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Engaging the Voices of Children: A Scoping Review of How Children and Adolescents Are Involved in the Development of Quality-of-Life–Related Measures

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Patient-Reported Outcomes

Engaging the Voices of Children: A Scoping Review of How Children and Adolescents Are Involved in the Development of Quality-of-Life-Related Measures



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ABSTRACT

Objectives: Patient-reported outcomes are increasingly recommended to guide patient care, develop and evaluate interventions, and modify health systems. However, not enough is known about whether and how children and adolescents, as “experts” in their own health and quality of life (QoL), are being engaged in the development of instruments. Our goals in this review were (1) to identify all QoL-related instruments that have included children and/or adolescents in the development of questionnaire content, including identification of themes and items; and (2) to report how this was done; and (3) to highlight those that used qualitative methods.

Methods: MEDLINE and Embase were searched for child- or adolescent-completed QoL-related instruments, supplemented by hand-searching of relevant reviews until 2020. Original development papers were identified and retrieved when possible, from which instrument characteristics and details of qualitative development methods were extracted.

Results: We identified 445 instruments, of which 88 used qualitative methods for content development. Interviews and focus groups were the most common methods. A variety of play techniques were used to engage the child and adolescent participants. The specific criteria for the inclusion of children and adolescents (age, developmental stage, duration, and nonclinical location) varied considerably.

Conclusions: Researchers frequently involve children and adolescents in qualitative methods when developing QoL-related measures; however, there is little information about the methods used. Better reporting of methodology, improved dissemination of methods guidelines, and research into optimal ways of including children and adolescents in the process of instrument development would be useful.

Keywords: adolescent, child, content validity, patient-reported outcome measures (PROMs), qualitative methods, quality of life (QoL).

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Grown-ups never understand anything by themselves, and it is tiresome for children to be always and forever explaining things to them.

Antoine de Saint-Exupéry, *The Little Prince*

Introduction

Quality of life (QoL) is a broad-ranging concept formed by the summation of health factors and many existential components of life, which together contribute to overall well-being and satisfaction with life¹; however, confusion remains about the conceptual meaning of this term.² There is an increasing appreciation of the importance of QoL as a defined and desired outcome in research and clinical practice. To help capture this concept, patient-reported outcomes (PROs) are necessary. PROs refer to any report of a patient’s health condition that comes directly from them “without interpretation of the patient’s response by the

clinician or anyone else.”^{3–5} The premise is that an individual is the expert on their own health and life experience, goals, and expectations.⁴ PROs are increasingly important for those who work clinically, develop treatments, target and provide interventions, or modify health systems and services. PROs can be assessed using validated patient-reported outcome measures (PROMs).^{2,6,7} There is increased interest in the role of children and adolescents in the reporting of their own health and QoL; however, because children are not just “little adults,” care must be taken in the development of reliable and valid PROMs for children.⁸

PROMs reflect the importance of the source for the information of interest (the patient, or at least a close proxy, such as a parent) but avoid any reference to the content and the conceptual construct of the measure. Our contention is that, whenever possible, the population of interest—even if they are children—should identify the items that are of importance to them for measure development. Indeed, researchers have taken an interest

in asking children about their own life evaluations, and children's answers may be unexpected and surprising for adults.^{9,10}

For PROMs to be valid and useful for clinicians, policy makers, and others, particularly those related to QoL, their content must reflect the perceptions and conceptualizations of the target population—in other words, demonstrate content validity.^{8,11,12} Previous reviews have assessed the psychometric properties and content of QoL-labeled instruments designed for children and adolescents, but we are aware of no reports that assess how this content was acquired.^{13,14} In their 2008 review of 64 health-related QoL (HRQoL) instruments for children and adolescents, Solans et al found significant variability in the content and dimensions of the concepts measured and concluded that this was likely at least partly related to variability in the development process.⁷ They encouraged the inclusion of children's and adolescents' voices in the development process whenever possible.⁷

QoL-related instruments intended for self-report in children and adolescents are developed in several ways. The content is often determined by literature review, expert consultation, and adaptation of measures intended for adults. In the absence of the perspectives of the target population themselves, these other perspectives may provide valid components for instrument development, but the authenticity of the conceptualization of QoL is uncertain. There is little documented evidence as to whether children and adolescents conceptualize their QoL in the same way as adults; thus qualitative data-gathering methods are essential to provide authenticity and content validity.^{12,15,16} Child and youth perspectives about their own QoL are especially important to capture the crucial physical, emotional, psychological, and social aspects of development that are highly sensitive to diverse biopsychosocial and societal factors of young people.¹⁷ Bevans et al note that PROMs developed for adults “may not capture the realities of childhood” or “be sensitive to developmental change.”⁴ Contextual variables affecting QoL in children, such as the roles of family and peer systems, are particularly important.^{10,18} Qualitative methods to develop PROMs help people understand young people's lived experience, identify children's perspectives on the phenomena to be measured and the contexts thereof, and inform item wording, format, and presentation.^{4,5}

There are many advances and guidelines, such as the ISPOR Task Force guidelines and the PROMIS initiative,^{4,19} formulated to standardize and ensure that a solid scientific foundation exists for the use of PRO assessments in pediatric clinical research. However, there is minimal reporting of the qualitative methods that have been used to engage children and adolescents during the development of PROMs.^{12,17,19,20} For future measures development, the PROMIS initiative has been developing an item bank from a large pool of items, and it consists of 6 steps: (1) item identification, (2) item classification and selection, (3) item review and revision, (4) focus group input on domain coverage, (5) cognitive interviews with individual items, and (6) final revision before field testing. Thus, although the original item pool includes items from different sources, all went through scrutiny to ensure appropriateness for children and parents.²¹

We hypothesized that children and adolescents are inconsistently included in instrument development and that the methods used are varied and variably reported. We also hypothesized that we would identify a small number of instruments that used the perspectives of children and adolescents in the development process, and a smaller number still that reported the qualitative methods used, sometimes in separate qualitative papers. Reporting these methods is useful both for those using the instruments in clinical practice or research and for those wanting to develop their own PROMs.¹²

Methods

Choice of Review Type

This article presents a scoping review of the qualitative research methodology used with children and adolescents in the development of patient-reported QoL-related measures. Arksey and O'Malley's scoping review methodology,²² modified by Levac et al,²³ guided our review. This approach highlights that one of the common reasons for undertaking a scoping review is “to examine the extent, range and nature of a research activity”²²—our exact goal regarding PROMs for children and the methods used to capture their voices. A scoping review is also useful to determine the “breadth and depth of a field” about which little is known.²³ It is particularly useful in an emerging field with significant variability in study design.²³

The first aim of this study was to identify instruments that measure various aspects of health and QoL (QoL, HRQoL, vision-related QoL [VRQoL], and oral health-related QoL [OHRQoL]) with children and adolescents as respondents. The second aim was to identify, collate, and report qualitative methods used to collect the raw material used to develop the content and items for these instruments.

The scoping review steps included: (1) identifying the research question, (2) searching for relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results (the sixth optional step of “consultation” was not pursued in this project).^{22,23} This method was appropriate because it addressed the exploratory nature of our research aims and broad research question; given that we were unsure of the number of instruments that would meet our eligibility criteria, it allowed us to revise our search and data collection strategies iteratively. Our research question was well defined at the outset, and per Levac et al's methodology, the inclusion and exclusion criteria evolved as the search progressed and as the scope of our search helped inform the data extraction process.²³ Data were reviewed with a descriptive analytical lens.²⁴

Search Strategy

The search strategy was developed based on our research question: “What are the methods used to engage children and adolescents in qualitative research, from which operational definitions and conceptualization of QoL outcome instruments are developed?” The question was designed to identify the instruments themselves, or research studies that used the instruments as outcomes measures. The original development papers, or studies that described the development of the instruments, were then identified and used to chart the methodological data. The search strategy was developed in consultation with a medical librarian as a 2-step process. First, the database search was constructed to identify original QoL-related instruments designed for use with children and adolescents. Second, 2 reviewers worked together in pairs at different stages of the study (J.D., D.Z., J.T., J.W., and G.M.R.) to assess the identified publications on the development of the eligible instruments, which were then used as the raw material for data extraction and charting.

Medline and EMBASE were searched through the Ovid interface from inception to April 2020 using both Medical Subject Headings (MeSH) related to “Quality of Life” or “Wellbeing” or “Patient Reported Outcome Measures” and “Child” or “Adolescent” or “Pediatrics” and instrument development (“Psychometrics/is, mt (instrumentation, Methods)” or exp “Reproducibility of Results” or “Self-Report” or (“Questionnaires” and exp

Reproducibility of Results”) or “Content Validity Testing” or “Concept Elicitation” or “Qualitative Research” or “Qualitative Interview” or “Focus Groups,” combined using Boolean operators. This search was supplemented with instruments identified in 2008 by Fayed et al for a systematic review of QoL/HRQoL-related instruments and hand searching of relevant reviews.^{6,7,14}

Search results were used to identify unique self-report instruments that were developed with the intent of measuring QoL or HRQoL (either exclusively or as a domain of a larger construct) in children and adolescents (usually under 18 years). We excluded econometric scales, instruments with only proxy respondents, and instruments that were developed for use in adult populations but later validated for use with children or adolescents without explicitly seeking their voices.⁷ If an instrument was a module, we included only the prototype of the instrument development and did not include any subsequent measures developed using the original methodology. The list of 445 instruments was reviewed by 2 reviewers (from among JD, DZ, J, JW, GMR), and further exclusions were made using the criteria noted above.

We used REDCap to create data charts to extract relevant information from each study: population age, condition(s) studied, conceptualization of QoL, methods used in developing the content of the instrument, and specific process information related to conducting qualitative research in a child/adolescent population.²⁵ The data chart was then used to create a numerical description of the instruments and methods as well as a descriptive analytical summary of methodological features, techniques, and themes.

Results

Our search identified 118 instruments designed to measure QoL (as conceptualized by the original authors) in children/youth by self-report, between 1993²⁶ and April 2020, all of which engaged children and youth in some way. Details of development are presented in [Tables 1](#) and [2](#).

Twenty-eight instruments did not use qualitative methods in instrument development; rather, their methods included 1 or more of literature review ($n = 14$), expert consultation ($n = 19$), art-based methods ($n = 1$), review of other instruments ($n = 3$), and conceptual models. Sixty-nine of the 118 instruments used multiple methods. Of the instruments included, 1 development paper was not in English²⁷ and we were unable to access 7 original papers.^{26,28-33} However, subsequent development and validation studies provided sufficient information to include these instruments. Eighty-eight instruments used qualitative development approaches, details of which are presented in [Tables 2](#) and [3](#). Nineteen papers, marked with an asterisk in [Table 3](#), separately reported the qualitative studies used to inform the development of the instruments themselves.^{29,34-51} These papers provided greater methodological detail.

[Table 4](#) outlines the features of focus groups, wherein the number of participants was highly variable (between 2 and 12). Several papers described the setup of the environment during focus groups, including the use of a “nonclinical environment,” “quiet cozy rooms,” and the effort to “approximate a normal social context.”^{44,47,51-54} [Table 5](#) describes interview features. Interviews were described as being “flexible,”^{41,42} “open-ended,”^{42,43,54-64} “friendly and relaxed,”¹⁵ and “free-ranging.”⁴⁴ They varied in duration from 5 to 15 to 30 minutes.

Six of the instruments that used interviews and focus groups were developed using a multistep process that combined techniques. Interviews were a starting point to develop guides for the focus group sessions,⁶⁵ or focus groups were used to develop

content for interviews.⁴⁸ Two used interviews to delve deeper into the content after the focus group process.^{66,67} Developers of the Youth Quality of Life Instrument used focus groups as a validity check for the interview results.⁴⁵ One measure used interviews for feasibility issues with the younger age groups,⁶⁸ and 3 used the techniques in parallel.^{28,54,69} Focus groups with experts were also used in conjunction with interviews with children to create interview topic guides^{46,70} and to identify missing items from interviews.^{46,71}

The majority of instruments did not include children under age 5 years in the development process. However, children as young as 3 years, 9 months were interviewed in the development of the Child Amblyopia Treatment Questionnaire.⁴⁶ Developers who used only focus groups or those that employed both interviews and focus groups generally included only children 8 years and older.

Discussion

The number of patient-reported instruments identified in this exploration of child and adolescent measures demonstrates the growing interest in PRO/QoL-related outcome measures for children and adolescents. Several themes emerged from our analysis of the methods used to develop the measures.

Methodological Variation to Obtain Child and Youth Perspectives

Recognition of the value of the direct input of the children and adolescents is apparent in the number of instrument developers who, despite significant variation in methods used, have included children’s perspectives in various ways. Loose guidelines exist for the development of QoL instruments,^{3,15,72} but only recently have researchers produced detailed methodological instructions.^{8,17,19} Few instruments used multistep iterative qualitative development; a sizeable proportion used traditional expert consultation, literature review and previous instruments, or their own semi-qualitative methods, suggesting that greater dissemination of state-of-the-art guidelines would be useful.

Several papers reported detailed instrument development methods:

- The developers of the Adolescent Quality of Life Mental Health Scale employed both interviews and focus groups,⁶⁵ beginning with interviews based on open-ended questions about their perception of QoL and concluding with perceptions of QoL from the perspective of having a diagnosis. Focus groups were then used to refine the themes from the interview stage. Data were analyzed using a grounded theory approach.
- The Vision-Related Quality of Life for Children and Young People instrument also used both interview and focus groups.⁴⁸ Along with contributions from the literature and clinical observation, a focus group with 11 children was used to establish content for the interview guide, which was then piloted with 4 children and led to the inclusion of an icebreaker activity in the interview process. Information was coded by age group and analyzed using thematic analysis.
- The developers of the Youth Quality of Life Instrument included adolescents aged 12 to 18 with and without disabilities in their 2-phase development process.⁴⁵ The first step used one-on-one semistructured interviews with participants as “expert informants”; the second involved a focus group of nondisabled youth as a validity check of the interview data. Parents/guardians and adolescent health and welfare professionals participated in focus groups, in which participants were asked to

Table 1. QoL, HRQoL, VRQoL, and OHRQoL titled instruments.

Feature	n (%)
Language	
English	99 (85%)
Non-English*	12 (10%)
Multilingual	6 (5%)
Population focus	
Generic	14 (12%)
Condition-specific	103 (88%)
Label	
QoL	43 (38%)
HRQoL	68 (60%)
OHRQoL/VRQoL	4 (3%)
Content development (could involve >1 method)	
Qualitative	88 (76%)
Literature	66 (57%)
Questionnaire	15 (13%)
Expert Consultation	56 (49%)
Technology-based	1 (1%)
Other	10 (9%)

HRQoL indicates health-related quality of life; OHRQoL, oral health-related quality of life; VRQoL, vision-related quality of life.

*Instruments that were originally published in languages other than English—but the development papers are in English.

elaborate on and add to the themes that were generated from the interviews; no new themes were added. Grounded theory was used to analyze the interview data.

- The Child Amblyopia Treatment Questionnaire used semi-structured interviews for development.⁴⁶ The topic guide for the interviews contained themes rather than specific questions, to avoid leading the children with adult perspectives. The topic guide was developed from a literature review and focus groups with clinicians. Simple personal questions were asked at the start of the interviews to develop rapport. Thematic content analysis was used to analyze the data from the interviews.
- The Cochlear Implant Quality of Life Instrument was developed in 3 stages. First, a literature review led to the development of a conceptual framework and discussion guides for focus groups with key stakeholders and interviews with children and parents. Second, open-ended interviews were completed with children ages 6 to 12 and their parents. Finally, content analysis

Table 2. Qualitative methods of development.

Qualitative details	Frequency
Qualitative method	
Interview	43
Focus group	22
Interview and focus group	14
Other*	12
Qualitative analysis	
Grounded theory	7
Content analysis	9
Thematic analysis	8
Interpretive phenomenological analysis	2
Framework analysis	1
Grounded theory and content analysis	1
Other†	4

*Other methods of qualitative collection included discussion, personal consultation, rating of item importance, and documentation.

†Other methods of qualitative analysis were nonspecific, such as “qualitative review.”

of the focus groups and interviews led to the preliminary draft instrument, which was then tested using cognitive interviews with children and parents.⁷⁰

Innovative Approaches

The majority of instruments reviewed were developed using methods traditionally employed with adults, adapted for use with children and youth, but 4 were developed using focus group sessions that incorporated novel activities to elicit information from the participants.

- The Quality of Life in Children with Epilepsy (CHEQOL-25) used environmental maps of life and play dough to describe experiences and emotions.^{36,73} Child-life specialists were involved in the design, planning, and facilitation of the focus groups.
- Another hands-on activity, used in the Hearing Environments and Quality of Life development, involved asking children to find pictures in magazines that corresponded to their feelings about certain statements.⁴⁷
- The Aboriginal Children’s Health and Well-Being Measure used a full-day focus group method that involved bike riding and a photography exercise to guide discussions about health and well-being.⁵⁹ The discussions were guided by the Medicine Wheel, a cultural framework of health.
- The Oxford Ankle Foot Questionnaire developers used 2 main activities in their focus groups: (1) participants were asked to agree or disagree with a series of preset statements, following which discussion ensued as to why someone agreed or disagreed; (2) life-mapping took place by asking children to create a day in the life of a child with ankle and foot problems, allowing the participants to express their own experiences through their created character.⁴⁴

In interviews, the SOLE Neuromuscular Disorder study⁶¹ used cartoon strips and the asthma-related QoL study⁷⁴ used “colourful pictures in an asthma education book” as guides. The Brisbane Burn Scar Impact Profile completed their semistructured interviews using the Q-sort method; participants were asked to sort 17 words or phrases into groups, based on their importance to the participant.⁶²

Arbuckle notes that props or activities such as drawing may be a fun and helpful strategy for engaging children, but they risk becoming distracting.⁸ This points to a need to explore such methods in children; there seems to be potential in engaging children in this way; however, these methods have yet to be used by many developers and are therefore untested. More exploration and analysis of innovative techniques geared directly to children may be of benefit for those developing QoL measures for children.

Qualitative Analysis

We found limited information regarding the processes by which qualitative data were analyzed; fewer than half the papers reported using a formal qualitative analytic method. Methods of qualitative analysis are well published and disseminated, so the lack of utilization may point to a lack of familiarity or comfort with these methods, a lack of recognition of the value of rigorous qualitative analysis, or feasibility and personnel issues. However, consistent and transparent reporting of qualitative methods is essential for those wishing to interpret the final output.¹² It is also notable that there are few suggestions in the literature about the specific type of qualitative analysis to use¹⁷ or the ethical implications of involving children in this type of research.

Table 3. All studies that used qualitative data collection, with method of collection and content development and method of qualitative analysis, listed by year of publication.

Measure	Year	Age group in years (unless specified)	Collection of qualitative data	Other methods of content development	Specific method of qualitative analysis	Notes
Childhood Asthma Questionnaires ²⁶	1993	8-11	-			Unable to access original paper
Adolescent Rhinoconjunctivitis QoL Questionnaire ^{*,29}	1994	12-17	Int.	Lit./Quest./Exp.		
Children's Dermatology Life Quality Index ³⁴	1995	3-16	Other			
QoL Instrument for Adolescents with Spinal Deformities ²⁷	1995	10-20	Int.			Original paper not in English
QoL Life Headache in Youth ⁹⁵	1995	12-18	Int.	Lit./Other		
Acne-specific QoL questionnaire ⁹⁶	1996	13-35	Int.	Lit.		
Pediatric Asthma QoL Questionnaire ⁹⁷	1996	7-17	Other	Exp.		Unable to access original paper
QoL Profile - Adolescent Version ⁹⁸	1996	Grades 9-13	FG	Lit./Exp.		
QoL in Children with Spina Bifida ⁹⁹	1997	5-20	Int.	Lit./Exp.		
Child QoL Questionnaire ¹⁰⁰	1997	9-15	Int.	Lit.		
Pediatric Rhinoconjunctivitis QoL Questionnaire ¹⁰¹	1998	6-12	Other	Lit./Quest./Exp.		
Pediatric Cancer QoL Inventory ^{102,103}	1998	8 to 18	Int.	Lit./Exp.		
QoL Index for Pediatric Inflammatory Bowel Disease ¹⁰⁴	1999	8-17	Int.			
QoL Measure for Children ⁸⁴	2000	5-8	FG	Lit.		
Generic Children's QoL Measure ³⁰	2000	6-14	Other			Unable to access original paper
Pediatric Epilepsy QoL Assessment ¹⁰⁵	2000	3 mo to 18 y	Other			
TedQL ¹⁰⁶	2001	3-8	Other	Lit./Exp		
Adolescent Asthma QoL Questionnaire ²⁸	2001	12-17	FG/Int.	Lit./Exp.		
Impact Inflammatory Bowel Disease ⁷⁸	2002	8-17	Int.	Lit./Exp.		
Youth QoL Instrument ^{*,45,107}	2002	12-18	FG/Int.		Grounded theory	
Minneapolis-Manchester QoL-Adolescent Form ⁶⁶	2002	13-20	FG/Int.			
Cystic Fibrosis Questionnaire ¹⁰⁸	2003	8-13, 14+	Int.			
HRQoL in Children with Epilepsy ^{*,36,73}	2003	6-15	FG		Thematic analysis	
ITP-Child QoL Questionnaire ³¹	2003	1-17	Int.	Lit.		Unable to access original paper
Pediatric Allergic Disease HRQoL Questionnaire ¹⁰⁹	2003	6-16	Other			
Simple Measure of Impact of Lupus Erythematosus in Youngsters ^{*,49}	2004	Under 21	Other		Grounded theory	
ADDQoL-Teen ⁶⁹	2004	Teens	FG/Int.	Lit./Exp./Other		Unable to access original paper
Canadian Hemophilia Outcomes - Kids Life Assessment Tool ⁸⁵	2004	5-18	FG	Lit./Other	Content analysis	
Minneapolis-Manchester QoL-Youth Form ⁶⁷	2004	8-12	FG/Int.	Exp.		
DISABKIDS ⁶⁸	2005	8-12, 13-16	FG/Int.			

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Table 3. Continued

Measure	Year	Age group in years (unless specified)	Collection of qualitative data	Other methods of content development	Specific method of qualitative analysis	Notes
Pediatric Functional Assessment of Cancer Therapy - Childhood Brain Tumor Survivor ⁷⁹	2005	7-11	Int.			
Asthma-related QoL Scale ⁷⁴	2005	6-12	Int.		Content analysis	
Cerebral Palsy QoL Child ^{*,40,110}	2005	Parents and children 9-12	Int.		Grounded theory	
Brace Questionnaire ¹¹¹	2006	9-18	Int.	Exp.		
Congenital Cardiac Disease QoL ³²	2006	8-11;12-18	Int.			Unable to access original paper
The Acne QoL Index ⁷⁶	2006	12-62	FG		Other	
Idiopathic Thrombocytopenic Purpura-QoL ⁸⁹	2006	3-7; 8-18	FG	Lit./Quest.		
KIDSCREEN ^{*,51,112}	2006	8-9; 12-13; 16-17	FG		Grounded theory	
Eating Disorders QoL Scale ¹¹³	2007	14-60	Int.	Lit.	Content analysis	
QoL in Children with Vernal Keratoconjunctivitis ¹¹⁴	2007	5-12	Int.	Lit./Exp.		
The Gap Study ¹¹⁵	2007	6-17; parents	Int.	Lit./Exp.		
The Oxford ankle foot questionnaire ^{*,44,83}	2007	5-7, 8-11, 12-15	FG		Grounded theory Content analysis	
Celiac Disease DUX ⁵²	2008	8-18	FG		Other	
Food Allergy QoL Teenager Form ¹¹⁶	2008	13-17	Int.	Lit./Exp.		
Glasgow Epilepsy Outcome Scale for Young Persons ^{*,37,75}	2008	10-18	FG	Lit.	Thematic analysis	
Hearing Environments and Reflections on QoL (Hear-QoL) ^{*,47,117}	2008	7-17	FG		Content analysis	
Impact of Vision Impairment for Children ^{*,35,118}	2008	8-18 instrument; 11-17 development	FG	Exp.	Grounded theory	
Pediatric Cardiac QoL Inventory ¹¹⁹	2008	8-18	Other	Exp.		
Food Allergy QoL Child Form ¹²⁰	2009	8-12	Int.	Lit./Exp.		
QoL in School ¹²¹	2009	Grades 3-6	Int.	Lit.		
QoL Evaluation in Epidermolysis Bullosa ⁸⁰	2009	All ages	Int.	Lit/Expert		
Intermittent Exotropia Questionnaire ^{*,34,122}	2010	5-17 (2-17 for proxy)	Int.			
Pediatric Rheumatology Quality of Life Scale ¹²³	2010	7-18	Int.	Lit./Exp.		
KID-CLOT ¹²⁴	2010	1-18	FG	Lit/Quest		
Akram QoL in patients with hypodontia ⁵³	2011	11-18	FG		Thematic analysis	
Pediatric GERD Symptom and QoL Questionnaire ⁹⁰	2011	9-17	FG	Lit./Exp.		
Effects of Youngsters Eyesight on Quality of Life ¹²⁵	2011	8-18	Int.	Lit./Exp.		
Vision-related QoL for Children and Young People ^{*,48,126}	2011	10-15	FG	Lit./Exp.	Thematic analysis	
Adolescent QoL -Mental Health Scale ⁶⁵	2012	12-18	FG/Int.		Content analysis	
CP QoL-Teen ^{*,38,77}	2012	13-18	Int.		Grounded theory	

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Table 3. Continued

Measure	Year	Age group in years (unless specified)	Collection of qualitative data	Other methods of content development	Specific method of qualitative analysis	Notes
Congenital Aural Atresia Questionnaire ¹²⁷	2012	6-18	Int.	Exp.		
You and Your Food Allergy ^{*,39,128}	2012	13-18	Int.	Lit.		
Satisfaction in Life for Children with Own Report Measures ³³	2012	3-11	Other		Interpretive phenomenological analysis	Unable to access original paper
Velo-pharyngeal Insufficiency QoL ⁸⁷	2012	5-17; parents	FG			
Pediatric Neuro QoL ^{*,50,129}	2012	10-17	FG	Lit./Exp./Other	Grounded theory	
Celiac Disease-Specific Pediatric HRQoL Instrument ¹³⁰	2013	8-12; 13-18	FG	Lit./Exp.		
QoL in Short Stature Youth ⁵⁷	2013	8-18	FG		Content analysis	
Children's Vision for Living Scale ⁵⁸	2013	5012	Int.	Lit./Exp.	Thematic analysis	
Child Amblyopia Treatment Questionnaire ^{*,46,131}	2013	4-7	Int/FG	Lit./Exp.	Thematic analysis	
Aboriginal Children's Health and Well-Being Measure ⁵⁹	2013	8-18	FG	Quest./Exp./Other		
The Impact of Hearing Loss on Children ⁵⁴	2014	8-18	FG/Int./Other	Lit.		
Pediatric Liver Transplantation QoL ⁶⁰	2014	0 to 18	Int./FG	Lit./Other		
SOLE Questionnaire for NMDs ⁶¹	2014	5 to 13	Int.	Lit./Exp.		
Brisbane Burn Scar Impact Profile ⁶²	2015	8-18	Int.	Lit./Quest.	Content analysis	
Spina Bifida Pediatric Questionnaire (SBPQ) ⁶³	2016	6-18	Int.	Other		
QoL Assessment in Spina Bifida for Children ⁶⁴	2016	8 to 12	Int.	Quest./Exp.		
QoL Evaluation in ALL Patients Receiving Steroids ¹³²	2016	8-24	Int./FG	Lit./Quest./Exp.	Interpretive Phenomenological Analysis	
Malocclusion Impact Questionnaire ^{*,42,55}	2016	10-16	Int.	Lit.	Framework analysis	
Craniofacial Conditions p-PROM ¹³³	2017	0-18+	Int.	Lit./Exp.	Content analysis	
QoL in Children and Adolescents with Esophageal Atresia ^{41,134}	2017	2 to 7 8 to 17	FG	Lit.		
Pancreatic Exocrine Insufficiency Questionnaire ⁸¹	2017	All ages	Int.	Lit./Exp.	Thematic analysis	
CLEFT-Q ^{71,135}	2017	6-29	Int/FG	Lit./Exp.	Other	
FACE-Q ⁸²	2017	>8	Int.	Lit./Quest./Exp.	Other	
CHILD-QoL for pediatric patients with interstitial lung disease ⁸⁸	2018	8-18	FG	Lit.		
Ear and hearing-related impact on QoL ¹³⁶	2019	6-18	Int.	Lit./Quest./Expert		
PedEye Q ^{*,43,56}	2019	0-18	Lit./Quest	Int		
Cochlear Implant-QoL ⁷⁰	2019	6-12	Int/FG	Lit	Content analysis	
Type 1 Diabetes and Life: T1DAL ¹³⁷	2020	8-17	Int.	Lit./Quest.	Thematic analysis	

ADDQoL-Teen indicates audit of diabetes dependent QoL in teens; CHILD, children's interstitial lung disease; CLEFT-Q, PRO instrument for children and young adults with cleft lip and/or palate; CP, cerebral palsy; DISABKIDS, disease specific HRQoL instruments in children and adolescents with various chronic conditions; FACE, Face aesthetics questionnaires; FG, focus group; GERD, gastroesophageal reflux disease; HRQoL, health-related quality of life; Int., interview; ITP, idiopathic thrombocytopenic purpura; KID-CLOT, QoL inventory for anticoagulated children; KIDSCREEN, HRQoL screening instrument for children and adolescents; Lit., literature review; Exp., expert opinion; NMD, neuromuscular disorders; PROM, patient-reported outcome measure; QoL, quality of life; SOLE, Strips Of Life with Emoticons.

*Specifically qualitative paper.

Table 4. Focus group features and techniques.

Focus group features/techniques	Frequency of mention
Structure	
Semistructured/open-ended/guided discussion	16
Unstructured/free discussion	2
Moderator	
Trained/experienced	7
Researcher/clinician	5
Social worker/Psychologist	2
Child life	1
Participants	
Children alone	8
Parents present	3
Stratification	
By age	9
By sex	5
By disease severity, stage, or diagnosis	4
Features	
1-2 hours in duration	7
Ice breaker/warm-up used	6
Break/refreshments	6
Innovative approaches	
Environmental mapping	2
Toys (eg, puppets, play dough)	1
Pictures*	3
Bike ride	1
Mind maps	1
Flipcharts	1

*Includes pictures taken by participants or selected by participants.

Developmental Considerations

Conceptualization of the theoretical construct of QoL is likely to vary with age and life experience, so it is necessary to ensure accurate measurement over the developmental trajectory.¹¹ This is particularly relevant if the intent is to measure change over time, independent of the effect of aging. There were many innovative approaches to developmental issues. Although the literature suggests that the lower age limit for child interviews is 6 years, our review found that children over 8 were usually targeted, but occasionally those as young as 3 were included.^{8,46} Children in focus groups were generally older, because younger children may be less able to stay on task effectively.

Of the 22 instruments that were developed using only focus groups, authors most commonly chose to stratify participants according to age.^{36,44,51,52,57,59,68,75,76} Feasibility, sample size requirements, personnel issues, and lack of awareness of the substantial differences in comprehension, conceptualization, and individual developmental differences may influence the decision whether to stratify participants by age. The DISABKIDS development paper reports using different methods based on the age group, including interviews in the youngest age group, where focus groups were deemed to be not useful.⁶⁸ However, in general, methods were not varied based on age.

Multiple instruments used sex-stratified focus groups that, with the sensitive nature of some of the subject matter, may help eliminate social pressures experienced by some children and adolescents.^{51,52,54,59,69} The Glasgow Epilepsy Outcome Scale focus groups provided an opportunity for participants to write down

Table 5. Interview features and techniques.

Interview features/techniques	Frequency of mention
Structure	
Unstructured	4
Semistructured	25
Structured	3
Interview guide	9
Open-ended	20
Location	
Home	4
Clinic/hospital	4
Option of location	7
Telephone	2
Nonclinical environment	1
Interviewer	
Trained	6
Psychologist	3
Researchers	8
Clinician/social worker/nurse specialist	4
Experienced qualitative interviewer	2
Participants	
Child alone	8
Parent present	11
Option for parent present	2
Chaperone	1

any sensitive information that they did not want to share with the whole group.³⁷ This approach could be particularly helpful in focus groups related to specific conditions with sensitive or potentially embarrassing aspects (such as loss of bowel or bladder control).

Specific developmental considerations of various target populations were addressed in several ways. For example, the CP-QoL Teen recognizes that not all children and youth with cerebral palsy may be able to participate in the qualitative research methods, so the decision as to whether their individual child ought to participate was left to families.⁷⁷

Role of Environmental Factors

The length and setting of focus groups appear to have been structured with the needs of children and adolescents in mind. Numerous authors engaged in a nonclinical setting, a “warm and cozy environment,” using an icebreaker or warm-up activities, and breaks with refreshments.^{36,44,47,48,51,53,54,59,75} In some circumstances, children were interviewed, or given the option to be interviewed, in their own homes.^{38-40,42,78-82} These approaches point to the need for participants to be as comfortable and secure as possible in order to engage openly in this process, and they identify the importance that environment, familiarity, rest, and nourishment play in ensuring this. The time limit suggested by Arbuckle et al (2013) is 45 minutes,⁸ but most focus groups reported durations of 1 to 2 hours.^{35,47,54,75,83-85} Given the desire to maximize data collection opportunities and minimize the administrative difficulties (eg, multiple sessions), limiting a focus group to 45 minutes might be difficult; on the other hand, exceeding the suggested time limit might create an emotional burden and so must be carefully considered.

Parents

Varying approaches to parents were reported in the qualitative components of item development. Parents have been shown to

rate their children's QoL differently than the children do, and the literature suggests that parents may influence their children to give responses that the parents perceive.^{8,86} Only 3 studies used focus groups including both parents and children.^{60,87,88} More commonly, developers used individual parent focus groups for additional material, a step that might provide useful insights with regard to behavioral or observable factors.^{41,45,47,52,54,89,90}

Parental involvement was encompassed in many ways in the interview processes: some included parents throughout; some separated children and parents; and some participants had the option to have their parents present.^{34,71} During the international multicenter development of the CLEFT-Q, children were offered the opportunity to have their parents present. It was thought that children would be more at ease if their parent was present when being interviewed by someone who was foreign to the country.⁷¹ Inclusion of parents in the interview process poses an interesting dilemma: instrument developers want the views of children and adolescents unfiltered by the presence of parents; however, parents may offer useful perspectives, and their information about signs, symptoms and behaviors may be particularly relevant. One interesting technique is to interview parents and children separately and then bring them together to discuss discrepancies or dissimilar perceptions.⁸ Asking parents, in advance and out of earshot of the child, about words the child uses for their condition, will make it easier to communicate with a child.¹⁷

Limitations

This scoping review presented several challenges. First, scoping review methodology is still in its early development and lacks, among other things, the ability to evaluate adequately the quality of the identified papers of interest,⁹¹ thus limiting us to reporting major findings in tabular form. Second, because we were interested in the ways in which instrument developers engaged their child/adolescent stakeholders in the creation of the domains and items of these PRO constructs—whatever content researchers meant—we chose not to analyze the concepts and definitions of any of the constructs employed by the instrument developers. Our summary of the qualitative methods used was limited by the extent to which they were reported by the authors. Finally, we did not attempt a systematic review of all QoL PROMs, and the reader may therefore not find many PROMs, even commonly used ones, because the source of the items was not explicitly established and described as coming from the pediatric population of interest.

Conclusions

We were encouraged by the number of instruments that included children's perspectives in their development process. However, the degree and nature of inclusion, and the methods used, were highly variable. In general, the reporting of qualitative methods and data analysis by instrument developers remains limited. Improved guidelines on this issue, and the expectations of editors and reviewers, would allow individuals planning to use these instruments more effectively and accurately to establish content validity, developmental appropriateness, and trustworthiness. Better dissemination and uptake of instrument development guidelines would be useful to encourage the inclusion of children and adolescents in a constructive and ethical development process and to establish methodologic consistency and improve the quality of the measures created.^{92,93} We hope that this information will inform and inspire those interested in using or developing similar instruments to engage children's unique voices in the development process; these perspectives and finding may also serve as the foundation to evaluate existing QoL-related

PROs for children and adolescents beyond the important and commonly reviewed psychometric evaluations.

Future Directions

Future directions include an evaluation of the quality of the instruments identified, subgroup analysis, and how the inclusion of children and adolescents in content development affected the ultimate concepts of QoL. We would also like to assess further the innovative approaches to child and youth engagement in instrument development to assess their value in these settings.

Supplemental Material

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