ORIGINAL ARTICLE

Adaptation of the Manchester-Minneapolis Quality of Life instrument for use in the UK population

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Introduction: The availability of health-related quality of life (HRQL) measures that are reliable, valid, brief and comprehensible and appropriate for use with UK children is limited. We report the validation of a HRQL measure suitable for UK use in healthy children, children with chronic disease conditions and socially disadvantaged children.
Patients: A total of 1238 children took part in the study, including healthy children as controls (n = 824) and five exemplar groups: children diagnosed with asthma (n = 87), diabetes (n = 103) or inflammatory bowel disease (IBD; n = 69), children in remission from cancer (n = 68) and children in public care (n = 87).
Methods: In phase I, the Manchester-Minneapolis Quality of Life instrument (MMQL) Child Form was translated into UK English. In phases II and III, the questionnaire was shortened and validated.
Results: MMQL was anglicised and shortened to five components comprising 29 items. Good internal reliability was found with α reaching at least 0.69 for all subscales. Construct validity was established through moderate correlations with comparable PedsQL subscales (Pearson's *r* ranged from 0.38 to 0.58, $p<0.01$). Discriminant validity was also demonstrated in children with asthma and IBD, children in remission from cancer and children in public care, all of whom reported significantly lower HRQL than healthy children. Children with diabetes showed similar HRQL to their healthy peers. Good reproducibility and moderate responsiveness were demonstrated for the new measure.
Conclusions: The anglicised and shortened MMQL was shown to be valid and reliable and could be a valuable new tool for the assessment of HRQL in children.

The value of measuring health-related quality of life (HRQL) is now well recognised within medicine. Measuring HRQL includes recording patient perceptions of their physical, emotional and social health and function that can supplement clinical information on their health status. There has been a rapid growth in the number of scales available for the measurement of HRQL.[1] Disease-specific questionnaires allow the detection of relatively small changes in patients with a specific condition, whereas generic instruments allow comparisons of patients with different conditions or with healthy peers.

New HRQL scales have been mainly developed for adult populations; less attention has been given to the development of paediatric HRQL scales.[2 3] Existing adult HRQL measures for various reasons are not appropriate for use in paediatric populations.[2–4] The subscales measured may not be appropriate to children, for example issues relating to sexuality, employment or income may not be relevant. Children's HRQL measures have to take account of change and the stage of development of the child. Children and adults do not always share the same views about their illness, they may interpret questions differently and have different perspectives regarding disease course and impact.[5 6]

Proxy assessments of HRQL, completed by clinicians, parents or carers, have been used to assess a child's HRQL.[3 7–10] Although proxy assessments can provide useful information on a child's health status,[6 11] especially where a child is too ill or young to provide their own HRQL, it is now widely recognised that children should as far as possible rate their own HRQL.[12 13] It has been documented that children as young as 5 can provide valid judgements on aspects of their health such as pain, but older children would be required to provide more valid feedback on emotional aspects of functioning.[3 13] In addition, it has been documented that parental reports of a child's HRQL can differ substantially from the child's own self-reported HRQL.[8–10]

Thus reliable, well-validated child-specific measures designed to assess the problems experienced by children are required. The aim of this study was therefore to anglicise, refine and validate a child HRQL measure that had been developed in the USA (the Minneapolis-Manchester Quality of Life instrument, MMQL[14]) for use with healthy UK children, children in public care and children with chronic health conditions.

METHODS

The study was carried out in three phases. Phase I involved anglicisation of the existing measure and refinement of MMQL coding categories and questionnaire layout. In phase II a short form of the MMQL was developed and in phase III the psychometric properties of the short form were tested.

Minneapolis-Manchester Quality of Life instrument (MMQL)

This questionnaire was originally developed in the US by a UK paediatrician for use with cancer survivors.[14] The original version has three different forms, one for children aged 8–11 years (Child Form, MMQL-CF), one for 12–18 year olds (Youth Form, MMQL-YF) and one for young people aged 19–25 years. The questionnaire measures the subscales of sports and activities, activity, feelings, physical appearance, friendships, intimate relationships, school and outlook.

Abbreviations: HRQL, health-related quality of life; IBD, inflammatory bowel disease; MMQL, Manchester-Minneapolis Quality of Life instrument; MMQL-CF, MMQL Child Form; MMQL-YF, MMQL Youth Form

Table 1 Selection of questions for the shortened MMQL-YF30

	Pattern matrix showing significant component coefficients (after oblique rotation)				
Question content	Component 1 Appearance	Component 2 School Functioning	Component 3 Social Functioning	Component 4 Emotional Functioning	Component 5 Physical Functioning
Unable to do sport					0.656
Unable to keep up					0.624
Feeling tired					
Feeling strong					
Needing a rest					
Having lots of energy					
Having lots of energy for sport					0.550
Unable to do many activities					0.709
Prefers to watch sport					0.509
Feeling sad				−0.724	
Feeling angry				−0.595	
Feeling lonely				−0.524	
Feeling fear				−0.742	
Feeling anxious				−0.752	
Worrying in general				−0.728	
Worrying about health				−0.513	
Worrying about dying					
Feeling less good than others					
Happy with weight	0.755				
Happy with looks	0.739				
Happy with body development	0.799				
Liking body as it is	0.871				
Self conscious about body					
Uncomfortable about body	0.616				
Difficulty making friends					
Feeling left out by others					
Others like me			−0.699		
Lots in common with others			−0.777		
Getting on well with others			−0.827		
Having many friends			−0.857		
Sharing hobbies			−0.789		
Being happy with others			−0.688		
Having intimate relationships					
Getting on with opposite sex					
Concentrating at school		0.716			
Concentrating at other times		0.614			
Finding study difficult		0.824			
Needing help with schoolwork		0.820			
Memory problems		0.769			
Reading difficulties		0.659			
Problems with maths		0.606			
More difficulties than others		0.843			
Feeling happy now					
Feeling happy with life					
Feeling happy with situation					
Cumulative eigenvalue (%)	27.31	35.36	42.41	47.40	51.86

PedsQL version 4.0 core module

The PedsQL measurement model is a modular approach to measuring HRQL in children and adolescents which is rapidly becoming established in the US.[15 16] Anglicised versions are also available.[17] It consists of a brief, practical generic core module, which is complemented by a number of condition-specific measures. The child self-report is suitable for children between 5 and 18 years of age. The subscales measured by the PedsQL are Physical Functioning, Emotional Functioning, Social Functioning and School Functioning.

Phase I

Anglicisation of the MMQL questionnaire followed the guidelines defined by Varni[18 19]and Quittner[20] and was carried out by three of the research team (PU, CE and MJ). Any phrases and terms that were not used or understood by a sample of UK children were removed and possible alternatives were suggested. Some refinement of coding categories and questionnaire layout was also undertaken. An opportunistic sample of school children (age range 10–18 years) was recruited from a local school where interviews and completion of the MMQL took place.

Phase II

A total of 660 children aged between 8 and 18 and meeting the inclusion criteria were approached to take part in phase II. Five groups were chosen as exemplars representing four chronic conditions (asthma, diabetes, chronic inflammatory bowel disease (IBD) and cancer (long-term survivors)). In addition children looked after in public care were recruited as the fifth exemplar. Children with a chronic health problem were identified with the guidance of collaborating clinicians and completed the questionnaires in clinic or at home. Children in public care were identified by a consultant paediatrician following a routine clinical assessment of a child in state care. Children in public care completed the questionnaires at home.

Controls were recruited from schools in Swansea, Neath, Port Talbot and Bridgend (Wales, UK). Permission to approach

Table 2 Internal consistency of the MMQL-YF30 components

Subscale	Minimum corrected item subscale correlation	Maximum corrected item subscale correlation	Cronbach's α
Appearance	0.43	0.82	0.87
School Functioning	0.56	0.81	0.89
Social Functioning	0.64	0.79	0.90
Emotional Functioning	0.48	0.67	0.83
Physical Functioning	0.44	0.53	0.72

schools was obtained from the directors of education in each local education authority. School children completed the questionnaires in the classroom.

In both the exemplar and control groups, children with moderate to severe learning difficulties and children and parents for whom English was not their first language were excluded from the study.

Phase III

A total of 1347 children were approached to take part in phase III. Eligible subjects were recruited from the same five exemplar groups as in phase II. Inclusion criteria for the cancer group were altered slightly to make this a more homogeneous group. Specifically, only children aged 8–18 years who had received an allogeneic bone marrow transplant (BMT) following acute lymphoblastic leukaemia (ALL) and had completed therapy at the time of assessment were included in the study. Controls were recruited from schools using the same method as in phase II.

In phase III, all children completed the shortened and anglicised version of the MMQL-YF. Non-attenders at clinic visits were sent letters and offered the opportunity to take part in the study as it was felt that this group were not having an equal opportunity to be recruited into the study.

Subjects in this phase of the study were asked to complete the MMQL-YF twice (initial and follow-up clinic visit) for the purpose of evaluating test re-test reliability and responsiveness.

The study was approved by the Welsh Multi-centre Research Ethics Committee (MREC). Informed consent was sought from all children and their parents or those with parental responsibilities (for children less than 16 years of age), following oral and written explanation of the study.

Analysis

Data were analysed using the Statistical Package for Social Sciences (SPSS, Chicago, IL) version 11.4.

Assessing underlying dimensions and internal consistency

The internal consistency and underlying dimensions of the MMQL were assessed with the subjects from phase II and phase III. In phase II, principal component analysis[21] was performed to determine the relevant components. A ''direct oblimin'' oblique rotation method was then applied to determine the structure of the questionnaires being shortened and produce a pattern of components that could be interpreted more easily. A component was considered important if its eigenvalue exceeded 1.1.[22] The eigenvalue of a component represents the amount of variance explained by that component. Each component also had to exhibit face validity, that is, it appeared at face value to be measuring a clinically recognisable aspect of the patient's health. Questions were considered as contributing to a component if they had a factor loading of at least 0.4 on that component. Questions not contributing to any of the important components were considered for removal.

The internal consistency of the shortened MMQL components were assessed by item-total correlations and Cronbach's alpha (α).[23] Questions yielding item-total correlations below 0.4 were considered for rejection.[24] Questions were also considered for rejection if more than 75% of individuals gave the same response, because such questions are not sensitive enough to discriminate between different levels of severity.[24] Questions were also considered for exclusion if they were disliked or considered difficult to answer by the children completing them. Finally, Cronbach's α for each of the resulting components should exceed 0.7.[25]

In phase III, principal components analysis was performed again without any restrictions on the data and the structure was compared to the initial emergent structure from phase II. This was carried out in order to validate the underlying components of the short form of the MMQL. Internal consistency was assessed by Cronbach's α.

Assessing validity

The construct validity of the shortened MMQL components was assessed in phase III by comparing them with the appropriate PedsQL subscales. If the components were valid measures of childhood HRQL, they would be expected to show significant small to moderate levels of correlation with each of the PedsQL scales, with the largest correlations being seen between the PedsQL scales measuring physical, social, emotional and school function and the comparable MMQL components.

In phase III, the discriminant validity was assessed by comparison of components scores between exemplar and control groups. If the shortened components were valid measures of the effects of childhood HRQL, the exemplar groups would be expected to score lower on the MMQL components than the control group. Independent samples *t* tests with Bonferroni corrections were used to compare control and exemplar groups.

Assessing reproducibility

Reproducibility of the MMQL was assessed in phase III. Following completion of the initial shortened MMQL in clinic, the exemplar groups were asked to complete a second ''retest'' questionnaire on their next visit to clinic. Children who were

Table 3 Correlation between the MMQL-YF29 components and PedsQL self-report subscales

	PedsQL			
MMQL-YF30	Physical Functioning	Emotional Functioning	Social Functioning	School Functioning
Appearance	0.28**	0.37**	0.28**	0.29**
School Functioning	0.31**	0.27**	0.33**	0.54**
Social Functioning	0.16**	0.24**	0.37**	0.19**
Emotional Functioning	0.36**	0.58**	0.44**	0.41**
Physical Functioning	0.55**	0.32**	0.47**	0.35**

**Significant at the 0.01 level.

Table 4 Mean scores (SD) on the MMQL-YF29 components for different patient groups and controls

MMQL-YF29 subscale	Control (n = 563)	Asthma (n = 56)	Diabetes (n = 73)	Cancer (n = 44)	IBD (n = 57)	Public care (n = 72)
Appearance	69.81 (27.36)	67.29 (32.25)	77.14 (25.52)	61.51 (27.16)	67.87 (24.82)	64.61 (34.97)
School Functioning	68.99 (23.02)	67.54 (23.19)	72.90 (25.91)	59.16 (29.76)	69.11 (26.48)	57.00 (30.65)**
Social Functioning	83.73 (16.67)	85.57 (14.50)	87.68 (12.11)	82.23 (15.54)	85.82 (12.07)	84.04 (21.48)
Emotional Functioning	66.05 (15.36)	66.77 (15.48)	67.48 (15.76)	64.20 (15.14)	64.26 (15.45)	64.63 (20.71)
Physical Functioning	80.06 (19.46)	62.68 (26.67)**	81.34 (17.96)	64.94 (24.49)**	60.35 (29.74)**	77.46 (24.65)

Independent samples *t* test with Bonferroni correction for multiple comparisons. IBD, inflammatory bowel disease; SD, standard deviation.
**Significant at the 0.01 level (compared to controls).

not due to return to clinic for 3–4 months were asked to complete the retest questionnaire at home. In addition to completing the MMQL, children were asked to rate whether their health had changed (improved, got worse or stayed the same) since the first questionnaire was completed. Those reporting no changes were included in the reproducibility analysis. Reproducibility was assessed using the intra-class correlation coefficient.[26]

Assessing responsiveness

The responsiveness of the MMQL was assessed in phase III by using the scores of children who reported a change in their health. The response ratio (mean change in scores for subjects reporting a change divided by the standard deviation of the subjects reporting no change) was used to quantify the responsiveness. The larger the ratio, the more responsive the instrument.

RESULTS

Phase I

Thirty children completed the anglicised MMQL and were interviewed. Children reported no problems with the language in the new versions of the MMQL. Minor comments were made on the length, amount of repetition and personal nature of some of the questions. However, no further modification of the MMQL was deemed necessary.

Phase II

A total of 390 children completed questionnaires in phase II.

The MMQL-CF performed poorly in phase II and principal component analysis could not identify a reasonable component structure. The child form was therefore withdrawn from subsequent analysis and field work in phase III. All children (aged 8–18 years) were administered the shortened YF in phase III.

The principal component analysis of the data for the MMQL-YF found five meaningful underlying components (table 1). A total of 30 items were selected for inclusion in the shortened MMQL (MMQL-YF30). Fourteen items were excluded because of a factor loading below 0.4 and one item was excluded because all children gave the same response to the item. Table 1 illustrates the five new proposed components.

Cronbach's α for the proposed MMQL-YF30 components exceeded the accepted criterion of 0.70 (see table 2).

Phase III

A total of 865 children completed questionnaires in phase III. Principal component analysis of the phase III data confirmed the underlying structure of the MMQL-YF30 identified in phase II. The item ''feeling uncomfortable with body development'' was found to be redundant (factor loading less than 0.40) and was removed from the final version of the MMQL short form (MMQL-YF29).

Internal reliability of the MMQL-YF29 was confirmed by Cronbach's α values for each of the components, all but one of which reached or exceeded 0.70 (Appearance 0.89, School Functioning 0.86, Social Functioning 0.84, Emotional Functioning 0.84, Physical Functioning 0.69).

Validity of the MMQL-YF29 was demonstrated by significant correlations between the MMQL-YF components and the PedsQL subscales. This was most apparent in those components measuring similar constructs (table 3).

Table 4 illustrates significant differences between the mean component scores for the control and exemplar groups. Children with cancer, IBD and asthma reported lower physical functioning than control groups. Children in public care reported lower school scores than the control group. Children with diabetes reported higher scores than controls for all the component scores, although none of these reached significance once the Bonferroni corrections were applied.

The reproducibility of the MMQL-YF29 was good and was demonstrated by strong test-retest intra-class correlations in those children with no change in their health status (Appearance 0.86, School Functioning 0.83, Social Functioning 0.66, Emotional Functioning 0.74, Physical Functioning 0.87).

The responsiveness of the MMQL-YF29 was tested in those children reporting a change in their health (table 5). All children in this group reported an improvement in their health. Moderate levels of responsiveness were demonstrated for all components except social functioning, where children had lower HRQL despite reporting improved physical health. Physical functioning was the only component with a statistically significant difference in scores.

DISCUSSION

The MMQL was successfully shortened to five components comprising 29 items (MMQL-29). In addition the coding categories and questionnaire structure were refined, and the

Table 5 Responsiveness of the MMQL-YF29 components for children reporting an improvement in their health

	Mean difference for subjects reporting a change (n = 32)	Two-tailed significance	SD of the scores of stable subjects (n = 45)	Responsiveness ratio
Appearance	3.90	0.300	13.10	0.30
School Functioning	5.36	0.125	13.70	0.39
Social Functioning	−5.47	0.117	9.71	−0.56
Emotional Functioning	4.87	0.092	11.55	0.42
Physical Functioning	6.80	0.016*	11.57	0.59

*Significant at the 0.05 level.

language was made more appropriate for use with a UK population. It appears that the items selected for the MMQL-29 reflect those of universal concern for both children and young people as this version of the MMQL was found to be suitable for 8–18 year olds. One benefit of this feature is that it will facilitate the evaluation of differences in HRQL across and between age groups, as well as tracking of HRQL longitudinally. The PedsQL is the only other empirically validated paediatric HRQL instrument to span a broad age range.[27]

Good internal reliability was found for the MMQL, with α exceeding 0.70 for all but one component.[25] The only component not reaching 0.70 was Physical Functioning, which at 0.69 approached the recommended minimum standard. Construct validity of the MMQL-29 was established through moderate correlations with the PedsQL core module. PedsQL is an established generic instrument which has been shown to be reliable and valid[16] and is often heralded as one of the more promising paediatric measures of HRQL currently available.[6]

Discriminant validity was demonstrated for the MMQL-29, with differences being noted in HRQL between healthy children and those with chronic health conditions. In most cases, these differences were in the expected direction, with children with chronic health conditions reporting lower HRQL than healthy children. However, this was not always the case, with perhaps the most notable exception being children with diabetes. This group reported better HRQL than healthy children on all components, although this did not always reach statistical significance. The similarity in HRQL between children with diabetes and their healthy peers has been highlighted previously.[17 28]

Other than the PedsQL, the MMQL-29 is the only anglicised generic measure which fulfils the recommendations advocated for a childhood HRQL scale, that is, it is brief, comprehensive, reliable and valid.[29] It is also recommended that a parent proxy form be available for child HRQL measures, a condition which the PedsQL also fulfils. A parent version of the MMQL was also developed in parallel with our anglicisation and shortening of the child MMQL (results of which will be reported elsewhere).

What is already known on this topic

- There are no well developed measures to assess health-related quality of life (HRQL) that are suitable for children in the UK.
- HRQL measures need to be brief, reliable, multi-dimensional and include a proxy rating.
- The Minneapolis-Manchester Quality of Life instrument (MMQL) was developed from focus groups with children and adolescents and has established psychometric properties.

What this study adds

- We report a relatively brief (29 items), reliable measure of HRQL for UK children aged 8–18 years.
- The measure distinguished between children with different chronic conditions as would be expected.
- Validity was confirmed through predicted relationships with subscales of the PedsQL.
- Responsiveness was confirmed through ratings made by children experiencing a change in health.

Furthermore MMQL has the advantage of considering self-image as well as physical, social, emotional and school functioning. It therefore has excellent potential value as a reliable and valid outcome measure for use in both research and clinical settings.

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IMAGES IN PAEDRIATRICS

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Mixed messages

Figure 1 The vending machine next to information on diabetes.

Health promotion, an objective of most hospitals, can be compromised by commercial or other interests. The consumption of fizzy drinks, especially those with a high sugar content, is known to be harmful to childrens' health. There are also strong associations with tooth decay and obesity, the latter being linked to an increase in diabetes and cardiac disease in the adult population.[1]

Less well known is the interaction of acidic drinks with some drugs, most notably carbamazepine, which is an anticonvulsant commonly used in paediatric practice.[2] There is also an association with fizzy drink consumption and reduced bone mineral density in girls, which may be related to these drinks displacing milk in the diet.[3]

Increasingly, machines dispensing soft drinks are being introduced into schools with the expected consequences.[4]

The vending machine shown in fig 1, which was in a local paediatric unit, was placed beside the outpatient waiting area. There were no healthy alternative drinks available. Waiting children were drawn to this machine and often demanded these drinks from their parents. Ironically it is strategically placed close to notice boards advocating healthy eating and diabetes awareness.

It has, finally, been removed following the closure of the adjacent inpatient ward.

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