

Paediatric quality of life instruments: a review of the impact of the conceptual framework on outcomes

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With an increasing number of paediatric quality of life (QOL) instruments being developed, it is becoming difficult for researchers and clinicians to select the most appropriate instrument. Reviews of QOL instruments tend to report only basic properties of the instruments such as domains and psychometric properties. This paper seeks to appraise critically the conceptual underpinnings of paediatric QOL instruments. A systematic review was conducted to identify QOL instruments for children aged 0 to 12 years, and to examine and compare their conceptual frameworks, definitions employed, and structure. Both generic and condition-specific measures were reviewed. Fourteen generic and 25 condition-specific QOL instruments were identified. Eleven types of definition of QOL and health-related QOL and three theories of QOL were identified. QOL was measured by a variety of domains including emotional, social and physical health, and well-being. Items commonly assessed difficulties, or intensity/frequency of feelings/symptoms, in contrast to positive aspects of life and happiness. The findings highlight the diversity that is apparent in the conceptualization of paediatric QOL and draw attention to the lack of empirical evidence for many of the fundamental assumptions. The impact of the conceptual underpinnings of the instruments on the resulting QOL scores is discussed.

Traditional outcome measures used in medicine, especially survival or reduction of symptoms, do not capture the whole range of ways in which a patient may be affected by illness or treatment.^{1,2} The inclusion of more holistic outcomes, such as measures of quality of life (QOL) and health-related quality of life (HRQOL), is gaining increasing interest. QOL is generally conceptualized as a broad assessment of well-being across various domains,³ and HRQOL is considered to be a subdomain of the more global construct of QOL.^{4,5}

The paediatric QOL literature includes both generic and condition-specific instruments. Generic instruments are designed to be applicable to all population subgroups and are useful for comparing outcomes between them.³ Condition-specific instruments are designed to be applicable to one group (i.e. individuals with a specific illness), and are useful in detecting outcomes arising from changes in this condition or factors associated with it.³

Many paediatric QOL instruments have now been developed and several reviews have been published.^{1,6-13} These reviews have assembled basic attributes of those available (i.e. number of items, the domains, country of origin, reliability, validity, age range, and respondents). Although this information is useful, it is an incomplete basis on which to make a judgement about the utility of a particular scale for a given application. It is argued that if an instrument is to be useful it

must have readily identifiable and conceptually strong underpinnings. The conceptual background is particularly important in the area of QOL given that there are such distinct and widely varying perspectives on QOL.

It is possible that an instrument can have good psychometric properties yet poor conceptual underpinnings. Although an instrument may report adequate construct validity, there is no criterion standard against which to measure QOL. A QOL instrument may correlate well with a health or functioning instrument; however, given that they are conceptually different constructs to QOL, it does not provide evidence that an instrument is measuring QOL.

It is a critical assertion of this review that, to be conceptually strong, any measure of QOL must also have the following characteristics: (1) it must rest on a clear, operationalized definition of QOL; (2) it must be based on a theory of QOL; (3) it must include the important domains of life for children; and (4) it must have well-constructed items. The definition of QOL can have major implications for the type of items that are used in an instrument and can, therefore, substantially affect the results recorded. The theoretical framework that underlies a QOL instrument is also important because it speaks of the process by which children reflect on and give voice to their QOL and may well suggest the process by which QOL could be enhanced. The domains that are included as representing QOL clearly affect the scoring and interpretation of results. The wording of the items directly affects the responses given by parents and children.

Despite the importance of the conceptual underpinnings of an instrument, only three reviews consider the theoretical basis of paediatric QOL instruments.^{7,9,11} Two of them^{9,11} consider only definitions of QOL rather than theoretical models of QOL, and none appraise the conceptual underpinnings of instruments. This paper seeks to conduct a systematic review to evaluate the range of definitions, theories, domains, and items that are used, and to develop recommendations for future instrument refinement and development. These issues are critical for researchers developing new paediatric QOL instruments and for clinicians and researchers interpreting the results of paediatric QOL scores.

Method

A systematic review was conducted to identify paediatric condition-specific and generic QOL and HRQOL instruments for children aged 0 to 12 years. This age range was chosen to focus on the QOL issues affecting children. New issues are expected to emerge during adolescence (13–18y of age). This review employed a search strategy of the published literature on the Medline and PsychLit electronic databases to identify papers published between 1990 and 2004, using the terms 'children' and 'quality of life' (encompassing health-related quality of life) or 'QOL' or 'HRQOL' as keywords. With this strategy, 332 abstracts were identified. The abstracts were reviewed to identify QOL/HRQOL instruments. The title of each instrument was then entered into Medline and PsychLit to obtain further articles about its construction and psychometric properties. The inclusion criteria were instruments that were specifically designed to measure paediatric QOL or HRQOL. Instruments that were used to measure QOL or HRQOL but were actually designed to measure health status or functioning were excluded (such as the Child Health Questionnaire,^{14,15} the Child Health and Illness Profile¹⁶ and the Warwick Child Health and

Morbidity Profile¹⁷), as well as those designed to assess caregiver difficulties.¹⁸ Health status, functioning, and caregiver difficulties are theoretically different from QOL and the conceptual background of these instruments is expected to be different from QOL instruments.

The instruments were reviewed to obtain the underlying definition of QOL/HRQOL, the theory, domains, and items. All the theories of QOL that were used in developing the instruments were recorded. Given the large number of definitions, domains, and items, they were categorized into themes by two of the authors (EW, ED). Agreement on key themes was achieved by discussion. Psychometric studies conducted on the instrument were examined to determine whether reliability and validity had been tested.

Results

Table I shows the 14 generic and 25 condition-specific instruments identified (a full reference list is given at <http://www.deakin.edu.au/hbs/chase/publichealth.php>). Condition-specific instruments were identified for a range of illnesses including asthma, cancer, and spina bifida. Overall, the reliability and validity of most of the instruments have been tested.

DEFINITIONS OF QOL AND HRQOL

The definitions of QOL and HRQOL on which these paediatric QOL instruments were based were varied and distinct. QOL was defined as position in life, functioning, feelings about functioning, existence, and discrepancy between actual and ideal self (Table II). HRQOL was defined as functioning, feelings about functioning, health, and value assigned to duration of life. Perhaps as a result of the varied definitions, it was not uncommon for some researchers to neglect to provide any definition of the construct measured by their instruments.^{19–24}

THEORIES OF PAEDIATRIC QOL/HRQOL

Of the 38 QOL instruments that were reviewed, only three were based on an explicit theory of QOL. These were the Exqol²⁵ (discrepancy theory), the Health Utilities Index²⁶ (utility theory), and the Nordic QOL Questionnaire²⁷ (Lindstrom's model of QOL). The discrepancy theory proposes that poorer QOL is the result of discrepancies between an individual's actual and ideal self ('like me' and 'how I would like to be').²⁵ The utility model assigns values to different health states based on judgements by experts or lay people (people without professional or specialized knowledge; the general population). These values usually lie between zero (equivalent to death) and one (perfect health). Finally, the QOL model developed by Lindstrom considers four spheres of human existence: global (ecological, societal, and political resources), external (social and economic resources), interpersonal (social relationships and supports), and personal (physical, mental, and spiritual aspects of the individual).²⁸

DOMAINS OF QOL

The most common domains of QOL are those that refer to emotions ($n=27$), social interactions medical/treatment ($n=9$), cognition ($n=9$), activities ($n=6$), school ($n=6$), family ($n=4$), independence/autonomy ($n=4$), pain ($n=4$), behaviour ($n=3$), future ($n=3$), leisure ($n=3$), and body image ($n=3$). Domains that were only included in one instrument were vocation, environment, caregiver concerns, coping, self-esteem, sleep, and bullying.

ITEMS

The items in the instruments referred to problems or difficulties, intensity of feelings, frequency of feelings, or comparisons between ideal self/other children. Instruments that examine problems include items such as ‘how much of a problem have you had with...?’,²⁹ ‘have you had any difficulty...?’,^{30,31} and ‘how much were you bothered by...?’^{32,33} Instruments that assess intensity of feelings examine feelings of satisfaction and being upset.^{34,35} Instruments that examine frequency of feelings include items such as ‘how itchy, scratchy, sore or painful has your skin been’ (‘not at all’ to ‘very much’)²³ and ‘have you felt...’ (‘never’ to ‘always’).³⁶ Finally, instruments that examine comparisons between actual self and ideal self include items such as ‘how much are you like...?’ and ‘how much do you want to be like...?’^{25,37}

Discussion

This review provides, for the first time in the published literature, an assessment and analysis of the major conceptual underpinnings of paediatric QOL instruments. The review highlights

the large number of paediatric QOL instruments in some medical fields, such as cancer, epilepsy, and asthma, and the apparent lack of instruments in other fields such as cerebral palsy (CP) and autism. New instruments may emerge; for example, a new international instrument to measure the QOL of children with CP is currently being developed.^{38,39} To assist clinicians and researchers in evaluating paediatric QOL instruments and in developing new instruments, the various definitions, domains, and theories of QOL are discussed.

DEFINITIONS OF QOL AND HRQOL

This review demonstrates that QOL and HRQOL are commonly cited as functioning and health status. Although functional status, health, and QOL/HRQOL are related, they are not interchangeable.⁴⁰ Functional status is defined as ‘a child’s ability to perform daily activities that are essential to meet his or her basic needs, fulfil roles, and maintain health and well-being’.⁴⁰ Functional status refers to what a child can do, whereas QOL refers to how a child feels. There is no evidence to suggest that a child’s perception of his or her life

Table I: Generic and condition-specific quality of life (QOL) and health-related quality of life (HRQOL) scales included in review

<i>Instrument type</i>	<i>Instrument name</i>	<i>Domains</i>	<i>Total number of items</i>	<i>Has reliability/ validity been tested?</i>
Generic	AUQUEI ³⁴	Family life, social life, children’s activities (school and leisure), health	3–5y, 26; 6–11y, 33	Yes ⁴⁷
	Child QOL Questionnaire ³⁵	Getting about and using hands, school, out of school activities, family, bodily symptom discomfort, worries, depression, seeing, communication, eating, sleep, appearance	15 questions, each with 3 parts	Yes ³⁵
	Exeter QOL Measure ²⁵	Symptoms in a social context	12, each rated twice	Yes ²⁵
	Generic Children’s QOL measure ^{37,48}	General affect, peer relationships, attainments, relationships with parents, general satisfaction	25, rated twice	Yes ³⁷
	Health Utilities Index-Mark 2 and 3 ⁴⁹	Sensation, mobility, emotion, cognition, self-care, pain, fertility	15	Yes ⁵⁰
	How Are You? ⁵¹	Functioning: physical, social, cognitive, physical complaints, happiness	32	Yes ⁵¹
	Infant Toddler QOL Questionnaire ⁵²	Infant concepts: physical abilities, growth and development, bodily pain/discomfort, temperament and mood, general behaviour perceptions, getting along with others, health perceptions, change in health. Parent concepts: impact-emotional and time, mental health, general health, and family cohesion	103	Yes ⁵²
	KIDSCREEN ^{36,53}	Physical well-being, psychological well-being, moods and emotions, self-perceptions, autonomy, parent relations and home life, peers and social support, school environment, bullying, financial support	10, 27, or 52 item versions	Yes ⁵³
	KINDL ^{54,55}	Psychological well-being, social relationships, physical functioning, everyday life activities	24 plus disease-specific module; 12-item short form	Yes ^{54,55}
	Nordic QOL Questionnaire ²⁷	Global, external, interpersonal, and personal: objective and subjective	25	No
	PedsQL ²⁹	Functioning: physical, social, emotional, school	23	Yes ⁵⁶
	Quality of life Questionnaire for Children ⁴⁴	Functioning: physical, psychological, and social	118	Yes ⁴⁴
	TNO-AZL TACQOL ³⁰	Pain and symptoms, functioning: social, motor, autonomy, cognitive, global emotional (negative and positive)	56	Yes ^{57,58}
	TAPQOL ³¹	Pain and symptoms, functioning: social, motor, autonomy, cognitive, global emotional (negative and positive)	43	Yes ⁵⁹

continued...

Table I: continued

<i>Instrument type</i>	<i>Instrument name</i>	<i>Domains</i>	<i>Total number of items</i>	<i>Has reliability/ validity been tested?</i>
Condition-specific				
Arthritis	Juvenile Arthritis Quality of life Questionnaire ⁶⁰	Motor function: gross, fine; psychosocial function, general symptoms	74	Yes ⁶⁰
Asthma	Childhood Asthma Questionnaire ^{61,62}	Quality of living subscale, symptoms and feelings about illness, distress, severity	4–7y, 14; 8–11y, 23; 12–16y, 16	Yes ⁶²
Asthma	Pediatric Asthma QOL Questionnaire ^{33,63}	Symptoms, emotional function, activity limitation	23	Yes ³³
Asthma	About My Asthma Questionnaire ¹⁹	Number, intensity and type of stressors	44	Yes ¹⁹
ADHD	AIM-ADHD ⁶⁴	Child scale (well-being) and home scale (influence on the overall family and/or parent/s)	Child scale, 8; home scale, 10; descriptor items, 9	Yes ⁶⁴
Cancer	Pediatric Cancer QOL Inventory-32 ⁶⁵	Disease and related symptoms; functioning: physical, psychological, social, and cognitive	32	Yes ⁶⁶
Cancer	Miami Pediatric QOL Questionnaire ²⁰	Competence: social and self, emotional stability	56	Yes ²⁰
Cancer	Perception of Illness Experience ⁶⁷	Functioning: physical and psychological	34	Yes ^{67,68}
Cancer	Paediatric Oncology QOL Scale ^{24,69}	Physical functioning, emotional distress, externalizing behaviour	21	Yes ^{24,69}
Cancer	Behavioural, Affective and Somatic Experiences Scale ⁷⁰	Somatic distress, compliance, mood disturbance, quality of interactions, activity	Parent report, 30; nurse's report, 38; child report, 14	Yes ^{70,71}
Cancer	Quality of Life in Childhood Cancer ⁷²	Physical, psychological, social, and cognitive functioning, treatment/disease related symptoms	34	Yes ^{72,73}
Crohn's disease	Quality of Life in Children with Crohn's Disease ⁷⁴	Disease and treatment, social, emotional, family, education, future aspects	88	No
Cystic fibrosis	Cystic Fibrosis Questionnaire ⁷⁵	Physical symptoms, emotional functioning, social functioning, body image, eating disturbances, treatment burden, respiratory, and digestive symptoms	Child report, 33; parent report, 43	Yes ⁷⁶
Epilepsy	Epilepsy QOL Questionnaire ⁷⁷	Interpersonal/social, future worries, present worries, intrapersonal/emotional, secrecy	25	Yes ⁷⁸
Epilepsy	Impact of Childhood Illness Scale ⁷⁹	Treatment impact on: child, parents, family; cumulative impact	30	Yes for validity ⁷⁹
Epilepsy	QOL Childhood Epilepsy Questionnaire ⁸⁰	Function: physical, social; emotional well-being, cognition, and behaviour	77	Yes ⁸⁰
Epilepsy	Quality of Life in Children Epilepsy-89 ⁸¹	Self-concept, home life, school life, social activities, and medication issues	25	No
Haemophilia	Haemo-Qol Questionnaire ^{21,82}	Physical health, feeling, attitude, family friends, other people, sport and school, coping, treatment, future, relationships	Long version for children and parents (21–77 items, depending on age of child); short version 8–18y for parents and children, 35	Yes ⁸²
Inflammatory bowel disease	IMPACT ⁸³	Concerns: bowel, body image, functional/social impairment, emotional impairment, tests/treatments, and systemic impairment	33	Yes ⁸³
Inflammatory bowel disorder	QOL index for Pediatric Inflammatory Bowel Disease ⁸⁴	Treatment, body image, emotional, bowel, functional/social, systemic	32	No
Otitis media	QOL of Children with Otitis Media ⁸⁵	Physical suffering, hearing loss, speech impairment, emotional distress, activity limitations, caregiver concerns	6	Yes ⁸⁵

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necessarily corresponds with the ability to perform various tasks/activities. It is possible that some children may have poor functioning yet have a high HRQOL/QOL if they have adapted to their current health state or if they have not experienced a healthier state.⁴¹

Health status 'concerns a child's level of wellness versus illness, including the presence of biological/physiologic dys-

function symptoms and/or the level of illness control'.⁴⁰ One way of distinguishing QOL/HRQOL and health status is to consider whether they measure well-being or ill-being. It has recently been proposed in the adult QOL literature that QOL instruments should assess only well-being. Domains that assess ill-being should not be included in QOL instruments because the optimal functioning of these domains can have

Table I: continued

<i>Instrument type</i>	<i>Instrument name</i>	<i>Domains</i>	<i>Total number of items</i>	<i>Has reliability/ validity been tested?</i>
Rhino conjunctivitis	Pediatric Rhinoconjunctivitis QOL Questionnaire ³²	Symptoms: nose, eye, other; practical problems, activity limitations	23	Yes ³²
Short stature	QOL of Short Stature Children ²²	Academic, self-esteem, leisure, relationships	45	No
Skin disease	Children's Dermatology Life Quality Index ²³	Symptoms and feelings, leisure, school or holidays, personal relationships, sleep, treatment	10	Yes for reliability ²³
Spina bifida	Spina Bifida HRQOL Scale ⁸⁶	Social, emotional, intellectual, financial, medical, independence, environmental, physical, recreational, vocational	Child report, 47; adolescent report, 50	Yes ⁸⁶

AUQUEI, Pictures Child's Quality of Life Self Questionnaire (Autoquestionnaire de qualité de vie enfant imagé); TNO-AZL TACQOL, Netherlands Organization for Applied Scientific Research Academic Medical Centre, Children's Quality of Life measure; TAPQOL, Preschool Children's Quality of Life measure; AIM-ADHD, attention-deficit-hyperactivity disorder impact module - child.

Table II: Definitions of quality of life (QOL) and health-related quality of life (HRQOL)

<i>Type of definition</i>	<i>Example of definition</i>
QOL is...	
Position in life	'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' ^{35,87}
Functioning	'Multidimensional, including aspects such as physical function, psychological state, social interaction, and somatic sensation, or cognitive, social, physical, and emotional functioning' ^{61,88,89}
Functioning and feelings about functioning	'The child's perception and evaluation of performance in relevant life areas and its feeling related to problems in functioning' ⁵¹
Existence, measured objectively or subjectively	'The total existence of an individual, a group or a society describing the essence of existence as measured objectively and perceived subjectively by the individual or group or society' ⁹⁰ 'Should take into account subjective as well as objective perceptions of the circumstances of life' ⁷⁴
The discrepancy between actual and ideal self	'QOL in people with epilepsy is an individual's perceptions of the impact of their condition and its treatment. It reflects the discrepancy between the person's actual and desired physical and psychological health, level of independence, and social relationships' ^{81,91}
HRQOL is...	
Functioning	'Includes physical functioning, and emotional, social, and role functioning' ⁵⁶ 'A multidimensional construct including three broad domains i.e. the physical, psychological, and social functioning domains' ^{43,44}
Functioning and feelings associated with functioning	'Usually defined as an individual's subjective assessment of quality of functioning and associated satisfaction or distress' ³⁵
Functioning and well-being	'A multidimensional construct covering physical, emotional, mental, social, and behavioural components of well-being and function as perceived by the patients and/or individual feelings associated with health' ³⁶
Health and feelings about health	'The combination of health status and affective responses to problems in health status' ^{30,31,85}
A component of health	'A component of overall QOL that is determined primarily by the person's health, and which can be influenced by clinical interventions' ^{19,63}
Value assigned to duration of life	'The value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy' ^{50,92}

only a neutral effect on QOL, not a positive effect.⁴² For example, if a child has no pain or symptoms, this should have a neutral effect on QOL, not a positive effect. In contrast, it is appropriate and necessary for measures of health status to assess well-being and ill-being (e.g. symptoms). Although this method of conceptualization requires empirical testing, it is the first attempt at distinguishing between these concepts. It is recommended that researchers do not use the terms QOL, HRQOL, health status, and functioning interchangeably.

THEORIES OF QOL

Three theories of QOL were identified, including the discrepancy theory, the utility theory, and Lindstrom's model of QOL. The utility theory is useful for examining cost effectiveness for adults; however, it may not be useful for children because children have difficulty in understanding and formulating preferences between quality and quantity of life,⁴³ and perhaps as a consequence it is rarely used in paediatric studies of QOL.⁴⁴ Lindstrom's model of QOL is unique because it considers both the micro and macro aspects of QOL and is applicable for all children. However, the QOL Index for Nordic Countries has few subjective items, does not have a child self-report version, and omits several important domains, such as child physical well-being, social well-being, and emotional well-being.⁴⁵ Finally, although the discrepancy theory has some empirical support,²⁵ it is not particularly useful in providing directions for interventions to increase QOL. The theory essentially proposes that children have a low QOL because they want to be different from how they are. However, it is somewhat obvious that if children have a low QOL, they are not happy with themselves. Researchers need to know which factors determine whether a child is happy with themselves.

Given that only three theories of QOL were identified in this review, it is recommended that paediatric QOL research invests time into theory development and evaluation. A paediatric theory of QOL needs to be developed and rigorously evaluated across cultures and countries. In the absence of an appropriate theory, and given the time required to develop new theories, in the short term it is recommended that researchers invest greater time and effort in domain and item selection.

DOMAINS AND ITEMS OF QOL/HRQOL

The major concern with the domains and items that were identified in this review is that some of them may have only a neutral effect on QOL. Domains that assess ill-being, such as pain or symptoms, may have the capacity only to elicit reduced QOL. Similarly, items that refer to problems or difficulties are assessing ill-being rather than well-being and are assuming that the absence of ill-being equals the presence of well-being. This underlying assumption has not been well tested empirically in paediatric research; however, research with adults has demonstrated that high ill-being is not the same as low well-being, and the absence of ill-being is not high well-being.⁴⁶ Given the increasing popularity of including negative domains or items assessing the presence of problems, it is strongly recommended that the assumption that the absence of illness equates with the presence of well-being be empirically tested in a paediatric population. In the short-term, it is recommended that researchers and clinicians acknowledge that an instrument is based on the assumption that the absence of ill-being equals the presence of well-being. Some of these recommendations

may also be useful to appraise instruments that were originally developed to measure health but are increasingly being used to measure QOL or HRQOL. A commonly used instrument to measure HRQOL that was originally designed to measure functional health and well-being is the Child Health Questionnaire (CHQ).^{14,15} If it is being used as a measure of QOL/HRQOL, the theory, domains, and items can be critically appraised with the recommendations in this review.

LIMITATIONS

Although the review has highlighted a range of definitions, theories, domains, and items to measure paediatric QOL, it may be possible that there are QOL instruments that were not captured by the search strategy, particularly for condition-specific scales. There may be some research that remains unpublished or in the grey literature. Furthermore, this review examined only whether the psychometric properties of the instruments had been tested; it did not critically evaluate these statistics. Thus, researchers and clinicians are encouraged to review the psychometric properties (reliability, validity, and sensitivity to change) when selecting an instrument.

Conclusion

Given how difficult it is to conceptualize QOL, it is essential that researchers appraise critically, in addition to the psychometric properties, the conceptual underpinnings of QOL instruments that are employed. In the long term, future research efforts need to focus on developing theories of QOL and empirically testing underlying assumptions of the instruments. These issues must be addressed if the field of paediatric QOL is to progress beyond instrument development and testing to the planning and empirical testing of programmes and interventions to increase QOL.

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