# DEVELOPING A DESCRIPTIVE SYSTEM FOR A NEW PREFERENCE BASED MEASURE OF HEALTH RELATED QUALITY OF LIFE FOR CHILDREN

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## Introduction

The use of preference based measures (PBM) of health related quality of life (HRQoL) is increasing in health care resource allocation decision making. Whilst there are measures widely used for this purpose in adults, research in the paediatric field is more limited. Research to develop a new generic preference based measure of HRQoL for children age 7-11 years is currently being undertaken at The University of Sheffield. The first part of this research was to develop the dimensions for inclusion in the measure and qualitative interviews were undertaken with children which identified 11 dimensions of HRQoL. The next stage of the research was to develop a descriptive system amenable to valuation from these dimensions and this is reported here. The aim was to develop a descriptive system suitable for health state valuation, based on the 11 dimensions identified in the previous work. The 11 dimensions were worried/scared, sad/upset, annoyed/frustrated/angry, hurt/pain, school work, daily routine, tired/weak, joining in activities, sleep, jealous and embarrassed.

## Methods

The main constraint in designing a descriptive system for a PBM is that the health states defined by the system should be amenable to valuation. Ideally, each dimension needs to contain levels that are ordered within it to fit this criteria well. There is very little guidance in the literature about how to develop levels from dimensions directly. To develop these levels, the first stage was to determine whether they should be frequency or severity based. To do this, data from the original qualitative work for developing the dimensions was used, reviewing how children described the dimensions, whether in terms of frequency or severity. Once this was determined, existing scales from the paediatric literature were reviewed for their suitability and if none were found to be suitable, scales were developed empirically, based on the original qualitative interview data from children. The empirical scales were developed by taking the adverbial phrases for the dimensions from the interview work and using the following approach: levels were ordinal using an adjectival scale with discrete responses; scales were developed with between 5 and 7 levels, language was kept simple and based on the qualitative data and double barrelled questions and negative wording styles were avoided. To confirm the ordinality of these new scales, a ranking exercise was undertaken with children, which also identified whether there were any redundant levels if levels were ranked equally by looking at the mean rank order. The redundant level was determined by looking at the amount of variation and the preferences of the children for the forms of wording where they had ranked them as equal. The resulting scales were applied to the dimensions and a draft descriptive system was developed.

## Results

For every dimension, severity arose as the predominant characteristic, therefore scales were developed based on severity. The only severity based scale found in the literature for paediatric generic measures was for the KIDSCREEN, developed for children age 8-18 years which uses the scale:

Not at all slightly moderately very extremely

The phrases moderately and extremely were never used by children in the original qualitative interviews in this research and are difficult words for children age 7 – 11 years to understand and so this was felt to be unsuitable for use.

Empirical scales based on the original qualitative interview data were therefore developed, which resulted in 7 different types of scale. These scales varied due to the dimensions and what made sense.

Children were successfully able to rank all of these scales to determine the ordinality and the ordering of the levels they gave made sense at face value.

The 7 scales and their mean rank order and difference in mean rank order are shown in the table on the right.

The mean rank order showed that there was very little difference between the levels containing very and really, indicating that only one was needed for the descriptive system. The difference in mean rank order is shown in bold type. Based on the variation and the preferences of the children for the wording, the following levels were dropped:

my sleep is very affected,

my school work is very affected

I feel really worried

The final scales were applied to all the dimensions in order to form a draft descriptive system.

| Level | Mean rank order | Difference |
|---|---|---|
| I can join in with any of the activities that I want to | 1.10 | |
| I can join in with most of the activities that I want to | 2.02 | 0.92 |
| I can join in with some of the activities that I want to | 3.08 | 1.06 |
| I can join in with a few of the activities that I want to | 3.81 | 0.73 |
| I can join in with none of the activities that I want to | 5.00 | 1.19 |
| | | |
| My sleep is not affected | 1.00 | |
| My sleep is a little bit affected | 2.52 | 1.52 |
| My sleep is a bit affected | 2.77 | 0.26 |
| My sleep is quite affected | 3.82 | 1.05 |
| My sleep is affected quite a lot | 5.08 | 1.26 |
| My sleep is affected a lot | 6.31 | 1.23 |
| My sleep is very affected | 7.23 | 0.92 |
| My sleep is really affected | 7.27 | 0.05 |
| I can't sleep at all | 9.00 | 1.73 |
| | | |
| My school work is not affected | 1.19 | 1.32 |
| My school work is a little bit affected | 2.52 | 0.32 |
| My school work is a bit affected | 2.84 | 1.02 |
| My school work is quite affected | 3.85 | 1.16 |
| My school work is affected quite a lot | 5.02 | 1.27 |
| My school work is very affected | 6.29 | 0.00 |
| My school work is really affected | 6.29 | 1.71 |
| I can't do my school work | 8.00 | |
| | | |
| I don't feel worried | 1.00 | |
| I feel a little bit worried | 2.27 | 1.27 |
| I feel a bit worried | 3.00 | 0.73 |
| I feel quite worried | 3.73 | 0.73 |
| I feel very worried | 5.42 | 1.69 |
| I feel really worried | 5.58 | 0.16 |
| | | |
| I don't have any pain | 1.00 | 1.29 |
| I have a little bit of pain | 2.29 | 0.42 |
| I have a bit of pain | 2.71 | 1.58 |
| I have quite a lot of pain | 4.29 | 0.79 |
| I have a lot of pain | 5.08 | 0.55 |
| I am really in pain | 5.63 | |
| | | |
| I have no problems with my daily routine | 1.00 | |
| I have a few problems with my daily routine | 2.27 | 1.27 |
| I have some problems with my daily routine | 2.73 | 0.45 |
| I have many problems with my daily routine | 4.03 | 1.31 |
| I can't do my daily routine | 4.97 | 0.94 |
| | | |
| It doesn't hurt | 1.00 | |
| It hurts a little bit | 2.34 | 1.34 |
| It hurts a bit | 2.89 | 0.55 |
| It hurts quite a bit | 3.77 | 0.89 |
| It hurts quite a lot | 5.29 | 1.52 |
| It hurts a lot | 5.95 | 0.66 |
| It really hurts | 6.76 | 0.81 |

## Conclusions

This work has empirically developed a descriptive system from the 11 dimensions of HRQoL identified in the original interview work. As the methods were based on using data from children, the content validity of the final measure should be increased and the language and terminology is appropriate for this age group. Further research is needed to test the descriptive system on a paediatric population and to test the psychometric performance. In addition, due to the constraints of preference based measures, the number of dimensions will need to be reduced to be amenable to valuation. Further research is required to do this.

For further information see www.chu9d.org

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