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PinQ: A valid, reliable and reproducible quality-of-life measure in children with bladder dysfunction

W.F. Bower [a,*], F.K.Y. Sit [a], N. Bluyssen [b], E.M.C. Wong [c], C.K. Yeung [a]

[a] *Division of Paediatric Surgery and Paediatric Urology, Department of Surgery, The Chinese University of Hong Kong, Prince of Wales Hospital, Shatin, New Territories, Hong Kong*
[b] *Jeroen Bosch Ziekenhuis, Kinder Incontinentie Team, Hertogenbosch, Netherlands*
[c] *Centre for Epidemiology and Biostatistics, School of Public Health, The Chinese University of Hong Kong, Shatin, New Territories, Hong Kong*

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Abstract *Objective:* Recently, a cross-cultural continence-specific paediatric quality-of-life measurement tool (PinQ) has been developed and tested psychometrically. The aim of this study was to evaluate the test re-test reliability of this new tool in a cohort of children with bladder dysfunction in order to evaluate the reproducibility of scores. A secondary aim was to compare the parent-completed proxy version with child-reported scores.
Methods: PinQ was translated and back-translated from English into Chinese and Dutch and scrutinized for cultural and linguistic appropriateness or ambiguity. Forty children aged 6—15 years from both countries were asked to self-complete the measure at first consultation and then again 14 days later. No new treatment was implemented between data collection points. On the initial visit, parents also completed a proxy version of PinQ. Intraclass correlations (one-way random effects model) were used to analyze the data.
Results: The intraclass correlation coefficient (ICC) for comparison between items and factors showed little variability in scoring. One item was not reproducible and was removed from the tool. Overall proxy scores varied little from the child-reported scores. However, the impact on the child of his/her parent's concern about the bladder problem was poorly perceived (ICC = 0.18) as was the impact on the child's sense of self-worth (0.17).
Conclusion: PinQ has been shown to be reliable under test re-test conditions when completed by children from the age of 6 years. Proxy PinQ suggests that parents accurately evaluate the effect of bladder dysfunction on wellbeing in their

* Corresponding author. Tel.: +852 2632 2924; fax: +852 2632 4658.
E-mail address: wendyb@surgery.cuhk.edu.hk (W.F. Bower).

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children. A 20-item measurement tool will now be introduced clinically and subjected to sensitivity testing for treatment outcome and diagnostic grouping.

Introduction

Quality-of-life, which denotes a more general and holistic measure of wellbeing than disease impact [1], is a validated way of measuring a patient's perspective of his/her life situation [2]. Self-completion of a robust questionnaire communicates the individual child's perceptions and views, which may differ from those of his/her parents or clinicians. Recently a cross-cultural continence-specific paediatric quality-of-life measurement tool (PinQ) has been developed and tested psychometrically [3]. This new tool has the potential for use as an outcome measure and may also alert the clinician to compromised areas of wellbeing directly related to bladder dysfunction. A holistic treatment approach can address such psychosocial issues, facilitating child and family compliance, a factor known to be associated with positive treatment outcome.

The aim of this study was to evaluate the test re-test reliability of PinQ in a cohort of children with bladder dysfunction, in order to appraise the reproducibility of scores. A secondary aim was to compare the parent-completed proxy version with child-reported scores.

Subjects and methods

Forty children aged between 6 and 16 years (mean age 9.18 years, SD 2.65), who were attending a children's continence care service for management of a bladder disorder in either Holland or Hong Kong, were invited to participate in test re-test evaluation of PinQ. Ethics approval was obtained from the Survey and Behavioural Research Ethics Committee of the Chinese University of Hong Kong.

The PinQ was translated into Chinese and Dutch by native-speaking bilingual health professionals. It was then back-translated by independent translators and evaluated for cultural suitability. A panel of native speakers in each country reviewed both translations for conceptual equivalence, appropriateness of language, ease of completion and to identify any ambiguity.

The tool was self-administered by consecutive children attending an initial consultation and completed a second time at least 2 weeks later. Parents did not assist in PinQ completion; any question or request for clarification was referred to the clinician. No treatment was instituted during the testing interval and, on re-test, children did not have access to answers given on the initial visit. A proxy version of PinQ was created by changing only the pronouns. Thirty consecutive parents attending their children's initial continence appointment self-administered proxy PinQ (pPinQ).

Data were entered into SPSS and analyzed using the intraclass correlation coefficient (ICC) one-way random effects model, which gives a measure of agreement rather than a value of association. Test and re-test data were compared for total scores, sub-total factor scores (intrinsic and extrinsic), and child vs proxy total and sub-total scores. P value of <0.05 was considered significant.

Results

Aside from one parent and one child who failed to complete the second page of PinQ, there were no missing values in the data set. As can be seen from Table 1, the ICC for comparison between total scores and factor scores showed excellent agreement [4]. Individual items showed excellent agreement in five cases (>0.7) and moderate agreement in 14 cases (0.4—0.7). One extrinsic item was not reproducible (ICC = 0.25, $P = 0.063$).

Overall, proxy scores varied little from the child-reported scores. Five items evidenced excellent ICC and 12 demonstrated moderate agreement. Table 2 shows that there were four areas of discord between parental perceptions and children's actual concerns. The impact on the

Table 1 Comparison of ICC between total scores, factor sub-scores and child and proxy scores

	ICC	95% Confidence interval	P value
Total score	0.884	0.789—0.939	<0.0001
Extrinsic sub-score	0.876	0.775—0.934	<0.0001
Intrinsic sub-score	0.862	0.750—0.926	<0.0001
Proxy total vs child total	0.681	0.416—0.840	<0.0001
Child extrinsic vs proxy extrinsic	0.543	0.218—0.761	=0.0012
Child intrinsic vs proxy intrinsic	0.698	0.443—0.850	<0.0001

Table 2 Items from proxy PinQ that demonstrated very poor agreement with child scores

Factor	ICC	95% Confidence interval	*P* value
E: worried about smell of urine on clothes	0.1194	−0.462 to 0.257	0.732
I: parents worry about problem	0.1799	−0.196 to 0.512	0.172
I: would feel better about self without bladder problem	0.1680	−0.208 to 0.503	0.188
I: feel unhappy because of bladder problem	0.388	0.021−0.664	0.019

E: extrinsic factor items; I: intrinsic factor items.

child of his/her parent's concern about the bladder problem was poorly perceived (ICC = 0.18) as was the impact on the child's sense of self-worth (ICC = 0.17). Parents did not realize that children worried about other people smelling urine on their clothes (ICC = 0.12). The item ''I feel unhappy because of my bladder problem'', while significant in agreement between parents and children, showed poor reproducibility.

Discussion

This study has demonstrated that the new tool PinQ for use in children with bladder dysfunction gives reproducible responses and scores. Furthermore, it appears to be easily completed and, when attention is drawn to the two sides of the tool, the data sets are likely to be complete. Total scores and factor sub-scores all showed excellent test re-test reliability. One item ''I wear clothes that will hide any wee accidents'' was found to have a pronounced floor effect; that is, on initial testing the score was low and therefore could not improve with symptom resolution. Since this item also generated a non-significant ICC, it was subsequently removed from the tool. All other items were retained.

We have previously reported the findings from children completing early versions of PinQ that showed wellbeing in boys to be more adversely affected by bladder dysfunction than in girls [5]. Magnitude of impact increased with the presence of day and night symptoms and further with co-existing bowel dysfunction. There is ample evidence in the literature of improvement in self-esteem, self-worth, self-image, behavioural symptoms and socialization following successful treatment of bladder dysfunction [6−9]. Intrinsic factor items showed high scores in this population completing PinQ related to children feeling both shy and unhappy because of their bladder problem and reporting that they would feel better about themselves if the symptoms were resolved. The next step in the evolution of this new paediatric bladder dysfunction-specific tool is to conduct sensitivity testing in order to assess responsiveness to change in symptoms following treatment (both when successful and when a poor response is obtained). A template that specifically checks for items that were markedly high pre-treatment may be helpful in evaluating individual impact of treatment and directing holistic input.

In recent years the psychological impact of bladder dysfunction has been understood to be due to, not causative of, urinary symptoms. Both internalizing and externalizing behaviours have been noted in children. Evaluation of proxy measures of PinQ indicated that at least the parent accompanying the child to his/her appointment was able to accurately perceive the impact of bladder dysfunction on their child. There is a suggestion from this data that the extent of negative effect on the child's sense of self-worth is, however, poorly understood by parents. Furthermore, children are adversely affected by their concerns over how much worry the bladder problem causes to their parents. Discussion of PinQ results with families in the early stages of treatment may improve empathy and understanding within families and facilitate greater intra-family support and treatment compliance.

Whilst this high level of proxy reproducibility is encouraging, it should be remembered that a parent accompanying the child to a help-seeking appointment may have a much higher level of concern and investment in the bladder problem than the non-attending parent or other family members. Results of this study do not allow the conclusion that all parents have an accurate perception of the impact of their children's bladder dysfunction.

In conclusion, the definitive PinQ (see Appendix) is a 20-item measure that has undergone rigorous reliability and validity testing, and is now ready for application in the clinical arena.

Appendix

PinQ

1. I get shy because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

2. People in my family treat me in a different way because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

3. I am worried that people might think my clothes smell of wee

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

4. I think that my bladder problem won't get better

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

5. Mum and dad worry about me because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

6. I would feel better about myself if I didn't have a bladder problem

☐ NO ☐ MAYBE ☐ PROBABLY ☐ YES ☐ DEFINITELY

7. My bladder problem makes me feel nervous

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

8. Mum or dad sometimes seem a bit cranky because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

9. My bladder problem stops me going on sleep-overs or holidays

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

10. My bladder problem makes me feel bad about myself

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

11. I wake up during my sleep because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

12. I miss out on doing things because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

13. I feel unhappy because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

14. My bladder problem makes me feel sad

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

15. I think about my bladder problem when choosing which sport to play

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

16. I have to go to the toilet when I'm watching a movie

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

17. If my bladder problem was fixed I would invite more friends to my house

☐ NO ☐ MAYBE ☐ PROBABLY ☐ YES ☐ DEFINITELY

18. I choose hobbies that won't be spoiled by stopping to go to the toilet

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

19. My bladder problem makes me feel different to other people

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

20. I miss out on being with friends because of my bladder problem

☐ NO ☐ HARDLY EVER ☐ SOMETIMES ☐ OFTEN ☐ ALL THE TIME

Your name:_____

Date ___ / ___ / ___

References

[1] Wallander JL, Koot HM. Quality of life measurements in children and adolescents: issues, instruments, and applications. J Clin Psychol 2001;57:571—85.
[2] Donovan JL, Badia X, Corcos J, Gotoh M, Kelleher C, Naughton M, et al. Symptom and quality of life assessment. In: Abrams P, Cardozo L, Khoury S, Wein A, editors. Incontinence. Plymouth: Health Publication Ltd; 2002.
[3] Bower WF, Wong EMC, Yeung CK. Development of a validated quality of life tool specific to children with bladder dysfunction. Neurourol Urodyn, in press.
[4] Landis JR, Koch GG. The agreement of observer agreement for categorical data. Biometrics 1977;33:159—74.
[5] Bower WF, Yeung CK. Self-reported effect of incontinence on quality of life. Proc Int Child Cont Soc 2004; Gent, Belgium. 2004:55—6.
[6] Theunis M, van Hoecke E, Paesbrugge S, Hoebeke P, Vande Walle J. Self-image and performance in children with nocturnal enuresis. Eur Urol 2002;41:660—7.
[7] Butler RJ. Impact of nocturnal enuresis on children and young people. Scand J Urol Nephrol 2001;35:169—76.
[8] Longstaffe S, Moffatt ME, Whalen JC. Behavioural and self-concept changes after six months of enuresis treatment: a randomized, controlled study. Pediatrics 2000;105: 935—940.
[9] Moffatt ME, Kato C, Pless IB. Improvements in self-concept after treatment of nocturnal enuresis: randomized controlled study. J Pediatr 1987;110:647—52.