Development of the MobQoL-7D patient reported outcome measure for mobility-related quality of life

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Summary

We interviewed and surveyed people with various forms of mobility impairment. We used this data to develop and pilot a novel mobility-related quality of life outcome measure, called MobQoL-7D. This outcome measure will have practical uses in research and practice.

Aims and objectives

Our overarching aim was to develop a novel way to measure mobility-related quality of life. Our objectives were:

1. To qualitatively examine how mobility and mobility impairment affect quality of life and health
2. To develop a descriptive system (i.e. questions and answers) for a novel mobility-related quality of life outcome measure
3. To assess the basic measurement and psychometric properties of the initial descriptive system
4. To develop a parsimonious health state classification system covering the key dimensions of mobility-related quality of life

Background

Mobility impairment is the leading cause of disability in the United Kingdom (UK), accounting for almost half of all reported disabilities [1]. It is estimated that 6.5million people in the UK have some form of mobility impairment [1]. The NHS supports more than 1.2million people with long-term mobility needs through the provision of wheelchairs and other assistive mobility technology, spending almost £200million per year on wheelchairs alone [2].

The National Wheelchair Managers Forum's guidance on healthcare standards for NHS posture and mobility services states that cost-effective provision of assistive mobility technology is a key priority [3], however to date only limited evidence has been published about the cost-effectiveness of the various forms of assistive mobility technology.

Although there are several mobility-related outcome measures available to therapists and assistive technology providers, none are focused specifically on the impact of mobility and mobility impairment on quality of life. We therefore sought to develop a novel outcome measure for mobility-related quality of life, initially called the MobQoL tool. Furthermore, in order to ensure that the MobQoL tool was suitable for outcome measurement in economic evaluations, we focused design of the tool around preference-based outcome measurement, in accordance with NICE guidance [4].

Methods

Firstly, an exploratory descriptive study was undertaken, using a qualitative framework analysis approach [5,6]. In order to develop a thematic framework for mobility-related quality of life, qualitative data were collected through semi-structured interviews with adults with varying degrees of mobility impairment. This framework was used to disaggregate the concept of mobility into the key dimensions of mobility-related quality of life. Using this data, the initial MobQoL descriptive

system was developed. Secondly, the initial MobQoL descriptive system was piloted and psychometrically analysed to assess the validity and reliability of the MobQoL tool. Exploratory factor analysis and Rasch analysis were used to determine dimensional structure and to select items for the final health state classification system, called MobQoL-7D.

Results
In total 46 participants were interviewed in stage one and 342 participants completed the piloting survey in stage two. Eleven dimensions of mobility-related quality of life were identified from the qualitative data: accessibility; safety; relationships; social inclusion; participation; personal care; pain and discomfort; independence; energy; self-esteem; and mental well-being.

After piloting the initial MobQoL descriptive system, nine of the MobQoL items demonstrated adequate validity and reliability. Exploratory factor analysis and Rasch analysis confirmed two sub-scales within the item structure: 1) physical and role functioning, and 2) mental wellbeing. Seven items were found to have adequate model fit and were retained in the final health state classification system of the MobQoL-7D, these items refer to: accessibility, contribution, pain/discomfort, independence, self-esteem, mood/emotions and anxiety.

The findings of this research illustrate the many ways in which mobility can impact quality of life, well-being and health. For instance, many participants discussed the emotional impact of mobility impairment and the role of adaptation in coming to terms with changes to mobility; similar findings have been found in previous research with children [7]. Adaptation is an important process which includes emotional, physical and behavioural changes, and, without proper adaptation, quality of life can be severely impacted by changes to mobility [8].

At present no other generic preference-based measures take full account of the impact of mobility on quality of life, or the influence of adaptation on subsequent health state preferences. For instance, there is limited correlation between three of the most commonly used generic preference-based measures (EQ-5D, HUI3 and AQoL) and other clinically relevant outcome measures [9-13]. Furthermore, there are significant discrepancies between the health state valuations of theses common measures in patient groups with impaired mobility [9,12,14,15]; illustrating the need for the MobQoL-7D. Please read the accompanying papers [16,17] to find out more about this project, or visit the MobQoL website: https://cheme.bangor.ac.uk/mobqol

Discussion
We designed the MobQoL outcome measure to avoid a normative definition of mobility, and thus hope that it will facilitate a nuanced approach to measuring the impact of mobility impairment on quality of life. The pilot findings demonstrate that the MobQoL-7D is a valid and reliable tool for researchers and rehabilitation professionals to measure and monitor mobility-related quality of life.

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