

PERCEPTION OF THE NEED FOR A PAEDIATRIC BLADDER DYSFUNCTION QUALITY OF LIFE MEASURE.

Aims of Study

Until recently 'quality of life' in children has been a paradigm associated more with life-threatening diseases than with organic or functional disorders (1). Although the psychological impact of incontinence has been frequently measured in children (2), a more general and holistic assessment of bladder dysfunction from the child's perspective has not been routinely obtained. Given that quality of life measures are a potent indicator of treatment outcome in adult continence patients, and that data can be used to assist in clinical decision-making (3) and to justify resource allocation (4), the use of such tools in children warrants consideration.

The aim of this study was to evaluate the perception among expert clinicians in the field of paediatric bladder dysfunction of the need for a cross-cultural tool capable of measuring the breadth of quality of life issues in affected children. A further aim was to identify international centers willing to conduct structured interviews or focus groups with patients and to collect data from children across a number of cultures that informs an understanding of the impact of bladder dysfunction on their individual wellbeing.

Methods

120 expert clinicians within the field of childhood bladder dysfunction were contacted by email and asked to complete a questionnaire seeking an opinion on six aspects of the measurement of quality of life in children. This is a similar methodology to that used successfully in the first phase of the conception of the European Kidscreen, a generic health-related quality of life questionnaire (5). Clinicians were also questioned about their willingness to conduct a small number of structured patient interviews / a focus group with the aim of identifying the relative importance to children of bladder function, dysfunction and treatment. An interview package for administration to affected children was then prepared and sent to study collaborators.

Results

None of the clinicians were aware of a specific bladder dysfunction quality of life measure that could be used in children, and 76% of responders did not routinely attempt to measure the psychosocial effects of this disorder. The most commonly used tool was the Child Behavioural Checklist. An overwhelming 94% of clinicians perceived a need to measure quality of life aspects in children with bladder dysfunction and cited two equally important benefits: the ability to evaluate treatment outcome / treatment quality assurance, and the facilitation of research. When presented with 11 possible domains of measurement that are evaluated in generic paediatric tools, clinicians prioritised measures of: social relations with peers (82%), self-esteem (79%), family and home function (66%), body image (64%), and independence and mental health (58% and 55% respectively). There was minimal support for the evaluation of cognitive competence, energy levels or aspirations for the future. Despite the fact that proxy completion of impact questionnaires may not adequately reflect the child's perception of wellbeing, 76% of clinicians perceived value in having a parallel tool completed by a parent or caregiver. Opinion was equally split between the need for a stand alone bladder dysfunction quality of life measure and a specific module that could be appended to an existing generic paediatric quality of life measure. Responders represented 13 countries and in 97% of cases were willing to collaborate with structured patient interviews. These sessions are currently being conducted and the data collected will be available within a few months.

Conclusions

There is a perceived clinical need for a robust disease-specific measure of psychosocial aspects of quality of life in children with bladder dysfunction that can be used as an outcome measure of treatment efficacy and an adjunct to research initiatives. Once the child-reported impact of bladder dysfunction on individual wellbeing is understood, a paediatric bladder

dysfunction quality of life tool will be tailored and tested for content and construct validity, sensitivity to change and reliability.

References

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