

Quality of life of children with acute lymphoblastic leukemia

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Abstract

Background Acute lymphoblastic leukemia (ALL) is the most common cancer in children worldwide, which requires long treatment. This condition and its subsequent treatment change the body's physiology, reducing children's quality of life.

Objective To describe the quality of life in children with acute lymphoblastic leukemia in Java, Indonesia.

Methods This descriptive study with a cross-sectional approach included parents who had children with ALL at three referral hospitals in Java, Indonesia, between January 2021 and May 2022. We recruited 188 mothers or fathers who accompanied their children for follow-up visits or hospitalization. Children's quality of life as the primary outcome was evaluated by parent proxy using the *PedsQL* 3.0 cancer module.

Results Most parents were mothers (81.9%); parents' ages ranged from 22 to 59 years. The mean age of children was 7.63 (SD 3.85) years, with 63.3% boys and 147 (78.2%) treated in maintenance phase during the study. The mean overall children's QoL score was 84.37 and it classified as high (73.9% of subjects), no children had very low QoL. The lowest mean sub-scale QoL score was in procedural anxiety (72.25), whereas the highest sub-scale score was in communication (91.56).

Conclusion There is an improvement in QoL of children with ALL in Indonesia. However, the procedural anxiety sub-scale requires more interventions to reduce anxiety and alleviate pain during invasive procedures. [Paediatr Indones. 2023;63:405-10; DOI: <https://doi.org/10.14238/pi63.4.2023.405-10>].

Keywords: acute lymphoblastic leukemia; cancer; children; quality of life

Leukemia still dominates the incidence of cancer in children and causes 3.8% of deaths due to childhood cancer worldwide.¹ The majority of children with leukemia have acute lymphoblastic leukemia (ALL), which reached 76-80% around the world.^{2,3} Similarly, in Indonesia, the incidence reached 4.32 childhood ALL per 100.000 children.⁴

Although the number of cases continues to increase, survival rates have improved, particularly in developed countries such as Finland which reached 95.2%.⁵ Unfortunately, the increase in survival rate has not been accompanied by an improvement in children's quality of life (QoL). Most studies reported that the QoL of children with leukemia during active treatment was low.⁶⁻⁸ Similarly, studies in several hospitals in Indonesia found that the QoL of children with ALL was low (mean score ranged between 42.1 to 68.8).⁹⁻¹¹ Those studies evaluated QoL but were

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quite old and involved a small sample size of less than 100 respondents.

Quality of life can be used as an actual indicator of treatment, as it is used to evaluate the intervention and its outcomes.^{12,13} The QoL is a consequence of the adverse effects of treatment.^{2,14} Therefore, it is necessary to carry out ongoing QoL evaluations in children with ALL in Indonesia.

Methods

This descriptive study with a cross-sectional approach included parents of children aged 2 - 17 years with ALL from January 2021 up to May 2022. There were 188 mothers or fathers who had children diagnosed with ALL during active chemotherapy at Dr. Moewardi Hospital, Surakarta, Central Java; Dr. Kariadi Hospital, Semarang, Central Java; and Dr. Soetomo Hospital, Surabaya, East Java, Indonesia, which were referral hospitals for cancer patients. Parents were consecutively recruited while accompanying their children at follow-up outpatient clinic visits or during hospitalization for chemotherapy.

Demographic characteristics were obtained from a questionnaire filled by parents about themselves and their children. The characteristics of parents consisted of sex, age, and religion, while the characteristics of children were sex, age, and phase of chemotherapy. To measure children's QoL, the Indonesian version of parent proxy the *PedsQL 3.0* cancer module (*PedsQL™ Modul Kanker Versi 3.0*) was used.¹⁵ This validated Indonesian version of the questionnaire consists of 27 items for children aged 5-18 years and 25 items for those age 2 to 4-year-old. The scale had five Likert response options: never, almost never, sometimes, often, and almost always. The scoring for this Likert scale was reversed, with 100, 75, 50, 25, and 0 for never, almost never, sometimes, often, and almost always, respectively. Higher scores (75-100) indicated better, while lower score (0-25) indicated lower level of QoL in children. The Cronbach's alpha values of each sub-scale were between 0.69 and 0.91.¹⁶

This study was approved by the Human Research Ethics Committee, Faculty of Medicine Ramathibodi Hospital, Mahidol University and the Ethics Committees from the three hospitals. The parents were informed about aims, procedures and benefits of

the study before signing the informed consent. Data were analyzed using *SPSS version 18* software.

Results

The characteristics of parents are shown in **Table 1**. Most parents were mothers (81.9%); the parental age range was 22 to 59 years; 96.8% were Moslem and the others were Christian. The average number of children per family was 2.15 (46%), while 3.2% of parents had more than 4 children. The mean age of the pediatric patients was 7.63 (SD 3.85; range 2-17) years; 63.3% were boys; and 147 (78.2%) patients were being treated during the maintenance phase of chemotherapy (**Table 2**).

Table 3 shows the percentages of patients in each QoL category (low, moderate, or high) for overall

Table 1. Characteristics of parents

Parents	(N=188)
Sex, n (%)	
Female	154 (81.9)
Male	34 (18.1)
Religion, n (%)	
Moslem	182 (96.8)
Christian	6 (3.2)
Mean age (SD), years	36.3 (7.2)
Age by group, n (%)	
<30 yrs	43 (22.9)
31-40 yrs	92 (48.9)
41-49 yrs	44 (23.4)
>50 yrs	9 (4.8)

Table 2. Characteristics of children with ALL

Characteristics	(N=188)
Sex, n (%)	
Male	119 (63.3)
Female	69 (36.7)
Mean age (SD), years	7.6 (3.9)
Age by group, n (%)	
2-3 yrs	29 (15.4)
4-6 yrs	60 (31.9)
7-12 yrs	77 (41.0)
13-17 yrs	22 (11.7)
Chemotherapy phase, n (%)	
Induction	12 (6.4)
Consolidation	7 (3.7)
Intensification	22 (11.7)
Maintenance	147 (78.2)

QoL and its components (8 clusters), as reported by parents. The mean overall QoL score was high (84.37), and only 6.4% children experienced low level of QoL. The lowest mean QoL score was for procedural anxiety (72.25). Specifically, each of the other QoL constituents had a mean score of more than 75 (range 81.98-91.56), including pain, worry, nausea, cognition problems, treatment anxiety, physical appearance and communication problem, respectively.

Discussion

It was not surprising that our study involved more mothers (81.9%) than fathers. It is common in families, particularly in those who have children with cancer, that mothers are the main figures involved in caring for their sick children.¹⁷ Similarly, a study in Canada found that more mothers than fathers participated in study on pediatric cancer survivors (90.4%), while another study had only 10.8% paternal respondents.^{8,18} Furthermore, Indonesian women, particularly in Javanese culture, are expected to carry out wifely duties, including “macak, manak, masak,” which means that they must take care of themselves, their children, and their house.¹⁹

The mean age of children with ALL was 7.63 years, with more boys than girls. ALL is found predominantly at ages 4-14 years.²⁰ More boys than girls with ALL or other cancers were noted in two Canadian studies, in which 64.2% and 58.7% of subjects were boys with cancer.^{8,18} Moreover, a study in Iran reported that boys had a higher incidence of leukemia (55.86%) than girls.²¹ Most of our subjects

were in the maintenance phase of chemotherapy. This phase requires the longest time, which is about 2 to 3 years compared to other phases which average a month.²²

The overall QoL of children with ALL was high (mean score 84.37). This was interesting and different from previous studies which showed low QoL. In Turkey, the QoL of children with cancer 3 months after diagnosis was low (61.7), and even decreased during the COVID-19 pandemic to 48.8.²³ Our finding also contradicted a previous study in Indonesia, in which only 27.2% of children with ALL had good general QoL.²⁴ A recent study in Greece also found fairly high QoL scores in children with cancer.²⁵ Similarly, a Chinese study carried out on children with chronic myeloid leukemia (CML), another type of leukemia, showed the overall QoL scores during the chronic phase tended to be high at 80.9 (SD 10.7) and 79.1 (SD 12.3), based on child self-report and parent proxy report, respectively.²⁶ The better QoL was in agreement with the success rate of remission in children with ALL which reached 80% in Indonesia.²⁷

The high children's QoL score could have been closely related to large numbers of children in the maintenance phase of chemotherapy. During this phase, children receive anti-cancer agents less intensively than in previous phases, therefore, side effects of treatment are generally milder.²² In addition, an Indian study reported that cycle 1 of chemotherapy for children with ALL had significant highest toxicities (38.8%) compared to other cycles ($P=0.0001$).²⁸ Another study from Turkey stated that most children with cancer suffered adverse events during the intensive phase of chemotherapy, in which

Table 3. Quality of life of children with ALL (N=188)

QoL	Low	Moderate	High	Range	Mean (SD)
Overall	12 (6.4)	37 (19.7)	139 (73.9)	27.00-100.00	84.37 (17.71)
Pain	38 (20.3)	17 (9.0)	133 (70.7)	0-100.00	81.98 (23.34)
Nausea	19 (10.1)	30 (16.0)	139 (73.9)	15.00-100.00	84.49 (21.13)
Procedural anxiety	56 (29.8)	17 (9.0)	115 (61.2)	0-100.00	72.25 (31.68)
Treatment anxiety	23 (12.2)	16 (8.5)	149 (79.3)	0-100.00	87.23 (23.37)
Worry	34 (17.5)	15 (8.0)	139 (73.9)	0-100.00	84.21 (26.46)
Cognition problems	33 (17.6)	11 (5.9)	144 (76.6)	0-100.00	85.39 (22.61)
Perceived physical appearance	24 (12.8)	10 (5.3)	154 (81.9)	0-100.00	87.68 (22.34)
Communication problems	13 (6.9)	17 (9.0)	161 (85.6)	0-100.00	91.56 (18.39)

*data are shown as n(%)

they suffered a lower level of heart rate variability compared with maintenance therapy.²⁹ Furthermore, another study from India found more children with cancer experienced more vomiting during the acute phase rather than the delayed phase.³⁰

Of the 8 QoL subscales, 7 subscales had high mean QoL scores (mean scores >75), with communication as the top score. After several days and times of hospitalization, children adapt and become familiar with the room, their situation, and the coming and going of healthcare staff. One interesting finding in our study was that anxiety about the procedure had the lowest mean score (72.25), which was considered to be in the moderate QoL category. Furthermore, in this subscale, many children had low and very low QoL (almost 30%). This result was consistent with a Turkish study in which children with cancer, including leukemia, had low QoL score (31.6) with regards to procedural anxiety.²³ This finding indicated that treatment procedures were still a major problem for children, causing injury and pain during hospitalization. In addition, a US study found that children with cancer had poor pain scores during invasive procedures, while anxiety during procedures was quite high.³¹ Furthermore, a qualitative study in the US stated that caregivers of children in the emergency department reported that insertion procedures and venipuncture have a negative impact on children.³²

In conclusion, the overall QoL of childhood ALL in Indonesia is high and in line with results that reported for most developed countries. Procedural anxiety is the paramount problem in children, even for children who receive long-term treatment of chemotherapy (maintenance phase).

Conflict of interest

None declared.

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