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Practitioner Review: Quality of life in child mental health – conceptual challenges and practical choices

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The terms 'quality of life' (QoL) and 'health related quality of life' (HRQoL) are fraught with preconceptions, misconceptions and, frequently, confusion: How are these terms best defined? What are the best ways to measure them? These challenges, which are present even in the relatively well-studied fields of adult physical health, are magnified considerably when considered in the context of child and adolescent mental health. They are, however, concepts that are being increasingly discussed by child and adolescent mental health clinicians, researchers and service planners. The purpose of this review is to analyse and discuss the concept of QoL and HRQoL (for simplicity we will use the umbrella term QoL in this paper except when there is a need to draw more fine-grain distinctions) as they relate to child and adolescent mental health, and review the various reasons for measuring QoL in this population. The paper is divided into three main sections. First, we introduce the concept of QoL and draw out the issues raised with regard to the field of childhood mental health research and practice. Second, we discuss the range of challenges raised as we move from concept to measurement. Third, we review and contrast some of the many different measurement tools currently available.

The concept of quality of life: generic and child-specific considerations

Definitions and concepts

Definitions of quality of life. The concept of QoL and its relationship with health status has received increased consideration over recent years. Indeed Spitzer and colleagues suggested that the main goal of healthcare is to improve patients' *perceptions of their health* and the extent to which health problems *interfere with* their QoL (Spitzer et al., 1995). There are multiple definitions of QoL: At its most simple it can mean happiness, or economic security and stability, or even a sense of community and belonging. From an academic perspective, Eiser and Morse (2001a) describe five relevant levels of definition (philosophical, economic, sociological, psychological and medical) of which the psychological and medical perspectives are most clearly relevant here. The psychological approach emphasises individual self-appraisal; a person with a good QoL will have high self-esteem, be able to make decisions, be active, happy and feel fulfilled. Even where these goals remain unmet there is a clear implication that the closer one is to attaining them the higher is one's QoL.

The medical perspective on QoL initially emerged as a response to advances in healthcare. These made it possible to keep patients, suffering from previously fatal conditions, alive while not actually curing their disease. With such advances, the measurement of treatment benefits was extended from indices of mortality to incorporate patients' feelings and perceptions about the quality of their extended lives. The QoL concept encourages a contrast between whether a patient 'feels' better (QoL) or 'is' better ('health status'). This shift has encouraged clinicians to focus on outcomes which are more difficult for them to assess directly themselves and, which,

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therefore, often have not received adequate attention in either clinical or research settings. Objective measurement of functional impairment is of course possible in most of these domains; however, impairment in relation to the norm does not necessarily imply that a patient's perception of their status in that domain is suboptimal. As such, 'health status' (i.e., presence/absence of symptoms), functional impairment (an objective measurement of impact on functioning) and QoL (self-perception of well-being) are three different potential outcomes of disease and treatment impact research.

Another important aspect of the original QoL construct is its intrinsically subjective nature and the associated assumption that it can only be properly assessed from the patient's perspective (Matza, Swensen, Flood, Secnik, & Leidy, 2004b). Whilst we agree that an individual will have a unique and privileged insight with regard to their own situation and that it is important to draw a distinction between this and other perspectives, it is clear that others, and in particular where children are concerned, parents, can make important contributions to our understanding of the broader impact of a child's health status on QoL. Important questions include: What are the relationships between these different perspectives? Do these relationships vary depending on which aspect of QoL is measured, the informant, the age and gender of the child/adolescent and the specifics of their mental health condition?

It is also important that we acknowledge the often complex relationships between what *is* happening to you in your life, what you *think is* happening to you and how you *feel* about what you think is happening to you. In so far as self-report QoL measures are subjective they will be more likely to capture the '*think*' and '*feel*' aspects of a situation. Clearly this may correspond more or less closely to the relevance/importance attached to a situation by a significant other. Whether this is a strength or a weakness depends on your frame of reference and the questions you are seeking to answer. Some authors have proposed combining independent observations and subjective perspectives within a single measure of QoL (Testa & Simonson, 1996) and ask *'what can (or can't) the child do?'* and *'how does the child perceive the illness and what attributions are attached to it?'* (Schipper, Clinch, & Olweny, 1996). However, reserving the term QoL for the subjective perception of well-being, and the term 'functional impairment' for the objective measurement of disease (and treatment) impact, would be one way of clarifying these broader measures of outcome. For this to occur, current QoL measures would have to be refined considerably as most currently include several questions on functional impairment.

Multidimensional approaches. QoL is generally accepted as a multidimensional construct which requires the integration of several domains. Leidy, Rich, and Geneste (1999) defined QoL as *'an individual's subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social functioning'.* This is compatible with the World Health Organisation's (WHO) definition of health as *'a state of complete physical, mental, and social well-being not merely the absence of disease or infirmity'* (World Health Organisation, 1947) and the WHOs QoL group's description of QoL as *'the individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns'* (WHOQOL, 1995). Almost all QoL definitions and measures include physical, social and psychological domains (unfortunately similar domains are often labelled differently). A cognitive domain is also commonly included (Eiser & Morse, 2001b). One implication of this multidimensional approach is that QoL cannot be easily reduced to a single score (Eisen, Ware, Donald, & Brook, 1979; Ware, Jr., 1984). Whilst there is general agreement over the major domains they have then been subdivided in many different ways. As a consequence, the resulting measures of QoL each have a different structure and are thus difficult to compare directly. For instance, taking three popular child instruments we see that the *Pediatric Quality of Life Questionnaire* (PedsQL; Varni & Burwinkle, 2006) is the simplest of the three, with three core domains and no sub-domains, the *Child Health Questionnaire* (CHQ; Landgraf, Rich, & Rappaport, 2002) has 11 domains and seven sub-domains, and the *Child Health Illness Profile – Child Edition* (CHIP-CE; Riley et al., 2001) has five domains and 12 sub-domains (Table 1).

Contextual issues. Health-related experiences occur within contexts and these can affect the way QoL is perceived. It is, therefore, desirable that QoL is measured across a range of different life-settings. Age-related differences may be especially important in this respect. Children, adolescents and adults operate in different ways across multiple social contexts (e.g., family, peer groups, school) and each of these will contribute to their perceived QoL. Significantly, children are often less able than adults to move from one context to another – an adult facing significant stresses within a work environment may choose to leave it, while this is not so easy for a child who is suffering a similar situation at school. Furthermore, parental stress and family disharmony can be both a cause and a consequence of a child's mental health difficulties. Broader socio-cultural factors such as ethnicity, religion and social class clearly influence QoL and should also be taken into consideration.

Conceptualising quality of life in childhood

Initial attempts to describe the impact of childhood disease and its treatment focused on functional

Table 1 Domain and sub-domain structures of the PedsQL, the CHQ and the CHIP-CE

	Domain	Sub-domain
PedsQL	Physical functioning	
	Psychological functioning	
	Social functioning	
CHQ	Physical functioning	
	Role/Social functioning	Physical
		Emotional
		Behavioural
	General health perceptions	
	Bodily pain/discomfort	
	General behaviour	
	Mental health	
	Self-esteem	
	Parental impact	Emotional
		Time
	Family functioning	Family activities
		Family cohesion
	Global item	
	Change in health	
CHIP-CE	Comfort	Physical comfort
		Emotional comfort
		Restricted activity
	Satisfaction	Satisfaction with health
		Satisfaction with self
	Risk Avoidance	Individual risk avoidance
		Threats to achievement
	Resilience	Family involvement
		Physical activity
		Social problem solving
	Achievement	Academic performance
		Peer relations

difficulties (e.g., physical abilities, school attendance) and were based on assessments carried out by the clinician rather than reports by children. However, pioneering work by Herndon et al. (1986), and Henning, Tomlinson, Rigden, Haycock, and Chantler (1988), who respectively assessed both physical and psychological outcomes for 21 children who had suffered major burns and 31 survivors of end-stage renal failure, demonstrated that a child's view is important in understanding their adaptation to major injury (Eiser & Morse, 2001a). QoL has also been a particular focus in paediatric oncology and neonatal intensive care. For instance, Lansky and colleagues developed a simplified set of QoL criteria for use with children with brain tumours; for use at the time of hospitalisation, clinic visits, and/or diagnostic procedures (Lansky, List, Lansky, Cohen, & Sinks, 1985; Lansky, List, Lansky, Ritter-Sterr, & Miller, 1987).

Two separate lines of work emerged from these landmark studies. One sought to develop *generic* measures that allowed the comparison of QoL across different health problems and between those who do and do not have health problems. One goal was to allow for the assessment of a broad range of areas from the patient's perspective without over burdening individuals with questionnaires. Prior to this time patients were being presented with increasingly bulky booklets that brought together a disparate set of detailed questionnaires, one for each domain of interest. One of the achievements of Quality of Life research has been to enable the assessment of a range of different areas of functioning whilst using a relatively small number of items. The other line of work focused on disease-specific measures of QoL which, among other things, allowed researchers to measure change following treatment. In these studies QoL was often seen as synonymous with 'psychosocial problems' and so broader aspects of QoL described above were not measured.

The number of QoL studies has grown enormously. Bullinger and Ravens-Sieberer (1995) estimated that 13% of the over 20,000 QoL related-publications involved children, while 320 were specifically concerned with QoL and childhood disease. The authors pointed out several limitations and concluded that many studies should be considered as little more than descriptions of instruments rather than studies of QoL and disease. Common problems were the lack of a developmental approach (only 19% of studies addressed age differences) and the failure to assess the children's views.

Since 1995, with more measures of childhood QoL appearing, the lack of consensus regarding the precise definition of QoL is even more pronounced (e.g., Eiser et al., 1999; Koot, 2001; Spieth & Harris, 1996). For instance, general measures of cognitive development, temperament or social abilities are included in some scales whilst others adopt a narrower view. Using strict inclusion criteria, Eiser and Morse (2001a) identified 19 generic and 24 disease-specific childhood QoL measures. Of these, 17 measures were child report only, 7 were adult report only and 16 had both child and adult versions. Establishing the psychometric properties of QoL measures is now seen as a priority, partly because of their use as important supplementary outcomes in clinical trials.

QoL and mental health in childhood

There are several reasons to measure QoL in children with mental health problems.

Quality of life as gold standard. For Eiser and Morse (2001a) QoL is a 'gold standard' against which other health outcomes should be assessed. This implies, for instance, that within clinical practice short-term reductions in symptoms can be outweighed by disadvantageous longer-term outcomes that reduce overall QoL. This insight leads to questions such as: Does the weight gain often associated with the use of atypical antipsychotics outweigh the reduction in aggressive behaviour? Is a reduction in the core symptoms of attention deficit/hyperactivity disorder (ADHD) treatment with medication also associated with an improvement in QoL? The usefulness of QoL as a gold standard for accessing healthcare outcomes is, however, dependent on a

wide range of measurement issues many of which are as yet unresolved (see below).

Helping to establish clinical priorities. QoL measures can play an important role in clinical decision making and service planning. Although childhood mental health problems are now recognised more frequently, it is not clear whether this reflects a real increase or greater awareness, better classificatory and diagnostic systems, increases in parents and/or clinicians willingness to report symptoms or decreased tolerance by society of certain behaviours. To complicate matters further, there are differences both between and within countries regarding the most appropriate ways to assess, categorise and manage childhood mental health problems (Remschmidt, Belfer, & Goodyer, 2004). However, despite considerable between-country-variation recognition levels, it appears that ADHD has a profound impact on QoL irrespective of national and cultural boundaries (Preuss et al., 2006), a finding that could help healthcare planners set priorities This sort of thinking is reinforced by the demonstration that mental health problems often impact on QoL more than common physical disorders (Sawyer et al., 2000, 2002). Introducing QoL into the equation may redress the current imbalance of provision between mental and physical health services.

Health economics. The decisions of health providers are often hindered by a lack of good quality data on both the impact on QoL of childhood mental health problems and the potential benefit of therapeutic interventions. This is because QoL measures are central to estimates of the cost-effectiveness of treatments and so to decisions about reimbursement of treatment costs. Unfortunately, there are currently few reliable data within child and adolescent mental health to enable accurate cost-effectiveness calculations. King and colleagues (2006) attempted a cost-effectiveness comparison between different pharmacological treatments for ADHD. They found that most data had been calculated on a hypothetical basis by experts and concluded that '*It may be useful when possible to collect data from the children to obtain a better understanding of treatment from a patient's perspective and to estimate patient-based measures of clinical outcome*' (King et al., 2006; p. 127). In an attempt to remedy this situation, four studies have calculated health-state related utility scores (QUALYs; see below) for children with ADHD (Coghill et al., 2004; Gilmore & Milne, 2001; Matza et al., 2005b; Secnik et al., 2005).

Community health status. QoL measures can also play an important part in measures of the health status of communities enabling an evaluation of how well a healthcare system is meeting the health needs of the population as a whole and of various important and vulnerable subgroups within it (e.g., children in local authority care, victims of abuse and neglect, those suffering from chronic physical or mental health problems etc.). The use of QoL data ensures that the voice of the consumer is heard and considered alongside other objective evidence.

Service level planning and audit. Within individual services the routine measurement of QoL can provide a more comprehensive picture for service managers of the similarities and differences between patient groups and, therefore, increase the potential for more evidence-based resource allocation. This can potentially facilitate treatment planning to improve the holistic management of children's problems. Before this can be achieved we need, for example, to develop a better understanding of the impact that different treatments known to be effective in reducing symptoms have on QoL and how different treatments compare.

Planning individual treatment. At an individual level, QoL can allow clinicians to better integrate the child's perspective into their clinical management. The importance of involving children in their own healthcare has been stressed by many governments and organisations (House of Commons Health Committee, 1997). The potential benefits of such an approach include not only the targeting of treatments more effectively to areas which really matter to the child but also the promotion of better concordance between the patient and the clinician and, therefore, compliance and adherence to treatments. Whilst QoL and clinical status are linked, they are not synonymous with each other. Smith et al. (1999) found that patients placed greater emphasis on psychological functioning when rating their QoL, and on physical functioning when rating health status. Interestingly, neither QoL nor health status was predicted by social functioning (Smith, Avis, & Assmann, 1999). Although somewhat limited by the use of a single summary score to describe the multifactorial QoL concept, Rimmer, Campbell, and Coghill (2007) found that whilst the correlation between child and parent QoL judgements was strong (r = .67), the correlations between parent and clinician (r = .42) and particularly between child and clinician (r = .29) were substantially lower. This suggested that, whilst in one sense parents can act as reasonable proxies for their children, it seems likely that parents and their child are rating different aspects of the child's life and that both are rating something different from the clinician. An alternative approach to integrating QoL into treatment involves assessing the discrepancy between an ideal and perceived self, indicating potential targets for intervention.

The development of new treatments. There has been much interest recently in the use of QoL measures to index the value of new treatments. QoL

measures, as noted above, represent a key patient-reported outcome (PRO) considered by regulatory authorities in licensing and labelling claims. The rationale for this comes from the realisation that some treatment effects are known only to the patient. The systematic assessment of the patient's perspective can provide valuable insights into treatment costs and benefits that may be obscured when filtered through the clinician's perspective. The demonstration of a differential impact of different treatments with respect to QoL, which are otherwise similar in terms of symptom reduction, could also assist purchasers to make decisions regarding the reimbursement of new and more expensive treatments and promote evidence-based choices between treatments amongst clinicians.

Measuring QoL in relation to child mental health

The practical value of the QoL concept depends entirely on whether it can be operationalised appropriately and measured with reliability and validity. Many issues remain unresolved in this regard (see Committee For Medicinal Products For Human Use, 2005; Eiser & Morse, 2001b; FDA, 2006). Arpinelli and Bamfi (2006) point out that whilst the *'operational application of concepts and their validation process have been well codified, few attempts have been made to standardise the evaluation of instruments characteristics'.*

General issues

Distinction between physical and mental health domains. Whilst difficulties in 'psychological' functioning are frequently associated with physical disorders, they are the signature component of mental health problems and psychiatric disorders. However, there are also subtle differences between psychopathology (e.g., *'are you feeling happy?'*) and QoL (e.g., *'are you feeling as happy as you think you should?'*). Whether or not these distinctions are appropriately realised by QoL measurement tools will depend to some degree on the precise wording of the questions and also on the individual's appraisal of their situation. Second, in many physical disorders there is often a much clearer distinction between symptoms of disorder and impairment than there is in mental health. It is, for example, possible to have a very serious disease like cancer without suffering any obvious impairment. Impairment is, however, explicitly required in order for a psychiatric diagnosis to be made. Sawyer and colleagues (2002) suggest several differences between impairment and QoL. Impairment is usually rated or measured by the clinician, QoL by the patient; impairment is integral to the illness; QoL is a broader multidimensional assessment of the impact of illness. However, the two concepts are related and frequently interact with each other. Impairment can be broken down into limitation of function (previously known as disability) and limitation of participation (previously known as handicap). Some aspects of impairment can be measured directly (e.g., academic functioning in terms of reading or math levels) whereas others will have to be derived indirectly (e.g., social integration via peer nominations). Some domains of impairment are heavily reliant on self or proxy reporting (e.g., ability to keep friends or build up close relationships) and as a consequence the boundaries between these domains and QoL are particularly blurred.

Item overlap. This can arise because of similarities between mental health and QoL items (Ormel et al., 1994). Interestingly, when Sawyer and colleagues removed items that potentially confounded mental health problems and QoL, they found that this made little difference to the relationships identified between mental illness and QoL (Sawyer et al., 2000).

The process of instrument development. This is a complex iterative process typically involving several stages and which often progresses in a non-linear fashion. The US Food and Drug Administration (FDA) (FDA, 2006) and the European Agency for the Evaluation of Medicinal Products (EMEA) (Committee For Medicinal Products For Human Use, 2005) have published detailed guidance on the development of patient-reported outcome measures (including QoL). Both emphasise good measurement science and systematic development, and both are 'consistent with best practices in health-outcomes research' (Revicki, 2007).

The US Food & Drugs Administration (FDA, 2006) describes several key stages:

(i) The identification of concepts and domains important to patients, and the hypothesised relationships among these concepts.
(ii) The creation of an instrument including; the generation of items; choosing an appropriate administration method; appropriate recall period and response scale. The piloting and refining of the scale.
(iii) The assessment of the measurement properties of the instrument including reliability and validity; respondent burden; further revision of instrument; the development of scoring procedures and training materials; identification of meaningful differences.
(iv) Further modification of instrument allowing for a change in concepts measured, populations studied, research application, instrumentation or method of administration.

Whilst reliability is relatively easy to measure using standard psychometric parameters, validity is harder to establish definitively in the absence of any agreed QoL gold standard. However, a number of

quantitative (e.g., factor analysis) and qualitative (e.g., cognitive debriefing) techniques have been introduced to address this limitation (Fayers, Hand, Bjordal, & Groenvold, 1997; Schmidt & Bullinger, 2003). Content validity has been assessed using panels (including patient panels) to judge whether an instrument fully examines the domain of interest. Predictive validity involves assessing whether an instrument can reliably assign individuals to clinical groups and can predict subsequent events, outcomes or treatment response. Schwartz and Rapkin (Rapkin & Schwartz, 2004; Schwartz & Rapkin, 2004) have highlighted the potential importance of the individuals' appraisal processes when assessing their own QoL. They argue that some of the apparent psychometric weaknesses in QoL instruments may be due to a change in how an individual appraises their situation as they habituate to symptoms, develop coping strategies or reframe their goals and expectations. They recommend the integration of an assessment of appraisal into QoL research and clinical practice. These processes of accommodation make interpreting change in QoL following treatment particularly difficult.

Generic versus disease-specific measures. Disease-specific measures maximise sensitivity as they focus on areas of particular concern in relation to a specific disorder. They are especially valuable for measuring intervention effects. Generic measures are designed to be more comprehensive, but are less likely to be sensitive to treatment-related change. However, such measures will be more appropriate when comparing different disorders in different patient groups or in different individuals. For planning individual treatment, a combined disease-specific and generic measure may be the most appropriate. Whether generic or disease-specific, the QoL measure must add value to symptom counts or syndrome diagnosis.

Profile- or preference-based measures? A profile-based measure will cover multiple QoL domains (e.g., physical, psychological, cognitive and social). Preference-based measures, sometimes referred to as utility-based measures, share some similarities with profile-based measures. For example, both measures often examine the same dimensions of health. However, whilst profile-based measures report a series of scores and characterise respondents on each independent dimension of the profile, utility measures use human judgement to combine and scale health effects over several different dimensions into a single score (Lenert & Kaplan, 2000). The scaling of preference based/utility measures is always made in terms of some absolute reference point (often, 'perfect health' and death), as opposed to the population reference point used in many health-status measures. A preference-based measure is derived from an initial study of health-related preferences (e.g., state A vs. state B) that allows the creation of a metric (i.e., health utilities) which allows the QoL of an individual to be estimated. Utilities are numeric measurements that reflect an individual's beliefs about the desirableness of a health condition and their willingness to take risks to gain health benefits. This approach is favoured by health economists as health state utilities can in turn be used to provide an estimate of quality adjusted life years, known as QUALYs, which are central to many cost utility analyses.

Choice of domains and sub-domains to be measured. Domains of interest should be identified through a mixture of patient interviews, literature reviews and expert opinion. Physical, psychological, cognitive and social domains need to be measured; however, there is less agreement how to best define sub-divisions within these broad domains. Consequently, current measures feature a wide range of both overlapping and non-overlapping sub-domains. This makes it difficult to compare directly the results of different studies. It is important, therefore, that the hypothesised relationships between individual questions, sub-domains and broad domains be explicitly stated and their scoring algorithms to be set out clearly. A related difficulty concerns the equivalence (or non-equivalence) of different domains and sub-domains across different instruments. A partial solution is to use a standardised scoring system based on general population scores (e.g., by using *T* scores). Another technique, often used in cost-effectiveness studies, is to generate empirically determined patient-preference ratings to assign a relative weighting for items and domains in different instruments.

Measurement issues relating specifically to children

These can be broadly separated into those relating to age and those relating to proxy reports.

Age issues. Given that QoL is seen primarily as a patient-reported outcome, the question is raised: 'at what age can a child report their QoL?' This is a complex issue and one on which expert opinion varies. A number of factors need to be considered.

Children develop at different rates and it is not possible to say for certain that a particular child of a certain age will be able to report their QoL reliably. For example, some children with generalised learning disability whose developmental age is lower than their chronological age will have more difficulty reporting on their QoL than age-matched peers. Mental health may manifest as a slowing in the rate of development and lead to delay in mastering normal maturational tasks and skills. Some psychiatric disorders may lead to slower development and difficulties in reporting QoL in some domains. For example, children with autism may have difficulties

reporting on peer relationships; children with depression and anxiety may find reporting on their internal state more difficult due to emotion-based cognitive distortions.

Language development will impact upon a child's ability to report their QoL and determine the type of instrument most appropriate to use at particular ages. Rebok and colleagues (2001) found that only 57% of 5-year-olds, but all 8-year-olds, had a good understanding of the word 'nervous'. Reading ability will determine which children will not be able to complete particular types of questionnaires.

Effects may be domain specific. Between the ages of 4 and 6 years children can report about more concrete domains, like pain and medication use, whereas only older children can describe the emotional impact of their illness (Annett, 2001; Connolly & Johnson, 1999; Wallander, Schmitt, & Koot, 2001). Bibace and Walsh (1980) described six developmentally ordered categories of explanation the emergence of which was consistent with Piaget's stages of cognitive development. Four-year-old children tended to attribute illness to contagion and 7-year-olds to contagion or vaguely internalised causes, whilst by 11 years of age the children were much clearer about the physiological causes of illness (Bibace & Walsh, 1980). Children as young as 4 or 5 years appear able to report on limited and concrete aspects of QoL when methods are developmentally appropriate. Children become more able to provide a more complete description of QoL with age; many 9- or 10-year-olds were able to give an account of subjective concepts such as self-esteem (Landgraf & Abetz, 1996).

Recall also varies as a function of age/developmental level. Whilst 8-year-old children were able to recall fairly accurately over a 4-week period, younger children can have difficulties with much shorter intervals (e.g., 1 week; Rebok et al., 2001). Children with mental health problems may have increased difficulties with recall. It is therefore important that an appropriate recall period is chosen when designing QoL instruments for use with children.

Several of the above issues have been addressed by the careful design and testing of QoL instruments for use in children. Some, however, remain incompletely resolved with regard to one type of health problem at a specific age or developmental level. Each instrument needs careful assessment and pilot testing in each new group of children that it is applied to, in order to determine the lowest age at which accurate reports of QoL can be made.

Paediatric QoL measures should be as child friendly as possible. Unfortunately, many scales are rather long; some 'child versions' are as long as adult versions and may exceed the attentional capacity of children. Adult questionnaires typically require a reading age of around 13 years (Titman, Smith, & Graham, 1997), making them difficult for many adults let alone children. Unfortunately, even though reading age can be easily calculated, it is rarely reported for child scales.

A range of different response formats (i.e., Likert scales, graphic, facial expression or visual analogue scales) and presentations styles (i.e., written, pictorial, verbal, computerised and the use of props) have been utilised in different QoL instruments (Cremeens, Eiser, & Blades, 2006, 2007). Likert scales are the most frequently used and developmental differences have been noted in children's ability to understand and respond to them (Rebok et al., 2001). For younger children instruments need to be administered as an interview rather than as a questionnaire (Juniper, Guyatt, Feeny, Griffith, & Ferrie, 1997). Several authors have compared the psychometric properties of the same measure across several different response formats. Such careful attention to the formatting and presentation of the measure is likely to assist completion and increase the reliability of the measure. Rebok and colleagues (2001) found that pictorial and graphic techniques assisted younger children with completion of Likert scales in the CHIP-CE. Whilst *smiley*, *neutral* and *sad* faces and other pictorial and graphic techniques are often used to assist younger children with completion of Likert scales (Christie et al., 1993), a degree of care is required before applying them with regard to mental health. For example, children with depression may respond differently to *smileys* than healthy children.

Pictures can be used to engage the child's interest, increase their understanding, improve the accuracy of responding and lower the minimum age of assessment to around 4 years (Eiser & Morse, 2001b; Harter & Pike, 1984). In other fields, researchers have shown that the use of props and puppets increases the number of responses made by 4- and 5-year-olds (Lawford, Volavka, & Eiser, 2001; Mize & Ladd, 1988). Computer administered measures may potentially increase the child-centredness of measures (Eiser, Cotter, Oades, Seamark, & Smith, 1999; Gringras, Santosh, & Baird, 2006). Cremeens et al. (2007) compared three different rating scales (circles, faces and a thermometer-shaped continuous scale) in children aged between 5 and 9 years of age at two time points. The results were complex. Overall, faces and thermometer scales showed highest reproducibility over time. There was an interaction between age and scales, whereby for reproducibility over time, the thermometer was most reliable for 5–6-year-olds and faces was most reliable for 7–9-year-olds.

One potential solution to ensuring that the scales are age appropriate is to create multiple versions of a measure for use with different ages, each measuring the same general constructs but in slightly different, and age appropriate, ways. This approach ensures that each measure is appropriate to measure QoL at a particular developmental level, but it becomes difficult to pool and/or compare data across different

age. Whatever scale is used, greater variability of responding and subsequent measurement error is likely with younger children. This means that large samples will be required.

Whilst the application of QoL measures to young children may well be feasible and reliable, the validity and stability of the QoL concept in this group remains somewhat unclear. Many developmental psychologists would argue that the majority of children below the age of 8 will have restricted abilities with respect to introspection, meta-communication, abstract thinking, reflection and communication about their feelings and experiences beyond the here and now (Bibace & Walsh, 1980). In older children, other potentially important mechanisms may become more important in prejudicing their responses to questions about their QoL, including: social desirability, intimidation or influence of adults, wish to conceal their feelings. A demonstration of validity in terms of longer-term temporal stability or prediction of adult QoL is lacking.

In order to make a comprehensive assessment of QoL in children and adolescents, additional QoL domains specific to these age groups are required. Eiser and Morse (2001a) argue that in addition to the generally accepted domains, domains relating to autonomy and body image are of particular importance in adolescence. Felce and Perry (1995) added *'material well-being'* and *'productive well-being'* domains to their description of the QoL concept for adults, and although Wallander, Schmitt and Koot (2001) suggested that these domains could also be helpfully integrated into child measures, this has not yet happened. A domain of family functioning and/or impact on family life is, however, present in most child QoL measures, but may be more relevant to the assessment of impairment or disease impact than QoL per se. Unfortunately, despite these helpful suggestions, the striking lack of agreement over which domains are important and should be measured continues to be a problem for the field.

The use of proxy raters. Who is the most appropriate person to provide information about children's QoL? Whilst accepting that a proxy may, at times, be asked to provide a rating, Matza et al. (2004b) suggest that whenever possible a child's QoL of life should be based on self-rating. This is because (i) it is consistent with the QoL concept, (ii) it allows for the inclusion of information from multiple domains and settings (i.e., school or day-care vs. home) and (iii) ensures that the child's perspective and perceptions are acknowledged in the decision-making process. Others advocate using the parent/carer as a proxy respondent where patients are either too young or too unwell to provide information. If one takes into account a child's relative dependence on their parents and the fact that many decisions about their healthcare will be made either by, or in conjunction with, their parents, it seems reasonable to include parental ratings as a supplement to child ratings when making a comprehensive assessment of a child's QoL.

No matter which perspective one takes, there are several important issues to consider. Concordance between proxy and child ratings appears limited (Vogels et al., 1998). A review by Upton, Lawford, and Eiser (2008) found evidence to suggest that whilst the parents of children from non-clinical samples tend to report higher child QoL than children themselves, the reverse is true for clinical samples. Agreement is higher in some domains (e.g., observable domains such as physical functioning) than others (e.g., non-observables ones such as emotional or social functioning) (e.g., Eiser, Havermans, Craft, & Kernahan, 1995; Varni et al., 1998; Varni, Seid, & Rode, 1999; Vogels et al., 1998). Exceptions include low proxy–child correlations for physical functioning (Czyzewski, Mariotto, Bartholomew, LeCompte, & Sockrider, 1994; Theunissen et al., 1998) and high correlations for social interaction items (Langeveld, Koot, & Passchier, 1997). There was more variability in agreement for social and emotional functioning than for physical functioning. Little is still known about the impact of age, gender or type of disorder on agreement. There seems to be a greater degree of concordance between parents and their children where an illness is chronic (Eiser & Morse, 2001b). In one study, the presence of oppositional defiant disorder/conduct disorder (ODD/CD) in children with ADHD was associated with larger discrepancies between parent and child reports (Klassen, Miller, & Fine, 2006). However, in general it is not yet clear whether these associations will differ for children with different types of mental health problems or whether there is an interaction between age, gender and type of disorder.

Proxy ratings from different adults are not equivalent (Landgraf & Abetz, 1996). In most instances it is most appropriate for the proxy to be the parent/carer as they are closest to the child and are involved daily with the child. While proxy reports appear to be more accurate when the proxy lives in the same house as the subject (Epstein, Hall, Tognetti, Son, & Conant, 1989), parents' assessment of the impact of an illness on a child may be biased by how they themselves, and others in the family, are affected. Relative to parents, clinicians are not in a good position to assess a patient's QoL and tend to underestimate it (Sprangers & Aaronson, 1992). Glaser, Abdul Rashid, U, and Walker (1997) found that teachers were reasonably reliable proxies for most domains of QoL, while children tended to rate their QoL lower than did their teachers. However, the potential role of teachers, day-care staff or other family members has not been studied sufficiently to make recommendations.

Proxy ratings, even where they do not agree with a child's views, can provide an important additional perspective and may be useful in identifying potential areas of conflict or concern. This may be especially important where parents and children have different levels of maturity or have different under-

Table 2 The psychometric properties of the three commonly used QoL instruments

		Reliability		
		Internal consistency (Cronbach's α)	Test–retest	Self/proxy correlation
CHIP				
CHIP-CE	Child Health and Illness Profile – Child Edition	All domains: ≥ .70 6–7y: .64–.84; 8–11y: .72–.85	6–7y: .35–.69 8–11y: .63–.76	
CHIP-CE-PRF	Child Health and Illness Profile – Child Edition – Parent Report Form	EU–sample: 11/12 sub-domains: > .70		
CHIP-AE	Child Health and Illness Profile – Adolescent Edition	2/4 samples (sub)domains: ≥ .7	1week r > .60	
CHQ				
CHQ-PF50	Child Health Questionnaire – Parent Form	US population: median .84 Australian population: median .83 ADHD sample: subscales: 8 ≥ .7; 3 .5–.7		
CHQ-CF87	Child Health Questionnaire – Child Form	US population: median .81 Australian population: .85		parent/child: .40–.75
Peds-QL		Epidemiologic sample & pediatric clinic sample:		Clinical pediatric sample:
PedsQL child version PedsQL parent version	Pediatric Quality of Life Inventory	Total scale child α ∼.90 Total scale parent α ∼.90		parent/child: .50–.75 ADHD population sample: parent/child: .59–.75

CDI = Children's Depression Inventory; STAI = State-Trait Anxiety Inventory; FAD-GFS = Family Assessment Device – General Functioning Scale; SDQ = Strengths and Difficulties Questionnaire; FSI = Family Strain Index; CGI-S = Clinical Global Impression Severity.

		Construct validity	
		Discriminant validity	Convergent validity
CHIP			
CHIP-CE	Child Health and Illness Profile – Child Edition		
CHIP-CE-PRF	Child Health and illness Profile – Child Edition – Parent Report Form	Discriminate ADHD versus 'norm'	Risk Avoidance SS/ADHD symptoms: – .48 Other domains/ADHD symptoms: –.18 to –.28 Domains/SDQ-total score: –.28 to –.65 Domains/FSI: –.28 to –.63 Domains/CGI-S: –.15 to –.30
CHIP-AE	Child Health and Illness Profile – Adolescent Edition		Sub-domain ED/CDI and STAI: .68 and .67 Sub-domain FI/FAD-GFS: .59
CHQ			
CHQ-PF50	Child Health Questionnaire – Parent Form	Discriminates ADHD versus normal controls (9 studies) Discriminates depression, CD versus controls Discriminates ADHD versus depression Discriminates ADHD versus ADHD+comorbidity Discriminates mental disorder versus physical condition	PsychosocSS/ADHD symptoms: –.33 to –.60 Family activities/ADHD symptoms: –.32 to –.57 Parent impact emot. & time/ADHD symptoms: –.28 to –.42 Role emot.&beh/ADHD symptoms: –.28 to –.35 Behaviour/ADHD symptoms: –.34 to –.75 Change in HRQL correlates with change in symptoms 8 Subscales / CGI-ADHD-S: –.26 to –.55

Table 2 Continued.

	Construct validity		
		Discriminant validity	Convergent validity
CHQ-CF87	Child Health Questionnaire – Child Form	Discriminates healthy versus chronic physical condition No discrimination ADHD versus normal controls (3 studies)	
Peds-QL		Discriminates healthy versus chronic condition	In clinical ADHD sample:
PedsQLchild version PedsQL parent version	Pediatric Quality of Life Inventory	Discriminates ADHD versus normal controls (2 studies)	parent PedsQL/clinician CGAS: –.42 child PedsQL/clinician CGAS: –.29

CDI = Children's Depression Inventory; STAI = State-Trait Anxiety Inventory; FAD-GFS = Family Assessment Device – General Functioning Scale; SDQ = Strengths and Difficulties Questionnaire; FSI = Family Strain Index; CGI-S = Clinical Global Impression Severity.

		Responsiveness to treatment
CHIP		
CHIP-CE	Child Health and Illness Profile – Child Edition	
CHIP-CE-PRF	Child Health and illness Profile – Child Edition – Parent Report Form	Significant difference between 2 types of ADHD treatment on total scale and on all 5 sub-domains
CHIP-AE	Child Health and Illness Profile – Adolescent Edition	
CHQ		
CHQ-PF50	Child Health Questionnaire – Parent Form	Change in most psychosocial subscales following treatment (2 studies); no change (1 study)
CHQ-CF87	Child Health Questionnaire – Child Form	
Peds-QL		
PedsQLchild version PedsQL parent version	Pediatric Quality of Life Inventory	not known

CDI = Children's Depression Inventory; STAI = State-Trait Anxiety Inventory; FAD-GFS = Family Assessment Device – General Functioning Scale; SDQ = Strengths and Difficulties Questionnaire; FSI = Family Strain Index; CGI-S = Clinical Global Impression Severity.

standings and perceptions of the meaning and consequences of illness. Children may not want to 'let down' either themselves or their parents by admitting how much an illness is affecting them or they may be unaware of the restrictions brought about by their illness. Some authorities have suggested that the question is not how accurate are parental reports but rather what additional information can be gained from asking a parent to rate their child's QoL (Annett, 2001; Eiser & Morse, 2001b).

Whilst the use of a proxy as an additional source of information has the potential to provide the most complete picture of a child's QoL, it brings with it several methodological problems (Matza et al., 2004b). Should researchers pool the child and proxy data into a single rating (overall or per domain) or should they be analysed and reported separately? How should disagreement be handled? Unfortunately, there is not yet enough information to inform the clinician how best to interpret such discrepant information.

Instruments for measuring children's quality of life

Given the complexity of the task of operationalising and measuring QoL in children, it is important that researchers and clinicians ensure that they understand the measurement and psychometric properties of scales they use, both in a general sense but also in terms of the precise context in which it will be used. If this data is not available from previous reports then it will need to be collected.

Desirable characteristics

In reflecting the discussion above, the ideal QoL instrument would have the following characteristics:

- Validly represent the concept of QoL; i.e., encompass all relevant domains and sub-domains in a well-balanced multidimensional measure (i.e., face, content and predictive validity).
- Avoid overlap with disorder symptoms.
- Take into account important developmental aspects, both in content and method, thereby retaining a maximal parallel between different versions.
- Reliably measure self and proxy perspectives.
- Be able to measure the discrepancy between a perceived self and an ideal self.
- Be sensitive to differences or change in QoL (e.g., responsiveness to treatment change, discriminant validity etc.).
- Be applicable to a wide scope of mental health disorders, as well as somatic diseases and healthy children.

In addition to these characteristics, a disease-specific QoL measure should be able to give a detailed assessment of the burden of the disorder and the effects of its treatment.

Unfortunately, few if any instruments for child QoL have been assessed against all of these criteria (Upton et al., 2008).

Generic measures

At least seven reviews of generic QoL measures for children/adolescents have been published over the past few years (Cremeens et al., 2006; Eiser & Morse, 2001a, 2001b; Grange, Bekker, Noyes, & Langley, 2007; Raat, Mohangoo, & Grootenhuis, 2006; Schmidt, Garratt, & Fitzpatrick, 2002; Upton et al., 2008). A comprehensive review of these instruments is beyond the scope of this review. We focus on three instruments used in the context of child and adolescent mental health that have been intensively studied from a psychometric perspective and exist in multiple languages (Tables 1 and 2). Other measures are detailed in Table S3 (supplementary material).

Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1999). The CHQ:

- Is a widely used QoL measure developed using traditional qualitative techniques.
- It is available in different languages.
- It has been used in a range of clinical conditions.
- It has 12 subscales and 2 summary scores.
- It has several versions: a lengthy child form (CHQ-CF-87 items) and different versions of the parent form (CHQ-PF -28, 50 and 98 items). Unfortunately, these are not parallel versions. There are many differences between versions to the extent that scales with similar names contain very different items and are, therefore, difficult to compare with each other.
- Raw scores can be transformed to a 0–100 score, allowing a comparison of the functioning of children across the different domains.
- It has test–retest reliability estimated to be around .80 (Landgraf et al., 1999; Waters, Salmon, & Wake, 2000). In a clinical sample, the parent summary score is reliable, but not all subscale scores (Raat, Botterweck, Landgraf, Hoogeveen, & Essink-Bot, 2005). Good reliability has also been found for the child format ($\alpha \geq .80$) in 6 out of the 10 multi-item scales (Landgraf & Abetz, 1997).
- It has moderate inter-informant agreement (Klassen, 2005).
- It shows convergent validity reflected in correlations between subscales (especially family subscales, behaviour and the psychosocial summary score) and symptoms of disorder (Klassen, Miller, & Fine, 2004; Rentz, Matza, Secnik, Swensen, & Revicki, 2005).
- It discriminates between children with mental disorders and normal controls in terms of psychosocial interference with family life subscale

scores (Landgraf & Abetz, 1996). In particular, the parent version of psychosocial sub-scales and the psychosocial summary scale discriminated between children with ADHD and normal controls (Brown et al., 2006; Klassen, Miller, & Fine, 2004; Landgraf et al., 1999; Matza et al., 2004a; Matza, Secnik, Mannix, & Sallee, 2005a; Perwien et al., 2004; Perwien et al., 2006; Rentz et al., 2005; Sawyer et al., 2002). In contrast, although the child version discriminates between children with a severe physical illness (e.g., end stage renal disease) and normal controls, no differences were found for children with ADHD (Klassen, 2005; Klassen, Miller, & Fine, 2006; Landgraf & Abetz, 1997). Therefore, an association between ADHD symptoms and CHQ QoL was found for the parent but not child form, suggesting possible single reporter-bias. However, similar correlations were found between eight CHF-PF50 subscales and a clinician-based rating of ADHD symptom severity (CGI-ADHD-S; Matza et al., 2004). The parent emotional and behavioural subscales discriminated between children with ADHD and children with depressive disorder (Sawyer et al., 2002). Children with ADHD scored lower on family activities and parent time impact scales. The psychosocial summary scale differentiated between children with ADHD and those with other psychiatric diagnoses (Klassen, Miller, & Fine, 2004).
- It is sensitive to ADHD treatment effects in some, but not all studies (Matza et al., 2004; Perwien et al., 2004; Rentz et al., 2005; Brown et al., 2006).
- It has minimally important treatment differences defined (Rentz et al., 2005).

Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Kurtin 2001). The PedsQL:

- Has 23 items and four subscales and also gives one total score;
- Was developed through focus groups, cognitive interviews, pre- and field-testing;
- Takes about five minutes to complete (Varni et al., 1999);
- Has parallel versions for parent/proxy and child self-report with essentially the same items, but wording adapted to different age-groups;
- Can be transformed into a 0–100 scale, with higher scores indicating better QoL;
- Has correlated parent and child forms (between .50 and .75; Bastiaansen et al., 2004; Varni, Limbers, & Burwinkle, 2007b);
- Has high consistency for the child and parent proxy-form (Varni et al., 2007b);
- Differentiates children with chronic illness from health children on both parent and child reports;
- Can be completed reliably by children as young as 5 years old (Varni, Limbers, & Burwinkle, 2007a);
- Has differentiated children with ADHD and healthy controls in terms of total score for some (Varni & Burwinkle, 2006) but not other studies (Pongwilairat, Louthrenoo, Charnsil, & Witoonchart, 2005). Where effects for total score are absent, effects have found for several subscales between ADHD/disruptive behaviour and other psychiatric diagnoses (Bastiaansen et al., 2004). Children with anxiety disorders demonstrated lower scores than children with ADHD/disruptive behaviour on the emotional subscale. Effect sizes of differences between the ADHD subgroup and healthy children were the largest on the school functioning subscale both in the parent (ES = 1.35) and child (ES = 1.13) form (Varni & Burwinkle, 2006). These results may be explained by the fact that the PedsQL has items on the emotional subscale that overlap with symptoms of depression and anxiety, and there is an apparent overlap between the items of the school functioning scale and symptoms of ADHD;
- Has not been used in treatment studies to date.

Child Health and Illness Profile (CHIP; Riley et al., 2004a, 2004b). The CHIP:

- Has three versions: an adolescent form (CHIP-AE), an illustrated form for children (CHIP-CE) and a parallel version to measure the parental perspective on children's health and well-being (CHIP-PRF);
- Produces standardised scores (mean 50 – standard deviation of 10) allowing comparison between the different domains;
- Has a pictorial version where a cartoon illustrates the question, and different sizes of response circles differentiate the response format;
- Has demonstrated criterion validity against existing measures. The highest correlations were for the emotional discomfort items (r = .63) and the lowest for the peer relationship items (r = .44) (Riley et al., 2004a);
- Has two items that overlap with ADHD-symptoms and five with depression or anxiety problems;
- Has adequate internal consistency and convergent reliability in the parent report form when applied to 12–18-year-olds (Riley et al., 2004b);
- Has a replicable factor structure (Riley et al., 2006);
- Has some subscales (i.e., risk-avoidance) that correlate with ADHD symptoms. (Riley et al., 2006) and measures of general behaviour problems (e.g., Strengths and Difficulties Questionnaire);
- Has been used in treatment studies showing sensitivity to change in patients with ADHD following atomoxetine treatment in an open label study (Prasad et al., 2007).

In summary, all three QoL measures provide some data in relation to children with mental health problems, but are largely restricted to those with ADHD. Content validity is most convincingly demonstrated for the CHIP-CE, making it scientifically the most attractive measure. Parent versions of all three measures have been shown to discriminate clinical ADHD samples from controls or norm populations, but self-report versions have not. Correlations between symptoms and QoL-subscales are more pronounced for the CHQ-PF50 than for the CHIP-CE. A direct comparison of these measures within the same population so far is unavailable.

Disease-specific measures

In somatic medicine, more than 30 disease specific instruments or additional modules to generic questionnaires exist, whereas in mental health care, these are, so far, restricted to ADHD. Both contain a mixture of QoL and impairment questions, but clearly avoid the overlap with symptoms.

The *Weiss Functional Impairment Rating Scale* is a 50-item parent-rated measure of functioning across six domains: family, learning and school, life skills, child's self-concept, social activities and risky activities. Each item is measured on a four-point Likert scale. Ongoing research suggests that the scale has strong internal consistency, a well-established domain structure and is sensitive to change (Weiss & Brooks, 2007). Correlations with the CHIP-CE domains ranged from –.32 to –.72 (Weiss, personal communication).

The *ADHD Impact Module* (AIM) developed by Landgraf et al. (2002) has still to be widely utilised. It has identified statistically significant differences between ADHD-combined and ADHD-inattentive subtypes, with better functioning at home for the latter.

Disease-specific instruments may be promising but are still largely in an experimental phase.

Discussion

The QoL field is relatively young and continues to evolve. The definition and operationalisation of QoL has, as yet, reached no generally accepted consensus, hence the variety of instruments in the field. Initial definitions have battled with the issue of whether the concept is best defined for the general population or for specific disease entities. Instruments developed from a conceptual point of view appear to have a stronger theoretical and psychometric strength. However, health care assessment requires that such instruments are both reliable and valid and that they can reliably measure changes in QoL following treatment from the perspective of the child, parents and caregiver. Whilst this has proved a challenge, it is possible that this is not entirely due to failings in the measurement tools. New approaches to the psychometric evaluation that assess appraisal alongside standard QoL domains could help move the field forward (Rapkin & Schwartz, 2004; Schwartz & Rapkin, 2004).

There are outstanding issues concerning the relationships between QoL, symptoms and impairments. Many studies have identified significant correlations between QoL, impairment and symptomatology. Whilst a correlation between two items does not indicate that both are necessarily measuring the same factor (a third intervening or moderating factor could be responsible for this association), it is clearly possible that overlap between these factors may lead to some redundancy. In order to determine the functional meaning of the association, future QoL research needs to employ experimental designs whereby levels of an independent variable are manipulated to assess effect on levels of QoL independently of symptoms.

Issues specific to children include an urgent need for a better understanding of the development of QoL from childhood to adulthood. There are no longitudinal studies of development and it is not possible to discuss the progression or stability of QoL across development. Age-related differences in language ability, understanding of the concept of 'illness' and reading ability are each likely to influence the appraisal and reporting of QoL.

Questions remain even about the most intensively studied QoL instruments. For example, it is not entirely clear whether instruments such as the CHQ, PedsQL and CHIP take fully into account the developmental level and cognitive abilities of the child. Proxy informants, while providing useful information, cannot be considered a replacement for the child, hence, when making interpretations of data from studies using proxy information one needs to bear in mind that this proxy information is primarily providing the proxy's perspective, which may be very different from that of the individual being described.

The value of the concept of QoL to child and adolescent mental health

QoL has the potential to be an extremely important concept for the field of child and adolescent mental health, which can add value to scientific study and promote improved clinical practice. From a scientific point of view, including measures of QoL in studies could result in a better, more broadly contextualised, understanding of both the causes and consequences of mental health conditions and include the patient's perspective. The inclusion of the QoL concept in intervention research can facilitate a shift toward a more general and generalisable improvement and/or impact on psycho-social well-being. This has the potential to help ground evidence of symptom remission within the broader context of the costs and benefits of a treatment, which in turn can facilitate

the sort of comprehensive account required for health economic analyses. More importantly, it can result in a better understanding of the impact of a treatment and the significance of treatment effects from the child's point of view: a perspective almost completely overlooked in current clinical trials.

The QoL concept may also be applied usefully in clinical practice at several levels. Child self-completed QoL scales could help identify which outcomes are most important as treatment targets and provide a more ecologically valid measure of the positive and negative impact of a treatment regime. Using parent ratings can provide a sense of the wider impact of the treatment on the family. Sawyer et al. (2002) demonstrated that there were greater similarities than difference in QoL between groups of children with different psychiatric disorders (e.g., major depressive disorder, ADHD and conduct disorder) and between these children and those with chronic physical illnesses. Both they and Stein and Jessop (Stein & Jessop, 1989) argue that there will be situations where it would be better to classify patients by their QoL profiles rather than their diagnostic groupings. For example: it may be worthwhile to develop treatments addressing QoL domains, rather than symptom domains. QoL measures are also particularly useful in assessing the impact implementing new treatments or treatment protocols. The publication and dissemination of such information would be of great value to service planners. Whilst there are several examples from paediatric practice where this has occurred (Bichey et al., 2002; Larsson & Carlsson, 1996) similar data from mental health is sparse at the present time.

There is, however, an important caveat to all this: these ideals remain to a large degree aspirational until there is a systematic and comprehensive data on the psychometric properties of QoL instruments in children and adolescents and of the various interrelationships between development, age, gender and disorder in QoL (and its measurement). Especially the validity of the QoL concept in early childhood still needs thorough consideration. The QoL concept and measures clearly still need purification to ensure that QoL is disentangled from both functional impairment and symptoms. Also, an improvement in short-term self-perceived well-being may not be predictive at all for long-term (adult) clinical outcome.

Taking on board issues relating to QoL will have considerable implications for developers, regulators, purchasers and providers of healthcare. If QoL is taken seriously by the healthcare systems, this will require health regulatory bodies to reconsider what information is required for determining the effectiveness of an intervention. Similarly, any development of a new therapy or modification of an existing one will need to take account of the distinction noted between effect and effectiveness. This suggests that serious implementation of QoL has considerable consequences not only for the patient and their family but the entire complex around healthcare, planning, evaluation and regulation.

Supporting information

Additional supporting information may be found in the online version of this article:

Table S3. Measures of QoL in children and adolescence (Word document)

Please note: Wiley-Blackwell Publishing are not responsible for the content or functionality of any supplementary materials supplied by the authors. Any queries (other than missing material) should be directed to the corresponding author for the article.

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Areas for future research

- To establish the developmental trajectory, longitudinal stability and predictive value of QoL in healthy children and adolescents and children and adolescents with ill health.
- Does QoL measurement contribute added value over and above symptom-based measures?
- Do disease-specific QoL measures add value over and above generic measures?
- To determine the relationships between the QoL concept and measures of functional impairment on the one hand and more abstract concepts such as self esteem and happiness, on the other.
- To validate child-self report and parent proxy- report measures and their appropriate roles within the assessment of child mental health outcomes including how, if at all, should information from these two perspectives be combined.
- To describe the dynamic nature of QoL in relation to child mental ill health as patients adapt to and cope with illness.

Key points

- Quality of life is an intrinsically multidimensional subjective concept defined by the World Health Organisation as '*the individuals perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns'* (WHOQOL, 1995).
- The QoL concept could also be applied usefully in clinical practice at a several levels relating to the planning and delivery of care to individuals and populations.
- The use of child self-completed QoL scales could help identify which outcomes are most important as treatment targets and provide a more ecologically valid measure of the positive and negative impact of a treatment regime.
- Using parent ratings can also give a sense of the wider impact of the treatment on the family.
- There is, however, relatively little data on quality of life in children with mental health problems.
- There are a wide range of 'measurement issues' to consider when rating quality of life in children. For this reason it is necessary to carefully assess the applicability of any QoL measure when using it in a new group of children (e.g., new age group, cultural setting or disorder).

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