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Sources of Emotional Distress Associated with Diarrhea Among Late Middle-Age and Older HIV-Infected Adults

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Abstract

Although the experience of physical symptoms can adversely influence emotional well-being, the specific emotional reactions experienced in response to specific symptoms are not well understood. The current report examines the emotional impact of diarrhea among HIV-positive late middle-age and older adults (i.e., age 50 and over). In-depth interviews were conducted with 100 participants, of whom 29 had experienced diarrhea and spoke about the emotional impact it had had on them. Three principal themes emerged: (1) I don't control the diarrhea, the diarrhea controls me; (2) I feel ashamed, dirty and tainted; (3) I fear what the diarrhea is doing to me and what it means. Their inability to control when and where their diarrhea would occur was a great source of emotional distress for participants. Almost all feared the possibility of fecal incontinence while out in public and the humiliation it would bring. To avoid this, many greatly restricted their time outside the home or where they would go to ensure access to a restroom. Others felt shame and perpetually "dirty" even when not dealing with a bout of diarrhea. Many also worried about the effect the diarrhea would have on their health and whether it signaled progression to end-stage disease. The data strongly support the need to aggressively manage diarrhea in HIV-infected adults as the social and emotional consequences can be profound. When it cannot be effectively controlled physicians and social service agencies should address the isolation by providing home-based opportunities for social support and interaction.

Keywords

HIV/AIDS; diarrhea; emotional distress; control over symptoms; embarrassment; shame; social isolation; social support; elderly; geriatric

Introduction

When people experience a bodily sensation, sign, or symptom that they recognize as a deviation from their usual state, they try to understand its cause. The causal attributions they make, the meanings they assign to the symptom (e.g., progression of disease, medication ineffectiveness), and/or the limitations the symptoms place on their daily life can all be sources of psychological distress or diminish their perceived quality of life.[1–3] For instance, a symptom that is

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interpreted as a possible sign of serious disease in a well person, or of disease progression in an already ill individual, can obviously arouse powerful emotions such as dread, anxiety and sadness. Symptoms can also raise anxiety by undermining one's sense of control over one's health and heighten one's feelings of personal vulnerability.[4] The psychological distress associated with symptoms may be amplified when the cause of a symptom is unclear, because under these circumstances the nature of the threat is poorly defined making it is difficult to appraise the symptom's significance and mount an appropriate remedial response.[5–7] Lazarus[8] has written, "ambiguity concerning the significance of a stimulus situation will usually intensify the threat because it limits the individual's sense of control and increases the sense of hopelessness over the danger" (p. 117).

Ambiguity regarding the cause of a symptom is a common and distressing problem among late middle age and older HIV-infected adults.[9] This is because they are more likely than younger individuals to have independent comorbid conditions (e.g., diabetes, arthritis, heart disease).[10,11] These conditions, along with the diverse physical and cognitive changes associated with normal aging, often represent plausible explanations for a range of symptoms such as fatigue, poor concentration, and stiffness.[9]

HIV and Symptom Distress

Individuals with HIV often are symptomatic throughout the disease trajectory regardless of CD4 counts.[12] Even in the era of highly active antiretroviral therapy (HAART), symptoms remain a prevalent problem.[13] Significantly, physical symptomatology has been one of the most consistently identified correlates of psychological distress, depression and/or quality of life in adults with HIV/AIDS.[1,14–22]

A number of studies of HIV-positive men and women have demonstrated a strong association between HIV-related symptoms and high psychological distress. Among 173 HIV+ gay or bisexual men with symptomatic HIV disease (mean age = 40), the number of self-reported physical symptoms was directly associated with levels of psychological distress.[23] This association was independent of CD4 cell count and HIV RNA viral load, suggesting that treatments that improve patients' "clinical status" may not necessarily alleviate psychological distress. In a study of 49 HIV-infected men ranging in age from 27 to 64 (mean age = 43), greater physical limitations in daily activities predicted higher levels of depressive symptoms independent of disease stage, physical symptoms and CD4 cell counts.[24] Among 113 HIV+ middle-age and older adults (mean age = 53.4), those with higher levels of depressive symptomatology as measured by the BDI were more likely to report severe HIV symptomatology that altered their daily functioning.[17] More recently, in a prospective longitudinal study of a nationally representative cohort of individuals in care for HIV infection (*n*=2267), investigators found "that changes in HRQOL [health-related quality of life] were strongly and consistently associated with changes in symptoms."[19 (p. 954)]

Diarrhea

Only a few investigations have examined the association between specific symptoms and the specific types of emotional responses they evoke or have fully explored the range of potential emotional responses such as anger, frustration, fear, and embarrassment that symptoms may elicit. Diarrhea is a common and quite distressing symptom among individuals with HIV/AIDS, even in the HAART era.[12,15,25–28], Yet, it has received very little attention.

Lorenz and colleagues[29] examined the association between specific symptoms and health-related quality of life among a nationally representative sample of HIV-infected adults interviewed in 1996 and again between 1997 and 1998. Their investigation indicated that pain in the mouth, lips or gums; trouble with eyes; pain, numbness or tingling of hands and feet;

and diarrhea or loose or watery stools were associated with significantly poorer perceived quality of life than other symptoms. Another study of AIDS patients (mean age = 38.6) found that many reported substantial distress related to common symptoms such as lack of energy, feeling drowsy, and diarrhea.[27] As with most of the HIV studies examining the association between physical symptoms and psychological distress or quality of life, these studies did not focus on adults age 50 and over.

Although most studies have not examined the distress associated with specific symptoms, there have been a few notable exceptions that have examined the emotional distress associated with diarrhea in particular among HIV-positive individuals. In a study of 504 AIDS outpatients, 35% reported diarrhea as a symptom they had during the previous week and one-third of these individuals said it caused “quite a bit” or “very much distress.”27 Snijders and colleagues[30] examined the ways and the extent to which diarrhea influenced daily life. Semi-structured interviews were conducted in 1995 (prior to the availability of protease inhibitors) with 59 men and three women with HIV/AIDS who were classified by the severity of their diarrhea. A majority reported that due to their diarrhea they experienced restrictions on their social life, with 39% describing these restrictions as moderate or severe. Most (60%) spontaneously reported that they were scared or worried about their diarrhea and that it might indicate the “start of decay” or the “beginning of the end.” They feared incontinence, worsening diarrhea, or resulting weight loss. They reported feeling worried and helpless because of their decreased control over their bowel functions and the potential for incontinence. Some reported feelings of loss of control, both physically and psychologically due to the diarrhea. Finally in a multicenter, prospective study in Italy, 100 consecutive HIV-infected patients receiving HAART with diarrhea were matched with control cases at the same disease stage, but without diarrhea.[21] Investigators found that patients with diarrhea experienced a significantly lower quality of life.

Clearly, very little is known about the specific emotional responses symptoms, including diarrhea, evoke in HIV+ infected individuals and what we do know is based almost entirely on younger and early middle age adults. The present report expands our understanding of this issue by examining the emotional responses of HIV-infected adults age 50 or older to the symptom of diarrhea.

Methods

Choice of a Qualitative Research Approach

In formulating any study design, we always begin from the position that no research approach is *a priori* superior to others. It is the problem under investigation and the state of existing knowledge in a field that should dictate the most suitable approach for any study. For several reasons, we have chosen a qualitative research methodology for the proposed study. First, the principal focus of the study from which the data in this paper were drawn was on how individuals assign causes and significance to the various symptoms they experience and on their associated remedial actions. This process is often a dynamic one that evolves over time and has behavioral, cognitive and affective components. That is, unless a symptom episode is brief and self-limiting, initial appraisals and coping responses may well change over time as one acquires new information, as network members are consulted, or as the symptom’s characteristics (e.g., severity, disruptiveness) change. This process, we believe, is best explored and elucidated through qualitative research methods that allow the individual to relate their experiences in context, as they unfolded, and reveal their personal interpretation of events. A quantitative approach would, as Mechanic[31 (p. 154)] has contended, ignore “the processual nature of illness perceptions and response.”

We chose a qualitative approach in this study because it is particularly well suited to discovering the personal meaning that individuals assign to their somatic experiences. This is because qualitative methods can "expose" how infected individuals mentally organize and cognitively structure their experiences. Indeed, Pearlin[32] has characterized social scientists who rely primarily on survey samples and quantitative methods of analysis as "structure seekers;" while those who depend primarily on qualitative methods of data collection and analysis, typically applied to smaller samples, he has called "meaning seekers." The importance of the ascription of meaning to understanding stress has been emphasized by Lazarus[33] who has written, "I am confident that personal meanings are the most important aspect of psychological stress with which the person must cope, and they direct the choice of coping strategies." [33 (p. 101)]

Sample

The data reported below were gathered as part of a qualitative study that investigated the symptom appraisal process (i.e., the assigning of cause and significance to symptoms) of late middle-age and older HIV-infected adults. Further details can be obtained in earlier reports from this study.34,35 A total of 100 adults participated in the study. Of these, 29 reported diarrhea or loose stools as a symptom they had experienced recently and these individuals are the focus of the current report. In order to be eligible for the study, individuals had to: (1) be 50 to 75 years of age; (2) have experienced three or more common illness- and treatment-related symptoms during the past 30 days (although they did not have to attribute those symptoms to HIV-disease or related treatments); and (3) be cognitively competent to provide reliable and meaningful data.

Recruitment

Study participants were recruited through a variety of methods. Flyers were distributed to a wide range of health, social service and advocacy organizations that serve HIV+ adults including two that focus on the needs of those 50 and older living with the virus. Additionally, friend referrals were used as participants referred other older HIV+ adults to the study. In particular, special efforts were made to have participants help us to recruit women, particularly White and Puerto Rican women, and individuals over 60 years of age. Individuals interested in participating in or learning more about our study were asked to call the study telephone line. Members of the research team screened potential participants for eligibility. Those eligible and interested in participating individuals were scheduled for an interview. Interviews were conducted in English and Spanish. Each participant was paid $50 for their participation which they could choose to completed in one or two sessions; they were also reimbursed for all reasonable transportations costs.

Data Collection

Each participant met with an interviewer for approximately 4 – 5 hours (often divided into two separate days). Interviews were conducted between November 2000 and February 2002. After informed consent was obtained, each participant completed a small battery of standardized measures related to quality of life, social and physical functioning, depressive symptomatology, pain, and psychosocial adaptation to illness. Following this, the tape-recorded interview began with a brief interview-administered questionnaire focusing on demographic information, health status and other medical conditions, the HIV testing process and risk behaviors related to HIV. The remainder of each session consisted of an in-depth semi-structured interview. The interviewer followed an interview guide covering key topics related to symptom experiences, symptom appraisal and coping responses. Interviewers were trained to cover all of the topics included in the interview guide, while also exploring any participant-generated issues related to the research topics of interest. Interviewers used neutral probes to explore a participant's experiences with symptoms, and to gain more complete narratives. In each interview, participants discussed in detail three symptoms. The data obtained through the in-depth interviewing process is the focus of this report.

Data Analysis

The focused interviews were audio-taped and transcribed for thematic content analysis. Analysis began with the development, testing and refinement of a coding scheme that allowed us to systematically identify and conceptually define the themes and sub-themes present in the text, as well as the relationships among them while keeping them in context. The development of a provisional coding scheme was based on the initial analysis of 20 interviews. These 20 cases were chosen to be half male and half female and ensure variability by age, race/ethnicity and disease stage. Based on these cases a provisional coding scheme was constructed. The scheme was then applied to 5 new cases to see if it captured all of the data relevant to the key research aims. In the current study, because the sample was quite homogenous, the initial 20 cases chosen provided a very adequate provisional coding scheme and only a few additions and refinements to the coding scheme were necessary before coding of the rest of the sample could proceed. After these changes to the scheme were made, the coders went back and reviewed the 20 previously coded cases to consider if any of the additions applied to them, and if so, carried out the additional coding. The coding scheme consisted of several main domains related to the study aims. These included: symptom experiences; symptom interpretation (assigning cause and significance to the symptom); remedial coping strategies enacted and their efficacy; and emotional responses to the symptom.

Once the coding scheme was finalized, two coding staff read and applied the codes to all of the transcribed interviews using ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, German), a software program for qualitative data analysis. Application of the coding scheme to the qualitative data set served to systematically organize the data and facilitate analysis of the text. High consistency was achieved during the training of the coding staff in the use of each thematic code. For the present analysis, data contained in the codes and subcodes that addressed “symptom interpretation” and “emotional responses to symptom” were extracted for those participants who experienced diarrhea. These extracted texts were then read and thematically analyzed to identify the specific emotional reactions experienced in response to their experiences with diarrhea.

Results

Sample Characteristics

Of the 100 participants interviewed, 29 participants discussed diarrhea, including 22 (75.9%) males, six (20.7%) females, and one (3.4%) who was transgender. Of those who reported diarrhea, Blacks comprised 37.9%, Hispanics 24.1%, and Whites 31.0%, while two participants (6.9%) were classified as “other.” Participants with diarrhea ranged in age from 50 to 67 (mean age = 56.6); 24.1% of the sample was 60 or older. Concerning marital status, 6.9% were married, 17.2% were separated or divorced, 10.3% were widowed and the remaining 65.5% were single, never married. However, 44.4% reported a current steady partner. Less than half of these participants (41.4%) reported having children, and only 6.9% reported children living in their home. Few were working; none full-time and only 6.9% part-time, while 13.8% were volunteering. Approximately 27.6% of the subsample had less than a high school education, 20.7% had graduated from high school, 24.1% had completed some college, while the remaining 27.6% had completed four or more years of college. The sample reported very low household incomes: less than $10,000 for 48.2% of the sample, and $10,000-$19,999 for 31.0%, with only 3.4% reporting a household income of $35,000 or more. Regarding sexual orientation, 32.1% described themselves as completely heterosexual, 39.3% as completely homosexual, with the remainder reporting some degree of bisexual orientation. While only

3.4% reported injection drug use during the six months prior to their interview, 27.6% reported a history of use (since 1977). The mean time since diagnosis was approximately 10 years and 6 months (range= 50–204 months), with 89.7% diagnosed more than six years prior to their interviews. Approximately three-fourths of participants (75.9%) reported a T-cell count below 200 at some point during their illness.

Emotional Responses to Symptom

The data revealed that participants had strong emotional responses to their diarrhea primarily related to three themes that reflected concerns the symptom raised: (1) their inability to control the symptom, which necessitated that they restrict their activities outside the home; (2) the shame and feeling of being dirty that the diarrhea evoked; and (3) the medical significance they assigned to the symptom and its potential consequences.

I Don’t Control the Diarrhea, the Diarrhea Controls Me—Participants who felt they were unable to predict and control their diarrhea experienced significant fear and worry associated with the possibility of becoming incontinent in public and being humiliated. This risk was so anxiety-provoking that many chose to severely restrict the time they spent away from home. Virtually all participants with this symptom felt the need to plan carefully where they went to ensure ready access to a bathroom if they felt an attack coming and/or to minimize the likelihood their incontinence would be obvious if they could not get to a restroom in time. Most felt their diarrhea controlled them in that it often dictated what they could and could not do socially or when they could leave the house, and as a result, it greatly impacted their mood. For example, a 65-year-old White male expressed irritation over his inability to control when or where the diarrhea would occur and how much this impeded his ability to engage in some activities. As he described it, “Your total planning is *what if?*” That is, participants felt the need to always have a plan regarding what to do if they were out and felt a bout of diarrhea coming on, or if they could not get to a bathroom or home in time to avoid an episode of incontinence. Several mentioned their concern about their diarrhea occurring while trapped in the subway car or station. Some expressed how hard it was when out to gain access to a bathroom, as many businesses, such as restaurants or luncheonettes, restricted use to their customers.

A 63-year-old Black male was distressed about how his diarrhea substantially interfered with his activities. He explained:

> R: Yeah. Yes, because it, it wasn’t goin’ the way I wanted it to go. [LAUGHTER] And soon as I get downstairs I’d have to go back upstairs. Or it’s like once or twice I’ve gotten caught on the street. I’d go on the subway.
>
> I: Yeah, an accident?
>
> R: An accident. I’d get into the subway station and have an accident. I had to go between cars. I had an accident and I had to come right back upstairs and change my clothes because I couldn’t hold it no more. So that’s why, and that makes it embarrassing for me. But then I just get, I don’t go nowhere.

A 51-year-old Hispanic male who said that his diarrhea was not physically painful nevertheless explained the anger he felt because of the restrictions it imposed on his activities. When asked how his diarrhea made him feel, he replied:

> R: Angry
>
> I: Angry, okay. Why do you say angry?
>
> R: Because I couldn’t get around the way I could, you know, normally. Like a normal person. Would I get to the bathroom on time? Sit on the bathroom stool, you know,

> like a normal person. … I have to be conscious if I am out on the street. Make sure that there's a restaurant around, somewhere where there's a toilet I could run to. Because otherwise, it hasn't happened, but I would hate, you know, if it did happen. That'll be embarrassing. It's embarrassing you know. I have to be very careful. That's why I'm, you know, choosey about when I am out.

A 62-year-old Hispanic male felt distressed about many aspects of his diarrhea, including his confusion over its cause and the unpredictability of its timing. Like many other participants with this symptom, his concerns about publicly soiling himself caused him to stay at home a great deal. As a result, he felt isolated and frustrated by his situation.

> I: When did you no, notice that symptom for the first time? When did it come?
>
> R: (PAUSE) Well, this…before the three months, it comes, it comes… How do I tell you …the diarrhea comes to you… suddenly. I don't know if it is because of the system that is weak, because of the very same medicines, or what one eats… that also produces wasting, the diarrhea…
>
> I: Uh huh.
>
> R: And so, and, and you have to be, eh, be in the bathroom, you're afraid to go out… because you can dirty yourself while you are walking, eh, eh …you're compromised, or be on the train and need to go to the bathroom, and so I prevent myself from going out, and….it's frustrating, I feel bad, embarrassed.

A 60-year-old Black male, who also feared being publicly incontinent, explained how the uncertainty he was forced to live with regarding when his diarrhea would occur, left him feeling powerless. He expressed that he felt controlled by his diarrhea and was very upset by how much it limited his freedom to engage in activities away from home.

> I: How uncomfortable did the diarrhea make you feel physically?
>
> R: Mmm, I would say extremely uncomfortable.
>
> I: Painful or just overall kind of discomfort?
>
> R: Yeah. Like not being in control, you know? I like to get up and go when I want to go somewhere. I don't like to be, you know, how would you say---? Um, controlled by my physical movements and stuff, you know. So I couldn't handle that because, you know, like you don't know when you'll have to use the bathroom when you got that. So you know, I was like upset kind of, you know, bent out of shape about that.
>
> I: So it makes you feel kind of constrained as to what you do?
>
> R: Yeah, kind of powerless.

A 53-year-old Black female stated that she was "pretty concerned" when her diarrhea began because she "wasn't expecting that." As it continued, she became increasingly worried because she was not "holding anything" and her "anal spot" was hurting. Like the participants discussed above, she went out of her house very little to avoid a potentially embarrassing situation. Her lack of control over the diarrhea made her feel helpless.

> I: And besides worried, you know, about your diarrhea how else did this symptom make you feel emotionally?
>
> R: Helpless.
>
> I: Helpless, OK.
>
> R: You know, you can't hold your stuff you feel real helpless, yeah.
>
> I: OK. And again, how would you rate the level of helplessness?

> R: Three [quite a bit].
>
> I: Any, any other feeling that you've had, apart from?
>
> R: Embarrassed, 'cause I would --
>
> I: Embarrassed?
>
> R: Yeah, I didn't want to go out because I knew that this was happening.....I didn't go out.

A 57-year-old Native American male reported that he was able to go out when the diarrhea was less severe, if he took adequate "precautions" like carrying toilet paper with him. However, when the diarrhea was at its worst, he felt immobilized even within his own apartment. When asked how much the diarrhea interfered with his daily activities when it was at its worst, he replied: "I couldn't go out. I couldn't go out. I couldn't do anything, not even from one room to the other, 'cause I would be manuring myself and becoming liquid."

A 62-year-old Hispanic male explained how his diarrhea had similarly forced him to remain homebound most of the time:

> R: Well, this--- How do I tell you? The diarrhea comes to you…suddenly. I don't know if it is because of the system that is weak, because of the very same medicines, or what one eats… that also produces wasting, the diarrhea…
>
> I: Uh huh.
>
> R: And so you have to be, eh, be in the bathroom, you're afraid to go out… because you can dirty yourself while you are walking, eh, eh …you're compromised, or be on the train and need to go to the bathroom, and so I prevent myself from going out, and….it's frustrating, I feel bad, embarrassed

Later when the interview asked this respondent how long his bouts of diarrhea typically last, he replied:

> R: It's been about a week, a week and half. Do you understand? And so that's bad … I feel ashamed to use pampers, and so then… you have to wear tight underwear, with something, put some paper, but always uncomfortable! Because one is not going to be dirty and walking one feels bad!
>
> I: No, of course.
>
> R: Of course, and so it's preferable I don't go out. I stay home. There are many times you have to be there for an hour! Sitting there so as to not return again to, oh the bathroom! I take something to read to just be sitting there! Like a waiting room!

A 53-year-old White male, who had been experiencing diarrhea for about a year, felt embarrassed over his occasional inability to control his diarrhea and the "times when I didn't make it" [inside his apartment to the bathroom], which he seemed reluctant to even reveal to the interviewer. He remarked how diarrhea preoccupied his thoughts whenever he left his apartment:

> R: Yes. And every time you leave your apartment you're always wondering, oh, what's going to happen next.
>
> I: Yeah, yeah.
>
> R: And it's very unpleasant to say the least. So it's, it might be silly for people who have not experienced it, but for those who are affected --
>
> I: I don't, I don't think it's that silly.

> R: It's a very dominating factor there.

A 56-year-old Hispanic female, spoke of her fear of becoming incontinent, especially while on the subway train. She explained:

> R: You know. It's discomfortable because you never know when you're going to get a diarrhea. You never know where you're at. Oh, please, don't let it be on the train. Then you're really in trouble. You know. Try to hold it before you could make it out, and don't make it all the way to your house, is a very, so it's kind of --
>
> I: Is a what?
>
> R: You know, like, if you're going on the train, and you know you feel the diarrhea, or you've got to, oh, and you've got to hold it in. If you don't hold it in, or it comes out, see, now, lots of times, I get in, don't even make it inside the door. But at least I was close to the house.
>
> I: Right.
>
> R: I wasn't on the train.

I Feel Ashamed, Dirty and Tainted—Several participants with diarrhea spoke of the self-shame they felt about having to wear a diaper like a baby due to their uncontrollable bowel movements. The diapers that some were forced to wear were a constant reminder of this lack of control and the infantilizing and demeaning nature of their condition. Others, most of whom had experienced incontinence in public, said the diarrhea made them feel "dirty" and "tainted." For example, when asked which of the several symptoms he had reported was the most difficult for him to live with, a 60-year-old Black male, first stated that they were all about the same. However, he then quickly differentiated diarrhea from the rest, describing it as the most mentally upsetting because of "accidents." He explained that, despite having this problem for years, he has not gotten used to it and it remained very stressful for him. Later, he also went on to describe how his diarrhea caused him to constantly feel "dirty" and how it affected him psychologically.

> I: All right, when you have the diarrhea, how uncomfortable does it make you feel physically?
>
> R: Very.
>
> I: OK. Why is that? Or how is --
>
> R: Because it, it, because it, I, I don't know. I really don't know what you mean, actually. It's psychology, psychology it works against me. That's all. It's not, it's like etiquette. It's like, um, slurping soup. I don't want to be around it. I don't want anybody to do it. Do you know what I mean?
>
> I: Mm-hmm, mm-hmm.
>
> R: It's just --
>
> I: Mm-hmm. And phys-, ah, ah, psychologically I can understand.
>
> R: And I, and I always felt unclean. I felt unclean. It didn't matter whether I just got out of the shower or not, I just felt [unclean] --

When asked about his emotional responses to his diarrhea, this man described his depression related to his apparent shame about always feeling dirty as well as needing to wear a diaper.

Similarly, the 62-year-old Hispanic male discussed earlier, who reported frustration and anger over his ability to control his diarrhea, talked about getting yourself dirty and then "you have to clean yourself like a baby." These remarks reflected the shame he felt being a grown man who because of his uncontrollable diarrhea was transformed into a small, powerless baby who soils himself.

A 55-year-old Hispanic female also described the emotional distress her lack of control over her diarrhea caused her. Like many others, she noted that the train was a particularly stressful place for it to occur. She described difficulty in fulfilling her responsibility of walking her granddaughter to school because she was unable to make it the whole way due to uncontrollable diarrhea. She also related the embarrassment associated with her incontinence.

> I: OK. OK. So, it's, it comes and goes. It's not an everyday thing?
>
> R: Well, I, well, it was, it was just for three weeks. And – it was hard, because you couldn't really do too much. Nothing. Every time I, you know, I was able to go home and change, because I, I could be taking my granddaughter to school and never make it, because I have to run back.
>
> I: Oh, no.
>
> R: Or, or the stuff would come out of me.
>
> I: Oh.
>
> R: So, that was, that was uncomfortable, and embarrassing --
>
> I: Yeah.
>
> R: -- and smelled.

A 56-year-old White female discussed also the discomfort and embarrassment she endured when she has diarrhea while out in public, reporting:

> R: Because I'll be walking along and it plops out. You know how embarrassing that is? And I got to run and look for a place that got a bathroom. And then it smells. And then I got to run to a store and buy panties, then take all these things off, then take those panties off, wrap them up in paper and throw them away in the garbage. Then get all the toilet paper or Handiwipes, get them wet and get washed. In a public bathroom! Sometimes I try to rush home, but it's a long ride from Manhattan all the way to the Bronx. After I get off the train in the Bronx I got to take a bus 40 blocks. So imagine.
>
> I: Yeah, that's a long ride.
>
> R: That's right.
>
> I: And if you had to rate how uncomfortable it makes you feel physically?
>
> R: Extremely.
>
> I: Anything else you would like to tell me about having this symptom of diarrhea? Anything that comes to mind related to the diarrhea?
>
> R: No. Just embarrassing and uncomfortable.

A White 50-year-old man talked about the embarrassment he felt when others made comments about him when he passed gas or had an attack of diarrhea before he could remove himself from a social setting:

> I: When you first started experiencing it, when you thought it was a stomach virus or something, how worried or concerned were you about it?
>
> R: I was worried about how many pairs of underwears am I going to go through?

> I: Because you were having accidents?
>
> R: Yeah, and I don’t like to leave the house unless I’m clean.
>
> I: Yeah.
>
> R: Especially my underwears, my socks, my T-shirt. Those things have to be clean on me. No matter where I’m going I have to be clean. And also when I’m around people and if I can’t get out of that area at the time the embarrassment, I can’t take that. Or to be around people that are drinking and you know kidding around but might set me off by saying something that I don’t want to hear. Then somebody else starts and the other one starts, I can’t take that. I am really concerned about that. First thing I do is if I’m around somebody, usually if I blow wind, like they say, after the second time I blow wind then I say let’s be on the safe side if I start to feel like that--. Where’s the bathroom at? I go to the bathroom. So this way I’ll be on the safe side. And sometimes it’s just air. Sometimes it’s the runs. So I take more precaution now in what I eat and what I drink.

Later in the interview, he spoke more about how important cleanliness was to him personally and how uncomfortable he felt when he had wet underpants because of his diarrhea:

> R: Yeah. Oh, that is annoying. To walk around with your pants wet? Oh. I cannot deal with that. That is a no-no. Yeah. I won’t work with anything with oil, grease or oil. That’s dirtiness. I can’t. I’d hate being a mechanic. I said this isn’t my type of job. It’s very annoying. Very uncomfortable that I have to walk around and smell that bad, and having some people make a smart remark. I’m not one to bite my tongue. I’ll try to bite my tongue. I’ve learned to bite my tongue but not as far as when they make a wisecrack when there’s other people around and try to insult, like there’s seven or eight people around.

A 53-year-old Black male stated that his current loose stools did not affect him too much emotionally, because he had experienced much worse in the past. His prior experiences with diarrhea began in the 1980s (prior to his HIV diagnosis). In explaining how he no longer let his diarrhea control how he felt about himself, he described the shame, humiliation and anger that went along with his diarrhea in the past when he did not have control over this bodily function.

> I: And, um, did you do anything to try to cope with the way the loose stool made you feel emotionally? I know you said you were slightly concerned, but did you do anything to try to cope with the way it made you feel emotionally?
>
> R: No, I, I, um, I’m not gonna let it control me. If, ah, see you have a wish, having loose stool would take you from being Michael Jordan to feeling like Porky Pig.
>
> I: The thing about Space Jam [the movie]?
>
> R: You could use that. I’ve been there, did that, have a couple of T- shirts. I have been there inside of my house, I had put the key in the door and went on myself. I have been in the street, been on the train with people and went on myself and felt less than or like I was the lowest person in the world. But not in the sense that I’m a dirty person, a, how do I say, I’m not low, but that I was losing it in that sense. My own self-worth leaving. Um, your humiliation, um, see you can do it and come in the house, nobody knows and you can, um, [unintelligible]. You can also do it, clean it up and tell somebody. I’m at that point now where if I do it I’ll tell you about it. But I was at, I started at the other end, the bottom.
>
> I: Where you didn’t tell anybody about it.
>
> R: No. I only kept it here and here and here.

> I: Your mind and in your heart --
>
> R: And my gut.
>
> I: -- and in your gut, right?
>
> R: Yes. And it was eating me up because I was putting myself down. That I thought I was dying, my body's betraying me, it's falling apart, I was angry, oh, was I angry. I didn't think I could go nowhere.

I Fear What the Diarrhea Is Doing to Me and What It Means—Many of the participants were worried about how their chronic diarrhea might compromise their health and/or lead to wasting -- a syndrome of unplanned and progressive loss of weight and lean body mass -- which some believed signaled that they were entering the late or final stage of the HIV disease. A 56-year-old Black male initially had not been very concerned about his diarrhea as it was an expected side effect of a new regimen he had begun. Additionally, he viewed himself as having more control over this problem than others who suffered from it. However, as over time he began to lose that control and became incontinent, his anxiety escalated. He thought that it was perhaps due to the loss of sphincter function his physician had warned him might result from the radiation and chemotherapy he was receiving for the anal cancer he also had. But he also feared that his diarrhea and incontinence could represent the beginning of the final stages of his HIV disease having seen others with uncontrollable diarrhea soon after die from AIDS. He discussed how his lack of control over his diarrhea, combined with the possibility that it was AIDS-related, made him feel.

> I: You had mentioned that it got worse. It was exacerbated by the treatment [radiation and chemotherapy for anal cancer].
>
> R: That became upsetting to me. The waking up in the middle of the night and finding that I had an accident. And um, I remember one night I woke up three times, and three times I had to clean myself. The last time I just started crying. As I said, I did, losing control of your body. You're dying. And um, I don't know what was going on then, but that happened oh, a few months every night at least once. And I was becoming quite concerned about it because I mean I know quite, so many people that have died from this illness. In the last stages, you have this uncontrollable diarrhea.

Similarly, a 58-year-old Hispanic male said he knew his diarrhea was HIV-related and "of course, it was a cause for great concern." He was worried about the changes it might bring about in his appearance, but also that like other HIV infected individuals he had known with diarrhea, he would develop wasting syndrome.

> I: Mm-hm. OK. Um, how worried or concerned were you about the diarrhea and the gastrointestinal problem when you first started to experience it?
>
> R: Well, I knew it was, when I knew that I had HIV I knew it was related to that. And of course, it was a cause for great concern.
>
> I: What kind of concerns?
>
> R: Because in talking to a lot of other clients I knew that, you know, there were a lot of people that were going through the same stuff that I was going through or a lot worse. And I would see people, you know, one of the things that, that bothered me was I didn't want to develop a wasting syndrome you know, and that, that, you know, so that, I would see you know, how that affected other people. Of course, it, you know, I didn't want to look like that.
>
> I: Uh-huh. And were you worried that what you were experiencing would lead into wasting syndrome?

> R: Exactly.

A 59-year-old Black male whose concerns about being incontinent on the train were described above, also expressed worry over having diarrhea as an HIV-infected person, and his fear of continued weight loss and the potential for wasting, a condition which he said people with HIV "hate."

> I: How worried or concerned were you about the diarrhea when you first noticed it? You said you cried a little bit because it was kind of overwhelming.
>
> R: Yes, it was. Because, you know, with people, to me the people with HIV, I found that out by being in the hospital, when you have diarrhea or anything like that's all your food is leaving your system. And I can't, I'm like six two and a half. I was weighing 235 pounds. Now I went down to 211. And half my clothes don't even fit no more. And I know once you got diarrhea you start wasting. And most of all, you know, I'm scared of losing any more weight. You know, a matter of fact I've got lipodystrophy. You know, my face has got it and I thought that was because I was losing, that was from the medicine. And that's the only thing I'm afraid of, you know, losing weight.
>
> I: The wasting and the losing weight.
>
> R: Right. That's most of us with HIV, we hate to waste. And that really what happened to me because when I got on the scale about seven days after I lost about a couple of pounds.
>
> I: OK, OK. And if you were to rate how worried or concerned you were about the diarrhea would you say you were not at all worried, slightly, moderately, quite a bit or extremely worried?
>
> R: Extremely worried.

A 62-year-old male was upset by his own and his health care providers' initially unsuccessful attempts to determine the cause of his diarrhea. Ultimately it appeared to be a side effect of his anti-viral medication although a rare one, which may account for why it took a long time to clarify. However, before that determination was made, he knew diarrhea was a symptom of HIV disease and because it was occurring in the context of another HIV symptom, weight loss, he feared that he might be experiencing wasting, which he said caused many infected people to die.

> I: How worried or concerned were you when you first experienced the diarrhea about that symptom itself? Just in relation to the diarrhea how worried were you about it?
>
> R: I was concerned because, you know, one of the things with the virus is what you call wasting syndrome.
>
> I: Right.
>
> R: And that's the number one killer from all of the things that you can die from it.

Similarly, another 62-year-old Hispanic male, described above as being frustrated by his inability to prevent soiling himself, also shared his "dread that this becomes chronic," a condition he also believed was potentially fatal. He explained:

> R: And I dread that this becomes chronic. Because there are many people that have it for a lot longer. That's the dread as well…because there are people that are chronic, they're constantly with diarrhea and so I, and I feel… I give thanks to God that it's time to time, but I'm doing my part, helping myself….yes because eh, eh diarrhea can kill you.

A 56-year-old White female who had been having diarrhea off and on for several months, stated she was depressed by the problem. She anticipated that her diarrhea would lead to dehydration and weight loss that would make her sicker.

> I: And any other reason [besides having had an accident on the street] why it made you worried when you first had the diarrhea in February?
>
> R: No, because then I knew I'm going to start losing weight.
>
> I: So how did that make you feel, worried?
>
> R: Depressed.
>
> I: Depressed?
>
> R: Worried.
>
> I: And what did you think? You thought OK, I'm going to start losing weight and then?
>
> R: I'm going to start getting sick. Because I figured the diarrhea, I'm going to get dehydrated. If I keep eating, whatever, it's just going to keep coming out, I'm going to start losing the weight and the diarrhea, I'm going to start getting sick.
>
> I: And you did mention that you felt depressed in addition to being worried.
>
> R: Depressed thinking I'm going to get sick now, with all this.

In addition to distress over incontinence, a 51-year-old Black female who had diarrhea off and on for over three years following the initiation of medications for HIV and diabetes, was also worried about how it made her feel weak and tired.

> I: When you first started really experiencing the diarrhea were you worried or anxious about it?
>
> R: Of course. Yes. Because it made me, it drained me. I felt very drained and tired and weak.
>
> I: Yeah.
>
> R: And I had to drink a lot of water so that kept me running to the bathroom. So it's like when I go, a lot of times I end up trying to make it to the bathroom and getting it on myself and stuff like that. I thought oh, man, I can't live like this, you know? So I had to adjust.

A 55-year-old Hispanic female reported that when her diarrhea began six months earlier, she was initially not worried about it because she thought it was due to HIV medications. However, she also considered that her diarrhea might be due to HIV, especially in the context of also having "sweats," another symptom she related to HIV. She discussed why if HIV was the cause she would be worried while if her medication was the cause, she would not. She indicated that if the diarrhea was HIV-related, testing would need to be done to determine the specific cause of the diarrhea.

> I: Um, so, if it's due to medication, you're saying, it's not that concerning?
>
> R: No, because all I do is stop taking the medication, and then go to the next cocktail or that --
>
> I: OK
>
> R: Right.

> I: You also had mentioned, um, that you thought it might be the HIV that was causing your diarrhea.
>
> R: Mmm, yeah.
>
> I: Did that worry you, or?
>
> R: That worried me, because then I think, if I can't control the diarrhea, I'm going to have to be hospitalized for them to find out what's wrong with me.
>
> I: Mmm.
>
> R: What is causing the diarrhea.

Despite his confusion as to the specific cause of his diarrhea, a 59-year-old Hispanic male related his concerns about having diarrhea while being HIV+. He believed that with a compromised immune system, the diarrhea could be due to many things. He related his belief that for someone with HIV, diarrhea has an unknown trajectory, including the potential for rapid weight loss, decreased energy and stamina and possibly death.

> I: Before you realized where it came from what were you thinking was happening?
>
> R: Well, that's the whole thing. One never knows what's happening or what's causing the symptoms. So you're dealing with blanks. Blank spaces again.
>
> I: Where do you fill in when you have a blank?
>
> R: You [terrorize]. You [terrorize] because you don't know what's going on. You've lost control entirely of the situation. And uh, everything is a blank. There's nowhere to turn. Until it either gets worse or you die or whatever. But you have no way of projecting what's wrong. In something like when you start, when you get the symptoms, because it could be a host of, a multitude of things going on.
>
> I: What kind of things were you worried about happening when you first started getting sick?
>
> R: With GI things the first thing that, you know, at least in my case at the time, it wasn't the worst thing but weight loss. Additional weight loss. Rapid weight loss. Then everything else follows. The loss of energy. Your stamina, this, that, everything becomes like a domino effect. And who knows? You know, you wonder well, is this the end of the line?
>
> I: End of the line meaning?
>
> R: Meaning, you know, is my life over on this natural earth as we know it?
>
> I: Right. Is that what you mean when you talk about feeling that hysteria?
>
> R: Yeah. Although, I mean I call it hysteria but, it is hysteria. It seizes your entire attention, turns you right around. If you've been there before and I've been there a number of times. With the KS [Kaposi's sarcoma] I was there, with the two heart operations I was there. So you know, you wonder, you know, again, you have to, you get into death mode.

Later in the interview, he commented again on the death anxiety his diarrhea had evoked:

> I: What kind of things were you worried about happening when you first started getting sick?
>
> R: With GI things the first thing that, you know, at least in my case at the time, it wasn't the worst thing but weight loss. Additional weight loss. Rapid weight loss. Then everything else follows. The loss of energy. Your stamina, this, that, everything

> becomes like a domino effect. And who knows? You know, you wonder well, is this the end of the line?
>
> I: End of the line meaning?
>
> R: Meaning, you know, is my life over on this natural earth as we know it?

Discussion

That physical symptoms are a critical determinant of the psychological well-being of individuals with HIV/AIDS has been well documented as shown above. The data revealed that diarrhea is an extremely distressing symptom for participants who experienced it. This seems to result from the fact that it not only often imposed significant limitations of patients movements and ability to participate in valued social activities outside their home, but it also was laden with social stigma and strong cultural association of feces with dirtiness, pollution and being tainted. Most participants felt they had little control over it and when and where it would occur. This raised the constant fear of being humiliated in public if they experienced fecal incontinence while they were out and unable to get to a bathroom quickly enough to prevent soiling themselves. As the study was conducted in New York City, most travel around by subway and the prospect of being trapped on the train underground, between stops or in stations where there was no public bathroom was an especially daunting prospect.

In Goffman's [36] terms, these individuals were discreditable. They had a stigmatizing condition that they sought to conceal, but recognized that this was not always in their power to do. The shame and stigma of having diarrhea was strongly linked to its cultural and symbolic associations with dirtiness, pollution, waste and its foul repugnant odor. Thus, they lived with the constant specter of their condition being discovered by others who they assumed would then devalue or shun them once they knew their secret. They were also discreditable because having control of one's body is something society expects if someone is to be judged a competent adult. While infants are permitted to not have such control adults are expected to. Many spoke of the embarrassment and feelings of being "dirty" they experienced due to their condition and the personal shame associated with having to wear diapers life an infant.

The recognition that they were "discreditable"[36] if their inability to control their diarrhea became public knowledge led many to lead a very constricted life that limited their time in public. They spoke of missing support groups, doctor's appointments, work, church, and funerals rather than risk going out and having an "accident." Others lived a "what if" existence. That is, when out in public or anticipating going out, they had to constantly be thinking *what if* they felt a bout of diarrhea coming on, or *what if* they became incontinent and soiled themselves; what they would plan to do. Those who ventured out more used strategies like carrying around clean underwear and clothes when they left in case they did have an accident and had to change while out. Some wore clothing that would make it easier to conceal that they had soiled themselves if an accident did occur. Others wore a diaper or put a cloth or a towel in their underwear to prevent their diarrhea from leaking through and becoming evident on their clothing if they did not have time to get to a bathroom. Some chose to only travel short distances from home or to places where they felt confident a bathroom was readily accessible. Some felt that the diarrhea controlled their lives. Their failed efforts to gain control over it led to feelings of frustration and powerlessness.

As discussed in the literature review, when there is ambiguity about the cause of a symptom, individuals tend to experience more distress because it is hard to evaluate the symptom's significance or take appropriate remedial action. For many, the cause of their diarrhea was unknown and therefore it was unclear what to try to do to control it. Some thought it was related to their antiretroviral medications and with their doctor tried to come up with an alternative regimen. When this did not solve the problem, many were very disappointed and started to despair that they would never get control of the situation. Others tried changes in their diet with very limited success. Those who believed it was associated with their HIV infection or could not rule this possibility out experienced more worry because they believed that it could signal disease progression or even entry into the late stages of the disease. This was especially true when they found themselves losing weight which some felt might be wasting or cachexia, an involuntary loss of body weight and lean mass, a syndrome most associated with dying patients. Many had seen others die of AIDS and wasting and the loss of control over their bowels was what they had in some cases witnessed. Obviously this raised the specter of impending deterioration and possibly death which greatly heightened participants' anxiety.

Even those who did not express that they feared wasting or progression into late stage or advanced disease, many worried about the impact their chronic diarrhea was having on their health. A few complained of pain in the area of their anus. Others felt the loss of weight and body mass would eventually deplete their energy and cause debilitating fatigue, while others feared dehydration. In all cases, worries about the consequences of their protracted diarrhea were prominent and distressing.

The data reveal the significant emotional distress diarrhea can cause for older HIV infected patients. Not only does it make them fearful of public humiliation if they experience fecal incontinence, but in many cases it leads to their feeling they must live a more constricted life to avoid this possibility. This can have secondary consequences such as heightened feeling of loneliness, social isolation and a diminished quality of life and depression. Given that HIV-infected older adults already perceive themselves as lacking sufficient social support, [37–39] symptoms that potential exacerbate this social isolation are of particular concern. Clearly, in choosing a treatment regimen for HIV-positive patients' physicians should consider the potential impact of side effects, especially of diarrhea, on the patients' social and physical well-being. In addition, physicians must work with patients to aggressively try to manage their diarrhea. Patients should be made aware of not just mainstream possible remedies but also directed to sources that might inform them about dietary, complementary, and alternative medicine options for alleviating the symptom. Physicians may also want to find ways for patients suffering with diarrhea to share information on self-management strategies they have found to have some effectiveness in controlling their symptoms.

Diarrhea appears to have a very distressing impact because of the stigmata that are associated with feces and the cultural symbols associated with it, such as dirtiness, pollution and loss of control over one's body. Therefore, any skills patients with this symptom can be taught to manage it more effectively could yield important emotional gains. When more effective management isn't possible physicians and social service agencies should address the social isolation that often comes along with diarrhea among HIV-positive persons and provide additional home-based opportunities for social support. These might include home access to computers for social networking with other patients and "online support groups" for those who fear traveling due to potential incontinence. Physicians should also recognize that diarrhea might be an embarrassing problem for some patients to discuss and may have to inquire about it directly. Patients who may already feel devalued because of the older age (especially when they sense ageism) or because they have a stigmatizing disease may be even more reluctant to bring up this symptom.

While the study from which the data reported on here were drawn did not include younger adults and so no direct comparisons can be made, the extant literature suggests there may be some important differences between younger and older patients in general. First because of the many changes associated with normal aging, e.g., diminished energy, greater problems with concentration, functional limitations, older adults may experience greater uncertainty in assigning a casual attribution and, therefore, significance to some common symptoms.[40] This may in many instances account for delay in seeking professional care. Related, to this, it is well documented[41,42] that older adults have a tendency to make normalizing attributions for many symptoms, especially ones that have a slow onset and ones that are not severe. That is, they will generally, at least initially attribute these types of symptoms to normal aging or transient conditions (e.g., recent stress), and often only when they persist and become more severe will they consider an organic explanation. On the other hand, Leventhal and colleagues[43] have contended that older adults are motivated to preserve what they perceive as their reduced psychic and physical resources. Consequently, they adopt a general strategy that includes greater risk aversion and a stronger need to resolve uncertainty in order to reduce anxiety and distress, for example, by reporting symptoms to a physician sooner than younger adults would. Further, in a study of beliefs about aging and illness among a convenience sample of community residents,[44] investigators found that across all age groups surveyed (i.e., 20–34, 35–59, 60+) two beliefs about aging and illnesses were common: (1) aging is the cause of a set of serious illnesses; and (2) any illness is more threatening (i.e., more serious, less treatable) when it occurs in later life rather than middle age. Such beliefs might also foster a greater readiness among older adults to take action in response to symptoms they regard as possibly indicative of incipient or underlying disease. However, alternatively it might be argued that the greater threat symptoms might arouse in older adults might contribute to delay or denial. Further, some have contended that because the elderly face fewer high demand situations (e.g., work, parenting), they can often contain and tolerate a higher level of symptoms longer without social pressure to seek professional care and can adopt the sick role, perhaps providing them with greater latitude to practice self-care.[45,46] That older adults do treat many of the symptoms they experience through some form of self-care without consulting with a physician or other health care professional is well documented.[47–49]

Finally, several limitations of this study must be acknowledged. First, the study utilized a convenience sample of participants who were willing to disclose their HIV-positive status and who were physically able to complete the interview. Although we sought to accommodate more infirm individuals by conducting interviews in homes or health care facilities, as needed, it is possible that those who were quite ill felt unable to participate. Or those who experienced the most uncontrollable diarrhea, or just the most anxiety about soiling themselves, may have chosen not to participate because they were unwilling to risk traveling more than a short distance from their home and were comfortable have the interviewer come to their home. Nevertheless, despite the potential for some self-selection bias, the current study does provide important data on the significant emotional distress that diarrhea causes these participants and the help they needed to address both the practical and emotional repercussions of diarrhea.

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