Pediatric Health-related Quality of Life Measurement in Indonesia: A Systematic Review

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Abstract. Measuring health-related quality of life (HRQOL) in children is essential for evaluating the impact of illness and treatment beyond clinical outcomes. This systematic review aims to identify HRQOL instruments used in Indonesia pediatric populations and assess their validation status. Following PRISMA2020 guidelines, we searched PubMed, Scopus, Cochrane Library, and Web of Science for studies published since 2008. Eligible studies measured HRQOL in Indonesian children or involved the translation or validation of HRQOL instruments and reported quality of life (QoL) scores. Data were synthesized descriptively. A total of 38 studies were included, most of which were cross-sectional and hospital-based. Eighteen instruments were identified: three generic tools (PedsQL™ 4.0, EQ-5D-5L, WHOQOL-BREF) and fifteen disease-specific instruments, including four studies that focus on validation. The PedsQL™ 4.0 was the most frequently used. While some instruments had been translated into Indonesian, only a few had undergone formal psychometric validation. The limited availability of validated, culturally adapted, disease-specific instruments remain a major challenge. This review highlights the need to strengthen validation efforts and promote standardized use HRQOL tools to improve the quality of pediatric care and research in Indonesia.

Keywords: HRQOL, Children, Indonesia, Quality of Life, Validation.

1 Introduction

Understanding and measuring health-related quality of life (HRQOL) in children has become increasingly important in pediatric healthcare, particularly in the context of chronic illness and long-term treatment. As advances in medical care have improved survival rates for conditions such as cancer and other noncommunicable diseases, the focus has shifted from merely prolonging life to enhancing the quality of life lived by affected children [1,2]. HRQOL encompasses not only physical functioning but also emotional, social, and school well-being, all of which can be significantly impacted by illness and treatment [3]. The inclusion of HRQOL as an outcome measure supports

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more holistic and patient-centered care, aligning with a growing recognition of children's subjective experiences and psychosocial needs [4,5].

Reflecting this growing emphasis, there has been a rapid increase in the development and use of HRQOL measurement tools for children and adolescents over the past two decades [6]. These instruments generally fall into two categories: generic instruments, which allow for comparisons across different diseases and healthy populations, and disease-specific instruments, which are tailored to capture the specific impacts of particular health conditions [7,8]. Generic tools such as the Pediatric Quality of Life Inventory (PedsQL™) and Kid-KINDL have become widely used due to their flexibility and applicability across varied clinical and research settings [3,9]. Disease-specific tools, while more limited in scope, offer greater sensitivity to clinical changes and are thus particularly valuable in evaluating treatment outcomes in clinical trials [1].

Despite the proliferation of HRQOL instruments globally, there remains a notable gap in validated HRQOL tools specifically tailored for children in Indonesia. Few studies have systematically evaluated the psychometric properties of these instruments within the Indonesian context, limiting their applicability and validity in local clinical practice and research. Moreover, while several international reviews have mapped the landscape of HRQOL instruments in pediatric populations [6,10], these reviews often lack specific insights relevant to Indonesian children. This gap highlights the need for localized assessments of cultural relevance, especially given the linguistic and socio-cultural differences that may influence HRQOL perceptions and reporting.

In this context, identifying the HRQOL instruments currently used in Indonesia, particularly those that have undergone validation or adaptation for local use, is both timely and essential. Such mapping is critical not only for advancing pediatric quality of life research in Indonesia but also for informing clinical practice and health policy. Evaluating the methodological rigor and cultural adaptability of these instruments will help ensure their reliability and validity in measuring children's health outcomes and in supporting patient-centered care approaches. This study aims to fill this knowledge gap by systematically reviewing the instruments currently used to assess HRQOL in children in Indonesia and examining the extent of their validation and contextual appropriateness.

2 Methods

2.1 Eligibility criteria

This systematic review was conducted in accordance with the Preferred Reporting Items for systematic Review and Meta-Analyses (PRISMA) guidelines [11] The review focused on studies measuring HRQOL in children or involving the development or translation of HRQOL instruments. Other inclusion criteria were as follows: use a quality of life (QoL) measurement instrument, presentation of results in the form of QoL score, conducted in Indonesia setting, full-text availability, original research articles, publication in scientific journals, and publication year from 2008 onward. Studies were excluded if they were economic evaluation studies and focused on oral QoL.

2.2 Search strategy

We conducted a screening of the available academic literature from February 2, 2025, to March 6, 2025, using the following database: PubMed, Scopus, Cochrane Library, and Web of Science. The search term used were ((“quality of life”[MeSH Terms] AND “child”[MeSH Terms] OR ”Pediatrics”[MeSH Terms] AND “indonesia”[MeSH Terms]. We used a combination of search terms tailored to each database. MeSH Terms were applied only in PubMed and Cochrane Library, as Scopus and Web of Science do not support MeSH-based queries. Details of search strategy are presented in Supplementary Material.

All citations retrieved from the databases were uploaded into Mendeley Reference Manager software. Studies that were not automatically imported into Mendeley were excluded by automation tool as ineligible. After removing duplicates, all authors screened the titles and abstracts, followed by a full-text assessment of the eligible studies. Reasons for the exclusion of studies were documented and reported. A flow diagram illustrating the review process was created using a tool which developed in accordance with PRISMA2020 [12].

2.3 Data extraction and quality assessment

The extracted information from the included studies comprised the following: (1) study characteristics, including study setting, study design, number of subjects, age range of subjects; and type of respondent (child/adolescent self-report, parent-proxy report, or both); (2) the HRQOL construct or disease being measured; (3) details of the instrument used, including the questionnaire name, number of domains, number of items, and the dimensions assessed; (4) results related to quality of life; and (5) psychometric properties including validity and reliability.

The studies included in the review were evaluated using the Newcastle-Ottawa Scale (NOS) quality assessment for cohort and cross-sectional studies [13]. The maximum attainable scores were 4 for cohort studies and 16 for cross sectional studies. Studies were included if they achieved a minimum score of 2 for cohort studies and 8 for cross-sectional studies.

The extracted data were the categorized and presented based on: (1) the type of instrument (generic or disease-specific) and (2) whether the study focused solely on the validation of an HRQOL measurement instrument.

3 Results

3.1 Search results

Fig. 1 illustrate the study selection process. The figure was created using software developed in accordance with PRISMA2020 guideline [12]. The database searches yielded a total of 1,061 articles. After screening abstracts and full-text, 38 articles were included in the review.

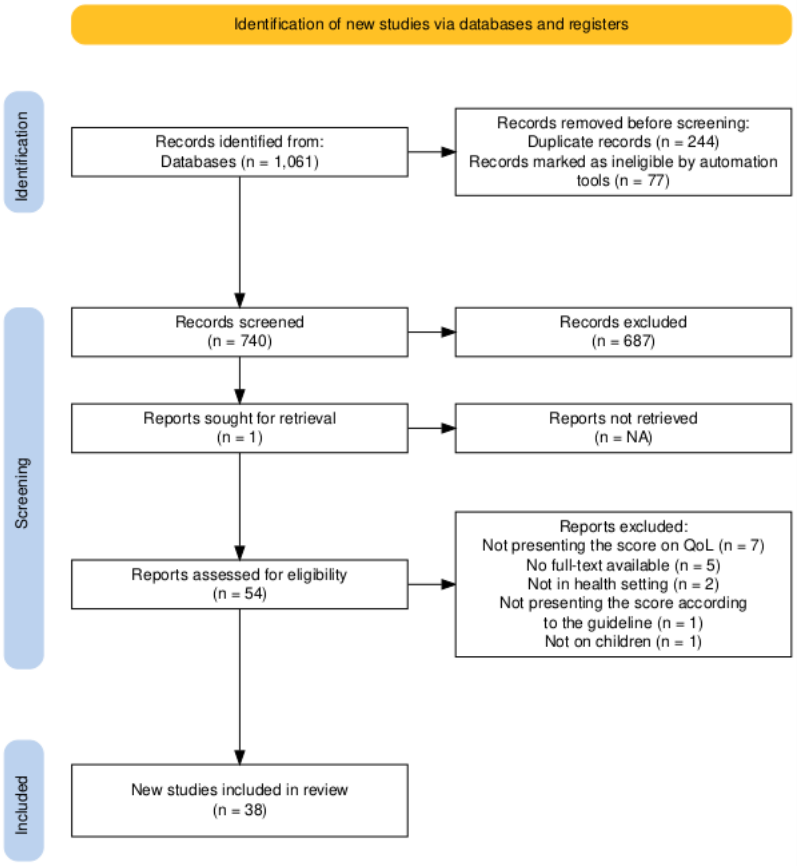

Fig. 1. PRISMA flow of diagram of review process

3.2 Study characteristics

The characteristics of the included studies are presented in Table 1. Most studies were conducted in hospital settings, either in inpatient or outpatient departments. The research was carried out in various cities across Java and Sumatra, including Jakarta, Yogyakarta, Medan, Bandung, and Surabaya. Nearly all studies employed a cross-sectional design, with sample sizes ranging from 11 to over 1,000 respondents. Approximately half of the studies included participants aged 2 to 18 years, and in most cases, quality of life data was collected through both child self-reports and parent proxy-reports.

The HRQOL domains assessed varied widely, with most studies focusing on disease-specific quality of life. Only three studies evaluated HRQOL using a generic approach. The most commonly studied condition was cancer, including acute lymphoblastic leukemia, thyroid cancer, and brain tumors. Nearly all diseases examined fell within the category of chronic noncommunicable disease (CNCD), such

as diabetes mellitus, asthma, cardiovascular disease, thalassemia, and chronic kidney disease.

Table 1. Characteristics of included studies (N=38).

Study Characteristics	Details	N (%)
Study setting	Hospital	26 (68.4)
	Community	10 (26.3)
	School	2 (5.3)
City setting	Jakarta	9 (23.7)
	Yogyakarta	8 (21.0)
	Medan	7 (18.4)
	Bandung	6 (15.8)
	Surabaya	2 (5.3)
	Multicenter	1 (2.6)
	Other cities	5 (13.2)
Study design	Cross-sectional	35 (92.1)
	Cohort	2 (5.3)
	Mixed method	1 (2.6)
No. of subjects	<100	22 (57.9)
	100–200	11 (13.2)
	>200	5 (13.5)
Children's age range (years)	All range (2–18)	19 (50.0)
	School age (5–18)	10 (26.3)
	Adolescent (10–19)	6 (15.8)
	Other age range	3 (7.9)
Type of respondents	Self and parent report	24 (63.1)
	Self-report only	9 (23.7)
	Parent-report only	5 (13.1)
HRQOL assessment	Generic	3 (7.8)
	Cancer	5 (13.1)
	Chronic Kidney Disease	4 (10.5)
	Thalassemia	3 (7.9)
	Type 1 diabetes mellitus	2 (5.3)
	Acute lymphoblastic leukemia (ALL)	2 (5.3)
	Cerebral palsy	2 (5.3)
	Congenital heart disease	2 (5.3)
	Asthma	2 (5.3)
	Gastroesophageal reflux disease (GERD)	1 (2.6)
	Thyroid cancer	1 (2.6)
	Brain tumor	1 (2.6)
	Pneumonia	1 (2.6)
	Hemophilia	1 (2.6)
	Epilepsy	1 (2.6)
	Anemia	1 (2.6)
	HIV-AIDS	1 (2.6)
	Hirschsprung disease	1 (2.6)
	Nephrotic syndrome	1 (2.6)
	Cleft lip and/or palate	1 (2.6)
	Neuromuscular disease	1 (2.6)
	Rheumatology disease	1 (2.6)

The quality assessment scores using the NOS for cross-sectional studies ranged from 8 to 14, with five studies meeting the minimum threshold score of 8. For cohort studies, two studies received a minimum of 2 [14] and 3 [15], respectively. Details of data extraction and quality assessment score results are provided in Supplementary Material.

3.3 Generic instruments

In total, eighteen quality-of-life measurement instruments were utilized, comprising three generic HRQOL instruments—namely the PedsQL™ 4.0 Generic Core Scale, EQ-5D-5L, and WHOQOL-BREF—and eleven disease-specific instruments. Description of generic instruments are shown in Table 2.

The PedsQL™ 4.0 Generic Core Scale was the most frequently used, either as a standalone measure of generic health status or in combination with disease-specific instruments. This instrument has been translated and validated for use in the Indonesian population. Eighteen studies employed the PedsQL™ 4.0 Generic Core Scale to assess various conditions, ranging from general quality of life to specific diseases such as cancer, congenital heart disease, brain tumors, chronic kidney disease, thalassemia, HIV/AIDS, acute lymphoblastic leukemia, nephrotic syndrome, and asthma. Four studies used the PedsQL™ 4.0 Generic Core Scale alongside disease-specific PedsQL™ modules, such as the cancer and cardiac modules, to compare results across instruments [16–19].

Table 2. Generic quality of life assessment instruments used in pediatric.

QoL instruments	HRQOL assessment	No. of domain	No. of items	Dimensions	References
PedsQL™ 4.0 Generic Core Scale	Generic, cancer, congenital heart disease, brain tumor, chronic kidney disease, thalassemia, HIV-AIDS, acute lymphoblastic leukemia, nephrotic syndrome, asthma	4	23	Physical, emotional, social, and school	[16–19,23–36]
EuroQoL(EQ) -5D-5L	Pneumonia	5	5	Mobility, self-care, usual activity, anxiety or depression, and pain or discomfort	[20]
WHOQOL-BREF	Generic, anemia	4	26	Physical, psychological, social relationship, and environmental	[21,22]

The EQ-5D-5L was used in one study to assess the quality of life of children with pneumonia. Although the EQ-5D-5L is not specifically designed for use in children, the study employed parent proxy-reports to gather information [20]. Similarly, two studies used the WHOQOL-BREF to measure HRQOL in children [21,22]. Like the EQ-5D-5L, the WHOQOL-BREF was originally developed for adult populations.

3.4 Disease-specific instruments

A total of eleven disease-specific instruments were identified in this study. The most commonly applied tool was the PedsQL™ 3.0 Cancer Module, used in five separate studies. The PedsQL™ 3.0 Cardiac Module and the PedsQL™ 3.2 Diabetes Module were each used in two studies. To assess HRQOL in children with cerebral palsy, two instruments were employed: the PedsQL™ 3.0 Cerebral Palsy Module and the Cerebral Palsy QoL-Child Questionnaire. Further details regarding the disease-specific instruments are provided in Table 3.

Table 3. Disease-specific quality of life assessment instruments used in pediatric.

QoL instruments	HRQOL assessment	No. of domain	No. of items	Dimensions	References
PedsQL™ 3.0 Cancer Module	Cancer, acute lymphoblastic leukimia	7	27	Pain, nausea, procedural anxiety, treatment anxiety, worry, cognition problems, and perceived physical appearance	[17–19,37,38]
PedsQL™ 3.0 Cardiac Module	Congenital heart disease	5	5	Mobility, self-care, usual activity, anxiety or depression, and pain or discomfort	[16,39]
PedsQL™ 3.2 Diabetes Module	Type 1 diabetes mellitus	4	26	Physical, psychological, social relationship, and environmental	[40,41]
PedsQL™ 3.0 Cerebral Palsy Module	Cerebral Palsy	7	35	Daily activities, school activities, movement and balance, pain, fatigue, eating activities, and speech and communication	[42]
Pediatric Gastroesophageal Reflux Disease Symptom and Quality of Life (PGSQ) questionnaire	Gastro esophageal reflux disease (GERD)	4	20	Physical, emotional, social, and school	[14]
Cerebral Palsy QoL-child questionnaire	Cerebral Palsy	7	52	Social wellbeing and acceptance; feelings about functioning; participation and physical health; emotional	[43]

(CP QOL-child)				wellbeing; pain and feeling about disability; access to services; and family health	
Pediatric Asthma Quality of Life Questionnaire (PAQLQ)	Asthma	3	23	Symptom, activity, and emotional	[44]
Haemo-QoL short version	Hemophilia	9	35	Physical health, feeling, view, family, friends, others, sports and school, dealing with haemophilia, and treatment	[45]
TranQOL	Thalassemia	4	29	Physical health, emotional health, family functioning, and school/work functioning	[46]
Quality of Life in Childhood Epilepsy Questionnaire -55 (QOLCE-55)	Epilepsy	4	55	Cognitive, emotional, physical, and social	[47]
HSCR/anorectal malformation quality of life questionnaire (HAQL)	Hirschsprung disease	8	36	Laxative diet, constipating diet, presence of diarrhea, fecal continence, urinary continence, social functioning, emotional functioning and body image and physical functioning	[15]

Table 4. Validation of quality-of-life assessment instruments used in pediatric.

QoL instruments	HRQOL assessment	No. of domain	No. of items	Dimensions	Results on validation	References
ThYCA-QoL questionnaire	Thyroid cancer	7	24	Neuromuscular, voice, concentration, sympathetic, throat and mouth, psychological and sensory problems	Questionnaire is valid and reliable	[48]
PedsQL™ 3.0 Rheumatology Module	Rheumathology (systemic lupus erythematosus (SLE) or juvenile idiopathic arthritis (JIA))	4	22	Pain and hurt, activities, treatment, worry, and communication	Validity varied from good to very good for child report and from poor to good for the parent report. The questionnaire is reliable.	[49]

CLEFT-Q©	Cleft lip and/or palate	4	119	Appearance, facial function, and HRQOL. HRQOL scale: psychological state, school life, social life, and speech distress	Indonesian CLEFT-Q© is reliable after iterative translation and cultural adaptation. The tool is valid (acceptable to excellent internal consistency and ideal inter-item correlation).	[50]
PedsQL™ 3.0 Neuromuscular Module	Neuromuscular disease	3	25	(1) About My/My Child's Neuromuscular Disease subscale (17 items: disease process and associated symptomatology), (2) Communication subscale (3 items: patient's ability to communicate with health care providers and others about his/her illness) and (3) About Our Family Resources subscale (5 items: family financial and social support system)	The instrument is reliable (good to very good criteria) and valid (fair to good)	[51]

3.5 Validation of instruments

Four articles focused on the validation of pediatric HRQOL measurement instruments, including the PedsQL™ 3.0 Rheumatology Module, the PedsQL™ 3.0 Neuromuscular Module, the ThYCA-QoL question-naire, and the CLEFT-Q©. Details of these instruments are presented in Table 4.

4 Discussion

To our knowledge, this is the first systematic review assessing pediatric HRQOL instruments applied in the Indonesian context. Although numerous studies have utilized HRQOL tools, our findings highlight several methodological limitations and areas for improvement in the selection, validation, and application of these instruments. Some studies utilized instruments that lacked comprehensive validation according to established standards, and some failed to reference appropriate validation sources or relied on non-licensed translations, potentially compromising the validity of the

quality-of-life data. Additionally, the scope of our review was constrained by predefined eligibility criteria, which may have limited the inclusion of other relevant studies [41,44].

A key concern identified is the use of adult instruments to measure disease-specific HRQOL in children. Such tools are not recommended for pediatric populations, as they often fail to capture develop-mentally relevant domains and may impose cognitive or linguistic burdens on younger respondents [52]. Using inappropriate tools can result in inaccurate assessments and limit the validity of the findings.

Moreover, while disease-specific instruments are generally more sensitive in capturing the impact of specific conditions on children's quality of life, several studies in Indonesia relied solely on generic measures. In this review, 14 studies used only generic instruments to evaluate HRQOL in children with specific health conditions. This limitation may stem from the unavailability of culturally and linguistically validated disease-specific instruments in the Indonesian context, particularly for conditions such as for chronic kidney disease or HIV/AIDS.

Encouragingly, four studies adopted a combined approach, utilizing both disease-specific and generic instruments, such as the PedsQL™ 3.0 Cancer Module or the PedsQL™ 3.0 Cardiac Module in conjunction with the PedsQL™ 4.0 Generic Core Scales. This practice, recommended by the instrument developers [3,53], enhances the comprehensiveness of HRQOL assessments by capturing both general and condition-specific aspects of children's well-being.

Another important finding relates to respondent selection. Best practices recommend obtaining HRQOL data directly form children whenever developmentally appropriate [54]. Most of the reviewed studies followed this guidance by including child self-reports or combining them with parent proxy-reports. However, five studies (15.15%) relied exclusively on proxy reporting by parents. While proxy reports are necessary for very young or cognitively impaired children, overreliance on them can introduce bias and may not accurately reflect the child's subjective experience.

Together, these findings emphasize the need for greater adherence to internationally recognized standards in instrument selection, validation, and application. There is a pressing need to support the local adaptation and validation of disease-specific HRQOL instruments in Indonesia to enhance their relevance, accuracy, and cultural sensitivity.

While this review provides important insights into the use and validation of pediatric HRQOL instruments in Indonesia, several limitations should be acknowledged. First, by including only peer-reviewed articles published in reputable databases and written in English, the review may have excluded relevant studies published in local databases or written in Indonesian. Second, heterogeneity in study designs, populations, and measurement tools made direct comparisons across studies challenging. Third, the review did not assess the psychometric properties of each instrument in detail (e.g., responsiveness or measurement error), as not all studies reported such data.

Moreover, the quality of reporting in some studies was insufficient, particularly regarding translation processes and adherence to established validation frameworks, such as COSMIN. Finally, the scope was restricted to studies conducted in Indonesia, which may limit generalizability to broader Southeast Asian or low- and middle-income country (LMIC) contexts.

5 Conclusion

This systematic review highlights the current landscape and challenges associated with the use of pediatric HRQOL instruments in Indonesia. Although several instruments are in use, not all have undergone thorough validation processes, and some studies employed adult measures that are not appropriate for pediatric populations. The limited availability of culturally adapted and psychometrically sound disease-specific instruments appears to be a key barrier.

To strengthen the quality of HRQOL research in Indonesian pediatric populations, greater attention must be paid to the selection, adaptation, and validation of instruments according to international standards. These improvements will contribute to more accurate, reliable, and meaningful assessments of quality of life, ultimately informing better clinical care, policy development, and intervention strategies.

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Ethical Statement. This study is a systematic review and did not involve any primary data collection or research involving human participants. As such, ethical approval from an institutional review board was not required. Nevertheless, the review was conducted in compliance with recognized ethical standards for conducting and reporting systematic reviews, including transparency, accuracy, and proper citation of sources. In addition, the authors declare that there are no competing interests associated with this study.

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