

# Collective AIDS Activism and Individuals' Perceived Self-Advocacy in Physician-Patient Communication

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*In a study of AIDS activism and communication patterns between people with HIV or AIDS and health care personnel, parallel persuasive processes are described between social or political activism and personal self-advocacy. The analysis of public and private discourse leads to 3 interrelated conclusions about AIDS activist behaviors at the collective and individual levels: (a) greater patient education about the illness and treatment options is encouraged, (b) a more assertive stance toward health care is promoted, and (c) mindful nonadherence is considered. Activists perceived that their self-advocacy behaviors, in turn, impact the physician-patient interaction. In communicative interactions, education allows patients to challenge the expertise of the physician, assertiveness allows them to confront paternalistic or authoritarian interactional styles, and mindful nonadherence allows them to reject treatment recommendations and offer reasons for doing so. Participants reported that physicians had mixed reactions to their self-advocacy attempts.*

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Individuals in society are situated within groups and organizations—social collectives that are produced and reproduced through interaction. The idea that individuals are embedded within larger social units is reflected in communication-related conceptions of chaos theory (e.g., Witte et al., 1996), systems theory (e.g., Fisher, Glover, & Ellis, 1977), the bona fide groups perspective (e.g., Putnam & Stohl, 1990; Stohl & Putnam, 1994), and perspectives on relational communication (e.g., Wilmot, 1995). In these theoretical perspectives, communication is thought to connect individuals to the collective and to create and maintain collective identities.

Others have suggested important relationships among the attitudes, intentions, and behaviors of individuals and collectives (Alexander, Giesen, Münch, & Smelser, 1987). Schelling (1978) argued that micromotives (i.e., the motivations behind individual behaviors) and macrobehavior (i.e., the behaviors of aggregates) are closely linked. He noted that his theoretical purpose was to “explore the relation between the behavior characteristics of the *individuals* who comprise some social aggregate and the characteristics of the *aggregate*” (p. 13). According to his theory, individuals operating in aggregates are likely to be influenced by the behaviors of others in the aggregate, thus “we usually have to look at the *system of interaction* between individuals and their environment, that is between individuals and other individuals or individuals and the collective” (Schelling, 1978, p. 14). Because of this, to study collectives we should “inquire first of all what it is that the individuals in the system seem to be doing and how it is that their actions, in large part, produce the patterns we see [in the collective]” (Schelling, 1978, p. 22).

In related theory and research, W. A. Gamson and colleagues (W. A. Gamson, 1979, 1990, 1992a, 1992b; W. A. Gamson, Fireman, & Rytina, 1982) argued that the nature of collective action is, in large part, dependent on the characteristics of individuals who comprise the group. As an extension of resource mobilization theory, W. A. Gamson et al. (1982) maintained that, on one hand, individuals who mobilize for collective action bring skills and assets to their encounters with “unjust authorities.” On the other hand, the collective learns as it mobilizes, suggesting that individuals adopt behavioral patterns and structures based on their experiences in collective action.

The connection between the collective and the individual also has been explored by Adelman, Frey, and colleagues in a research program on communication and community in a residential facility for persons living with a Human Immunodeficiency Virus (HIV) infection or an Acquired Immune Deficiency Syndrome (AIDS) diagnosis. Frey, Adelman, and Query (1996) offered that “communication intertwines psychological, physical, and collective worlds” (p. 383; see Brashers & Babrow, 1996, for a related

idea). Because these worlds are linked, they reasoned, collective communication practices shape and constrain an individual's interpretations of health and illness experiences. Among the dialectics that Adelman and Frey (1994) noted in their studies of the AIDS residential facility are the tensions between (a) private life and public life and (b) individual identity and group identity. At the same time Adelman and Frey recognized the tensions between individual and group levels of identity, they acknowledged the important relationship that exists between behaviors at each level. As Adelman and Frey (1997) argued, "from a dialectical perspective, the individual and the collective are two sides of the same coin—one cannot exist without the other" (p. 2).

In the present paper, we begin to extend the theoretical ideas of Schelling, W. A. Gamson, and Adelman and Frey. What is not explicit in these theories is a conception of how communication behaviors at each level (the collective and the individual) might be reciprocally influencing. We propose that behaviors of the collective simultaneously influence and reflect the behaviors of the individual that, in turn, can impact the dynamics of the relational encounters. Belonging to a collective may familiarize members with certain sorts of strategies that they will subsequently enact in situations in which they are acting as individuals (i.e., out of the context of the collective). On the other hand, individuals may bring to the collective and to relational encounters strategies specific to them as individuals.

The current study lays the groundwork for subsequent investigations of the possible reciprocal causal relationships between collective and individual behaviors. Specifically, the current study establishes parallels between these two levels of action and examines the participants' own understanding and experiences of these parallels in the context of living with HIV or AIDS. Research on the social effects of an HIV infection or an AIDS diagnosis is a fertile ground for examining the relationships among collectives and individuals. People with HIV or AIDS have become one of the most organized groups of individuals experiencing a chronic or life-threatening illness. Perhaps because of the high need for practical and experiential information (Brashers, Hass, & Neidig, 1999) or because of the stigma associated with HIV or AIDS (Adelman & Frey, 1997; Frey, Adelman, & Query, 1996), many community-based organizations, activist and advocacy groups, and elaborate social networks have formed. AIDS activists engage in activities to promote participation in health care decision making and to give persons living with an HIV infection or AIDS the tools needed to become persuasive agents in health care interactions (Brashers & Jackson, 1991; Fabj & Sobnosky, 1993, 1995; J. G. Gamson, 1989; Melcher, 1995) and to affect how AIDS is "popularly understood" (Sobnosky & Hauser, 1999, p. 26; see also Christiansen & Hanson, 1996).

The specific aims of the current study are (a) to demonstrate the important parallels between social activism (defined as persuasive communication behaviors of a collective that are intended to serve the common interest) and self-advocacy (defined as persuasive communication behaviors of an individual that are intended to serve the individual's interest) and (b) to describe patients' perceptions of how their activism and self-advocacy affects communication patterns between themselves and health care personnel.<sup>1</sup> To accomplish these goals, we address two research questions:

- RQ1: What collective and individual behaviors are associated with AIDS activism?  
 RQ2: How are these behaviors perceived by activists to influence physician-patient interactions?

To answer these questions, we first highlight the literature on AIDS activism. Next, we overview literature on physician-patient communication to provide a basis for analyzing the relational impact of activism. We then investigate the parallel behaviors of collective AIDS activism and individual self-advocacy in physician-patient communication by examining data from activist documents, participant observation of activist meetings, interviews with activists, and finally, open-ended questionnaire responses of individuals with HIV or AIDS. Finally, we discuss the results of this investigation and offer implications for future research.

### AIDS Activism

AIDS has been one of the most significant health and social crises of the past 2 decades. The Centers for Disease Control and Prevention (CDC, 1998) reports that AIDS is among the leading causes of death in adults between the ages of 25 and 44 in the United States, with over 641,000 cases of AIDS and 390,000 deaths from AIDS reported by the end of 1997. With more efficacious treatments, life expectancies of persons with HIV or AIDS have increased in recent years and AIDS has come to be viewed as a long-term chronic illness (Nokes, 1991), although it remains a disease marked by high degrees of uncertainty about illness progression and treatments (Brashers, Neidig, Cardillo, Dobbs, Russell, & Hass, 1999; Brashers, Neidig, Reynolds, & Haas, 1998; McCain & Cella, 1995; Weitz, 1989).

Because the disease produces significant life-altering changes, more needs to be known about how living with HIV or AIDS affects collective and individual communication patterns (see Derlega & Barbee, 1998, for a discussion of many social and interactional issues associated with HIV infection). Collective communication practices toward those with chronic

illnesses such as HIV infection often produce social isolation (Biordi, 1995) or stigmatization (Saylor, 1995). On the other hand, collective communication practices (such as bereavement rituals, see Adelman & Frey, 1997) can help persons with HIV or AIDS manage their need to grieve over the loss of others with AIDS and cope with their own potential deaths. On both the collective and individual levels, communication patterns can be altered because of the need to exchange information that will help manage uncertainty about HIV illness and its associated treatments (McCain & Cella, 1995; Weitz, 1989) as well as the need for caregiving and social support (Hays, Catania, McKusick, & Coates, 1990; Hays, Turner, & Coates, 1992; Johnston, Stall, & Smith, 1995; Miller & Zook, 1997; Nicholas & Webster, 1993; Zook & Miller, 1993).

One communication implication of the AIDS crisis that has not received sustained attention is the rise of activism among persons living with HIV or AIDS and their supporters. The best known example in the United States of an organized activist group dedicated to promoting the rights of individuals with HIV or AIDS is ACT UP (the AIDS Coalition to Unleash Power). ACT UP was formed in March 1987 in New York City in response to the slow action taken by government and federal agencies responsible for AIDS research and drug approval (e.g., the Food and Drug Administration). Political and religious organizations also have been targeted by the group. According to ACT UP, the Catholic church's objection to condom use slowed AIDS education efforts, leading to protests at New York's St. Patrick's Cathedral. The group is dedicated to promoting the rights of individuals with HIV or AIDS by critiquing and challenging the existing power structures. As Brown (1997) notes, "ACT UP's goal is to challenge existing hegemonies around AIDS. ACT UP has striven to provide a counterhegemony to the prevailing social understanding of AIDS" (p. 60).

Today there are ACT UP chapters in over 60 cities across the United States, including New York, San Francisco, Washington, Philadelphia, and Cleveland, and abroad in cities such as Berlin, Moscow, Paris, and London. Comprised of people living with HIV or AIDS and their supporters (e.g., families and friends of persons with HIV or AIDS), ACT UP defines itself as "a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis" (ACT UP New York, 1999c). ACT UP's logo ("Silence = Death") often appears on T-shirts and posters over a pink triangle (an inverted version of the symbol used to identify homosexuals in Nazi concentration camps during World War II). Public demonstrations are aimed at bringing the AIDS crisis to the foreground of public concern because, ACT UP argues, too little governmental and public concern have slowed efforts toward AIDS relief. ACT UP groups stage "die-ins," in which activists lay in the street and have

their outlines chalked, as though they were homicide victims. ACT UP chapters have organized events such as funeral processions in which members carry coffins and protest signs down busy city streets to stop traffic in protest of continuing deaths from AIDS and have lowered banners and blown whistles on the floor of the New York Stock Exchange to halt trading in protest of high drug prices.

Thus, on one level, ACT UP and related activist organizations focus on social or institutional changes through assertive confrontation. These are the activities that have been discussed most frequently by the media and scholars alike. Brashers and Jackson (1991) demonstrated that ACT UP has been largely responsible for altering drug approval processes at the Food and Drug Administration by engaging the medical scientific community in a dialogue that ultimately "changed its practices and its presumptions about the generation of knowledge" (p. 287; also see Byar et al., 1990). Fabj and Sobnosky (1995) argued that ACT UP used publicity about AIDS treatment research to bridge public and technical debates, which forced medical researchers to be accountable to public scrutiny. Through its influence on researchers, government agencies, and pharmaceutical companies, ACT UP has "changed forever the way medicine is done in America" (Fabj & Sobnosky, 1993, p. 108).

On another level, ACT UP attempts to affect the beliefs, attitudes, and behaviors of those who are HIV infected or who have AIDS. For example, in addition to political and social activism, ACT UP is devoted to providing the latest health-related AIDS information to people living with HIV or AIDS. This information is intended to enable people living with HIV or AIDS to participate more fully in health care decision making. However, little or no attention has been directed at these individual changes and how they are affected by collective actions and, in turn, affect important social outcomes, such as the interpersonal communication patterns of activist patients and their health care providers. AIDS activists become persuasive agents at the collective level (i.e., focusing on social or institutional changes) and the individual level (i.e., advocating for their own needs).

### Physician-Patient Interaction

One context in which activists advocate for themselves as individuals is within the physician-patient interaction. Traditionally, physicians and patients have interacted within a relationship in which physicians have been afforded an asymmetrical position of authority largely because of their expertise. In the last decade, researchers have observed a gradual shift in attitudes of physicians and patients about physician-patient encounters from a traditional, paternalistic model (Parsons, 1951) to a model

based on consumerism (Beisecker & Beisecker, 1993).<sup>2</sup> Although patients generally have expressed a desire for increased control and information in their interactions with physicians (Ballard-Reisch, 1990; Beisecker & Beisecker, 1993; Waitzkin, 1984, 1985), current evidence does not indicate that patients have adopted behaviors that promote equality in the physician-patient encounter (Guadagnoli & Ward, 1998). In one study, Haug and Lavin (1981) found that a large proportion of patients held consumerist attitudes toward medical care, yet very few reported actual instances of challenging or assertive behavior with physicians. Robinson and Whitfield (1985) reported that patients in medical interviews are "loathe to ask questions because they are afraid of wasting the doctor's time, because they think it is inappropriate for them to do so, or because they do not wish to challenge the doctor's authority" (p. 916). Klinge (1993) demonstrated that patients only felt free to ask questions and offer their opinions when medical consultations were longer than 19 minutes. In sum, although patients generally desire more information from their physicians, they do little to elicit it (Beisecker, 1990).

The problem is exacerbated by physicians who generally prefer not to be questioned during medical consultations (Frankel, 1986), because the act of questioning often is perceived as a threat to physicians' authority and a loss of valuable time (West, 1983). Often, when physicians perceive that inadequate time is available for the medical consultation, they attempt to retain control over the pace and structure of the interaction by avoiding questions, giving ambiguous responses, or changing the topic (Beisecker, 1990). When physicians perceive that patients are attempting to control the interaction, many utilize dominant or control behaviors in response to similar behaviors by active patients. For instance, Beisecker (1990) reported that many doctors, when confronted with questioning patients, try to reassert control by "questioning the patient's intelligence, letting the patient know that the doctor had incredible intelligence, and questioning the patient's stability or normality if the patient wanted a different treatment" (p. 114). Cerling (1989) also found that assertive patient communication that challenges physicians' knowledge leads to physicians forming negative impressions of patients and, subsequently, engaging in less pleasant communication styles.

Thus, the asymmetrical position of authority afforded physicians is a process that is both encouraged and sustained by behaviors of physician and patient. On one hand, although patients often desire to participate more in health care interactions (perhaps to become more participative in decisions made about their health care), they frequently do not assert this desire. On the other hand, physicians are trained and often conduct the medical interview in a way that discourages, rather than encourages, patient input.

*Summary.* One group of individuals that has been particularly aggressive in challenging the traditional medical model of health care in the United States is AIDS activists. Because these behaviors are a challenge to traditional power structures in health care, they have the potential to impact the physician-patient relationship. In the following sections, we describe a study designed to study communication in social activism and self-advocacy.

## METHOD

This study is part of a larger study of AIDS activism. For the present portion of the study, data were collected in two phases. The first phase focused on the communication of the collective (i.e., ACT UP chapters). The second phase addressed the perceptions of individual participants (persons living with HIV or AIDS) who were exposed to and involved in the communication behaviors of the collective. Each phase is detailed below.

### Phase 1

In the first phase, three qualitative methods of data gathering and analysis were triangulated.<sup>3</sup> First, over a period of 4 months, the first author engaged in participant observation of regular business meetings, special meetings of the education committee, and demonstrations of an ACT UP chapter in the central United States. Major issues and collective strategies were observed during that time. For example, issues of concern for the group included (a) discriminatory immigration policies, (b) the lack of widely available anonymous HIV testing, and (c) the lack of AIDS prevention educational guidelines for high school students. Strategies for change included (a) demonstrating at the local health department and immigration and naturalization service office, (b) distributing leaflets at a meeting of the state's high school principals, and (c) "wheat pasting" (i.e., gluing posters) near gay bars to encourage safer sex.

Second, during the time period in which the local ACT UP chapter was being observed, a list of ACT UP chapters from throughout the United States and Europe was obtained from ACT UP in New York. These chapters were contacted by mail to solicit information about their local organizations. Informational and educational documents were collected from ACT UP chapters in the United States (New York, Los Angeles, Long Beach, Philadelphia, Minneapolis, Oklahoma City, San Francisco, Shreveport, and Puerto Rico) and Europe (London, Paris, Moscow, and Berlin). The documents included new member information packets, leaflets and fliers from many different demonstrations, educational materials for activists, news-

letters, and press releases. These documents were analyzed for themes related to activist approaches to health care communication. Two of the authors read the materials to extract themes that, taken together with information collected through participant observation, provided a theoretical basis for understanding influences and strategies of activist communication in the health care environment. In particular, the documents were examined for elements that appeared to be critical to collective or individual activism. Key issues were discussed by the two authors until agreement was reached on three predominant themes (described below). Additional documents were collected during subsequent years from the members of various ACT UP mailing lists as well as from World Wide Web sites of several ACT UP chapters and were used to supplement this analysis.

Third, during that same time period, interviews were conducted with a sample of five members of that ACT UP chapter. Five members were deemed a theoretically adequate sample because (a) the five members interviewed were considered key opinion leaders in the group by the members of the ACT UP chapter; (b) the purpose of the interviews was to validate information obtained from participant observation and document analysis; (c) the responses across individuals were relatively consistent, which demonstrates redundancy or saturation (Strauss, 1987); and (d) the ACT UP chapter was relatively small (the number of individuals at most meetings ranged from 5 to 10). These interviews were mainly open ended and were used for clarification and to seek face validity of initial themes derived through participant observation and textual analysis. In general, the interviews focused on the salience or importance of various issues addressed by the ACT UP chapter and individual perceptions of the relative success and nonsuccess of various strategies for preparing for social confrontation, such as educating oneself about health care issues and technical information prior to engaging in debates with scientists or encouraging assertive styles of interaction. Motivations for belonging to an activist organization also were addressed. Because these interviews were highly informal and unstructured, general notes of the interviews were kept, as opposed to detailed transcripts. Using the method of constant comparative analysis (Glaser, 1978; Glaser & Strauss, 1967; Strauss, 1987), data collection, sampling, and analysis occurred simultaneously as this part of the study progressed.

As a result of this phase of the study, three dominant themes emerged as constructs underlying collective activism: (a) encouragement of greater education about issues and technical information in health care, (b) a more assertive stance toward health care, and (c) mindful nonadherence as reasoned decision making. These three themes were identified by two authors and verified by interviewees as important precursors to collective

action.<sup>4</sup> Brashers and Klingle (1992) reported a preliminary analysis of the theoretical implications of our observations of Phase 1. To further investigate the validity of these themes, and to explore the effect of these collective level dimensions on individual level behaviors and relational encounters, a sample of self-identified activist patients was sought to provide open-ended responses concerning their perceptions of their interactions with health care personnel. This data collection and analysis is described as Phase 2 of this study.

## Phase 2

In this phase of the project, a sample of 174 adults with HIV or AIDS was obtained from 2 AIDS service organizations ( $n = 33$ ), 10 AIDS activist organizations from throughout the United States ( $n = 31$ ), and an AIDS clinical trials unit at a large Midwestern teaching hospital ( $n = 110$ ). Participants in this sample self-identified as being HIV positive ( $n = 79, 45.4%$ ) or as having AIDS ( $n = 92, 52.9%$ ).<sup>5</sup> The mean time since diagnosis was 57 months ( $Mdn = 48$  months, range = 1 month to 156 months,  $SD = 40.59$  months). The sample was composed of 155 males (89.1%) and 16 females (9.2%). Of those, participants were included in the analysis for the current study if they met one of two conditions: (a) reported membership in an AIDS activist organization ( $n = 30, 17.2%$ ) or (b) described themselves as an AIDS activist ( $n = 68, 39.1%$ ).

As part of the larger study of persons with an HIV infection or AIDS, participants provided written responses to the following open-ended request: "Often persons with AIDS or HIV infection begin seeing health care professionals much more frequently than they have had to see them in the past. On this page, we would like for you to share any thoughts or feelings you have about your communication with your physician or primary health care provider since you found out you have HIV or AIDS." This request gave informants the opportunity to respond freely and helped the investigators gain new insights with minimal control over the information provided (Morse, 1992). Utilization of an open-ended request also allowed the authors to readily compare informant answers for themes.

Analysis of the responses by two of the authors was used to discern the themes of individual-level activist communication strategies and approaches to physician-patient interaction. These data provided illustrative examples of participants' descriptions of their behaviors and their perceptions of the influence those behaviors have on the physician-patient encounter. Because we were not certain what influence social activism and self-advocacy might have on these interactions, we examined the data for a range of responses (e.g., both positive and negative impacts of activism and advocacy) that related to the three themes from Phase 1

of the study. This level of analysis provided detailed richness to our emerging description of patient self-advocacy.

## RESULTS AND DISCUSSION

Our analysis of these data draws parallels between activism at the collective level and self-advocacy at the individual level. This analysis resulted in three interrelated precursors to collective action associated with the communicative behaviors of collective activism and individual self-advocacy in physician-patient encounters: (a) Education about the illness and treatment options is encouraged, (b) an assertive approach toward health care is promoted, and (c) mindful nonadherence is considered reasonable. Moreover, patients perceive that their self-advocacy behaviors impact their encounters with physicians. We address each of these dimensions below, drawing examples from the collective practices (social activism) and individual behaviors (self-advocacy) of AIDS activists.

### Increased Education About the Illness and Treatment Options

A first general result of this investigation is that AIDS activism encourages increased education about the disease and treatment options. Activists often find themselves engaged in scientific debates about complex issues (e.g., immunology or virology). From a communication perspective, education enables activists to confront or "encounter authorities" (see W. A. Gamson et al., 1982) on a more equal basis. At a collective level, ACT UP chapters encourage members to use education to fight the "influence of 'expertism,' where public health officials, government researchers, bureaucrats, doctors, and pharmaceutical companies (the ones which are generally recognized in the public eye as being experts on AIDS) have all the power over people living with AIDS" (ACT UP New York, 1999c).

In the ACT UP New York (1989b) document *Treatment and Data Teach In: How to Negotiate with Drug Companies*, members are advised: "Know your shit. Knowledge is power. Every significant gain won by ACT UP has flowed from our unassailable command of the issue. There is a wealth of information about new AIDS treatments." Specific strategies for educating oneself about scientific issues surrounding HIV or AIDS are recommended: "Reading is fundamental. Get a hold of the latest scientific journals. Start a science club to discuss important articles and share what you learn. Attend scientific meetings in your community and represent your point of view." Another education strategy is the 'teach-in,' used to inform a group about an issue prior to an action. Members are told that power for negotiation results from being educated:

Teach-ins help members of your group inform themselves and others about the background and facts concerning a particular AIDS issue. A teach-in, along with the materials you gather together, can continue to inform new members of your group, members of your community, and others about the issues. It can significantly enlarge the pool of people who feel competent to work on an issue. As part of the action planning process, teach-ins enable everyone to understand the mouths, and to be articulate and informed spokespeople without putting words into their mouths. Teach-ins provide an alternative to "experts" by enabling people without a formal education or previous knowledge of a subject to become knowledgeable. When you meet with politicians, directors of agencies, reporters or others, they will have to contend with your group's knowledge as well as its numerical strength. (ACT UP New York, 1989b)

Similarly, in ACT UP New York's (1989a) *Treatment Activism Outline* document, members are told that, when they are educated about the issues, activists can consider themselves experts in the dialogue: "Knowledge is our key to fighting the HIV epidemic and the HIV bureaucracy. Scientists often discount activist input, we lack experience and expertise. This is not true. Activists have made themselves experts. We must share this expertise."

In addition to its collective or "public campaign" activism, ACT UP provides the latest health-related AIDS information to people living with HIV and AIDS to facilitate individual action (self-advocacy). Through resources such as ACT UP's Treatment and Data Committees' *Treatment and Data Digest*, AIDS activists encourage people with HIV or AIDS to become educated more fully about the disease so that they can argue better for their needs (i.e., to advocate for themselves). The information provided by ACT UP includes "information about support groups, information about new and experimental drugs, as well as medical advice and suggestions for how to talk to doctors about AIDS" (Fabj & Sobnosky, 1993, p. 97). At the ACT UP chapter in New York, the second item on the meeting agenda is "Life Saving Information—Critical up-to-date medical information which may impact members' medical treatment decisions" (ACT UP New York, 1999c). Access to this information puts the HIV-positive individual in the atypical role of persuader (rather than the target of persuasion) in health care interactions.

Data from individual responses to the open-ended survey reinforced the evidence that information acquisition is an important component of self-advocacy for persons living with HIV or AIDS. One AIDS activist explained how increasing his level of understanding about the disease has become an important part of negotiating his health care:

I'm now knowledgeable of how the virus works in my body, how to read and follow my own lab work. I even ask for different tests to check things out myself. It's important for me to know how my body works, follow my own health care, and try or seek out alternative treatments and to work with my doctor like a partnership. Doctors can always learn from their patients!!!

Other participants in the survey reinforced the idea that learning about treatments was an important component of education efforts about HIV or AIDS. Seeking information about treatments led to an awareness of a broader range of options, perhaps increasing the likelihood of finding a treatment that would halt disease progression. One activist stated, "I am actively involved in educating myself and trying new therapies—both mainstream and other." In another example, an activist told of how he became better able to ask his physician to prescribe specific medications through increased education. He stated, "Since finding out I was HIV positive in 1988, I have become even more involved in treatment decisions than before. I read of drugs like Acyclovir, Cimetidine, Pentoxifylline, Naltrexone, etc., and ask my doctor to prescribe them." Finally, one person asserted that information was important in health care decision making because it "allows patients to critique the quality of their care."

Illness and treatment education emerged as an important component of both social activism and self-advocacy. The documents examined from various AIDS activist groups and the interviews with ACT UP members reinforced the idea that these people with AIDS felt that they can, and should, keep informed about the progression of their illness as well as about mainstream and complementary therapies. As described in the following section, one purpose of these illness and treatment education efforts appears to be to facilitate assertiveness in health care interactions.

### Increased Assertiveness Toward Health Care

Activist behaviors also include a more aggressive interactional style of the collective as well as individuals. When ACT UP activists target changes at the societal level (e.g., ending discriminatory immigration practices or improving drug testing and approval processes), collective practices often are confrontational. The group member's central slogan, "Silence = Death," and accompanying "Action = Life" point to a basic philosophy that guides much of their behavior. That is, in order to stay alive, the members of ACT UP believe that they must be vocal and take control of their own health care decisions, even at the level of changing drug testing and approval processes (see Brashers & Jackson, 1991, for a more complete description of this issue). The *Denver Principles* (1983) document rec-

commended that people with AIDS be “involved at every level of decision-making and specifically serve on boards of directors of provider organizations.” At the International AIDS Conference in Montreal, ACT UP New York (1989, p. 15) noted that “those with power to redirect our nation’s AIDS research effort must listen and work with us. We will not rest until they do.”

Behaviors seen at the collective level also are encouraged in the individual actions of ACT UP members in multiple ways. For example, in ACT UP Shreveport’s (n.d.) document *Some Questions a Patient Wants to Ask*, activists are encouraged to visit their physicians armed with specific questions about HIV illness and its treatments. The document ends with the “reminder that even those who believe themselves to be experts occasionally ride for a fall, although they may be extremely loath to admit it, especially to their patients. It is sometimes the bitterest pill they have to swallow.” ACT UP Philadelphia (1995) described a “standard of care” as “a practical document you should be able to take into your doctor’s office to help you advocate for good health care.”

Assertiveness also is encouraged through interactions with others during group meetings. During one ACT UP meeting, Adam reported on his interactions with a local physician known to have a large practice comprised of people with HIV or AIDS.<sup>6</sup> When asked by John how he secured Pentamidine (a prophylaxis for *Pneumocystis carinii* pneumonia that was being used experimentally at the time) from the doctor, Adam noted “You don’t ask Dr. Jones what medications you need, you *tell* her.” Adam’s advice was echoed by other members of the group, who agreed that an assertive approach was needed because of the reluctance of many physicians to try experimental therapies and the often fatal trajectory of pneumonia.

Participants responding to the open-ended question further reinforced the idea that they had become increasingly assertive in health care interactions. They reported a developmental process in which their use of assertive behaviors increased as they became more accustomed to the medical setting, their physicians, or to both. One informant explained his changed behavior with his physician as follows:

When I first began seeing my physician 7 years ago I was a “yes” patient. I never asked questions, I did whatever the doctor said. The doctor was an authority figure and I was afraid to question his decisions or report how I really felt. I’ve since learned the importance of communication with my doctor. He’s a human being just like me, he doesn’t always know what’s best for me. I know best about my body and how I feel. I’ve since become an activist.

Thus, behaviors at the collective and individual level reflect activists’ desire to be increasingly assertive in their interactions. This level of

assertiveness seems atypical, given the preponderance of research described earlier that indicates that people are normally passive in health care interactions.

### Willingness to be Mindfully Nonadherent

A third dimension that emerged as a precursor to collective and individual action is the willingness to be nonadherent. "Mindful" (Langer & Weinman, 1981) nonadherence is a form of reasoned decision making in which the suggested or prescribed alternative is declined in favor of another alternative. At the collective level, activists resist authority through civil disobedience (i.e., nonadherence to civil law). Disruptive actions can be successful means of persuasion in social movements (W. A. Gamson, 1990). Acts of civil disobedience often are justified through the injustice frame, which is "an interpretation of what is happening that supports the conclusion that an authority system is violating the shared moral principles of the participants. An alternative to the legitimating frame, it provides a reason for noncompliance" (W. A. Gamson et al., 1982, p. 123; see also W. A. Gamson, 1992).

The ACT UP *New Member Information Packet* (ACT UP New York, 1999c) describes actions that are intended to "target a person or organization who is not responding effectively, or morally, to the AIDS crisis." The purposes of these actions are threefold: "Make specific demands for change from the target; increase public awareness, concern, and knowledge of AIDS issues; [and] expose, through media coverage, the inaction and improper actions of the target." ACT UP New York (1999a) describes direct actions (e.g., "confronting in numerous manners a specific group of people for the purpose of change") as either (a) no risk (e.g., "organize an obituary action locally: clip and send obituaries of people who have died of HIV-related illnesses along with a personal note to Bill Clinton at the White House"); (b) low risk (e.g., "pass out condoms, safer sex information, and fact sheets at local high schools, bars, shopping malls, and sporting events"); or (c) high risk (e.g., "take over the office(s) of a local politician, insurance company or drug manufacturer, chain or handcuff yourself to the desk or doorway, and refuse to leave until your demands are met"). Further, it is noted that "CD [civil disobedience] involves breaking a law to call attention to a larger injustice in society. People who choose to participate in civil disobedience take responsibility for their own arrest." Members often talk with pride about their history of arrests, because it symbolizes their willingness to put themselves in jeopardy to facilitate change. In a letter designed to solicit funds for the organization, one member observes:

Why do I participate in direct actions and risk arrest? Because I am a member of ACT UP New York. Because I believe I can make a difference! Because if we don't do it, nobody will. Will I risk arrest again? Yes! (ACT UP New York, 1999b)

At the individual level, self-advocacy behaviors include mindful nonadherence to treatment regimens. Self-advocating persons living with HIV or AIDS often decide what treatment options are best for them, which can lead to nonadherence that can be viewed as mindful rather than "mindless." In the *Denver Principles* (1983), the right to make rational decisions about treatments (either accepting or rejecting prescribed regimens) is reiterated: "People with AIDS have the right: to full explanation of all medical procedures and risks, to choose or refuse treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives." Among the responses to our open-ended request, one activist with AIDS explained his reasoning process about nonadherence as follows:

At this time, after having HIV for 7 years, I feel your body will take care of itself. I've watched friends and my "companion" of 8 years pass away and I feel the medication killed them, such as AZT and ddI. These medications do more harm than good. I took medication for 3 years and thought I was dying sick with weight loss, vomiting, fainting spells, and fatigue. I stopped taking the medications and the last 4 years I have felt great.

Another example illustrative of a willingness to be nonadherent occurred at an ACT UP meeting, in which members were encouraged to decrease their dosages of AZT (as had been argued in a recently published study), but to continue to collect dosages prescribed by their physicians (to create an underground stockpile of AZT for those who could not afford it or whose medical insurance would not pay for it). This type of action puts the medical decision making in the hands of the person affected, rather than the physician. It also demonstrates the group's ability to respond to the needs of its members through collective action.

### Implications for Physician-Patient Communication

In this section, extant research on physician-patient communication is incorporated with our findings thus far and with additional data based on activist perceptions of their interactions with physicians to build a description of patients' perceptions of self-advocacy in physician-patient interactions. In overview, we have found through this investigation that there are parallels between collective (social activism) and individual (self-advocacy) responses from people with HIV or AIDS whereby those per-

sons seek to become more educated, more assertive, and more willing to be mindfully nonadherent. Participants perceive that these collective and individual elements play a role in the experience of physician-patient interactions. In communicative interactions, education allows patients to challenge the expertise of the physician, assertiveness allows them to confront paternalistic or authoritarian interactional styles, and mindful non-adherence allows them to reject treatment recommendations and offer reasons for doing so.

From observations of AIDS activists, their documents, and their self-reported behaviors, it is clear they believe that an important component of activist teaching is to enforce the idea that patients, in physician-patient encounters, should be empowered to make decisions about their own health and welfare. ACT UP Paris (1999) proposed:

. . . calling into question the medical authorities and the doctor/patient relationship. In the same way that AIDS has occurred everywhere there are social deficiencies, and primarily targets those who don't have a right to express themselves, the illness places patients in a position of absolute dependence on their doctors. They are deprived of their status as adults, and can only remain silent while awaiting the verdict. However, AIDS has seriously discredited a part of the medical establishment, and the medical establishment has seriously discredited itself in turn—through the infection of hemophiliacs and transfusion patients, and the corporatist reflexes of certain doctors who quickly close ranks against patients who they don't know how to treat. Fighting AIDS is about teaching AIDS patients to regain the upper hand and establish a dialogue with doctors as equals, to give them a chance to choose their treatments and decide their own future.

Our survey data reveal that some people with AIDS perceive that their physicians have reacted positively to their assertive attempts at increased involvement in health care decision making. Several participants' perceptions of their interactions with physicians confirm this notion. One activist patient commented on how his physician engaged in a more participative approach, acknowledging a lack of expertise about the disease and its progression in each individual:

I think most doctors understand and admit that even now they know little about HIV and their best source of information is their patients. They also understand that the effects of HIV differ widely in each individual, and therefore it is necessary to listen closely to their patients and not assume that what works for one will work for all.

Another activist described the development of a partnership with his physician because of his level of education about the disease:

Since my physician had so little to do with my early care, and because I have become a well-known proponent of self empowerment, she is careful with her suggestions. I tend to educate her as much as she educates me. I'm probably the longest-lived full-blown PWA [Person with AIDS] in this city, so who is to argue with my success?... My physician and I are partners in learning how to win this fight.

One activist patient reflected that his relationship with his physician changed largely due to his increased education. He explained:

I've gone to several [physicians] over the years, some have been rather arrogant and argumentative. But in general, over the years as I have educated myself, I've noticed that they have seemed to be more cooperative and seem to treat me with more respect. They listen to what I have to say, and honor my point of view.

Similarly, the following quote from an activist notes that increased involvement with the physician had facilitated the development of skills needed to be assertive and that the physician's acceptance and interest had helped to develop their relationship:

The frequency of my visits to the doctor has allowed me to develop my communication skills with all of my health-care providers. I have learned to be more assertive and question their decisions. My primary care physician is new to me since my diagnosis. Over the years we've developed an understanding and relationship that I value. We guide each other through the process of my disease. She takes an interest in my life outside of AIDS which has helped increase my trust. How important that is because she has become an integral part of my life.

Another respondent described a similar experience:

My primary doctor listens to me. He knows that I take an interest in what we are going to do, and *how* we are going to treat me. I also respect his knowledge and concerns. I trust him because he respects my questions and concerns on my treatment of HIV and other health related needs.

Another participant responded that his assertiveness had created a more open dialogue with his health care providers. He noted, "I've become more assertive in my health care [since being diagnosed HIV positive] and I can talk more with my doctors and nurses about my care, health, treatment, etc. I think this is a better way to operate than sitting passively and doing nothing."

Another participant described that he was the one who chose adherence or nonadherence, despite having a cooperative relationship with his physician. He stated:

My doctor is very straightforward and truthful with me whatever the situation, and I prefer it that way. He also allows me to make the final decision, which I like. We have talked a lot about the infection. I have asked for his advice many times, and have taken it many times, but not always.

Finally, one informant described negotiation with the physician over the decision to continue a drug treatment as follows:

The doctors I have seen have expressed both a genuine interest in helping me maintain my level of relatively good health and a respect of my choices concerning my own treatment. For example, after doing some research on my own, I decided not to take AZT, the most widely prescribed HIV treatment in the U.S. to date. My physician listened to my arguments and accepted that it was my decision.

Thus, many participants in the survey commented on how their relationships and communication with their physicians had been affected positively because they had become more participative in decision making (facilitated through education, assertiveness, and mindful nonadherence). On the other hand, several AIDS activists described what seemed to be less productive physician responses to their attempts at participation in health care decision making. For instance, one person, who described himself as "much more involved and assertive regarding my health care" than he had been previously, said this of his interactions with various physicians:

My first physician seemed uneducated, unresponsive, and prejudiced. I changed to one I knew to be HIV/AIDS competent. However, the second one seemed to be threatened by my active participation in my health-care decisions, even calling me a "difficult" patient.

Another person with AIDS commented that his primary care physicians often ignore his informed advice. He noted, "The blood tests they'll run only take CD4 counts, when I've mentioned they might want a fuller profile." Similarly, an activist participant recalled his frustration when he felt his physician was not keeping up with the latest HIV or AIDS research and his fear of the consequences of making uninformed choices:

When I bring in the newest research notes and such, my doc usually brushes them off; then we laugh a year later when he begins using them. I'm beginning to not see very much humor because I think that over one of those 'one year lags' I could be drastically ill, or die, on account of him not following my research based advice.

Finally, some participants also noted that a difficulty in being assertive was adapting their behaviors within the familiar paternalistic context of physician-patient interactions. As one activist's response reflected:

My main intervention with my, so far, three different doctors is asking questions and listening to their explanations. Sometimes I feel a little shy—do not want to make them feel stupid or lacking information. I usually try to let them know that I respect them and follow their instructions, let them feel that they are in charge.

Several explanations for the perceived effects of collective and individual features of activism and advocacy on physician-patient relations seem reasonable. First, one implication of increased education among activists with HIV or AIDS is the need to rethink classic divisions of informational resources. For example, patient expertise has been defined as knowledge of personal responses, preference for some outcomes over others, and knowledge of personal, social, and financial resources, whereas health care professional expertise has been defined as knowledge of physical outcomes and course of disease, risk and probability of outcomes, and health care resources (required and available; Rothert & Talarczyk, 1987). Activist organizations, such as ACT UP, encourage and facilitate education about health care options and treatments—so that, in some cases, activists become more knowledgeable than their physicians. Moreover, many primary care physicians report they do not want to treat people with HIV or AIDS because they cannot keep up with the amount of information being generated by AIDS drug trials and research on AIDS and opportunistic infections (Gerbert, Maguire, Bleecker, Coates, & McPhee, 1991).

This research underscores the need to develop relationships of mutual respect for the influence attempts of both persons living with HIV or AIDS and HIV-specialist physicians. Patient knowledge has the potential to alter traditional physician-patient relationships by placing the participants in the medical encounter in either nonnormative symmetrical power relationships (Lerner & Luby, 1992) or nonnormative asymmetrical power relationships (e.g., where expert power resides with the patient), at least in the form of knowledge about HIV and its treatments.<sup>7</sup> Studies have demonstrated that physicians typically use expertise strategies (e.g., telling the patient that the physician's experience dictates that the patient should seriously consider the physician's recommendations) as a frequent compliance-gaining device (Schneider & Beaubien, 1996). One must consider what happens when the physician's major source of power—expertise—is challenged. Although the physician often is considered the primary persuasive agent in health care interactions (i.e., to gain compliance

to a treatment regimen; see Klinge, 1995), self-advocating individuals find themselves in the unusual position of being persuasive agents in health care interactions (i.e., making arguments for or against specific treatments), which is facilitated by their own expertise.

Second, patient assertiveness in health care interactions can lead physicians to reassess and alter their interactional styles. As noted previously, people generally are nonassertive, nonquestioning, and nonchallenging as patients. Divergence from societal communication norms, or violations of communication expectations, have arousal or attention-gaining potential that shifts receivers' attention from the content level of the interaction to the relational level (Burgoon & Hale, 1988). The resulting relational messages attributed to unexpected actions then influence person perceptions (Burgoon & Walther, 1990). Thus, the assertive, questioning, and challenging behaviors of AIDS activist patients are likely to draw physicians' attention to the communicative behavior of their patients to determine the meaning behind these nonnormative communication choices (see, for example, Geist & Hardesty, 1990). Increased attention to the communication behavior of the persons they are treating can lead physicians to alter their interactional patterns (see Schelling, 1978, for a discussion of "contingent behavior"). AIDS patient activism appears to have the potential to result in either positive physician-patient communicative outcomes—such as gaining more information and developing a partnership orientation—or more negative, authoritative physician communication behaviors, perhaps dependent on how closely the physician is tied to a traditional authoritarian model of interaction or on the interactional style of the patient. If an individual's assertive behavior is viewed negatively by the physician, a spiral of challenging communication behaviors is likely to emerge on the part of both participants that could discourage effective participative decision making and thus decrease the person's commitment to treatment regimens. In that case, people seemingly are placed in a double-bind situation in which their nonassertive patient behaviors inhibit them from gaining necessary information and treatment (Beisecker, 1990), while their assertive patient behaviors prevent them from developing the type of partnership orientation with their physicians that is vital to information flow and willingness to try new treatments. Similar circumstances have been reported, for example, when women enact "stereotypically male" communication behaviors as an attempt to enhance their credibility (see Putnam, 1983, for a discussion of the "damned if you do, damned if you don't" double-bind women often experience in organizations). Because authoritative and aggressive communication styles used by physicians have been shown to leave patients feeling misunderstood and unwilling to cooperate with medical prescriptions (see Bensing, 1991; Rowland-Morin & Carroll, 1990), researchers need to address how

people can communicate assertively as patients without having their communication cues interpreted negatively by physicians.

Third, mindful nonadherence may elicit more cooperation from physicians. Implicit in most research on "compliance" in physician-patient communication is the notion that nonadherent patients generally fail to follow prescribed routines because they do not understand the physician's orders (Francis, Korsch, & Morris, 1969) or are unable or unwilling to cease harmful behaviors (Karoly, 1982). Donovan and Blake (1992) asserted that nonadherence actually may not indicate deviance on the part of patients, but instead may represent reasoned decision making involving rational choices regarding lifestyle and treatments based on patient beliefs, responsibilities, and preferences. Physicians who encounter patients who provide reasons for their nonadherence may be encouraged to be more cooperative in negotiations about treatment options than physicians who have patients that seem to be nonadherent due to a failure to comprehend medical advice or to a lack of motivation to comply to prescriptions. Because adherence to treatment regimens is critical for the success of most antiviral drugs for HIV (because drug resistance can result from failure to take medications as prescribed; see Gilden, Falkenberg, & Torres, 1997; Vasudevachari et al., 1997), negotiated treatments in which both physician and patient are comfortable with the drugs and their methods and schedules of delivery are increasingly important.

Several directions for further research are suggested by these findings. Future research that examines actual physician-activist patient interaction patterns is needed. The current investigation was limited to evidence of behaviors of the collective and individuals within the collective (e.g., documents, meetings, etc.) and the perceptions of individuals within the collective about their interactions with physicians. Studies of interaction can help us to describe further the nature of self-advocacy behaviors and the types of responses that those behaviors elicit. Through studies of interaction, we might find explanations for differences in physician responses to patients' attempts at participation. For example, we might discover that some individuals' behaviors may seem competitive (e.g., hostile or aggressive), whereas others seem cooperative. Physician style, then, possibly might reflect the communicative style of the patient. On the other hand, we might find that it is the style of the physicians (e.g., paternalistic, authoritarian, or democratic) that determines the physicians' reactions to patient attempts at participation (for a discussion of physician communication styles, see Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996, or Roter et al., 1997).

To have a clearer picture of the impact of collective social activism and individual self-advocacy behaviors on physician-patient relations, it also is important to investigate the perceptions of physicians. Some physi-

cians have cautioned against abdicating authority in the face of "consumerist" patients (e.g., Fairhurst & May, 1995; Marzuk, 1985). Lerner and Luby (1992) argued that several malpractice cases could be traced to physicians who acceded to empowered patients rather than their own clinical judgment. Other physicians have noted the important role of patient participation and cooperative decision making (e.g., Ratzan, 1993). Melanie Thompson, a primary care physician and researcher, described the plight of the primary care physician trying to keep up to date with AIDS treatments. After being questioned by her patient on the potential for him using ZDV, and contacting the Food and Drug Administration (FDA), National Institutes of Health (NIH), and the American Foundation for AIDS Research (AmFar) for data and information, Thompson related:

I feel the patient needs to have a certain amount of information about this [use of the drug ZDV]. He really knows the situation quite well. He knows the natural history of his disease. I tell him about the side effects of ZDV, which he already knows. I also tell him that his physician is flying by the seat of her pants and that we will do the best we can and we will make the best choices together. However, it really is a collaboration.<sup>8</sup> (Corey, Del Vecchio, Brown, & Thompson, 1990, p. S143)

As was suggested in the introduction, we also need to explore causal relationships associated with membership in activist organizations. What we observed in this study (directly and through participant reports) leads us to believe that the activist group (collective) is an environment in which members learn and rehearse social skills and strategies that are subsequently enacted by the collective and the individual. Much of what occurs behind the scenes for ACT UP is education in both the substance (e.g., immunology, virology, pharmacy, law) and form (e.g., direct action, confrontation, negotiation, debate) of activist action. Many attribute ACT UP's remarkable success to careful attention to these details (Brashers & Jackson, 1991). However, it also seems that individuals vary in the achievement of activist values and strategies, perhaps because of individual characteristics (e.g., prior social skills, level of communication apprehension, or cognitive ability). Thus, we need to further explore the nature of social activism and self-advocacy to determine (a) what differentiates activists and nonactivists, (b) how membership in an activist organization influences an individual's communication behaviors, and (c) why people differentially adopt and enact activist and self-advocating behaviors.<sup>9</sup>

Finally, research that examines other collective practices and their influence on individuals and relationships is needed. Collective communication practices have both relational and instrumental purposes. Important to collective action are patterns of behavior that signal solidarity (W. A. Gamson et al., 1982; Melucci, 1996). Solidarity is promoted by (a) sym-

bolic expressions of the group as a collectivity; (b) treatment of the collective as a group by others; (c) a common style of life, norms, and values; and (d) greater social interaction with members than with nonmembers (W. A. Gamson, 1992). Frey, Adelman, and Query's (1996) analysis of bereavement rituals (releasing balloons at a memorial service or making panels for the Names Project quilt) is one example of this type of research. Other collective actions may have important instrumental implications for the experiences of individuals within those collectives. Early in the AIDS epidemic, the gay community was credited with slowing the epidemic among its members through education practices prior to any organized response by the government or social service agencies. These actions included condom and safe-sex information distribution at bars and other locations where men gathered to meet and "lifeguards" (groups of individuals who would remind others to have safe sex) in bathhouses and sex clubs. These self-education and self-monitoring practices served to demonstrate the ability of the collective to take care of individuals within the collective. Other collective practices, such as fundraising efforts (e.g., marathon walks or bike rides) or support groups, are likely to impact the experiences and behaviors of individuals in many significant ways. Taken together, these practices demonstrate the importance of viewing individual behaviors in the context of collectives within which they function.

## CONCLUSION

Studying activism and the development of self-advocacy in physician-patient interactions is an important new direction in health communication research. The results of this study indicate that social activist and self-advocating communication behaviors might affect the dynamics of the medical interaction by making persons with HIV or AIDS more knowledgeable and, thus, influencing them to take a more aggressive stance with their physicians or to choose not to adhere to the specific recommendations of their physicians. As members of an activist organization, persons living with HIV or AIDS reported that they perceive themselves to be developing persuasive skills in the collective which in turn impact their private behaviors. As HIV or AIDS becomes more of a chronic disease (Gallo, 1996; Nokes, 1991), rather than a rapidly progressing terminal illness, questions addressed and raised in this essay that affect a person's ability to actively live with HIV or AIDS will become increasingly important. Although some may have difficulty accepting an active patient model, the shift on the part of both physicians and patients to more participative decision making has received the support of researchers (e.g., Frederikson, 1993; Greenfield, Kaplan, & Ware, 1985) who have argued that increased participation leads to greater trust in the physician

(Ratzan, 1993), which might, in turn, lead to "higher quality decisions, greater commitment to decisions, increased satisfaction with interaction, and increased compliance with treatment regimens" (Ballard-Reisch, 1990, p. 94). And because there is evidence that AIDS activist strategies are being adopted by other groups (e.g., people with breast cancer, Alzheimer's disease, or hepatitis C; see Anglin, 1997; Brashers & Jackson, 1991; Melcher, 1995), persons with chronic illnesses may benefit from the model of activism and self-advocacy described here. The potential for both patients and physicians to experience more effective and satisfying health care outcomes through partnership-building interactions calls for continued investigation.

## NOTES

1. Activism and advocacy acts can be differentiated on at least two dimensions: the actor and the intended beneficiary of the act. For the purpose of this paper, we distinguish the actor as either an individual (one person) or a collective (a collection of individuals acting together to achieve a goal). We distinguish the beneficiary as either self (egoistic), other (altruistic), or combined (common interest). Of the six possible combinations of these two dimensions, our specific focus in the paper will be on comparisons between persuasive efforts of a collective that are in the common interest (which we label social activism) and persuasive efforts of an individual that are in the individual's interest (which we label self-advocacy).

2. The rise of "consumerism" has been a widely discussed topic in a variety of areas, including goods and services (Knights, 1993), public services and government (Cheung, 1996; Hood, 1996), the environment (Easterling, Miller, & Weinberger, 1995), as well as health care (Beisecker & Beisecker, 1993; Fairhurst & May, 1996; Marzuk, 1985) and mental health care provision (Morrison, 1991).

3. Issues of reliability and validity can be a concern in qualitative research. We believe we address these issues in our study through (a) utilizing triangulation with multiple data sources and multiple authors (Denzin, 1978) and (b) establishing credibility with member checks (Lincoln & Guba, 1985). Of course, the ultimate test of the claims in any study is the adequacy of the description and the data used to establish those claims (see Jacobs, 1986, for a version of this argument for the method of discourse analysis; see Jackson, 1986, 1989, 1992, for an explication of the view of "method as argument"). Other useful sources on reliability and validity issues in qualitative research include Denzin and Lincoln (1994), Silverman (1997), Miller and Dingwall (1997, especially chapters by Silverman and Bloor).

4. It was not our purpose in this study to develop an exhaustive typology of precursors to collective action. Rather, we saw the themes of education, assertiveness, and mindful nonadherence as three important dimensions of collective action of AIDS activism which, if enacted by individuals, have the potential to impact physician-patient encounters. We test this idea in Phase 2 of the study.

5. Percentages do not add to 100% due to missing data.

6. Names have been changed.

7. Of course, many other factors influence the power balance between physicians and their patients. Societal norms, availability of alternative care, and other contextual features are all important determinants of the power afforded a physician.

8. ZDV is now commonly known as AZT or Retrovir (trade name of the drug "zidovudine," registered to Glaxo Wellcome).

9. It seems vital to determine if there are differences between activist and nonactivist persons living with HIV or AIDS. In a separate report, Brashers, Haas, and Neidig (1999) describe the development and reliability and validity assessment of the Patient Self-Advocacy scale (PSAS) that was administered to 392 participants (174 adults living with HIV or AIDS as well as to an additional 218 adults from the general population). Activists were more likely to report that they educated themselves about HIV illness and its treatments, behaved more assertively in health care interactions, and were more willing to be mindfully nonadherent than were nonactivist persons living with HIV or AIDS or the members of the general population. In addition, patient self-advocacy was correlated positively with desire for control, desire for autonomy in health care, and preference for involvement and information in health care and correlated negatively with external locus of control (i.e., when individuals believe that circumstances are under the control of external forces, they are less likely to advocate for themselves). Brashers, Haas, and Neidig (1996) also demonstrated that, in comparison to nonactivists, activists (a) used more problem-focused coping strategies, (b) used fewer emotion-focused strategies, (c) were more likely to communicate with their physician, and (d) were more likely to perceive communication with their physician as rewarding. Finally, Brashers, Haas, and Neidig (1998) found that activists exhibited familiarity with a greater number of health information sources than nonactivists.

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