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Health-related quality of life and its determinant factors in Thai children with cancer: parents vs. children perspectives

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Abstract

Background Health-related quality of life (HRQOL) is a vital assessment to demonstrate the achievement in pediatric cancer care parallels that of medical treatment. The Pediatric Quality of Life Inventory (PedsQL) 3.0 Cancer Module in the Thai Version has become a standard tool to access the HRQOL among Thai children with cancer and their families. This study aimed to explore the HRQOL and factors related to HRQOL among pediatric oncology patients using the PedsQL 3.0 Cancer Module.

Methods In 2018–2019, a single-institution, cross-sectional study was conducted among children with cancer and their families in Bangkok, Thailand. A paired-sample *t*-test was performed to evaluate the differences between the HRQOL scores of the child and parents' reports. Linear regression was used to evaluate factors associated with HRQOL and which particular domains of the PedsQL 3.0 Cancer Module were influenced.

Results Eighty-five children with cancer and their families were enrolled. The patients' mean age was 10.82 ± 5.48 years. The most common cancer types included acute lymphoblastic leukemia ($n = 32$, 67%), central nervous system tumors ($n = 13$, 15%), osteosarcoma ($n = 10$, 27%) and neuroblastoma ($n = 9$, 24%), in rank. The mean HRQOL scores in child and parent reports were 74.37 ± 15.7 and 70.42 ± 17.15 , respectively ($p = 0.034$). Factors negatively correlated to HRQOL in parent reports were the number of outpatient visits ($p = 0.019$) and hospital admissions ($p = 0.002$). The number of hospitalizations was the only independent factor that affected HRQOL ($p = 0.044$). The number of outpatient visits and/or hospital admissions was influenced by pain and hurt, nausea, procedural anxiety and communication domains ($p < 0.05$). Only the number of hospitalizations was an independent factor influencing the procedural anxiety domain in HRQOL ($p = 0.005$).

Conclusion HRQOL among Thai children with cancer was desirable from both children's and parent's perspectives. Differences between child and parent HRQOL scores were observed. The number of outpatient visits and hospital admissions affected HRQOL, particularly in the procedural anxiety aspect.

Trial registration Thai Clinical Trials Registry (TCTR) Number: TCTR20200904001 (04/09/2020), <https://www.thaiclinicaltrials.org/>.

Keywords Health-related quality of life, Children with cancer, Thailand, Parents, Factors

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Introduction

Childhood cancer is one of the major public health problems, with an overall incidence rate of 140.6 per million person-years globally [1]. Different types of cancer require specific treatment plans according to the disease and its severity. The wide range of treatment modalities includes systemic chemotherapy, surgery, radiation, immunotherapy and hematopoietic stem cell transplantation. Although the increased survival rate of up to 80% [2] underlines the success of advanced medical care for devastating diseases, cancer treatment among children remains a major physical and psychological stressor for both patients and families.

The World Health Organization (WHO) defines health, “as a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity” [3]. Therefore, measuring health with the presence or absence of diseases remains insufficient. Physical and biochemical measurements may indicate only disease and treatment strategies. However, these do not demonstrate the patient’s well-being and mental health, which should be considered as an important health dimension called the quality of a person’s life.

Quality of life (QOL) constitutes “an overall sense of well-being including aspects of happiness and satisfaction with life as a whole” [3]. Health-related Quality of life (HRQOL) is a multidimensional aspect that defines how disease and treatment affect a patient’s sense of overall function and well-being [4]. Also, the clinical symptoms of cancer and the aggressive treatment substantially impact a patient’s life in multiple aspects, which may affect HRQOL. As a result, children and families have experienced a reduction in their QOL after being diagnosed with cancer and treatment has been initiated [5]. In Pakistan, cancer patients exhibited a lower HRQOL than healthy youngsters [6]. For these reasons, the intention of cancer treatment currently is to cure the disease and improve the QOL of patients and families.

To achieve this goal, an assessment and understanding of HRQOL among children with cancer both from the patient themselves and their family’s perspectives is crucial. Our study aims to illustrate HRQOL among Thai children with cancer using a standard instrumental questionnaire, The Pediatric Quality of Life Inventory (PedsQL) 3.0 Cancer Module, Thai Version [7], and explore factors associated with HRQOL. The results would establish adapted treatment strategies to achieve patient outcomes of both physical and mental health for Thai children with cancer, which may be further expanded to neighbors having a similar context perspective.

Methods

Participants

Oncology patients aged 2 to 18 years and their parents or guardians, who were treated primarily at the Division of Hematology-Oncology, Department of Pediatrics, Phramongkutklo Hospital, Bangkok, Thailand from May 1, 2018, to November 30, 2019, were eligible for this study. Patients with terminal illnesses, developmental disorders, intellectual disabilities, learning disorders, in palliative care or illiterate were excluded from the study. All participants and their legal guardians were provided informed consent and assented to participate in the study.

Instrument

The original version of the PedsQL 3.0 Cancer Module was translated to Thai under a full linguistic validation process. The PedsQL 3.0 Cancer Module, Thai version was approved by the Mapi Research Trust for academic purposes, with evidence of excellent internal consistency among child and parent reports (0.92 and 0.94, respectively) [7].

The PedsQL 3.0 Cancer Module, Thai version was designed to evaluate the QOL among children and young adults with cancer aged 2 to 25 years. The PedsQL 3.0 Cancer Module has two parallel versions (child and parent forms) in each different age group: child (5–7, 8–12, 13–18 and 18–25 years) and parent (2–4, 5–7, 8–12, 13–18 and 18–25 years) reports. The PedsQL 3.0 Cancer Module consists of 8 domains and a total of 27 items: 1) pain and hurt (2 items), 2) nausea (5 items), 3) procedural anxiety (3 items), 4) treatment anxiety (3 items), 5) worry (3 items), 6) cognitive problems (5 items), 7) perceived physical appearance (3 items) and 8) communication (3 items). The child and parent rate a score in each item based on a 5-point Likert scale (0 = never, 1 = almost never, 2 = sometimes, 3 = often, and 4 = almost always). The 5- to 7-year child report is exceptional; the child rates a score in each item based on a 3-point Likert scale according to a visual aid, (0 = never/happy face, 2 = sometimes/neutral face, and 4 = almost always/sad face). The score in each item was reverse-scored and linearly transformed to a 0 to 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). Scores in each domain were calculated as the sum of the items divided by the number of items answered. Higher scores indicated a better HRQOL.

Procedures

After informed consent and assent forms were obtained, parents then completed the demographic data information and PedsQL 3.0 Cancer Module, Thai Version. For patients aged 2 to 4 years, only parents filled out the questionnaires. Children aged ≥ 5 years completed the

PedsQL 3.0 Cancer Module, Thai Version separately from their parents. Children aged 5 to 7 years completed the questionnaires with support from a research assistant to ensure reading competency and to clarify each question. Children aged 8 to 18 completed the questionnaires independently or with support when needed.

This study comprised a secondary analysis of data from the related cohort of Sudnawa KK, et al. [7] and was approved by the Institutional Review Board, Royal Thai Army Medical Department according to the ethics principles of the Declaration of Helsinki (1964) and its revision (reference number: IRBRTA 700/2561). The study was also registered and approved by the Thai Clinical Trials Registry (TCTR <https://www.thaiclinicaltrials.org/>), number TCTR20200904001 (04/09/2020).

Statistical analysis

Demographic data were analyzed using descriptive statistics and presented as mean with standard deviation (SD) for continuous variables and demonstrated as frequency and percentage for categorical variables. A paired-sample *t*-test was conducted to evaluate the differences between the HRQOL scores of the child and parent reports from each domain of the PedsQL 3.0 Cancer Module. Univariate and multivariate linear regression were used to evaluate factors correlated to HRQOL and which particular domains of the PedsQL3.0 Cancer Module were influenced. Statistical significance was considered at *p* < 0.05. Statistical analysis was performed using IBM SPSS Software for Windows, Version 23.0 (Armonk, NY: IBM Corp., USA).

Results

Patient characteristics

Eighty-five eligible children with cancer and their parents participated in the study. Patient demographic data including age, sex, diagnosis, disease and treatment status, hospital visits, school attendance, parental marriage status and household incomes are summarized in Table 1.

The male to female ratio was 3:2, and the mean age of patients was 10.8 ± 5.5 years. The mean duration of disease from diagnosis to assessment was 4.99 ± 4.96 years. The most common cancer types were acute lymphoblastic leukemia (ALL), brain or central nervous system (CNS) tumors, osteosarcoma, neuroblastoma and chronic myeloid leukemia, in rank. Four (4.7%) patients were in advanced stage. Most participants were newly diagnosed (70.6%), in remission (22.4%), and in relapse/refractory (7%) of disease, in rank. Therefore, 77.6% of patients were in the treatment process while 22.4% of patients had completed treatment. The majority of treatments received were chemotherapy (62.4%) and surgery (15.3%). Treatment complications occurred for 81.2%,

Table 1 Patient demographic data (n = 85)

Demographic data (n = 85)	n(%)
Age (years)	
Mean ± SD	10.82 ± 5.48
Gender	
Male	50(58.8)
Female	35(41.2)
^aDuration of disease (years)	
Mean ± SD	4.99 ± 4.96
Diagnosis	
Hematologic malignancy	48(56.5)
Acute lymphoblastic leukemia	32(66.7)
Chronic myeloid leukemia	5(10.4)
Non-Hodgkin lymphoma	4(8.3)
Acute myeloid leukemia	3(6.3)
Hodgkin lymphoma	1(2.1)
Others	3(6.3)
Solid tumors	37(43.5)
Brain/central nervous system tumor	13(15.3)
Osteosarcoma	10(27)
Neuroblastoma	9(24.3)
Wilms tumor	1(2.7)
Hepatoblastoma	1(2.7)
Rhabdomyosarcoma	1(2.7)
Ewing sarcoma	1(2.7)
Retinoblastoma	1(2.7)
Stage of disease	
Advanced (stage III, IV for lymphomas and solid tumors)	4(4.7)
Disease status	
Newly diagnosed	60(70.6)
Relapse/refractory	6(7)
Remission of disease	19(22.4)
Number of outpatient visits/month	
Mean ± SD	1.3 ± 1.3
Number of hospitalizations/month	
Mean ± SD	1.0 ± 1.3
Treatment status	
During treatment	66(77.6)
Completed treatment	19(22.4)
Type of treatment	
Chemotherapy	53(62.4)
Surgery	13(15.3)
Radiation	8(9.4)
Hematopoietic stem cell transplantation	1(1.2)
Complications	
Electrolyte imbalance	59(69.4)
Febrile neutropenia	37(43.5)
Mucositis	10(11.8)
Current school attendance	
Primary school or lower	31(57.4)
Secondary school or higher	23(42.6)

Table 1 (continued)

Demographic data (n = 85)	n(%)
Parental status	
Married	69(81.2)
Divorced/separated	16(18.8)
Household incomes (THB/month)	
< 15,000	33(38.8)
15,000—30,000	20(23.5)
> 30,000	32(37.6)

Data are presented as mean \pm SD for continuous variables and number (%) for categorical variables

Abbreviations: SD standard deviation, THB Thai baht

^a Duration of disease refers to the time from diagnosis to assessment date

with mostly encountered with electrolyte imbalance (69.4%), followed by febrile neutropenia (43.5%). The number of monthly outpatient visits and hospitalizations totaled 1.3 ± 1.3 and 1.0 ± 1.3 , respectively.

Fifty-four (63.5%) patients attended school, of which 57.4% studied in primary school or lower and 42.6% studied in or higher than secondary school level. Most parents were married (81.2%) and still lived together with household monthly incomes of less than 15,000 THB (38.8%) (Table 1).

HRQOL among children and parents

Overall, children with cancer reported higher HRQOL scores of the PedsQL 3.0 Cancer Module compared with those found in parent reports, except for the perceived physical appearance and communication domains. The highest HRQOL scores of the PedsQL 3.0 Cancer Module in child reports were observed in the treatment anxiety domain (88.15 ± 17.37), while the nausea domain (78.98 ± 18.99) had the highest HRQOL scores in parent reports. On the contrary, the lowest HRQOL scores in child reports were observed in the cognitive problems domain (66.31 ± 22.26), while the worry domain (55.34 ± 30.37) had the lowest HRQOL scores in parent reports.

However, statistically significant differences were noted between child and parent reports on procedural anxiety (70.05 ± 26.67 vs. 60.03 ± 25.6 , $p=0.003$), treatment anxiety (88.15 ± 17.37 vs. 76.82 ± 26.7 , $p=0.001$), worry (66.67 ± 25.59 vs. 55.34 ± 30.37 , $p=0.003$) and total score (74.37 ± 15.7 vs. 70.42 ± 17.15 , $p=0.034$) (Supplementary Table 1).

Factors associated with overall HRQOL among children and parents

From the parent report, patients having completed the treatment were positively correlated to the total HRQOL

score ($\beta=9.34$, $p=0.039$). On the contrary, the number of monthly hospitalizations ($\beta=-4.49$, $p=0.002$) and number of monthly outpatient visits ($\beta=-3.53$, $p=0.019$) were negatively correlated to the total HRQOL score (Table 2). Other factors including age, sex, duration of disease, cancer type, treatment, febrile neutropenia occurrence, school or family factors were unassociated with the HRQOL.

Using multivariate analysis, only the number of monthly hospitalizations remained independently, negatively correlated to the total HRQOL score from the parent reports ($\beta=-5.77$, $p=0.044$) (Table 3).

Factors associated with individual domains of HRQOL among parents

Each domain of the PedsQL 3.0 Cancer Module parent report was analyzed to determine whether the number of monthly hospitalizations, outpatient visits or treatment with chemotherapy correlated to HRQOL. The number of outpatient visits and/or hospital admissions was influenced by pain and hurt, nausea, procedural anxiety and communication domains ($p<0.05$). Treatment with chemotherapy was influenced by pain and hurt and procedural anxiety ($p<0.05$). Only the number of monthly hospitalizations remained independent and significantly correlated to the procedure anxiety domain ($\beta=-13.2$, $p=0.005$) (Fig. 1 and Supplementary Table 2).

Discussion

HRQOL assessed by PedsQL3.0 Cancer Module, Thai version from parent and child reports received mean total scores of 70.4 and 74.4, respectively, which was comparable with other countries either in resource-available or limited-resource settings [8–15]. However, the total HRQOL scores in this study were higher than those of related studies [6, 16], which had fewer participants comparing between healthy children and children with cancer [6] or in hospitalized patients [16]. On the other hand, our study had slightly lower scores than those of the study of Ocak E, et al., [17] enrolling only children with leukemia in a younger age range (Table 4).

A strong agreement between child and parent reports was found in observable functioning or physical HRQOL domains [7]. Nevertheless, a disagreement was detected in nonobservable functioning or emotional or social HRQOL domains. In general, patients themselves reported higher HRQOL scores of the PedsQL 3.0 Cancer Module compared with parents, except for the perceived physical appearance and communication domains. These discordances were similarly illustrated in related studies by Sand P, et al. [9] and Tomlinson, D et al. [18]. The treatment consequences definitely change physical appearance such as hair loss,

Table 2 Univariate analysis of factors correlated with HRQOL scores of PedsQL 3.0 Cancer Module between children and parents

Factors	Parent report (n=85)			Child report (n=65)		
	β	p-value	95%CI	β	p-value	95%CI
Sex; male	-0.99	0.789	-8.68 to 6.70	-1.44	0.731	-9.76 to 6.88
Age (years)	0.32	0.354	-0.37 to 1.02	0.03	0.946	-0.96 to 1.02
^a Duration of disease (years)	0.56	0.143	-0.20 to 1.32	-0.19	0.628	-0.96 to 0.58
Number of outpatient visits/month	-3.53	0.019	-6.45 to -0.60	-1.81	0.209	-4.66 to 1.04
Number of hospitalization/month	-4.49	0.002	-7.32 to -1.67	-0.97	0.514	-3.92 to 1.98
Diagnosis						
Hematologic malignancy						
Solid tumors	9.34	0.603	-9.63 to 5.62	-3.48	0.388	-11.49 to 4.52
Disease status						
During treatment						
Completed treatment	9.34	0.039	0.49 to 18.20	1.11	0.798	-7.53 to 9.77
Treatment with chemotherapy	-6.62	0.090	-14.30 to 1.06	0.16	0.968	-7.81 to 8.13
Treatment with surgery	2.30	0.664	-8.20 to 12.81	5.51	0.293	-4.88 to 15.90
Encountered with febrile neutropenia during treatment	-0.61	0.873	-8.25 to 7.02	-2.17	0.589	-10.16 to 5.82
Current school attendance	4.63	0.241	-3.17 to 12.43	3.20	0.495	-6.11 to 12.50
School level						
Primary school or lower						
Secondary school or higher	-7.27	0.119	-16.48 to 1.95	-0.38	0.937	-10.05 to 9.29
Parental status						
Married						
Divorces/separated	0.86	0.861	-8.82 to 10.54	5.73	0.230	-3.73 to 15.19
Household income (THB/month)						
<15,000						
15,000-30,000						
>30,000	1.68	0.440	-2.63 to 6.0	1.38	0.543	-3.13 to 5.89

^a Duration of disease refers to the time from diagnosis to assessment date

Univariate analysis of factors associated with HRQOL scores of PedsQL 3.0 Cancer Module between child- and parent reports were calculated using linear regression. $P < 0.05$ is considered as statistical significance

Abbreviations: HRQOL Health-related quality of life, PedsQL The Pediatric Quality of Life Inventory, THB Thai baht

Table 3 Multivariate analysis of factors associated with total HRQOL scores of PedsQL 3.0 Cancer Module between children and parents

Factors	Parent report (n = 85)			Child report (n = 65)		
	β	p-value	95%CI	β	p-value	95%CI
Number of outpatient visits/month	0.82	0.773	-4.84 to 6.49	-4.79	0.121	-10.87 to 1.30
Number of hospitalization/month	-5.77	0.044	-11.4 to -0.17	1.41	0.663	-5.05 to 7.88
Treatment with chemotherapy	-2.33	0.583	-10.76 to 6.10	1.41	0.761	-7.84 to 10.67
Treatment with surgery	3.28	0.527	-6.99 to 13.54	5.55	0.304	-5.16 to 16.26

Multivariate analysis of factors associated with HRQOL scores of PedsQL 3.0 Cancer Module between child- and parent reports were calculated using linear regression. $P < 0.05$ is considered as statistical significance

Abbreviations: HRQOL Health-related quality of life, PedsQL The Pediatric Quality of Life Inventory

surgical scars or extremity loss which negative effect to patient emotions [19]. Physical appearance perception comprises internalized and emotional sensations

that may be either difficult to interpret or considered less sentimental by the parents. Marginean CO et al. [20] reported that children were not satisfied with the

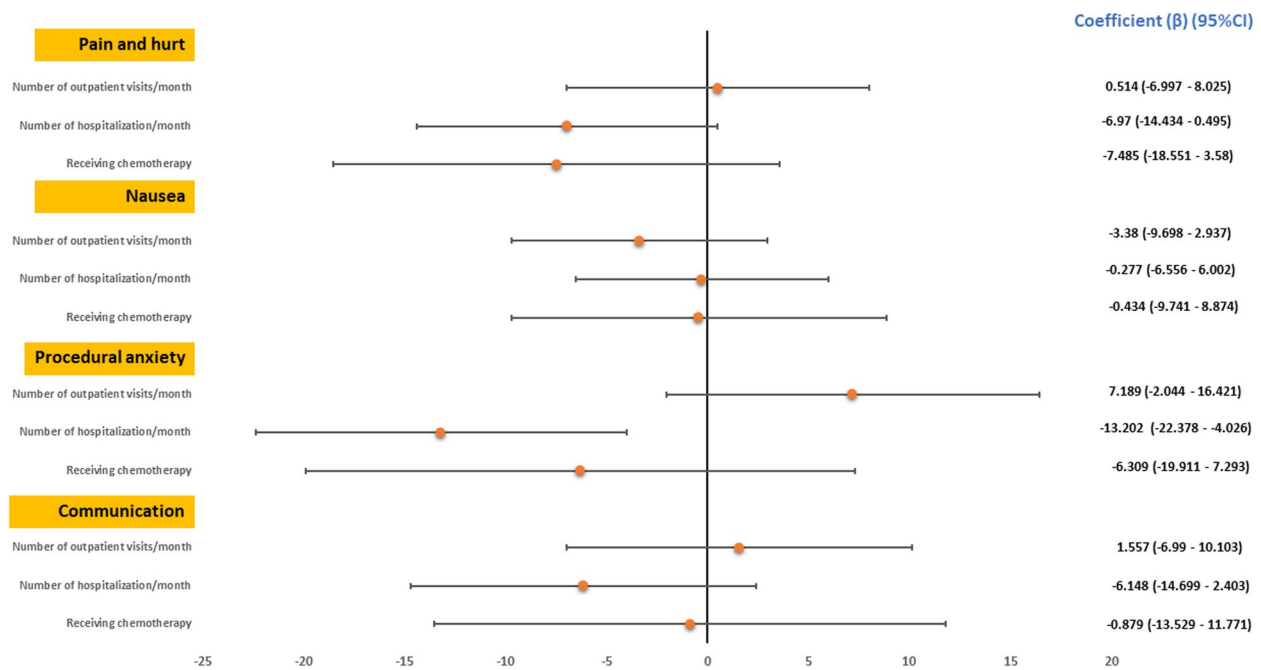


Fig. 1 Forest plot shows multivariate analysis factors correlated with HRQOL scores of PedsQL 3.0 Cancer Module parent reports in pain and hurt, nausea, procedural anxiety, and communication domains

amount of time their doctor communicated with them. These underline the communication between physicians and pediatric patients remains insufficient or inappropriate, especially in serious situations which children may be left behind. Good communication and emotional supports between children, their care givers and doctors may better comprehend the patients' emotions and support for each other.

From the parents' perspectives, higher score domains were reported for "Nausea" and "Pain and hurt." This may imply that symptomatic and supportive care programs in Thailand was sufficient to provide positive emotions for parents, especially the appropriate protocol for bedside invasive procedural sedation among patients undergoing multiple painful procedures such as bone marrow procedures or lumbar puncture [21, 22]. Moreover, providing proper analgesics and anti-emetics can improve HRQOL [23–25], particularly in patients who require repeated or multiple invasive procedures for diagnosis and treatment [21, 22], ranging from weekly intrathecal chemotherapy during the induction phase to every three months during the maintenance phase of ALL treatment [26]. A higher HRQOL score in the communication domain was demonstrated in parent reports rather than child reports corresponding to many studies [8, 11, 17]. It conveys that the communication between families and medical teams particularly shared decision-making will benefit and improve HRQOL among children with cancer [27].

Some aspects were contradictory between parent and child perspectives, for example, "Treatment anxiety" received superior HRQOL scores in child reports compared with those in parent reports, which was similar to related studies [9, 10, 13, 14, 17]. The lower score domains from the parent reports included "Worry" and "Procedural anxiety" whereas "Worry" and "Cognitive problems" were addressed as the lowest score domain in child reports which was parallel to related studies [8, 10, 12, 14, 16, 17]. Anxiety and depression-related findings were frequently reported among children with cancer [28, 29]. Screening tests for early detection of mood problems and early intervention such as enhancing communication skills or psychotherapy will support patients and families with cancer [30].

Cognitive problems among children with cancer may be directly caused by specific types of cancer and treatment, such as CNS tumors, cranial irradiation, chemotherapy crossing blood–brain barriers or prolonged hospitalization leading children to incompetency in school activities [31, 32]. Early detection of cognitive problems among pediatric oncology patients along with broad strategies such as educational intervention, and cognitive training are essential to remediate cognitive and learning dysfunction [31, 33].

Interestingly, we found that the total HRQOL score was positively correlated to completed treatment status. This finding corresponded to that of Meeske K

Table 4 Assessment of HRQOL scores of PedsQL 3.0 Cancer Module in literature review

	This study		Alabbas F [8]		Sand P [9]		Santos S [10]		Abu-Saad Huijjer, H [11].		JIY [12]		Tsuji N [13]		Sitairesmi MN [14]		Hegazy A [15]		Nunns M [16]		Ocak E [17]	
	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child
N	85	95	94	332	85	266	245	98	51	38	59											
Age (years)	10.8	7	9.9	13	12.5	8.8	10.5	6.6	10.5	12.1	7.3											
Male (%)	58.8	46.3	41.5	52.4	48.2	57.9	55.1	55	62.7	65.8	52.5											
Report	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child
Pain and hurt	77.0	79.3	75.5	70.3	77.9	81	70.4	77.4	74.2	82.9	84.7	71	80.1	65.6	67.3	81.9	78.7					
Nausea	79.0	79.8	78.3	59.7	72	74.1	55.2	73.2	75.7	80.5	83	78.8	82.6	76.9	54.6	80.5	84.1					
Procedural anxiety	60.0	70.1	60.1	69.7	78.2	76.9	77.2	64.1	68	63.2	72.9	60.1	69.9	60.8	56.8	67.4	81.7					
Treatment anxiety	76.8	88.2	67.6	80.3	89.5	89.6	67.7	67.1	71.7	84.9	93.1	74.4	88.2	66.0	61.4	83.2	90.9					
Worry	55.3	66.7	71.2	69.2	75.6	55.6	68.6	62.9	68.1	81.4	76.6	74.6	75.5	61.8	45.6	85.1	81.5					
Cognitive problems	64.3	66.3	78.3	70.2	75.3	72.3	80.5	73.9	71.7	68.8	72.4	77.6	76.9	92.5	62.5	81.5	78.1					
Perceived physical appearance	76.2	73.8	67.4	67.6	73.2	77.7	75.7	77.9	76.4	73.8	70.3	82.5	76.4	69.8	70.1	72.8	78.7					
Communication	73.3	71.6	80.2	77.6	82.4	78.6	86.6	71.6	72.2	62.2	67.0	60.2	68.3	82.7	65.0	84.6	82.6					
Total score	70.4	74.4	72.3	69.3	77	75.1	72.8	NA	NA	74.9	77.9	72.2	77.1	73.5	59.1	79.6	82.0					

Abbreviation: HRQOL Health-related quality of life, NA Not available, PedsQL The Pediatric Quality of Life Inventory

et al., [34] which found that patients with CNS tumors and ALL who were undergoing treatment had lower HRQOL scores of PedsQL™ 3.0 cancer module compared to those who had completed treatment. This result can be attributed to the absence of hospitalization, treatment-related anxiety, and unpleasant emotions. Furthermore, we addressed that the number of monthly in- and outpatient visits were negative indicators correlating to the HRQOL score. Hospitalizations subsequently remained independent and negatively correlated to the "Procedure anxiety" domain from the parent report. However, Baggott CR et al. [35] identified that pediatric oncology patients with prolonged hospitalization possibly had a higher nausea score assessed by PedsQL™ 3.0 cancer module, but no correlation was observed in the total or "Procedure anxiety" HRQOL score. These contradicting results may stem from different intravenous catheterization access levels between resource-available and resource-limited settings. In resource-available countries, central venous catheters (CVC) always applied to all children with cancer needing repeated systemic chemotherapy, in contrast with low and middle income countries in which patients regularly received services for repeated peripheral venous catheters at each single visit [21]. This made patients more anxious when hospitalization was required. CVC placement should be considered among patients requiring multiple invasive and distressing procedures or prolonged treatment, especially for inhouse patients. Moreover, early detection of infectious complications which is the most common cause of prolonged and increased number of hospitalizations, may increase HRQOL among children with cancer.

Nonpharmacologic treatments, either hypnosis or nonhypnosis interventions, may reduce procedural anxiety for pediatric inpatients [36], particularly those younger than five years who reported a strong association with "Procedural anxiety" [8, 14, 37, 38]. Robson PC, et al. [37] reported lower household income correlated to poorer child's HRQOL in the US, which was not identified in our study. This observation may be explained by the accessible and successful implementation of Thailand's universal health coverage applying to all Thais regardless of different income levels [39].

This is the very first study to initiate the assessment of the HRQOL among Thai children with cancer using the standard tool of PedsQL 3.0 Cancer Module in the Thai Version, applied in both parent and child reports. Results will elucidate HRQOL in children with cancer and further generate an appropriate institutional policy that may expand to the whole nation to improve the QOL for Thai children with cancer.

Limitations of the study

The relatively small sample size in some age groups with a single institution may have affected the generalization and power to identify outcomes. However, the study's focus on the Thai population may be of interest to the Asian-Pacific community. Additional factors such as delayed diagnosis, should be further explored to determine their impact on HRQOL. Longitudinal HRQOL follow-up studies in multicenter settings or focus-group studies are recommended to gain a deeper understanding and better comprehension of HRQOL among Thai children with cancer.

Conclusion

HRQOL among Thai children with cancer was desirable from both children and parents' perspectives, comparable with most countries around the world. Differences between child and parent HRQOL scores were observed.

Cognitive issues and unpleasant emotions, especially worries, impact HRQOL. The frequency of outpatient visits and hospitalizations diminished HRQOL and was further associated with procedure anxiety.

This study emphasizes the importance of assessing the HRQOL and raises concerns regarding patient and family support services, appropriate protocols for chemotherapy-induced nausea and vomiting, bedside invasive procedural sedation to reduce nausea and vomiting, as well as worrisome and treatment-related anxiety. Early screening and early intervention can reduce hospitalizations. Good communication with early psychological consults along with in-house educational approaches that will enhance the patient's cognitive function should be applied among children with cancer.

Abbreviations

ALL	Acute lymphoblastic leukemia
CNS	Central nervous system
CVC	Central venous catheter
HRQOL	Health-related quality of life
PedsQL	The Pediatric Quality of Life Inventory
QOL	Quality of life
SD	Standard deviation
TCTR	Thai Clinical Trials Registry
THB	Thai baht
WHO	World Health Organization

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12887-024-05010-8>.

Supplementary Material 1

Supplementary Material 2

Acknowledgements

The authors gratefully acknowledged the Mapi Research Trust for providing translational agreement approval and permission to use the Thai Version of the PedsQL 3.0 Cancer Module for academic purposes and Mrs. Supak

Cae-Ngow, Office of Research and Development, Phramongkutklao Hospital, and Phramongkutklao College of Medicine for statistical analysis. The authors also thank the physicians, nurses, patients and families for participating in this study.

Authors' contributions

KS contributed to conceptualizing and designing the study, interpreted data and drafted and edited the manuscript. JY was involved in patient care and collected and interpreted the data. CM contributed to patient care, conceptualized and designed the study, managed the program overall, analyzed, and interpreted data, and was a major contributor in writing the manuscript. All authors contributed to patient care, collected data, and critically reviewed and approved the final version of the manuscript.

Funding

The funding to conduct and analyze the study was provided by the Phramongkutklao College of Medicine.

Availability of data and materials

The datasets generated or analyzed during the current study are not publicly available due to privacy or ethics restrictions. The data are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Written informed consent and assent forms were obtained from all participants. This study was approved by the Institutional Review Board, Royal Thai Army Medical Department (reference number: IRBRTA 700/2561) following the ethics principles of the Declaration of Helsinki (1964) including revisions. The study was also registered and approved by the Thai Clinical Trials Registry (TCTR <https://www.thaiclinicaltrials.org/>), number TCTR20200904001 (04/09/2020).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 15 February 2024 Accepted: 13 August 2024

Published online: 20 August 2024

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