



# How Do you Focus on Quality of Life When Kids Cannot Go to School or Outside?

Teresa Vente<sup>1</sup>

Accepted: 25 February 2021 / Published online: 12 March 2021

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2021

## Abstract

**Purpose of Review** This paper seeks to explore the definitions of quality of life and its application to pediatric research and clinical practice. This paper also highlights some of the imperfections in evaluating patient-reported outcomes designed to measure quality of life in pediatrics. Additionally, this paper explores some of the unique challenges in promoting quality of life during the COVID-19 pandemic.

**Recent Findings** There are numerous different measurement scales to examine quality of life in children of different ages, and with a variety of disease states.

**Summary** Despite the number of quality of life measurement tools, not every patient population has a validated measure, including patients with palliative care needs. There is no consensus on how to incorporate findings from patient-reported outcomes into clinical practice recommendations. Professional organizations offer guidance and resources for families to encourage focus on quality of life during the COVID-19 pandemic.

**Keywords** Quality of life · Health-related quality of life · COVID-19 · Palliative care

## Introduction

The COVID-19 pandemic has significantly changed daily life for children and families. Children and adolescents find themselves confined to their homes with loss of previously utilized outlets for socialization and physical activity. This sense of isolation may be new to many families and yet, it is familiar to some such as a child with serious illness who has experienced periods of prolonged hospitalizations, or quarantine at home away from friends and limited interaction in the community. Whether it be the novel pandemic, or living day-to-day with a serious illness, providers should provide families with outlets and resources to help make each day the best in can be under stressful circumstances. This process starts with screening pediatric patients for what brings them joy and what creates challenges. This paper will seek to better define those metrics

while discussing the imperfections of examining what is popularly known as quality of life. This paper will also provide an overview of ways to promote quality of life with particular attention paid to the adjustments patients and families are challenged with during COVID-19.

## Defining Quality of Life

Quality of life (QOL) has become an important healthcare metric. The notion of QOL was first identified in healthcare literature in the 1950s [1, 2]. There is no absolute consensus on the definition of QOL and the term QOL can be used as a catch all to describe health-related quality of life (HRQOL) or functioning, disability, and health (FDH) [3, 4]. One of the most widely cited definitions of QOL comes from the World Health Organization (WHO) and is as follows: “an individuals’ perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [5]. This definition focuses on three key features: (1) QOL is subjective; (2) QOL is multi-dimensional; and (3) QOL has both positive and negative values [5]. There are six broad domains of QOL as defined by the WHO: physical, psychological,

This article is part of the Topical Collection on *Pediatric Palliative Care*

✉ Teresa Vente  
tvente@luriechildrens.org

<sup>1</sup> Division of Palliative Care, Ann & Robert H. Lurie Children’s Hospital of Chicago, 225 East Chicago Avenue Box 117, Chicago, IL 60611, USA

level of independence, social relationships, environment, and spirituality [5].

The concept of HRQOL was developed to describe and measure the dimensions of quality of life that can affect both physical and mental health. The Centers for Disease Control (CDC) defines HRQOL as “an individual’s or group’s perceived physical and mental health over time” [6]. There are four domains attributed to HRQOL: disease state, functional status, social functioning, and psychological functioning [7, 8]. In healthcare literature, QOL and HRQOL are sometimes used interchangeably. HRQOL is often identified as an outcome measure for research that seeks to measure QOL in both healthy populations and those with specific disease states. It is therefore important to differentiate HRQOL from functioning, disability, and health (FDH) which “comprises the biopsychosocial components and interactions among body structures and function, and activities and participation in the context of the environment and personal factors” [3•]. The International Classification of Functioning, Disability, and Health (ICF) is a framework conceptualized by the WHO to provide a system that recognizes that a person’s level of function is multi-dimensional and interactive between health-related conditions and the environmental and personal factors [9]. The relationship between domains of QOL, HRQOL, and FDH is outlined in Fig. 1.

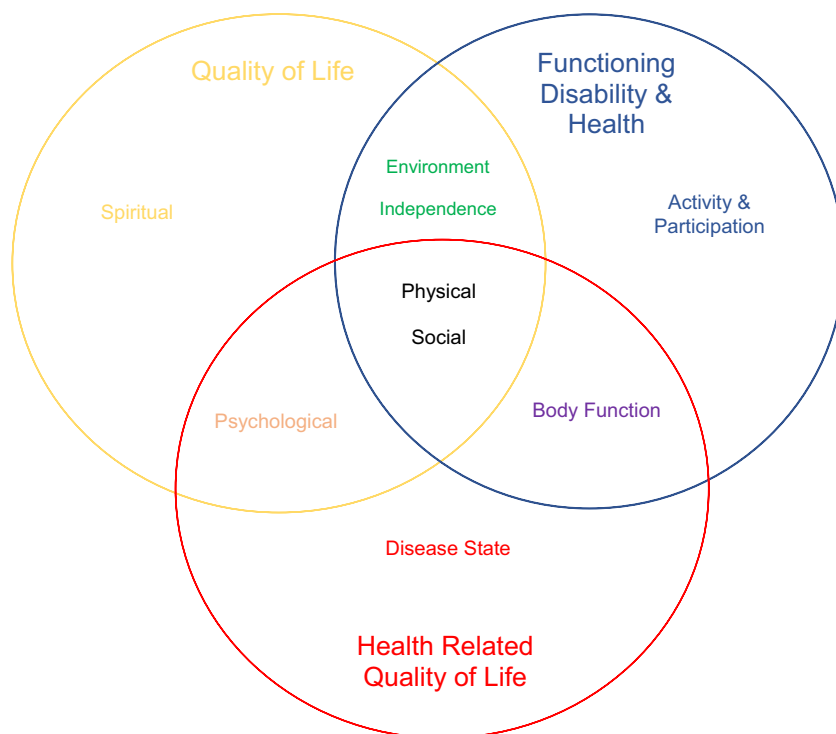
The formal definitions of QOL, HRQOL, and FDH are important in a research context; however, when attempting to address health promotion, it is also important to consider how individuals themselves define quality of life. This is particularly true for children and adolescents where QOL and

HRQOL have historically been perceived by parent and provider proxy. Perceptions of QOL by proxy tend to focus more on health status and normalcy, whereas children view QOL as being related to physically participating in developmentally appropriate activities, and spending time with friends and family [10, 11]. Adolescents view QOL as separate from health and functional status and identify overall satisfaction with life as being a core feature along with self-confidence, self-image, and relationships with friends as key influences [12].

## Measuring Quality of Life

In the 1980s, efforts were made to focus on HRQOL as an outcome measure for research in clinical trials, clinical practice improvement, and evaluation of healthcare service [1]. In order to measure improvements in patient health for research purposes, tools were designed to measure patient-reported outcomes (PROs) [13]. Adult data suggests that HRQOL measurement may improve communication between patients and providers [14]. By the mid-1990s, an interest grew in measuring HRQOL specifically for children and adolescents, and the development of HRQOL outcome measures for pediatrics followed [15]. Research in pediatric populations has identified that HRQOL measures may help to screen for psychosocial problems that are typically under identified, and longitudinal monitoring of HRQOL may help to evaluate effectiveness of treatments such as those aimed at pain or fatigue [14]. Despite benefits of integrating HRQOL into clinical practice, there are common barriers to implementation including lack of

**Fig. 1** Relationship between domains of quality of life (QOL), health-related quality of life (HRQOL), and functioning disability and health (FDH)



resources such as time and money, concern for additional burden to patients and families, and uncertainty about how to incorporate PROs into clinical practice.

There are two main categories of HRQOL measurement tools: generic vs disease/population specific. Both categories rely on patient-reported outcomes. Generic tools allow for comparison across healthy pediatric populations while disease-specific tools can detect smaller changes or have higher sensitivity for patients with a specific disease or condition [13, 16]. A review by Solans et al. in 2008 identified 30 generic-specific and 64 disease-specific pediatric HRQOL measures [17]. Some disease-specific measures are designed for children with chronic illnesses such as asthma and diabetes [15, 18, 19]. In applying HRQOL measures to children with palliative care needs, studies show that children with life-limiting illness have significant impairment across all domains of HRQOL; however, the validity of using even the most popular and widely used HRQOL measures is questioned [20, 21]. It is thought that generic HRQOL measurement tools may not fully capture all the domains necessary for a child with palliative care needs and applicable domains may change over the course of an illness [11, 21]. Additionally, measurement tools typically focus on limitations and lack an emphasis on capturing daily accomplishments, and many lack the ability to consider how nonverbal cues communicate a child's overall state of being [22]. Further, parents of children with life-limiting illness who are providing proxy reports may have a different interpretation of questions than that of parents of children without a life-limiting illness [20].

## Proxy Report

Many of the initial HRQOL instruments have relied on parent proxy report. Despite significant research showing that proxy-respondents are not equivalent to patient self-report, even for children, many instruments still rely on parent proxy [8, 14, 16, 23, 24]. Two of the main arguments for including proxy report are the following: (1) parent perspectives remain important as parents are typically responsible for a child's healthcare utilization and assessing function should be evaluated in relation to contextual factors including the family; (2) some pediatric populations (based on age or specific disease) cannot self-report [18, 25]. Several instruments seek to resolve the issues with proxy report by including child self-report in addition to parent proxy. Self-report has been validated in children as young as 4–6 years of age [16].

## Specific Instruments

One of the most long-standing PRO measures in pediatrics is The Pediatric Quality of Life Inventory (PedsQL) now in its

fourth iteration. PedsQL was designed to measure HRQOL by integrating both generic- and disease-specific modules [18]. PedsQL has been validated to measure child self-report for children 5–18 years of age and includes proxy report for parents of children ages 2–18 years [18]. Due to the number of specific disease modules that can be used including Asthma, Cancer, Pain, Fatigue, and Cardiac, and with translation into more than 65 languages, PedsQL is one of the most popular HRQOL measurement tools for pediatrics particularly within the USA [18].

KIDSCREEN is another popular HRQOL screening measure developed under the collaboration of 13 different countries in Europe. It utilizes condition-specific questionnaires incorporating self and proxy reports for children ages 8–18 years [26]. KIDSCREEN has evolved to be administered as a computer-adaptive questionnaire aimed at reducing question fatigue and administrative burden for patients and clinicians [26].

Kwaliteit van Leven In Kaart “Quality of Life in Clinical Practice” (KLIK) is a HRQOL developed in the Netherlands to electronically report HRQOL PROs [13]. Children and parents providing proxy report have access to questionnaires a week prior to clinic visits and responses are accessible to members of a multidisciplinary pediatric team facilitating communication among team members, as well as communication between providers and families [13]. A similar model is being studied in pediatric hospitals in the USA through Pediatric Quality of Life and Evaluation of Symptoms Technology Study (PediQUEST) which also uses an electronic PRO system for children ages 2 and older with advanced cancer [27]. Children and parents complete online feedback about symptoms and function to improve symptom burden and HRQOL [27].

One critique of HRQOL measures is that the content of the measure and how it is applied may not measure HRQOL or QOL at all but rather functional status and FDH [2, 13]. A review by Fayed et al. in 2012 found that when WHO definitions for QOL, HRQOL, and FDH were applied to the content of popular pediatric HRQOL measurement tools, the tools did not necessarily measure the targeted outcome of HRQOL [3]. The PedsQL for example was found to measure FDH as opposed to HRQOL.

A full comparison of specific pediatric HRQOL measurement tools is beyond the scope of this review, and a more thorough review can be found in Connolly and Johnson, Matza et al., and Haverman et al. [13, 16, 25].

## Promoting Quality of Life

There is no one size fits all model to that incorporates HRQOL data into meaningful change in clinical practice, and promotion of quality of life may be more challenging for children

and families with chronic health needs or those with serious or potentially life-limiting illness. For children with cancer or other serious illness, addressing symptom burden is one area where clinicians may be able to have meaningful impact. Fatigue has been identified as a factor affecting quality of life in children with cancer and with chronic illness. Several HRQOL measures have a specific module or dedicated screening tool to assess for fatigue in relation to impact on HRQOL [28]. Clinical approaches to address this issue include focus on alternating periods of activity and rest with adjustments made to routines that allow focus on desired social activities [4]. Additional interventions from adult studies suggest CBT and introduction of graded exercise may also play a role in reducing fatigue [4]. Disrupted and disordered sleep may not only impact fatigue but can also exacerbate other underlying health concerns and has been shown to negatively impact HRQOL in children [29]. Providing guidance to parents on good sleep hygiene and the importance of bedtime routines may help to mitigate some sleep disturbance. Additional workup may be necessary in children where routine sleep hygiene does not improve disordered sleep. Pain is another symptom that can have significant impact on HRQOL. Uncontrolled or poor pain control can impact multiple dimensions of QOL for adolescents including perceptions of self and psychological well-being as well as relationships with parents and engagement at school [30]. Providers should take a holistic approach to pain control to address physical, emotional, and existential sources of pain and discomfort while promoting realistic return to function with assistance of adaptive functioning where applicable.

In adolescents where QOL is related to self-confidence and relationships, it is important to find ways to promote healthy body image specially for adolescents whose physical appearance may be impacted by underlying illness or treatments and in particular for female adolescents who typically rate HRQOL lower than males [31, 32]. It is also important to support healthy relationships with friends and provide adaptive functioning to allow engagement with peers [12]. This includes promoting safe socialization to mitigate the isolation that adolescents with serious or complex medical illness may experience which is distressing to QOL [11]. Access to peers with similar lived experience may also provide an outlet for adolescents to explore sensitive topics regarding their health and function that they may not be comfortable exploring with parents and providers. Having the support of others with a similar lived experience may also be important for families of children with increased medical needs. A study of families of children who require home mechanical ventilation found that support from other families with similar lived experience enhanced caregiver support and decreased their sense of isolation [33].

## Quality of Life in COVID

The COVID-19 pandemic has disrupted daily life for children and their families. Practices such as physical distancing and restrictions on social gatherings have limited interactions and ability to engage in physical play. Public park space and playground use have also been restricted in some areas. With stay-at-home advisories and community lockdowns, there has been disruption to schooling with education taking place virtually and in the home.

Health researchers have attempted to characterize the impact of COVID-19 on QOL and daily activity for children and adolescents. Cross-sectional surveys of youth in China, Europe, and Canada have been performed. A cross-sectional survey of adolescents in Norway used KIDSCREEN 10 to measure HRQOL [34•]. Researchers found that adolescents relied on family and television for health-related information, as well as social media (Facebook and Snapchat), and lower health literacy regarding COVID-19 was associated with lower HRQOL [34•]. In addition, isolation and quarantine in the setting of COVID-19 was negatively associated with HRQOL [34•].

Survey data in Canada and Europe has also attempted to examine behaviors around eating habits during the pandemic, and findings have been notable for perception of increase in appetite as well as increase in consumption of snacks and snack food among children and adolescents [35, 36, 37•], although not all eating habits have been negatively impacted as families have reported increase in cooking and eating meals together with less consumption of take-out meals [35, 37•].

There have also been changes to engagement with physical activity. Children and adolescents are overall engaged in less physical activity during the pandemic including fewer sporting activities and spending less time outdoors [37•, 38]. The types of physical activity children and adolescents are engaging in has also changed with more time spent in reduced intensity activities during the pandemic compared to before [37•]. This may be in part due to limitations on the space available to engage in physical activity or the variety of activities available with most after school and club sports teams having cancelled or postponed their seasons [38]. In addition, children and adolescents are occupying their time with increased screen time with virtual learning and efforts to stay connected to family and friends [36–39].

Health researchers have also examined the effect of the COVID-19 pandemic on mental health of children and adolescents. Cross-sectional surveys were conducted among Chinese adolescents during the COVID-19 lockdowns in mainland China to examine the prevalence of symptoms of anxiety and depression [40•, 41•]. Rating scales including the Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder Scale (GAD-7) were used. Surveys showed that anxiety and depressive symptoms were present among

Chinese adolescents during the lockdown periods with symptoms higher among females, older adolescents, and adolescents in rural areas [40•, 41•]. Depressive symptoms were also found to be associated with smartphone and Internet addiction, and children reported increased use of Internet and smartphones during lockdown periods [39, 42]. An inverse relationship was found between anxiety and depressive symptoms and knowledge about COVID-19 prevention and control measures [40•, 41•]. Separate survey studies screening younger school-aged children for anxiety and depression symptoms showed evidence of anxiety symptoms, as well as externalizing behaviors such as clinginess and irritability with physical activity associated with lower levels of distress [43, 44].

With the prevalence of anxiety and depression in youth during the COVID-19 pandemic, there is a risk that mental health concerns may not be fully addressed. In the USA, the closure of schools may exacerbate these concerns as many children and adolescents receive some form of mental health services in the school setting [45]. While telemedicine has sought to close the gap for students unable to receive in-person services, some families may not have the technology hardware or Internet access needed to receive such services [45].

QOL has been examined in children with underlying chronic health conditions during COVID-19 pertaining to stress and anxiety levels. In one study, PedsQL scores (completed by parent proxy) for children followed in an obesity clinic in the Netherlands were compared at baseline and during the COVID-19 pandemic. A notable decrease in PedsQL scores were seen for children between baseline and COVID-19 with the biggest decrease in scores among children for whom anxiety was reported [46]. A separate study of stress levels in adolescents in India with type 1 diabetes mellitus during COVID-19 found that over half of adolescents surveyed reported moderate stress levels which was also correlated with reported worsening of glycemic control [47]. Not all children with chronic illnesses have reported increased stress or anxiety levels. A study of anxiety levels of children with cystic fibrosis (CF) and their mothers in Turkey during COVID-19 found no difference in anxiety levels for children with CF compared to their age-matched healthy peers [48]. Anxiety scores for mothers of children with CF however were higher than mothers of age-matched healthy controls although higher maternal anxiety scores were not correlated with child's disease severity or changes in disease severity [48]. It is important to recognize that each of these studies was conducted early in the pandemic and longitudinal impacts on child and parental stress levels and anxiety are not yet known.

## Promoting Quality of Life in COVID

Professional organizations including the American Academy of Pediatrics (AAP), American Academy of Child and Adolescent Psychiatry (AACAP), and the National Association of School Psychologists (NASP) have published guidelines and statements to address the need to support the physical, emotional, and behavioral health of children and their families during the COVID-19 pandemic [49••, 50••, 51]. The AAP Interim Guidance on supporting emotional and behavioral health needs of children, adolescents, and families during COVID-19 encourages promotion of health literacy and knowledge related to COVID-19 [49••]. The report emphasizes open communication using age-appropriate language. Guidelines from AACAP reinforce the use of open communication to address a child's fears and remind parents that conversations should not be forced but rather guided by a child's questions. Parents are encouraged to provide reassurance but not to make unrealistic promises such as telling a child there will be no cases of COVID-19 in their community or in their family [50••].

[Healthychildren.org](https://www.healthychildren.org), the online resource for parents published by the AAP, offers multiple resources for guidance about dealing with the COVID-19 pandemic. One resource identifies ways to boost mood and encourages parents to help children focus on positive aspects of spending time with family with a particular focus on gratitude [52]. There are also resources aimed at building resilience which can come from maintaining a sense of purpose [53]. This is echoed in guidance from NASP where parents are encouraged to model self-forgiveness and self-compassion for children [51]. Empathizing with children and talking openly about their emotions will also help to build resiliency. It is also important for parents to recognize when children or they themselves need a "time out" or break. AAP and AACAP guidelines encourage parents to recognize signs of stress which are often age dependent [54]. Externalizing signs such as disturbed sleep, separation anxiety, tantrums, frustration, or developmental regression are more common signs of stress in younger children [54]. Older children may experience more internalizing signs such as changes in mood or eating habits, trouble with concentration, and loss of interest in activities [54]. It is important to recognize that grief over loss not only of loved ones, but loss of personal milestones such as graduations, birthdays, and Bar Mitzvahs may increase risk of mental health challenges during COVID-19.

In an effort to mitigate mental health challenges, the AAP recommends setting a schedule and keeping a routine for screen time (both online learning and social use) and consider using mealtimes or breaks for physical activity as transition periods off of electronic devices [55]. Our Family Media Use Plan is an online tool developed by the AAP available on [healthychildren.org](https://www.healthychildren.org) to assist with limitations for electronic

device use [56]. While increased screen time is expected, real time communication should be prioritized over passive viewing [55]. Alternative indoor activities to reduce screen time are also encouraged such as arts and crafts, puzzles, and family games [52]. The AAP also suggests looking for opportunities to volunteer or participate in community engagement through projects such as making masks or donating to a food drive [52]. Keeping a normal bedtime and discontinuing screen time prior to bed is also an important part of maintaining a routine for children and adolescents [55].

Engagement with physical activity may have changed but should not be neglected. A study of physical activity in Canadian adults during COVID-19 showed higher mental health scores among adults engaged in physical activity compared to those adults not engaging in physical activity [57]. The AAP encourages family participation in physical activity and recommends 30–60 min of outdoor time daily as exposure to nature is associated with increased mood and reduction in stress in adults [52, 57]. For families looking to keep children engaged in sports, the AAP recommends sports participation that occurs outdoors and allows for physical distancing, where equipment is not shared, and there is limited contact between participants [58].

For families caring for children with special healthcare needs, there are important issues to consider [59]. Providers should assist families in ensuring access to medical care, especially for vulnerable patients with increased symptom management needs such as those suffering from diseases with

chronic or acute pain [60]. Some providers may be able to offer appointments via telemedicine and some interventions such as those for chronic pain (mindfulness/CBT) may be able to be delivered online [60]. For any child with increased medical needs, ensuring access to medications and durable medical supplies is crucial. This is especially true for patients on opioids. Providers should pay close attention to safe prescribing practices which may include prescribing naloxone. Any increase in pain medication utilization warrants in-person follow-up and evaluation, and families should be educated on signs of withdrawal [60].

Universal precautions should also be emphasized in families with children who have underlying medical issues including proper hand hygiene and use of cloth face coverings, especially for those providing care inside the family's home such as a home health nurse [59]. For children with hearing impairment or who rely on lip reading, transparent face masks should be utilized [59]. In addition, caregiver self-care should be encouraged to avoid caregiver burnout [59]. Providers should also screen for social determinants of health including stable housing, Internet connectivity, and food security, which may be affected by parental job loss, financial stress, or even school closure where access to free or reduced cost meals may no longer be available. Providers should work with families to help identify clinic, hospital, and community resources that can assist with access to food and housing if these essential needs are threatened. A summary of recommendations for promotion of quality of life during COVID-19 can be found in Table 1.

**Table 1** Recommendations for promoting quality of life during COVID-19

Quality of life domain	Recommendations
Physical	<ul style="list-style-type: none"> <li>• Universal precautions (face masks, handwashing)</li> <li>• 30–60 min of exercise daily</li> <li>• Outdoor activities: bike riding, nature walk, hiking</li> <li>• Safe sports participation</li> <li>• Access to medical appointments, medications, and medical supplies</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>• Age-appropriate dialogue</li> <li>• Open-ended communication</li> <li>• Take breaks</li> <li>• Recognize signs of stress</li> <li>• Mental health screening by professional</li> </ul>
Environment	<ul style="list-style-type: none"> <li>• Setting limits for screen time</li> <li>• Bedtime routine</li> <li>• Community volunteer projects</li> </ul>
Social relationships	<ul style="list-style-type: none"> <li>• Family mealtimes</li> <li>• Virtual interactions with family and friends</li> </ul>
Level of independence	<ul style="list-style-type: none"> <li>• Families screened for access to essential needs (food, housing, Internet)</li> <li>• Adaptations to adjust for impairment (i.e., transparent masks for lip reading)</li> </ul>
Spiritual	<ul style="list-style-type: none"> <li>• Focus on gratitude</li> <li>• Maintain a sense of purpose</li> </ul>

## Future Areas of Research

PRO use and measurement of HRQOL have made significant advances within pediatric clinical practice and research over the last 30 years. Future research should seek to refine the practical use of PRO data by focusing on additional means by which to incorporate QOL PROs into clinical practice. In addition, children with palliative care needs such as those with life-limiting illness lack validated measurement tools for HRQOL and development of measures specific to this population should be a focus of research. Using HRQOL data for health promotion remains an important area of continued focus. The COVID-19 pandemic has presented unique challenges for health promotion. Understanding the long-term effects of social distancing and engagement in virtual learning and socialization for children and families will be important to provide guidance for health promotion through the duration of this pandemic, and in future health crisis affecting our communities. Efforts should also be made for optimization and delivery of telemedicine and tele mental health services to address disparities in access to care, especially for the most vulnerable pediatric patients.

## Conclusion

Optimizing QOL remains a challenge for healthcare providers in part due to the difficulty in defining exactly what QOL is and how to measure it. Measurement tools have been refined and adapted across age groups and even for children with specific disease states. Measures have been translated to accommodate different languages and cultures worldwide. Yet, imperfections remain in exactly how to translate PROs into clinical practice. There are however some common themes for promoting QOL in children and adolescents including managing difficult to control symptoms and encouraging healthy peer relationships, especially for youth with serious illness. With the onset of COVID-19, new challenges have emerged in promoting QOL. Eating habits, participating in physical activity, limits to screen time, and socialization with friends have all been upended. Continuing to encourage families to focus on structure and routine, open and honest communication, and being aware of the need to take a step back for both parents and children can help to navigate the adjustments needed during this time. Referring families to resources from the AAP, AACAP, and others can help to provide further guidance for families to practice safe and healthy behaviors while optimizing individual and family activities focused on improving QOL.

## Compliance with Ethical Standards

**Conflict of interest** The author declares no competing interests.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

## References

Papers of particular interest, published recently, have been highlighted as:

- Of importance
  - Of major importance
1. Boss RD, Kinsman HI, Donohue PK. Health-related quality of life for infants in the neonatal intensive care unit. *J Perinatol*. 2012;32(12):901–6. <https://doi.org/10.1038/jp.2012.82>.
  2. Huang IC, Revicki DA, Schwartz CE. Measuring pediatric patient-reported outcomes: good progress but a long way to go. *Qual Life Res*. 2014;23(3):747–50. <https://doi.org/10.1007/s11136-013-0607-2>.
  - 3• Fayed N, de Camargo OK, Kerr E, Rosenbaum P, Dubey A, Bostan C, et al. Generic patient-reported outcomes in child health research: a review of conceptual content using World Health Organization definitions. *Dev Med Child Neurol*. 2012;54(12):1085–95. <https://doi.org/10.1111/j.1469-8749.2012.04393.x> **An important review discussing the difficulty in measuring and reporting on quality of life in pediatrics.**
  4. Eddy L, Cruz M. The relationship between fatigue and quality of life in children with chronic health problems: a systematic review. *J Spec Pediatr Nurs*. 2007;12(2):105–14. <https://doi.org/10.1111/j.1744-6155.2007.00099.x>.
  5. The WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL). Development and psychometric properties. *Soc Sci Med*. 1998;46:1569–85.
  6. Centers for Disease Control and Prevention. Measuring healthy days: population assessment of health-related quality of life. In: Centers for Disease Control and Prevention. Atlanta, Georgia; 2000.
  7. Spieth LE, Harris CV. Assessment of health-related quality of life in children and adolescents: an integrative review. *J Pediatr Psychol*. 1996;21(2):175–93. <https://doi.org/10.1093/jpepsy/21.2.175>.
  8. Fekkes M, Theunissen NC, Brugman E, Veen S, Verrips EG, Koopman HM, et al. Development and psychometric evaluation of the TAPQOL: a health-related quality of life instrument for 1-5-year-old children. *Qual Life Res*. 2000;9(8):961–72. <https://doi.org/10.1023/a:1008981603178>.
  9. World Health Organization. International Classification of Functioning, Disability, and Health: Children and Youth Version: ICF-CY. Geneva: WHO; 2007.
  10. Green AL, McSweeney J, Ainley K, Bryant J. Comparing parents' and children's views of children's quality of life after heart transplant. *J Spec Pediatr Nurs*. 2009;14(1):49–58. <https://doi.org/10.1111/j.1744-6155.2008.00173.x>.
  11. Anthony SJ, Selkirk E, Sung L, Klaassen RJ, Dix D, Klassen AF. Quality of life of pediatric oncology patients: do patient-reported outcome instruments measure what matters to patients? *Qual Life Res*. 2017;26(2):273–81. <https://doi.org/10.1007/s11136-016-1393-4>.
  12. Helseth S, Misvaer N. Adolescents' perceptions of quality of life: what it is and what matters. *J Clin Nurs*. 2010;19(9-10):1454–61. <https://doi.org/10.1111/j.1365-2702.2009.03069.x>.
  13. Haverman L, Limperg PF, Young NL, Grootenhuis MA, Klaassen RJ. Paediatric health-related quality of life: what is it and why

- should we measure it? *Arch Dis Child*. 2017;102(5):393–400. <https://doi.org/10.1136/archdischild-2015-310068>.
14. Varni JW, Burwinkle TM, Lane MM. Health-related quality of life measurement in pediatric clinical practice: an appraisal and precept for future research and application. *Health Qual Life Outcomes*. 2005;3:34. <https://doi.org/10.1186/1477-7525-3-34>.
  15. Ravens-Sieberer U, Bullinger M. Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Qual Life Res*. 1998;7(5):399–407. <https://doi.org/10.1023/a:1008853819715>.
  16. Connolly MA, Johnson JA. Measuring quality of life in paediatric patients. *Pharmacoeconomics*. 1999;16(6):605–25. <https://doi.org/10.2165/00019053-199916060-00002>.
  17. Solans M, Pane S, Estrada MD, Serra-Sutton V, Berra S, Herdman M, et al. Health-related quality of life measurement in children and adolescents: a systematic review of generic and disease-specific instruments. *Value Health*. 2008;11(4):742–64. <https://doi.org/10.1111/j.1524-4733.2007.00293.x>.
  18. Varni JW, Limbers CA. The pediatric quality of life inventory: measuring pediatric health-related quality of life from the perspective of children and their parents. *Pediatr Clin North Am*. 2009;56(4):843–63. <https://doi.org/10.1016/j.pcl.2009.05.016>.
  19. Eiser C. Children's quality of life measures. *Arch Dis Child*. 1997;77(4):350–4. <https://doi.org/10.1136/adc.77.4.350>.
  20. Huang IC, Shenkman EA, Madden VL, Vadaparampil S, Quinn G, Knapp CA. Measuring quality of life in pediatric palliative care: challenges and potential solutions. *Palliat Med*. 2010;24(2):175–82. <https://doi.org/10.1177/0269216309352418>.
  21. Hinds PS, Gattuso JS, Fletcher A, Baker E, Coleman B, Jackson T, et al. Quality of life as conveyed by pediatric patients with cancer. *Qual Life Res*. 2004;13(4):761–72. <https://doi.org/10.1023/B:QURE.0000021697.43165.87>.
  22. Avoine-Blondin J, Parent V, Fasse L, Lopez C, Humbert N, Duval M, et al. How do professionals assess the quality of life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement? *BMC Palliat Care*. 2018;17(1):71. <https://doi.org/10.1186/s12904-018-0328-y>.
  23. Vogels T, Verrips GH, Verloove-Vanhorick SP, Fekkes M, Kamphuis RP, Koopman HM, et al. Measuring health-related quality of life in children: the development of the TACQOL parent form. *Qual Life Res*. 1998;7(5):457–65. <https://doi.org/10.1023/a:1008848218806>.
  24. Landgraf JM, Vogel I, Oostenbrink R, van Baar ME, Raat H. Parent-reported health outcomes in infants/toddlers: measurement properties and clinical validity of the ITQOL-SF47. *Qual Life Res*. 2013;22(3):635–46. <https://doi.org/10.1007/s11136-012-0177-8>.
  25. Matza LS, Swensen AR, Flood EM, Secnik K, Leidy NK. Assessment of health-related quality of life in children: a review of conceptual, methodological, and regulatory issues. *Value Health*. 2004;7(1):79–92. <https://doi.org/10.1111/j.1524-4733.2004.71273.x> **A comprehensive review of HRQOL measures in pediatrics.**
  26. Ravens-Sieberer U, Herdman M, Devine J, Otto C, Bullinger M, Rose M, et al. The European KIDSCREEN approach to measure quality of life and well-being in children: development, current application, and future advances. *Qual Life Res*. 2014;23(3):791–803. <https://doi.org/10.1007/s11136-013-0428-3>.
  27. Wolfe J, Orellana L, Cook EF, Ullrich C, Kang T, Geyer JR, et al. Improving the care of children with advanced cancer by using an electronic patient-reported feedback intervention: results from the PediQUEST randomized controlled trial. *J Clin Oncol*. 2014;32(11):1119–26. <https://doi.org/10.1200/JCO.2013.51.5981>.
  28. Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer*. 2002;94(7):2090–106. <https://doi.org/10.1002/cncr.10428>.
  29. Magee CA, Robinson L, Keane C. Sleep quality subtypes predict health-related quality of life in children. *Sleep Med*. 2017;35:67–73. <https://doi.org/10.1016/j.sleep.2017.04.0>.
  30. Haraldstad K, Christophersen KA, Helseth S. Health-related quality of life and pain in children and adolescents: a school survey. *BMC Pediatr*. 2017;17(1):174. <https://doi.org/10.1186/s12887-017-0927-4>.
  31. Haraldstad K, Christophersen KA, Eide H, Natvig GK, Helseth S. Predictors of health-related quality of life in a sample of children and adolescents: a school survey. *J Clin Nurs*. 2011;20(21–22):3048–56. <https://doi.org/10.1111/j.1365-2702.2010.03693.x>.
  32. Shin H, Bartlett R, De Gagne JC. Health-related quality of life among survivors of cancer in adolescence: an integrative literature review. *J Pediatr Nurs*. 2019;44:97–106. <https://doi.org/10.1016/j.pedn.2018.11.009>.
  33. González R, Bustinza A, Fernandez SN, García M, Rodríguez S, García-Teresa MÁ, et al. López-Herce J; Spanish Children Home Mechanical Ventilation Multicentric Study Group. Quality of life in home-ventilated children and their families. *Eur J Pediatr*. 2017;176(10):1307–17. <https://doi.org/10.1007/s00431-017-2983-z>.
  34. Riiser K, Helseth S, Haraldstad K, Torbjørnsen A, Richardsen KR. Adolescents' health literacy, health protective measures, and health-related quality of life during the Covid-19 pandemic. *PLoS One*. 2020;15(8):e0238161. <https://doi.org/10.1371/journal.pone.0238161> **One of the first studies to examine quality of life in adolescents in Europe during COVID-19.**
  35. Di Renzo L, Gualtieri P, Pivari F, Soldati L, Attinà A, Cinelli G, et al. Eating habits and lifestyle changes during COVID-19 lockdown: an Italian survey. *J Transl Med*. 2020;18(1):229. <https://doi.org/10.1186/s12967-020-02399-5>.
  36. Pietrobello A, Pecoraro L, Ferruzzi A, Heo M, Faith M, Zoller T, et al. Effects of COVID-19 Lockdown on lifestyle behaviors in children with obesity living in Verona, Italy: a longitudinal study. *Obesity (Silver Spring)*. 2020 Aug;28(8):1382–5. <https://doi.org/10.1002/oby.22861>.
  37. Carroll N, Sadowski A, Laila A, Hruska V, Nixon M, Ma DWL, et al. The impact of COVID-19 on health behavior, stress, financial and food security among middle to high income Canadian families with young children. *Nutrients*. 2020;12(8):2352. <https://doi.org/10.3390/nu12082352> **One of the first papers to examine impact of COVID-19 on determinants of health for families in Canada.**
  38. Moore SA, Faulkner G, Rhodes RE, Brussoni M, Chulak-Bozzer T, Ferguson LJ, et al. Impact of the COVID-19 virus outbreak on movement and play behaviours of Canadian children and youth: a national survey. *Int J Behav Nutr Phys Act*. 2020;17(1):85. <https://doi.org/10.1186/s12966-020-00987-8>.
  39. Chen IH, Chen CY, Pakpour AH, Griffiths MD, Lin CY. Internet-related behaviors and psychological distress among schoolchildren during COVID-19 school suspension. *J Am Acad Child Adolesc Psychiatry*. 2020;59(10):1099–1102.e1. <https://doi.org/10.1016/j.jaac.2020.06.007>.
  40. Zhou SJ, Zhang LG, Wang LL, Guo ZC, Wang JQ, Chen JC, et al. Prevalence and socio-demographic correlates of psychological health problems in Chinese adolescents during the outbreak of COVID-19. *Eur Child Adolesc Psychiatry*. 2020;29(6):749–58. <https://doi.org/10.1007/s00787-020-01541-4> **One of the earliest studies to report on mental health of Chinese adolescents during COVID-19 pandemic.**
  41. Qi H, Liu R, Chen X, Yuan XF, Li YQ, Huang HH, et al. Prevalence of anxiety and associated factors for Chinese adolescents during the COVID-19 outbreak. *Psychiatry Clin Neurosci*. 2020. <https://doi.org/10.1111/pcn.13102> **One of the earliest studies to report on mental health of Chinese adolescents during COVID-19 pandemic.**



42. Duan L, Shao X, Wang Y, Huang Y, Miao J, Yang X, et al. An investigation of mental health status of children and adolescents in china during the outbreak of COVID-19. *J Affect Disord*. 2020;275:112–8. <https://doi.org/10.1016/j.jad.2020.06.029>.
43. Jiao WY, Wang LN, Liu J, Fang SF, Jiao FY, Pettoello-Mantovani M, et al. Behavioral and emotional disorders in children during the COVID-19 epidemic. *J Pediatr*. 2020;221:264–266.e1. <https://doi.org/10.1016/j.jpeds.2020.03.013>.
44. Chen F, Zheng D, Liu J, Gong Y, Guan Z, Lou D. Depression and anxiety among adolescents during COVID-19: a cross-sectional study. *Brain Behav Immun*. 2020;88:36–8. <https://doi.org/10.1016/j.bbi.2020.05.061>.
45. Golberstein E, Wen H, Miller BF. Coronavirus disease 2019 (COVID-19) and mental health for children and adolescents. *JAMA Pediatr*. 2020;174(9):819–20. <https://doi.org/10.1001/jamapediatrics.2020.1456>.
46. Abawi O, Welling MS, van den Eynde E, van Rossum EFC, Halberstadt J, van den Akker ELT, et al. COVID-19 related anxiety in children and adolescents with severe obesity: a mixed-methods study. *Clin Obes*. 2020;10(6):e12412. <https://doi.org/10.1111/cob.12412>.
47. Agarwal N, Harikar M, Shukla R, Bajpai A. COVID-19 pandemic: a double trouble for Indian adolescents and young adults living with type 1 diabetes. *Int J Diabetes Dev Ctries*. 2020;18:1–7. <https://doi.org/10.1007/s13410-020-00869-6>.
48. Pınar Senkalfa B, Sismanlar Eyuboglu T, Aslan AT, Ramaslı Gursoy T, Soysal AS, Yapar D, et al. Effect of the COVID-19 pandemic on anxiety among children with cystic fibrosis and their mothers. *Pediatr Pulmonol*. 2020;55(8):2128–34. <https://doi.org/10.1002/ppul.24900>.
49. •• Interim guidance on supporting the emotional and behavioral health needs of children, adolescents, and families during the COVID-19 pandemic. American Academy of Pediatrics. 2020. <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/interim-guidance-on-supporting-the-emotional-and-behavioral-health-needs-of-children-adolescents-and-families-during-the-covid-19-pandemic/>. Accessed 8 Nov 2020. **Official statement of interim guidance and recommendations from AAP regarding emotional and behavioral health needs during COVID-19**
50. •• Fassler D. Talking to children about Coronavirus (COVID-19). American Academy of Child and Adolescent Psychiatry. 2020. [https://www.aacap.org/App\\_Themes/AACAP/Docs/latest\\_news/2020/Coronavirus\\_COVID19\\_\\_Children.pdf](https://www.aacap.org/App_Themes/AACAP/Docs/latest_news/2020/Coronavirus_COVID19__Children.pdf). Accessed 8 Nov 2020. **Official resource from AACAP for guidance on talking to children about COVID-19**
51. Sievering K. Talking to children about COVID-19 (Coronavirus): a parent resource, National Association of School Psychologists and National Association of School Nurses, NASP, 2020 [https://www.nasponline.org/Documents/Resources%2520and%2520Publications/Resources/Crisis/COVID-19\\_parent\\_handout\\_NASP\\_NASN\\_2-20\\_FINAL%2520\(6\)\(0\).pdf](https://www.nasponline.org/Documents/Resources%2520and%2520Publications/Resources/Crisis/COVID-19_parent_handout_NASP_NASN_2-20_FINAL%2520(6)(0).pdf) Accessed 8 Nov 2020.
52. Kemper K. Mood boosting tips for families during COVID-19 pandemic. American Academy of Pediatrics Section on Integrative Medicine and Mental Health Leadership Workgroup. 2020. <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/Mood-Boosting-Tips-for-Families-COVID-19.aspx>. Accessed 28 Oct 2020.
53. Ginsburg K. How to help children build resilience in uncertain times. American Academy of Pediatrics. 2020. <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/Building-Resilience-in-Uncertain-Times.aspx>. Accessed 8 Nov 2020.
54. Mental health during COVID-19: Signs your child may need more support. American Academy of Pediatrics. 2020. <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/Signs-your-Teen-May-Need-More-Support.aspx>. Accessed 28 Oct 2020.
55. Cross C. Working and learning from home during COVID-19 outbreak. American Academy of Pediatrics. 2020. <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/Working-and-Learning-from-Home-COVID-19.aspx>. Accessed 28 Oct 2020.
56. How to make a family media use plan. American Academy of Pediatrics. 2019. <https://www.healthychildren.org/English/family-life/Media/Pages/How-to-Make-a-Family-Media-Use-Plan.aspx>. Accessed 28 Oct 2020.
57. Lesser IA, Nienhuis CP. The impact of COVID-19 on physical activity behavior and well-being of Canadians. *Int J Environ Res Public Health*. 2020;17(11):3899. <https://doi.org/10.3390/ijerph17113899>.
58. Youth sports and COVID-19: Understanding the risks. American Academy of Pediatrics, American Medical Society for Sports Medicine, and the National Athletic Trainers' Association. 2020. <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/Youth-Sports-and-COVID-19-Understanding-the-Risks.aspx>. Accessed 8 Nov 2020.
59. • Kuo DZ, Coleman C. COVID-19: Caring for children and youth with special health care needs. American Academy of Pediatrics Council on Children with Disabilities 2020. <https://www.healthychildren.org/English/health-issues/conditions/COVID-19/Pages/COVID-19-Youth-with-Special-Health-Care-Needs.aspx>. Accessed 28 October 2020. **Paper outlining challenges for children with special health needs during COVID-19**
60. Shanthanna H, Strand NH, Provenzano DA, Lobo CA, Eldabe S, Bhatia A, et al. Caring for patients with pain during the COVID-19 pandemic: consensus recommendations from an international expert panel. *Anaesthesia*. 2020;75(7):935–44. <https://doi.org/10.1111/anae.15076>.

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.