

Social Support and the Management of Uncertainty for People Living With HIV or AIDS

Dale E. Brashers

*Department of Speech Communication
University of Illinois at Urbana–Champaign*

Judith L. Neidig

The Ohio State University

Daena J. Goldsmith

University of Illinois at Urbana–Champaign

People with chronic and acute illnesses experience uncertainty about their prognosis, potential treatments, social relationships, and identity concerns. In a focus group study of people living with HIV or AIDS, we examined how social support may facilitate or interfere with the management of uncertainty about health, identity, and relationships. We found that support from others helps people with HIV or AIDS to manage uncertainty by (a) assisting with information seeking and avoiding, (b) providing instrumental support, (c) facilitating skill development, (d) giving acceptance or validation, (e) allowing ventilation, and (f) encouraging perspective shifts. Respondents also reported a variety of ways in which supportive others interfered with uncertainty management or in which seeking support imposed costs. Problems associated with social support and uncertainty management included a lack of coordination in uncertainty management assistance, the addition of relational uncertainty to illness uncertainty, and the burden of others' uncertainty management. Our study reveals strategies respondents used to manage costs and complications of receiving support, including developing an active or self-advocating orientation, reframing supportive interactions, withdrawing from nonproductive social situations, selectively allowing others to be support persons, and maintaining boundaries.

People living with acute and chronic illnesses experience many forms of uncertainty (Babrow, Kasch, & Ford, 1998; Mishel, 1988, 1990). For example, medical, social, and personal forms of uncertainty in HIV illness are well documented (Weitz, 1989). People living with HIV experience uncertainty because of the unpredictable progression of the disease, the ambiguity of symptoms, the large number of possible opportunistic infections, the experimental nature of most medications, possible negative reactions of others based on stigma or fear associated with the disease, possible risk of infecting loved ones, and unknown financial consequences of long-term treatment (Brashers, Neidig, Reynolds, & Haas, 1998; Brashers et al., 2003). Improved treatments and prophylaxis for opportunistic infections have increased life spans for many individuals, which in turn has increased uncertainty and demanded long-term uncertainty management (Brashers et al., 1999).

Because uncertainty is a common feature of illness, researchers have increased attention to how it is managed (Babrow & Kline, 2000; Mishel, 1990). Brashers, Neidig, et al. (2000; also see Lazarus & Folkman, 1984; Mishel, 1988, 1990) proposed that uncertainty management for people living with HIV involves an appraisal of the consequences of uncertainty (e.g., the potential for harm or benefit) and an associated emotional response (e.g., anxiety or hope). Appraisals and corresponding emotions motivate behavioral and psychological actions directed toward managing uncertainty. For example, people seek or avoid information to manipulate uncertainty to a comfortable level. Brashers, Neidig, et al. (2000) found that individuals with HIV or AIDS are likely to engage in active information seeking (e.g., by directly inquiring about their health and treatments from health care providers, others with HIV, and media sources) and passive information seeking (e.g., by placing themselves in situations in which they are likely to encounter information) when they appraise uncertainty as a threat or danger (see Mishel, 1988). Experiential information or "vigilance in monitoring symptoms" (Mishel, 1988) also was an important source of information that helped to reduce uncertainty. In contrast, when uncertainty was appraised as opportunity (i.e., when uncertainty allowed hope to be maintained), participants reported that they avoided information by avoiding health care interactions (e.g., not getting tested for HIV or refusing to hear results of lab tests), avoiding situations in which information is likely to be presented (e.g., support groups), and taking "holidays" from information by storing it away for future use. They also reported seeking information to increase uncertainty; for example, by looking for alternative or complementary therapies to increase the number of options for consideration or by locating information that called into question their current beliefs. Finally, in addition to seeking and avoiding information to decrease, maintain, or increase uncertainty, participants reported managing *chronic* uncertainty by changing orientations toward uncertainty, focusing on day-to-day activities, and redefining decision-making tasks (Brashers, Neidig, et al., 2000; also see Mishel, 1990).

Communication with others often is the means whereby people seek or avoid information to manipulate uncertainty to a comfortable level, which is defined through the negotiation of emotional, relational, identity, and decision-making concerns. The ways in which others help facilitate uncertainty management have been studied under the rubric of social support (Albrecht & Adelman, 1987; Mishel, 1997, 1999; Mishel & Braden, 1987, 1988). Social support is a multi-faceted concept that includes the ways in which individual well-being and coping are enhanced by involvement in social networks, the perceived availability of help and acceptance by others, or the exchange of tangible and symbolic support in interactions between people (see Albrecht & Goldsmith, 2003, for a review). Previous theory and research suggested a variety of ways in which social support may facilitate or inhibit uncertainty management (Mishel, 1988, 1990). Ford, Babrow, and Stohl (1996) studied the management of uncertainty in the experience of breast cancer, and found that supportive messages can increase, decrease, or maintain certainty or uncertainty. Albrecht and Adelman (1987) described processes through which social support affects uncertainty by encouraging perspective shifts on cause-effect contingencies or by enhancing perceptions of control through skill acquisition, tangible assistance (instrumental support), acceptance or assurance, and opportunities for ventilation. Miller and Zook (1993) elaborated the ways in which care partners participate in uncertainty management, including information searched through passive information collection (e.g., being attuned to media sources), moderate information collection (e.g., participating in community and support groups), and full information search activity (e.g., developing elaborate information networks).

Taken together, these theories suggested that *social support* can contribute to adjustment and well being by aiding in *uncertainty management* (Mishel, 1988; Neville, 1998); however, social support is not without costs that can exacerbate stress and uncertainty (Albrecht & Adelman, 1987; Albrecht, Burleson, & Goldsmith, 1994). *Dilemmas of support* arise when the benefits of receiving support are accompanied by costs or complications. For example, seeking or receiving social support could *create* uncertainty about stigma and impression management, dependence on others, ease of interaction with others, obligations to accept or reciprocate assistance, invasion of privacy, and relational conflict (Albrecht & Adelman, 1987, see especially pp. 242–252). For people living with HIV, interactional behaviors that are negative or unhelpful have been identified (Fleishman et al., 2000; Hays, Magee, & Chauncey, 1994; Pakenham, 1998) and linked to negative outcomes (Ingram, Jones, Fass, Neidig, & Song, 1999; Siegel, Raveis, & Karus, 1994, 1997). Participants in one study described *unhelpful* attempts at social support as those that seemed intrusive, insincere, dismissive, or avoidant (Barbee, Derlega, Sherburne, & Grimshaw, 1998). In another study (Hays et al., 1994), participants described similar problems with support attempts. One man noted that his mother's supportive behavior included unreasonable demands, such as when she "insisted I eat, and expressed

frustration when I'd throw up" (p. 388). Others described costs (e.g., having to clean house and prepare for visitors when not feeling well) that outweighed the benefits of support.

The complexities inherent in uncertainty management and in the communication of social support, *and* the apparent relationship between the two, invite further investigation of these phenomena. Given the potential for attempts at support to have both positive and negative effects, we need theory and research to help explain circumstances under which social support is helpful or harmful and processes through which these effects come about. In this article, we explore these phenomena in the context of people living with HIV or AIDS, a population in which the illness experience is profoundly affected both by uncertainty (Brashers, et al. 1999; Brashers, Neidig, et al., 2000; Brashers et al., 2003; Weitz, 1989) and by social support (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001; Leserman et al., 1999; Swindells et al., 1999). Our approach builds on a growing body of research that examines dilemmas of support and their management (see Albrecht & Adelman, 1987 or Goldsmith, 1992 for reviews). Specifically, we draw on the normative approach to studying the communication of support outlined by Goldsmith and Fitch (1997; also see Goldsmith, 2001). Many dilemmas of support can be usefully understood as arising from the multiple goals individuals may have when they seek, provide, or receive support (see O'Keefe, 1988, 1991 or Wilson, 2002 for discussions of managing multiple communication goals). In addition to giving or receiving assistance, social support also has implications for how the giver and receiver of support view themselves and their relationship. For example, accompanying a partner to a doctor's appointment may provide assistance in uncertainty management by providing another set of ears or a source of moral support; however, this social support may come at the cost of making the recipient feel more dependent. Receiving information from a friend may be a valued symbol of caring but also could interfere with attempts to manage uncertainty through information avoidance.

A normative approach to understanding the communication of support focuses on explaining why some attempts at communicating social support are more effective than others by examining how support providers and recipients adapt to the multiple goals of providing assistance *and* affirming valued identities and relational qualities. The ways in which support is communicated may influence the outcomes of support attempts, therefore it is important to develop explanatory models addressed to the questions of how and why some attempts at social support are beneficial, whereas others are not. Goldsmith and Fitch (1997) proposed that *better* attempts at support are those in which the communication features are adapted to the conflicting goals and dilemmas that are inherent in social support interactions. A first step in developing explanatory models to account for these variations is to identify the dilemmas of support and features of messages, conversations, and relationships that serve as resources for responding to dilemmas.

Although general human wants (e.g., acceptance or autonomy) and general behavioral processes (e.g., uncertainty management) may be involved in any social support interaction, the dilemmas that participants experience and the discursive resources for responding to those dilemmas are shaped by the particular circumstances. Thus, the experience of uncertainty and the ways that social support may be used to manage uncertainty may have both general, cross-situational components and specific instantiations. Consequently, an important step in a normative approach is the identification of (a) the particular ways in which social support may aid in adaptive processes (e.g., uncertainty management); (b) some of the particular costs to the individual and complications for the relationship that arise from seeking, providing, and receiving support; and (c) strategies individuals may use to adapt to the dilemmas that result from the co-occurrence of benefits, costs, and complications. Because the goals and dilemmas of support are different in professional relationships (e.g., health care providers or counselors), we focus this article on members of the informal social networks of people living with HIV or AIDS. Specifically, to accomplish the aims of this article we addressed the following research questions: (a) What are the ways in which social support functions to manage uncertainty? (b) What problems are associated with social support in the management of uncertainty? and (c) How do people deal with dilemmas of social support in the management of uncertainty?

In the following sections, we describe the method and results of our study that was conducted to investigate uncertainty, the communication of support, and uncertainty management experiences. Finally, we elaborate a theory of uncertainty management based on these findings, which extends theories of social support (e.g., Albrecht & Adelman, 1987; Goldsmith & Fitch, 1997) and theories of uncertainty management (e.g., Brashers, 2001; Brashers, Neidig, et al., 2000; Goldsmith, 2001).

METHOD

Data were collected from six focus groups of adults diagnosed with HIV or AIDS. Focus groups allowed us to develop descriptions of participants' perspectives on meanings of social support and on the effectiveness of social support in aiding uncertainty management.

Sample

Following approval by the Institutional Review Board for the Protection of Human Subjects, recruitment was conducted by a research nurse at an Adult AIDS Clinical Trials Unit (ACTU) at a large university hospital in the Midwestern United States. Each participant received \$40 for his or her participation. Because we hoped to in-

clude individuals from throughout the HIV 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 of participants from individuals 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 HIV-infected individual is diagnosed with AIDS and opportunistic infections and malignancies (OIs) are increasingly likely. 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 to 59 years). Of the 33 participants, 21 (64%) were Caucasian, 11 (33%) were African American, and 1 (3%) was Hispanic. Of the 29 men, 28 (97%) identified as homosexual and 1 (3%) identified as bisexual. All 4 women identified as heterosexual. Most participants ($n = 27$, 82%) had completed at least 2 years of college, with 3 (9%) having masters and 3 (9%) having doctoral or professional degrees. Average time since testing positive for HIV infection was 59 months ($SD = 46$ months, range 0 to 144 months). Twenty-one participants (64%) had been diagnosed with AIDS.

Procedures

The first and second authors were present at all focus group discussions. In addition, in each group one research assistant acted as a primary moderator while another noted speaking order to facilitate transcription. Before the discussions began, each participant signed an informed consent statement and completed a brief demographic questionnaire. Discussions ranged from 1 and 1/2 to 2 hr in length and were audiotaped for subsequent transcription. Names were changed 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 experiences since testing positive for HIV. Then participants were asked to describe things that made them feel unsure or have questions since testing positive for HIV. They next were asked to describe how uncertainty affected their lives. Finally, group members were asked to describe methods they had used to manage their uncertainty.

Data Analysis

As part of a larger study of HIV-associated uncertainty and uncertainty management, we analyzed data about social support in uncertainty management experi-

ences in this study. We used constant comparative techniques (Lincoln & Guba, 1985) to analyze interview transcripts. Two of the authors read through the transcripts and each developed independent lists of references to communication with members of the speakers' informal support networks. We then identified positive and negative communication experiences associated with seeking, receiving, or providing support. We next met together and discussed these lists to come to a central set of themes for the analysis. The other author then tested the themes against the transcripts to provide an external assessment of their validity. Examples that appear in this report were selected by discussion between the two authors and subsequent validation from the other author. Conducting multiple group interviews and coding and development of categories by independent researchers helped to strengthen data credibility. The following section details the findings of our study and elaborates each of the themes.

RESULTS AND DISCUSSION

The results of this study reveal that communication with a support network was an important part of uncertainty management for participants in the study; however, these supportive attempts do include costs and complications that create dilemmas for uncertainty management. Participants also reported strategies for managing dilemmas.

Social Support in Uncertainty Management

There was a clear link between social support and efforts to manage high levels of uncertainty over issues such as unpredictable disease progression, experimental medications, and ambiguous symptoms. The various ways in which social support facilitates uncertainty management parallel the methods described by Albrecht and Adelman (1987), except that we elaborate their conceptualization by considering uncertainty management, rather than uncertainty reduction, as the goal of support seekers. Support from others helps people with HIV or AIDS manage uncertainty by (a) assisting with information seeking and avoiding, (b) providing instrumental support, (c) facilitating skill development, (d) giving acceptance or validation, (e) allowing ventilation, and (f) encouraging perspective shifts.

Assisting With Information Seeking and Avoidance

Family, friends, and peers (i.e., other people infected with HIV) contribute to uncertainty management for people with HIV by helping them to seek or avoid information. For example, Wayne needed information to reduce uncertainty about participation in trials of experimental treatments in which the long-term efficacy and safety of medications had not been established. He noted that other individuals

with HIV could be important *sources of information*: “I will pick up the phone, I will write letters, I will ask my friends that are involved in studies ... I will call them and ask them: ‘Listen what do you think of this?’ ”

As sources of information, peer support has been shown to be particularly important for people with HIV (Adelman & Frey, 1997; Spirig, 1998), perhaps because of the high levels of uncertainty associated with the illness. Adam said

I still think the best, the *best* resource though is other people who are going through what you are going through ... So you hit the support groups, or the AIDS service organizations and you rely on the experiences of other people.

The use of peers by Adam, Wayne, and others suggests that those who share similar experiences are an important source of information in uncertainty management.

In addition to being sources of information, supportive others can assist in information search and selection as *collaborators in information gathering* (Miller & Zook, 1997). Clark described his partner’s role in information gathering: “From the very beginning, I used to go to all my doctor’s appointments with my partner, and he’d ask questions, and I pretty much was being taken care of through all this.” Participants also noted that they needed others to advocate for them when they were too ill or distressed to effectively seek or process information.

Supportive others also can serve as *evaluators of information*. Because information about HIV and its treatments is advancing and changing rapidly and because information may be inconsistent or contradictory, people living with HIV may want to discuss what they find with others. Paul noted that “Sometimes after you get the information, you need to discuss it. And I’m fortunate to have family and friends I can talk to.” The ability to collaborate with others may allow the person with HIV to reduce uncertainty through information management (Brashers, Goldsmith, & Hsieh, 2003).

Finally, supportive others can be *buffers against information*. Participants suggested that friends and family sometimes wanted to not discuss HIV issues, which can facilitate information avoidance. Others reported being able to relax more around peers, because they did not feel the need to discuss HIV issues when together. Clark noted

I’ve found that it’s easier for me to retreat sometimes around people who are in the same position. And, many of us were just at the healing weekend, and places like that I find I can actually escape more from this illness than I can when I’m around my friends who aren’t HIV positive. Because we laughed hysterically the whole weekend. And it was a real social—you can get beyond all that with people.

In various ways, support functions to manage uncertainty for people with HIV through control of information. Support seekers may want assistance in gathering

or interpreting information about their illness (Mishel & Braden, 1988). Alternatively, they may want to be sheltered against thinking about their HIV status, which signals a need for information avoidance.

Providing Instrumental Support

Having a reliable source of tangible assistance demonstrates stability in the relationship (Albrecht & Adelman, 1987), which might reduce or buffer uncertainty. Hugh described uncertainty about his illness progression and potential for opportunistic infections and how his mother's consistent reactions to health threats contributed to his sense of stability. He noted "You know my Mom's on the phone and I'm coughing, so she's on a Greyhound coming up here to take care of me." The unpredictability of his disease left him without a clear vision of his illness trajectory. His mother shared his experience, and responded supportively in situations of heightened uncertainty. Although she could not alleviate or explain his threatening symptoms, Hugh's mother was able to demonstrate that one aspect of his life (her assistance) was predictable.

Paul similarly noted that he found support from his mother to be a source of reassurance. He described one supportive interaction with her:

So I thought, "if all else fails, go back to what you know." So I went back to what I knew. And I called my parents on the phone and I said "I have 64 T cells." Mom says "well how many are you supposed to have?" And I said, "Thousands!" She says "quit your job and come home." You know, she said "you and Peter pack up and you just come home." So I called my boss and I said "I quit."

As was the case for Hugh and Paul, receiving instrumental support may enhance the perception of support availability that has been shown to be an important predictor of adjustment. These interactions "help perpetuate a working model of relationships as sources of security, reinforcement, and noncontingent support" (Albrecht et al., 1994, p. 431). This type of support availability is particularly relevant when the illness experience is framed by uncertainty.

Allowing Ventilation

Participants reported that having another person with whom to talk was a means of managing uncertainty by reducing stress or by making issues seem more concrete. Informational support may be complemented or supplemented by the opportunity to openly discuss salient topics. Hugh described the benefit associated with talking to another person with HIV:

If I was newly diagnosed today, I would love to have Greg to talk to because he's been through so much more. And not that he's going to fill me with a wealth of information, but he just knows what I'm going through because he went through it.

As Albrecht and Adelman (1987) noted, "the 'sounding board' function enables receivers to articulate their uncertainties and problems in ways that help them to be more objective and perhaps even resolve the troubling issues they face" (p. 33; also see Wortman, 1984).

Facilitating Skill Development

Supportive others also can facilitate uncertainty management by encouraging the person with HIV to develop coping skills. Brashers, Haas, Klingle, and Neidig (2000) argued that interactions with others living with HIV lead to the development of decision-making and self-advocacy skills. Carol noted that her husband encouraged her to begin information seeking and decision making:

I got yammered at by my husband. He also was diagnosed in 1989 and he was in and out of the hospital about five different times throughout 1989. And he kept putting more and more pressure on me to do something for myself. He knew his time was short. So December of '89 is when I started getting active with the university. Then he passed away in February. So by that time I was in the ddI [the antiviral drug didanosine] study and then I've been involved ever since then. And in March I got involved in a support group and became active in the community after that. The rest is history.

Development of skills may be necessary for individuals unfamiliar with health care settings (e.g., newly diagnosed individuals) or those who lack needed social skills. As Paul argued, "In some situations, you just need someone—*not* to do it for you, but to give you that boost and to guide you on the right path."

Providing Acceptance or Validation

Participants valued the symbolic affirmation that others could provide through social support. As Clark suggested, even when one knows information or how to cope, others can help reduce uncertainty by validating knowledge, plans, or feelings:

Yeah, sometimes I think maybe it's just not so much that you want the information from a friend as you want the support, that what you're doing is right, so that as you go on your way to the emergency room and you walk in and say, "yes, you need to go." You want that support that, "no, you're *not* being a hysterical middle-aged queen."

Validation or acceptance by supportive others helps increase confidence in the veracity of information, increase perceptions of relational stability, and decrease uncertainty (Albrecht & Adelman, 1987).

Encouraging Perspective Shifts

Others can encourage perspective shifts including reappraisal of uncertainty. Brashers, Neidig, et al. (2000) demonstrated that people living with HIV or AIDS reappraise uncertainty so that it is no longer threatening, perhaps by coming to view chronic uncertainty as a “normal rhythm to life” or as an opportunity to maintain hope (also see Mishel, 1990). Participants in our study noted that perspective shifts could involve refocusing on important questions about their lives. Kent described an interaction with his father, which helped him to focus on important decisions:

That day I went home and I had lunch with my father. And dad wanted to find out what these results were from these meningitis diagnoses. Dad came home and we were eating lunch, [and I said] “Well, I found out what the results of the tests were.” He didn’t even flinch. “Yep, what were they?”, expecting me to say negative. “Oh, I’m positive and the T-cell counts aren’t that great.” And he said the coolest thing, “So, how are you going to live?” Wow! Well, that’s the same thing I asked myself, so I made a few decisions.

On other occasions, supportive others pushed participants to face realities and to seek care for themselves, when they have avoided doing that. Daniel described an episode in which his partner encouraged him to seek care for his health:

Well, in my relationship, my doctor knows my partner, so she’ll call and give him results on the phone if I’m not there. [Facilitator: And is that okay with you?] Yeah, I mean, that doesn’t bother me, but when I first had the biopsy done on my skin for a mole to be removed and they said, “We want you to come back and have a little more cut out.” I said, “I’m not doing that.” And he said, “Yes you are. If that’s what they tell you, then you’re going to do it.” So, in some times, it was good. You know, it helped. Because I probably wouldn’t have done it.

Although Daniel decided to avoid further testing (perhaps to avoid negative information), his partner questioned his decision. Daniel accepted the advice and changed his uncertainty appraisal.

Support from others, including family, friends, peers, and partners was important for the management of uncertainty. As shown in the following sections, however, support is not without costs and complications, which can make uncertainty management difficult.

Costs and Complications Associated with Social Support

Our participants' narratives demonstrated that the role of social support in uncertainty management is not unproblematic. The problems associated with receiving support for uncertainty management were of two types. *Costs* were negative outcomes or risks that accompanied the useful uncertainty management functions of social support. These costs did not necessarily interfere with uncertainty management but represent drawbacks to receiving assistance. In contrast, *complications* were negative outcomes or risks of social support that created new forms of uncertainty or interfered with any assistance in uncertainty management that might be obtained by seeking support.

Costs of Support

There are costs associated with seeking or receiving support. For example, accepting support from others can diminish feelings of control over one's own circumstances. In a discussion of care partners who accompany participants to their appointments with physicians, Adam suggested

It's about keeping control as long as you can. Because, as Miguel said, we're losing control of so many aspects of our lives that as long as we can be our own best advocates, it's a good thing. I think it works for some people to take somebody [to an appointment], if they're not aggressive enough to pursue issues with physicians; but the longer you are living with this disease and dealing with physicians, the more assertive you become. And you want to hold on to that as much as possible.

Individuals with HIV also may want to *project* an image of being in control. This creates a "self-presentational dilemma" (Silver, Wortman, & Crofton, 1990) as support seekers try to simultaneously project an image of competence in coping while at the same time signaling a need for support.

Peer support can have costs as well. Groups for peer support may be difficult when members of the group become ill or die (Brashers, Neidig, et al, 2000). Friends and lovers in informal peer support networks also are vulnerable, which creates an added difficulty if support becomes unavailable because of severe illness or death *or* if the fear of such losses induces social withdrawal. James described the loss of his partner as a crisis event and turning point in his life:

I tested in '91 and at that time I had already been living with a lover who was positive. I started coming to his appointments at the clinic when I tested positive. I was a little more aware and, I guess, I didn't freak out until he died. Because, until he passed away, I always had him to talk about things with and he took me through the [AIDS] task force and he got me hooked up with the clinic, so once he passed away, that's when it hit me the most.

For individuals living with HIV who have contact with others who are HIV infected (as friends, family, or partner), chronic caregiving and repeated bereavement can be significant stressors (Miller & Cole, 1998). Greg explained

As far as losing friends goes, that's harder to take. When you get to know someone, you go through some tough times together and then you end up losing that person then that's kind of tough to take.

One of the pitfalls of peer support for people with life-threatening illnesses, therefore, is that they may lose part of their support system, which in turn may call into question their own mortality.

Complications of Social Support

Lack of coordination in uncertainty management assistance. Depending on their appraisal of it (i.e., whether uncertainty represents a threat or an opportunity to them), people with HIV may want to reduce, increase, or maintain uncertainty. Incongruence between the goal of the person with HIV and the actions of a support provider can present a dilemma. For example, the uncertainty management goal of the support seeker may be to avoid information to preserve uncertainty, yet the support provider may provide information. As James and Victor noted, difficulty in *avoiding information* may stem from support providers not understanding the goals of the support seeker.

James: I do have a lot of people that are all too willing, because they love me, they are all too willing to volunteer what I should be reading.

Victor: Sending you articles...

James: Yes, you know, and I get the phone call from mom, or people at work will say "oh, did you hear about this?" or "did you read that?" "No, I haven't yet, but I will now."

An individual with HIV may simply want emotional support, which may come at the cost of being subjected to new information. Given the complexity of uncertainty management, these misperceptions of goals may undermine adaptation.

Receiving social support can also prove problematic when individuals want confirming information but are met with disagreement or confrontation. Several participants noted that information seeking was often about confirming existing beliefs, rather than finding new information. Others reported a dispreference for negative information. For example, when his partner questioned the medical care that Edward was receiving (an area in which he had felt confident), a new form of uncertainty was created. Edward noted

I saw somebody for a long time who was a pain to deal with. He got mad. Not mostly at me, but whatever medical care I was getting was not good enough or whatever, and there was just a lot of anger there and I didn't want to deal with it. I mean, I was comfortable with the medical care I was getting, and I didn't think that I really needed to respond to his issues.

Similarly, Clark described uncertainty caused when his friends, who were usually his support system, questioned his decision to move to a new city:

I know when I moved here, every single friend of mine, without exception, was hysterical. "How could you move to a place in the middle of no where? When you have AIDS? What are you possibly going to do? I mean, *you have AIDS*. You can't go to a place like that."

Clark's friends created a new form of uncertainty when they expressed doubts about his decision. These examples demonstrate that attempts at supportive communication may stimulate the need for further uncertainty management when the goals of the support seeker are not met or when new forms of uncertainty are introduced.

Addition of relational uncertainty to illness uncertainty. Participants in our study noted that social support is differentially available from their social networks. People with HIV can have difficulty in maintaining close personal relationships because of the stress associated with the disease (Haas, 1999) and they often lack certainty about the support available from friends and family (Kimberly & Serovich, 1996). Although some participants in our study reported that they were important sources of support and information, others reported rejection by families and friends who stigmatized HIV illness because of its association with homosexuality or injecting drug use. Because they had experienced stigma and rejection, participants reported that they feared disclosure of their HIV status and felt less confident about their ability to elicit support from friends and loved ones. Ian explained his approach:

I haven't told anybody in my family. When I became diagnosed, I said, "you know I really *do* think there's a need there, but I can you better wait and think about this for, oh let's say, two years." Because when I told them I was gay, I kind of decided in the afternoon and told them in the evening. And it was very, very ugly. So I thought, I'm not going to have an ugly scene like that again, so I kind of have done that with everyone. My group of friends, you never know how they're going to react, so I thought about it a while and there are some people that I've told and there wasn't a real bad reaction, but I know not to mention it again. Don't tell about what studies you're in or what medication or how you're feeling. They know [about the HIV status], and that's all they want to know. But because of the uncertainty on a lot of things, treatments, relationships, telling people, jobs, I think about it a long time.

Dindia (1998) described this as a dialectical tension for people living with HIV. People may be motivated to avoid disclosure by the desire to avoid stigmatization or rejection (Cline & McKenzie, 2000; Derlega, Winstead, & Folk-Barron, 2000). On the other hand, as Alonzo and Reynolds (1995) noted, "by keeping the diagnosis secret, the individual is deprived of social support from his or her social network that presumably would be normally available to him/her" (p. 309).

The *anticipation* of rejection also led to decreased social support for some participants. Several reported they had not disclosed to family members, even years after diagnosis, because they expected negative reactions. As Rebecca found out, the prospect of rejection sometimes was worse than the real consequences of disclosure:

It took me two and a half years to tell my family. And I was positive that that was going to end my family relationships, especially my mother. And they really surprised me, they've been really supportive and have been there for me. If someone would've told me my mother would have responded in the way that she has, I would have told them they were full of shit. They did not know my mother. Well, I was wrong. I was the one who didn't know my mother.

The expectation of stigma or rejection can suppress support seeking as much as experienced stigma or rejection. Fears may be increased with the realization that disclosure results in a loss of control over the information, which may result in others disclosing the information to third parties.

Relational uncertainty also may come about when potential supporters avoid interactions with those who need support because it becomes too emotionally taxing (e.g., if HIV becomes the center of most conversations). Hugh recalled his friends' reaction to talking about HIV:

I've had friends say, "can we have a day without having to discuss this?" And I say, "yeah, *you* can have a day without discussing it because you're not infected." But it's not a choice. I don't feel it's a choice on my part. But it would be nice, I guess, at times to just not have it in the back of your head.

Thus, individuals may seem to withdraw support if they experience stress due to talking about HIV, which can threaten the sense of relational stability and support availability.

Burden of others' uncertainty management. Family and friends also experience uncertainty (Brown & Powell-Cope, 1991), which may heighten the uncertainty of the person living with HIV. Seeking support comes at the cost of causing worry for the other person, as Adam demonstrated:

There are times when I wish my partner would want to know more and take more of an interest, but there's not any there. So it's just easier for me to say, "No, don't bother." That's just kind of the way it is. So that can be a source of stress. And I think a stress on the relationship because of him not knowing and being uncertain about what's going on and—I've had a lot of different health issues—can make him kind of crazy. But at the same time, he really doesn't want to know, and it's kind of—so it's a really odd place to be in our relationship.

People with HIV who have support needs find themselves in the quandary of worrying about the other's needs (may lead to concealment of HIV-positive status, see Mason, Marks, Simoni, Ruiz, & Richardson, 1995), perhaps creating a new source of uncertainty. Vic noted

I just don't think there's any kind of objective distance that somebody who's emotionally involved with you can have handling your medical care. And we've talked about it several times, you know, it's probably really for the best that he allow me to do it by myself and to rely on him when I need to, you know, about practical things.

Participants reported problems in support seeking associated with concerns about others' support needs. In addition to not disclosing, because of fear of rejection, some reported not disclosing their HIV status to others because of a desire to spare them uncertainty or anxiety associated with the news.

Managing Costs and Complications

Participants reported a variety of strategies for managing the costs and complications associated with social support in uncertainty management. One method for handling supportive interactions was by *developing an active or self-advocating orientation* (see Brashers, Haas, et al., 2000; Brashers, Haas, Neidig, & Rintamaki, 2002). Peter explained that he felt his support group was different because

there are things that we're empowering ourselves to do so that we can be an active part of this instead of sitting back and waiting for someone to bring the information to us. And that's what I mean by empowerment rather than support, you know.

As part of the active orientation they developed, participants stressed the importance of using multiple sources and being vigilant in information seeking.

Others reported managing dilemmas by *reframing support attempts*. Wayne reframed the loss of control he felt by focusing on the possible benefits to support providers. He explained that

I find, in terms of advocacy, there are two people in particular in my life that, in me allowing them to be an advocate for me, seems to be sort of a healing process for them,

or a coming to terms with the disease that I have. One is my dad. My father will call me long distance and say, “Hey, I read so-and-so and so-and-so. What do you know about this? What do you know about that?” And at first, I reacted in my own typical way—to me, he was taking control of my situation at first. But I had to think a little deeper. And I realized that, hey, this was a way of him mending his heart with regard to me having this disease. And the other is my fiancée, who is more interested in this whole process than I am, and again, it’s a process of coming to terms with her. I don’t know if it’s necessarily healing, but it’s coming to terms with it. And so, I let certain people take on that responsibility. It’s not that I don’t do for myself. I certainly can talk enough to be my own advocate, I have the gift of gab, yet I believe that sometimes people need that just for their own coming to terms with it.

Participants reported also *accepting a lack of support* from some in their lives. Greg’s relationship with his mother changed when he recognized that she was not available to him for support:

I asked my mom to come to help take care of me when I had PCP the last time and she said that she couldn’t because my sister was eight months pregnant and she wanted to be there for her. And my sister was married and had a husband to take care of her. So my partner had to take five weeks off of work. Sick leave and vacation to take care of me because she couldn’t. *Wouldn’t*. [Facilitator: How do you deal with that?] Well, I get pissed off. I’ve grown away from my parents. I still have a relationship with them. It’s a different kind of relationship than what I am used to. We’re civil to one another. We speak to one another. But the closeness isn’t there. I don’t think the respect is there. And I also realize that they’re not going to come over to my side, I’m sure as hell not going to go over to their side. So this is the way it’s going to be. And, like I said I draw my support from the friends in my life. And I don’t need to deal with that. I don’t have to deal with her stuff.

When Greg realized he was unable to elicit support from his mother, he shifted his focus to others who were available for support

Others argued that *withdrawing from social situations*, such as those in which peer support was available, was necessary for the uncertainty management goal of avoiding negative information. Being in situations where others were sick or dying created an alarming certainty—the likelihood of death. Bruce recalled that he “withdrew because it was too much.” He added, “I haven’t been to a support group probably in two years. I’ve buried all the friends I want to bury, and I’ve stopped putting, associating myself with those people I was burying. How could you live and keep thinking you were dying?” Withdrawal allowed Bruce to avoid negative certainty, perhaps allowing him to maintain a comfortable level of uncertainty about his own prospects for survival.

Another method for managing dilemmas was *selectively allowing others to be support persons*. Because disclosure of information about his condition could lead

to the need to support others, at a cost to his own adjustment, Edward noted that “I love my family to death, but I let them in on a need to know basis, because it’s just too difficult to explain anything. There would just be some things that they just wouldn’t understand.” Later he added, “Actually, I like bringing people [to medical appointments] who I think might be able to contribute something. I don’t like bringing people who need to be educated themselves. I don’t want to do that. It’s too time-consuming.” Rebecca noted that she avoided disclosure to some individuals because of her perception about their reactions: “Some of my friends would not deal with it. You can just tell. They tell AIDS jokes, or whatever. You know, they’re just narrow minded enough. I think they would still like me, but it would just be different.”

Maintaining boundaries also was an important means of managing problems with social support and uncertainty management. Vic described the boundaries that he and his partner, a physician’s assistant, established for his partner’s role in Vic’s healthcare:

He’s the one who urged me to approach the university and a couple of doctors in particular because he knew them from way back and could get me in to be seen. Beyond that, he really does not try to influence my own medical care. I think that that’s probably for the best because, if he did, if he tried to, it’d be like pushing my natural button and I would come to rely on him to try and fix everything.

To maintain boundaries, Alan argued that those in need of supportive communication needed to filter messages they received:

I think the important thing is to maintain boundaries. Because I know my mother is well meaning, but sometimes there’s a shaming message in it. I remember over the summer, my T count dropped some, and she said, “well, school’s out, I thought that it would be going up,” which being interpreted is, “Why do you allow yourself any stress in the summer? You’re the reason your T count is falling. You’re not doing enough, you’re not good enough.” That was the message I was taking from it.

In summary, participants reported managing uncertainty through social support. These results are used to extend theories of social support and uncertainty management in the following section.

SOCIAL SUPPORT IN THE THEORY OF UNCERTAINTY MANAGEMENT

Our results demonstrate that social support is important in the experience of uncertainty. These results make important and unique contributions to the literatures of social support, uncertainty management, and coping with HIV infection. First,

there is a wealth of research that explores the association between social support and various outcomes (e.g., mental and physical health, quality of life, or adherence with medications), but little is known about the *processes* that link social support to those outcomes. Our study focused on uncertainty management as a pathway through which social support has positive and negative effects. The results support conceptualizing these positive and negative effects as a function of how well interactants manage conflicting goals and dilemmas, as predicted in Albrecht and Adelman's (1987) theory of social support. Second, our study highlights the interactive nature of uncertainty management. In their theory, Brashers, Neidig, et al. (2000) focused on the role of cognitive appraisal and behavioral or psychological action in uncertainty management. This study extends that theory by outlining the ways in which social support is *assisted* uncertainty management. That is, we recognize the communal or collaborative nature of coping with stressors—a fundamental principle in some theories of social support (Lyons, Mickelson, Sullivan, & Coyne, 1998). Interdependence can be the source of facilitating and inhibiting influences on coping efforts (Coyne, Ellard, & Smith, 1990). Third, our results contributed to the research evidence that social support and uncertainty management are important processes for people living with HIV. Social determinants of health and well-being for this population are of increasing concern for people with HIV as a chronic condition. In the following sections, we elaborate these three contributions by discussing how social support can serve important functions in uncertainty management for people living with HIV. This is especially important in accounting for mixed effects of support in previous literature and in providing a basis for practical recommendations.

Communication and Uncertainty Management

Supportive communication is important in interpersonal relationships (Goldsmith, 1992, 1994, 2000) and in health care contexts (Adelman & Frey, 1997). The desire to manage uncertainty arises from a need to make decisions, to solve problems, to maintain a coherent identity, and to develop and sustain relationships. The role of social support in managing uncertainty is complex. Supportive others participate in uncertainty management by assisting with information seeking and avoiding, providing instrumental support, facilitating skill development, giving acceptance or validation, allowing ventilation, and encouraging perspective shifts. The mechanisms by which these supportive acts facilitate uncertainty management parallel the processes of awareness, evaluation, and action (i.e., how people experience, appraise, and manage uncertainty; see Brashers, Neidig, et al., 2000). Our study shows that supportive others enhance these processes as (a) sources of uncertainty or certainty, (b) influences on the process of uncertainty appraisal, and (c) assistants in the uncertainty management process.

Supportive others can affect the *experience of uncertainty* by providing a sense of relational stability (through the validation, ventilation, or instrumental support functions). The illness experience includes personal, social, and medical forms of uncertainty. Supportive others help minimize social uncertainties when they engage in acts that project availability of support and lack of stigmatization or rejection. Supportive others can influence *appraisal processes* by encouraging perspective shifts or reappraisals of uncertainty. Based on interactions with members of their support networks, people come to refocus on important questions, to reappraise uncertainty as either a danger or an opportunity, or to change their perspective to view uncertainty as a normal part of life. Supportive others can affect *uncertainty management processes* by providing direct or indirect assistance with information seeking and avoiding. They can be sources of information (e.g., peers or coworkers who share similar experiences with the support seeker), collaborators in information gathering, and evaluators of information, or they can serve as buffers against information. They also facilitate information management by encouraging development of information-seeking and decision-making skills.

Peer support appears to be particularly useful for uncertainty management. Peers can provide experiential information and may be less likely to be judgmental or to stigmatize. It was evident from our data that peers provide support, which assists with managing personal, social, and medical forms of uncertainty for individuals living with HIV. For example, participants reported that peers could describe symptoms of HIV and side effects of medications with greater clarity and accuracy than health care providers or others, which helped to increase attributional confidence and event coherence.

Supportive communication to manage uncertainty presents costs and complications that become dilemmas for support seekers, however. Peer support may be difficult when the experiences of the support provider are negative or threatening. For people with HIV (or other life-threatening illnesses), supportive others may die or become too disabled to provide support, which can call into question the health and well-being of the support recipient. The need for *mutual* support among peers may increase stress and anxiety (although the opportunity for reciprocation might predict satisfaction with support, see Barroso, 1997). Social support also can undermine uncertainty management efforts when the goal of the support seeker is incongruent with the actions of the support provider. Support provision can *match* the support seeker's goal, such as when acquiring information is the goal and support providers assist in the information search. Or support provision can be *mismatched* to the goal, such as when avoiding information is the goal and support providers give information. Dilemmas also result when support providers challenge the support seeker's uncertainty appraisals by encouraging reappraisal.

Uncertainty management efforts also are complicated when support seekers have multiple conflicting goals, such as when managing identity conflicts with managing uncertainty. Our participants reported the self-presentational dilemma

of needing to represent oneself as coping effectively while at the same time in need of support (also see Silver et al., 1990). Others reported that the need to protect themselves (e.g., to avoid rejection or to maintain control) or the desire to spare others the uncertainty and anxiety associated with the illness led to nondisclosure of HIV status, which in turn led to decreased social support. This supports Goldsmith and Fitch's (1997) contention that an explanation of the effects of advice or support "needs to consider not only informational effects but also effects on the identities and relationships of the participants and the features of discourse that are more or less responsive to these multiple and potentially conflicting demands" (p. 455).

Failure to elicit support may sustain existing uncertainty or create new forms of uncertainty. Participants in our study noted that social support was differentially available from their family and friends for the reasons mentioned above. Although some participants in our study reported that their families were important sources of support and information, others experienced or expected rejection from their families because of the stigma of HIV infection. Our results support and extend past studies of the important role of familial involvement in social support of people with HIV (e.g., Schwarzer, Dunkel-Schetter, & Kemeny, 1994; Siegel & Krauss, 1991). As Turner, Hays, and Coates (1993) found, "family appear to have the potential to be particularly helpful or especially harmful to gay men trying to cope with the AIDS crisis" (p. 37).

The problems that lead to dilemmas of support can be managed by developing an active or self-advocating orientation, reframing supportive interactions, withdrawing from nonproductive social situations, selectively allowing others to be support persons, and maintaining boundaries. Uncertainty can be resolved when there are matches *or* mismatches of actions and goals, either because the original goal is achieved or because a new goal is formed as a consequence of interaction. Reappraisals can lead to new perspectives and new uncertainty management goals as well. Unachieved goals or new forms of uncertainty lead to on-going appraisal and management.

What we labeled costs and complications associated with social support are parts of the unfolding experience of uncertainty and its management (see Babrow, Hines, & Kasch, 2000). Managing these dilemmas likely involves realigning goals and actions to facilitate decision making, problem solving, identity management, and social integration. Personal growth across the HIV illness trajectory may likewise affect people's experience of uncertainty and social support (Siegel & Schrimshaw, 2000). Our approach to the study of support presumes that, in addition to any assistance that is provided, social support also carries messages about the participants' identities and relationships. These multiple goals can be sources of conflict and dilemmas; however, support recipients may also develop strategies for managing these dilemmas. Consistent with this assumptive framework, our findings reveal that how recipients choose to interpret or frame the identity and re-

lational implications of support can make a difference in whether support aids or interferes with uncertainty management. For example, social support could come at the cost of perceived dependence on another; alternatively, some support recipients were able to take advantage of help in managing uncertainty by adopting an identity as *empowered* or *activist*. Although the objective properties of the information or aid they received might have been the same, the incorporation of giving and receiving support *within an empowered identity* resulted in a more positive interpretation of receiving support. Another example comes from those respondents who recognized the relational meaning and significance of allowing others to give support, even if the assistance they provided was only minimally useful to their own uncertainty management attempts. An awareness of the relational dimension of support giving and receiving allowed these participants to look beyond the narrow informational utility of support and to recognize other ways in which support might be useful (also see Haas, 2002). These examples have implications for intervention: Helping people living with HIV or AIDS to become aware of the multi-dimensional nature of support (i.e., its meaning and utility for uncertainty management and for identity and relational definition) may help them utilize support that is available in their environment.

The efficacy of support attempts depends on cooperative influences between the support seeker and support provider (Ell, 1996). Individuals may choose different methods for seeking or providing support that may be more or less effective given situation-specific circumstances. For example, the solicitation of support may be direct (e.g., asking for advice or information) or indirect (e.g., disclosing a problem) (Goldsmith, 2000). The support seeker's preference or dispreference for directness may depend on his or her concern for managing face needs (Goldsmith, 1992), perhaps based on expectations or experiences that contribute to relational uncertainty. The effectiveness of direct versus indirect strategies may depend on how support providers perceive those messages. The effectiveness of seeking social support as a coping strategy can differ from individual to individual due to differences in communication skills in social support seeking (Schwarzer & Leppin, 1992) or in reactions of potential support givers (Herbert & Dunkel-Schetter, 1992). In similar situations, one individual may offer support by assisting with information seeking whereas another might encourage reappraisal.

Choice of support source is a key strategy for responding to dilemmas (e.g., withdrawing from those whose costs and complications threaten to outweigh benefits, accepting a lack of support from some people and then seeking help elsewhere). However, the choice of the most helpful source did not fall out neatly according to types of relationships (as has been suggested in previous research). For example, peers were identified as the most credible sources of information but peer support was also particularly risky because of peers' own vulnerability to stress and loss. Help from family carried potent individual and relational symbolism. Family members were the sources of some of the most valued and meaningful sup-

port and the source of some of the greatest fears and most hurtful interactions. Our findings regarding peers and family members as sources of support suggest that relationship type alone cannot account for when support will be helpful or harmful to uncertainty management. How support is communicated and interpreted (e.g., messages of acceptance, rejection, credibility, or understanding) makes a difference in a recipients' evaluation of the support.

This study relied on participant reports of interactions to determine their perceptions of the ways in which close relational partners can facilitate or interfere with uncertainty management for people living with HIV or AIDS and to describe communication responses to these dilemmas that may vary in adaptability and satisfaction. Future research should focus on support messages to determine the discursive features that yield successful uncertainty management efforts (Goldsmith & Fitch, 1997). Given that supportive communication had the potential for positive and negative effects, interventions that teach people to increase social support in *adaptive* ways are needed (see Lutengorf et al., 1998 for an example). Support seekers and support providers need to be aware that the successful management of uncertainty and stress involves coordination of complex goals and actions. Support providers can be taught about the broad range of behaviors that can facilitate uncertainty management, including such things as collaborating in information gathering and encouraging self-advocacy skill development. Support seekers can be taught strategies for managing dilemmas of social support, including how to select support providers and how to frame support situations.

CONCLUSION

The integration and extension of theories of social support and theories of uncertainty management is a move toward understanding the interactive, collaborative nature of uncertainty management. Our results contribute to the growing body of research on the mechanisms through which support has effects (i.e., by uncertainty management), the dilemmas of utilizing support in adaptive ways, and the strategies for managing these dilemmas.

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