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Assessment of Health-Related Quality of Life in Children and Adolescents: An Integrative Review[1]

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Reviewed and integrated the medical and psychological literature on the assessment of health-related quality of life (QOL) in pediatric populations. Definitions of QOL and the utility, health status, battery, and modular approaches to QOL assessment are presented. Measures currently available for use with children and adolescents were evaluated with respect to psychometric properties, QOL domains included, targeted age range, mode of administration, number of items, and time period assessed. The need to address methodological issues and practical barriers so as to encourage the inclusion of QOL outcomes in future clinical trials and other research is discussed.

KEY WORDS: quality of life; assessment; children; adolescents; health status; functional status; chronic illness.

The assessment of quality of life (QOL) in chronically ill children and adolescents has become increasingly important as the mortality rates associated with various chronic diseases have decreased and survival rates have increased (Pantell & Lewis, 1987). Because survival rates have increased dramatically, pediatric illnesses previously considered terminal are now treated as chronic conditions (Newacheck & Taylor, 1992).

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Although medical intervention often results in the improved health status of pediatric patients, there is evidence to suggest that frequent hospitalizations, intrusive medical procedures, and uncertainty of survival, negatively impact childhood development and adjustment (Barbarin, 1990). Hence, there is growing interest in the inclusion of QOL outcome measures in clinical trials to evaluate differential changes in morbidity and the relative efficacy of medical interventions. More general rationales for assessing QOL include the identification of acute dysfunction secondary to illness or treatment, residual dysfunction of long-term survivors, and patient subpopulations at risk for psychological or behavioral problems. QOL assessment can also facilitate improvements in clinical decision making, evaluation of the quality of medical care, estimation of the health care needs of a population, and an understanding of the causes and consequences of differences in health.

The purpose of this paper is to review and evaluate the extant literature on QOL assessment in chronically ill children and adolescents. This report includes a discussion of QOL definitions, an evaluation of conceptual models of QOL, and a review of QOL instruments used with pediatric patients.

DEFINITION OF QUALITY OF LIFE

Use of the term "quality of life" has become widespread in recent years, but unfortunately there is no universally accepted definition (Aaronson, 1992; Spilker, 1990). Within the context of health care, it is important to distinguish "health-related QOL" from broader concepts of general well-being. Health-related QOL refers to the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and health care policy. For ease of reference throughout this paper, health-related QOL is referred to as QOL.

Having established that pediatric QOL refers to those areas of a child's or adolescent's functioning that are directly affected by an illness or its treatment, the problem remains to identify the specific areas of functioning encompassed by this definition. One point of agreement in the literature is that QOL is a multidimensional construct comprising several domains (Aaronson et al., 1991; Eisen, Ware, Donald, & Brook, 1979; Gotay, Korn, McCabe, Moore, & Cheson, 1992; Nayfield & Hailey, 1990; Ware, 1984). The multidimensional approach originated with the World Health Organization's (WHO, 1947) definition of health which identified three dimensions: physical, mental, and social. The WHO definition has become the cornerstone of the QOL construct, and these three dimensions have been expanded to four "core" QOL domains: disease state and physical symptoms, functional status, psychological functioning, and social functioning (Aaronson, 1988; De Haes & Van Knippenberg, 1985; Eisen et al., 1979; Nayfield & Hailey, 1990; Ware, 1984). Each of these domains is considered briefly.

Disease State. Physical symptomatology is the most widely accepted measure of health status, and is often interpreted as a measure of QOL. The association between physical symptoms and health is well established and requires little justification. Thus, it makes intuitive sense that a valid QOL measure would accurately reflect changes in physical health. However, it has often been difficult to establish correlations between physiological indices of health and other QOL domains (Bradlyn, Harris, Warner, Ritchey, & Zaboy, 1993; Czyzewski, Mariotto, Bartholomew, LeCompte, & Sockrider, 1994; Harris et al., 1994; Schipper, Clinch, & Powell, 1990). Additionally, it has been found that physical dysfunction does not necessarily negatively impact overall childhood adjustment (Drotar et al., 1981). Thus, it is possible that compensatory adjustments override physical symptomatology, rendering disease state an imperfect indicator of QOL (Gotay et al., 1992).

Functional Status. The second core component of QOL, functional status, has received the bulk of the attention in the medical literature. It is generally characterized as the ability to perform a variety of age-appropriate daily activities. This category includes self-care, mobility, physical activity, role activities (such as play), and leisure activities (Eisen, Donald, Ware, & Brook, 1980). Although the term functional status is often used interchangeably with the term QOL, there is a clear distinction between the two. Functional status is the *objective* degree of impairment caused by an illness, whereas QOL also includes the *subjective* evaluation of the impairment (Richards & Hemstreet, 1994).

Psychological Functioning. The inclusion of psychological functioning as a core QOL component has presented theoretical and practical problems. Difficulties inherent in measuring psychological states independent of illness states in children have been noted (Eisen et al., 1980; Perrin, Stein, & Drotar, 1991). The primary difficulty is that affective and somatic states often co-occur and may influence one another. For example, complaints of depression frequently accompany somatic changes and vice versa. Additionally, mental health scales of QOL measures are often normed on samples of healthy children, which calls into question their use with illness populations (Schipper et al., 1990). To address these issues, QOL measures may include a scale designed to assess overt, behavioral problems in chronically ill children and adolescents that are largely independent of somatic states (Eisen et al., 1980).

Social Functioning. Social functioning broadly refers to an individual's ability to maintain social relations (Shumaker & Czajkowski, 1993), and may be defined as the number and/or quality of social contacts. Child social functioning has been primarily defined with respect to peers, but may also include interactions with family members, teachers, and health care professionals. There is evidence to suggest that chronically ill children do not differ from their healthy peers in social adjustment. However, little systematic research has been done on the impact of chronic illness on peer relations (La Greca, 1990). Additionally, the

assessment of social functioning is complicated by definitional inconsistencies and methodological problems (Spirito, DeLawyer, & Stark, 1991).

Additional Domains. A number of additional areas of functioning have been identified as relevant for children and adolescents. Specific aspects of functioning may be impacted directly by an illness or treatment; for example, "satisfaction with appearance" may be important to pediatric oncology patients experiencing alopecia (Kamphuis, 1987). Additional childhood QOL domains considered important by health professionals are (a) academic achievement, (b) neuropsychological functioning, and (c) overall satisfaction with life (Harris, Bradlyn, & Spieth, 1993). Research investigating the inclusion of such domains in QOL assessment may be warranted (Calman, 1984; Starfield, 1987).

In summary, there is consensus that health-related QOL is a multidimensional construct that refers to subjective and objective evaluations of dysfunction caused by an illness and its treatment. Beyond this agreement, inconsistencies across definitions and in the identification of specific domains of QOL are common. This is problematic insofar as the definition of QOL has profound implications for how it is measured (Gotay et al., 1992). The lack of consistency across definitions is further compounded by differences in conceptual models of QOL.

CONCEPTUAL MODELS OF QOL

Two primary conceptual models of QOL assessment exist: (a) the utility concept (Kaplan & Anderson, 1990; Torrance, 1987), and (b) health status measurement (e.g., Ware, 1984). The original objective of the utility approach was to direct the allocation of medical funds appropriately. The intent of the health status measurement approach was to assess the impact of health care policies on the health of the general population. Despite these fundamental differences, the assessment instruments that resulted from these divergent approaches have been referred to as "QOL measures." In an effort to clarify these differences, the two models are described below.

The Utility Model

The utility model is derived from economic decision theory and is used to compare alternative treatments based on subjective preferences of medical treatment effects (Torrance, 1987). Essentially, respondents are asked to imagine a particular health condition, and to express their relative preference for that condition as a choice between quantity and quality of life. That is, respondents are asked to decide between a shorter life with less dysfunction or a longer life with

more dysfunction. Responses can be quantified in terms of Quality Adjusted Life Years (QALYs).

An application of the utility model is the General Health Policy Model developed by Kaplan and his colleagues (1989; Kaplan & Anderson, 1990). This model focuses on health-related outcomes of mortality, morbidity, symptoms, and prognosis, and expresses the benefits of medical care, behavioral intervention, and preventive programs in terms of "well-years." The General Health Policy Model led to the development of the Quality of Well-Being Scale (QWB; Kaplan, Bush, & Berry, 1978). The QWB is typically used to evaluate the relative efficacy of health care programs and interventions based on QALYs. The utility approach reduces questions of health funding allocation to a statement of cost-benefit ratios expressed by a single numeric index.

One of several criticisms of the utility approach is that it may not be applicable to pediatric populations because children have difficulty understanding and formulating abstract preferences between quality and quantity of life (Hinds, 1990; Richards & Hemstreet, 1994).

Health Status Measurement

Eisen et al. (1979, 1980) of the Rand Corporation conducted the Health Insurance Study (HIS) to assess the impact of insurance plans on the health status of children in the United States. These investigators conceptualized child health status as a multidimensional construct encompassing five components: disease state, physical functioning, mental health, social adjustment, and overall health. The resulting conceptual model is a five-level hierarchy of concentric circles that emphasizes the impact of physical health on level of functioning (Ware, 1984). The Rand Health Status Measure for Children (HSMC; Eisen et al., 1979, 1980) was based on this model and was developed for use in the HIS.

A criticism of this model, from a population-based perspective, is that health status measurement is ill-suited to the assessment of outcomes of preventive health care programs (e.g., vaccinations) because health status is measured as "present functional status" (Kaplan & Anderson, 1990). Moreover, the HSMC does not predict an individual's future prognosis (Kaplan & Anderson, 1990). However, Eisen et al. (1980) hold that longitudinal assessments obviate the need to incorporate prognostic considerations into a QOL measure.

Criticisms of each model reflect not only a difference in objectives but also a primary theoretical difference between those who favor the aggregation of QOL ratings into a single numeric index and those who favor the independent assessment of each QOL domain (e.g., Aaronson, 1988; Ware, 1984). The issue of whether to use a single index or profile score for comparison purposes has not been adequately addressed (Osoba, 1994) and varies according to the questions

raised in each investigation. Ideally, the score for each domain would be weighted according to its relative importance, as it cannot be assumed that all QOL domains are equally important across time or individuals (Croog, 1990; Osoba, 1994).

APPROACHES TO QOL ASSESSMENT

In addition to the two conceptual models of QOL assessment, two practical approaches have been suggested: (a) the battery approach, and (b) the modular approach.

The Battery Approach

In the absence of well-validated QOL measures for children, a battery of the best available measures may be used to assess each of the component domains of QOL (Shumaker, Anderson, & Czajkowski, 1990). It is hypothesized that, taken together, the separate evaluation of each QOL domain will result in an overall estimate of a child's QOL. This approach is illustrated by an investigation of pediatric burn victims (Herndon et al., 1986). In addition to standard medical tests, several psychosocial measures were administered including measures of body image satisfaction, self-esteem, anxiety, depression, and interpersonal relationships. The results were not synthesized into a global rating of QOL, but served to identify psychosocial sequelae of pediatric illness and areas for intervention (Herndon et al., 1986). Unfortunately, there are several significant drawbacks to this approach. First, because instruments differ in their conceptual framework, psychometric properties, and scaling systems, it is impossible to determine interrelationships between various aspects of health and the relative importance of each area of dysfunction across instruments (Guyatt & Jaeschke, 1990; Starfield et al., 1993). Second, an analysis of change over time is difficult when multiple measures are used. Finally, the use of separate instruments is often impractical in terms of patient and staff burden (Shumaker et al., 1990).

The Modular Approach

As an alternative to the battery approach, the modular approach was introduced by Aaronson, Bullinger, and Ahmedzai (1988). They recommended the development of a series of brief assessment devices (i.e., modules), which would measure one aspect of QOL. Aaronson (1988) suggested that the creation of *modules* is a flexible and practical alternative to attempts to devise one QOL measure that is "all things to all people." However, for the modular approach to

be psychometrically sound, the reliability and validity of all possible combinations of such modules need to be established. As of this writing, modular measures for children are not yet available.

GUIDELINES FOR REVIEW OF QOL MEASURES

The two primary conceptual models of QOL and the two practical approaches to QOL assessment have limitations that preclude their universal use. Thus, a comprehensive conceptual framework of QOL has not yet emerged to guide the development and selection of QOL measures for children and adolescents. However, consensus has been reached on a number of points. First, QOL is a multidimensional construct, and instruments should include at least the four core QOL domains (i.e., disease state, physical, psychological, and social functioning). Second, given the multidimensional nature of QOL, profile scoring systems that provide a score for each QOL domain are preferable to index or total scores in studies where the richness of QOL data are desired for outcome comparisons. Finally, groups of investigators agree that QOL measures should (a) be reliable and valid, (b) be brief, (c) be easy to administer and score (Mulhern et al., 1989; Schipper & Levitt, 1985), (d) be normed with children at various stages of disease and treatment (Mulhern et al., 1989), (e) discriminate between stages of disease and level of dysfunction (Boggs, Graham-Pole, & Miller, 1991; Mulhern et al., 1989), and (f) assess the frequency of problems rather than estimates of the child's capacity.

This review and evaluation of QOL measures for children and adolescents is not intended to be exhaustive. Measures were selected for review if clearly identified in the literature as QOL instruments, or if used in this capacity. Measures that did not include items or scales for each of the four core QOL components were excluded (with the exception of a global rating scale used extensively to assess childhood QOL). For example, the Functional Disability Inventory (Walker & Greene, 1991), a well-validated measure of functional status, was not included because it does not assess several QOL domains (i.e., disease state, psychological and social functioning). Adult measures of QOL were also excluded unless used with children and adolescents. In general, adult QOL measures are inappropriate for use with children because of the level of abstract decision making that may be required, the advanced reading levels, the lack of developmental considerations, and the inclusion of content areas that may be irrelevant (e.g., financial concerns). The measures meeting the criteria noted are listed in Table I.

In the following section, each QOL measure is reviewed with respect to its psychometric properties (i.e., reliability and validity). It should be noted that when evaluating a QOL measure, traditional standards of reliability may not

Table I. QOL Measures Available for Use with Children and Adolescents[a]

Measure	Domains	Respondent	Targeted age group	No. of items	Psychometric properties	Specificity
Generic Measures						
Play Performance Scale for Children (Lansky et al., 1985)	Functional status	Parent or physician	1–16	1	Interrater reliability Concurrent validity	Disease (cancer)
Utility Measures						
Quality of Well-Being Scale (Kaplan, Bush, & Berry, 1978)	Physical symptoms Mobility Physical activity Functional status	Parent	All ages	Varies (23–38)	Test–retest reliability Construct validity	
Health Profiles						
Health Status Measure for Children (Eisen et al., 1979)	Physical health Mental health Social health General health Somatic symptoms Behavior problems	Parent	0–4, 5–13	38, 59	Internal consistency Content validity Construct validity	
Child Health and Illness Profile (Starfield et al., 1993)	Activity Comfort Satisfaction Disorders Achievement Resilience	Adolescent	11–17	275	Internal consistency Content validity Construct validity	
Disease-Specific Measures						
Pediatric Oncology Quality of Life Scale (Goodwin et al., 1994)	Physical status Emotional status Treatment-related adj.	Parent	4–18	21	Interrater reliability Internal consistency Concurrent validity Discriminant validity	Disease (cancer)
Diabetes Quality of Life for Youths (Ingersoll & Marrero, 1990)	Disease impact Disease worries Life satisfaction	Adolescent	11–18	53	Internal consistency	Disease (diabetes)

[a]All measures are administered in a questionnaire format with the exception of the QWB which is a structured interview.

apply. First, it is expected that interrater (child and proxy) reliability values may be low given the inherent differences between the information available to an individual about his or her own well-being, and that available to an independent observer, even with close, daily contact. Second, test–retest reliability may not be a useful standard for judging QOL instruments because changes in scores over time are expected due to changes in disease state and treatment phase. Thus, the sensitivity of a QOL measure to these changes is a more meaningful criterion.

QOL ASSESSMENT MEASURES CURRENTLY AVAILABLE

There are two general types of QOL instruments, generic and specific. Generic measures assess the range of dimensions that comprise QOL. As such, these instruments may be administered to different illness populations and the results can be compared across groups. Alternatively, specific QOL measures assess concerns that may be particular to a disease, function, or population (Guyatt & Jaeschke, 1990; Patrick & Deyo, 1989).

Generic Measures: Global Ratings

The most basic generic QOL measures are one-time global rating scales. Global ratings of QOL presumably provide a subjective summary of functioning across the independent domains subsumed under QOL (e.g., Eisen et al., 1980). Typically, a global measure comprises a numeric Likert rating in response to a single question (e.g., "How would you rate your child's quality of life during the past 6 days?"). Despite their appeal as brief, easily scored measures, the utility of global rating scales is limited. First, there is a paucity of well-validated global QOL rating scales (Moinpour et al., 1989). Second, global measures provide only a crude estimate of QOL (Ware, Brook, Davies, & Lohr, 1981), and although such measures often *supplement* comprehensive QOL assessment, their sole use is not recommended. Finally, global ratings represent an averaging of patient functioning across domains and do not capture differential ratings (Spilker, 1990).

Play Performance Scale for Children (PPSC)

The PPSC (Lansky, List, Lansky, Cohen, & Sinks, 1985; Lansky, List, Lansky, Ritter-Sterr, & Miller, 1987) is reviewed here as an example of a global rating of QOL developed specifically for pediatric oncology patients. The PPSC is a one-item numeric rating of a child's functional status as reflected by changes in the child's play. The PPSC comprises an 11-point scale from 0 to 100, with

anchors provided for each decile (e.g., 0 = *unresponsive;* 50 = *no active play;* 100 = *fully active, normal*).

Validation studies of the PPSC have shown good interrater reliability between mothers and fathers, and between parents and physicians ($r = .71$ and $r = .74$, respectively) (Lansky et al., 1987; Mulhern, Fairclough, Friedman, & Leigh, 1990). However, Mulhern et al. (1990) found low absolute agreement (kappa = .30, $p < .01$) between health professionals and parents. Concurrent validity has been demonstrated by significant correlations between PPSC ratings for cancer inpatients and outpatients with age-corrected total adaptive behavior composite scores on the Vineland Adaptive Behavior Scale (Sparrow, Balla, & Cicchetti, 1984), a measure of functional status, and three global QOL scales (Mulhern et al., 1990).

Thus, the evidence supporting the use of the PPSC as an assessment instrument of QOL in children is equivocal. Its strengths include the developmental framework on which it is based (an integral issue in the assessment of QOL in children) and the fact that response biases are minimized because of its relatively objective nature (Lansky et al., 1987). The primary weakness of the PPSC is that it is a one-item rating scale, rather than a multidimensional measure of QOL, and is thus a relatively crude instrument (Mulhern et al., 1990).

Generic Measures: Utility Measures

Multiple-item generic instruments are divided into two classes: utility measures and health profiles (Guyatt & Jaeschke, 1990). As noted earlier, the advantage of generic measures is that results can be compared across studies and illnesses. The disadvantages of generic measures are that they may lack precision and sensitivity.

Quality of Well-Being Scale (QWB)

The QWB (Kaplan, Bush, & Berry, 1976; Kaplan et al., 1978) is a utility measure that has been used with both adults and children. The QWB was developed to evaluate health policies by comparing the health outcomes of different disease populations (Kaplan, 1989; Kaplan, Atkins, & Timms, 1984; Kaplan & Bush, 1982). The QWB comprises four scales that focus on the physical impact of an illness. The QWB interview, which takes an average of 12 minutes to complete (Harris et al., 1994), utilizes a 6-day follow-back format wherein a parent reports on the child's status on each of the preceding 6 days.

Extensive preparation is required to administer the QWB, as interviewers must be trained to criteria through practice with audiotaped interviews available from its developers. The scoring procedure is complex, although a computer program is available. A single index score (range: 0–1.0) is obtained, based on

the relative preferences for dysfunction derived from community surveys with adult respondents (Kaplan, et al., 1976).

The QWB index scores have been shown to be reliable over a 1-year period (Kaplan et al., 1978), and interday reliability has been demonstrated (Anderson, Kaplan, Berry, Bush, & Rumbaut, 1989). Low to moderate correlations (rs = .23 to .55, $p < .05$) between parent and adolescent reports on the QWB were obtained in a recent investigation (Czyzewski et al., 1994). The construct validity of the QWB was supported by significant positive correlations between scores on the QWB and self-rated well-being (rs = .42 to .49), as well as negative correlations between QWB scores and age ($r = -.75$), number of chronic medical conditions ($r = -.75$), and number of physician contacts ($r = -.55$) (Kaplan et al., 1976). A recent investigation also obtained significant correlations between QWB scores and treatment history in that children with a greater number of prior hospitalizations and surgeries were rated by their parents as more impaired on the QWB (Bradlyn et al., 1993).

Although there is some evidence to support the discriminant validity of the measure (Kaplan et al., 1976), this has been questioned due to the measure's apparent insensitivity to disease status and variations in health (Ware, 1984). The QWB is believed to be most useful in assessing individuals with high levels of impairment and is relatively insensitive in assessing low levels of impairment (Czyzewski et al., 1994; Richards & Hemstreet, 1994). Similarly, there is mixed evidence regarding the concurrent validity of the QWB with physiological measures (Czyzewski et al., 1994; Harris et al., 1994; Orenstein, Nixon, Ross, & Kaplan, 1989). A more general concern about the QWB is that only the "least desirable" symptom on each day is scored, thus attenuating the scores of patients who report several symptoms.

The applicability of the QWB to pediatric populations has been questioned due to its development on adult samples (Rosenbaum, Cadman, & Kirpalani, 1990). The measure is also judged inappropriate for direct administration with children younger than 14 years of age because young children may have difficulty remembering symptoms for the previous 6 days (Hinds, 1990; Richards & Hemstreet, 1994). Furthermore, the lack of correspondence between patient and parent respondents, and the absence of significant correlations between the QWB and well-validated measures of psychosocial functioning may preclude the use of the QWB with pediatric populations (Czyzewski et al., 1994). Thus, although the QWB has proven to be useful in health policy decision making for adults, there are several limitations with respect to its use with children.

Generic Measures: Health Profiles

An alternative type of generic measure is the health profile. Health profiles are useful for identifying *specific* domains impacted by illness and treatment,

obviating the need for multiple measures, and comparing intervention outcomes across illnesses (Guyatt & Jaeschke, 1990). The primary disadvantage of health profiles is that they may not assess symptoms related to a particular disease or treatment, and thus may be insensitive to changes in health in some populations (Guyatt & Jaeschke, 1990; Patrick & Deyo, 1989). Health profiles are commonly used with adults; the only available health profile for children is the Rand HSMC (Eisen et al., 1980).

Health Status Measure for Children

As noted earlier, the Rand HSMC was developed to assess the impact of different insurance plans on the health status of children in the general population (Eisen et al., 1979, 1980). The HSMC is based on a multidimensional model of child health and is designed to assess the four core QOL domains as well as general health perceptions and behavior problems (Eisen et al., 1979). There are two versions of the measure, one for children ages 0–4, and the other for children ages 5–13. The time frame for individual items varies widely (i.e., from the past 2 years to the past 5 days).

There is evidence to support the psychometric properties of the HSMC (Eisen et al., 1979, 1980). Specifically, the internal consistency for all scales was sufficient for both the 0–4 version (r = .53–.77) and the 5–13 version (r = .57–.87) (Eisen et al., 1980). Test–retest reliability has not been determined; however, internal consistency estimates approximate test–retest data from heterogeneous populations (Eisen et al., 1979). Interrater reliability has not been demonstrated.

The HSMC has been determined to have content, face, and construct validity, and the separate scales contribute unique information to the assessment of child health status (Eisen et al., 1980). In terms of concurrent validity, a modified version of the HSMC correlated significantly and in the expected direction with three of four global QOL ratings and with the Cystic Fibrosis Problem Checklist (Sanders, Gravestock, Wanstall, & Dunne, 1991) in a sample of cystic fibrosis patients (Harris et al., 1994). That is, more positive QOL ratings were associated with reports of less dysfunction and fewer behavior problems.

It has been suggested that the HSMC is not sensitive to different levels of dysfunction in pediatric populations (Pantell & Lewis, 1987), which may reflect the fact that the normative sample primarily comprised healthy children (Eisen et al., 1979). Thus, norms are not available for chronically ill children. However, the HSMC was not designed for diagnostic purposes, nor to detect differences between specific treatments in specific disease populations, but rather to measure changes in children's health status due to health care financing arrangements (Eisen et al., 1980).

Overall, the Rand HSMC holds substantial promise as a generic QOL instrument for children. Its strengths include its multidimensional and develop-

mental framework and the fact that there is empirical support for its validity. Furthermore, the profile scoring system of the HSMC is useful for identifying specific areas of dysfunction. The primary weakness of the HSMC is the lack of normative data for pediatric populations.

Child Health and Illness Profile (CHIP)

The CHIP, a 275-item adolescent self-report measure, is being developed to (a) assess health status in epidemiologic surveys, (b) identify high-risk subpopulations, and (c) assess the impact of health services and policies on child health (Starfield et al., 1993). The CHIP includes six scales: activity, comfort, satisfaction, disorders, achievement, and resilience. These scales were rationally derived through reviews of the existing literature, focus groups, and a convenience sample of 121 adolescents, but have not yet been confirmed through factor analytic procedures. Each item is rated on a 5-point scale ranging from 0 (*most healthy*) to 4 (*least healthy*). The time frame for the measure is not specified. The CHIP currently takes 45 minutes to complete, which may be inconvenient in some settings (Starfield et al., 1993). Content validity, construct validity, and internal consistency have been demonstrated. Alpha coefficients ranged from .78 to .92. Further research is planned to establish the reliability and sensitivity of the CHIP (Starfield et al., 1993). Thus, although the CHIP is still under development, it promises to be a useful generic measure.

Specific Measures: Disease-Specific Measures

It has been recommended that generic QOL measures be supplemented with disease-specific measures (Aaronson, 1988). Disease-specific measures are most likely to provide information that is clinically relevant, and thus may be more readily incorporated into clinical or research protocols than generic measures. The main objection to using disease-specific measures is that they are not comprehensive and do not allow for comparisons of dysfunction across illness groups. Hence, there are trade-offs to consider when choosing between a generic and disease-specific measure. Ideally, the two types of measures may be used in a complementary fashion. It should be noted that disease-specific measures designed for use with children and adolescents are also population-specific measures by definition.

Pediatric Oncology Quality of Life Scale (POQOLS)

An example of a disease-specific measure is the POQOLS (Goodwin, Boggs, & Graham-Pole, 1994). The POQOLS is a brief, cancer-specific, parent-

report assessment of children from preschool age through adolescence. The POQOLS includes three empirically derived scales: physical functioning, emotional distress, and treatment-related adjustment. All items require a frequency rating of observable behaviors during the previous 2 weeks.

Preliminary results indicate the measure has good interparent reliability (r = .89), and internal consistency (alpha coefficient = .85). Concurrent validity has been demonstrated. Specifically, Factor 1 of the POQOLS, a measure of physical functioning, correlated significantly (r = .60, $p < .001$) with PPSC (Lansky et al., 1985) ratings of physical activity. Factor 2, a measure of emotional distress, correlated significantly with internalizing (r = .68, $p < .001$), externalizing (r = .67, $p < .001$), and total scores (r = .67, $p < .001$) on the Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1973). Factor 3, a measure of response to active treatment, was correlated significantly with CBCL externalizing subscale scores (r = .51, $p < .001$). Discriminant validity has also been demonstrated, in that scores on Factors 1 and 3, and POQOLS total scores accurately classified children undergoing treatment and those in remission (Goodwin et al., 1994).

The POQOLS meets many of the important requirements of a useful QOL measure. First, it was developed within both a multidimensional and developmental framework. Second, it is a brief instrument that measures observable behaviors, has good psychometric properties, and discriminates between stages of illness. A useful extension of this measure would be age-appropriate self-report versions that would allow children and adolescents to provide subjective evaluations.

Diabetes Quality of Life Instrument (DQOL)

The DQOL is a diabetes-specific self-report measure for adolescents (Ingersoll & Marrero, 1990). The rationally derived scales are disease impact, disease-related worries, and life satisfaction. Items on the first two scales are rated in terms of frequency, and items on the third scale are rated by degree of satisfaction. The DQOL also includes a global rating of overall health.

Cronbach's alpha estimates ranged from .82 to .85 across the three scales, demonstrating internal consistency. The three scales were not found to be statistically independent, indicating that separate factors are not measured by this instrument. Scale scores did not correlate with a physiologic measure of diabetes metabolic control (i.e., total stable glycosylated hemoglobin; HbA_1), although the global health rating was significantly correlated with glycosylated hemoglobin values.

A strength of the DQOL is that it is a self-report measure that assesses adolescents' subjective evaluations of the impact of diabetes on their functioning.

However, the subjective evaluations are based on covert behaviors (i.e., degree of worry or satisfaction), rather than on the occurrence of observable behaviors. A weakness of the DQOL is that it does not assess QOL as it is generally conceptualized in that the four core QOL domains are combined within the three scales which precludes the identification of specific areas of dysfunction. Another weakness of the DQOL is that a time frame for item ratings is not specified, thus hindering judgments about the impact of changes in health or treatment on QOL.

Specific Measures: Function-Specific Measures

Generic QOL instruments may also be supplemented by measures that address a specific area of functioning that is relevant to a particular illness or treatment. For example, the assessment of the neuropsychological functioning of acute lymphocytic leukemia patients treated with irradiation and/or intrathecal medication might be indicated to obtain comprehensive QOL evaluations. However, by definition, function-specific assessments focus on one aspect of QOL, and should not be interpreted as proxy measures of the multidimensional construct of QOL.

As noted earlier, although QOL and functional status are often used synonymously, they are distinct concepts wherein functional status refers to degree of impairment and QOL refers to both the subjective and objective evaluation of the impairment (Richards & Hemstreet, 1994). Therefore, as an instrument becomes more specific to function, disease, and population, or a combination thereof, it may no longer meet the comprehensive goals of a QOL measure. For example, the Cystic Fibrosis Problem Checklist (Sanders et al., 1991) and the Asthma Problem Behavior Checklist (Creer, Marion, & Creer, 1983) were both developed to assess behavior problems among children with a particular illness. Such measures aid in identifying patient behaviors that exacerbate a chronic illness or hinder effective treatment and they may provide important supplemental information within the context of a QOL investigation. However, their specificity precludes their sole use as QOL instruments.

FUTURE CHALLENGES IN CHILD AND ADOLESCENT QOL ASSESSMENT

As discussed earlier, QOL assessment generates clinical information that can provide a basis for improvements in the medical and psychological care of children and adolescents. However, despite the numerous and compelling arguments in favor of obtaining QOL data, such data are not typically collected in

pediatric clinical trials and research protocols. During the past two decades (i.e., 1972–1992), only 5% of all Phase III Cooperative Group pediatric oncology clinical trials included QOL outcomes (Bradlyn, Harris, & Spieth, 1995).

Although a comprehensive discussion of the methodological issues and practical problems encountered when conducting child and adolescent QOL assessment is beyond the scope of this paper, it is important to consider briefly the following barriers. First, as highlighted in this paper, the use of psychometrically sound QOL measures is an important prerequisite for obtaining valid QOL outcomes. The lack of such measures greatly hinders advances within this area. Second, practical problems such as the amount of professional and patient time required for completion, scoring, and interpretation of QOL data must be considered. Third, despite overwhelming agreement that QOL assessment should include subjective evaluations as well as objective data, self-reported health perceptions continue to be viewed with skepticism by the medical community.

The inclusion of QOL outcomes in future clinical trials can be facilitated by addressing each of these points. Clearly, the demonstration of the psychometric properties of available measures as well as the development of well-validated measures would encourage their use. Several investigators are currently developing measures that promise to meet the criteria discussed here (e.g., F. D. Armstrong, personal communication, January 1995; Landgraf, 1991). Additionally, pediatric QOL instruments that account for developmental changes in cognitive and language abilities will yield more accurate results and thus could lead to greater confidence in the subjective ratings of children and adolescents. Evidence that children and adolescents provide unique and reliable information about the quality of their lives should be emphasized. In conclusion, it is important to address these issues to encourage the systematic consideration of QOL outcomes that can inform interventions designed to improve the qualitative aspects of the lives of child and adolescent patients.

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