Quality of Life Measurement in Children and Adolescents: Issues, Instruments, and Applications

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There is increasing interest in measuring quality of life (QL) in children and adolescents, but this interest has developed without careful attention given numerous important issues. Consequently, there is much diversity and confusion in this measurement area. We discuss at a conceptual level herein how to construe and define QL, approach its measurement, and the implications of for whom this is done. Methodological issues pertaining to validation, proxy report, and child development are also discussed. Guidelines for selecting QL measures are provided and a set of generic QL measures is recommended for further consideration. Finally, applications of the QL concept in the policy, service and care, and science areas are delineated. © 2001 John Wiley & Sons, Inc. J Clin Psychol 57: 571–585, 2001

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The psychosocial well-being and development of children and adolescents of course have received a great deal of attention, in terms of research, care, and policy. Using quality of life (QL) as an overarching concept for this age group has only recently been recognized...
as useful, mainly in the context of health care. Consequently, children’s QL is underinvestigated compared to that in adults. Of over 20,000 articles pertaining to QL published between 1980 and 1994, only 3,050 (approximately 13%) pertained to children (Bul linger & Ravens-Sieberer, in press). Those between 13 and 18 years of age were the most frequently studied, with much less investigation of children ages 6 to 12. Only 9% of the studies on children involved evaluations of QL by the children themselves.

Nonetheless, interest in children’s QL is on the increase. This is due to variety of factors. In general, our society has recently become more concerned about quality in general, for example, in product development and manufacturing and consumer services. This development has seen parallels in considerations for the human condition. Examples are concerns about the contribution of services, programs, and policies to the life experience of individuals. A prominent impetus for QL considerations has been the desire to compare outcomes from different efforts, be they different policies and resource allocations to address different needs in a society, alternative service programs for an identified group of people, or specific interventions for a health condition. In particular, in the health care context, the progression from a biologically based curative model to an alternative outcomes model is becoming more prominent (e.g., Kaplan, 1990, 1994, 1996), with the commensurate interest in quality measurement.

Not surprisingly, then, being a relatively young endeavor, there is considerable diversity in conceptualization of and operational approach to QL with children (for simplicity, we will use the terms “children” to designate the whole age range up to adulthood). This creates confusion and hinders the utility of the QL concept. Our aims herein, therefore, are to clarify the most salient conceptual and methodological issues regarding QL in children. We will also recommend a set of measures of QL in children and discuss applications of this concept.

Conceptual Issues

There are numerous conceptual issues in using the notion of QL in children. Choices, therefore, need to made regarding these issues in any application of the QL concept, each of which has significant implications. The major points of divergence can be identified by the questions: What?, How?, and Why? We will discuss specific issues regarding each general question in turn.

What?

The “What?” question has several levels. First, there is a major of issue how to construe QL at a rather general level. Then there are issues of how to define it and what domains to encompass.

Health-Related QL. Within the field of QL, a great deal of effort has gone into attempting to distinguish “health-related” QL from more general QL. The former is evidenced, for example, in the proliferation of numerous disease-specific measures of QL (e.g., for children with diabetes or asthma). However, we find the notion of disease-specific (e.g., “diabetes-related”) QL misleading.

QL is by its nature a holistic concept, an attempt to describe how well or poorly life works at a particular point in time. How can one’s life be separated into what is influenced by a disease from that which is influenced by all current and past experiences. The
instrument developer cannot do so at the theoretical level. Neither can the individual make these distinctions reliably or accurately when completing a measure of QL.

Consider as an example a child who is lacking social contacts with other children her age. Is this related to her experiencing immunosuppression during cancer treatment, temperament being characterized by avoidance, or living in a rural area with few children? Of course, we may at times be interested in learning about “disease impact.” Presumably, this becomes an issue of what specific known symptoms and consequences of a disease are present. These may, in turn, be correlates of QL. However, QL and disease impact are theoretically distinct concepts, the former clearly being more general. As such, they need to be labeled and measured separately from one another.

In addition to difficulties differentiating health-related QL from general QL, there is also an even more basic underlying conflict. Theoretically, the goal for any services provided to individuals with a specific condition is to restore a life of quality that cannot be differentiated from one achieved by individuals without the specific condition. Thus, as Cummins (1995) stated, “[i]t is imperative that all definitions of [QL] be referenced to the general population both in their conception and operational measures” (p. 14). Because the generic approach to QL considers all relevant QL domains that are likely to be affected by the condition, it is more comprehensive than health-related QL. Furthermore, the generic approach makes it possible to compare QL outcomes across conditions and can aid in the allocation of resources among multiple service systems.

Thus, we believe that much will be gained if efforts from this point forward are devoted primarily to considering QL as a construct that is applicable across all children. No differentiation should be made between those who have specific health conditions, any health conditions, and no health condition. That is, standards for a life of quality cannot depend on the challenges a young person experience. Those standards must be universal.

**Definition.** First, it is important to bear in mind that QL is a construct, and as such has no physical or temporal basis (Wallander, 1992, in press). It is not a directly measurable entity or “thing.” As Caws (1959, p. 16) eloquently stated, a construct “is not a visual image, nor is it external to the mind; it is analogous to a piece in a game in which thought plays.” A construct, such as QL, is an organizing concept that exists to guide its users (Foster & Cone, 1995; Silva, 1993). Observed variables are presumed to be tangible but imperfect indices of the underlying construct. Therefore, the user of a QL measurement need to view it as an indicator of an underlying construct. However, a construct can never be fully operationalized by its measurements. There is always a figurative distance present between that which we are truly interested in (e.g., QL) and its measurements (e.g., responses to a set of items). In addition, hypothetical constructs, including QL, rarely have universal agreement as to their definition. Reasonable minds will have reasonable disagreements as to “the best” definition.

Indeed, a multitude of definitions, content, and criteria of QL have been proposed and applied (Cummins, 1995; Wallander, in press). In fact, so many different QL criteria and measures exist, representing largely different definitions, that they have been described as “almost researcher specific” (Borthwick-Duffy, 1996). This plethora led Schalock (1996) to propose that QL should not be considered “an entity that one has or does not have to some degree, [but] should be viewed as an organizing concept. [As such, QL] can be used for a number of purposes” (p. 123).

This tendency for researchers to utilize diverse definitions, criteria, and measures of QL limits comparisons of results across studies and populations. Diversification to an extreme may also have the unintended effect of retarding the progress of research on the
field of QL in children. It would, therefore, be desirable to move towards a unifying
definition of QL. Indeed, there are commonalities in conceptualizing and defining QL
evidenced in the many offerings that can serve as the basis for such an effort (cf. Borthwick-

Building on these similarities, we propose that (cf. Wallander, in press):

QL is the combination of objectively and subjectively indicated well being in multiple domains
of life considered salient in one's culture and time, while adhering to universal standards of
human rights.

This definition encompasses the most important aspects covered in the literature on
QL. While broad, it is at the same time precise enough to allow operational definitions
and empirical testing. Furthermore, by allowing individual and cultural variation in con-
tent, it avoids premature closure, and enables further conceptual and empirical develop-
ment. Because life itself is experienced in myriad ways, it is important to allow multiple
domains to be included in a definition of QL as well as multiple perspectives.

Domains. There is widespread agreement that QL is a multidimensional concept.
However, a variety of methods have been used to delineate these domains. These include
content analysis of existing QL measures (e.g. Hughes, Hwang, Kim, Eisenman, & Kil-
lian, 1995), utilizing a theoretical-philosophical framework (e.g. Woodhill, Renwick,
Brown, & Raphael, 1994), or employing informal methods of analysis (e.g. Cummins,
1997; Felce & Perry, 1997; Schalock, 1996). Typically, 5 to 15 dimensions emerge from
these various methods and often include hierarchically organized subdimensions.

Despite the numerous different schemes, there is, in fact, considerable overlap. Most
differences are related to whether and how much to divide the domains into subdomains.
We find Felce and Perry’s (1997) dimensional framework of QL especially useful because
it balances comprehensive and parsimonious coverage. Within this framework, QL encom-
passes the domains of material, physical, social, emotional, and productive well-being,
each of which is further subdivided into subdomains as listed in Table 1.

How?

The “how?” question herein refers, not to the method of measurement per se, but to what
is the basic conceptual approach for obtaining measurements (Borthwick-Duffy, 1992;

| Table 1 |
| Dimensional Structure of QL (Felce & Perry, 1995) |
| --- | --- |
| Material well being | Emotional well being |
| Finance/income | Positive |
| Housing quality | Status/respect |
| Transport | Mental health/stress |
| Physical well being | Fullfillment |
| Health | Faith/belief |
| Fitness | Self-esteem |
| Mobility | Productive well being |
| Personal safety | Competence |
| Social well being | Productivity/contribution |
| Personal relationships | |
| Community involvement | |
Felce & Perry, 1995; Wallander, in press). These approaches differ in whether the focus is on: (a) the objective quality of the conditions in which the child lives; (b) the child’s subjective satisfaction with their life conditions; (c) some combination of the objective and subjective approaches (e.g., multiplying or adding the subjective ratings and the objective indicators); or (d) some combination of the objective and subjective perspectives in which specific domains of QL are weighted by the child’s values, aspirations, and/or expectations.

A number of problematic implications arise from utilizing a purely objective (a) or a purely subjective (b) approach in isolation. Emphasizing the objective quality of life conditions (e.g., economic resources, residence, production, illness days) implies that what is important is the “life status” of the child compared to some normative standard and not that child’s satisfaction with his or her “life status” (Felce & Perry, 1995). In addition, normative standards for each of these areas are likely to vary widely between cultures and even within cultures due to a variety of factors, such as age and ethnic background. Therefore, a QL index based on objective data only will not be necessarily transferable beyond the reference group.

Although the objective characteristics of a person’s environment are important in any evaluation of life quality, as a personal construct, QL is a subjective state. However, placing the emphasis on a child’s subjective satisfaction with his/her experiences also raises issues. Making a judgement on satisfaction is a comparative activity (Felce & Perry, 1995) and therefore depends upon one’s frame of reference. That, in turn, depends upon one’s experiences and judgement of what is typical and possible within one’s situation. These are of course limited in children. Subjective QL ratings may also be heavily influenced by personal frames of reference that run counter to generally accepted standards. In addition, it is possible that individuals may lower their own standards to what would be objectively unacceptable levels as a form of adaptation to life conditions (Bury, 1991; Edgerton, 1990). The extent to which these latter two issues apply to children, however, is unknown at present.

Given shortcomings with either the objective or subjective approach, we concur with, for example, Cummins (1997), that a combination of the objective and subjective approaches is preferable for assessing QL in children and adolescents. However, while conceptually appealing, this approach requires more research because it is not clear how such a combination would best be implemented (e.g., by adding, multiplying, or weighing items). The contemporary literature is quite consistent in its determination that, while both of the objective and subjective perspective form part of the QL construct, they generally have a very poor relationship to one another. Furthermore, objective and subjective approaches may need to be utilized differently, depending on the developmental level of the child. Thus, it may be necessary for there to be a relatively stronger emphasis on objectively measurable aspects of QL when the child being assessed is younger or less developmentally mature. In addition, it may not be possible to obtain reliable subjective information from children who are very young, have cognitive limitations, or are severely ill. Cummins (1997) instrument provides a nice example of how objective and subjective information can be combined for the assessment of QL in adolescents.

Why?

The “why?” question refers to the overall purpose of a QL assessment or who is the stakeholder and why does the stakeholder desire QL information? In most cases stake-
holders for QL assessment fall into four categories: Society, Health Care Policy, Patient Group, and the Individual Patient (Koot, in press). Each stakeholder has different desired outcomes and value systems, with corresponding implications for choice of assessment tool or method.

_Society_ is influenced by the need to make decisions concerning the distribution of public resources among services, for example, education, housing, public transportation, and health care. From this perspective, data to be used for making these decisions should be gathered through population studies and values to be used in making decisions should reflect the societal viewpoint as assessed from a representative general population sample.

_Health Care Policy_ is influenced by the need to make decisions regarding the allocation of health care funds as a result of knowledge of costs and outcomes of different intervention strategies. For example, the question of “What QL outcomes are associated with preventive prenatal services compared to kidney transplantation in the elderly?” can be addressed. From this perspective, data concerning the outcome of different diseases and interventions is necessary for decision making. Thus, generic and comprehensive instruments that can be utilized with a wide variety of diseased and nondiseased populations are necessary. As with the societal perspective, values used in the decision-making process should reflect the societal viewpoint as assessed from a representative general population sample.

_Patient Group_ QL assessment has the goal to enhance the ability to make decisions concerning alternative treatments for specific patient groups (e.g., bone marrow transplant vs. radiation treatment for leukemia in children). Consequently, a QL measure must be able to detect differences among groups, such as different treatments for the same disease. From this perspective, values used to select a treatment strategy for a specific disease group should be based upon values attached to possible outcomes by the members of the patient group itself. With children, this must also include parents.

_Individual Patient_ QL assessment emphasizes the selection of the most appropriate treatment for an individual patient by the patient (i.e., child and parents) and his/her physician. Subjective QL is most useful for this. From this perspective, both the values of the patient and the physician as individuals are important in the decision making process.

**Methodological Issues**

In addition to the above conceptual issues, there are also a number of methodological considerations in the development and structure of QL measures. We will highlight herein the most important issues regarding children in QL, namely validation, proxy report, and child development.

**Validation**

Due to the fact that QL is a construct and not a concrete entity in and of itself, the establishment of construct validity is of paramount importance. Of course, the other traditional validity notions of content and criterion-referenced (concurrent and predictive) validity are also important. Construct validity refers to the extent to which an instrument is a good representation of a construct (cf. Clark & Watson, 1995; Loevinger, 1957). Different approaches have been proposed for developing and evaluating construct validity. Because it explicitly recognizes that construct validity is an ongoing, overriding issue from the initial conceptualization to the use of a finished measure, Loevinger’s (1957) discussion of construct validity in terms of substantive, structural, and external validity is helpful (cf. Clark & Watson, 1995).
Substantive validity is concerned with theoretical context, definition, and content. It is developed primarily through a series of cognitive activities during the initial phases of measurement development. These activities consist of theoretical conceptualization of the construct, a thorough literature review, and creation of the initial item pool, and form the foundation upon which the measure itself is based.

Structural validity refers to the connection between the instrument and the construct. It is established through a series of behavioral activities. These activities include test construction in which item selection strategy should be related to the goals of instrument development and the theoretical conceptualization of the construct, initial data collection, and psychometric evaluation.

External validity can only be demonstrated when clearly explicated construct definitions and theory form the basis of instrument development. Demonstrating external validity is an ongoing process through which an instrument accumulates more or less support for its validity in measuring the target construct. There are a number of methods that may be used to examine external validity of QL measures in children and adolescents. Methods that can be used to demonstrate the external validity include, for example: comparison of scores between groups that should differ on the measurement, comparison of scores within a group that should change over time, inspection of associations with scores on different instruments of the same or highly similar constructs, and comparison of instrument scores between or within groups that should differ due to experimental manipulations.

Proxy Report

Some groups of children cannot provide useful ratings about their QL, such as those who are too young, physically ill, or disabled. Consequently, for some children, the only way of obtaining information about their QL is by using a proxy reporter, such as a parent, who is asked to reflect the child’s own perception of his or her QL.

However, considerable previous research with children has indicated that different reporters generally have low to modest agreement (Achenbach, McConaughy, & Howell, 1987; Bates, Pettit, Dodge, & Ridge, 1998). In addition, it has been found that agreement among raters may differ as a result of factors such as child sex, age, and condition (Verhulst, Koot, & Van der Ende, 1992). Lack of agreement among multiple raters has been investigated within the field of adult QL. Sprangers and Aaronson (1992) concluded that, although proxy raters (i.e., health care providers, family members, close companions) generally provide similar reports, they also usually underestimate QL compared to the patient’s own report.

Although there are concerns that must be addressed, proxy reports of children’s QL cannot be discarded for a number of reasons. Again, proxy reports are likely the most appropriate source of information about QL in some groups of children who are unable reliably to report about their own experience. In addition, it is important to consider the type of information being requested from a proxy reporter. Ratings of objective aspects of QL by proxy reporters are likely to be more valid than their ratings of subjective aspects by the same proxy rater. Even though proxy reports may differ from the child’s own report, the consensus that is forming is that each source may provide valuable information for the clinician and researcher (cf. Koot & Wallander, in press).

Child Development

There are several issues regarding children reporting on their own QL that can be broadly termed “developmental considerations.” We will highlight four of these here: develop-
mental competence in verbal comprehension, understanding and use of time, developmental differences in QL markers, and identifying QL domains and markers that are relevant to children themselves.

Comprehension. The quality of children’s self-report is highly influenced by expressive and receptive language abilities. To provide self-report information, a child must first understand what is being asked and then must be able to formulate a response. When utilizing paper and pencil measures, the cognitive demands on the individual are generally increased by the addition of a specific response scale to which the child must match his or her response. This is sometimes dealt with by providing fewer response options in versions intended for younger children. However, there is rarely an empirical basis for choosing which types of response formats are suitable for which ages or, better yet, level of developmental competence.

Time Frame. Many QL measures require the respondent to reply based upon experiences during a specific time period, such as in the past week or month. Other instruments do not provide a time frame, leaving open which experiences and events occurring when are to influence the child’s ratings. The ability of a child to respond to a time frame demand will be influenced by developmental differences in, for example, time perception and memory.

Developmental Differences in QL Markers. Developmental tasks vary by age in a given culture such that some QL items may be appropriate for a specific age range, but not for another. That is, markers of a life of quality are in some ways different at different ages. The tasks and experiences differ between, for example, 5, 10, and 15 year olds, such as in the role of opposite-sex relations, play versus educational opportunities, and availability of transportation in determining QL. Therefore, QL is experienced in different ways at different ages. While some instrument developers do not appear to have dealt with this explicitly, others appear to have chosen only age universal markers. However, the latter approach, while producing a consistent set of items across ages, which facilitates the immediate comparison of information, likely misses important information about QL that is relatively age specific.

While we are not keen on equating disease-impact with QL, French, Christie and Sowden (1994) provide a nice example of how to address several developmental issues in the construction of the Child Asthma Questionnaires. They developed three different forms for three age ranges. These forms differ in item content, length, response scale, and independence required for completion. Children in the youngest age group (4–7) complete a 14-item measure concerning feelings about disease-related problems together with their parents, using face representations with different affective expressions as the response scale. The middle age group (8–11) completes a slightly longer 23-item form, which has a more advanced response scale and items addressing frequency of symptoms and activities. It is completed with adult help, if necessary. The oldest age group (12–16) independently responds to 41 items concerning feelings as well as frequencies of activities and symptoms using a numerical scale.

Child Relevance. Another developmental concern in the construction of QL measures is the lack of information obtained from children themselves concerning what constitutes a life of quality. Little is known about the relative importance that children attach to different life states. The perceptions of adults concerning a life of quality for children
cannot be assumed to accurately reflect the opinions and ideals of youth themselves. Fortunately, a few investigators have obtained the views of children concerning QL in their measurement development (e.g., Eiser, Havermans, Craft, & Kernahan, 1995; Varni, Seid, & Rode, 1999). For example, Ronen, Rosenbaum, Law, and Streiner (1999) describe a QL measure for childhood epilepsy where the views of children were explicitly sought. They formed separate focus groups for the children and their parents from which information concerning living with epilepsy was obtained and used to formulate specific domains of QL related to childhood epilepsy.

Recommended Measures

We propose, in Table 2, a set of guidelines for selecting a QL measure for children that addresses many of the conceptual and methodological concerns outlined above (cf. Cummins, 1997; Koot, in press).

Generic Measures

To reiterate, efforts from this point forward should be devoted primarily to considering QL as a construct that is applicable across all young people. No differentiation should be made between those who do or do not have specific conditions when QL is assessed. We believe that standards for a life of quality cannot depend on the challenges a young person experience. Rather, QL standards are universal (within a culture and at a point in time). Therefore, the body of generic QL measures should provide the most useful pool from which to develop the next generation of QL measures for young people. Information about “health-related QL,” which is really about disease impact, can be useful, but this does not inform about QL.

We will not review the rather extensive pool of generic measures here, but refer to Spieth (in press; Spieth & Harris, 1996), for example, for detailed reviews of numerous generic QL instruments. It is not easy to select a few specific instruments from those available that are worthy of further consideration. Different instruments were developed for different purposes, such as epidemiological surveys, policy and program evaluation, etc.

Table 2

Guidelines for Evaluating Child QL Measures

<table>
<thead>
<tr>
<th>QL measure for children should:</th>
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<tbody>
<tr>
<td>1. Operationalize an accepted, clear, generic QL definition.</td>
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<td>2. Include broadly encompassing QL domains applicable to all children.</td>
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<td>3. Include both objective and subjective approaches.</td>
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<td>4. Have parallel forms for children and other informants.</td>
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<td>5. Weigh satisfaction on domains of perceived importance to the child.</td>
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<td>6. Demonstrate satisfactory psychometric characteristics.</td>
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<td>7. Provide norms for the general population in addition to any specific group of children it targets.</td>
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<td>8. Recognize explicitly that children are developing beings (e.g., through the use of different item sets, response formats, or entirely different forms dependent upon the developmental level of the child).</td>
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Note. Based in part on Cummins (1997) and Koot (in press).
and patient assessment. Furthermore, each instrument has shortcomings, such as being overly long, targeting only adolescents, requesting only self- or parent-report, or representing a limited health-related perspective on QL.

Nonetheless, we recommend that further consideration be given five generic QL measures. These are listed and summarized in Table 3. Although none of these are completely satisfactory at present, they contain elements that will serve well as a base for further work.

We highlight the most recent addition to our recommended measures to illustrate careful attention to most, if not all of these guidelines. The PedsQL is a measurement system developed by Varni and colleagues (Varni, Seid, & Rode, 1999). Although the initial goal was to measure QL in children with cancer (Varni, Katz, Seid, Quiggins, Friedman-Bender, 1998; Varni, Katz, Seid, Quiggins, Friedman-Bender, & Castro, 1998), it is now available in a fourth generic edition. It consists of a 15-item core, addressing the physical, mental, and social health domains. These scales provide an overall QL score. To this can be added disease-specific modules, of which several are available or currently being tested (e.g., cancer, diabetes, cystic fibrosis). This is a reasonable way of avoiding confusion between generic QL and what others term “health-related” or “disease-specific QL.” However, we prefer that these types of modules would be labeled as “disease impact” measures. Non-English versions are also being developed in numerous countries.

Different forms are used for ages 8–12 and 13–18, differing in wording only to match the ability of each age range. Formal assessment of reading levels has confirmed this. There are also parallel forms for self- and proxy-report. A pictorial response format version for ages 5–7 is being tested. Internal consistency reliability estimates for the total score as well as for the three domain scores were found to be adequate. Discriminate validity, using the known-groups approach, was demonstrated for young patients with cancer on- and off-treatment. Construct validity has received initial support from confirming the expected correlation patterns with standardized psychosocial questionnaires. The PedsQL appears promising. It is clearly a second generation instrument, but is in need of further, and especially independent, use and testing.

Disease-Specific Measures

As discussed previously, we find the disease-specific approach to QL measurement limited, if not misguided. It is hard for us to understand the idea of disease-specific QL. It seems impossible to differentiate what conditions or circumstances influence what aspect of one’s life. Moreover, it makes little sense to us to measure the impact on QL from a disease by limiting a priori what could be due to the disease, as is typically done in the disease-specific measures. Rather, QL must be viewed as having universal standards (see earlier proposed definition), and the impact of any disease then is best learned through comparing the QL, broadly construed, of people with and without the disease (either through a between- or within-groups study). Given this premise, therefore, we can not recommend any disease-specific QL measures. However, we do not object in principle to the development and use of generic or specific disease impact measures as separate efforts from QL measurement endeavors. It is an empirical question how useful disease impact measures can be, but this should be examined.

Applications with Children

There are many different possible applications of QL in the contexts of services, programs, and care for children (cf. Koot & Wallander, in press). Some examples are:
<table>
<thead>
<tr>
<th>Measure</th>
<th>Source</th>
<th>Domains</th>
<th>Respondent</th>
<th>Age Range</th>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAND health status measure for children</td>
<td>Eisen, Ware, &amp; McDonald, 1979</td>
<td>Physical health, Mental health, Social health, General health, Somatic symptoms, Behavior problems</td>
<td>Parent</td>
<td>0–4</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Parent</td>
<td>5–13</td>
<td>59</td>
</tr>
<tr>
<td>Child health rating inventories</td>
<td>Kaplan, Barlow, Speeter, Sullivan, Kahn, &amp; Grand, 1995</td>
<td>Physical functioning, Role functioning, Cognitive functioning, Emotional well being</td>
<td>Child</td>
<td>5–12</td>
<td>18</td>
</tr>
<tr>
<td>PedsQL</td>
<td>Varni, Seid, &amp; Rode, 1999</td>
<td>Physical health, Mental health, Social health</td>
<td>Child and parent*</td>
<td>8–12</td>
<td>15</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Child and parent*</td>
<td>13–18</td>
<td>15</td>
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*Note.* Based in part on Spieth (in press).

*Separate forms are used for the child and parent, who complete these independently.
• Inform public policy decision making.
• Guide allocation of public resources.
• Evaluate effects of policy or service program implementations or changes, such as in the areas of child welfare, education, and health care.
• Evaluate effects of clinical interventions or specific treatment procedures, for example in randomized controlled trials.
• Determine QL differences between different groups, for example, to identify vulnerable children for whom screening and prevention program can be implemented.
• Determine how complications (e.g., depressed affect) that are not uniformly related to a specific condition (e.g., disease, poverty, stressful event exposure) affect QL in children with that condition in conjunction with or independent of the condition itself.
• Determine associations between childhood QL and other prognostic factors and outcomes in prospective studies.
• Assess relationships between different supports and QL outcomes.

This is not an exhaustive list of the potential applications of QL measures. Their use in varied settings and as part of varied methodologies will increase as the conceptual and methodological underpinnings of QL in children can be advanced. Regardless of the context of the application of QL measurement, we identify in Table 4 guidelines for effective implementation in studies on children (cf. Bullinger & Ravens-Sieberer, in press; Huerny et al., 1992; Koot & Wallander, in press).

Table 4

<table>
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<tr>
<th>Question to Guide the Implementation of QL Measurements</th>
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<tr>
<td>Study design</td>
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<tr>
<td>• Is the QL assessment an integral part of the study?</td>
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<tr>
<td>• Are objectives, methods, and guidelines explicitly stated in the protocol?</td>
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<tr>
<td>• Are all study participants, including children an parents/caretakers, consulted during the design and development of protocol?</td>
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<tr>
<td>Instrument</td>
</tr>
<tr>
<td>• Are items included that are labeled by study participants as the most important in their daily lives?</td>
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<tr>
<td>• Is the instrument sensitive to adverse effects of intervention or treatment?</td>
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<td>• Is the instrument format appropriate for this age group?</td>
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<tr>
<td>• Can proxy report be considered valid, if needed?</td>
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<tr>
<td>• Is the instrument reliable and valid?</td>
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<tr>
<td>• Is the instrument cross-culturally adapted?</td>
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<tr>
<td>• Is the instrument short enough to be filled out repeatedly, for example, during the course of an intervention?</td>
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<tr>
<td>• Does the instrument discriminate between groups with different conditions or with different treatments/interventions within one condition group?</td>
</tr>
<tr>
<td>• Is the instrument sensitive to changes in participants’ experience over time?</td>
</tr>
<tr>
<td>Data collection and analysis</td>
</tr>
<tr>
<td>• Is selective inclusion for QL assessment avoided?</td>
</tr>
<tr>
<td>• Are participants fully informed about study goals and requests?</td>
</tr>
<tr>
<td>• Is assistance of the participants in questionnaire completion available?</td>
</tr>
<tr>
<td>• What statistically significant effect on QL will be considered practically and clinically significant?</td>
</tr>
<tr>
<td>• What method will be used to express the effect size?</td>
</tr>
<tr>
<td>• Will the results have an impact on the way children and parents/caretakers will be informed, treated, supported, or cared for, now or in the future?</td>
</tr>
</tbody>
</table>

Note. Based in part on Huerny, et al. (1992); Koot & Wallander (in press); and Bullinger & Ravens-Sieberer (in press).
Conclusions

Although, the use of the QL notion and its empirical knowledge base for children is in an early stage of development, we strongly believe that it will be worthwhile to further this development. We also believe that the QL notion has the potential to represent the ultimate standard against which to judge the impact on children from whatever conditions they encounter (e.g., physical, social, environmental) and the efforts of society to enhance their development (e.g., policy, resource allocation, interventions). Certainly, all who work with or are otherwise concerned with children would hold as one of their most important goals to ensure that children experience a life of quality.

References


