dimensions and total of 12 statement items. The three dimensions of MSPSS are first, indicator of comfort with family, support and feel valuable to family. The second is an indicator of comfort with friends, support and feel valuable to friends. The third is an indicator of feel comfortable with important people or partners, advice, support, and feel valuable to partners. This questionnaire was assessed using a Likert scale scoring.

Data Analysis

Data processing was conducted systematically in five stages to ensure accuracy and consistency. These stages included editing, where the collected data were reviewed to identify and correct any errors or inconsistencies, ensuring completeness and clarity; coding, in which each response was assigned a numerical or categorical code to facilitate data entry and analysis; tabulating, where the data were organized into tables for easier interpretation; data entry, during which the coded data were entered into statistical software for processing and analysis; and cleaning, where the dataset was thoroughly reviewed to identify and rectify any anomalies, such as duplicate entries or missing values, to ensure reliability. Once the data were processed, univariate analysis was performed to summarize the distribution of variables. Descriptive statistics were used to present the results, with categorical data



displayed in terms of frequencies and percentages, providing a clear and concise representation of the findings to facilitate interpretation and discussion.

Ethical consideration

This research was conducted in adherence to ethical principles and received formal approval from the Research Ethics Commission of Sari Mulia University, Banjarmasin, Indonesia, under approval number 192/KEP-UNISM/IV/2024. The study ensured that all participants were informed about the purpose, procedures, and potential risks involved and provided their written informed consent prior to participation. Confidentiality and anonymity of the participants were maintained throughout the research process, and participation was entirely voluntary, with the option to withdraw at any stage without consequences.

3. Results

Characteristics of respondents

Based on table 1, it is known that most respondents aged >35 years as many as 22 people (73.3%). The highest elementary school respondent's education level was 13 people (43.3%) and some of other junior high schools were 4 (13.3%). Most of respondents 'work namely housewife as many as 16 people (53.3%) and a small number of respondents' jobs were 2 people (6.7%). Meanwhile, majority of parents who have leukemia are mothers, as many as 24 (80%) people. Respondents were 30 respondents of parents who had children with leukemia as shown in Table 1, as follows.

Table 1. Characteristics of respondents

Characteristics	Frequency (persons)	Percentage (%)
Age (year)		
20 – 35	8	26.7
>35	22	73.3
Education		
Elementary school	13	43.3
Junior High School	4	13.3
Senior High School	7	23.3
Bachelor	6	20
Occupation		
Housewife	16	53.3
Private employees	12	40
Government employees	2	6.7
Parents		
Mother	24	80
Father	6	20
Total	30	100



The mean social support score by respondents, who are parents of children with leukemia, is 66.43, indicating an average level of support perceived by the respondents. The median and mode values are both 72, suggesting that the most common and central tendency of the social support scores are relatively high. Additionally, the standard deviation of 16.711 reflects variability in the level of social support experienced by the respondents. The table illustrates the distribution of social support categories among respondents. The majority of respondents (76.7%) reported a high level of social support, while 13.3% experienced a medium level of social support. Only 10% of respondents indicated a low level of social support. This data demonstrates that most respondents perceive strong social support in their circumstances.

Table 2. Social support criteria

Social Support Category	Frequency (n)	Percentage (%)
Low	3	10
Medium	4	13.3
High	23	76.7
Total	30	100

The table presents an analysis of social support across three dimensions: family, friends, and the closest person, categorized into upper and lower levels of support. For the dimension of family, emotional support is predominant. In the upper category, a score of 178 with 11 responses highlights strong family involvement in decision-making. In contrast, the lower category, scoring 166 with 8 responses, reflects the ability to share problems with family members.

In the dimension of friends, both emotional and instrumental forms of support are evident. The upper category, with a score of 155 and 9 responses, underscores the presence of friends who provide emotional support by sharing joys and sorrows. Meanwhile, the lower category, scoring 145 with 7 responses, shows reliance on friends during difficult or undesirable situations, indicating instrumental support.

The dimension of the closest person reveals significant emotional support. The upper category, scoring 184 with 5 responses, highlights the comfort derived from a close individual. The lower category, with a score of 172 and 1 response, reflects the availability of someone who provides consistent support when needed. These results emphasize the varying levels



and types of social support across different relationships, with emotional support being the most prominent across all dimensions.

Table 3. Social support questionnaire items based on dimensions and forms

Social Support	Score	Number	Statement item	Information
Dimension of Family			Form of social support	
Upper	178	11	My family wants to help me to make a decision	Emotional
Lower	166	8	I can tell the problems that I face with my family	Emotional
Dimensions of Friends				
Upper	155	9	I have friends to share joys and sorrows	Emotional
Lower	145	7	I can rely on friends when things happen that are not desirable	Instrumental
Dimensions of the closest person				
Upper	184	5	There is someone who is a source of comfort for me	Emotional
Lower	172	1	There is someone who is always ready when I need it	Instrumental

4. Discussions

The results of the study indicate that most respondents fall into the age category of over 35 years. This is because individuals aged above 35 are considered mature and more likely to have children. However, advancing age is often associated with an increased risk of genetic mutations. As the body ages, cells undergo more divisions, heightening the likelihood of genetic errors or mutations. These mutations can be inherited by offspring, increasing the risk of diseases such as leukemia (Bannon et al., 2017; deSmith et al., 2019; Kallai et al., 2024; Walsh, 2024).

In terms of education, the findings show that the majority of respondents are elementary school graduates, while the fewest are junior high school graduates. Lower levels of education, such as only completing elementary school, are closely linked to suboptimal health behaviors, including smoking, lack of physical activity, and poor dietary habits. These behaviors not only impact parental health but also influence the health of their children, both during pregnancy and after birth. On the other hand, education can enhance parents' competencies, leading to greater awareness and improved health outcomes for their children (Hidayah & Fariana, 2024). The predominance of respondents with only elementary-level



education can also be attributed to financial constraints, as limited family income restricts access to higher education. Socioeconomic factors play a significant role in determining access to educational facilities and opportunities, ultimately shaping decisions about continuing education (Basyuk et al., 2023).

The results show that the majority of parents in the study were housewives, while the fewest were civil servants. This is likely because housewives often hold the primary responsibility for managing the household and caring for children. The pressures and stress associated with these responsibilities, coupled with potential deficiencies in social and emotional support, can negatively impact the health of both mothers and their children. Additionally, housewives are more likely to come from families with lower incomes compared to civil servants. This lower socio-economic status can limit access to healthcare services, proper nutrition, and a healthy living environment. These constraints may contribute to an increased risk of leukemia in children (Ruhban et al., 2024; Wheeler et al., 2023).

The results reveal that in the parental dimension, mothers represent the majority, while fathers are the smallest group. Mothers often have a stronger emotional bond with their children, making them more attuned to changes in their children's health. This heightened awareness prompts them to seek medical assistance promptly when noticing concerning symptoms. In many cultures, mothers serve as primary caregivers, deeply involved in their children's daily activities, including health monitoring and providing care when they are sick. Their role makes them more likely to recognize the symptoms of leukemia and seek treatment, resulting in higher representation among parents of children diagnosed with leukemia (Eiser & Upton, 2007; Khalil et al., 2019).

Respondents who reported receiving low social support may experience this due to feelings of shame or fear of stigma associated with their child's illness. Cultural contexts that perceive illness as a disgrace or weakness often discourage parents from seeking support or sharing their struggles, resulting in minimal social support (Ma et al., 2024; Shettima et al., 2022; Zhang et al., 2022). High levels of social support, on the other hand, contribute positively to treatment outcomes and emotional well-being. Parents with adequate social support are better equipped to cope with the stress and anxiety related to their child's care. This support enhances their ability to effectively meet their child's medical and emotional needs (Boyden et al., 2020; Shrestha, 2019).



Regarding family dimension, highest statement is "My family wants to support me in making decisions". This includes emotional support. When the family takes part in decision making, respondents feel very helped. Families who provide emotional support to children are believed to get comfort, warmth, and affection from their parents. In addition, for parents who experience psychological burdens that require them to rise above the problems that occur for their child's recovery. The family environment, support and advice from family members are often a source of valuable inspiration and guidance (Umar et al., 2022). On other hand, the lowest score was "I can tell my family about my problems". This indicates that most respondents are not open about telling their problems to their families. Being closed about problems in the family can have various negative consequences. When someone is not open about the problems they are facing, feelings of depression and stress tend to increase, because they feel they have to face everything alone. The aspect of emotional distance between family members will reduce the sense of trust and closeness that should be established. In addition, undisclosed problems can grow bigger and more complex, because there is no support or solution provided by other family members. Open communication is very important to create a harmonious and supportive family environment, where each member feels appreciated and heard (Shaw et al., 2021).

For the findings on friend dimension, highest score was on "I have friends to share my joys and sorrows". This includes appreciation of support. Most of responses stated that they have friends to share burdens of life. Sharing joys and sorrows is one of greatest gifts in life. True friends are a place to share joy when celebrating success and achievements, and become solid supporters when facing challenges and sadness Maharani et al. (2015). In difficult times, presence of loyal friends can provide emotional support, wise advice, and encouragement to keep moving forward. They help reduce loneliness and provide new perspectives that often help find solutions to problems faced. In this case, in addition to family members, parents can also ask for support from their friends, even though they are not blood relatives, and friends often have a higher emotional connection compared to family members. Furthermore, the lowest result was "I can rely on my best friend when something unexpected happens". This includes instrumental support. That not everyone can rely on their best friend when something unexpected happens. Although having a supportive best friend is valuable, it is not always possible to rely on them in every situation. Sometimes friends also face challenges and



personal bustling that makes them not always ready to help. In addition, each individual has limitations in terms of providing support, both emotionally and practically. Therefore, it is important for us to learn to be independent and develop our own problem-solving skills. Eilertsen et al. (2016) by realizing that friends cannot always be there, they must be wiser in managing expectations and maintaining friendly relationships with mutual understanding and realistic support. So, it is recommended that parents increase their knowledge and understanding of leukemia and treatments needed.

In connection the closest people dimension, highest score was on "There is someone who is a source of comfort for me". This statement includes emotional support. Close people such as family and friends are often irreplaceable sources of comfort in life. Their presence provides a sense of security and calm, because we know that they understand us well and are always there to support. In difficult times, the presence of those closest to us provides warm hugs, words of comfort, and sincere support that can relieve anxiety and stress Nurlina et al. (2021) closest people such as family members should provide more support to parents of children with leukemia so that they can provide encouragement to help parents and children with leukemia get better. And finally, the lowest result of statement "There is someone who is always there when I need them". This is instrumental support. Most respondents said that not all friends are always there when I need them. The reality that must be accepted is that friends also have their own lives and responsibilities that may limit their ability to be there at all times. Sometimes, they face personal problems, work, or other urgent situations that require full attention. Friends have the lowest relationship to support received from parents (Nursyamsiyah, 2019). From explanations and discussions above, in line with Kolcaba's theory in Utami & Puspita (2020), comfort interventions are divided into three, one of which is comfort food for soul where nurses can provide or carry out special interventions so that patients and families feel cared for both physically, mentally, spiritually, and emotionally.

This study has several limitations that should be acknowledged. First, the sample size was relatively small, comprising only 30 respondents, which may limit the generalizability of the findings to larger populations. Second, the study relied on self-reported data through a questionnaire, which is subject to response bias as participants may not always provide accurate or truthful answers. Third, the study was conducted in a single location, limiting the diversity of socio-cultural factors that could influence the perception and availability of social



support for parents of children with leukemia.

Future studies should consider using a larger and more diverse sample size to enhance the generalizability of the findings. Expanding the study to multiple locations with varying socio-cultural contexts could provide a broader understanding of the role of social support across different settings. In addition, incorporating qualitative methods, such as in-depth interviews or focus group discussions, could provide richer insights into the subjective experiences of parents and uncover deeper emotional and social dynamics that are not captured through quantitative measures. Finally, longitudinal research could examine the long-term impact of social support on the psychological well-being of parents and the treatment outcomes of their children.

5. Conclusion

Social support is closely related to parents who have children with leukemia. Social support can provide positive energy for parents and children with leukemia. The attention, sense of security, and comfort provided through social support allows parents and children with leukemia to adapt to the surrounding environment and increase their self-confidence. Recommendations for friends and parents to provide instrumental support in the form of being ready to help parents who have children with leukemia when they experience difficulties with simple but useful educational facilities or materials.

6. Conflict of interest

All authors declare no conflict of interest.

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