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Using children to develop the dimensions for a new generic paediatric health related quality of life measure

Katherine Stevens

Health Economics and Decision Science

The University of Sheffield

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Background

- n There are a range (27) of generic paediatric QoL measures available which have been developed for different purposes and adopt different definitions of QoL, all with different age ranges, different lengths and modes of completion
- n Most have some evidence of performance in a paediatric population.

Background

- n Children have been involved in the development of some of the measures, but tend to be involved at a later stage, for example when testing out the items or refining the wording
- n There is a growing interest in the use of preference based measures to make resource allocations decisions
- n No measure has been found that has been explicitly developed for use in economic evaluation which uses children to develop the dimensions of HRQoL that it contains.

Background

- n There is some evidence that children can provide information about their HRQoL, as low as 6 years of age, however there is not much evidence on whether health related quality of life frameworks are similar across the paediatric population.

Development of a new measure - what's new?

- n Explicitly developed for the purpose of use in economic evaluation
- n Developed using bottom up methods
- n Only children used in the development of the descriptive system
- n Designed to include work to see whether there is a similar HRQoL framework across age.

Aims

- n Development of the dimensions
- n Development of a health state classification system
- n Psychometric testing
- n Valuation

Methods

- n Interviews with children age 7-11 years
- n 2 schools in Sheffield chosen – represent diversity
- n Parent rates child's health from 1 (excellent) to 5 (poor).
- n Two age groups 7-9 years and 9-11 years
- n Purposive sampling based primarily on age, then level of health with gender and ethnicity as secondary criteria.
- n Children interviewed about their health and how their health affects their life.
- n All interviews recorded and then transcribed verbatim

Topic guide

- n **Tell me about your health** (make sure acute and chronic both recognised as valid – probe to check)
- n **How does your health affect your life?**
 - n Probe: home, school, other places (community)
 - n Probe: family, friends, weekends, spare time

Qualitative Analysis

- n Objective of qualitative analysis was to identify how health affects children's lives and to develop dimensions of HRQoL.
- n Guided by research question – how does health affect children's lives and then use this to develop key dimensions of HRQoL.
- n Thematic content analysis.

Results

- n 74 interviews undertaken
- n All interviews were 1 to 1 except for 1 as a pair (at the children's request).
- n Interviews varied in length from 4 minutes to 26 minutes.
- n Saturation was reached in both age groups. Final number of interviews more than needed, but this has increased confidence that saturation was reached

List of Health Problems Covered in Interviews 7-9 years

headache	Allergies - various
Feeling sick, being sick	Nose bleeds
Hearing, glue ear – grommets	Ear ache
Poor vision	Muscle not growing properly in stomach
Tummy ache	Fever
Eye infection	No feeling in legs
Dyslexia	Badly cut nose
Asthma	Nausea
Broken arm	Verruca
Tooth decay	Chicken pox
Leaky ear	Heat rashes
Flu	Sensitive to food colouring/hyperactivity
Pneumonia	Tonsillitis
Hay fever	Sticky/lumpy eyes
Cough	Twisted ankle
Spots/rash	Fits
Sore throat	Eczema
Broken toe	Itchy eyes

School/Education

- Concentration
- Off school
- Managing work
- Learning/education

Physical

- Pain
- Sick
- Tired
- Energy/feeling weak
- Feeling unwell/poorly
- Not wanting to do anything
- Sleep

Emotions

- Anxious/worried
- Isolated/bored
- Unhappy
- Annoyed

Physical Activities

- Sports/games
- Bathing/self care
- Playing out

Social

- Appearance
- Teased
- Friends
- Joining in

Senses

- Hearing
- Talking
- Taste
- Smell

Food

- Eating

Forming dimensions

WORRYING

- n What was going to happen to them
- n Health would get worse
- n Would always have the health problem
- n Physical symptoms

I felt like really, really worried, worry me, like, um it felt really scratchy and itchy just really worried like it's never gonna stop and it's never gonna go away.

(B33, female, 8, fair health)

SLEEP

- n Symptoms – coughing, sick, itching
- n Worrying
- n Medication – broken sleep

Yeah I couldn't sleep cos it really hurt my throat when I slept, so I couldn't sleep at all.

(B110, female, 11, good health)

In the night I wake up because I'm scratching it.

And how does that feel?

Horrible because I can't get back to sleep.

(B28, male, 9, excellent health)

Dimension	7-9 Years	9-11 Years
1	Worried Scared	Worried
2	Sad Upset	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		Embarrassed
11	Jealous	

NEW MEASURE	HUI2	PEDSQOL	CHQ (CF87)
Worried/Scared	Emotion	Physical functioning	physical functioning
Sad/Upset/Unhappy/Miserable	Mobility	psychological functioning	role/social functioning (physical)
Annoyed/Frustrated/Angry	Sensation	social functioning	general health perceptions
Hurt/Pain	Pain	pain	bodily pain
School work/Learning	Cognition	nausea	Discomfort
Daily Routine	Self Care	procedural anxiety	General behaviour
Tired/Weak/Drowsy/Energy/Weary		treatment anxiety	mental health
Joining in activities that want to		worry	self-esteem
Sleep		cognitive problems	role/social functioning (emotional)
Jealous		perceived physical appearance	Parental impact (emotional)
Embarrassed		physician/nurse communication	Parental impact (time)
			family activities
			family cohesion
			Global item: change in health

Conclusions

- n Interviews successful
- n Reached saturation of health problems within schools
- n Gaps - Those whose health is very low
- n General areas of HRQoL covered – physical, emotional and social.
- n Many reasons why dimensions emerged, because lots of different situations often led to the same or very similar dimensions.
- n Evidence of similar HRQoL frameworks across age



Next steps

- n Development of a draft descriptive system amenable to health state valuation
- n Psychometric testing of the questionnaire on general and clinical populations
- n Valuation work to obtain preference weights for the health states

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