

## Managing Uncertainty About Illness: Health Care Providers as Credible Authorities

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### Abstract

*People living with chronic or acute illnesses often face uncertainty about their health and about their medical care. Health care providers can affect the uncertainty patients experienced by providing information about the causes, symptoms, and consequences of the illness, as well as descriptions of medical procedures and treatments that might be needed. This chapter explores the role of credible authority—the “degree of trust and confidence patients have in health care providers” (Mishel, 1988, p. 228)—as an influence on the uncertainty that patients experience. In overview, health care provider influence on uncertainty management was defined by HIV patients’ beliefs and attitudes about (a) the health care provider’s knowledge about HIV and treatments for the disease, (b) communication behaviors displayed by the health care provider (e.g., exhibiting comforting skills, signaling willingness to negotiate, or alternatively, engaging in stigmatizing behaviors), and (c) the state of knowledge and technology in the health care system. Participants also reported strategies for managing challenges associated with the credible authority role, including (a) using multiple sources of information, (b) taking an active, self-advocating role in health care interactions, (c) confronting negative or stigmatizing behavior, and (d) learning to live with chronic uncertainty. These findings have implications for the theory of communication and uncertainty management and for patient and health care provider training programs.*

People with chronic or acute illnesses often have medical, social, and personal sources of uncertainty (e.g., Babrow, Kasch, & Ford, 1998; Brashers et al., 2003; Mishel, 1988, 1990, 1997, 1999). This includes such things as how to interpret their symptoms, what treatments are available and whether they will be effective, how others might react to news of the illness, and what effect the illness might have on long-term career and family plans. To manage their uncertainty, patients rely on various individuals (e.g., health care providers, family members, and fellow patients), resources (e.g., clinical trials, library, and the Internet), and coping strategies (e.g., information seeking and avoiding, see Brashers, Goldsmith, & Hsieh, 2002).

Physicians, nurses, and other health care providers often are the trusted experts who help patients manage the illness experience (including uncertainty), especially through diagnosis and treatment decision-making. In uncertainty in illness theory, Mishel (1988) defined *credible authority* as the “degree of trust and confidence patients have in health care providers” (p. 228) and she proposed that it helps patients reduce their uncertainty through two pathways. First, health care providers can provide stability in the *stimuli frame*, which subsequently can reduce uncertainty. Providers do this by (a) explaining the causes and consequences of *symptom patterns*, (b) increasing *event familiarity* with information about the illness and about the health care system, and (c) promoting *event congruence* by helping patients interpret the meaning of illness experiences. Second, health care providers can reduce a patient’s uncertainty by taking charge of treatment decisions. When patients have trust and confidence in decisions that their health care provider makes, their uncertainty will be less.

Trust (i.e., credible authority) is a critical foundation of an effective provider-patient relationship; however, trust may be a function of external variables such as the general state of knowledge about an illness or the availability of effective treatments. Moreover, patient trust in health care can be influenced by specific communication strategies of providers (Ogden et al., 2002). Thom (2001) found that patient trust is strongly associated with provider behaviors that signal comforting and caring, demonstrate technical competency, encourage and answer questions, explain procedures, and refer to a specialist if needed. Finally, some researchers have suggested that patient trust is correlated with a match between the providers’ and the patients’ communicative beliefs. For example, in one study, individuals treated by patient-centered physicians (i.e., those with a preference for providing information and facilitating patient control) were not necessarily more trusting of their physicians or satisfied with their medical encounters; rather, the congruence between providers’ and patients’ beliefs about an appropriate communication style was a

stronger predictor of trust and satisfaction (Krupat, Bell, Kravitz, Thom, & Azari, 2001).

### **A Theory of Communication and Uncertainty Management**

This chapter extends the theory developed by Brashers and colleagues by more explicitly including credible authority as an important dimension of communication and uncertainty management (Brashers, 2001; Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000; Brashers, Neidig, & Goldsmith, 2004). Brashers (2001) noted that patients experience and appraise uncertainty about their illness, which leads to psychological and behavioral actions to manage the uncertainty. Appraisals are a form of evaluation response. As Mishel (1990) previously had argued, uncertainty can be appraised as a danger (i.e., not knowing can lead to harm), as an opportunity (i.e., not knowing can help a person maintain hope or optimism), or as a fact of life (i.e., life is uncertain in general). Responses can include such communication actions as seeking information to decrease uncertainty when it is appraised as danger, avoiding information to maintain uncertainty when it is appraised as an opportunity, or seeking social support to help manage emotional and informational needs when uncertainty is appraised as ongoing.

To address the impact of a person's social network on illness-related uncertainty, Brashers et al. (2004) studied the role of social support in uncertainty management. For example, Brashers, Goldsmith, et al. (2002) had noted that "information that facilitates coping with life stresses, including illness, is one form of social support that may be exchanged among members of a support network" (p. 260; also see Goldsmith, 2004). Consistent with Albrecht and Adelman (1987), Brashers et al. (2004) found that supportive others collaborated on uncertainty management with patients in a variety of ways, including (a) assisting with information seeking and avoiding, (b) being a consistent source of instrumental support, which provides a general sense of stability, (c) facilitating coping skill development by encouraging education and self-advocacy, (d) conveying acceptance or validation, which provides feelings of relational stability, and (e) encouraging perspective shifts or the reappraisal of uncertainty. They also noted several challenges associated with social support as uncertainty management, including diminished feelings of control associated with needing support, difficulty coordinating the multiple goals that might be present in a support situation, the possible addition of relational uncertainty to illness uncertainty, and the uncertainty that the support person often experiences, which may complicate the patient's experience of uncertainty. Participants in Brashers et al.'s (2004) study reported that they managed those challenges by developing a self-advocacy orientation, reframing support at-

tempts as helpful to support providers, accepting a lack of support, withdrawing from social situations, selectively allowing others to be support persons, and maintaining boundaries by selectively sharing information with others. These findings reveal that other individuals can be an important source of collaborative uncertainty management, but that the mechanisms by which that assistance occurs are complex and can be challenging to negotiate.

Compared with other variables in Mishel's model of uncertainty in illness, credible authority to date has received much less attention overall (Mishel, 1999; see Clayton, Mishel, & Belyea, 2006 and Wallace, 2005, for recent exceptions). Providers may create an illusion of medical certainty in an effort to retain patients' trust (Katz, 1984; Quill & Suchman, 1993); however, more needs to be known about the dynamics of these situations (e.g., whether the strategies for creating those illusions are successful). This chapter explores in more detail how the degree of trust and confidence patients have in health care providers influences the uncertainty management of patients. It is important to examine how providers gain the role of credible authority and provide assistance to patients who are managing uncertainty about an illness. Through the narratives of people living with HIV, we investigate the following research questions:

*RQ1:* What dimensions do patients use to evaluate health care providers as credible authorities?

*RQ2:* How do health care providers as credible authorities influence patients' uncertainty and uncertainty management?

### Method

This chapter is part of a larger study of communication and uncertainty management for people living with HIV or AIDS. Patients with HIV confront multiple sources of uncertainty (Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas, 1999; Brashers et al., 2003) and use various resources for managing that uncertainty (Brashers, 2001; Brashers et al., 2000), including social support (Brashers et al., 2004) and information seeking and avoiding (Brashers, Goldsmith, et al., 2002). This chapter examines another factor in the management of uncertainty—the credible authority of health care providers.

### Participants

Following approval by the Institutional Review Board for the Protection of Human Subjects, participant recruitment was conducted by a nurse at a large university hospital in the Midwestern United States. Each participant received \$40 for his or her participation. Because we hoped to include individuals from

throughout the HIV illness spectrum, we sampled two groups of participants from individuals with more advanced disease (i.e., self-reported CD4 counts  $<200/\text{mm}^3$ ;  $n = 12$ ) and two groups with less advanced disease (i.e., self-reported CD4 counts  $>200/\text{mm}^3$ ;  $n = 12$ ). CD4 cells, a type of white blood cell that fights infection, are used as one marker of the progression of HIV illness. When CD4 cells fall below  $200/\text{mm}^3$ , the individual living with HIV is at greater risk for medical complications and is considered to have AIDS according to the Centers for Disease Control and Prevention (CDC, 1992) guidelines. All participants in the study were receiving medical care at the infectious diseases clinic.

To increase the participation of women and African Americans, recruitment continued beyond the initial four groups until six focus groups ( $N = 33$ ) were convened. The resulting total sample was composed of 29 (88%) men and 4 (12%) women with an average age of 37.1 years ( $SD = 9$  years; range, 22–59 years). Of the 33 participants, 21 (64%) were white, 11 (33%) are African American, and one (3%) was Hispanic. Of the 29 men, 28 (97%) identified as homosexual and one (3%) as bisexual. All four women identified as heterosexual. Most participants ( $n = 27$ , 82%) had completed at least two years of college, with three (9%) having masters and three (9%) having doctoral or professional degrees. Average time since diagnosis was 59 months ( $SD = 46$  months; range, 0–144 months). Of the 33 HIV-infected adults, 21 (64%) had been diagnosed with AIDS. Nine individuals participated in follow-up interviews four years later. The same procedure was used for those interviews. Interviews from both time periods are used in the results; however, because participants did not necessarily discuss the same topics in each time period, the results are not compared across the two sets of interviews.

### Procedures

Six groups were convened for focus group interviews (five groups of five participants, one group of six participants, and one group with only two participants). All interviews were conducted in a meeting room at the College of Nursing. Before the discussions began, each participant signed an informed consent document and completed a brief demographic questionnaire. Discussions ranged from one and a half to two hours in length and were audiotaped for subsequent transcription. Names were changed in the transcriptions to protect the confidentiality of research participants.

To elicit accounts of uncertainty experiences, we asked participants a variety of open-ended questions. Probe and follow-up questions also were included to clarify issues and to validate researcher interpretations. We covered four major areas in each group discussion. The interviewer began by asking the

participants to talk broadly and generally about their life experience since testing positive for HIV. (In the second round of interviews, the researcher began by asking the participants to talk generally about their life experience since the last interview. These interviews were also conducted in groups—one group with five participants and one group with four participants.) Participants then were asked to describe things that made them feel unsure or have questions since testing positive for HIV and how uncertainty affected their lives. Finally, group members were asked to describe methods they used to manage their uncertainty.

### **Data Analysis**

Two of the authors completed coding of the data, with each examining the interview transcripts for statements about the influence of health care providers and the health care system on uncertainty and uncertainty management. The first author combined the coding categories to create a conceptual scheme describing the role of credible authority in uncertainty management. He returned to the transcripts to verify the coding and select examples for presentation. The remaining two authors verified the final classification by returning to the transcripts to evaluate the coherence and completeness of our theoretical description.

### **Results**

The results of this study revealed that coordination and collaboration between health care providers and participants in this study were important for patient uncertainty management. However, instead of treating health care providers as default experts, participants exhibited a multidimensional understanding of credibility and authority and of the challenges providers faced in assuming their role. In overview, health care provider influence on uncertainty management was defined by patients' beliefs and attitudes about (a) the health care provider's knowledge about HIV and treatments for the disease, (b) communication behaviors displayed by the health care provider (e.g., exhibiting comforting skills, signaling willingness to negotiate, or alternatively, engaging in stigmatizing behaviors), and (c) the state of knowledge and technology in the health care system. Participants also reported strategies for managing challenges associated with the credible authority role, including (a) using multiple sources of information, (b) taking an active, self-advocating role in health care interactions, (c) confronting negative or stigmatizing behavior, and (d) learning to live with chronic uncertainty. Each of these findings will be discussed in more detail.

### Health Care Providers as Credible Authorities

***Knowledge about HIV illness and treatments.*** One dimension of credible authority that influenced uncertainty for participants in the study was the perceived expertise demonstrated by the health care provider. As highly trained professionals, providers are an important source of medical knowledge in helping patients to make sense of their illness events. Daniel, who reported low levels of uncertainty, stated, “I haven’t run into a situation where my physician hasn’t been able to give me the answer.” Clark, who had been troubled by “odd” neurological symptoms, said his physician reduced his uncertainty by providing medical explanations of his illness experience:

[My physician] sat down with me, with my MRI, and said, “Look at this. Look at these patterns. Look at what’s here. We’ve got to watch this.” And you know, I felt better, even though I knew that there was at least some potentially serious neurological damage. I didn’t feel like I was a character in a 19th century novel anymore having unidentifiable “spells.”

Clark’s physician provided information that allowed him to understand his symptom patterns and to be familiar with possible scenarios for his illness events, which are important factors in uncertainty management.

A provider also may act as a secondary resource, helping the patient to evaluate the quality of information located elsewhere. Greg explained, “I find myself putting [HIV-related information] in a pile. Then, about a week or so before I’m going to see the doctor, I’ll kind of go through and dog-ear and put post-it notes on things that I want to ask the doctor about.” Even though Greg did research on his own, he felt it important to verify and/or share information he found with his physician.

On the other hand, when health care providers were unable to demonstrate medical knowledge, the patient experienced uncertainty. Edward explained, “when [my physician] says, ‘well, you know more about that than I do,’ that’s when I get nervous.” Participants noted that providers varied in their expertise on HIV and its treatments. For example, Miguel said that some physicians are more “on top of new things coming on” than others in their knowledge of HIV-related research and new medication.

***Communication behaviors.*** Participants described communication behaviors of their health care providers that gave them more or less confidence in their health care, which could cause fluctuations in their uncertainty. Alice noted that her physician was a source of comfort in uncertain times:

Gosh, when you're first diagnosed, you're so vulnerable. Kind of numb. I think you need someone with sincerity, someone who's not afraid to hold that person's hand and just listen while they cry. And someone who's not going to make judgments. Someone who's more concerned about your needs than well "I've got 15 minutes for you. Let's get you out of here, you know, let's see what you have to say and move on." Sometimes a lot of the warmth is gone. That was one of the things I liked about my doctor when I had my first appointment. I mean, he sat there and he held my hand and...he just sat there and he listened to me cry.

Having a reliable source of comfort and reassurance provides a sense of stability, which helps patients manage anxiety and uncertainty. Kent similarly explained that willingness to listen to patient concerns was important to the development of trust:

The education of doctors is slowly changing, especially in the area of infectious disease realm. The doctors are being taught to listen to what the patient has to say. Now, sure the rest of them in the medical profession might not, but I think that infectious disease profession, they really are coming around quicker. My doctor *listens*. She is really cool. I am really happy with her.

Patients also may rely on their health care providers to avoid distressing information or stressful decision-making situations. From this perspective, providers can help patients manage uncertainty by taking control over the treatment decisions, especially when the patient wishes to avoid responsibilities or illness-related information. For example, Alice said,

I didn't want to know anything. So whatever *my doctor* thought was best, I did. I figured he knows. I didn't want to be bothered. Let him deal with it. I would pick up an article and I would read something. And I would throw it back down; I just didn't want to know. Maybe it was a form of denial. The less I knew the better. I mean, I couldn't have told you how HIV invaded my body any more than—I really didn't know. And *I didn't want to know*.

Alice trusted her physician to make decisions for her, and avoided reading about HIV because it overwhelmed her. Avoiding information and active decision-making allowed her to manage her uncertainty.

Perceptions of negative communication behaviors also influenced the credible authority of providers and uncertainty management of patients. Greg expressed frustration because health care providers did not seem to understand his symptoms:

I get tired of medical personnel saying, "Well, we've never had anyone have that kind of problem with the medication before." You know, there's like this disbelief on their

part that you're actually going through what you're going through. And that's kind of a challenge sometimes.

Participants noted that the subjective nature of the HIV illness experience (i.e., people may experience different kinds of symptoms or different side effects of medications) often left them feeling that health care providers did not understand their specific experience. And providers can communicate that lack of understanding in ways that invalidate the experience of the patient, as opposed to communicative strategies that offer support and understanding (e.g., “Well we haven’t heard of that symptom, but let’s investigate it more to see if we can find out what might be happening”).

Negative interactions with providers also included communicative behaviors perceived to be stigmatizing, which can damage the credibility of the provider and lead to heightened uncertainty. Health care providers are expected to understand illness and to show empathy with the ill: Violations of those expectations can increase uncertainty. David explained that he had been asked to change providers when he disclosed his diagnosis:

One thing I experienced, I found out in September of 95 and I had a dentist appointment in December of 95. I called my dentist a month before just to let him know that I was HIV positive. He did not refuse me but he *suggested* that I go somewhere else. I’d been going to him for like six years and I really liked him a lot. And I was kind of hurt by that. But I didn’t want to go back to him then, so I went to somebody else.

Kent noted that precautions taken by emergency department staff, which he felt were extraordinary, left him feeling stigmatized and increased his uncertainty:

The worse thing that hurt for me, well, it wasn't any family member, but the one thing I noticed the most was when I was going to the Emergency Room and telling them that I'm positive and the next thing you know they have this plastic shield on their faces, fully clothed with flame retardant suits. Yeah, and the saving grace was the other doctor or nurse who would come around the corner and say "Oh, yeah, what's your problem?" and “Well this is what my problem is okay.” And they’re like, “All right.” But meanwhile you see this other person with the shield across their face. “God, am I going to explode?”

Both of these examples demonstrate the connection between medical, social, and personal forms of uncertainty. Negative reactions of others can heighten social uncertainties—even in the medical context. Thus, communication behaviors that signal comforting, caring, or willingness to adapt to the needs of the patient help reduce or manage uncertainty for participants in this study. Negative communicative behaviors—those that signal a lack of understanding

or empathy, or those that are perceived as stigmatizing—can lead to heightened uncertainty.

*State of medical knowledge and technologies.* Another dimension of credible authority discussed by participants in our study was the general state of information about HIV illness and treatments. Rapid advances in HIV-related medical knowledge make it a challenge for health care providers to maintain their expertise. Many treatments, for example, are prescribed as part of clinical trials; therefore, the long-term safety and efficacy are unknown. Bruce said, “They can’t tell you that much about the newer medicines because it’s being tested as we take it.”

Emerging advances in medical knowledge and technology, which may be speculative but widely reported, can lead patients to question the knowledge of their providers. For example, new discoveries about opportunistic infections or malignancies are common. Greg became unsettled when he realized his physician did not know about recent evidence of an increased risk for cancer for gay men with AIDS:

There was a very interesting article that I got from the Task Force, and it was dealing with the higher rate of particular types of cancer in people living with AIDS, and specifically with gay men living with AIDS. I talked with my doctor about it and I said, “Do you think this is something that we should be screening for?” And he had no idea. He wasn’t even aware that there was a protocol, and he had to contact the pathology department at the hospital to find out what’s the procedure for screening for these particular diseases. I thought that was interesting.

Thus, rapidly changing information to which patients are exposed may have not yet made its way into medical practice, which may cause patients to call into question the authority of the physician.

Similarly, failure of medical technologies directly threatens the credible authority of health care providers. In biomedicine, health care providers rely on the seemingly definite, conclusive, and objective medical tests to validate their judgment and medical knowledge. When those tests fail, it creates doubt about the health care system and the provider’s ability to manage the illness. For example, Edward recalled a failure to diagnosis *Pneumocystis carinii* pneumonia (PCP, a potentially life-threatening illness):

Last winter I came down with PCP. It did not show up on chest X-rays, did not show up on Bronchoscopes, did not show up on Gallium Scan. So anyway, my doctor threw up his hands and said “I’m going to treat you for PCP” and he did. And it was fine. But that to me is really unnerving. I mean the Gallium Scan, of all things, should not have failed. But it did. I mean, it has a failure rate of like 3%. It makes me

a little uncertain about the definitive nature of diagnostic tools that are *supposed to be* definitive.

Daniel described a similar episode in which he believed he possibly had pneumonia or some other illness that affected his breathing, but medical tests were unable to uncover the problem. He described his frustration and fear based on the inability of his health care providers to make a diagnosis:

I went to my doctor about four months ago because I had PCP a year ago in December, and I knew I was not breathing right. I mean I'm 28 years old, or I'll be 28 on Thursday—after breathing all these years, you just know what breathing feels like—And now it's not the same. It requires an effort now where it didn't before, and there's times when it's worse. And I even came in one day when it was at its worst and, you know, they want to check your saturation: "Run up and down the stairs, come on put the clamp on. You're fine." "No, I'm not! There's something wrong." And they took chest X-rays, it was clear. But in my personal experience, when I came down with PCP the first time, I had six chest X-rays and missed it every time. So I mean I was pretty scared at that point. [It's] a horrifying experience when you know there is something wrong and you've gone to the doctors, and gone back the next week because you know there's something wrong, and they keep saying "Can't find anything wrong." And you want to scream "*But you know I've got AIDS, so surely you must suspect something is wrong!*"

As another "failure" of medical technology, Clark explained an incident in which his viral load (a measure of how much virus a person has in his or her bloodstream) became undetectable. Because a lower viral load was a good sign, Clark expected that his health should be improving. His expectations soon were violated, however, when he became more ill. He noted,

The doctor calls me up and says, "Your viral load is almost undetectable." Two days later, I am in the hospital with pneumonia. So you spend two days celebrating and then you think, "Well, what's up with this?" You know, "What is going on?"

Thus, the violation of expectations (or lack of event congruence, see Mishel, 1988) can cause increased uncertainty for patients.

The failure of medical procedures also threatens providers' credible authority. Daniel noted that, after repeated treatments for a skin condition, "every time I get it done, she says, 'I got it. It's not coming back.' And two weeks later, there it is, you know. I mean, just give me a knife, I will take care of it myself." Repeated experiences of a provider's failure to provide medical certainty may be a frustrating experience and lead to increased uncertainty. Such frustration lies in the fact that "traditional medicine, it's not as certain as we think it is, especially when it comes to AIDS," said Miguel.

### **Managing Challenges to Credible Authority and Uncertainty Management**

Participants in this study clearly recognized that their trust in health care providers and the health care system influenced how they managed their uncertainty. They also described many challenges that could threaten the provider role of credible authority and reported various strategies for managing the uncertainty created by those threats. The strategies are described in the following sections.

*Using multiple sources of information.* A number of participants said that their health care provider was one of several sources they used to gather information about HIV and its treatments. For example, Larry noted,

That's where my analytical part comes out. I'll research everything and I'll go around and talk to people. I'll talk to medical professionals and ask them questions about this, that, and the other, because basically you do kind of have to mix them all together.

Alan similarly described his approach, mixing information from his health care providers and from written information he acquired (e.g., magazines such as *Positively Aware* or internet resources):

The best way for me [to manage uncertainty] has been reading and then sort of measuring that against what my doctor says or talking to my doctor about what I've read and trying to hear what he believes and then from there trying to make a decision on my own.

Multiple sources of information might also include having several health care providers. Clark argued, "Yeah, I think it's important that you have access to as many medical professionals as humanly possible." Others noted that referral to specialists (e.g., oncology, dermatology, gynecology, ophthalmology) often was necessary because of the complexity of the illness.

One rationale that participants noted for using multiple sources of information was the subjective nature of the HIV illness experience. Randy explained the difficulties of finding the right authority for his illness experiences:

We all react to these drugs differently. Our body reacts to HIV in different ways. The physicians look at HIV in a specific way....I mean, there are so many different things and no one's an expert on all of these, so we don't have a choice but to draw from all these sources. And to pick and choose what we feel is right for us specifically. We can't draw blanket generalities from one source.

This attitude highlights the differences between the knowledge of objective medical information and the knowledge of subjective experiences. Adam argued, “The best, the BEST resource though are other people who are going through what you are going through....I go to medical professionals more for the treatment issues.” Daniel explained,

[Other patients'] personal experiences may be a lot better to rely upon than the statistics. You know, the medications made them sick and they can tell you how they made them sick or how bad they made them sick, you know, versus reading it in a text.

A persistent theme throughout the interviews is participants' emphasis on the importance of *knowledge*, stating “knowledge is power” and “knowledge is strength.” By obtaining knowledge, patients were able not only to make decisions about their treatment choices but also to manage their uncertainty.

***Engaging in self-advocacy.*** Patients also may realize that they need to advocate for themselves and to modify their expectations of provider and patient responsibilities. When Alan experienced increased anxiety and uncertainty because he believed he was getting inconsistent information about Kaposi's sarcoma (KS, an opportunistic cancer that can be life threatening), he acknowledged that he and his physician both had responsibilities. Alan said,

[My insistence on learning more] led to an ongoing dialogue about KS and finally led to me being referred to an oncologist, the confirmation that no, I don't have internal lesions; that these are in fact, not as serious as they could be, which was what my doctor had said. But I needed that confirmation for my own peace of mind. But on the other hand, *my responsibility* in all that was to go in with some concrete questions for my doctor. It's not enough to go in thinking, “Well, they are going to tell me if I need to do something.” They are human, they are overwhelmed, and they have a great number of patients. I don't know how they do as well as they do. So, I mean, it's a *partnership* and I've needed to be this involved in the treatment.

Similarly, Vic noted that he felt it was his responsibility to ask questions and participate fully in interactions with his providers:

I've found that unless I'm really quite frank with whichever doctor I happen to be seeing, whether it be my oncologist or whether it was somebody in Infectious Diseases here, and said “Wait, back up to that word. Now tell me a little bit more about this. What exactly does that mean?”—that I didn't feel like I was being really a very good patient and really wasn't committed to understanding my own condition as I should have been.

The advancement in technology and the chronic nature of the illness allow patients with HIV to have numerous opportunities to access and research the objective medical knowledge. Bruce noted that he felt that, because of his constant search for information, he often was more up-to-date than his physician on HIV information:

And the information changes so fast, you know, we read the journals before they do or we've read it some place before they've been able to see it. So it's not knowing more than the doctors I guess—maybe we're tuned in better because they're busy treating the things that are there.

Others noted that they believed that ultimately decision-making was their right. For example, although Greg and his physician coordinated on information and resource management, Greg explained that he made the final decisions about treatments and courses of action:

In deciding upon a medical regimen, sometimes I suggest medications to my doctor based on information that I've read and sometimes, my doctor suggests medication. And if *we* decide that he's going to prescribe something, then *I* try taking it and if my body doesn't tolerate then *I* don't take it. *I stop it.*

The provider-patient relationship becomes a partnership in which individuals' responsibilities and efforts are coordinated. Some physicians are appraised not only because they are knowledgeable but also because they are “more willing to try newer things and even to pick up the phone and call someone else to learn a little bit more about it because they know they are going to be seeing it more often,” said Miguel.

***Challenging negative communication behaviors.*** Another way of managing threats to credible authority was to challenge negative behaviors. A patient with a chronic illness may develop skills to interpret not only his or her symptoms but also related medical information. For example, Daniel said, “I can now read a chest x-ray better than the physician at the hospital, and I went there and told him that. And he's the one who looked at it six times and missed the pneumonia.” As described earlier, Daniel had experienced invalidation of his symptoms and illness experience because of a failure of medical technology and provider behaviors that signaled disbelief about his illness. He let the physician know that the failure to diagnose pneumonia made him question the physician's ability to read x-rays.

Others described strategies for managing stigmatizing behaviors, such as changing providers. Hugh noted that he had learned to directly confront those

providers he believed to be discriminating against him:

I had my dentist tell me, he says “I think that you should find someone who deals more with your kind of people.” I was like, “What do you mean, my kind of people?” And now I just love it because I make a huge scene. Because I can be just a big loud queer—and I make big scenes now. But then, I mean, you know, doctors didn't want to touch me or the neurologist, *a neurologist* would be all the way over there examining me from the other side of the room. I was like, “Girl you have to come over here.” Or I see a nurse drawing blood from somebody else without gloves but when they come to me they put a gown on, gloves, a face mask. And you know and I was like “You know I can pop my own line for you, you know, just let me do my draws. You know if you're that afraid to touch me.”

Challenging negative behaviors allowed patients to feel in charge of their situation and less dependent on medical authority. It allowed them to engage in self-advocacy (Brashers, Haas, & Neidig, 2002), which could promote problem-focused coping (Brashers, Haas, Neidig, & Rintamaki, 2002) and lessen the stress associated with HIV.

*Living with chronic uncertainty.* Participants also described the need to learn to live with chronic uncertainty. Clark reflected, “Most of the information we've gotten over the years has been so, nothing has been definite. So you learn to just live with things that aren't absolutes. You know, there are no absolutes when it comes to treating this.” Similarly, Adam described his realization that health care providers might not have all the answers to his questions:

The longer I have dealt with it, I realize that the physician doesn't have all the answers. And if I have a dollar for every time the physician has said, “I don't know,” in the last year, I would have a lot of money. So, I've been forced to kind of explore on my own and just deal with it on an ongoing basis. Makes it much easier realizing that she doesn't have the answers all the time.

Although not everyone agreed with him, Adam noted that he found it comforting when a health care provider was willing to admit not knowing information (rather than trying to give a false illusion of certainty).

### Discussion

Health care providers contribute to the uncertainty management of people living with HIV in a number of ways. They provide medical information and decision-making criteria, they can be sources of stability and comfort, and they have access to sophisticated medical technology available from the health care system. The participants in this study described criteria that they use to evalu-

ate health care provider performances as credible authorities. These evaluations were rarely based on health care providers' failure to demonstrate an absolute standard of medical knowledge. Rather, the perceived loss of credible authority by health care providers often was dependent on a patient's interpretation of the meanings and implications of the provider-patient interaction.

### **Providers as Medical Experts**

Health care providers' medical training, ability to interpret health-related information, and access to cutting-edge research and resources (e.g., library and clinical trials) allow them to assume the role of authorities for our participants. Information provided by health professionals was clearly an important part of managing both uncertainty and illness; they were used as primary information sources and as resources to verify information from other sources. They were often part of a complex network of informational and emotional support persons. Most participants reported positive experiences with health care providers, which helped them manage the uncertainty about their illness and gave them trust and confidence in their health care. They also noted that health care providers varied considerably in their knowledge of HIV and its treatments—perhaps reflecting the providers' specialization (i.e., infectious disease providers probably have more information on HIV than general practice providers) or their experience treating patients with HIV.

Biomedical expertise, however, was only part of what participants reported that they needed to understand their illness. As patients became more aware of their symptoms and bodies and more knowledgeable about their illness-related experiences, they began to see the limits (or boundaries) of medical professionals' knowledge. Participants in our study developed a complicated understanding of spheres of knowledge and their corresponding authorities. Participants reported that they came to understand that medical professionals could not have access to all illness-related knowledge—they argued that experiences (e.g., what symptoms feel like, or how one might react to a medication) were often subjective and in the purview of those with the illness. Because of that, information and advice from others, including peers living with HIV illness, might be especially important for illness and uncertainty management (Brashers, Peterson, Rintamaki, Neidig, & Goldsmith, 2003).

When providers were unable to assume the role of credible authority, some participants reported increased uncertainty and anxiety. In addition to the subjective experiences mentioned above, there are a variety of situations in which a provider may not be able to demonstrate his or her medical knowledge; for example, when there is no information available on the long-term effects of an experimental treatment, or the provider is unfamiliar with a new

medical procedure. Providers' loss of credible authority can challenge the patients' assumptions about the roles and abilities of medical professionals, the trajectory of illness experiences, and the meanings and the validity of illness-related information provided to them. One's credibility as an authority of medical knowledge depends on his or her access to information and ability to interpret information; but it is important to note that threats to credible authority often are not entirely under the health care providers' control. Nevertheless, patients who questioned a providers' credibility often experienced increased uncertainty and anxiety.

### **Coordination of Goals and Behaviors**

The coordinated effort between providers and patients in the treatment process and the uncertainty management was an important theme in our participants' narratives. Participants in this study often viewed health care providers as collaborators and partners in managing their illness. Individuals may collaborate with their health care providers to reduce or maintain uncertainty. For example, health care providers as an important source of information allowed a patient to find comfort in the fact that their providers are available when they need answers. Health care providers also offered a relatively safe fallback when participants needed to avoid the stress and anxiety of making decisions and seeking information.

The success of a patient's uncertainty management depends on the provider's ability to understand the patient's expectations and to respond accordingly. Because individuals rarely meta-communicate their communicative goals (i.e., explicitly talk about how to talk about things), providers may misunderstand their patients' expectations. For example, a patient may want information, but use indirect methods of information seeking that are not clear to a provider (Brashers, Goldsmith, et al., 2002; Cegala, McClure, Marinelli, & Post, 2000). Or a patient may want to avoid information, but may not be able or willing to communicate that to the provider (Brashers et al., 2000). Inadvertently forcing a patient to deal with illness-related information may increase his or her anxiety and distress. Steve explained, "When I was first diagnosed, and I went to a doctor, I didn't want to know enough about this disease. It was a lot of stress, every time." Patients, therefore, may abdicate decision-making when facing their situation is too stressful.

The expectations that patients have of their providers also may need to be adjusted. One study, for example, demonstrated that patient dissatisfaction with the provider-patient relationship was greater when the patient expected their physicians to always know the answers (Johnson, Levenkron, Suchman, & Manchester, 1988). Participants in our study reported that they realized

that physicians were busy and may not have access to information (and time to process the information) in the same way that they had. Some even reported that it was reassuring to them that their physician was willing to admit uncertainty. By changing their expectations, our participants were able to retain their trust and satisfaction. Patients also may develop trust over time with health care providers (Parchman & Burge, 2004). Higher levels of trust, for example, might lead to more reliance on provider decision-making (Phelan, Shadlen, & Anderson, 2001).

### **Implications for the Theory of Communication and Uncertainty Management**

The results of this study expand and clarify parts of the theory of uncertainty management (Brashers, 2001; Brashers et al., 2000; Brashers et al., 2004). For example, Brashers et al. (2004) noted that individuals in a patient's support network can influence the experience, appraisal, and management of uncertainty. Similarly, health care providers also can be thought to have these same influences on patient uncertainty. First, they can be sources of uncertainty when their behavior violates expectations about appropriate or effective actions (e.g., when they lack information or when they are perceived to engage in stigmatizing behaviors). Second, they can help patients reappraise uncertainty they are experiencing (e.g., by helping them understand that an uncertain situation is not always an immediate threat). Third, a provider can provide information when a patient wants to reduce uncertainty or, alternatively, can take charge when the patient is too distressed to process information and make decisions. This distinction further highlights the difference between reducing uncertainty and managing the effects of uncertainty (e.g., managing anxiety when uncertainty can't be reduced).

In addition, information seeking (or management) appears to be an important part of uncertainty management. As the present data showed, people with HIV seek knowledge in various ways. For example, they might actively seek information (e.g., eliciting information from multiple sources), passively receive information (e.g., positioning oneself in an information-rich environment), and even strategically seek information in an effort to manage their uncertainty (see Brashers et al., 2000). Although some participants argued that seeking knowledge is crucial for empowerment in the treatment process, others, at times, rely on medical professionals' knowledge to decide their treatment options. When patients are stressed and need relief from threatening information, they may allow physicians to be more directive. Higher levels of trust might decrease their uncertainty and allow them to be more comfortable with provider decision-making (Phelan, Shadlen, & Anderson, 2001).

**Implications for Practice**

The results of this study have implications for interventions into medical interactions. With our current and previous findings, we hope to further develop interventions that will help individuals living with chronic or acute illnesses. We have recently tested a peer support intervention along those lines—we now believe it is important to include discussions of the role of health care providers in patient uncertainty management. Understanding that function of a provider can ultimately lead to improved health outcomes. For example, trust in physicians, as well as general satisfaction with the physician-patient relationship, has been shown to be associated with better adherence to HIV medications (Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). Adherence is especially important in this population, given that a failure to take medications as prescribed can lead to a virus that becomes resistant to those treatments.

Interventions for physicians also can be developed to help promote their role as credible authority. Physicians may vary in their tolerance for uncertainty, which may result in “increased test ordering tendencies, variability in medical treatment, failure to comply with evidence based guidelines, and even guide career choices” (Ghosh, 2004, p. 60). Providers also may worry about prescribing medications under conditions of uncertainty (Gerbert, Bronstone, Clanon, Abercrombie, & Bangsberg, 2000). Thus, to help patients manage their uncertainty, providers may need to learn to manage their own. Gerbert et al. (2004) noted that HIV care providers in their study felt that learning to cope with uncertainty (i.e., being “comfortable with mystery,” see pp. 366–367) was an important aspect of their jobs. In addition, they reported that it was important to understand “the dual faces of knowledge: ‘knowing the facts’ and ‘knowing the patient’” (pp. 369–370). Based on our results, providers also may need to understand that assisting a patient with uncertainty management may be more than simply providing medical information—resources that assist with anxiety management (e.g., engaging in comforting behaviors and/or listening) may also help relieve the symptoms of stressful uncertainty. And providers may need to learn that certain behaviors (e.g., using universal precautions such as gowns, gloves, and face shields that may *seem* extreme to some patients) may need to be explained so that they are not perceived as stigmatizing.

It is also important for physicians to know, as others have suggested, that provider competence may be evaluated by patients on the basis of both interpersonal and technical skill (Mechanic & Meyer, 2000). Providers’ statements that reflect uncertainty (e.g., “I don’t know,” or “Let’s see what happens”) may have a detrimental effect on patients’ trust and confidence (Odgen et al.,

2002); however, it may be that *how* uncertainty is expressed and understood may be a more important factor in patient uncertainty management. In one study, physicians who expressed uncertainty more often in provider-patient encounters “also used more positive talk and partnership building, and gave more information to patients” (Gordon, Joos, & Byrne, 2000, p. 59), which might mitigate the potential negative impact of provider uncertainty. Similarly, many of our participants acknowledged that physicians may not know all the information regarding their disease, but highlighted the importance of a good patient-physician relationship.

### Conclusion

Health care providers are an important component of uncertainty management for individuals who are experiencing an illness. They can be a source of information, they can assist with decision-making in stressful circumstances, and they can provide comfort and stability in stressful illness experience. Their role as a credible authority might be challenged, however, by their lack of knowledge, by general uncertainty within the health care community, or by their own communication behaviors. The loss of the credible authority of health care providers poses a threat to an individual’s uncertainty management. When information from a provider is not considered credible or when providers violate expectations about communicating support, a patient may lose his or her confidence and trust in providers’ judgment and recommendations. Because many situations that can cause a loss of the credible authority often are beyond the control of health care providers, it becomes necessary for providers and patients to manage their uncertainty more effectively. They can manage the uncertainty in illness through (a) modified provider-patient relationships and (b) the coordinated management of uncertainty.

### Authors Note

We gratefully acknowledge support for this research from the National Institute of Nursing Research (1R29NR04376) and the National Institute of Allergy and Infectious Diseases (Adult AIDS Clinical Trials Group #A125924, R.J. Fass). We also wish to thank the men and women who participated in this study and Linda Cardillo, Linda Dobbs, Marie Garland, Stephen Haas, William McCartney, Sally Nemeth, Jane Russell, and Angela Swary for their help with data collection and transcription and Josh Stephens for his insight on the data analysis.

### References

- Albrecht, T. L., & Adelman, M. B. (1987). *Communicating social support*. Thousand Oaks, CA: Sage.
- Babrow, A. S., Kasch, C. R., & Ford, L. A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. *Health Communication, 10*, 1-23.
- Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication, 51*, 477-497.

- Brashers, D. E., Haas, S. M., & Neidig, J. L. (2002). Satisfying the argumentative requirements for self-advocacy. In F. H. van Eemeren (Ed.), *Advances in pragma-dialectics* (pp. 291-308). Newport News, VA: Vale Press.
- Brashers, D. E., Haas, S. M., Neidig, J. L., & Rintamaki, L. S. (2002). Social activism, self-advocacy, and coping with HIV illness. *Journal of Social and Personal Relationships, 19*, 113-133.
- Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding in health contexts. *Human Communication Research, 28*, 258-271.
- Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). "In an important way, I did die." Uncertainty and revival among persons living with HIV or AIDS. *AIDS Care, 11*, 201-219.
- Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV. *Health Communication, 16*, 305-331.
- Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs, 67*, 63-84.
- Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., Garland, M., McCartney, B., & Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing, 24*, 497-522.
- Brashers, D. E., Peterson, J. L., Rintamaki, L. S., Neidig, J. L., & Goldsmith, D. J. (2003, November). *The forms and functions of peer social support*. Paper presented at the annual meeting of the National Communication Association, Miami Beach, FL.
- CDC (1992). Revised classification system for HIV infection and expanded surveillance case definitions for AIDS among adolescents and adults. *Morbidity and Mortality Weekly Report, 41*, 1-19.
- Cegala, D. J., McClure, L., Marinelli, T. M., & Post, D. M. (2000). The effects of communication skills training on patients' participation during medical interviews. *Patient Education and Counseling, 41*, 209-222.
- Clayton, M. F., Mishel, M. H., & Belyea, M. (2006). Testing a model of symptoms, communication, uncertainty, and well-being, in older breast cancer survivors. *Research in Nursing and Health, 29*, 18-39.
- Gerbert, B., Bronstone, A., Clanon, K., Abercrombie, P., & Bansberg, D. (2000). Combination antiretroviral therapy: Health care providers confront emerging dilemmas. *AIDS Care, 12*, 409-421.
- Gerbert, B., Caspars, N., Moe, J., Clanon, K., Abercrombie, P., & Herzog, K. (2004). The mysteries and demand of HIV care: Qualitative analyses of HIV specialists' views on their expertise. *AIDS Care, 16*, 363-376.
- Ghosh, A. K. (2004). On the challenges of using evidence-based information: The role of clinical uncertainty. *Journal of Laboratory and Clinical Medicine, 144*, 60-64.
- Goldsmith, D. J. (2004). *Communicating social support*. New York: Cambridge.
- Gordon, G. H., Joos, S. K., & Byrne, J. (2000). Physician expressions of uncertainty during patient encounters. *Patient Education and Counseling, 40*, 59-65.
- Johnson, C. G., Levenkron, J. C., Suchman, A. L., & Manchester, R. (1988). Does physician uncertainty affect patient satisfaction? *Journal of General Internal Medicine, 3*, 144-149.
- Katz, J. (1984). Why doctors don't disclose uncertainty? *Hastings Rep, 14*, 35-44.
- Krupat, E., Bell, R. A., Kravitz, R. L., Thom, D., & Azari, R. (2001). When physicians and patients think alike: Patient-centered beliefs and their impact on satisfaction and trust. *The Journal of Family Practice, 50*, 1057-1062.

- Mechanic, D., & Meyer, S. (2000). Concepts of trust in patients with serious illness focused on physician interpersonal and technical competence. *Social Science and Medicine*, *51*, 657-668.
- Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, *20*, 225-232.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship*, *22*, 256-262.
- Mishel, M. H. (1997). Uncertainty in acute illness. In F. L. Cohen (Ed.), *Annual review of nursing research* (Vol. 15, pp. 57-80). New York: Springer.
- Mishel, M. H. (1999). Uncertainty in chronic illness. In J. J. Fitzpatrick (Ed.), *Annual review of nursing research* (Vol. 17, pp. 269-294). New York: Springer.
- Ogden, J., Fuks, K., Gardner, M., Johnson, S., McLean, M., Martin, P., & Shah, R. (2002). Doctors expressions of uncertainty and patient confidence. *Patient Education and Counseling*, *48*, 171-176.
- Parchman, M. L., & Burge, S. K. (2004). The physician-patient relationship, primary care attributes, and preventive services. *Family Medicine*, *36*, 22-27.
- Phelan, E. A., Shadlen, M., & Anderson, L. A. (2001). Women's perceptions of their interactions with physicians: A focus group study of hormone replacement therapy counseling. *Clinical Journal of Women's Health*, *1*, 199-205.
- Quill, T. E., & Suchman, A. L. (1993). Uncertainty and control: Learning to leave with medicine's limitations. *Human Medicine*, *9*, 109-120.
- Schneider, J., Kaplan, S. H., Greenfield, S., Li, W., & Wilson, I. B. (2004). Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *Journal of General Internal Medicine*, *19*, 1096-1103.
- Thom, D. H. (2001). Physician behaviors that predict patient trust. *The Journal of Family Practice*, *50*, 323-328.
- Wallace, M. (2005). Finding more meaning: The antecedents of uncertainty revisited. *Journal of Clinical Nursing*, *14*, 863-868.