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Strategies Adopted by Late Middle-Age and Older Adults with HIV/AIDS to Explain their Physical Symptoms

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Abstract

Although the attributions individuals make about what causes their physical symptoms are known to influence their care seeking and self-care behaviors, much less is known about the strategies they use to arrive at these attributions. The strategies employed to understand the causes of their symptoms were investigated using in-depth interviews with 100 late-middle-age and older adults with HIV/AIDS in New York City. The data revealed that most actively sought to explain their symptoms. The explanatory strategies identified included: relying upon illness or medication representations, lay beliefs about the body and aging, invoking pre-existing vulnerabilities, engaging in lay experimentation, social comparison processes, considering temporal ordering, and consulting authoritative sources. While most offered a single cause for their symptoms, some offered more complex multi-causal explanations. These findings provide understanding into the reasons why some older adults with HIV/AIDS misattribute symptoms resulting in delay in care or care over-utilization, suggesting the need for patient education.

Keywords

HIV/AIDS; Older people; Causal attribution; Symptom management; Illness representations

Introduction

For individuals living with HIV-disease, understanding the cause of their symptoms and evaluating their personal significance is often a puzzling and distressing activity as a variety of plausible alternative explanations may exist for many common illness-related symptoms (e.g., fatigue, pain, fever, memory problems). These include the disease itself, environmental or situational stressors, psychological states (e.g., depression, anxiety), and for those on antiretroviral regimens, medication side-effects. Further, those with a history of drug or alcohol abuse may also question whether their symptoms are related to physical problems associated with these earlier behaviors. The task of interpreting symptoms, however, may be especially difficult for older infected adults (i.e., 50+) who are more likely than younger individuals to have co-morbid conditions (Shah, McGowan, Smith, Blum, & Klein, 2002; Ship, Wolff, & Selik, 1991) that along with the diverse physical and cognitive changes associated with normal aging represent additional viable explanations for a variety of symptoms (Siegel, Dean, & Schrimshaw, 1999).

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Nevertheless, it is important to understand how HIV-infected individuals assign causes to symptoms and evaluate their significance because these appraisals will guide their coping responses, including choosing whether to seek formal medical care, attempt self care (including self-medication), consult an alternative health practitioner, or initially do nothing and see if over time the symptom abates (Cameron, Leventhal, & Leventhal, 1993; French, Copper, & Weinman, 2006; Frosthalm et al., 2005; Kremer et al., 2009; Perry, Petrie, Ellis, Horne, & Moss-Morris, 2001; Siegel, Schrimshaw, & Dean, 1999a). Symptom interpretation can also influence adherence to treatment regimens when, for example, symptoms are assumed to be medication side-effects or when their alleviation, persistence or worsening after treatment initiation is used to assess therapeutic efficacy (Bell, 2009; Horne, 2003; Horne & Weinman, 2002; Johnson et al., 2005; Kremer et al., 2009; Siegel, Schrimshaw, & Dean, 1999b).

Symptom Appraisal

Research suggests that somatic changes are typically evaluated according to well-structured pre-existing illness prototypes, representations, or schemata (Cacioppo, Andersen, Turnquist, & Tassinary, 1989; Cioffi, 1991; Croyle, 1992; Leventhal, Leventhal, & Schaefer, 1992; Meyer, Leventhal, & Gutmann, 1985). These prototypes guide the retrieval of stored information and simplify the processing of new symptom information by serving as models or templates against which to match that information. Illness representations are built from a variety of sources including previous illness experiences, cultural myths or stereotypes about an illness, lay understanding of health information provided by the media, and communications with health care professionals. They typically have five basic components: (1) an identity (i.e., an illness or disease label and its associated symptoms); (2) a time line (for the illness' development, duration or cure); (3) a perceived cause; (4) perceived consequences (death, impairment, disfigurement, sexual dysfunction); and (5) controllability (i.e., the extent to which the illness can be prevented, cured, controlled) (Lau, Bernard, & Hartman, 1989; Leventhal, Brissette, & Leventhal, 2003). Generally, symptoms are construed as indicative of the disease for which the prototype provides the best fit (Bishop, 1991; Cacioppo et al., 1989; Cioffi, 1991; Lau et al., 1989).

Causal attributions for symptoms have generally been classified along three dimensions: psychological, physical/somatic, or environmental/situational (i.e., normalizing attributions) (Robbins & Kirmayer, 1991; MacLeod, Haynes, & Sensky, 1998). However, research on racial and ethnic minorities suggests that additional categories -- such as natural vs. supernatural causes -- may be needed to understand the full range of symptom attributions (Landrine & Klonoff, 1994). Furthermore, some cultures also offer sociosomatic explanations for symptoms that link social condition and circumstances with physical distress (Kirmayer, Groleau, Looper, & Dao, 2004).

Factors that Can Influence the Symptom Appraisal Process

A variety of factors have been found to influence the symptom attribution process. Situational or contextual cues are often important (Angel & Thoits, 1987; Cioffi, 1991; Pennebaker, 1982). Easterling and Leventhal (1989), for example, found that the treatment-related side-effects of chemotherapy resulted in greater distress among women with metastatic breast cancer who viewed the disease as an active threat than among women receiving chemotherapy as adjuvant treatment to prevent recurrence who regarded themselves as currently "cured." Concurrent life stress may also influence symptom attributions. When symptoms are ambiguous -- as opposed to easily-recognized indicators of illness -- the presence of a concurrent stressor may enhance the likelihood the symptom will be attributed to stress rather than illness (Cameron, Leventhal, & Leventhal, 1993).

Leventhal, Leventhal, and Contrada (1998) have also noted that when self-attributes -- such as age and gender -- overlap with specific disease representations (e.g., older age is a risk factor for cancer), one's sense of perceived vulnerability to that disease may be heightened and influence symptom attributions. An individual's perception of his or her general health can also influence symptom appraisal. Those who judge themselves to be in good health are less likely to initially interpret a symptom as illness- or disease-related, while those who believe they are in poor health and feel more vulnerable are more likely to immediately consider such attributions (Stoller, 1993).

Studies suggest that judgments about the significance of symptoms, at least severe or highly threatening ones, are rarely arrived at without lay consultation (Edwardson, Dean & Bauer, 1995; Stoller & Kart, 1995; Stoller, Pollow, & Forster, 1994). Household family members are typically the first ones consulted (Glasser, Prohaska, & Roska, 1992). When symptoms are ambiguous, consulting family and friends may be necessary in order to legitimize adoption of the sick role (UCSF School of Nursing, 1994).

Given Festinger's (1954) observation that social comparison processes are commonly turned to in ambiguous situations, they may also be employed by patients try to clarify the cause or significance of puzzling symptoms (Croyle, 1992; Leventhal, Diefenbach, & Leventhal, 1992; Schachter & Singer, 1962). Personality or dispositional factors (Contrada & Coups, 2003; Rosenberg, Goedert, & Biggar, 1994), attributional styles (Robbins & Kirmayer, 1991; Lundh & Wangby, 2002), emotional states (Cameron, 2003; Cioffi, 1991; MacLeod, Haynes & Sensky., 1998) and prior symptom experience (Banks & Keller, 1971; Raveis, Siegel, & Gorey, 1998) can also influence symptom appraisals.

Aging and Symptom Attribution

Evidence suggests that age may also influence symptom appraisal and coping responses. For example, older adults have a tendency to attribute many symptoms, especially mild chronic ones, to the aging process. (Blaxter, 1983; Chewing & Sleath, 1996; Leventhal, Leventhal, Schaefer, & Easterling, 1993). Indeed, in a study of older adults, Stoller (1993) found they were strongly inclined to attribute many kinds of symptoms to normal age-related changes. Typically, only when these symptoms persisted or new ones appeared and they judged their health as poor, did they start to consider a medical or disease-related explanation. Levkoff et al. (1987) noted two circumstances that may complicate symptom interpretation among older adults. First, although there is a greater prevalence of chronic illness among the elderly, because the initial symptoms of such diseases tend to be vague, mild, of slow onset and relatively non-disabling, they can be more easily attributed to non-medical reasons such as normal aging or medication side-effects instead of an illness. Second, the atypical presentation of disease among the elderly -- resulting from the interaction of disease- and age-related changes -- may also contribute to their failure to recognize symptoms as indications of disease.

In the present paper, we examine the strategies that adults 50 and older living with HIV/AIDS employed to try to understand the cause of their symptoms. These data come from a larger study that examined how these adults tried to understand the cause and significance of the symptoms they experienced and the remedial actions they took to try to alleviate the symptoms and/or the accompanying emotional distress they experience.

Method

Study Sample

A sample of 100 late middle age and older adults living with HIV/AIDS in New York City were enrolled in the study To be eligible for participation in the study individuals had to: (1)

be HIV-infected; (2) be 50 -75 years of age; (3) have experienced three or more common illness-or treatment-related symptoms during the past 30 days (although they need not attribute these symptoms to the HIV-disease or related treatments); and (4) be cognitively competent to provide reliable and meaningful data. The characteristics of the study sample are presented in Table 1.

The race/ethnic distribution achieved for the study sample closely mirrored that for all cases of people 50 and older living with HIV/AIDS in NYC at the time of the study's data collection, except for a small under-representation in the sample of Hispanics. Those NYC figures were Blacks 45%, Hispanics 30%, Whites 23%, Other 2% (New York City Department of Health, 2001).

Recruitment

To ensure representation in the study sample of diverse elements of the older HIV-infected population in New York City, we employed a variety of recruitment tactics. Key medical and social service organizations that served HIV-positive adults, including some that specifically targeted older infected adults, were identified and contacted. To protect potential participants' confidentiality, referral sources were never asked to provide the names or personal contact information, but instead were requested to make the flyers available to potential participants who could then call the study telephone line. Flyers were available in both English and Spanish.. To remove financial barriers to participation, the flyer indicated that those taking part in the study would be reimbursed for all reasonable transportation costs associated with their participation. Further, to enable sicker individuals to participate who were unable to travel by public transportation to the research offices to be interviewed, car service was provided to transport them to and from the interview or, when necessary, the offer was made to conduct interviews in the participants' residence.

Interested individuals who called the study telephone line were screened for eligibility by a research team member, and if eligible, were scheduled for an interview. As part of the screening, potential participants' cognitive competence was assessed in a two-step procedure. First, in the list of symptoms individuals were asked to report, we included memory loss and feeling disoriented. Individuals endorsing these symptoms were further screened for cognitive impairment using the Orientation-Memory-Concentration Test (Katzman et al., 1983). A cut-off point of 20 (indicating severe impairment) was used.

Data Collection

The study protocol was approved by the Institutional Review Board (IRB) of the investigators' university and a federal Certificate of Confidentiality was also obtained to provide added protection of the participants' confidentiality. All data were collected between November 2000 and February 2002 in two sessions. A bilingual interviewer was available for participants who wished to complete the data collection in Spanish (n=7). For each interview session, participants were given a \$25 for their participation. All of the interviews were conducted at the investigators' research offices, except in the case of a few very ill individuals who were interviewed in their homes or in a nursing facility. In the first session, informed consent was obtained and the participant completed a small battery of standardized measures and a brief interviewer- administered questionnaire that elicited standard sociodemographic data. The remainder of the first session, about one hour, was used to begin the focused interview that continued and lasted throughout the entire second session. Some participants chose to complete all data collection on one day with a break for lunch in which case they received \$50 at the end.

Data on participants' symptom experiences were gathered using non-directive focused interviewing techniques and primarily unstructured questions (Merton, Fiske, & Kendall, 1990). In a non-directive interview approach, the course of the interview is largely determined by the participant. The interviewer aims to facilitate the discussion about the issues under investigation, primarily through neutral probes, unstructured questions, and by encouraging elaboration of comments. An unstructured question serves as a neutral stimulus that allows the participant to discuss issues most salient to him/her (e.g., "What can you tell me about that symptom?"), not those predetermined by the researcher to be most important. Since responses emerge spontaneously with minimum contamination from the interviewer, the flows of associations are in context, simplifying the analysis.

The interviews explored the participants' experiences with three symptoms they had had during the past 30 days, regardless of the time of the symptoms' onset. At the start of the focused interview, participants were asked to mention all the different symptoms they had experienced during the past 30 days, regardless of whether they attributed them to their HIV infection, its treatment or some other cause. Three of these symptoms became the focus of their interview. One of the symptoms discussed was the symptom that they indicated was 'the most difficult for them to live with,' day-to-day. The other two symptoms were chosen from among the remaining reported ones to ensure that among the three symptoms there was one of long-standing duration, one of recent onset, and when possible, one that was a prevalent symptom of HIV-infected adults (i.e., fatigue, sadness, numbness, nausea, diarrhea, night sweats). For each symptom, participants were asked to discuss their initial attribution, and when they indicated that over time it changed, they explained what contributed to this change in attribution.

Data Analysis

The focused interviews were audio-taped and transcribed for thematic content analysis. At the completion of the data collection, a coding scheme that reflected the key constructs in the study aims – e.g., the causal attributions for symptoms, contextual factors.—was developed based on a subsample of 20 cases. This provisional coding scheme was subsequently tested on 8 additional cases and small modifications were made to ensure that all the material relating to a particular construct was captured by a code (e.g., "causal attributions") or related subcodes (e.g., attributions to the disease, attributions to medications, attributions to age, attributions to other co-morbidities, etc.). Once the coding scheme was finalized, two coders read and coded all the transcripts. ATLAS.ti (version 4.2), a software program for qualitative analysis, was used to code and facilitate the analysis of the data. This allowed for the excerpting of all material assigned to the same code by different coders and across different interviews so that it could be reviewed to ensure reliability in the manner in which the codes were being applied. Inter-coder reliability achieved 90% agreement in the application of all codes. For the analysis presented here, all text coded "causal attribution," "sources of information in appraisal," "use of social comparison in appraisal," or "timeline" was excerpted using ATLAS.ti and its content was analyzed to identify the reasons participants offered for their symptoms and how those attributions may have changed over time.

Results

Participants adopted a variety of general explanatory strategies to arrive at causal attributions for their symptoms. While many offered a single direct cause for a symptom, some proposed multiple causes, sometimes using a different kind of logic to identify each cause. At times, participants' emotions appeared to influence their attempts to account for a symptom by steering them away from explanations likely to be threatening. Further, most

accessed information from a variety of sources both lay and professional to explain their symptoms. Below, we discuss the principal attributional strategies identified.

Use of Cognitive Schemata and Lay Beliefs

Relying upon Illness Representations—Many participants called upon existing illness representations or common sense models of illness they held for a particular disease or medical condition (e.g. HIV/AIDS, hepatitis C, or diabetes) to arrive at attributions for a new symptom. That is, when participants perceived their symptom as belonging to the set of symptoms they believed to be characteristic of a particular disease or condition, they tended to attribute it to that condition. Some participants who did not have a preexisting lay model of an illness constructed one that accounted for the symptom after its appearance based on discussions with others (e.g., medical professionals, other patients with HIV, or peers).

A 52-year-old Black man, for example, suggested that the pain in his hip was due to arthritis, because that was consistent with his preexisting illness schema of arthritis. He explained that his first thought about the cause of his pain was that it was related to a “bone problem.”

I: And, and how come arthritis came to mind?

P: Um, maybe 'cause I felt it was a bone problem, you know. And, and, you know, that was the most easiest thing to think about. Yeah, it, it wasn't necessarily anything that, ah, led me to that other than the fact that if it's a problem with your bones then it's usually arthritis. You know. [LAUGHTER] Some form of arthritis, yeah.

Most participants experiencing fatigue attributed it to the HIV disease as their illness representation of HIV and its associated immune suppression included fatigue as a primary symptom. Several described fatigue as “a symptom of the virus,” or said that “it comes with the virus,” or “this is the nature of the beast [AIDS].” Fatigue was also consistent with some participants' illness representation for hepatitis C and for anemia. When participants experienced a cluster of symptoms (e.g., diarrhea, fatigue, weight loss) all of which they associated with a particular disease or medical condition (e.g., hepatitis C, heart condition, a cold), they regarded the co-occurrence of the symptoms as additional evidence supporting their attributing the symptom to that disease.

The virus, usually together with antiretrovirals, was also a commonly offered explanation for diarrhea. Just over half of the participants with this symptom (51.7%) attributed it to this combination of causes. Some regarded diarrhea as a common symptom of HIV disease because they believed their compromised immune system caused by the virus left them more vulnerable to parasites or tainted food products (e.g. salmonella or food poisoning) which could cause diarrhea.

Viewing HIV as a Master Attribution—The common perception of HIV as a systemic disease that compromised the immune system and as a result can potentially affect every system in the body, contributed to the tendency of many participants to regard HIV as a plausible cause for almost any symptom. Thus, the virus or HIV disease was a kind of “master” attribution that was typically assumed to account for any symptom that did not have an obvious alternative explanation. Further, participants indicated that HIV was always in their consciousness as a possible cause when they noticed any bodily change, even when other attributional processes led them to believe that other causes were also involved. For instance, when a 53-year-old Black woman was asked if she ruled out HIV as a cause once she came to believe that her diarrhea was caused by bacteria she assumed she acquired in a steam room: “Yeah, but I never say, ‘This is not HIV.’...That is never cleared out completely.”

When faced with a new symptom, HIV was the default attribution for some participants until proven otherwise. For instance a 56-year-old White man stated that when he first experienced tiredness, he associated it to HIV because that was his assumed cause for any new symptom.

I: In '93, when you first started experiencing the tiredness what was your very first thought as to what was causing it?

P I thought that it was some complication of the HIV. But I didn't know what.

I: What made you think it was related to the HIV?

P: Because every time you experience anything new in your body you think it's because of the HIV.

The inclination to presume HIV was the underlying cause of all their symptoms was especially pronounced in the period following one's diagnosis with HIV, when one's serostatus is particularly salient. As a 68-year-old Black woman said in describing her attributional process, "Please, don't laugh. I blamed HIV [for the cramps in my legs] because then I was diagnosed with HIV. So anything is HIV."

Relying upon Lay Beliefs about How the Human Body Functions and Ages—

Participants often drew upon lay beliefs about how the body operates and the circumstances that may cause it to malfunction in interpreting their symptoms. For instance, using lay terms they explained how cigarette smoke damages one's lungs and causes shortness of breath, how fatigue can result from poor nutrition or drinking insufficient water, and how lack of exercise causes muscle spasms and pain. Many of the participants' lay beliefs about how the body functions included notions about the consequences of stress. Stress was seen as bringing about physiological changes, and thus causing all sorts of symptoms, especially fatigue and diarrhea. For example, a 50-year-old Hispanic woman believed that stress, in addition to diet, HIV medication, and a compromised immune system, caused her diarrhea by causing the production of acid in the stomach:

P: You know, because when you get stress it builds up acid, you know. And when you get, when you build acid up, you know, and then especially when your, well your physical health is compromised as mine is, you know. To have stress in my life and it builds up that acid, you know, nothing good can come of it. So, I mean, I'm, I'm quite a bit sure that it could be that.

Some participants accounted for their symptoms by referring to the physiological changes they associated with the process aging. According to these lay understandings, starting in middle age, the body begins to undergo a general physical deterioration that renders it more vulnerable to both external (e.g., environmental) and internal insults (e.g., the bones losing calcium) that could bring about all sorts of symptoms. "I thought it was old age. My body eventually breaking down -- old age," was how a 50-year-old Hispanic man accounted for his fatigue. Another 62 year-old Black female explained the pain in her knees in part by her age and menopause. She explained that as a result of growing older and going through menopause women experience a loss of calcium in the bones which she believed contributed to her knee pain.

Relying upon Medication Representations—Participants also drew on their lay beliefs about medications and on antiretroviral specific schemata to explain their symptoms. Using input from physicians, peers and their own experience with taking medications and using street drugs, they constructed models of the effects of drugs on the body. All medications were perceived as having side-effects, and HIV medications in particular were regarded as highly-potent substances that while beneficial in controlling the virus, were also

potentially destructive. “Poison,” “toxic,” “chemotherapy,” “harsh chemicals,” and “it wears and tears on your body” were among the expressions used to describe the nature of HIV medications and their consequences. A 50-year-old White man attributed his fatigue to the medication he was taking for hepatitis C coinfection. He explained:

P: Like this interferon chemo is eating my red blood cells away. That’s what’s causing the severe tiredness. Like I could go lay down right now. But that’s once the chemo starts and with the Procrit injection, that’s helping.

According to some participants’ lay beliefs about HIV antiviral medications, the body requires time to adapt to the agents. Thus symptoms experienced soon after beginning a new HIV regimen were attributed to the regimen and reflected the body’s attempt at this adjustment process. Another belief relied on when interpreting their symptoms was that extended use of any prescribed medication produced an accumulation of toxins in the body that manifested in a variety of symptoms. For instance, a 65-year-old White man believed that the neuropathy in his fingers and toes was due to his HIV medications in addition to the virus. He explained:

P: if I have taken something [some medication] for 16 years I think I should experience side effects from medication. I have become more convinced, the longer I live that it is the combination of medication and the virus. Because all medications, as you know, they’re very tox-, toxic. And in order to suppress something sick it might suppress something healthy too. So that’s my layman thinking sort of thing.

Another 64-year-old White male who started experiencing a lack of energy around the time of his diagnosis initially believed and continued to do so five years later that the virus was part of the cause, as was his age. However, he also felt his antiviral medications were contributing to his fatigue. He explained, “.... They’re harsh chemicals and they, they extract a lot out of my body. At the same time it’s controlling the virus, it is also doing damage to our bodies, uh, and that’s a cause of it as well.”

Pre-Existing Vulnerabilities

Some participants reviewed their personal and their family’s medical history and their past lifestyle to account for their symptoms. Identifying a relative who had a disease or medical condition (e.g., arthritis) commonly associated with the symptom the participant was experiencing (e.g., pain in the joints) often led to the conclusion that the symptom was caused by this same condition, and moreover that there was a familial or genetic susceptibility to developing this condition. “It [arthritis] runs in the family,” was how a 50-year-old Black woman bolstered her claim that arthritis was the likely cause of the pain in her hands and knees. The terms “genes” and “genetics” were also used to refer to a familial predisposition to certain diseases and conditions. Similarly, a 50-year-old Hispanic woman attributed her neuropathy to a nervous system compromised by a strong family history of alcoholism, drinking a lot of caffeine and living and working in very fast-paced New York City. The fact that she also had had Bell’s palsy and shingles in the past, two conditions she said “had to do with the nervous system,” convinced her of her vulnerability to neuropathy.

In addition, those with chronic conditions often perceived themselves as being continually susceptible to experiencing the symptoms associated with the condition. “I probably have what’s called irritable bowel syndrome. I have had problems [with diarrhea] for years. Well, it’s my constitution,” was how a 57-year-old White man drew the conclusion that his recent episodes of diarrhea were caused by his irritable bowel syndrome.

Finally, some participants believed that their past lifestyle or life circumstances (e.g., long-term injecting drug use, homelessness) or prior events (e.g., old injuries) had rendered them vulnerable to different afflictions that caused their current symptoms. For instance, long-

term injecting drug use was linked to poor blood circulation, which provided an explanation for leg pain, while the hardships associated with living on the streets (e.g. exposure to extreme temperatures, chronic physical exhaustion) were viewed by some as causes of various aches and pains.

Time-Related Attributional Processes

Temporal Contiguity—In some cases, participants assigned a cause to their symptom based on the timing of its appearance in relation to another event. If it first appeared at the same time or very soon after an event, they perceived this event as the likely cause or at least a contributing cause of the symptom. For example, if the first onset of a symptom such as neuropathy followed the initiation of antiretrovirals or soon after a change in one's medication regimen, the medications were typically blamed for the symptom. Using a similar logic, if the symptom (e.g. diarrhea) disappeared following the cessation of a medication, again it was assumed to have been caused by the medication. Participants described this co-occurrence of event and symptom or the close appearance of a symptom soon after some event with terms like "precipitate," "all of a sudden," "not until," "shortly after that," "as soon as," "the next week," or "the next day."

A 57-year-old White man concluded that his neuropathy was caused primarily by his medications and less so by HIV. He noted that his neuropathy started soon after he began using AZT in 1990 – "shortly after that [using antiretrovirals] I started, you know, having neuropathy." At the time of interview, 10 years later, he reported that his neuropathy had worsened again following the initiation of yet another drug regimen. He described his rationale for determining the cause of his neuropathy:

I: OK. And right now what do you think is causing the numbness? It's ten years later.

P: I would say it's probably a combination of the medication and the disease. Probably more so it's the medication because on the other medication I didn't have it noticeably.

Although my T cells, you know, weren't responding to that med. So.

I: And what caused you to change your mind? What caused you to decide that it's a combination of the medication and the illness? You mentioned --

P: Because on the previous regimen I wasn't experiencing it anywhere nearly, uh, intensely as I was now. It just seems to be coinciding with this new, you know, with this most recent regimen. So that's what causes me to suspect that somehow that's the worst culprit here.

Observing Covariation—When a change in some aspect of a symptom (e.g. its severity, frequency, pattern of appearing and disappearing) coincided in time with a change in some other specific factor or circumstance, it was often interpreted as an indication of a causal relationship. For instance, when a participant noticed that his/her symptom became more intense under a particular circumstance (e.g. when they weighed more, were more active, or the weather was colder) and disappeared or decreased in intensity under the opposite circumstance (e.g. when they weighed less, were less active, or the weather was warmer), they used this "covariation" as a basis for establishing a causal link. A 56-year-old White man reported that he believed spending too much time on his feet was a cause of his knee pain, "because the longer I would have to be on my feet the more that they [his knees] would hurt."

Another participant, a 52-year-old Black woman, reported that the numbness in her toes changed with the weather. Believing that this symptom became worse during the cold season also reinforced her notion that the numbness stemmed from arthritis, a condition

whose symptoms, according to her, were exacerbated by colder weather: P: Mainly I noticed when the weather started getting bad, and I had all this pain in the winter months. I don't feel pain like this in the summer months. In summer time I don't get pains like this. Not at all. It's the winter. It's the cold weather. ...It's the cold weather. That's what it is. I don't experience all this in the summer time. Not. That's how I know it has to do with the weather too. It's arthritis.

Considering Symptom Duration—The duration of a symptom -- that is, its acute or chronic nature -- was also sometimes relied upon for discovering or ruling out an attribution. Many participants initially attributed symptoms to transient events or circumstances. However, when the symptom persisted, they recognized that their original explanation was no plausible, and typically concluded that something of a more chronic nature must be responsible. When her fatigue began, six years prior to her HIV diagnosis, a 54-year-old Black woman initially attributed it to a variety of factors including sleep deprivation, lack of vitamins, withdrawal from street drugs, and anemia. However, by the time of her interview, the persistent nature of the symptom had led her to the conclusion that her fatigue was the outcome of her HIV infection which she presumed must have preceded her diagnosis by a few years since her fatigue had begun before she learned her serostatus.

I: How about now? What do you think is causing the fatigue now?

P: The virus.

I: What caused you to change your mind about what was causing the fatigue?

P: I don't know. I guess because I feel like it stayed with me so long. Staying with me so long I said it got to be from the virus.

Lay Experimentation

Some participants attempted to confirm their hypotheses about the causes of their symptoms by doing "experiments" to test them. For example, they altered some aspect of their behavior or lifestyle that they believed brought on a symptom to see if the symptom would resolve, or improve with the instituted change. Or, they adopted a remedy for the suspected cause of the symptom and assessed its effectiveness. For example, if they thought their fatigue was related to poor nutrition they altered their diet or took vitamins, and then observed whether these actions alleviated or eliminated their fatigue. Similarly, if they thought it was due to over-exertion, they reduced their activity level or rested more to see if this ameliorated the symptom.

A 59-year-old Black woman described "experimenting with her own body" as she took herself off her HIV medications to test if that would eliminate the tingling and pain in her feet. Although she expected discontinuation of her regimen to eliminate her symptom, she continued to experience the tingling. Nevertheless, she persisted in her belief that her medication was the cause of her symptom. She was able to explain why the experiment had not produced the expected results by resorting to lay beliefs about antiviral medications which included the notion that "once it's [the medication] in there, your immune system is not strong enough to make it just go away, disappear. And it stays with you."

Similarly, a 70-year-old Black man thought his shortness of breath was due to smoking cigarettes. Although he also raised other possible explanations, he felt confident the cause was his cigarette use because as he said, "I felt much better once I stopped and I'm breathing better." A "failed" experiment assisted a 52-year-old Black woman to rule out excessive eating as the cause of her shortness of breath. She report, "So I limited it [food intake], but that didn't help." This caused her to continue her search for another cause.

Comparison Processes

Comparing Present and Past Experiences with the Same Symptom—Some participants tried to discover the cause of their symptom by comparing their present symptom experience with an earlier experience of the same symptom. They relied upon their memories of a prior experience with the symptom and sought to identify differences or similarities in the intensity, duration, or speed of onset on the two occasions. When this comparison revealed significant differences, they typically rejected the idea that the same cause was operating at both points in time. For instance, a 55-year-old Black man compared his past experience of fatigue when going through drug withdrawal to his current fatigue and concluded that the latter was a qualitatively “different type” of fatigue. Although again he had recently stopped using drugs, the intractable nature of his current fatigue persuaded him to discount drug withdrawal as a possible cause:

P: Well, at that time I was freshly withdrawing from heroin, and I try, I first attributed it to that. But after I had withdrew enough times to know that, when I reach a point or when I adequately withdraw, I would start to feel different. But that point had passed and -I was still feeling the same way. And I couldn't explain it. And nothing I do would seem to make a difference.

On the other hand, when the comparison between past and present symptom experiences revealed similarities, participants assumed the same cause was at work. For example, a 60-year-old Black man who was using street drugs indicated that because of his prior experience with drug withdrawal he initially attributed the numbness and pain in his leg to “withdrawal from drugs or something, you know, going out of your system.”

I: What made you associate it with withdrawal from drugs?

P: Because I had went through withdrawal before and I went through some very painful withdrawals. I remember one time I was locked up in prison and I was withdrawing. I was coming off of methadone, and that was a horrible experience. And I was hurting for about a month. I had to take these hot showers and stuff. And my bones was all aching and everything, you know, so I just kind of related it to that type of feeling.

Comparing Oneself to Similar Others—Making social comparisons was another strategy participants employed to find a plausible cause for their symptoms. They compared themselves to others who also had the symptom and searched for some shared salient characteristic, such as their HIV-positive status, use of a particular antiviral medication, or history of drug use to interpret their symptom. When a characteristic was shared by multiple people with the same symptom, it was often identified as a plausible cause of the symptom. For example, a 56-year-old White woman attributed her diarrhea solely to HIV and said she was “100% sure” she was correct “because everybody [with HIV] I know had that same problem.” Conversely, when participants recognized through these comparisons that others did not experience the same symptom despite some important shared characteristic, they generally rejected the characteristic as a possible explanation. Usually others with HIV/AIDS or others on a similar treatment regimen were looked to first as a comparison group. If they had the same symptom -- such as fatigue, diarrhea, tingling and pain in hands or feet -- as the participant, it was usually assumed to be caused by the medications, or possibly the virus. For instance, a 62-year old Hispanic man attributed his diarrhea to using antiretroviral medication and to his compromised immune system after he recognized that other individuals with the virus who were also taking antiretroviral medications experienced the same symptom. He explained:

P: And since I see that those people [those HIV+ and on antivirals], not only me, always have problems, they have, they get that diarrhea thing and so for me, I think, I think of it

as if, it's the cause, the medicine, the immune system is weak and that's what causes the diarrhea. . . . I've always thought that it's the medicine.

I: But you also thought it could be... the diet, but now...

P: Yes, the diet, but since I see people that they eat as well and [still get diarrhea], and, and it's the medicine, because when they change the medicine it produces diarrhea. And so now I notice also that it is the medicines that are causing that.

Lay Consultation

As they attempted to understand what was causing their symptoms, many participants consulted their family, friends and others with HIV/AIDS, including support group members who offered them their opinions about the causes of symptoms. Support groups often served as forums in which symptoms were discussed and both lay and professional information about them was disseminated. A 50-year-old Hispanic woman explained, "Well, usually somebody [in the support group] has it [the symptom]. I'll say, yeah, I got it too. And, uh, we compare notes." The opinions of lay others, especially those with HIV disease, were usually taken seriously and often played a central role in shaping participants' attributions.

A few participants even suggested that they placed more weight on lay consultations than professional ones. One example of favoring HIV-infected peers' causal attributions over their physicians' was provided by a 56-year-old White woman searching for the causes of her diarrhea. She commented, "They [doctors] don't even know. But other people that are sick, they know." Similarly, a 66-year-old Hispanic man indicated that discussing with other HIV+ persons the numbness in his legs led him to attribute this symptom to the virus and the antiviral medications, rather than to his age as he originally suspected:

P: Sure, I thought it could be the illness or the medicine. And, then I would comment to friends and they would, would, and they would tell me, "I'm also like that. And it is what the doctor tells me, that it is, that it is the medicine." ...

I: So, you have changed your mind? That it is not the age?

P: Yes.

I: And what was it that caused you to change your, your mind?

P: The friendship, my friends advise me and, and that helps me a lot, an advice helps one a lot."

Reliance on authoritative sources

Many participants did accept the opinion of medical providers about the causes of their symptoms without appearing to explore other possible explanations. While some sought the input of a provider after unsuccessful attempts to find the causes for their symptoms through some of the other processes described above, others consulted them immediately. Few of the participants appeared to openly challenge their physicians' explanations for their symptoms, although many tended to add one or more of their own attributions to the attribution(s) offered by their doctors. An indicator of how some participants viewed their physicians as partners in reaching an attribution is suggested by their use of the word "we" when referring to the process of seeking to explain their symptoms. For instance, when asked whether he continued to believe, as he had when his diarrhea first appeared, that his HIV regimen was causing it, a 60-year-old Black man, replied: "No, I, we [me and my physician] don't think so. Actually, we are quite sure it's not the medicine."

Some participants also discussed the importance of the findings of medical tests (e.g., blood test, x-rays, MRI) their doctors had ordered in deciding on an attribution for their symptoms.

Another 59-year-old Black man described why he sought his physician's input about the pain in his legs by saying: "They [his doctors] told me I got neuropathy in my hands. Last week they took a test and they put some clamps on my hand and they gave me like electrical shock. And the doctor said my nerves are damaged from neuropathy. So I got neuropathy in my hands. It's a bad feeling, you know."

Discussion

Given that the sample was a group with a serious disease, it is not surprising the data revealed that most actively searched for an explanation for their symptoms. Unless the symptom resolved in a short period of time or a definitive cause was identified, finding an explanation for one's symptom tended to be an evolving process in which participants used a variety of attributional strategies, and incorporated new and emerging information that seemed relevant to understanding the cause. This often led to the identification of more than one cause for their symptom. When a symptom initially appeared, especially when it was not intense or disruptive, some participants tended to look for a natural or normal cause (e.g., less energy as a natural consequence of getting older) or a benign one (e.g., sleeping on hand or in an uncomfortable position, the weather). As the literature suggests, often only when a symptom persisted or intensified, its disruptiveness increased or such non-threatening causal attributions were no longer sustainable in light of the available evidence, did they consider a possible organic cause or seek medical care. It also appeared that when some participants found a "sufficiently plausible" explanation for their symptom, they were content to accept it and did not actively try to generate alternative possible causes.

Participants employed a variety of strategies to interpret their symptoms. Many had an illness representation of HIV as a serious systemic disease that compromised one's immune system and thus rendered them vulnerable to a wide range of illnesses and conditions. Some of these participants always entertained their HIV disease first as a possible cause for their symptoms, making it a kind of "master attribution" that took precedence over other possible causes. Even those who relied on other strategies that led them to different possible causes of their symptoms, suggested that HIV was always considered at least as a possible contributing cause.

In addition to different illness models, some participants had also constructed and often employed medication schemata in their attempt to find the cause of their symptoms. A wide range of symptoms, including neuropathy, diarrhea and fatigue, were often perceived as side effects of their antiretroviral regimens. These medications were typically assumed to be highly toxic and potentially damaging to the body, especially when used for extended periods of time. Some participants who relied on medication schemata to explain their symptoms also engaged in lay experimentation. For example, if they believed a specific medication was responsible for their symptom, they might take less of that drug or discontinue its use completely to investigate whether the symptom was resolved or at least alleviated, thus testing their hypothesis. These experiments often required some degree of non-adherence for a period of time, yet were in some cases conducted without the knowledge of their health care providers. This finding has direct implications for interventions that seek to provide education and support to promote adherence for HIV-infected individuals. To improve their efficacy, these interventions must identify and consider patients' lay beliefs about antiretroviral medications, rectify erroneous beliefs, and educate patients about the risks of even short-term non-adherence and about the expectable side-effects of different medications.

The study finding suggests the important the importance to patients of having explanations for their symptoms and find uncertainty distressing. Indeed, Petrie & Weinman (2003) found

that more anxious patients were more likely to attribute their symptoms to a significant underlying medical problem than their less anxious peers. They noted that subsequent clinical examination even when it produces normal clinical findings that appear to rule out a serious condition is often not enough to reassure these patients; that is, they may also need to be offered a plausible alternative non-threatening explanation for the symptom. When left with uncertainty about the cause of their symptoms, patients are likely to continue to worry and search for a satisfying explanation. Moreover, Kirmayer et al. (2004) have observed that finding an explanation for symptoms that is mutually satisfying to doctors and patients typically involves a negotiation which requires a dialogue. In the current cost-containment environment which often dictates brief office visits, the opportunity for such dialogue may be limited.

Several participants also believed that they had a pre-existing vulnerability (e.g., related to genetics, prior injuries or conditions, lifestyle or physical constitution) that rendered them prone to certain kinds of physical symptoms or problems with specific parts of their body. Therefore, pre-existing vulnerabilities –e.g., a weak nervous system -- were not always conceptualized as direct causes per se, but as characteristics that rendered participants more susceptible to experiencing a particular symptom.

A number of the strategies employed to explain symptoms relied on time considerations. Participants had a common sense notion that a cause had to precede an effect, or at least occur simultaneously. They usually looked for causes that were in close temporal proximity to --typically no more than a few hours or days -- and before the onset of the symptom. Similarly, causal inferences were also made when participants noticed a covariation between the presumed cause and a dimension of the symptom (e.g., severity, persistence).

Aging was also identified by quite a few participants as a possible cause for at least one of their symptoms. This is not surprising given that the sample consisted entirely of late middle-age and older adults. Lay beliefs about the impact of aging on one's body that included the perception of greater vulnerability to a variety of chronic (e.g., arthritis) and expected changes like decreased energy or aching joints were drawn upon by the participants to explain their symptoms.

The data also highlighted the important role of lay consultation with others with the disease in a number of the attribution strategies employed. Comparing their symptoms to those of other HIV-infected persons and directly asking other peers to assist them in their interpretation of their symptoms were common processes for arriving at a symptom attribution. As found in other research (Siegel & Gorey, 1997; Siegel, Schrimshaw & Dean, 1999b), many participants gave greater weight to the opinions and experiential knowledge of HIV-infected people than to those of health care providers because the former had first-hand experience with the disease and the medication regimens. There are possible explanations for this. One is that many HIV+ individuals belong to marginalized or disadvantaged populations that may have a general distrust of institutions, such as medicine and science. Another possible explanation is that patients may feel that their physicians don't take adequate time interacting with them to make a well-informed judgment about the cause of their symptoms and instead resort to assigning a cause based on generalities rather than considering a patient's unique circumstances. Finally, because of the legacy of activism around the disease, patients may also contribute to patient's challenging medical authority

No differences were found in the symptom interpretation strategies associated with age or race/ethnicity. The homogeneity of the sample with regard to age may explain why age differences did not appear. All of the participants were between the ages of 50 and 71 and 74% were between 50 and 59. It is somewhat surprising, however, that no differences

associated with race/ethnicity were found given, as noted above, that some cultures have sociosomatic explanations that link social condition and circumstances with physical distress including symptoms (Kirmayer, Groleau, Looper, & Dao, 2004). Perhaps no differences emerged because within the subculture of the “HIV community” there is a widely shared illness representation of the disease as well as widely shared beliefs about the risks and side-effects of the antiretroviral medications used to treat the disease. These may be perpetuated through patients sharing information in support groups, at clinics and in disease-related workshops. Certainly we saw that relying on one’s illness representation of HIV and on lay consultations with other patients living the HIV/AIDS were common strategy used to try to understand the cause of one’s symptoms.

These findings yield new information on the wide variety of strategies older HIV-infected adults use in an effort to arrive at a cause for their symptoms. Describing these strategies can help us understand which ones are predicated on faulty logic or false beliefs and may lead to a erroneous inferences that either result in unnecessary use of medical services or worry, or alternatively to unfortunate delays in seeking and obtaining necessary care (e.g., Frosthalm et al., 2005; Perry, Petrie, Ellis, Horne & Moss-Morris, 2001). Indeed, there is some evidence that while older adults may be well informed, due to extensive public education, about potentially serious symptoms that might be associated with conditions such as a heart attack, stroke and glaucoma, they may under-estimate the potential medical significance of other symptoms (Stoller, Forster, Pollow & Tisdale, 1993). On the other hand, we found many patients in the study were well-informed about their illnesses possibly due to the widespread public education that has occurred around HIV/AIDS, as well as the advent of the Internet which offers easy access to medical information and websites where patients can share information with one another. Physicians should value the knowledge patients have acquired through personal research, exchanging information and experiences with other patients with the disease, and through enhanced self-awareness and knowledge of their bodies that patients with any disease often develop. Health care providers should also refrain from being dismissive of lay notions that often have validity although not based on scientific evidence. This is especially true when it is impossible to know the cause of a specific symptom. A more patient-centered approach to health care that treats patient more like partners on treatment decision-making appears to be a growing and important trend that can improve the doctor-patient relationship. Lack of recognition of the value lay understanding of symptoms and illnesses and of people’s own sensitivity to and awareness of their bodies may result in patients not seeking medical consultation. Patients may also be discouraged from seeking medical care when they feel providers are not sensitive to their social circumstances. This can be an especially salient problem with HIV/AIDS as the epidemic has disproportionately impacted vulnerable populations (e.g., socioeconomically disadvantaged minorities, injecting drug users).

While it is not always possible to assign a definitive cause to a symptom, HIV-infected individuals can be provided with certain kinds of information (e.g., likely drug-side effects) that may reduce the likelihood of misattributions. Symptoms frequently evoke great concern for HIV-infected patients because of the feelings of personal vulnerability that being immune compromised evokes. Interventions that address this anxiety and give patients clear guidelines on when to contact their physician about symptoms would likely enhance their sense of control and alleviate some unnecessary worry.

The field of research on symptom attribution would benefit from more theory driven investigations that can better illuminate the complex and often multiple strategies individuals use to make sense of their symptoms. It is clear from the results that illness representations are not by themselves sufficient to explain all the strategies that the patients used to make sense of their symptoms although they were implicated in several strategies.

Petrie and Weinman (2003) have also argued that there is a need for more laboratory-based research on symptom appraisal processes. Given that many factors can influence the symptom appraisal process, any research approach that would allow us to better isolate the relative importance of each would certainly advance our understanding of this process.

Several limitations of the study must be noted. First, given the absence of a comparison group of younger adults living with HIV it is impossible to know if these same strategies would have been identified in that population. Nevertheless, it seems reasonable to expect that most of the strategies identified, with the exception of those specifically related to aging, would be found in a younger sample; although, others not identified here might emerge too. Still, the findings can only reliably be generalized to late middle age and older adults living with HIV/AIDS. Another limitation of the study is it examined only one disease population. Thus we cannot know to what extent the same or different strategies would be identified in other patient populations. Again, however, it is already well established in the literature that patients often use illness representation to make sense of their symptoms and that they also consult informally with other patients with the same disease to share disease and treatment relation information. Thus, the findings reported here are likely to have relevance beyond the field of HIV/AIDS. Further, having identified a wide range of strategies employed by older adults with HIV/AIDS for arriving at causal attributions for symptoms, the findings from this study provide a good starting point for looking at patients with other illnesses to examine this issue. Finally, we must also recognize that the participants constitute a convenience sample and thus do not provide a good basis on which to draw any inferences about the true prevalence of any of the strategies identified, even in this patient population.

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Table 1

Study Sample Characteristics (n=100)

Variable	N	%	M	(SD)	Range
Age (in years)			56.3	(5.4)	50 - 71
50-59	74	74%			
60 +	26	26%			
Gender					
Men	63	63%			
Women	36	36%			
Transgender	1	1%			
Race/Ethnicity					
African American	46	46%			
Hispanic	21	21%			
White	26	26%			
Other	7	7%			
Marital Status					
Single	50	50%			
Divorce/Separate/Widow	46	46%			
Married/Commn Law	4	4%			
Household Income			Median = \$5,000-9,999		
< \$10,000	51	51%			
\$10,000-19,999	30	30%			
\$20,000 or more	19	19%			
Education					
Less than High School	26	26%			
High School Graduate	16	16%			
Post-secondary Education	29	29%			
College Graduate or more	29	29%			
Sexual Orientation (self-identified)					
Exclusively Heterosexual	42	42%			
Bisexual	27	27%			
Exclusively Homosexual/Gay	28	28%			

Variable	N	%	M	(SD)	Range
[Refused]	3	3%			
History of Injecting Drug Use					
Since 1977	40	40%			
In the past 6 months	4	4%			
HIV Disease Stage					
Asymptomatic	3	3%			
Symptomatic	20	20%			
AIDS	77	77%			
Currently on Antiviral Medication	79	79%			
Number of HIV-related Symptoms			13.2	(6.0)	1 - 27
Most Recent CD4 Cell Count			402	(240)	13 - 1300
Length of Time Since Testing HIV + (in years)			9.3	(3.6)	1.8 - 17 years