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Patients' experience compared to physicians' recommendations for the treatment of fecal incontinence: A qualitative approach

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Abstract

Introduction—To compare physician-recommended treatment options for fecal incontinence to patients' knowledge of treatment options using qualitative methods. Our hypothesis was that physician recommendations were not being communicated well to patients' and that this impaired patients' ability to cope with fecal incontinence.

Methods—Cognitive interviews were conducted with physicians who routinely care for women with fecal incontinence. Physicians were asked to describe their typical non-surgical treatment recommendations and counseling for fecal incontinence. Women with bothersome fecal incontinence were recruited to participate in focus groups and asked about personal experience with fecal incontinence symptoms and treatments. For both the physician interviews and patient focus groups, qualitative data analysis was performed using grounded theory methodology.

Results—Physicians identified several barriers patients face when seeking treatment: lack of physician interest towards fecal incontinence and patients' embarrassment in discussing fecal

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incontinence. Physicians universally recommended fiber and pelvic floor exercise; they felt the majority (approximately 70–80%) of patients will improve with these therapies.

Collectively, patients were able to identify all treatment recommendations given by physicians although many had discovered these treatments through personal experience. Three concepts emerged regarding treatment options that physicians did not identify but that patients felt were important in their treatment: hope for improvement, personal effort to control symptoms and encouragement to go on living life.

Conclusions—While physicians had treatment to offer women with fecal incontinence, women with fecal incontinence had found the best treatments through personal research and effort. Women want to hear a message of hope, encouragement and personal effort from providers.

Keywords

Fecal Incontinence; Patient Perspective; Physician Recommendations

Introduction

Fecal incontinence (FI) is common and undertreated. While FI affects both men and women, the causes of FI vary by gender. Estimates of the prevalence of FI among community living women vary widely depending on the definition used. Anal incontinence has a prevalence of 28.4% (95% CI 24.4–32.8) in women presenting for gynecological care. (1) One population-based study found that more than 1 in 10 adult women suffer from fecal incontinence. (2) FI appears to have greater impact on a woman's quality of life than flatus incontinence when using validated measures of severity, although both are reported as bothersome. (3) Women with FI report anxiety, depression and poorer perceived health. (2)

Estimation of the cost per patient treated with FI due to obstetrical injury is \$559,341 and physician charges account for 18% of these charges. (4) People living with FI have 55% higher overall health care costs when compared to continent patients. (5) First-line therapies for FI are non-surgical interventions aimed at managing symptoms. Given there is no single best treatment for FI, non-surgical therapeutic options typically involve multiple approaches which may be difficult for providers and patients to remember, including behavioral and physical therapy, medications and dietary changes. (6) Furthermore, maximization of inexpensive outpatient, non-invasive coping strategies for FI could reduce the FI surgical procedures which cost \$24.5million US per year. (7)

Understanding the patient perspective and experience of illness can lead to improved patient-centered care. (8–10) Patient centered care is “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” (11) Recent work found that “patients can contribute to improving chronic disease health care and research if mechanisms are in place to enable their experiences to be used.” (12)

A PubMed literature search showed that the FI literature currently lacks patient experience and perspectives of treatment options. We sought to explore the current therapy recommendations for FI as identified through cognitive interviews of experts in the care and

treatment of FI, as well as focus groups consisting of patients living with FI. Our primary aim was to explore the range of non-surgical treatments currently recommended for FI from both the physician and patient perspective. The ultimate goal of the focus groups and cognitive interviews was to generate a teaching tool describing therapies for FI that could assist in patient–physician communication.

Materials and Methods

After obtaining Institutional review Board approval for this study (#12-429), we conducted a qualitative research project that included physicians who routinely care for women with FI and patients who were living with FI. Physicians were asked to participate in a cognitive interview. These physicians were selected from a wide geographical area of North America and were intentionally recruited because of significant publications or notoriety in the field of FI. Physicians were screened by asking if they “routinely cared for women with FI,” physicians who affirmed routinely seeing FI patients were then consented and continued the interview process. Interviews followed an open-ended scripted and conducted in person or over the phone, and tape-recorded. Briefly, cognitive interviewing techniques are used “to study the manner in which targeted audiences understand, mentally process and respond to the materials we present--- with special emphasis on potential breakdowns in this process.” (13) Physicians were asked to describe the barriers they perceived to affect care-seeking behavior of patients with FI. Then physicians were asked to describe their typical non-surgical treatment recommendations and counseling for FI with an initial set of questions (see Table 1). The initial question set was designed as probe questions that then allowed the interviewer to ask additional questions as the physician began leading the conversation in a think out loud process that fully allows for the interviewee to express their opinions.

Two investigators then reviewed the de-identified transcripts of the physician cognitive interviews and coded them for themes after each interview. Questions were modified and further specific probe questions were added based on transcript coding, although minimal modification was needed. However all physicians were asked the initial screening questions and asked to pretend they were counseling a patient with FI on non-surgical options. We planned to interview physicians until thematic saturation was reached. These themes were also used to generate a patient focus group interview guide that addressed the treatments physicians typically recommended for FI.

Focus groups are often used when attitudes and behaviors about a specific clinical question is unknown. Focus groups form a basis for understanding new phenomena and help formulate clinical questions and hypotheses that can then be tested in quantitative research and are hypothesis generating. Women with bothersome FI for greater than 3 months were recruited from an academic Urogynecology clinic to participate in focus groups. Inclusion criteria for the focus group was age >18 years of age, diagnosed with FI by one of the attending physicians, bothersome FI symptoms for at least 3 months, able to give informed consent, and able to speak, read and comprehend English. Bothersome was defined as having sought care for FI combined with the patient’s subjective assessment that FI interfered with their daily activities. Exclusion criteria was diagnosis of colorectal or anal malignancy, inflammatory bowel disease, recto-vaginal fistula, rectal prolapse and/or history

of pelvic floor or abdominal radiation Topics discussed in the focus groups included: knowledge and personal experience with FI symptoms, barriers to seeking care, and knowledge of treatments.

Focus groups were scheduled for 90 minutes and conducted by trained moderators (not a care provider or any investigator in the study). The standardized interview guide allowed for probing and discussion around the topic of FI treatments but also allowed the focus group to collectively discuss their experience with non-surgical treatment for FI to fully express their opinions and feelings. This structure was used, and is typical for focus groups, in order to begin the conversation and provide a basis for discussion, but not squelch the focus groups discussion; participants were encouraged to bring-up the issues that were important to them. At the end of each focus group themes were summarized and the members of the group verified that the moderator's interpretation of discussion was agreement with their understanding. Based on investigator experience, planned recruitment was for 6–8 participants per group; we anticipated that we would reach thematic saturation in 3–4 focus groups.

Focus groups were recorded. Audiotapes of the focus groups were transcribed, de-identified and transcripts independently reviewed and coded. For both the physician interviews and patient focus groups, qualitative data analysis was performed using constructivist grounded theory methodology. (14) In contrast to classic grounded theory where the scientific observer is separate from the data, (15) constructivist grounded theory allows the researcher to observe and interact with the data collected and search for new hypothesis. (14, 16–18). Briefly, grounded theory assesses the current research situation and theory available for study. Initially, the researcher codes line-by-line transcripts identifying key phrases in the patient's own words. Then phrases are grouped together to create clusters and preliminary themes. (16, 19) These themes are then summarized into emergent concepts so that the researcher has taken an active role in the process of developing the emerging theory. (1, 16–18)

For this study, dominant trends were identified within each focus group and then groups were compared to generate themes or patterns in the way subjects described their experiences. Each transcript was reviewed by two independent researchers trained in grounded theory methodology and then reviewed collectively to look for consensus. One reviewer was external to research process and auditing for accuracy of the findings. If consensus was not reached, a 3rd reviewer reviewed the transcript. Content reviews were conducted after each focus group in order to modify the script and further explore concepts with subsequent focus groups. This was an iterative technique that ensured a thorough and systematic review of all thematic content in each transcription and the results generated a list of conceptual gaps in existing treatment recommendations for FI. The combination of physician cognitive interviews and patient focus groups provided different data sources and allowed for triangulation to better understand how physicians' and patients' perspectives overlapped and differed.

Results

Eight physicians with specialties in Colorectal Surgery, Gastroenterology or Urogynecology were recruited and agreed to participate in the cognitive interviews. No recruited physicians refused participation in the interview. Cognitive interviews lasted on average 30 minutes with a range of 10 to 50 minutes. When asked to describe barriers patients encounter when seeking treatment one physician said, "The physician's lack of interest in treating the problem because of the complexity of the treatment and the lack of efficacy of the treatment." Other comments included, "I think probably most important is that they (patients) don't understand the treatments available... that (the patients think) it's kind of a normal process of aging." Another physician notes that, "Often times I think it's a lack of a belief that it's (FI treatment) going to work." When discussing barriers to treatment one physician listed two items. "Not having good treatments. That's a big deal. [W]omen feel embarrassed to talk about it." In summary, physicians identified two key barriers patients face when seeking treatment: lack of perceived physician treatment options towards FI and patients' reluctance in discussing FI. Physicians identified embarrassment, and the assumption by patients that FI is "normal" or unable to be treated as potential reasons patients are reluctant to discuss FI.

When discussing treatment options for FI, physicians universally recommended fiber and pelvic floor exercise. Physicians also recommended using a food diary to identify triggers as well as optimization of bowel consistency and regularity. Most physicians agreed that laxatives, antidiarrheal medications, enemas, and biofeedback may be appropriate for specific patients. Physicians reported the majority (approximately 70–80%) of patients will improve with these therapies. For example one physician said, "There is a great deal of improvement to be had just with optimizing stool consistency often to the point that even if we are contemplating a surgical intervention we find the with improved stool consistency they are happy and they don't want to have a surgical intervention."

Focus group participants were recruited from an academic Urogynecologic clinic. 19 women were invited to participate, 6 declined participation and 13 consented to participate. Over the course of one month, two focus groups of 5–6 women were conducted, totaling 11 subjects (2 subjects initially consented were unable to participate: 1 due to illness and the other 1 for car problems). We had planned a priori to conduct a total of 3 to 4 groups to reach thematic saturation. However, after completion of the first two focus groups it was determined by the group moderator and the community research specialist that thematic saturation had been achieved. Thematic saturation means that in the 2nd focus group no additional ideas, themes, or concepts were identified. The mean age of the participants was 56 years, all women were parous, 5 were Hispanic and 6 were non-Hispanic white. The average duration of FI symptoms was 10 years.

Collectively, patients were able to identify all treatment recommendations given by physicians although many had discovered these treatments through personal experience and had not necessarily been counseled or informed of these treatments by a health care provider. For example, one woman living with FI said, "I have different specialists I see... but they couldn't tell me, you know, with all the tests they ran, they couldn't tell me what

was wrong. They didn't tell me what I could do to fix it... I guess now that I've been here, I'm an expert now." Table 2 describes the treatment options identified by both physician interviews and the participants of the focus groups with representative quotes.

Initial line by line coding revealed 12 themes the focus group discussed about FI: embarrassment, worry, ability to do things that you enjoy, effect on lifestyle, smell, no treatment recommendations from physicians, wanting to be/feel healthy, will to get better, desire to get better, personal effort, hope and living life. When we reviewed the context of these themes there was an overarching consensus in the groups that they wanted a motivational message from the physician. As one patient summarized, "That every word be an action word... how many of you let ourselves lapse into negative energy because of this condition? You can get really depressed about your life..." Therefore we synthesized the negative themes into a theme generated by the focus group that was positive. For example the themes of smell, embarrassment and worry were grouped into the theme of living life. The results of this analysis produced three emerging concepts regarding treatment options that physicians did not identify, but patients felt important. First, patients wanted doctors to communicate hope for improvement in their condition. Many women had experienced a feeling of futility after seeing a provider; "[I]t's not like our lives are like this or like this (makes a straight line or ascending line with her hand). They are like this (make an up and down motion with her hand). So we need to keep that emotion piece... Hope. Hope is really important."

Second, women wanted physicians to give guidelines about treatments, but overall wanted to hear physicians tell them to continue living their life. As one participant said, "There are many people who get really down and depressed about this condition... and you have to continue to be optimistic and live your life."

Finally, women wanted to be counseled that it would take personal effort to achieve improvement in their condition. As one women summarized, "It's like whatever works for you, because everybody's situation is so different. And I'm the only one who knows on a daily basis how I feel, how regular I am, how much signal I have of whether I'm going to poop or not, how often I have to change my pads, or how much of a regular or normal life I can have." Table 3 describes these patient concepts with representative quotes from the focus group participants.

Discussion

Our study explored the treatment recommendations of physicians who provide care for patients with FI and the experience of women living with FI when they sought treatment. Successful non-surgical treatment for FI does exist; previous studies have identified biofeedback, weight loss, loperamide and fiber as viable options. (20–23) These therapies as well as developing good bowel hygiene, such as regular toileting and routine eating habits, were identified by both patients and physicians.

We identified several conceptual gaps in patient perceived physician counseling of women for treatment of fecal incontinence. First, physicians interviewed listed specific treatments

they offer for FI. Patients reported that they were unable to access this knowledge even when seeking care. Importantly, most of the focus group participants had discovered these therapies on their own and not from specialist care. Second, in our physician interviews, physicians related that the majority of women will improve with FI treatment, while women reported that they have been counseled that treatment is futile. Paradoxically, physicians had reported that women with FI don't seek care because they (patients) "don't think treatment is available." Perhaps both patients and physicians not thinking treatment are available is true, and therefore ongoing research efforts should be made to educate physicians as well as the public.

This may be the reason that the resulting themes derived from the focus group discussions were concepts that didn't require specific knowledge of treatment for FI. Women reported that the context of physician counseling should include coping, hope and continuation of living their daily lives. This context was not addressed in any of the physician interviews or descriptions of their standard counseling for a patient with FI. The themes of hope, living and effort are universal to all care sought for chronic illnesses and important to include in patient counseling in order to achieve the best patient outcomes. (24)

Previous studies have found that 2.7%–29% of women with FI actually seek care; meaning the vast majority of women with FI do not seek care although those with more severe or more frequent FI are more likely to seek care. (5, 25) Brown et al identified reasons women with FI seek care; such as access to a primary care physician, to have heard of FI and to have suffered longer with more severe leakage. (25) Our study uniquely found that of those who seek care, many leave without knowledge of the therapies to cope with the symptoms of FI even when seeing specialists, and despite having symptoms of FI for an average of 10 years.

FI is known to negatively impact overall quality of life and be associated with depression and anxiety. (3) Our focus groups expressed that these experiences should be addressed as part of their treatment regimen while discussing therapy with physicians. Hope is the antithesis of the despair, depression and anxiety found in many FI sufferers.

Strengths of this study include the iterative process used for cognitive interviews and focus groups that allowed for thorough exploration of FI treatments. The patient centered approach to this study allowed for the discovery of the hopeful message that many patients felt they needed to hear from their physician. This patient centered study design also led to the discovery that women coping with FI uniquely recognize the pivotal role they play in managing their symptoms through dietary control, regular pelvic floor exercises and good bowel habits and offers guidance to physicians caring for them. Women reported that they wanted physicians to inform them that personal effort was necessary to achieve improvement. Combining these themes with the physician expertise explored through cognitive interviews did lead to a novel teaching tool that is currently being studied in a pilot randomized control trial to help patients recall and implement treatments for FI.

Limitations to this study include that we only studied women who had sought care for FI. This lends itself to self-selection bias. Therefore, we are unable to comment on women who

have FI but have not sought care. Women who have not sought care for FI may have different views and perceptions. Women who sought care are also likely to be different in their knowledge of treatments than those who do not seek care. Their experiences, both positive and negative as they sought care for FI may also affect their views on any given treatment recommended for FI. Despite this, many of the women in our focus groups reported seeking care and not being offered any treatment. Additionally this study interviewed physicians who are subspecialized and their knowledge is likely different than a primary care physician. We specifically recruited physicians known for their publications on FI and/or for their expertise in FI. Future studies should assess primary care physicians' knowledge and experience in treating FI. Last, while we asked physicians to provide their typical counseling during the interview, the counseling may have been more accurate if we recorded actual patient encounters.

We found that there is a disconnect between physician recommendations for FI and the important hopeful, personal-effort driven living that patients want to hear and believe to be helpful for improving their quality of life. Improving outcomes for women with FI means bridging this gap. The expert physicians in our study universally had treatment to offer patients and anticipated most patients improving. However, the focus group experience had been leaving physician after physician without specific treatment recommendations. This study lays the groundwork for exploring, studying and implementing effective FI counseling strategies for non-surgical management of FI.

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Table 1

Framework for Physician Interviews

Screening question	Do you routinely care for women with FI? (If a physician answered "no" they were excluded from the interview process.)
Comprehension question	How many patients with fecal incontinence do you see in a month? (If physician did not see any patients with FI they were excluded.)
Confidence Judgment	Are you comfortable caring for women with FI? Please pretend I am a new patient seeing you for fecal incontinence. How would you counsel me if my exam was normal and you did not identify a specific cause for my FI?
Specific Probes	What treatment options do you believe are well supported in the literature for fecal incontinence? What treatment options have you discovered or found through experience to be useful for women with fecal incontinence? How often do you believe a combination of these treatment options improve the quality of life for women with fecal incontinence? When do you recommend Loperamide? When do you recommend stool softeners? Do you ever recommend enemas? What fiber do you recommend?
General Probes	What do you think the barriers are to treatment for fecal incontinence? Do you think patients remember the treatment options you recommend to them for fecal incontinence?

Table 2

Treatments for Fecal Incontinence Identified by Patients and Physicians

Identified by Physicians and Patients	Quotes Bold= Physician <i>Italic</i> =Patient
Fiber and Kegels/Pelvic Floor Exercise	<p>“By conservative management we mean basically patient education, normalizing stool consistency, and implementing pelvic floor exercises.”</p> <p>“Typical first line of therapy is just dietary/behavioral or doing a really aggressive fiber regimen”</p> <p><i>“Primarily fiber and Kegel exercises like mad, in all different positions.”</i></p> <p><i>“And the number one thing that I can figure out is diet and exercise.”</i></p>
Food Diary	<p>“Often times piecing out the dietary patterns will help with optimizing stool consistency.”</p> <p><i>“Very important is keeping a food diary. You know I can see on a daily basis what things will trigger...”</i></p>
Bowel Regularity and Consistency	<p>“Regularity from a stool consistency standpoint but also regularity from a timing standpoint.”</p> <p><i>“If you eat at the same time of day, if you sleep properly with the same number of hours, if you diet is pretty much the same and there is consistency and regularity in it. That that will lead to an outcome.”</i></p>
Imodium, Laxatives, Enemas	<p>“Some women find that things that can harden their stool such as Imodium (Loperamide) can prevent accidents.”</p> <p><i>“He (the doctor) just tells me to take Miralax, (polyethylene glycol) so I started my own treatment.”</i></p>

Table 3

Emerging Concepts from Patient Focus Groups

Themes by Patients	Concepts	Representative quotes
Embarrassment Worry Ability to do things you enjoy Smell Effect on Lifestyle	<i>LIVE</i>	<i>"There are many people who get really down and depressed about this condition... and you have to continue to be optimistic and live your life." "Just-in-case pants are a must."</i>
Wanting to be/feel healthy	<i>HOPE</i>	<i>"But I think not talking about these things like hope is a mistake. I think we need to have hope and happiness to know that there is a positive outcome possible for us." "Emotions are important to include... because we have something going on in our bodies that we feel like we have no control over."</i>
Will to get better Desire to get better No treatment recommendations from physicians	<i>EFFORT</i>	<i>"You're not in contact with your doctor daily, but you're in contact with yourself... so I'm responsible for getting better." "You put energy into the process of healing."</i>