Validation of a Questionnaire to Assess Fecal Incontinence and Associated Risk Factors

Fecal Incontinence Questionnaire

W. Terence Reilly, M.D.,* Nicholas J. Talley, M.D., Ph.D.,†
John H. Pemberton, M.D.,* Alan R. Zinsmeister, Ph.D.‡

From the *Mayo Clinic Gastroenterology Research Unit, Section of Colon and Rectal Surgery, Mayo Clinic, Rochester, Minnesota, †Department of Medicine, University of Sydney and Nepean Hospital, Sydney, Australia, ‡Department of Biostatistics, Mayo Clinic, Rochester, Minnesota

PURPOSE: Although fecal incontinence is a topic of considerable importance, there are no validated self-report measures of fecal incontinence available. The aim of this study was to develop a questionnaire to measure fecal incontinence and its risk factors in the community. METHOD: The reliability and concurrent validity of the fecal incontinence questionnaire were measured by test-retest procedures in a population of clinic patients. The questionnaire was created for a sixth-grade reading level, with large print. Ninety-four adult patients were surveyed. Thirty-four patients repeated the questionnaire through the mail. Forty-one patients were independently retested over the telephone by a physician to assess concurrent validity. Nine patients refused retest, and ten patients did not respond to a second contact. RESULTS: The fecal incontinence questionnaire was well understood and well accepted. Reliability (overall median kappa, 0.68; interquartile range, 0.03–1) and validity (overall median kappa, 0.59; interquartile range, 0.27–1) were acceptable for the mailed retest and the telephone retest, respectively. The presence of fecal incontinence as measured by questionnaire was greatly increased when compared with physician history in clinical records; only 3 percent of patients reported no fecal incontinence on the questionnaire when the clinic chart had documented this problem. CONCLUSION: Our initial results indicated that this new self-report questionnaire is a useful tool for assessing the presence of fecal incontinence in the population and has greater sensitivity compared with a standard physician interview. Specific attention should be given to identifying fecal incontinence and associated symptoms during history taking. [Key words: Fecal incontinence questionnaire; Validation; Risk factors]


Fecal incontinence has gained considerable prominence in the literature during the past few decades. With the development of new physiologic tests,¹ research into the mechanisms of fecal incontinence has increased. Recent attention has focused on the magnitude of fecal incontinence in the population,²–¹⁰ with its attendant heavy resource use and financial burden.⁴,¹¹

The epidemiology and impact of fecal incontinence can become better understood only if the problem is accurately defined. Although several studies have investigated this issue,²–⁹,¹¹ no valid self-report questionnaire has been available to apply in population-based or clinical research. Validity refers to the ability of a questionnaire to measure exactly what it is designed to measure. We aimed to develop and validate a new questionnaire to measure the prevalence of fecal incontinence in the community and the risk factors associated with incontinence.

PATIENTS AND METHODS

Design of the Questionnaire. This survey was approved by the Institutional Review Board of the Mayo Clinic. The fecal incontinence questionnaire was developed based on previously validated instruments devised within our unit.¹²–¹⁴ Several questions were reproduced from these previous questionnaires. The wording of questions was set at a sixth-grade reading level. Extra-large print was used for maximum legibility. Where medical terminology was necessary, descriptions in layperson's terms were used to clarify the question. For example, regarding rectal prolapse, a parenthetical description stated that this is "a protrusion of rectal tissue through the anus, or back passage." A subset of questions referring to quantification of fecal incontinence are shown below. The questions were prefaced by the statement, "We would like to ask you about any leakage of stool in the past. (Please

A copy of the complete questionnaire is available from Dr. Nicholas J. Talley.
Address reprint requests to Dr. Talley: University of Sydney, Clinical Sciences Building, Nepean Hospital, P.O. Box 63, Penrith, New South Wales 2751, Australia.

146
do not include problems during short-term illness such as the flu or a virus.)

Have you had problems with leakage of stool (accidents or soiling because of the inability to control the passage of stool until you reached a toilet? (Check answer.)
- No
- Yes

IN THE LAST YEAR, did you have to take medication (like antidiarrheals, Lomotil, Imodium AD, etc.) to prevent leakage of stool? (Check one answer.)
- No
- Yes, sometimes (less than 25% of the time)
- Yes, often (more than 25% of the time)
- Yes, usually (more than 75% of the time)
If YES, what did you take? ________________

When in your life did this problem with leakage of stool FIRST begin as close as you can recall? (Check one answer.)
- in the last 6 months
- 7 months to 1 year ago
- more than 1 year to 2 years ago
- more than 2 years to 5 years ago
- more than 5 years to 10 years ago
- more than 10 years to 20 years ago
- more than 20 years ago

IN THE LAST YEAR, did you ever wear a pad to protect your underclothes from soilage or leakage of stool? (Check one answer.)
- never
- sometimes (less than 25% of the time)
- often (more than 25% of the time)
- usually (more than 75% of the time)

If you have to wear a pad to protect your underwear from stool leakage, when do you wear it? (Check one answer.)
- while awake
- while asleep
- both while awake and asleep
- I do not wear a pad

IN THE LAST YEAR, when was the leakage of stool MOST frequent? (Check one answer.)
- while awake
- while asleep
- there was no difference in leakage while asleep or awake

IN THE LAST YEAR, have you felt the need to always know where the nearest toilet is? (Check one answer.)
- No
- Yes

When leakage of stool has occurred IN THE LAST YEAR, did you have problems with leakage of LIQUID or RUNNY stool? (Check one answer.)
- never
- sometimes (less than 25% of the time that leakage occurred)
- often (more than 25% of the time that leakage occurred)
- usually (more than 75% of the time that leakage occurred)

When leakage of stool has occurred IN THE LAST YEAR, did you have problems with leakage of SOLID, or formed stool? (Check one answer.)
- never
- sometimes (less than 25% of the time that leakage occurred)
- often (more than 25% of the time that leakage occurred)
- usually (more than 75% of the time that leakage occurred)

When these “accidents” with leakage of stool occurred IN THE LAST YEAR, how much stool TYPICALLY leaked out? (Check one answer.)
- a small amount, with a stain about the size if a quarter
- moderate amounts (often requiring a change of pad or underwear)
- large bowel movements (often requiring a complete change of clothes)
- solid or formed stool

IN THE LAST YEAR, have you been able to tell when this leakage of stool was about to occur? (Check one answer.)
- never
- sometimes (less than 25% of the time)
- often (more than 25% of the time)
- usually (more than 75% of the time)

When these “accidents” with leakage of stool occurred, were you aware when the leakage was actually happening? (Check one answer.)
- never
- sometimes (less than 25% of the time)
- often (more than 25% of the time)
- usually (more than 75% of the time)

Have you had difficulty telling the difference between the need to pass gas and the need to pass stool IN THE LAST YEAR? (Check one answer.)
- never
- sometimes (less than 25% of the time)
- often (more than 25% of the time)
- usually (more than 75% of the time)

Questions were designed with specific goals in groups as follows: