

Introduction

The use of preference based measures of health related quality of life (HRQoL) in NHS decision making is becoming more common. Preference based measures allow the calculation of quality adjusted life years which can then be used in economic evaluation as part of the decision making process. Research in the field of paediatric preference based measures is lacking. This work is the first stage in the development of a new generic paediatric preference based measure of HRQoL for use in economic evaluation, using only children to develop the content.

The measure is being explicitly developed for use in economic evaluation and is using bottom up methods to develop the content of the descriptive system by interviewing children about how their health affects their lives. This research is also designed to include work to see whether children share a common HRQoL framework across age.

Methods

Two schools in Sheffield were chosen in collaboration with the Children and Young People's Directorate at Sheffield City Council to make sure the diversity of children in Sheffield was covered. All parents of children in the schools were written to asking for their consent to approach their child to take part. Parents were asked to rate their child's health from 1 (excellent) to 5 (poor). Children were sampled purposively, based primarily on age, then level of health, whilst trying to balance for gender and ethnicity. Children were split into two age groups Y3/Y4 (7-9 years) and Y5/Y6 (9-11) years. These groups were sampled and analyzed independently to test whether they share common HRQoL frameworks. Children were given the option of being interviewed one to one or in a small group. The topic guide was designed to identify how the child's health affects their life. Both acute and chronic conditions were recognised as valid and probing was used to make sure all areas of the child's life (home, school, community) were covered. All interviews were recorded and transcribed verbatim. The objective of the qualitative analysis was to identify how health affects children's lives and to develop dimensions of HRQoL. Thematic content analysis using Framework was used to analyse the data.

Results

School A had a 9.5% response rate and School B had a 35% response rate. 74 interviews were carried out, all 1 to 1 except for 1 as a pair. The sample was well balanced by age, gender and ethnicity and had a reasonable spread across level of health, although there were fewer children at the poor end of health. A range of health problems arose in the interviews, covering both chronic conditions such as asthma, epilepsy, allergies and eczema, and acute conditions such as flu, infections and headaches. Some were minor and some were more serious, for example some cases of eczema required hospital treatment. Some conditions also arose that involved hospitalisation, including pneumonia and muscle growth problems. Many conditions required treatment via the GP, such as hay fever, ear infections and chicken pox and some required hospital visits, such as losing the feeling in their legs, severe asthma and broken bones. Interviews varied in length from 4 minutes to 26 minutes and saturation was reached in both age groups. A range of dimensions emerged from the analysis and were very similar across age groups.

Dimension	7-9 years	9-11 years
1	Worried Scared	Worried
2	Sad Upset Unhappy	Sad Upset Unhappy Miserable
3	Annoyed Frustrated	Annoyed Frustrated Angry
4	Hurt Pain	Hurt Pain
5	School Work	Learning
6	Daily Routine	Daily Routine
7	Tired Weak Drowsy	Tired Weak Energy Weary
8	Joining in activities that want to	Joining in activities that want to
9	Sleep	Sleep
10	Jealous	
11		Embarrassed

I'd just sit down and be coughing a lot and disturb the class, I wouldn't be learning because I'd be concentrating on my cough instead of learning.

(A18, male, 10, good health)

I just felt unhappy because I'm missing things that I normally do on the weekend.

(A22, female, 10, excellent health)



Conclusions

- The interviews were successful and saturation of health problems within schools was reached.
- There were gaps where children's health is poor.
- General areas of health related quality of life are covered by the dimensions – physical, emotional and social.
- There were many reasons why the dimensions emerged, because lots of different situations often led to the same or very similar outcomes on quality of life.
- Further work is now needed to develop the dimensions into a descriptive system