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## Health Literacy and Emotional Responses Related to Fecal Incontinence

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### Abstract

**Purpose**—The primary purpose was to begin to examine continence literacy of individuals with fecal incontinence (FI) by describing terms by which these individuals referred to FI and to explore their emotional responses to FI. A secondary aim was to compare differences in these results between male versus female and younger (< 65 yrs) versus older persons with FI.

**Design**—Secondary analysis of data collected prospectively in a clinical trial of fiber supplementation for FI.

**Methods**—Content analysis of participants' statements reported in field notes of data collectors and their responses to data forms and questions.

**Results**—Six thematic categories of terms for FI emerged. Only one person used the term “fecal incontinence.” Alternate terms described stool characteristics, named other gastrointestinal problems, or referred to FI using a term that seemed to depersonalize the problems. Emotional responses to FI focused on the influence of bothersome symptoms of FI, interference with social activities, and need for control. Others showed use of humor for coping and emotional benefits gained from being in a study. Women were impacted by the social limitations of having FI more than men. Younger people expressed feelings of emotional upset.

**Conclusion**—There is need to increase health literacy about fecal incontinence. Continence nurse specialists are well qualified to educate patients about FI and to evaluate if higher continence literacy increases reporting of FI. Understanding the various emotional responses to FI may guide the optimal support that nurses can provide and facilitate better management of FI.

### Introduction

Fecal incontinence (FI) is the involuntary passage of stool. Approximately 10% of community-living people, both men and women, have FI.<sup>1–3</sup> FI interferes with many activities of daily life including sleep, work, and social activities. It can be distressing and embarrassing and lead to social isolation, low self-esteem, reduced intimacy, anxiety, and depression.<sup>4, 5–7</sup> Despite these emotional and psychological effects, as many as 40% of

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people with FI have not discussed the problem with their health care provider, and some do not discuss it even with their closest family members<sup>4,8-9</sup>. Therefore, FI has been referred to as the “silent affliction”<sup>9</sup> and the “unvoiced symptom”<sup>10</sup> and its reported prevalence is likely underestimated. Fisher, Bliss, and Savik<sup>2</sup> showed that community-living individuals who had FI underestimated its severity when they were interviewed.

Limited evidence exists about the barriers or facilitators to reporting FI to one’s healthcare provider. Potential barriers or facilitators may include stigma, emotional responses such as embarrassment, perceptions that FI is an expected consequence of aging or childbirth, and the reaction of a healthcare provider. Bliss, Fischer, and Savik<sup>8</sup> reported that elderly individuals were more likely to report FI to a healthcare provider if the condition was of recent onset, defined as a problem by the patient, or if the person was unsure about the cause of FI or thought they were in poorer health than their peers. They did not find any significant gender differences in reporting FI. Another factor that may deter discussion and management of FI is low health literacy. While screening potential participants for enrollment into the parent study of this analysis, our team observed that individuals were unfamiliar with the term “fecal incontinence” and lacked words to describe their condition. Chelvanayagam & Norton<sup>5</sup> observed that patients referred to FI in terms of other gastrointestinal conditions, such as diarrhea.

Low health literacy specific to incontinence can impair communication about this already sensitive topic and delay appropriate treatment. Peden-McAlpine, Bliss and Hill<sup>4</sup> reported that women who perceived that their healthcare provider’s response to a disclosure of having FI was minimizing, blaming, or belittling did not discuss the problem again and relied instead on self-management. However, self-care is not always an option; a survey of older community-living people revealed that one-third identified no self-care practices for managing their FI, and thus were in need of assistance.<sup>8</sup> Unless the topic of FI is discussed more readily, specifically, and comfortably, people will continue to be without the care they need.

## Review of Literature

Many people who have FI do not have a term with which to label the condition appropriately.<sup>11, 12</sup> Rather, they often confuse FI with diarrhea or defecation urgency.<sup>5</sup> Reasons for the lack of a label for FI may be unfamiliarity with the word incontinence or its meaning, avoidance of thinking much about the problem, or the social taboo against discussing FI with others. Some clinicians use the term of bowel leakage when discussing FI with patients.<sup>13</sup> The terms, labels, and descriptions of FI are part of health literacy. There is little information reported on communication about FI between patients and healthcare providers. Knowing which terms people use to refer to FI and describe its symptoms will facilitate clinicians to recognize when a patient is attempting to discuss the condition. This knowledge might also assist the clinician initiate questions about the presence of FI so that offering appropriate therapies can be determined and evaluated.

The U.S. Department of Health and Human Services identified health literacy as an objective in Health People 2010.<sup>14</sup> Health literacy can be defined as “the degree to which

individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate health decisions.”<sup>15</sup> Zarcadoolas, Pleasant, & Greer’s model of health literacy<sup>16</sup> contains four domains: fundamental literacy, science literacy, civic literacy, and cultural literacy. Specifically, the science literacy component includes “knowledge of fundamental scientific concepts” and requires the identification of terminology.<sup>16</sup> Patients with low health literacy levels are less likely to ask questions, request additional services, or seek new information during a medical encounter.<sup>17–18</sup> Relationships between limited health literacy skills and low levels of disease-specific knowledge have been demonstrated for a number of chronic conditions including asthma, diabetes, hypertension, and congestive heart failure.<sup>19–20</sup> Low health literacy increases healthcare costs.<sup>21–22</sup> For these reasons, it is important to assess the terminology used by people who have the chronic condition of FI. For patients lacking health literacy, nurses need to develop health education and communication interventions to increase knowledge and to evaluate effectiveness of the interventions in facilitating health-seeking behaviors.

Responses to a chronic condition such as FI and its management may be influenced by multiple factors including healthcare professionals’ responses to a report of FI and the patient’s sex and age. For example, women who perceived their healthcare provider as being blaming, belittling, or insensitive to a report of the FI or its impact on quality of life, avoided reporting the condition again for years.<sup>4</sup> Bliss and colleagues<sup>8</sup> also reported that older men and women differ in practices used for self-care of FI. For example, significantly more women wore an absorbent pad while more men took an anti-diarrheal medication. In addition, more women than men altered their diets for managing FI. Other responses to FI may differ between men and women. No study to date has compared the experiences of younger and older people with FI. Some older women perceive FI as an expected problem of aging.<sup>24</sup> It is unknown whether younger women who have FI after childbirth have different perceptions or emotional responses to FI than older women.<sup>25–26</sup> Differences in life developmental stages, as described by Erik Erikson, for example, suggest there may be differences in how older and younger people describe and perceive a health problem.<sup>27</sup>

The purpose of this study was to describe health literacy and emotional responses specific to fecal incontinence and its management as this information is lacking in the literature. The main research questions are: (1) What are the terms by which community living people who have FI refer to FI; and (2) What are the emotional responses to having and managing FI? A secondary research question was posed, Are there any differences in terms for and responses to FI based on age and sex? The findings have potential to promote better communication about FI, improve management efforts, and result in more people receiving appropriate care.

## Methods

This study is a secondary analysis of data obtained from the study, “Impact of Fiber Fermentation on Fecal Incontinence” (NINR, NIH, NR07756, PI: D. Bliss). The parent study is a randomized controlled clinical trial comparing the effectiveness of three types of soluble dietary fiber and a placebo for managing FI. Adults living in the community who leaked loose or liquid stool were eligible to participate in the study. Study staff screened potential subject’s eligibility by telephone. Individuals who participated in the study

protocol were asked to complete several data collection forms and surveys. Data collectors wrote field notes about interactions and discussions with participants in the study. The sources of data that were analyzed for this study are the Eligibility Criteria form, the Demographics form, and the field notes.

The Eligibility Criteria form reports the inclusion and exclusion criteria of individuals who were recruited for the study. After observing that some potential study participants were unfamiliar with the term, “incontinence” during the screening process, study staff began reporting the terms that individuals used to refer to their FI then later added a question about terms they used to describe or refer to their bowel condition (i.e., fecal incontinence) to the Eligibility Criteria form. The Demographics form contains information about participants’ age, sex, race, education, socioeconomic status, and caregiver status. It was completed by the data collector during a meeting with the study participants at the start of the study. This form was used to describe the sample and to obtain data about age and gender that were used in examining any differences in FI terms and descriptions. The field notes are descriptive notes of observations, communication, and reflections of interactions with the participants in the study. Field notes were completed by data collectors who interacted with the participants on a daily or weekly basis. In the field notes, the data collectors recorded direct quotes of participants, a summary of the content of their conversation with the participants, descriptions and reflections of the participants’ emotional and psychological reactions, behaviors, or comments. The field notes were analyzed for terms or descriptions for FI used by study participants.

### **Data Analysis**

Content analysis was used to assess participant responses and field notes. These data were typed in their entirety and carefully read and reread by the investigators. Themes that emerged were coded and categorized. The investigators reviewed, discussed, and recategorized coded themes until consensus was reached. Frequencies, percentages, and means of demographic data were used to describe the sample. A chi square test was used to determine if any significant differences in the FI terms and types of emotional responses between males vs. females and younger vs. older participants.

### **Results**

Data from 89 study participants were analyzed. The majority were female (73%), White (88%), and middle-aged (59 (14) years) (mean age (SD)). Seventy percent of participants had a high school diploma or equivalent, and approximately half were employed during the study. Twenty-one percent (19/89) were caregivers for another person; 44% cared for a child and 22% cared for a parent or spouse.

### **Terms for Fecal Incontinence**

Participants used a range of 0–5 terms to describe FI. Thirteen participants did not provide a term for FI when asked or said they did not like to talk about it. One hundred three statements by 60 participants contained a term used to describe FI. The median number of terms per subject was one. Six thematic categories of terms for FI evolved from our content

analysis: 1) Stool Characteristics, 2) Depersonalization/Slang, 3) Incontinence Related, 4) Loss of Control, 5) Gastrointestinal Problems, and 6) Defecation Pattern. The thematic categories and examples are listed in Table 1.

Most of the words used to name FI were descriptions of stool characteristics, such as “loose stool,” labels that depersonalized FI as “it” or “a bowel spell,” or slang expressions such as “skid marks.” Only one person used the term “fecal incontinence,” and one person used the term “incontinence.” Referring to FI as leakage was more common. The involuntary nature of FI was evident in expressions about the subject’s inability to control their bowels or lack of time to reach a bathroom to avoid leakage of stool. Other gastrointestinal health problems (e.g., diarrhea, irritable bowel syndrome) or aspects of the defecation such as frequency or urgency were terms substituted for FI.

### Responses to FI

There were 208 statements containing data about emotional responses to FI or its management. Content analysis resulted in six themes associated with FI and its management. Table 2 lists the themes and exemplar statements supporting those themes. The two most frequent responses were about the bothersome symptoms of FI and the variety of feelings that were elicited such as a desire to control the leakage. For example, numerous participants focused on knowing where the toilets were in public places when planning for their activities. Others described themselves as self-reliant in their management practices. Some participants reported that FI interfered in social activities, including sex, while a few commented on its affect on quality of life overall. The difficulty of discussing FI was noted by several participants. Despite the rigor of the research protocol due to the need to complete numerous forms, collect stools, and remember to consume supplements daily, 15% of the statements were about the benefits gained from participating in the study. Participating in the study seemed to provide some with the feeling that they were helping themselves others control the problem of FI and contributing to science to benefit others.

### Differences by Sex and Age

A greater percentage of men used incontinence-related terms when referring to FI than women (38% vs 13%,  $p=.02$ ). Twice as many women expressed a need to control their FI compared to men (32% vs 16%,  $p = .045$ ). More women stated that they had less or impaired socialization due to FI than men (15% vs 2%,  $p = .02$ ).

Approximately three times as many older individuals referred to FI using names of other gastrointestinal problems than younger persons (39% vs 13%,  $p = .03$ ). Older individuals frequently referred to FI as “diarrhea,” having “loose stools,” or “accidents.” Almost twice as many younger persons expressed responses to FI in the Feelings theme as compared to older individuals (40% vs 21%,  $p = .04$ ). The responses of a greater percentage of older individuals expressed self-reliance and self-care when compared to those of younger respondents (24% vs 6%,  $p = .004$ ).

## Discussion

To our knowledge this is the first study to examine health literacy related to FI. Our findings suggest a low level of health literacy pertaining to this condition. Only two participants used the term “incontinence” to refer to their stool leakage. Even when asked, nearly one-fourth of respondents did not have a term for FI or did not readily talk about the problem. Numerous statements referred to FI using terms for other GI problems such as diarrhea, colitis, or urgency supporting the observations of Chelvanayagam & Norton.<sup>5</sup> Older individuals were more likely to use these terms than were younger respondents.

Our results are consistent with other reported findings of these emotions and the reticence of discussing this sensitive health problem.<sup>28, 29</sup> Younger people expressed the emotional impact of FI more often. Because health literacy and emotions may affect an individual’s health seeking behavior, nursing intervention to facilitate communication and support the patient’s emotional response is important. A greater percentage of older persons with FI in this study described relying on their own self-care practices than younger persons. O’Connell and coworkers<sup>29</sup> found that a continence education brochure prompted individuals to take self-care actions. Actions included discussing their problem with family and friends or seeking professional help from a clinician. Their findings encourage the development and testing of strategies to increase health literacy and subsequent health seeking behaviors related to FI that are targeted to different age groups. Further research that examines terms used for FI by clinicians when talking to patients is also needed.

Negative emotional responses of participants in this study are consistent with the adverse impact of FI on quality of life reported by others<sup>4,5,7</sup>. Norton and Chelvanayagam<sup>30</sup> reported that some women with FI feel socially restricted, and in severe cases, remained in the home due to FI. More women than men in our study expressed the negative impact of FI on social interactions. Our findings reveal that some people used humor to cope with the impact of FI on quality of life. They were often self-reliant in managing FI and embarrassed to seek help from others including clinicians. There needs to be further research to evaluate interventions that might support positive coping responses.

Limitations of this study are its reliance on secondary data. Emotional response data were limited by what the data collector reported in their field notes and their impressions of what information they thought important to record. Because the participants were not asked a direct question about their emotional response to FI, the data reported may have been subject to the interpretation of the data collector. Direct recording and transcription of participants’ responses may have reduced the risk of bias. A larger sample of men might reveal different responses to FI.

## Clinical Implications for Practice

It is important for the WOC or continence nurse to recognize and clarify the meaning of the terms used by community-living people to describe their bowel complaints through careful and systemic inquiry to help distinguish between FI and other GI conditions. For example, commonly used terms for FI related to the looseness or frequency of stool, which are general

symptoms of several other gastrointestinal problems. Our findings make known some of the terms by which community-living individuals refer to FI so that they can be further explored. Results of this study suggest that there is a need for nurses to provide health literacy education for FI. Some individuals were reluctant to talk about FI even when asked. Clinicians are encouraged to initiate inquiry about FI during routine health history or when other gastrointestinal problems are reported or suspected, especially in older individuals. Inquiring about FI in a supportive, sensitive and non-judgmental manner is essential. It is important to be aware of the various emotional responses to FI to promote the appropriate types of therapeutic patient support and facilitate acceptance of management recommendations. Younger people appear more likely to express the emotional impact of FI but similar feelings may be experienced but not mentioned by the elderly.

## Conclusion

Health literacy influences patients' care seeking and communication about health problems.<sup>16</sup> Our findings show that FI is not easily discussed and there is a need for increased continence literacy. Persons with FI used a variety of alternate terms to label the problem of FI that can inform clinicians to inquire about the possibility of FI during a health assessment. They described adverse responses to FI including limiting socialization, dealing with bothersome symptoms, and feeling emotional distress. Younger people expressed the emotional impact of FI more than older people. More women felt a lack of control and described restricting social interactions than men. Participating in a research study was viewed as an opportunity to help oneself and others.

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**Key Points**

- There is a need for improving health literacy related to fecal incontinence in those who have the problem.
- The variety of terms by which fecal incontinence is referred suggests that identifying people who have FI requires discerning inquiry.
- Terms for FI and types of emotional responses differ between men and women and younger versus older patients.

**Table 1**

Themes and Terms Used by Community-Living People to Describe Their Fecal Incontinence

<b>Theme</b> (number of statements with term/number of participants stating term)
<b>Stool Characteristics</b> (26/22) loose stool runny stool loose bowels wet feeling dribble water coming out
<b>Depersonalization/Slang</b> (24/19) it when it leaks out this problem a bowel spell when things really get bad drainage poop skid marks mess my pants
<b>Incontinence related</b> (15/15) fecal incontinence incontinence leak, leaking, or leakage soiling my underwear
<b>Gastrointestinal Problem</b> (14/11) diarrhea IBS* Colitis
<b>Loss of Control</b> (12/11) accidents when I can't make it to the bathroom when I can't control my bowels pass feces without knowing it
<b>Stool Pattern</b> (12/11) urgency frequency when I go to the bathroom a lot BM <sup>‡</sup>

\* This abbreviation was used referring to irritable bowel syndrome

<sup>‡</sup>for Bowel movement

**Table 2**

Types of Responses to Having and Managing Fecal Incontinence

Theme of Response (Number of statements per theme/number of participants)	Example
<b>Bothersome FI Symptoms/ Characteristics (55/32)</b> <u>Subthemes</u> frequency of defecation or leaks loose consistency odor flatus/gas urgency lack of complete elimination	[Subject] mentions that some days she will have a BM and will have to go and leaks approximately every 20 minutes for a couple of hours, unable to control. (Frequency) “The worst accident that I had was in Disney. We had gotten off the bus and I didn’t make it. I had stool on my shorts and running down my legs.” (Loose consistency) “I can smell myself and maybe other people can smell it too.” (Odor) “I feel bad for my husband, I have plenty of gas.” (Gas) “When I have the urge, I gotta go right now. They should have a support group.” (Urgency) “I’m so sorry I don’t have control when I go to the bathroom; it’s like I don’t finish. I can’t get it all out.” (Lack of complete elimination)
<b>Feelings (53/43)</b> <u>Subthemes</u> embarrassment discomfort discussing FI with others humor minimization undervalue self guilt/shame isolation helplessness frustration/distress problem is very significant to them worry	She said she’s been dealing with this problem for 10 years ... She only told her MD this year, because she was embarrassed. (Embarrassment) Subject is not comfortable talking about his bowel pattern or leakage. He does not have good eye contact and says he is having a hard time with discussing these. (Discomfort discussing FI with others) “This is not something you talk about with anyone except a data collector on a fiber study.” (Discomfort discussing FI with others) Was joking around during visit; told me that he can only buy cars with leather interiors and no one understands why but it’s due to FI. (Humor) “I have a good sense of humor. Gas is “ick” for other people -- not me! I enjoy good gas. I’m looking forward to this.” (Humor) Minimized his problem, was embarrassed to talk about it and tell me how bad it was. (Minimization) [Being in study] “I realized having incontinence was not my fault.” (Guilt/shame) “I feel like there is something wrong with me” (Undervalue Self) He says I am the only person he can tell these things to. (Isolation) Feels that her problem is somewhat manageable now but what if it gets worse? How will she live as an older adult? She was crying on the way home and felt so helpless to control the problem. (Helplessness) Had gone to see couple of MDs concerning it but has had no luck or answers ... this problem is really an issue for him. He is desperate for a solution. (Frustration/Distress) “I’ve had major things happen in my life but when it comes to this, I can’t think of anything that affects me more physically and emotionally. I sometimes lose my edge about this.” (Problem is significant) “Sometimes I pass gas and start to worry.” (Worry)
<b>Need for Control (33/32)</b>	“Most of the time I make it to the bathroom. I know where they are, but I have to go and there’s no bathroom, I can’t control.” Wants to control FI when doing activities such as golfing, state fair, etc.
<b>Reduced or Impaired Socialization (15/14)</b>	“I never would use trains/planes or anything where I didn’t know where the bathroom would be available.” “Because of the leaks, we haven’t had sex.” Subject shared that she had been fairly house bound before the study and had good results allowing her to go out more and engage in social activities.
<b>Self-Reliance/Self-Care (13/13)</b>	“I rarely bother my doctor with problems but I did tell him about my leakage once. I solved the problem myself and I wear a little pad every day I go out.” Subject uses ‘chucks’, fans them out under her pants in case of big accidents.
<b>Quality of Life (4/4)</b>	“I have 3 children, 2 teenagers and one 10 year old. You could leak anything else from anywhere and they wouldn’t care, but not this. I’m glad you are looking at quality of life.”
<b>Benefits of and Positive Feelings from Participating in a Research Study (35/32)</b>	“I’m excited about the study. I’m gonna find out a lot.” “I’m doing this for the sake of research to help people with my problem.” “Now I’m getting to help myself by being in my study. My husband told me I’m contributing to science but I’m a little selfish, I want to help myself. I’m also glad I might be helping others with this problem. This study is so important.”

\* Statements in quotation marks indicate subjects’ verbatim statements that were recorded in field notes.

Others are notes of the data collectors.