



^aVictorian Children's
Continence Clinic, Melbourne,
Australia

^bPaediatric Gastroenterology
Victoria, Royal Children's
Hospital, Melbourne, Australia

^cDepartment of Medicine and
Community Care, Royal
Melbourne Hospital,
Melbourne, Australia

^dFaculty of Medicine, Dentistry
and Health Sciences, The
University of Melbourne,
Australia

^eFaculty of Urogynecology, The
University of Ghent, Belgium

^fPediatric Urology, Health
Services Research, University of
Utah/Primary Children's
Hospital USA

^gDepartment of Child and
Adolescent Psychiatry,
Saarland University Hospital,
Homburg, Germany

Correspondence to: J. Chase,
Cabrini Hospital, Victorian
Children's Continence Clinic,
183 Wattleree Road, Malvern,
Melbourne, 3144, Australia

janetchase7@gmail.com
(J. Chase)

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Review Article

Diagnostic scores, questionnaires, quality of life, and outcome measures in pediatric continence: A review of available tools from the International Children's Continence Society

Janet Chase ^{a,b}, Wendy Bower ^{c,d,e}, Susan Gibb ^b,
Anthony Schaeffer ^f, Alexander von Gontard ^g

Summary

Purpose

We reviewed and collated information concerning the available tools for the measurement of symptoms and outcomes in pediatric continence.

Materials and methods

MEDLINE, EMBASE, and CINHAI databases were searched for relevant articles published prior to December 2016 and independently screened by two researchers. Expert opinion was also widely sought through consultation with the ICCS Board membership and their professional networks and the multidisciplinary authorship group. The most relevant materials were then selected for analysis and

inclusion and resulted in a document available on the ICCS website for all members to review. Insights and feedback were considered with consensus and agreement reached to modify the document.

Results and conclusions

A variety of useful tools for the assessment and measurement of bladder and bowel dysfunction and quality of life and behavioral comorbidities are presented together with their indications and potential pitfalls. ICCS cannot recommend one over another as the most useful for each clinician will vary depending on the clinical setting, available time, and patient population. We provide a framework for choosing those that are most appropriate based on our findings.

Purpose

This document complements other ICCS standardization documents by summarizing all published symptom scores, questionnaires, and outcome measures relevant to pediatric incontinence.

Robust tools provide a reliable and efficient way for researchers and clinicians to understand many aspects of function or problems, but they do not provide a diagnosis. They allow us to measure the effects of our interventions. Providing professional accountability for effective and efficient outcomes, patient safety, wise use of the health dollar, and maintaining continual improvement in evidence-based care are facilitated by their use.

Which questionnaire or score to use can be confusing – they can be validated or non-validated, short or long, disease specific or not, parent or child completed for example. The aim of this document is to present tools

that can be used in all common areas of childhood incontinence in primary, secondary, and tertiary health care. Most tools will be validated and hence more robust, but other clinically useful measures are included. The most useful tool depends on each clinician's needs and the patient population involved.

Overview

Self-report of bladder and bowel variables is notoriously unreliable, largely because of recall bias, downplaying, catastrophizing, or anxiety about the problem. An understanding of the extent of symptoms, and their impact is best measured with robust clinical tools that quantify baseline variables and track changes over time. [Table 1](#) summarizes some of the pitfalls to avoid when choosing a measure to capture clinical variables. Moreover, it is critical that a clinician or researcher be aware of the methods that

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Table 1 Potential pitfalls of new measures.

Problematic characteristic	Limitation to clinical usefulness
Unvalidated tool	May not measure what it is meant to May not have been tested in specific patient populations
No reliability data reported	Data obtained may not be stable over time Unknown whether it will reproduce responses when administered by different clinicians
No proven sensitivity	The measure has not been shown to change with improvement in patient condition
Unacceptable to patients	Too long/complicated/repetitive/difficult to understand Uses age-inappropriate language Not developed for different cultural groups
Not relevant to your patients	Too cumbersome to repeat after treatment Doesn't appear to measure what is important to them Gender/Age/Education/Economic status bias
Complex scoring \pm challenging interpretation	Difficult to obtain immediate feedback to discuss with patient Time consuming to use

were used to generate the questionnaire, and that it is shown to measure what it is intended to measure, which is called validity. It is important to know which population was used in the development of a specific questionnaire. For example, if neurologically normal children with bowel and bladder dysfunction were the subjects used in questionnaire development, then the questionnaire is not valid for children with neurogenic bladder. Reliability is a term that determines if a questionnaire, when administered repeatedly to the same individual, produces the same or similar results. When using a questionnaire developed in another language, the researcher or clinician must ensure that appropriate culturally sensitive translations were done because simple word-for-word translation can substantially reduce the questionnaire's validity in the new language.

Treatment efficacy in childhood incontinence can be evaluated by resolution of signs and symptoms. In terms of the bladder, from a clinician's perspective the signs of interest relate to safe pressure within the urinary tract. This requires evidence of synergic voiding patterns (uroflowmetry \pm EMG), resolution of vesicoureteric reflux (VCUG) and urinary tract infections, minimal post-void residual volumes (US), while monitoring the status of the upper tracts. Improvement for patients and their families relates to their needs, goals, and motivation for seeking help. Symptoms communicate improved function and will include number and severity of incontinence episodes, severity of urgency incidents, intervals between urinary tract infections, and number of wet nights. Regarding bowel function, symptoms that are monitored are frequency and efficacy of defecation, stool consistency, the number and severity of fecal incontinence (FI) episodes, abdominal, rectal or anal pain, rectal distension and sensation.

ICCS has defined different levels of response to interventions by the proportion of reduction in specific symptoms rather than by grouping of children into responders and non-responders [1]. Initial success is defined as follows: no-response: <50% reduction in symptoms; partial response: 50–99% reduction; complete response:

100% reduction. Relapse is described as more than one symptom recurrence per month, continued success as no relapse in 6 months after interruption of treatment, and complete success as no relapse in 2 years after interruption of treatment. Repeating a measurement tool at review appointments helps identify the direction of progress even when the end goal has not been fully achieved. It serves as a motivator to the child and family and provides a basis for clinicians to augment or change intervention.

As the basis of this document, the MEDLINE (1966-December 2016), EMBASE (1974-December 2016), and CINHAL (1981-December 2016) databases were searched with text words and MeSH terms to identify articles pertaining to the development of questionnaires designed for pediatric urinary incontinence developed in or translated to English. Search criteria included terms for urinary incontinence (continence, incontinence, enuresis, wetting/bed-wetting, dysfunctional voiding/voiding dysfunction), questionnaires (severity of illness index, survey, checklist, scale, score, tool, index, evaluation), and appropriate subject age (toddler, child, boy, girl, pediatric/paediatric, prepuberty, puberty, teen, adolescent). The search yielded over 5000 titles and abstracts, which were independently screened by two reviewers before 37 articles were retrieved in full text. This resulted in 13 studies as the primary source article for urinary incontinence questionnaire development. Of these, one was excluded because it referenced a graduate school thesis which was not available from the publisher [2]. Two others were excluded as they are seldom referenced in the literature and were not adopted in routine clinical or research practice [3,4]. The gray literature and personal experience was also used to identify other articles pertaining to bladder diaries, pediatric behavior symptoms, and bowel dysfunction or fecal incontinence questionnaires.

The usual process for writing ICCS documents, as outlined in the abstract, was followed.

Table 2 summarizes some of the selected questionnaires and their characteristics, and Table 3 summarizes the relevant tools to use for given symptom sets.

Ethical approval was not required for this work.

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