

How to assess quality of life in child and adolescent psychiatry

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This article provides an overview of the conceptual foundations of measuring health-related quality of life (HRQoL) in children and adolescents in child and adolescent psychiatry, and of the current state of research in this field. The available procedures for determining quality of life are presented according to their areas of use and their psychometric characteristics. The internationally available generic instruments for measuring HRQoL in children are identified and assessed in terms of their strengths and weaknesses with regard to selected criteria. As a result, seven generic HRQoL instruments and two utility procedures have been identified which satisfy the following criteria: (i) psychometric quality; (ii) age-appropriate measurement; (iii) versions for self-reporting and external rating; and (iv) cross-cultural measurement. The identified instruments satisfy the individual criteria to different degrees. They are increasingly being used in health services research, treatment studies, and epidemiological research; however, they are not yet widely used as part of the clinical routine in child and adolescent psychiatrics.

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Introduction

The onset of a psychiatric disorder in children and adolescents often occurs at a time in life that is characterized by considerable upheavals. In adolescents, detaching oneself from one's parents, experiencing one's first love and first heartbreak, finishing school and starting vocational training, initial experiences with alcohol and drugs, as well as many other factors, play an important role, both as potential triggers or amplifiers of a psychiatric disorder and for the adolescents' subjective quality of life. In addition, there are important factors associated with the disorder itself, including the way adolescents cope with their first experiences with treatment, as well as dealing with the stigma of having a psychiatric disorder and being confronted with the need for potentially lifelong treatment. In addition, symptoms such as affective and cognitive disorders often arise many years before the psychiatric disorder

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itself becomes manifest, and may have a negative effect on the subjective well-being and everyday lives of those concerned long before the disease is recognised as such and treated. All these factors make it harder for children and adolescents suffering from psychiatric disorders to cope with their age-appropriate development and therefore have serious, long-term consequences for their quality of life.

The patients' subjective perception of the disorder and their living circumstances is subject to complex psychological assessment and processing. The connection between health-related quality of life, psychiatric disorders, and external living circumstances cannot be understood without knowledge of these processes. Both age-appropriate and disease-related aspects must therefore be taken into account when examining the quality of life of adolescents or patients with psychiatric disorders.^{1,2} In this paper, we will therefore look at age-specific aspects of measuring the quality of life of children and adolescents.

Aspects of measuring quality of life in children and adolescents

When evaluating medical interventions within the medical health services system, not only the quality of life of adults but also that of children and adolescents can be viewed as an important outcome criterion. The use of medical assistance affects not only somatic, but also emotional and social parameters; it is therefore necessary to shed light on the state of children and adolescents from their own point of view. Research into the quality of life of children and adolescents is particularly important also because the number of children and adolescents with chronic disorders, including psychiatric disorders, has increased despite the impressive progress made in medicine.

One reason why quality of life is increasingly being taken into account in clinical and health-economic studies is, therefore, the substantial changes in the range of disorders and treatments that have been observed in children and adolescents since the 1980s. This so-called "new morbidity" is characterized by a shift from acute to chronic diseases and from somatic to psychiatric disorders.³ This makes it necessary to take into account the long-term quality of life or subjective health of young patients, and to identify the everyday burden due to the disorder, so as to expose potential impairments in well-

being and function at an early stage. Hence, an understanding of the subjective perception among children and adolescents of their health status and their treatment can be used to assess treatment success, but also on an individual level to optimize the treatment itself.⁴

Although medical interventions often lead to an objective improvement in the health status of children and adolescents, the frequent hospitalization, multiple operations, and not least the uncertainty about the future can be shown to have a detrimental effect on the course of the disease and on how well patients cope with it.⁵ The question of how adolescents feel about their health and their treatment is just as important when assessing treatment success as it is for optimizing treatment in individual cases. So far, the diseases that have been examined most often—aside from diseases with high mortality rates—are those that may display sudden crises, in some cases on a life-threatening scale, as well as diseases whose treatment is very costly. Frequently occurring and less threatening diseases, or diseases that only persist for a limited time, take a back seat by comparison. Health-related quality of life (HRQoL) has therefore moved into the focus of the assessment of treatment options, particularly for those chronic disorders that do not reduce life expectancy but instead accompany patients throughout their lives, as may be the case with psychiatric disorders.⁶ By concentrating on the patients' needs, additional insights can be gained into the meaningfulness and usefulness of the respective procedures, and subjective differences between different treatment measures can be uncovered.

Compared with adults, the measurement of HRQoL in children and adolescents is still a relatively new field of research.⁷ Initially, the dimensions of HRQoL found in adults were usually simply transferred to children. The available measures primarily involved an external assessment by parents, and new instruments were often developed ad hoc for a specific study and without adequate quality checks. The guidelines for developing HRQoL instruments for children issued by the Mental Health Division of the World Health Organisation (WHO)⁸ demand that "such measures should be age-appropriate and child-centred, preferably take into account self-reporting, be usable independently of the health status and cross-culturally, and should include both positive and negative aspects" of the relevant domains (eg, family/social relations, physical function, social and material environment). Beyond this, quality of life instruments must

meet the quality criteria for psychometric procedures (reliability, validity, sensitivity to change).⁹

When measuring the HRQoL of children and adolescents, a series of aspects need to be taken into account in terms of contents and method, which will be outlined below.^{4,10,11}

Quality of life research in children and adolescents faces various challenges.⁷ The most important research questions for the measurement of quality of life primarily concern the following key aspects:

- What dimensions of HRQoL are relevant to children and adolescents, and do suitable instruments exist to measure these?
- What are the advantages and disadvantages of self-reported and proxy-reported measures of child and adolescent quality of life, and how can HRQoL be ascertained in an age-appropriate way?
- What are the advantages and disadvantages of disease-specific and generic measures?

Answering these questions is of far-reaching importance for the quality of the measurement of quality of life in children and adolescents, and hence for its usefulness as an outcome parameter, and for assessing and choosing between treatment options.

Measures relevant to children and adolescents

There is a general consensus that quality of life should be viewed as a multidimensional construct comprising at minimum a physical, an emotional, and a social component of well-being and function.¹² Concerning the question whether children and adolescents describe their quality of life on the same dimensions as adults, the general definition of quality of life given by Matza et al¹³ for adults, namely ‘an individual’s subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social functioning,’ also applies to children and adolescents. However, the specific aspects of children’s lives that are included in these three components are different. Although it is assumed that those dimensions that are relevant to adults are also significant to children and adolescents,¹⁴ their relative weights and constellations may be expected to differ at different ages. According to Schor,¹⁵ for example, the different quality of life dimensions are more closely connected in children than they are in adults. Adapting instruments designed for adults to

measure child and adolescent quality of life would therefore seem problematic.

Self-reported vs observed measures

HRQoL is generally considered to be a latent construct, which cannot be directly observed, and irrespective of its definition or underlying concept it includes the perception and judgement of one’s own life from the individual’s own subjective perspective, as well as one’s subjective well-being, or affective mood. These two assumptions mean that, when possible, quality of life should be measured using self-reporting.¹⁶ Hence the quality of life of children and adolescents, too, should ideally be ascertained by means of self-reporting. The parental assessment of children’s quality of life is an uncertain substitute for self-reporting, based on the assumption that the latter has higher (conceptual) validity, and should only be used as a “last resort” or as an additional source of information, for example concerning physical or emotional problems, since parental assessment does not represent the way in which the disease is perceived and experienced by the children themselves. Research to date has shown that, contrary to former doubts, the quality of life of children and adolescents can be measured using self-report questionnaires, provided these instruments are developed with the age, maturity and cognitive development of the subjects in mind.¹⁷ Although the understanding of the quality of life concept and the assessment of one’s own health and well-being is determined by the three factors described, children and adolescents over the age of 8 are able to understand and give reliable and valid answers to questions about their quality of life.¹⁸

Self-reporting has its limits, particularly in children under the age of 8, so that here an external assessment of a child’s quality of life must be obtained from his or her parents, or else from his or her teachers or the medical health care team. Such a proxy assessment can be obtained by asking parents to rate their child’s quality of life from the child’s point of view (proxy-patient perspective) or from their own point of view (proxy-proxy perspective).¹⁹ However, empirical studies have only revealed a low-to-moderate correlation between parental and self-reported ratings.^{20,21} A higher correlation between the self-reported and proxy ratings has been observed for the observable aspects of HRQoL, such as physical well-being, than for the non-observable aspects, such as emotional well-being.²¹

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There is a consensus that in children over the age of 8 parental ratings can supplement self-reporting but not replace it. Parents are not objective judges, but have their own perspective, which can serve as an additional source of information.²²

As a matter of principle, when assessing the HRQoL of children and adolescents it is necessary to take into account their development and the ongoing changes occurring over time, for example with regard to their perception of their own emotional state. A longitudinal evaluation of HRQoL must therefore take into account both the baseline level and the natural changes over time, since the effect of medical treatments cannot otherwise be distinguished from normal developmental changes. However, the possibility of an adaptation of internal assessment standards must also be taken into consideration in cross-sectional studies on chronic diseases, due to a phenomenon which is described as the “well-being paradox”²³ or “response shift.”²⁴ Some authors offer age-specific versions of their questionnaires in order to take into account the different stages of development. A key requirement for an age-appropriate measurement of quality of life is that the target concerned should be involved when developing an instrument: the contents of a quality of life measure should therefore ideally be obtained directly from the children concerned.

Disease-specific vs generic measures

Disease-specific quality of life measures are designed to determine the quality of life in certain diagnostic groups or patient populations. To do so, they look at those aspects which are particularly relevant to these groups or disorders, such as distinctive features of the treatment options. Disease-specific measures are generally appropriate for the clinical examination of specific treatment interventions; however, they make it more difficult to compare quality of life measurements across different—physical and psychological—disorders.

When studying general health and when comparing the effects and courses of different disorders, non-specific—so-called generic—measures are more relevant. These ascertain as wide a range of quality of life aspects as possible and can be used for different diseases, disabilities, situations, patients, and populations.²⁵ When additional disease-specific information is to be considered on top of generic aspects of quality of life, a number

of measures offer additional disease-specific modules, which examine the specific effects of chronic diseases in childhood on top of generic items and scales.

When it comes to the cross-cultural measurement of HRQoL, it should be noted that quality of life measures for children have often been developed in different countries and cultures, and therefore need to be translated and checked psychometrically before they can be used in another language.¹⁷ Multinational measures for children have so far primarily been made available by adapting existing instruments, which have then been confirmed in other countries (sequential approach).²⁶ In order to ensure a cross-culturally similar measurement of HRQoL, the corresponding instruments should ideally be developed, harmonized and tested using a simultaneous, multinational approach (simultaneous approach).²⁷ The two European quality of life measures for children, KIDSCREEN²⁷ and DISABKIDS,²⁸ are examples of this approach. Following a review of the literature and discussions by a panel of experts (Delphi), focus groups with children were carried out simultaneously in different countries to identify those dimensions of quality of life that were relevant to the children and to formulate the appropriate items.²⁷ To ensure a cross-culturally comparable measurement, the developers checked whether respondents with similar characteristics had the same likelihood of answering the items in a similar way, irrespective of their nationality. The results of this multinational approach show that it is indeed possible to measure HRQoL on different dimensions in a way that is comparable across different cultures.²⁹ Although such cross-cultural and simultaneous approaches are the exception, so far, they are desirable in view of their methodological quality. If data on the HRQoL of children and adolescents are to be compared cross-culturally, it is advisable to use measures that were developed using such a simultaneous approach (eg, KIDSCREEN, DISABKIDS).

HRQoL can be determined using profile and index measures. Profile measures map the individual dimensions of quality of life (eg, physical well-being, emotional well-being, social support, friends, relationship with parents, school environment). They are particularly suitable for clinical research and for measuring an individual's quality of life because they allow the effects of a clinical intervention on the different dimensions of quality of life to be examined, and comparisons to be made between the quality of life of different individuals,

also for individual dimensions.³⁰ In index measures, on the other hand, the individual ratings for the quality of life dimensions are collated to form a global aggregate score. This makes index measures particularly suitable for epidemiological studies and health reporting. However, one disadvantage of this is that they are limited when it comes to representing the multidimensionality of the quality of life construct.

Existing instruments for measuring the HRQoL of children and adolescents

In recent years, new instruments have increasingly been developed for measuring the HRQoL in children.¹⁰ The Quality of Life Instruments Database (QOLID; <http://www.qolid.org/>) provides a good overview of the existing generic and disease-specific measures.

Table 1 summarizes the health-related quality of life measures for children and adolescents, listed in order of the year they were introduced, that are currently most commonly used (internationally) and that satisfy the following criteria:

1. Can be used across different diseases and disorders
2. Are available internationally in several languages
3. Their psychometric quality has been tested and found to be adequate
4. Are available as a self-report measure
5. Have been published scientifically
6. Were primarily designed for children and adolescents
7. Measure the three main components of health-related quality of life (physical, emotional and social well-being) as defined by the WHO.

The questionnaire *Child Health and Illness Profile* (CHIP, www.childhealthprofile.org), originally developed in the US, primarily focuses on measuring functional aspects of quality of life and is available in a Child Edition CHIP-CE³¹; for children between the ages of 6 and 11, and as an Adolescent Edition CHIP-AE³²; for adolescents between the ages of 12 and 17. The Adolescent Edition comprises 108 items distributed between five health dimensions: satisfaction, complaints, resilience, achieving social goals, and risk avoidance. The shorter Child Edition (45 items) comprises the four dimensions satisfaction, complaints, resilience, and risk avoidance and is available as a self-report form and a parental questionnaire.

The CHIP produces a sum score for each of the dimensions as well as a multidimensional profile of the

quality of life, based on the different dimensions. The resulting personal profile can be characterized using a taxonomy of health profiles, allowing the subject's overall situation to be described comprehensively and yet manageably.³³

The CHIP has good psychometric properties, with a high reliability (Cronbach's $\alpha > .70$) for most of the subscales and satisfactory criterion validity. Furthermore, the measure enjoys a high level of acceptance among children and adolescents, as well as among parents.³⁴⁻³⁶

The widely used *Child Health Questionnaire* (CHQ), which also originated in the US, was designed for children and adolescents between the ages of 10 and 18.^{37,38} In addition to a self-report version (87 items) there is also a parents' version for children over the age of 5 (50 items or 28 items). Apart from assessing general health, the measure covers 14 different concepts of physical (physical function, physical pain, general health perception), psychosocial health (self-esteem, mental health, behavior, parental burden due to the physical/mental health of the child) and disabilities associated with these (physical and/or mental impairment of social roles and family activities). The individual scale scores can be combined to form a physical and a psychosocial aggregate score. The CHQ displays good psychometric properties (Cronbach's $\alpha > .70$) and the parental version has already been validated for more than 21 languages.³⁹ Weaknesses of the measure include the length of the self-report version (87 items) and its focus on those aspects of child health and well-being that are primarily relevant to parents (eg, burden imposed on parents by children's health).

The *KINDL-R* (www.kindl.org) is an originally German-language quality of life measure for healthy and ill children and adolescents, which has been translated into 22 languages.⁴⁰ The questionnaire was developed with the help of focus groups involving children and adolescents and is available in age-adapted self-report versions and proxy versions for parents, for the age groups 4 to 7 years (12 items), 8 to 12 years (24 items), and 13 to 16 years (24 items). In the case of 4- to 7-year-old children, self-reporting is achieved by means of standardized interviews. Another possible measure is the computer-assisted *CAT-SCREEN* program,⁴¹ which is available in German and English for self-completion by children from the ages of 6 to 12 years and by adolescents from the ages of 13 to 16 years. It measures the HRQoL of children and adolescents in a way that is

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Instrument	Country	Type	Perspective	Age range	No of items/ time	Available languages	Standard scores for Germany available	Profile/ Index
CHIP <i>Child Health and Illness Profile</i> ^{31,32}	USA	Generic	Self/Parents Self	6-11 12-17	45, 108 20 to 30 min	Parent version: incl. German, English, Polish, Russian, Turkish, Self-report version: Chinese, English, French, Portuguese, Spanish	No	Profile
CHQ <i>Child Health Questionnaire</i> ^{37,38}	USA	Generic	Self Parents	10-18 5-18	87 50, 28 (short form) 15 to 30 min	incl. German, English, French, Italian, Polish	No	Profile and Index
KINDL-R <i>Revised Children's Quality of Life Questionnaire</i> ⁴²	Germany	Generic + disease-specific modules	Self/Parents	4-16	24 (8-16y) 12 (4-7y) 5-10 min	incl. German, English, Italian, Polish, Russian, Serbian, Turkish	Yes	Profile and Index
PedsQL <i>Pediatric Quality of Life Inventory</i> ^{45,46}	USA	Generic + disease-specific modules	Self Parents Parents	8-18 2-18 0-2	23 23 45/36 (short form) 10-15 min	incl. German, English, Spanish, Russian, Turkish	No	Profile and Index
DISABKIDS <i>Quality of Life Inventory</i> ^{28,50}	Multinational (AT/DE/FR/GR/NL/SW/UK)	Chronic-generic + disease-specific modules	Self Self Parents	4-7 8-16 4-16	3 37/12 (short form) 5-15 min	incl. German, English, French, Greek, Dutch, Swedish	Yes	Profile and Index
KIDSCREEN <i>Quality of Life Questionnaire</i> ²⁹	Multinational (AT/CH/CZ/DE/FR/GR/HU/IE/NL/UK/PL/SP/SW)	Generic	Self Parent	8-18	52, 27 (short form), 10 (index)	incl. German, English, French, Polish, Serbian, Spanish, Romanian	Yes	Profile and Index
ILK <i>Inventory for Measuring Quality of Life in Children</i> ⁵⁴	Germany	Generic	Self/Parents	6-18	20 per dimension 15 min	German, English, French	Yes	Profile
Utility Procedures								
HUI 2 <i>Utility Index Mark 2</i> ⁶⁰	Canada	Generic	Self	4-18	7 8 min	incl. German, English, Polish, Romanian, Russian, Serbian, Turkish	No	Index
EQ-5D-Y ⁵⁶	Multinational (DE/I/NL/SA/SP/UK)	Generic	Self	8-18	6 8 min	incl. German, English, French, Polish, Spanish, Turkish	No	Index

Table 1. Internationally available instruments for measuring health-related quality of life in children and adolescents. AT, Austria; CH, Switzerland; CZ, Czech Republic; DE, Germany; FR, France; GR, Greece; HU, Hungary; IE, Ireland; NL, Netherlands; PL, Poland; SA, South Africa; SW, Sweden; SP, Spain; UK, United Kingdom

suitable for children and for their stage of development at the respective age. The KINDL-R includes indicators of physical, emotional, family, social, and school-related well-being, as well as of self-esteem. Furthermore, the core questionnaire can be extended by means of disease-specific modules (eg, obesity, asthma, diabetes, cancer). When interpreting the KINDL-R, a profile consisting of six scores is calculated, as well as an overall score for HRQoL. The good psychometric properties of the KINDL-R, such as the high reliability (Cronbach's $\alpha > .70$) of most of its subscales and its good ability to discriminate between different clinical diagnoses, have been demonstrated in various studies.^{42,43} Furthermore, standardized values are available for Germany for the purpose of comparison.⁴⁴

The questionnaire *Pediatric Quality of Life Inventory Generic Core Scales* (PedsQL 4.0, www.pedsql.org) was developed in the US in order to measure the HRQoL of healthy and ill children and adolescents (5 to 18 years old) and is available as a self-report and parent-reported version (23 items).⁴⁵ The newly-developed *Pediatric Quality of Life Inventory Infant Scale*,⁴⁶ allows the quality of life of young children between the ages of 1 and 12 months (36 items) and 13 to 24 months (45 items) to be measured by means of parent reporting. The core measure comprises dimensions for physical, emotional, social, and school-related (or cognitive) function. To evaluate the results, a psychosocial sum score can be calculated (emotional, social and school-related or cognitive function) as well as an overall score. The PedsQL subscales can optionally be augmented by various disease-specific modules (eg, asthma, brain tumor, diabetes). The Pediatric Quality of Life Inventory has already been used in numerous different research settings, and is characterised by a high reliability of its individual subscales (Cronbach's $\alpha > .80$) and the total score (Cronbach's $\alpha > .90$). Numerous studies have shown that healthy children achieve higher scores (indicating greater quality of life) on the PedsQL scales than do chronically or acutely ill children. It can therefore be assumed to display good construct validity.^{46,47}

The *KIDSCREEN* questionnaire (www.kidscreen.org) was developed simultaneously in 13 countries in an international collaboration and is based on probabilistic test theory. It measures physical (physical well-being), psychological (psychological well-being, moods and emotions), social (social support and friends, social acceptance), family (relationship with parents, auto-

my, financial possibilities), and school-related aspects of the well-being and function of children and adolescents between the ages of 8 and 18 years.²⁹ The questionnaire is available as a self-report and proxy version for parents. In addition to the long version, with 52 items and 10 dimensions, there is also a short version, as well as a 10-item index of general HRQoL. The high validity and reliability of the KIDSCREEN subscales have been demonstrated in multinational studies.^{29,48,49} Statistical analyses show that the items of the KIDSCREEN are understood similarly across different cultures, age groups, sexes, and for different diseases and disorders, and allow the principal components of HRQoL to be measured in a similar way in children and adolescents. The KIDSCREEN questionnaire therefore fulfils the standards required by the WHO for a child-appropriate measurement of HRQoL. The self-report version for children and adolescents is now available in 38 languages and the proxy version in 31 languages.

The *DISABKIDS Quality of Life Inventory* (www.disabkids.org) was developed in seven European countries using the same cross-cultural approach. It is a disease-specific or chronic-generic measure, which allows the HRQoL of children (4 to 16 years old) with various chronic disorders (eg, asthma, cystic fibrosis, cerebral palsy, diabetes, arthritis, and skin disorders) to be determined using so-called chronic-generic items and scales specific to the various diagnoses, either by self-report or by proxy.^{28,50} Age-adapted versions are available for children between the ages of 4 and 7 years, and children between 8 and 16 years. The instrument measures mental facets (independence, emotions), social facets (social inclusion, social exclusion), and physical facets (limitations, treatment) using 37 items, whereby a total score can also be calculated. A short form, consisting of 12 items, is also available. In addition to the chronic-generic module, seven disease-specific modules have been developed, each with 2 to 3 subscales and 12 to 17 items.⁵¹ Its psychometric quality has been examined in a multinational study, the results of which indicate high reliability scores (Cronbach's $\alpha > .70$) for the individual scales, as well as cross-cultural validity of the measure.^{52,53} The questionnaire is now available in six languages.

The *Inventory for Measuring Quality of Life in Children and Adolescents*, ILK,⁵⁴ developed in Germany, is a screening tool for measuring quality of life in healthy, as well as in psychologically or physically ill children

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and adolescents (6 to 18 years old). The instrument asks the children, their parents, and their doctors/therapists questions about four different areas of quality of life: school, family, social contact with peers, and interests and recreational activities. Beyond this, information is collected about their physical and psychological health, as well as an overall rating of their quality of life. In the case of children and adolescents suffering from a disease or disorder, additional questions are asked about the burden imposed by the current illness and by the diagnostic and therapeutic interventions. Overall, the instrument displays satisfactory psychometric properties and representative standard scores are available for Germany, as are comparative scores from child and adolescent psychiatric practices and clinics, as well as child and adolescent departments.⁵⁴

The *Health Utility Index Mark 2* (HUI2, <http://www.healthutilities.com>) is a generic measure and is one of the so-called preference-based instruments for children and adolescents.⁵⁵ Such instruments measure the individual aspects of HRQoL and then summarize them in the form of a one-dimensional score, or index. The HUI measures the health status along seven dimensions: emotions, perception, mobility, cognitions, self-care, pain, and fruitfulness. For each dimension, 3 to 5 alternative answers (levels) are available for selection, whereby a low level (eg, 1 = *able to walk, bend, lift, jump, and run normally for age* [Mobility dimension]) indicates good health, and a high level (eg, 5 = *unable to control or use arms and legs* [Mobility dimension]) indicates poor health. Subjects use these seven dimensions to rate their subjective health (eg, 3223242). Due to the different possible combinations, 24 000 different health scores can theoretically be determined, whereby the score 111111 corresponds to perfect health. An algorithm is used to convert the measured health scores into a unidimensional index, which can then be used in cost-benefit analyses. The reliability and validity of the measure have been demonstrated.⁵⁵

The *EQ-5D-Y*⁵⁶ is the children's version of the *EQ-5D*, a widely used, generic, preference-based instrument that was originally designed by the EuroQol Group to measure HRQoL in adults.⁵⁷ The *EQ-5D-Y* can be used for self-completion by children and adolescents from the age of eight years upwards, and uses five items to record the dimensions Mobility, Self-Care, General Activity, Pain/Physical Symptoms, Anxiety and Depression. Beyond this, children assess their current health using

a visual analogue scale (VAS) ranging from 0 (worst condition) to 100 (best condition).⁵⁸ In developing the children's version, cognitive interviews were carried out with children in four different countries.⁵⁶ A first multinational study has shown the *EQ-5D-Y* to be easy to use, and a reliable and valid instrument for measuring the HRQoL in children and adolescents⁵⁸; this needs to be confirmed by further population-based and clinical studies. The test scores can be transformed by means of an algorithm into index scores, and can then be used in cost-benefit analyses.

Examples of quality of life items (KIDSCREEN instrument) can be seen in *Table II*.

Discussion

In terms of the opening questions about the measurement of HRQoL in children and adolescents, it can be stated that international instruments for measuring HRQoL in children and adolescents are now available, which allow the most important dimensions of the construct to be measured. Although no single quality of life measure can claim to cover the entire universe of HRQoL in all its possible facets, the quality of life dimensions that are relevant to a specific subject of investigation can indeed be measured. The quality of life of children and adolescents can and should be measured through self-reporting. In order to do this, however, age-appropriate measures must be used, which take into account the subjects' maturity and cognitive development. Only generic quality of life measures allow HRQoL to be measured across different diseases and disorders, and can be used both for ill and for healthy children and adolescents.

Despite the availability of such instruments, longitudinal studies on the quality of life of children and adolescents are still rare in the field of medicine. In view of the increasing attention being paid to the psychosocial aspects of health, there is still a considerable need for research into the subjective health of children and adolescents. With the help of quality of life measures, studies can examine the well-being and function of large populations, thus providing reference data for ill children and adolescents as well as giving an indication of medical and health-policy interventions that may be necessary. In a clinical context, the health of young patients can be improved not only by performing medical procedures but also by teaching psychological strate-

Feelings - Thinking about the last week...
1. Has your life been enjoyable?
not at all slightly moderately very extremely
2. Have you felt pleased that you are alive?
not at all slightly moderately very extremely
3. Have you felt satisfied with your life?
not at all slightly moderately very extremely
4. Have you been in a good mood?
never seldom quite often very often always
5. Have you felt cheerful?
never seldom quite often very often always
6. Have you had fun?
never seldom quite often very often always
General Mood - Thinking about the last week...
1. Have you felt that you do everything badly?
never seldom quite often very often always
2. Have you felt sad?
never seldom quite often very often always
3. Have you felt so bad that you didn't want to do anything?
never seldom quite often very often always
4. Have you felt that everything in your life goes wrong?
never seldom quite often very often always
5. Have you felt fed up?
never seldom quite often very often always
6. Have you felt lonely?
never seldom quite often very often always
7. Have you felt under pressure?
never seldom quite often very often always
About yourself - Thinking about the last week...
1. Have you been happy with the way you are?
never seldom quite often very often always
2. Have you been happy with your clothes?
never seldom quite often very often always
3. Have you been worried about the way you look?
never seldom quite often very often always
4. Have you felt jealous of the way other girls and boys look?
never seldom quite often very often always
5. Would you like to change something about your body?
never seldom quite often very often always

Table II. Example items from the instrument “KIDSCREEN” for measuring health-related quality of life in children and adolescents.

gies, which means that the quality of life of the adolescents is an important target criterion here.

Future studies ought to focus more on the specific needs of young patients, in order for example to be able to assess how important individual quality of life dimensions are for the further course and for the prognosis of diseases. Also, despite the fact that the majority of patients suffering from psychological disorders live with their families, or in close contact with their families, hardly any studies exist that examine the quality of life of the families and relatives of patients with child and adolescent psychiatric disorders. Future studies should therefore take greater account of the social environment of child and adolescent patients when examining their quality of life, with a view to developing a better understanding of the interactions and interconnections, and being able to incorporate the results of quality of life research in future treatment concepts.

One of the particular challenges facing quality of life research in children and adolescents is the need to place even greater emphasis of self-reporting, and to take into account the way they process and cope with their disease or disorder. By systematically disseminating the empirically based understanding of the quality of life of young patients, as well as the possibility of measuring it and changing it by means of treatment strategies, quality of life research can continue to develop. It can contribute to the quality of life of children and adolescents undergoing treatment, not only as the subject of the individual doctor-patient relationship during treatment, but also as a target criterion in clinical trials and treatment studies. Such a set of tools ultimately serves the goal of assessing the treatment outcomes of child and adolescent patients, and of their families, and thus opens up new paths for further improvements in the medical and psychological care of those concerned.⁵⁹

Conclusions

Based on the existing findings, the following conclusions can be drawn about measuring the HRQoL in children and adolescents:

1. Instruments are now available for determining the HRQoL of children that allow the relevant dimensions of the construct to be measured.
2. HRQoL can be measured by means of profile or index instruments. Profile instruments reproduce the individual dimensions of quality of life. An index in-

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strument, on the other hand, converts the ratings of the individual quality of life dimensions into a single, global aggregate score.

3. Some instruments take different age groups into consideration and have corresponding versions as age-appropriate measures.
4. The quality of life of children and adolescents from the age of 8 and upwards can and should be determined through self-reporting.

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¿Cómo evaluar la calidad de vida en psiquiatría infantil y del adolescente?

Este artículo proporciona una panorámica de los fundamentos conceptuales de la medición de la calidad de vida relacionada con la salud (CdVRS) en psiquiatría de niños y adolescentes, y del estado actual de la investigación en este campo. Los procedimientos disponibles para determinar la calidad de vida se presentan de acuerdo con sus áreas de utilización y sus características psicométricas. Se identificaron y evaluaron los instrumentos generales disponibles a nivel internacional para medir la CdVRS en niños según sus fortalezas y debilidades en relación con los criterios de selección. Como resultado se identificaron siete instrumentos generales para CdVRS y dos procedimientos útiles que cumplieron con los siguientes criterios: 1) calidad psicométrica, 2) medición apropiada para la edad, 3) versiones para auto-reporte y medición externa, y 4) medición transcultural. Los instrumentos identificados cumplieron los criterios individuales en grados diversos. Ellos se están empleando cada vez más en investigación de servicios de salud, estudios terapéuticos e investigación epidemiológica; sin embargo, todavía ellos no son muy usados como parte de la rutina clínica en psiquiatría de niños y adolescentes.

Comment évaluer la qualité de vie des enfants et des adolescents en psychiatrie ?

Cet article présente une synthèse des concepts de base de la mesure de la qualité de vie (QdV) chez les enfants et les adolescents en psychiatrie et de l'état actuel de la recherche dans ce domaine. Les tests de mesure de la QdV disponibles sont présentés d'après leur champ d'utilisation et leurs caractéristiques psychométriques. Les outils génériques internationaux de mesure de la QdV pour les enfants sont identifiés et évalués en termes de force et de faiblesse d'après les critères sélectionnés. Sept outils génériques de la QdV et deux méthodes sont ainsi répertoriés, satisfaisant aux critères suivants : 1) qualité psychométrique 2) mesure adaptée à l'âge 3) versions d'auto- et d'hétéro-évaluation 4) mesure interculturelle. Ces outils répondent à des degrés divers aux critères individuels. Ils sont de plus en plus utilisés dans la recherche de Santé publique, les études thérapeutiques et la recherche épidémiologique mais restent cependant encore sous-employés en routine clinique chez l'enfant et l'adolescent en psychiatrie.

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