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Original Article

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Family support and quality of life of children with cancer : a cross-sectional study

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ABSTRACT

Introduction: Family plays an important role in supporting the care of children with cancer to improve their quality of life. This study aims to examine the relationship between family support and the quality of life of children with cancer.

Methods: This study used a cross-sectional design. The population in this study were children diagnosed with cancer who were getting treatment at the hospital, as well as their parents who cared for them. The sampling technique was consecutive sampling with a total sample of 51 children and 51 parents. Data was collected through a questionnaire consisting of two parts, namely the child's quality of life scale using PedsQLTM 4.0 and PedsQLTM 3.0 Cancer Module and family support using the family support questionnaire. Data analysis was performed using the Pearson correlation test.

Results: The study showed that there was a relationship between family support and the quality of life of children with cancer using both the general child quality of life scale ($p = 0.001$) and with the quality-of-life scale specifically for children with cancer ($p < 0.001$). Children who received greater family support tended to have a better quality of life compared to children with lower family support.

Conclusions: Families play an important role in improving the quality of life of children with cancer. It is important to involve families in the child's care process and to provide education on the importance of family support. Future research should explore other associated factors and family interventions to improve the quality of life of children with cancer.

Keywords: children with cancer, family support, quality of life

Introduction

Data on cancer patients in children based on the International Agency for Research on Cancer in 2020 totals around 280,000 children, of which 39% died (International Agency for Research on Cancer, 2022). Data from the World Health Organization (WHO) shows around 61,000 new cases of cancer diagnoses in children, and 45% of them died in the Southeast Asia region (World Health Organization, 2024). Based on data from the Indonesia Burden of Cancer, the number of children diagnosed with cancer in Indonesia in 2020 was 7,574 with leukemia totaling 4,027 cases, Hodgkin's lymphoma 2,251 cases, Burkitt's lymphoma 382 cases, low grade tumors 246 cases, retinoblastoma 245 cases, and other types of cancer 423 cases (Indonesia Burden of Cancer, 2020). The results of research conducted in 14 provinces in Indonesia show that North Sulawesi is the province with the third highest incidence of childhood cancer after the Jakarta and Bali provinces, looking at those aged 10-14 years, which is 4.8% (Agustina *et al.*, 2018). Medical advances provide a high chance of survival for children with cancer in high-income countries of more than 80% but the ability to survive in low-income countries is still less than 20% (Bhakta *et al.*, 2019).

There are many types of cancer treatment depending on the type and stage of cancer. Some patients undergo just one treatment but others have to undergo more than one. Cancer treatments consist of surgery, chemotherapy, radiation therapy, immunotherapy and hormone therapy (National Cancer Institute, 2023). Child and adolescent cancer patients will experience many side effects that can interfere with their quality of life, which not only affects the child but also their parents (Linder and Hooke, 2019). The side effects felt by children while undergoing cancer treatment consist of physical, emotional and educational problems. The physical problems felt by children include nausea, vomiting, fatigue, weakness, and difficulty walking, running, exercising, bathing and playing with their friends. The emotional problems include fear, sadness and anger with the circumstances they are experiencing, while their educational problems are that they do not have the same opportunity as their friends to go to school because they have to undergo therapy in the hospital, while some have a decreased memory. This can lead to a decrease in the quality of life of children with cancer (Nurhidayah *et al.*, 2016; Gannika, Mulyadi and Masi, 2023).

Health-related quality of life is a term that refers to a patient's perception of the impact of illness and its treatment related to their physical, psychological and social wellbeing aspects (Momani, Hathaway and Mandrell, 2016). Measuring the quality of life of pediatric cancer patients is one of the important health outcomes in healthcare and clinical trials where the physical, psychological (emotional and cognitive) and social health dimensions are measured (Klassen *et al.*, 2010; Racine *et al.*, 2018). Quality of life is defined as an individual's perception of their position in life in terms of the cultural context and value system in which they live, and in relation to their goals, expectations, standards and concerns. The patient's quality of life needs to be measured to determine the extent to which the patient makes an assessment of himself as well as it being a factor used when determining whether treatment is effective for the patient (Islam *et al.*, 2023). Measuring patient quality of life can be used in clinical practice to facilitate the detection of physical or psychological problems in patients so as to monitor the disease and treatment over time by improving the delivery of medical care (Moschopoulou *et al.*, 2021; Hetherington *et al.*, 2022).

Factors that can affect the quality of life of children with cancer are the type and stage of cancer, the side effects of treatment, social support (family, peer and community support), psychological aspects, adherence to treatment, and co-morbid health conditions (Hong, Kim and Min, 2022; Bakker *et al.*, 2023). One of the most influential factors is family support because at the point when the child is diagnosed and undergoes cancer treatment, not only does the child's life change but also the family's life as a whole as well (Mahmoud *et al.*, 2022). The family are the closest people who will therefore go on to be the best support system for children diagnosed with cancer. Family function can be related to the emotions of families who care for children with cancer and the quality of life of the children themselves (Andriastuti *et al.*, 2024). Other studies explain that family support can improve the children's quality of life, including social, spiritual, social and school functions (Utami, Puspita and Karin, 2020). There is also research that explains how family support is related to the quality of life of pediatric cancer patients (social function, school function, physical function and emotional function) when assessed over 7 days (Sari *et al.*, 2023). These three studies examined the relationship between family support and the quality of life of pediatric cancer patients using PedsQL™ 4.0 but not the PedsQL™ 3.0 Cancer Module. This study will test the relationship between family support and the quality of life of children with cancer using both PedsQL™ 4.0 and the PedsQL™ 3.0 Cancer Module.

Based on the results of the literature search, it was found that no research has previously been conducted on the relationship between family support and the quality of life of children with cancer in Manado, North Sulawesi, so the researchers of this study were interested because family support and the measurement of the quality of life of children with cancer are both very important when determining the provision of childcare. The purpose of this study was, therefore, to analyze the relationship between family support and the quality of life of children with cancer.

Materials and Methods

Research Design

This research is a quantitative study using a cross-sectional method because in this study design, all variables are measured and observed at the same time (Grove and Gray, 2019).

Participants

The study was conducted from July to October 2023 at the Children's Cancer Center at one of the hospitals in Manado, North Sulawesi. This cancer center handles pediatric cancer patients in North Sulawesi and is one of two pediatric cancer referral center hospitals in Eastern Indonesia. The population of this study was children diagnosed with cancer treated in the pediatric cancer center along with their parents, with a total of 62 children treated from January to October 2023. The sampling technique used was consecutive sampling (Grove and Gray, 2019).

The inclusion criteria in this study were children diagnosed with cancer who were willing to become respondents, who had received hospital treatment either chemotherapy, surgery or both for at least one month, and who were compos mentis, with a strong sense of consciousness, and could communicate well. In addition, the parents were also sampled. The inclusion criteria for the parents was that their children had become research samples, they were willing to become respondents, were the child’s biological parents, had taken care of the children in the treatment room for at least one month, and could read and write. The exclusion criteria in this study were children and parents who were willing to be sampled but at the time of the study their children were critical, had died or did not want to continue treatment. The number of samples in this study was 51 because during the study, there were 4 children who died, 3 children in critical condition and 4 children did not want to continue treatment. Based on the theory of attrition and retention, the number of samples was sufficient as the retention rate value in this study was 82.26% (51/62*100% = 82.26%), while the attrition value was 17.74% (11/62*100% = 17.74%). The recommended minimum retention rate for the sample was 70% and the recommended maximum attrition rate for the sample was 20% (Lee, 2003; Hindmarch *et al.*, 2015).

Data collection

Data collection was conducted at the pediatric cancer center. Children and parents who met the inclusion and exclusion criteria were given questionnaires to assess the child's quality of life during therapy. For the family support questionnaire, the parents read it to the child and the child chose the answer that they thought was the most appropriate. During the study, the researcher accompanied the parents and children when they were filling out the questionnaire so then if the child or parent was confused, the researcher could explain things directly. After filling in the questionnaire, the researcher checked the questionnaire again and read back the child and parent's answers to ensure that they were consistent.

Measurement Tool

Family Support Questionnaire

The measurement of family support using the Family Support Questionnaire was adopted from previous research where it has been tested for validity and reliability. The Cronbach's alpha value for the validity test is 0.871-0.884, while the Cronbach's alpha value for the reliability test is 0.883. This means that the questionnaire is valid and reliable to use. This questionnaire represents 4 sub-variables of family support including emotional support, instrumental support, information support and self-esteem support (Kusuma, 2011). This questionnaire has also been used in family support research to improve medication control adherence in patients with cancer (Yaner *et al.*, 2019).

PedsQL^{TM} 4.0 Generic & PedsQL^{TM} 3.0 Cancer Module

The PedsQL^{TM} 4.0 questionnaire measures the children's quality of life in general, while the PedsQL^{TM} 3.0 Cancer Module questionnaire measures the quality of life of children with cancer (Varni, Seid and Kurtin, 2001). The pediatric quality of life instrument has been tested for reliability and validity, and has been translated into 69 languages. The reliability of the instrument is demonstrated by good internal consistency, with alpha coefficients ranging from 0.70-0.90. The PedsQL^{TM} 4.0 questionnaire covers four general functions in children, namely their physical, emotional, social and school functions, consisting of two reports for the children and a report for the parents. The latter questionnaire consists of eight domains, namely pain and hurt, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and communication. The questionnaire also consists of two domains for the child's report and the parent's report. Prior to conducting the study, the researcher contacted Professor James Varni and obtained permission to use the Indonesian version of both the PedsQL^{TM} 4.0 and PedsQL^{TM} 3.0 Cancer Module questionnaires, downloaded through the Mapi Research Trust.

The scale of the PedsQL^{TM} 4.0 instrument is 0 to 4. The assessment will ask the individual filling it in to give a score of 0-4 for each question item with details: score 0 if there is never a problem with the statement item, 1 if there is almost never a problem with the statement item, 2 if there is sometimes a problem with the statement item, and 4 if there is always a problem with the question item. The way to determine the score is: questionnaire value 0 = score 100, value 1 = score 75, value 2 score 50, value 3 score 25 and value 4 = score 0. The total score is calculated by summing the values of the questions that were answered divided by the number of questions answered in each domain. To equalize the perception, the answers were determined as follows: almost always felt every day, often felt once a week, sometimes felt once a month, almost never felt in 2 or 3 months and never felt in the last three months. The higher the score, the better the quality of life.

Ethical consideration

This nursing research adheres to the principles of research ethics including self-determination, which is where the families and patients decide for themselves whether they want to be involved in the research or not. Anonymity was upheld, maintaining the privacy of the participants so then their identity could not be identified by anyone either during the research or afterwards. This was as well as protection from discomfort by ensuring that the research procedures do not cause harm while maximizing the benefits of the research. The research protocol was approved by the Ethics Commission of R.D. Kandou Hospital Manado issued by the Chairman of the Ethics Commission with number 082/EC/KEPK-KANDOU/VI/2023. The research permit was issued by the hospital director, number DP.04.03/D.XV/2990/2023.

Data Analysis

Quantitative data analysis was performed using univariate analysis to describe the characteristics of the respondents, family support and the quality of life of children with cancer using mean, standard deviation and frequency. Bivariate data analysis was done using the Pearson test, presented using standard error, mean, and p-value.

Results

The results of the study consisted of the respondent's characteristics, family support, the quality of life of

Table 1. Demographic Data of the Respondents (n=51)

Characteristics	n (%)	Mean (SD)
Child's age		8.33 (3.543)
Child gender		
Male	32 (62.75)	
Female	19 (37.25)	
Cancer Diagnosis		
Acute Lymphoblastic Leukemia	36 (70.59)	
Chronic Myelogenous Leukemia	5 (9.80)	
Teratoma	2 (3.92)	
Non-Hodkin's Lymphoma	2 (3.92)	
Wilm's Mass	1 (1.96)	
Osteosarcoma	1 (1.96)	
Retinoblastoma	2 (3.92)	
Ovarian Tumors	2 (3.92)	
Therapy		
Chemotherapy	41 (80.39)	
Surgery	6 (11.77)	
Chemotherapy and surgery	4 (7.84)	
Duration of Therapy (month)		7.08 (3.032)
Parent involved		
Mother	45 (88.23)	
Father	6 (11.77)	
Parent's Education		
Elementary school	6 (11.77)	
Junior high school	9 (17.65)	
Senior high school	26 (50.98)	
Bachelor's	10 (19.60)	

Table 2. Descriptive Statistics of the Quality of Life of Children with Cancer using PedsQLTM 4.0 and the PedsQLTM 3.0 Cancer Module, related to Family Support. (n=51)

Variable	Mean	SD	Min-Max
Quality of life of children with cancer using PedsQL™ 4.0			
Self-report			
Total Score	72.35	6.687	49-86
Physical function	68.61	12.63	41-100
Emotional function	71.18	9.88	45-95
Social function	80.78	9.77	55-100
School function	70.86	9.07	50-90
Parent-report			
Total score	72.35	6.69	49-86
Physical function	63.37	12.43	41-94
Emotional function	70.49	10.41	45-95
Social function	80.59	9.20	55-100
School function	70.24	8.96	50-90
Quality of life of children with cancer using the PedsQL™ 3.0 Cancer Module			
Self-Report			
Total score	70.69	5.36	60-85
Pain and hurt	71.44	10.62	50-100
Nausea	69.31	6.00	55-80
Procedural anxiety	66.41	9.62	50-100
Treatment anxiety	71.39	10.04	42-100
Worry	68.69	13.91	42-100
Cognitive problems	70.59	9.59	50-100
Perceived physical appearance	72.10	11.15	50-100
Communication	75.49	7.41	50-100
Parents-Report			
Total score	69.63	4.49	62-83
Total score	69.31	10.03	50-100
Pain and hurt	68.53	5.68	55-80
Nause	65.25	8.99	42-75
Procedural anxiety	70.43	8.22	42-83
Treatment anxiety	68.04	13.69	42-100
Worry	69.57	8.00	50-92
Cognitive problems	71.29	10.84	50-100
Perceived physical appearance	75.00	7.29	50-100
Family Support	23.41	5.25	16-36

Notes: M =Mean; SD = Standard Deviation; Min-Max = Minimum value and Maximum value.

children with cancer, and the relationship between family support and the quality of life of children with cancer.

Based on Table 1, it was found that 51 children participated in this research activity where the average age was 8.3 years. There were more boys, totaling 32 children or 62.75%. Most pediatric cancer patients suffered from acute lymphoblastic leukemia, totaling 36 children or 70.59%. The most common therapy was chemotherapy, which was used to treat 41 children or 80.39% with an average duration of therapy being 7 months. For the parents who accompanied their children, more were mothers, totaling 45 or 88.23%. The level of education of the parents was mostly high school, totaling 26 people or 50.98%.

Table 2 shows the mean scores of the four functions assessed using PedsQL™ 4.0, comparing the parental and child's ratings: physical functioning 63.37 vs 68.61 (SD = 12.43 vs 12.63), emotional functioning 70.49 vs 71.18 (SD = 10.41 vs 9.88), social functioning 80.59 vs 80.78 (SD = 9.20 vs 9.77), school functioning 70.24 vs 70.86 (SD = 8.96 vs 9.07) and a total score 72.35 vs 72.86 (SD = 6.69 vs 6.63). The parents' ratings for all four functions were lower than the children's ratings.

The mean scores of the eight subscales assessed using the PedsQL™ 3.0 Cancer module comparing the parents' ratings and children's ratings were as follows: pain and hurt 69.31 vs 71.44 (SD = 10.03 vs 10.62), nausea 68.53 vs 69.31 (SD = 5.68 vs 6.00), procedural anxiety 65.25 vs 66.41 (8.99 vs 9.62), treatment anxiety 70.43 vs 71.39 (SD = 8.22 vs 10.04), worry 68.04 vs 68.69 (SD = 13.69 vs 13.91), cognitive problems 69.57 vs 70.59 (8.00 vs 9.59), perceived physical appearance 71.29 vs 72.10 (SD = 10.38 vs 11.15), communication 75 vs 75.49 (SD = 7.29 vs 7.41) and total score 69.63 vs 70.69 (SD = 4.49 vs 5.36). The parents' ratings for all eight subscales were lower than the children's ratings. Family support had a mean score of 23.41 and a standard deviation of 5.25.

Table 3 shows that there is an association between family support and the quality of life of cancer children using both PedsQL™ 4.0 and the PedsQL™ 3.0 Cancer Module with p values <.001 and .001.

Table 3. Relationship between Family Support and Quality of Life for Pediatric Cancer Patients according to self-reporting with PedsQLTM 4.0 and PedsQLTM 3.0 Cancer Module (n=51)

NO	Variables	SE	95% CI Lower	95% CI Upper	Mean	SD	p-value
1	Family Support	0.735	21.94	24.89	23.41	5.250	
2	Quality of Life with PedsQL™4.0	0.928	70.47	74.23	72.35	6.687	<0.001*
3	Quality of Life with PedsQL™ 3.0 Cancer Module	0.751	69.18	72.18	70.69	5.361	0.001*

Notes: SE =Standard error ; CI =Confidence interval ; M =Mean ; SD = Standard Deviation

Discussions

The demographic data shows that this sample of children with cancer are on average 8 years old, and that there are more boys than girls. There are similar studies that have got the same results, namely that there are more children aged 8-12 years and that there are more boys among them (Nurhidayah *et al.*, 2016). Leukemia is the most common cancer in children. Some of the factors that can cause leukemia to occur frequently are rapid cell growth that allows the genetic errors that go on to cause the development of leukemia, an immature immune system resulting in an ineffective immune system unable to recognize and destroy abnormal cells, and also maternal health conditions during pregnancy such as exposure to radiation and certain chemicals (Caron *et al.*, 2020). Chemotherapy is the most widely used therapy in children because it is effective at stopping the growth of cancer cells. Additionally, the protocol is standardized, the management of side effects is more advanced, and prognosis is improved following treatment (Unguru *et al.*, 2019).

In the assessment using PedsQL™ 4.0, the highest subscale was social function, including being able to play with friends, no one mocking their appearance, and their friends wanting to play with them. Other studies have also reported that social function related to the quality of life of cancer children is the function with the highest score (Lubis and Siregar, 2015; Sari et al., 2022). Family support in social functions can take the form of social interactions with the children to help the children feel like they are not alone in their fight against cancer. This can increase their self-confidence and happiness. Actions taken can also include involving the children in various social activities including playing with their peers in a manner suitable for their health condition, as this can help reduce feelings of isolation (Wawrzynski *et al.*, 2021; Melguizo-Garín *et al.*, 2023).

In this study, the most decreased quality of life was physical function, including difficulty walking, running, doing sports, lifting heavy objects, bathing themselves, doing chores at home, feeling pain, and being too tired to play. Some children reported fatigue when playing or walking within a few minutes and even felt weak, especially after chemotherapy. Fatigue is caused because patients experience anemia and a lack of red blood cells, which causes the amount of nutrients and oxygen reaching the body to be reduced (Nunes *et al.*, 2017). There are studies that explain the most decreased aspect of quality of life among children with cancer, specifically physical function (Vlachioti *et al.*, 2016; Pan, Wu and Wen, 2017). Family support to improve the physical function of children with cancer can be done by encouraging physical activities that are in accordance with the child's health condition to help maintain and improve physical function overall, in addition to making schedules such as for eating, sleeping and other activities that can keep the child stable. Creating a safe and comfortable home environment, providing nutritional support to support the children's health and recovery, and helping to provide the equipment needed for physical therapy or other activities are other ways to help (Kowaluk, Woźniewski and Malicka, 2019; Devine and Kwok, 2022).

In addition to physical function, the school function has also been shown to decrease, especially for school-age children. This is because the parents are worried about what if their child goes to school and falls over, while among pre-school children, the parents tend not to enroll them in *playgroups* or *kindergarten* because they are afraid that their child will get sick (Tsimicalis *et al.*, 2018). Children with cancer also fall behind in school because they rarely go to class, and can suffer from decreases in memory and other cognitive abilities (Yilmaz *et al.*, 2014; Galán *et al.*, 2021). Family support can improve the children's school functioning by informing the school of the child's diagnosis, treatment plan and needs. Families also participate in adjusting to the school schedules and writing home education plans because the child cannot fully attend school. They can help their child to learn from home or from the hospital with the help of technology to keep the child connected to the curriculum (Children Hospital, 2011; Delloso, Gannoni and Roberts, 2021). There is research that has found that physical, emotional, social and school functioning is significantly lower in children with cancer than it is in healthy children (Abu-Saad Huijer, Sagherian and Tamim, 2013; Arslan, Basbakkal and Kantar, 2013).

Based on the results of research using the PedsQL™ 3.0 Cancer Module, the lowest subscale is *procedural anxiety*. The procedural anxiety that many children with cancer feel is often felt at the time of blood sampling because they have to routinely undergo laboratory tests. Infusions are also a heightened time for this, especially for children with chemotherapy. There are studies that explain that the quality of life of children with cancer using the PedsQL™ 3.0 Cancer Module measurement scale had the lowest results for procedural anxiety (Sitaresmi *et al.*, 2008; Hegazy *et al.*, 2019; Saleh *et al.*, 2023). The family support of children with cancer can reduce procedural anxiety by the parent accompanying the child during the treatment, providing explanations that are appropriate to the child's age, and setting a good example by being calm and engaging in relaxation techniques (Osman *et al.*, 2023; Boonchuaylua, Kongvattananon and Rutchanagul, 2024).

The highest quality of life aspect among cancer children based on the PedsQL™3.0 Cancer Module is communication. Some of the children reported that they did not have any difficulty telling their complaints to parents, doctors and nurses, and that they felt they could ask the doctors and nurses anything about their illness. Another study explained that communication was the highest scoring aspect when assessing children's quality of life using the PedsQL™ 3.0 Cancer Module (Abu-Saad Huijer, Sagherian and Tamim, 2013; Nurhidayah *et al.*, 2016). Children with cancer will undergo long periods of care and treatment, making the ability to explain their complaints to doctors and nurses important so then the interventions provided are in accordance with the needs of the child. Communication in pediatric oncology care is very important to build relationships with the children, as well as to exchange information, respond to emotions as they arise, and make decisions (Sisk *et al.*, 2018). Child-centered communication can help them engage with the treatment because the therapy provided is in accordance with the complaints and needs of the child (Høeg *et al.*, 2023).

The long-term, invasive, and painful nature of cancer treatment disrupts patients' lives, causing children and adolescents with cancer to have to adjust to changes in routine and altered family and peer relationships. This research explains that worry is the most prevalent in patients who visit the hospital more than three times per month. Children who also received therapy more than once experienced more treatment anxiety due to the high frequency of hospital visits (Hegazy *et al.*, 2019). When undergoing cancer treatment, the family is the best support system for children (Park *et al.*, 2018).

High family support will improve the quality of life of children with cancer. Children with cancer rely heavily on their families for care. Families who support their children will be involved in their care, as well as with the treatment information. This is important because the provision of clear information to the children can reduce their anxiety levels, allowing them to be calmer when undergoing treatment (Cowfer, Dietrich and Akard, 2021; Patterson *et al.*, 2024). In addition, the family should be involved; accompanying the child to and during the therapy, reminding the child to take their medicine and eat regularly, providing them with time and facilities during treatment, financing the child's treatment, and continuing to love and care for the child regardless of the circumstances (Pelletier and Bona, 2015; Salsman *et al.*, 2021). Children with cancer who are supported by their families will be better motivated to undergo treatment so as to improve their quality of life (Stam *et al.*, 2006; Andriastuti *et al.*, 2024).

The strength of this study was that it used the PedsQL™ 3.0 Cancer Module to measure quality of life associated with family support. Other studies have also used the PedsQL™ 4.0 Generic questionnaire. The limitations of this study are that the participants involved were all diagnosed with cancer, where the type of cancer was not specific and where the therapy given was also different, as was the treatment time. However, the researchers tried to limit the participants by setting inclusion and exclusion criteria so then there were no significant differences.

Conclusion

From this study, it can be concluded that family support is good, while the quality of life of children with cancer is the highest for social function and lowest for physical function based on PedsQLTM 4.0. Communication had the highest scale and anxiety procedures the lowest scale when assessing the quality of life of children with cancer using the PedsQLTM 3.0 Cancer Module. There is a relationship between family support and the quality of life of cancer children using both PedsQLTM 4.0 and the PedsQLTM 3.0 Cancer Module. The average respondent was 8 years and 3 months old, while more males had a diagnosis of acute lymphoblastic leukemia. Most generally underwent chemotherapy. The data needs attention from health workers, and there is also a need to increase family support efforts through education and appropriate interventions to improve the quality of life of children with cancer. The results of this study can be used as basic

data to support interventions to improve the quality of life of children with cancer such as improving physical functioning. In addition, educational material for families can encourage them to pay more attention to their children because family support is very important when it comes to improving their quality of life.

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Availability of data and materials

All data and research materials can be obtained by contacting the coresponding author and will be open if requested.

Authors' contributions

First author: Research idea, proposal drafting, research administration, data collection, data analysis, manuscript drafting, and manuscript revision; Second author: Providing ideas in research methods, data presentation, data analysis and guiding in the preparation of manuscripts and ensuring manuscripts are suitable for publication; Third author: Data collection, manuscript preparation and manuscript revision

Declaration of Interest

This publication does not involve commercial products and therefore has no potential conflict of interest

References

Abu-Saad Huijer, H., Sagherian, K. and Tamim, H. (2013) ‘Quality of life and symptom prevalence in children with cancer in Lebanon: the perspective of parents.’, *Annals of palliative medicine*, 2(2), pp. 59–70. doi: 10.3978/j.issn.2224-5820.2013.03.01.

Agustina, J. *et al.* (2018) ‘Epidemiology of Childhood Cancer in Indonesia: Study of 14 Population Based Cancer Registries’, *Journal of Global Oncology*, 4(2), pp. 67–78. Available at: https://doi.org/10.1200/jgo.18.75200 (Accessed: 20 March 2024).

Andriastuti, M. *et al.* (2024) ‘Family functioning, parental cancer-related emotions, and quality of life in childhood cancer patients’, *Paediatrica Indonesiana*, 64(3), pp. 250–7. doi: 10.14238/pi64.3.2024.250-7.

Arslan, F. T., Basbakkal, Z. and Kantar, M. (2013) ‘Quality of life and chemotherapy-related symptoms of Turkish cancer children undergoing chemotherapy’, *Asian Pacific Journal of Cancer Prevention*, 14(3), pp. 1761–1768. doi: 10.7314/APJCP.2013.14.3.1761.

Bakker, Anne *et al.* (2023) ‘A systematic review of health-related quality of life in children and adolescents during treatment for cancer’, *EJC Paediatric Oncology*. Elsevier B.V. doi: 10.1016/j.ejcped.2023.100134.

Bhakta, N. *et al.* (2019) ‘Childhood cancer burden: a review of global estimates’, *The Lancet Oncology*. Lancet Publishing Group, pp. e42–e53. doi: 10.1016/S1470-2045(18)30761-7.

Boonchuaylua, P., Kongvattananon, P. and Rutchanagul, P. (2024) *Effectiveness of Family-Based Intervention Program for Family Members of Preschool Children with Acute Lymphoblastic Leukemia Undergoing Chemotherapy: A Quasi-Experimental Study*. Available at: https://www.researchgate.net/publication/372950209.

Caron, H. *et al.* (2020) *Cancer in Children*. Seventh edition. United Kingdom: Oxford University Press.

Children Hospital (2011) *Helping Schools Cope With Childhood Cancer Current Facts and Creative Solutions*.

Cowfer, B. A., Dietrich, M. S. and Akard, T. F. (2021) ‘Effect of time on quality of parent–child communication in pediatric cancer’, *Pediatric Blood and Cancer*, 68(10). doi: 10.1002/pbc.29091.

Delloso, S., Gannoni, A. and Roberts, R. M. (2021) ‘Maintaining Schooling for Children With Cancer During and Post Treatment: Parents’ Perspectives of a Theory-Based Program’, *Continuity in Education*, 2(1), pp. 26–41. doi: 10.5334/cie.24.

Devine, K. A. and Kwok, G. (2022) ‘Improving Physical Activity in Pediatric Cancer Survivors - Engaging Parents’, *JAMA Network Open*. American Medical Association, p. E2219327. doi: 10.1001/jamanetworkopen.2022.19327.

Galán, S. *et al.* (2021) ‘Improving the quality of life of cancer survivors in school: Consensus recommendations using a delphi study’, *Children*, 8(11). doi: 10.3390/children8111021.

Gannika, L., Mulyadi, M. and Masi, G. N. M. (2023) ‘Long-term effects of chemotherapy in children with cancer’, *Malahayati International Journal of Nursing and Health Science*, 6(6), pp. 442–450. doi: 10.33024/minh.v6i6.12663.

Grove and Gray (2019) *Understanding Nursing Research : Building an Evidence-Based Practice, Seventh Edition*. Airlington, Texas: Elsevier.

Hegazy, A. *et al.* (2019) ‘Quality of Life in Pediatric Cancer Patients’, *Journal of Advances in Medicine and Medical Research*, pp. 1–11. doi: 10.9734/jammr/2019/v30i1030243.

Hetherington, K. *et al.* (2022) ‘Quality of Life (QoL) of Children and Adolescents Participating in a Precision Medicine Trial for High-Risk Childhood Cancer’, *Cancers*, 14(21). doi: 10.3390/cancers14215310.

Hindmarch, P. *et al.* (2015) ‘Recruitment and retention strategies and the examination of attrition bias in a randomised controlled trial in children’s centres serving families in disadvantaged areas of England’, *Trials*, 16(1). doi: 10.1186/s13063-015-0578-4.

Høeg, B. L. *et al.* (2023) ‘Child-centered communication interventions in pediatric oncology: A scoping review and proposed new communication model’, *Pediatric Blood and Cancer*. John Wiley and Sons Inc. doi: 10.1002/pbc.30533.

Hong, H. C., Kim, Y. M. and Min, A. (2022) ‘Factors influencing quality of life among childhood cancer survivors in Korea: A quantile regression approach’, *Research in Nursing and Health*, 45(1), pp. 108–122. doi: 10.1002/nur.22170.

Indonesia Burden of Cancer (2020) *Cancer Country Profile*. Available at: https://www.iccp-portal.org/system/files/plans/IDN_2020.pdf.

International Agency for Research on Cancer, I. (2022) ‘International Childhood Cancer Day 2022’, 15 February. Available at: https://www.iarc.who.int/featured-news/iccd-2022/#:~:text=According%20to%20estimates%20from%20the,000%20children%20died%20from%20cancer. (Accessed: 3 May 2024).

Islam, N. *et al.* (2023) ‘Assessment of quality of life (QOL) in cancer patients attending oncology unit of a Teaching Hospital in Bangladesh’, *Cancer Reports*, 6(8). doi: 10.1002/cnr2.1829.

Klassen, A. F. *et al.* (2010) ‘Quality of life questionnaires for children with cancer and childhood cancer survivors: A review of the development of available measures’, *Supportive Care in Cancer*, pp. 1207–1217. doi: 10.1007/s00520-009-0751-y.

Kowaluk, A., Woźniewski, M. and Malicka, I. (2019) ‘Physical activity and quality of life of healthy children and patients with hematological cancers’, *International Journal of Environmental Research and Public Health*, 16(15). doi: 10.3390/ijerph16152776.

Kusuma, H. (2011) *Hubungan antara Depresi dan Dukungan Keluarga dengan Kualitas Hidup Pasien HIV/AIDS yang Menjalani Perawatan di RSUPN Cipto Mangunkusumo Jakarta*. Universitas Indonesia . Available at: https://lib.ui.ac.id/detail?id=20282772&lokasi=lokal.

Lee, Una. (2003) *Panel attrition in survey data : a literature review*. Centre for Social Science Research, University of Cape Town.

Linder, L. A. and Hooke, M. C. (2019) ‘Symptoms in Children Receiving Treatment for Cancer—Part II: Pain, Sadness, and Symptom Clusters’, *Journal of Pediatric Oncology Nursing*. SAGE Publications Inc., pp. 262–279. doi: 10.1177/1043454219849578.

Lubis, B. and Rasiyanti Siregar, O. (2015) *Quality of life in children with cancer and their normal siblings, Paediatrica Indonesiana Original Article VOLUME*. Indonesia.

Mahmoud, A. M. *et al.* (2022) *Depression, Burden, and Self-Efficacy among Caregiving Parents of Children with Cancer, Original Article Egyptian Journal of Health Care*.

Melguizo-Garín, A. *et al.* (2023) ‘Importance of Social Support of Parents of Children with Cancer: A Multicomponent Model Using Partial Least Squares-Path Modelling’, *International Journal of Environmental Research and Public Health*, 20(3). doi: 10.3390/ijerph20031757.

Momani, T. G., Hathaway, D. K. and Mandrell, B. N. (2016) ‘Factors Affecting Health-Related Quality of Life in Children Undergoing Curative Treatment for Cancer: A Review of the Literature’, *Journal of Pediatric Oncology Nursing*. SAGE Publications Inc., pp. 228–240. doi: 10.1177/1043454215609585.

Moschopoulou, E. *et al.* (2021) ‘Measuring quality of life in people living with and beyond cancer in the UK’, *Support Care in Cancer*, pp. 6031–6038. doi: 10.1007/s00520-021-06105-z/Published.

National Cancer Institute (2023) ‘Cancer Treatment’, *https://www.cancer.gov/about-cancer/treatment*.

Nunes, M. D. R. *et al.* (2017) ‘Fatigue and health related quality of life in children and adolescents with cancer’, *European Journal of Oncology Nursing*, 29, pp. 39–46. doi: 10.1016/j.ejon.2017.05.001.

Nurhidayah, I. *et al.* (2016) *Kualitas Hidup pada Anak dengan Kanker*.

Osman, S. *et al.* (2023) *Parental Emotional Resilience and Procedural Anxiety of their Children with Cancer, Trends in Nursing and Health Care Journal*. Available at: https://www.researchgate.net/publication/377002418.

Pan, H. T., Wu, L. M. and Wen, S. H. (2017) ‘Quality of Life and Its Predictors among Children and Adolescents with Cancer’, *Cancer Nursing*, 40(5), pp. 343–351. doi: 10.1097/NCC.0000000000000433.

Park, M. *et al.* (2018) ‘Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews’, *International Journal of Nursing Studies*. Elsevier Ltd, pp. 69–83. doi: 10.1016/j.ijnurstu.2018.07.006.

Patterson, V. *et al.* (2024) ‘Impact of sociodemographic factors, stress, and communication on health-related quality of life in survivors of pediatric cancer’, *Pediatric Blood and Cancer*, 71(7). doi: 10.1002/pbc.31001.

Pelletier, W. and Bona, K. (2015) ‘Assessment of Financial Burden as a Standard of Care in Pediatric Oncology’, *Pediatric Blood and Cancer*, 62, pp. S619–S631. doi: 10.1002/pbc.25714.

Racine, N. M. *et al.* (2018) ‘Quality of life in pediatric cancer survivors: Contributions of parental distress and psychosocial family risk’, *Current Oncology*, 25(1), pp. 41–48. doi: 10.3747/co.25.3768.

Saleh, M. S. *et al.* (2023) ‘Evaluation of health-related quality of life and its domains in pediatric patients with cancer’, *Journal of the Egyptian National Cancer Institute*, 35(1). doi: 10.1186/s43046-023-00168-1.

Salsman, J. M. *et al.* (2021) ‘Systematic review of financial burden assessment in cancer: Evaluation of measures and utility among adolescents and young adults and caregivers', *Cancer*. John Wiley and Sons Inc, pp. 1739–1748. doi: 10.1002/cncr.33559.

Sari, W. *et al.* (2022) 'Characteristics of Quality of Life of Children with Cancer in RSAB Harapan Kita Jakarta', *Original Research International Journal of Nursing and Health Services (IJNHS)*, 5(5). doi: 10.35654/ijnhs.v5i5.653.

Sari, W. *et al.* (2023) 'Family Supporting on Quality of Life among Children with Cancer in Women and Children Harapan Kita Hospital, Jakarta', *International Journal of Nursing and Health Services (IJNHS)*, 6(3), pp. 218–224. doi: 10.35654/ijnhs.v6i3.717.

Sisk, B. A. *et al.* (2018) 'Communication in pediatric oncology: State of the field and research agenda', *Pediatric Blood and Cancer*. John Wiley and Sons Inc. doi: 10.1002/pbc.26727.

Sitaresmi, M. N. *et al.* (2008) 'Health-related quality of life assessment in Indonesian childhood acute lymphoblastic leukemia', *Health and Quality of Life Outcomes*, 6. doi: 10.1186/1477-7525-6-96.

Stam, H. *et al.* (2006) 'Health-related quality of life in children and emotional reactions of parents following completion of cancer treatment', *Pediatric Blood and Cancer*, 47(3), pp. 312–319. doi: 10.1002/pbc.20661.

Tsimicalis, A. *et al.* (2018) 'The Impact of a Childhood Cancer Diagnosis on the Children and Siblings' School Attendance, Performance, and Activities: A Qualitative Descriptive Study', *Journal of Pediatric Oncology Nursing*, 35(2), pp. 118–131. doi: 10.1177/1043454217741875.

Unguru, Y. *et al.* (2019) 'Chemotherapy and Supportive Care Agents as Essential Medicines for Children With Cancer', *JAMA Pediatrics*, 173(5), p. 477. doi: 10.1001/jamapediatrics.2019.0070.

Utami, K. C., Puspita, L. M. and Karin, P. A. E. S. (2020) 'Family support in improving quality of life of children with cancer undergoing chemotherapy', *Enfermeria Clinica*, 30, pp. 34–37. doi: 10.1016/j.enfcli.2020.07.007.

Vlachioti, E. *et al.* (2016) 'Assessment of quality of life of children and adolescents with cancer during their treatment', *Japanese Journal of Clinical Oncology*, 46(5), pp. 453–461. doi: 10.1093/jjco/hyw009.

Wawrzynski, S. E. *et al.* (2021) 'Social support and siblings of children with cancer: A scoping review', *Psycho-Oncology*. John Wiley and Sons Ltd, pp. 1232–1245. doi: 10.1002/pon.5689.

World Health Organization (2024) 'International Childhood Cancer Day : Reducing the Survival Gap', 15 December.

Yaner, N. R. *et al.* (2019) 'Family Support Required to Increase Compliance of Medical Control of Patients with Cancers', *Jurnal Ners*, 14(3 Special Issue), pp. 331–335. doi: 10.20473/jn.v14i3(si).17177.

Yilmaz, M. C. *et al.* (2014) 'Determination of School-Related Problems in Children Treated for Cancer', *Journal of School Nursing*, 30(5), pp. 376–384. doi: 10.1177/1059840513506942.

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