

Monitoring health related quality of life in adolescents with diabetes: a review of measures

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Particularly in chronic conditions, monitoring health related quality of life (HRQoL) of adolescents in clinical practice is increasingly advocated. We set out to identify and review the clinical utility of available generic and diabetes specific HRQoL questionnaires suitable for use in adolescents with type 1 diabetes. Four generic and five diabetes specific questionnaires were identified and evaluated. The responsiveness of most instruments warrants further research and standardisation of HRQoL measurement should be sought to facilitate comparisons across centres and countries. The PedsQL and the KINDL-R appear, at this time, to be the most suitable instruments.

developed and used as outcomes in research and clinical trials.¹⁰

The purpose of this review is to evaluate existing measures suitable for use in adolescents with diabetes, to guide potential users in their selection of instruments to monitor HRQoL in clinical practice.

METHODS

Selection of questionnaires

Medline, EMBASE and PsycINFO databases were searched (from the earliest data in the database until April 2006) combining keywords using MeSH terminology: diabetes mellitus type 1, adolescent or young people, quality of life, and questionnaire or measure or instrument. The references of retrieved articles were reviewed for other potential relevant articles and experts in the field were contacted in order to obtain information on questionnaires under development. Articles in English on self-administered HRQoL questionnaires (generic and diabetes specific) were included for review if they were developed for or used in teenagers with diabetes and data on psychometric properties were available. Information on the psychometric properties and practical aspects concerning the clinical utility of the selected questionnaires was extracted from the validation articles and from the authors.

Psychometric properties

The psychometric quality of a questionnaire is defined in terms of its validity and reliability. As no "gold standard" is available for HRQoL, criterion validity is difficult to establish. Both generic and diabetes specific questionnaires need to have face validity, that is, have good readability and pertain to domains of functioning and experience that are relevant aspects of the HRQoL of adolescents with diabetes. This implies that the content and format of the scale are developmentally appropriate. As a rule, the use of self-administered standardised questionnaires is feasible from the age of 8 years on.¹¹ Other, partly overlapping, aspects of validity include content validity (all relevant topics are sampled by an instrument), construct or concurrent validity (it

Monitoring quality of life in clinical practice in chronic illness, including diabetes, has been repeatedly advocated.^{1–4} However, to date only one study tested the feasibility and utility of implementing standardised health related quality of life (HRQoL) measurement in paediatric clinical practice, and reported positive effects.⁵ The use of HRQoL measurement has been studied in adult populations more thoroughly and a positive effect on patient–physician communication and mental health following feedback interventions was reported.^{1–6} Monitoring and discussing psychological well-being as part of routine outpatient care showed favourable effects on mood and satisfaction with care of adult diabetes patients.⁷ Research findings suggest that in the context of paediatric diabetes care, the use of self-report questionnaires could facilitate communication between patients and their care providers and help guide clinical decision making. Suitable questionnaires are therefore needed that can capture (changes in) relevant domains of HRQoL in young people with diabetes. While there is no consensus on the definition HRQoL, it is generally regarded to be a multi-dimensional concept pertaining to broad areas of physical functioning (disease and treatment related symptoms), functional status, social functioning and psychological functioning. By definition HRQoL is a method for uniform measurement of a subjective condition, thus expressing the teenager's experiences, beliefs, expectations and perceptions.⁸

For a HRQoL measure to be utilised in clinical practice, the questionnaire has to meet certain psychometric and practical criteria.¹ In 2001, Eiser and Morse reviewed generic and disease specific (HRQoL) questionnaires for children with chronic illnesses.⁹ Since then, new instruments have been

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Table 1 Psychometric and practical aspects of the clinical utility of the generic and diabetes specific questionnaires

Measures	No. of domains	No. of items	Validity	Reliability	Time to complete†	Recall period	Parent proxy	Norm scores‡	No. of languages	Disease modules
Generic CHQ-CF87	12: physical functioning role-social physical role-social emotional role-social behaviour bodily pain self-esteem mental health behaviour general health change in health family activities family cohesion	87	Content construct discriminative	0.63< α <0.91* test-retest inter-rater	20 min	4 weeks	Yes	Healthy/ chronic illness diabetes	20	None
PedsQL 4.0	4: physical emotional social school	23	Content construct discriminative responsiveness	0.68< α <0.88* inter-rater factor analysis	5–10 min	1 month	Yes	Healthy/ chronic illness diabetes	54	10: asthma brain tumor cancer cardiac cerebral palsy diabetes fatigue pain rheumatology
KINDL-R	6/7: physical wellbeing emotional wellbeing self esteem family friends every day functioning “disease”	24/30	Content construct discriminative responsiveness	0.63< α <0.84* factor analysis	10 min	1 week	Yes	Healthy/ chronic illness	15	5: asthma atopic- dermatitis cancer diabetes obesity
DISABKIDS	6: emotion independence physical social inclusion social exclusion medication	37/12	Content	0.79< α <0.90* factor analysis	NA	4 weeks	Yes	Chronic illness	6	7: arthritis asthma atopic- dermatitis cerebral palsy cystic fibrosis diabetes epilepsy
Diabetes specific DQOL-Youth	3: impact worries satisfaction with life	52	Content criterion	0.82< α <0.85*	NA	None	No	Diabetes	15	
ADDQoL-Teen	2: impact other impact self	25	Content	0.81< α <0.90* factor analysis	10–15 min	None	No	None	1	
PedsQL-DM	5: symptoms treatment barriers treatment adherence worry communication	28	Content construct	0.63< α <0.81*	5–10 min	1 month	Yes	Diabetes	12	
KINDL-R -DM	1	17	Content	α =0.80* factor analysis	5 min	1 week	Yes	None	2	
DISABKIDS- DM	2: impact treatment	10	Content	α =0.84 and 0.85* factor analysis	NA	4 weeks	Yes	None	6	

*Internal consistency for subscales represented in Cronbach's α ; †time to complete as indicated by the authors of the questionnaires; ‡norm scores available for healthy and/or chronically ill adolescents and/or adolescents with diabetes. NA, information not available.

measures HRQoL rather than some other concept as demonstrated by associations with related constructs) and discriminative validity (it is able to distinguish between different groups). Responsiveness is an important requirement, as measures must be sensitive enough to detect clinically relevant changes in a teenager's HRQoL over time or following an intervention. The validity of a questionnaire in one language or patient population does not necessarily apply to other settings. Cross-cultural validation is therefore required.

Reliability of a questionnaire refers to homogeneity or internal consistency (the different items that make up a scale are measuring the same thing, measured by Cronbach's α) and test-retest reliability (children will respond the same at different occasions when no change is expected). When using different sources of information, the inter-rater reliability needs to be established, for example when using a child and a parent (proxy) version of a scale.

Clinical utility

For a questionnaire to be utilised in clinical practice, various practical aspects of the questionnaire need to be taken into account.

1. Time for patient contacts is often limited in busy clinics, and therefore the time required and ease of filling out the questionnaire are relevant. Short, patient-friendly instruments that require little or no assistance are preferred.
2. The recall period (time reference) is of relevance, particularly when used repeatedly as part of periodic consultations. This can range from "recent days" to "last year". The absence of a time reference can be confusing for both children and health professionals.¹²
3. To interpret HRQoL outcomes and changes in time between and within patients, norm scores need to be available.
4. A parent (proxy) version may yield additional information. Adolescents are old enough to rate their own HRQoL and a parent's proxy questionnaire is not necessary because of age per se. However, availability of a proxy does allow for comparison of patient and parent views on HRQoL. In general, parents' rating of their child's HRQoL tends to be different than the child's own rating.¹²
5. The availability of different disease modules in addition to a generic module is an advantage when the questionnaire is also to be used in other chronic illnesses.

Finally, the availability of translations, ease of scoring and costs need to be considered.

RESULTS

In total, nine questionnaires meeting basic search criteria were identified: four generic questionnaires and five diabetes specific questionnaires. The authors of three questionnaires were contacted to obtain additional data on validity. The four generic HRQoL questionnaires used in studies concerning adolescents with diabetes are the Child Health Questionnaire-Child Form 87 (CHQ-CF87),¹³ the Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0),¹⁴ the Revidierter KINDer Lebensqualitätsfragebogen (KINDL-R)¹⁵ and the DISABKIDS chronic generic module.¹⁶ The five diabetes specific questionnaires that were identified are the Diabetes Quality of Life-Youth questionnaire (DQOL-Youth),¹⁷ the PedsQL-Diabetes Module (PedsQL-DM),¹⁸ the KINDL-R-Diabetes Module (KINDL-R-DM),¹⁵ the Audit of Diabetes Dependent Quality of Life-Teen version (ADDQoL-Teen)¹⁹ and the recently developed DISABKIDS-Diabetes Module (DISABKIDS-DM).²⁰

Table 1 provides an overview of the nine questionnaires and their psychometric and practical features.

Domains

The generic questionnaires cover the four domains of physical functioning, functional status, psychological functioning and social functioning, in some cases divided over more than one subscale. The diabetes specific questionnaires assess the contents of the domains at item level, but the subscales are grouped differently from the general HRQoL domains.

Number of items

The numbers of items range from 10 to 87. The KINDL-R has six complementary questions for chronically ill adolescents regarding their illness. The DISABKIDS generic module has two versions, the complete 37-item version and a shorter 12-item version. The ADDQoL-Teen divides the questions into two parts: part A in which the teenager is asked about the frequency with which diabetes impacts on each aspect of life, and part B in which the teenager is asked how much that particular domain bothers them.

Response categories

All the questionnaires use Likert scale response categories; most of them have a 5-point Likert scale, except for the CHQ-CF87, in which the response scale varies between four and six categories.

Table 2 displays example items from the different questionnaires and the response categories.

Validity

Validity of the generic questionnaires is reported to be generally good. Data on the validity of the diabetes specific questionnaires are less convincing. Efforts have been made by the authors to achieve good content validity. For this purpose children were consulted in the item development procedure, except for the DQOL-Youth. This questionnaire was a revision of the original adult version developed for the Diabetes Control and Complications Trial (DCCT)²¹ and scores on the questionnaire appear predictive of self-rated health.¹⁷ A recent study suggested a short form of the DQOL-Youth, with five subscales (18 items) instead of the three subscales with 52 items.²²

Construct validity for the diabetes specific questionnaires has only been tested in the PedsQL-DM, where scores of the diabetes module correlate positively with scores on the PedsQL 4.0 generic module. As to responsiveness, only the PedsQL 4.0 and the KINDL-R have been tested for sensitivity to change, with satisfactory results.^{5, 13} Children treated for fractures showed improvement in all subscales of the PedsQL 4.0 at follow up. After a 6 month in-patient rehabilitation program, children with asthma, atopic dermatitis and obesity showed significant improvement on the total, physical, self-esteem and friends subscales, as well as the disease specific modules.

Reliability

The recommended Cronbach's α of 0.90 for use at the individual patient level²³ is only reached in two subscales of the CHQ-CF87 (physical functioning and role functioning-emotional), the DISABKIDS general module (emotion) and in the total score of the ADDQoL-Teen. To test predefined subscales, confirmatory factor analysis was performed for all questionnaires except the CHQ-CF87 where factor analysis was only performed in the parent (proxy) forms (CHQ-PF28 and CHQ-PF50).¹³

Test-retest data (after 2 weeks) are available only for the CHQ-CF87.²⁴ Inter-rater correlations between parents and adolescents were significant for all directly comparable CHQ scales as well as for the PedsQL 4.0.^{4, 25} No inter-rater reliability data are available for other questionnaires with available proxy measures.

Table 2 Example items and response categories

Questionnaire	Example item	Response categories
CHQ-CF87	Have you been limited in the past 4 weeks in any of the following ways due to problems with your behaviour: limited in the kind of schoolwork or activities with friends you could do?	1 = yes, very limited 2 = yes, limited 3 = yes, a bit limited 4 = no, not limited
PedsQL 4.0 PedsQL-DM	In the past month, how much of a problem has this been for you... Other kids don't want to be my friend. My parents and I argue about my diabetes care.	0 = never 1 = almost never 2 = sometimes 3 = often 4 = almost always
KINDL-R KINDL-R-DM	During the past week... I got on well with my parents. I would best of all have liked to "stuff my face" with my favourite foods.	1 = never 2 = rarely 3 = sometimes 4 = often 5 = all the time
DISABKIDS DISABKIDS-DM	Think about the past 4 weeks: Do you feel lonely because of your condition? Does diabetes rule your day?	1 = never 2 = seldom 3 = quite often 4 = very often 5 = always
DQOL-Youth	How often are you teased because you have diabetes?	1 = never 2 = very seldom 3 = sometimes 4 = often 5 = all the time
ADDQoL-Teen	A: "Do you ever want to eat something but you don't eat it because of your diabetes?" B: "Does it bother you when you want to eat something but you don't because of your diabetes?"	Yes—a lot Yes—a fair bit Yes—a bit No—I do not Yes—It bothers me very much Yes—It bothers me a fair bit No—It doesn't bother me, it's OK No—It doesn't bother me, I like it

Parent proxy

For the CHQ-CF87, three versions with different lengths are available.¹³ The proxy questionnaires of the other instruments contain the same items as their complementary child forms.

Norm scores

Manuals and norm scores are available for all of the generic instruments; the CHQ-CF87 and the PedsQL 4.0 are also validated in a diabetes population and norm scores are available from these studies.^{18–26} The DISABKIDS generic module is designed for use in chronically ill children and therefore there are no norm scores for healthy children. A manual with norm scores for the ADDQoL-Teen is under development.

Languages

Most questionnaires have been developed in English. Information on existing translations is available on the internet.^{27–31} The DISABKIDS questionnaires were developed and validated in six languages in seven European countries; this should enhance cross-cultural validity, at least in Europe. Three versions of the CHQ-CF87 have been validated in countries other than the USA (Australia, The Netherlands and China)^{24–32–33} and the PedsQL 4.0 has been validated in four countries other than the USA (United Kingdom, China, Germany and The Netherlands).^{34–37} Besides information on the validity and reliability of a questionnaire, the validation studies can provide norm scores for the specific country as well.

Scoring

Of all the selected questionnaires, the scoring of the CHQ-CF87 is the most complicated, due to the large number of items, the different Likert scales used and reversed items. Different steps are required to obtain a standardised score of 0–100 in the

KINDL-R generic and DISABKIDS generic modules because of reversed items. Item subscale scores of the DQOL-Youth are simply summated. For the PedsQL, raw scores are reversed to obtain a score of between 0 and 100, with higher scores representing better HRQoL.

Our findings concerning clinical utility are summarised in table 3. It is important to note that fees have to be paid for the use of these questionnaires in clinical practice, except for the DQOL-Youth and KINDL-R which can be freely used by non-profit and research organisations.

CONCLUSIONS

We identified nine potential suitable instruments for monitoring HRQoL in adolescents with diabetes: four generic and five diabetes specific questionnaires. Of these questionnaires, the DISABKIDS generic module is the only one specifically developed for chronically ill children and therefore does not allow for comparison with healthy children. Generic and diabetes specific questionnaires have both strengths and weaknesses. Generic measures of HRQoL allow for comparisons with healthy individuals and other groups of patients. Disease specific HRQoL measures can only be used in patients diagnosed with a specific condition but have the advantage of having more relevance to patients and are typically more sensitive in detecting clinically relevant changes. Ideally, a combination of a generic and diabetes specific questionnaire is used to provide a comprehensive assessment of the teenagers' HRQoL.^{1–2} In general paediatric hospitals with different medical specialties, a generic instrument with additional disease specific modules could be preferred. The PedsQL and the KINDL-R both have a generic module, allowing for comparisons with healthy children, and different disease specific additional modules,

Table 3 Summary of psychometric and practical aspects

Measures	Psychometric	Practical
Generic		
CHQ-CF87	67%	56%
PedsQL 4.0	78%	89%
KINDL-R	67%	78%
DISABKIDS	33%	56%
Diabetes specific		
DQOL-Youth	38%	57%
ADDQoL-Teen	38%	14%
PedsQL-DM	33%	86%
KINDL-DM	33%	57%
DISABKIDS-DM	33%	43%

Percentages of the possible psychometric and practical aspects met for each questionnaire are shown.

with the PedsQL having the most translations and disease specific modules available.

Overall, the psychometric properties of all instruments are satisfactory, although the responsiveness of all questionnaires warrants further research. This should, in our view, not keep clinicians from using the measures for clinical purposes, as they are primarily used to focus attention on HRQoL issues and to facilitate communication with young patients regarding the impact of diabetes on their psychosocial functioning. Using HRQoL measures in clinical practice along with other indices of health (for example, BMI, hypoglycaemic episodes, glycaemic control) should help to improve our understanding of the instruments' sensitivity to change. It is important to note that although psychological and behavioural problems are likely to compromise glycaemic control, the association between HRQoL and glycaemic control is complex. Good glycaemic control does not always imply good HRQoL and vice versa.^{2 38 39}

The effects of introducing validated HRQoL measures in clinical practice obviously need to be evaluated, both in terms of process and clinical outcomes. In this context, standardisation of HRQoL assessment should be sought in order to allow for comparisons across centres and countries.

Although HRQoL questionnaires are not designed as screening instruments (ie, to detect psychological disorders such as depression, anxiety or eating disorders), routine HRQoL assessment is likely to facilitate detection and discussion of psychological issues related to diabetes and can help guide decisions regarding referral to a mental health specialist if required.

Clinicians may perceive time needed for assessment and discussion as a barrier to implementing the monitoring of HRQoL in busy clinics. However, administering, for example, the PedsQL generic and diabetes module takes on average 20 min. Computer-assisted assessment allows for quick automated scoring and therefore saves time. Research suggests that discussion of HRQoL issues as part of a consultation should not necessarily lengthen consultation time. In fact, consultation time may be shortened. Even in busy clinics, where time is a critical issue, administering a generic and diabetes specific measure of HRQoL should be feasible.

The question of who discusses the outcomes of the HRQoL assessment with the teenager depends on the care model and local resources. This could be the primary responsibility of the paediatrician, but research has shown that with some training, (computerised) monitoring of HRQoL as part of routine diabetes care is handled well by diabetes nurse specialists, and much appreciated.^{7 40} As most paediatric teams are multi-disciplinary, sharing the information regarding HRQoL as part of ongoing clinical care is crucial and should help to tailor care to the needs of the adolescent with diabetes.

What is already known on this topic

- There is consensus on the importance of including health related quality of life questionnaires in periodic assessments in adolescents with type 1 diabetes.
- A growing number of HRQoL measures appropriate for use in adolescents with a chronic illness have been developed, but there is uncertainty as to their utility in paediatric diabetes practice.

What this study adds

- Of the various validated generic and disease specific HRQoL questionnaires available for use in adolescents with diabetes, KINDL-R and PedsQL seem to be most suitable.
- Standardisation of HRQoL measurement in adolescents with diabetes should be sought, to establish cross-cultural validity and allow for between-centre comparisons of HRQoL outcomes.

Given the availability of sound measures of HRQoL specific for adolescents, the time seems right to start implementing the clinical recommendation to routinely monitor HRQoL in paediatric diabetes care.

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