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REVIEW ARTICLE

A Narrative Review of Health-Related Quality of Life (HRQOL) Assessment Tools in Peadiatric Healthcare: SDQ, PedsQL, and SF-36

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ABSTRACT

Health-Related Quality of Life (HRQOL) is a key therapeutic term for children, representing the complex effects of health status on physical, psychological, and social functioning. HRQOL measurements are increasingly used in clinical practice and research, making it difficult to choose instruments that can capture these varied dimensions. A narrative review of the Strengths and Difficulties Questionnaire (SDQ), Paediatric Quality of Life Inventory (PedsQL), and Short Form-36 Health Survey is presented. This review compares several HRQOL tools for children, focussing on their domains, psychometric robustness, and applicability for diverse healthcare contexts. A narrative review was conducted using PubMed/MEDLINE, SCOPUS, and Google Scholar papers from 2019 to 2025. Each instrument's purpose, structural composition, measuring qualities, and practical factors were examined in eligible research. Narratives showed their use's convergences and divergences. The instruments differ in focus and design. Psychosocial HRQOL determinants are best identified by the SDQ, which emphasises behavioural and emotional functioning. The most adaptable tool for children HRQOL research, the PedsQL assesses physical and psychosocial dimensions in a comprehensive and developmentally appropriate manner. SF-36 provides a standardised framework for cross-population comparisons but is less responsive to children's developmental needs. In conclusion, each HRQOL instruments in children has advantages and limitations. Choosing the right measure requires careful alignment with clinical or research goals to provide accurate and relevant results.

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INTRODUCTION

The World Health Organization (WHO) characterizes health as a state of complete physical, mental, and social well-being rather than only the lack of sickness or disability (1). However, a person's perception of their health status may be framed by their cultural context, values, goals, needs, expectations, and worries (2). The Centers for Disease Control and Prevention (CDC) indicates that Health-Related Quality of Life (HRQOL) is how well a person feels about their physical and mental health across time (3). HRQOL emphasizes the influence of health on an individual's capacity to lead to a fulfilling and meaningful existence. It includes both beneficial and detrimental elements of physical, psychological, and social health (4). In children's care, measuring HRQOL yields significant data on both the patient and the family unit. It offers insights into how a child's health status influences their quality of life, growth, and general well-being, while simultaneously evaluating the secondary effects on the family system, specifically the burden of caregiving and parental anxiety (5).

The need to evaluate HRQOL in children and teenagers is essential for a comprehensive understanding of their health perspective (6). This holistic approach helps healthcare providers comprehend the actual burden of disease, evaluate the effectiveness of treatments, and identify unmet needs. The importance of this assessment is further underscored by its alignment with the United Nations' Sustainable Development Goals (SDGs), specifically Goal 3, which aims to "Ensure healthy lives and promote well-being for all at all ages" (7). The necessity of lifelong management strategies is particularly important for chronic and uncommon illnesses in children. When addressing chronic conditions, studies indicate that 25% to 50% of children with chronic medical conditions experience a low quality of life, significantly impacting their overall health (8).

To facilitate this assessment, numerous children's HRQOL instruments have been developed, with hundreds identified in reviews, including many disease-specific tools (9). Widely used generic instruments include the Pediatric Quality of Life Inventory (PedsQL), the EQ-5D-Y, the Child Health Utility 9D (CHU-9D), and KIDSCREEN (9). The development and increasing use of these tools highlight the importance of HRQOL as an integral part of children's assessment (10). The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and the U.S. Food and Drug Administration (FDA) have issued guidance for the use of HRQOL assessments in clinical trials (11). ISPOR’s Task Force specifically recommends adapting age criteria to developmental stages, establishing content validity through child interviews, and addressing cross-cultural considerations in instrument design (12).

Ultimately, the growing integration of HRQOL assessment into children's healthcare is critical for improving the quality of life for children globally. Understanding both the child's and the parents' health-related quality of life is essential for effective communication, establishing a strong patient-physician rapport, and ensuring that treatment choices are guided by a comprehensive and patient-centered view of health (13). This study will examine the application of Health-Related Quality of Life (HRQOL) in children, the challenges associated with measuring HRQOL in children, and the three prevalent measurement instruments which includes the Strengths and Difficulties Questionnaire (SDQ), the Pediatric Quality of Life Inventory (PedsQL), and the Short Form-36 Health Survey (SF-36).

METHODOLOGY

We performed a narrative review to determine the available literature evidence on the three selected HRQOL tools assessment commonly used in pediatric research. Relevant literature was identified through targeted searches of major biomedical databases, including PubMed, Scopus, Web of Science, and Google Scholar, covering publications from 2019 to 2025. Keywords and Medical Subject Headings (MeSH) were combined using Boolean operators to capture both broad and specific concepts. Additional articles were identified through manual screening of reference lists and citation tracking. All study types were considered, including original research, reviews, guidelines, and case reports, provided they addressed the review objectives. Articles were screened for relevance based on titles and abstracts, followed by full-text evaluation. Given the narrative nature of this review, no formal quality appraisal or meta-analysis was performed; instead, findings were synthesised thematically to provide a comprehensive overview of current knowledge, gaps, and emerging trends in the field.

ASSESSMENT TOOL OF HRQOL IN PEDIATRICS

There are various HRQOL instruments available for children. However, this narrative review will focus on the discussion related to the three commonly used HRQOL instruments in paediatric research, which are Strengths and Difficulties Questionnaire (SDQ), The Pediatric Quality of Life Inventory (PedsQL) and the Short Form 36 Health Survey Questionnaire (SF-36) (Table I). We aimed to highlight the purpose, the validity, the advantages, and the limitations of every instrument.

The Strengths and Difficulties Questionnaire (SDQ)

Table I: A summary of strength and limitation of the Strength and Difficulties Questionnaire (SDQ), The Paediatric Quality of Life Inventory (PedsQL) and Short Form Survey (SF36).

HRQOL Assessment tool	Strength	Limitation
Strength and Difficulties Questionnaires (SDQ)	➢ Widely use and recognized in worldwide. ➢ Measure five key dimensions. ➢ Brief and easy to administer. ➢ Validated across population (75 languages translated) ➢ Effective in detecting changes in mental health following interventions.	➢ Variability rating between parent and teacher. ➢ Potential bias. ➢ Less suitable for complex diagnoses. ➢ Cultural factors may affect how behavior is rated.
The Paediatric Quality of Life Inventory (PedsQL)	➢ The PedsQL is applicable to both healthy children as well as those with acute and chronic health conditions. ➢ Dual perspective. ➢ Comparative utility between generic and disease-specific perspective.	➢ Potential rater bias. ➢ Cultural sensitivity. ➢ Limited responsiveness in certain population.
Short Form Survey (SF36)	➢ Widely use and validated. ➢ Measure eight subscale of health aspects. ➢ Cross cultural adaptability. ➢ Standardized scoring system.	➢ Cultural differences in health concept. ➢ Challenges for older adults. ➢ Lack of screening cut- off for parent’s HRQOL.

is a brief behavioral screening tool for children and adolescents aged two to seventeen years old, available in several versions for use by researchers, clinicians, educators, parents, teachers, and adolescents. It is counted from the view of self-report, teacher report, or parent report (14). A total of 25 psychological attributes grouped into five scales (emotional symptoms, conduct problems, hyperactivity/inattention, peer problems, and prosocial behavior) with the first four combining into a total difficulties score were assessed in SDQ questionnaires (15). The result is divided into categories such as normal, borderline, and abnormal, and the range for every category is different according to whom it is reported. Additionally, the SDQ includes internal issues, represented by the aggregate of emotional and peer difficulties scores, as well as external elements, indicated by the total conduct and hyperactivity scales; both categories have a range of 0-20 (16). The Malay version of the SDQ demonstrated Cronbach's alpha coefficients of 0.70 for the Total Difficulties scores and 0.71 for prosocial conduct, signifying acceptable internal consistency (16).

The measured item is concise, facilitating straightforward scoring of these instruments, which do not require specialised training or skills (17). It has minor wording changes and two antisocial behaviour item differences between versions: the four- to seventeen-year-old and two- to four-year-old versions in proxy reporting, but the scoring is similar for both versions (18).

As SDQ is a simple instrument, it has a moderate to high sensitivity and high specificity for differentiating between children with and without a psychiatric diagnosis (19). As teacher reports reveal, SDQ exhibits potential as a tool that might be applied consistently in elementary schools to assess treatments and track improvements in children's mental health (20). The original version is in English but has been translated to eighty-nine languages, including sign language (21). Using the mother tongue language will allow effective assessment. As a study in Africa found, when the SDQ was given orally in their native tongue, ninety – nine percent of mothers or primary caregivers were able to finish it, enabling an efficient evaluation of their child's mental health (22). However, this instrument has limitations, such as lack of consistency in response due to different cultures. The applicability of the SDQ in its original context may yield varying outcomes. For instance, Western children are more sensitive to many cultural values, and immigration may have contributed to the diversity of Western culture. In contrast to Malaysia, the many cultural values have been embedded in the community and are recognized by the children from birth. This may affect negative results in the domain of peer problems and conduct problems (23).

Another assessment tool for pediatric HRQOL is The Pediatric Quality of Life Inventory (PedsQL). In both healthy children and adolescents as well as those with acute and chronic medical disorders, this tool is used to assess health-related quality of life (HRQOL) (24). This instrument comprises sections for parents and the young child themselves, as well as a wide age range with developmental sensitivity. This instrument has been produced into more than 85 languages and is extensively utilized in research (25). It also provides a child-self report and parent-self report version for 8-12 years old (26).

For pediatric populations, the HRQOL construct is defined by Pediatric health-related quality of life instruments. These tools are multidimensional, addressing at least the physical, mental, and social health dimensions outlined by the World Health Organization (WHO) in 1948. The 23 items on the PedsQL Generic Core Scales were used to measure these crucial elements and role functioning in educational settings. The following key dimensions for evaluating pediatric HRQOL are included in the multidimensional structure of the PedsQL Generic Core Scales: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items). This tool has produced both generic and disease-specific approaches for conditions like diabetes, cancer, heart disease, arthritis, and asthma (26). While disease-specific scale modules are made to offer higher measurement sensitivity for limited clinical groups, the general core scales are made to allow comparisons between patient and healthy populations (51). Besides, PedsQL might be the best available HRQoL tools for use in the economic assessment of mental health services for children and adolescents (27).

Scoring the PedsQL Generic Core Scales is easy. The questions are divided into four categories: school functioning, emotional, social, and physical. This makes it simple to determine results for each category. Higher scores indicate stronger health-related quality of life (HRQOL), and the responses are reverse-scored to a 0–100 scale to make the results easier to comprehend (27). In terms of reliability and validity of this instrument, PedsQL showed fair–good test–retest reliability and no floor or ceiling effects in children and adolescents with mental health challenges (ADHD, Anxiety and/ or Depression). Other study show, the Cronbach’s alpha was good ($\alpha 0 = .80$–0.83) for the subscales of the PedsQL 4.0 and excellent for the psychosocial health ($\alpha = 0.90$) and total scale ($\alpha = 0.92$) of the PedsQL 4.0 (28).

The limitation of this instrument is that proxy-reports might indicate the parents' fear over their child, rather than the child’s condition (29). Another issue is potential bias in reporting, as young children may struggle to articulate their emotions openly to their parents. The Patient Reported Outcomes Measure (PROM) indicates that carers and adolescents encountered challenges in comprehending or responding to the school environment, as adolescents often did not attend regular school during treatment. Carers expressed difficulties in evaluating their child's functioning and symptoms due to limited time spent together or the belief that their child may not be disclosing daily emotional struggles (30,31).

The SF-36, commonly known as the Short Form 36 Health Survey Questionnaire, is a 36-item self-report measure designed to assess health-related quality of life. It comprises eight subscales: mental health (MH), role-emotional (RE), social functioning (SF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), and physical functioning (PF). All these components contribute to two component scores: physiological wellness as well as psychological wellness. It also features a single item examining perceived health improvements over the past year. Higher scores indicate better health and functioning. By 2011, almost 16,000 studies had been published using the SF-36 (32). The Cronbach's alpha coefficients ranging from 0.82 to 0.91 in cystic fibrosis among adolescents and adults in the UK (33).

This instrument has been broadly utilized in many populations and has been interpreted into several languages such as Malay, Chinese, French and Urdu (33-37). It is one of the most inclusive health surveys, verified across all age groups and containing a wide range of key health concepts (34). The Short Form-36 (SF-36) questionnaire is graded using a norm-based scale that goes from 0 to 100. The average score is 50; higher numbers indicate less disability, while lower values indicate greater disability. This standardized scoring is easy to use and can be utilized for evaluating health-related quality of life (HRQOL) in children and adolescents (38). Cultural differences in the definition or the structure of health may contribute to reduced accuracy of the SF-36 assessment tool (34). Some items from the mental health sub-scale may need to be modified or removed for older populations, as they might find it unsuitable to respond to or relate to these questions (39). Furthermore, there are no precise cut-off points for screening parents' children for cancer if they have a low HRQOL. Being the primary caretakers, they may have a negative impact on the HRQOL of the kid (40).

THE APPLICATION OF HEALTH-RELATED QUALITY OF LIFE

For too long, healthcare personnels has often treated children as passive recipients of care, overlooking their unique perspectives on their own illnesses. However, in recent decades, this lack of understanding has changed. Today, we recognize that the child's voice is essential in children's healthcare decisions. The UN Convention on the Rights of the Child (1989) emphasizes children's right to have their say in situations that involve or affect them, considering their age and maturity, including their health condition (41). Understanding the child's experience is therefore crucial for clinical assessment, disease progression management, cost budgeting, and health policy development for children's healthcare.

The application of HRQOL instruments in clinical assessments provides evidence-based clinical management. Instead of relying solely on medical tests, we gather information from multiple perspectives including patient-reported outcomes (PROs), observer-reported outcomes, clinician-reported outcomes, and performance outcomes (42). This has changed the dynamic of clinician-child-parent in clinical practice and given rise to the growth of child self-report and proxy-report instruments in children's clinical trials (43,44). Patient-reported outcome measures (PROMs) are standardised and validated self-administered questionnaires designed to evaluate patients' overall well-being, disease burden, and health-related quality of life. However, a child's cognitive development, reading proficiency, and language skills must be considered when selecting the most suitable PROM.

HRQOL assessments are vital for understanding and managing disease progression in children and adolescents. It offers practical insights into the impact of diseases on daily life, informing treatment and care strategies, forecasting clinical outcomes, and assessing the efficacy of interventions (45). Conversely, utilising HRQOL instruments to manage illness progression helps forecast future health trajectories, facilitating proactive modifications to care regimens. Parental distress must be considered throughout treatment, as this factor is linked to reduced HRQOL in the children receiving care (46).

HRQOL plays a major role in ensuring fairness and value within our healthcare systems. Tools like Cost-Utility Analysis (CUA) use this data to decide how to fund, price, and reimburse new medical treatments (47). Cost-effectiveness analysis is important to inform policy decisions to ensure that new treatments, which significantly improve patient lives, are appropriately compensated, thereby avoiding excessive costs for treatments with limited clinical value (48). The quality-adjusted life year (QALY) has served as a fundamental component of cost-effectiveness analyses in the US and around the world for more than 30 years. It is the academic standard for measuring how well various modalities of medical treatments lengthen and improve patients' lives. The QALY framework assists physiotherapists in efficiently implementing therapies to enhance patient outcomes by considering both the quantity and quality of life (49). In summary, HRQOL data is essential for guiding health policymakers in formulating cost-effective policies to enhance paediatric care.

THE CHALLENGES OF MEASURING THE HRQOL IN CHILDREN AND ADOLESCENTS

The continuous changes in a child's physical, cognitive, intellectual, and emotional development pose a problem in assessing their Health-Related Quality of Life (HRQOL). Since children and teenagers are developing at a rapid pace, life events such as puberty and the transition from primary to secondary school can influence their HRQOL (50). Due to that, different considerations may be applied according to a condition where the disease course is age dependent and/or a young child's rapid development (51).

Another challenge in measuring HRQOL in children is the different opinions between parents and children within the same domain. In a proxy report, the result data is supplied by a third party apart from the research participant been studied. Depending on the study population and sample needed, the proxy may be the child's parent, caregiver, physician, teacher, or principal (52). There was multiple report on discrepancies between the child's self-reported HRQOL in comparison to parents reporting (53,54). Different priorities, conceptualizations, and perspectives between a child and parent may lead to discrepancies (55). A systematic review encompassing 17 research indicated dimension-level concordance in children with and without health issues. Conversely, there exists a greater concordance between children and parent on observable functioning, such as physical aspects, in contrast to non-observable functioning, such as emotional aspects (55). This may result in underreporting of a child's functionality or domain. So, the report provided by parents must be closely evaluated to ensure it aligns with the child's perspective.

Health technology assessment (HTA) responsible for assessing a health technology's worth and providing suggestions on its application in global health systems (56). The new development and advancement of HRQOL measurement tools poses a new challenge to researchers as there is no consensus on whose preferences should be used to assign value to a child's health state (57). As researchers use many different methods to measure the value of a child's quality of life, these values are hard to interpret and difficult or impossible to compare with the values used for adult health states. This creates a lot of extra confusion and uncertainty for decision-makers like HTA and leads to a lack of construct validity (58).

Finally, adaptation is another challenge when assessing children's and teenagers' HRQOL. Those adaptation limitations are divided into traumatic experiences due to hospitalization and chronic illness and cultural adaptation. The traumatic experiences due to hospitalization and chronic illness can have a short-term impact, such as pain, activity constraints, and a painful treatment procedure. In the meantime, children with chronic illnesses may experience psychological effects that lead to attention deficit hyperactivity disorder, depression, and anxiety disorders (58). Additionally, children's experiences and adjustments can be influenced by differences in cultural backgrounds and healthcare systems in different nations. In other words, findings from specific studies might not be universally relevant, and additional research could uncover important details in these relationships, helping to inform the development of more effective interventions (58).

CONCLUSION

In conclusion, there are many tools to measure HRQOL in pediatrics. However, each has limitations that need to be considered when selecting the appropriate tools according to the objectives either for clinical assessment or research purposes. The studied population's age, the self- report or proxy report view or the validity and reliability of using translation version are some of the important determinants in selection of the HRQOL tool assessment. Making the right decision will result in meaningful outcomes.

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