

# Social activism, self-advocacy, and coping with HIV illness

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## ABSTRACT

Activist organizations are a relatively unique collective setting for people living with an HIV infection or AIDS. Communication within these organizations includes educational and motivational practices designed to facilitate change for the group and for its individual members. In this study, we examined differences between activist and nonactivist individuals ( $N = 174$ ) with HIV or AIDS. Results demonstrated that, in comparison with nonactivists, activists (i) used more problem-focused coping and less emotion-focused coping, (ii) had greater knowledge of HIV-treatment information sources, and (iii) had greater HIV social network integration. We speculate that there are two reasons for these differences: (i) there are behavioral and psychological predisposing factors that lead to membership in an activist group, and (ii) the educational and motivational environments established through the relationships of activist group members (i.e., the social tasks of the collective) lead to changes in individuals.

KEY WORDS: activism • coping • HIV • information seeking • information sources • self-advocacy

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Recent research highlights the importance of collective behavior for individuals experiencing acute or chronic illnesses. For example, theories of social support (e.g., Sarason, Sarason, & Gurung, 1997) and communal coping (e.g., Lyons, Mickelson, Sullivan, & Coyne, 1998) demonstrate how communication in social and personal relationships can facilitate and/or hinder the management of illness-related stress. For people living with HIV or AIDS, support groups (e.g., Cawyer & Smith-Dupre', 1995; Summers et al., 2000), residential facilities (e.g., Adelman & Frey, 1997), and community-based AIDS service organizations (e.g., Omoto, Gunn, & Crain, 1998) provide settings for offering and accepting mutual assistance and support. Because of the stigma often associated with the disease and the potential for devastating physical consequences and death, these collectives may be needed to provide a safe environment for those with the disease to develop relationships and adjust to the consequences of living with their illness (Brashers, Neidig, & Goldsmith, 2000). Sharing experiences and offering advice about treatments, financial and legal planning, and relational uncertainties, among many other things, may lead to improved physical and psychosocial management of the illness.

One of the most unique collective environments for people living with HIV or AIDS is the *activist organization*, a setting in which skills and resources are developed, shared, and mobilized to create social and individual change. For example, the AIDS Coalition to Unleash Power (ACT UP) is an influential activist organization dedicated to promoting the health and welfare of individuals with HIV or AIDS. At a macro level, ACT UP and related activist organizations focus on social and institutional reforms, such as encouraging increased government funding for prevention and treatment efforts, through public demonstrations as well as private deliberative interactions with government and industry representatives (see Brashers & Jackson, 1991; Sobnosky & Hauser, 1999). At a micro level, members of activist groups share information and experiences to enhance their ability as individuals to make informed choices about personal health care and treatments. Brashers, Haas, Klingle, and Neidig (2000) described these two features as *social activism* (i.e., persuasive communication by a collective for the purpose of benefiting the common interests of both members of the group and the broader society) and *self-advocacy* (i.e., persuasive communication by an individual that is intended to benefit the self).

Although collective action has been a significant part of the political and cultural contexts of people living with HIV or AIDS, little is known about (i) the individual characteristics and behavioral patterns of those who engage in social activism, or (ii) the influence of interpersonal relationships and interaction within the collective on those individual characteristics and patterns. The relationships and interactions of activist group members provide an important site for studying the interplay between the motives and behaviors of collectives and individuals (W. A. Gamson, 1992; W. A. Gamson, Fireman, & Rytina, 1982; Schelling, 1978). Accordingly, our goal for this study was to offer a preliminary test of the processes of social activism by assessing connections between engagement with a collective

(i.e., AIDS activism) and other key aspects of an individual's experience in coping with HIV illness. By doing so, this study serves as an important step toward developing explanatory theories about the impact of activist group membership on individual members.

To accomplish our goal, we first review literature on the nature of the AIDS activist movement, focusing on the social tasks and outcomes accomplished in collective action. Second, we extend these ideas through a study of activism and coping with a sample of people living with HIV or AIDS. Third, we conclude by discussing the results of that study and their implications for understanding the collective behaviors of people living with chronic or life-threatening illnesses.

### The nature of collective action in the AIDS activist movement

ACT UP was formed in 1987 in New York City in response to criticism of federal agencies (e.g., the Food and Drug Administration) and private pharmaceutical companies responsible for AIDS research (J. Gamson, 1989). The organization quickly called attention to the perceived inaction and ineffectiveness of efforts for managing the crisis (Brashers, Haas, et al., 2000) and focused on 'knowledge empowerment' for people living with HIV or AIDS (Epstein, 1996, pp. 216–234). These processes are highlighted in the following sections, through a discussion of the social tasks and outcomes of collective action.

#### **Social tasks of collective action**

People join together in collective action to overcome structural barriers to a preferred outcome, such as a change in social policies or improved personal well-being. The primary mechanism of change for AIDS activists is intragroup and intergroup communication. These social tasks of collective action include what W. A. Gamson (1992) called 'micromobilization processes,' which are 'highlighted by different kinds of encounters: recruitment meetings, internal meetings, mass media encounters, encounters with allies, encounters with countermovement groups, and encounters with authorities' (p. 72). He added that 'in the course of these encounters, potential challengers say or do things that help (or hinder) the development of a collective identity, solidarity, and a collective action frame' (p. 72).

**Planning and implementing actions.** The types of social policy changes that ACT UP has advocated include improving drug approval processes, changing immigration policies, and promoting education about safer sexual behavior. Opponents in these actions have included the Food and Drug Administration, the Immigration and Naturalization Service, and the Catholic Church, respectively (for histories of ACT UP actions, see ACT UP New York, 2000; Epstein, 1996).

The success of ACT UP in affecting change and sustaining its movement

depends on its ability to identify and obtain necessary resources (including group members) and, subsequently, to train its members in appropriate skills (e.g., media relations, scientific debate, and fund raising). Brashers, Haas, et al. (2000) noted that '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' (p. 394). ACT UP has been unusually successful at these educational efforts: organizers formed a network of members who are now recognized in HIV and AIDS communities (e.g., among health care providers, scientists, and people living with HIV or AIDS) as experts in the field.

Planning actions also involves making decisions, including identifying priorities, setting individual and collective goals, and adjudicating competition among the goals. ACT UP meetings are a form of 'radical democracy' that focus on developing consensus among the members through debate that is often vigorous and contentious (Brown, 1997). Carrying out actions involves interacting with and persuading outsiders. Because of the credibility they have established with many key decision makers, members of ACT UP frequently meet with government officials and industry leaders to debate changes in policy (Epstein, 1995). They also conduct various types of public actions (e.g., civil disobedience or protests; see Brashers, Haas, et al., 2000; Meyers & Brashers, in press) that direct the public's attention to their issues as well as cast an uncomfortable spotlight on their opposition. ACT UP members do both, as Epstein (1996) noted in his history of the group, because members know that 'the language of the street and the language of the meeting room' (p. 287) target different audiences and facilitate different goals.

**Managing identity and relationships.** People living with HIV or AIDS also may join a collective to manage identity or relationship issues connected to their illness. Individuals with chronic or life-threatening illnesses face a number of identity challenges (Ezzy, 2000) and self-presentational dilemmas (Brashers, Neidig, et al., 1999). Identity concerns for people living with HIV or AIDS include role ambiguity (Brashers, Neidig, Dobbs, et al., 2000) and stigma and stereotype threat (Alonzo & Reynolds, 1995; Leary & Schreindorfer, 1998). One way in which the challenges of both collective and individual identity development for people living with HIV or AIDS can be managed is by interacting with similar others (Roth & Nelson, 1997), thereby 'providing a less-threatening comparison environment and allowing those who are stigmatized the opportunity to be 'off-duty' from the attributional ambiguity, stereotype threat, anxiety, and mindfulness that are likely to accompany interactions with the nonstigmatized' (Crocker, Major, & Steele, 1998, p. 524).

The need to establish relational bonds characterized by mutual concern also is a strong motivation for joining a collective (Baumeister & Leary, 1995). After contracting HIV, people may experience a loss of their former social networks for various reasons (e.g., rejection because of stigma or loss of close friends and partners from the disease) and may find it difficult to

disclose their illness to loved ones (Derlega, Winstead, & Folk-Barron, 2000). Alienation from former in-groups can be felt acutely by those with HIV or AIDS, because affiliation needs may become central for those anticipating negative life events (Schacter, 1959). Participation in an activist group, such as ACT UP, consequently, can provide an environment in which members can develop and maintain relationships with similar others.

### **Outcomes of participation in the AIDS activist social movement**

The most obvious outcome of collective action is changes in public policies and practices. For example, one of ACT UP's major victories has been changing drug testing and approval processes in the U.S. (Brashers & Jackson, 1991; Epstein, 1995, 1996). These changes included expanding access to clinical trial participation (particularly for women and minorities), decreasing reliance on placebo-controlled drug trials (by utilizing drug-against-drug comparisons), and accelerating the drug approval process (Brashers & Jackson, 1991). Because of ACT UP's actions, community activists have become a central part of the National Institutes of Health's AIDS Clinical Trials Group (ACTG), participating with researchers in the development of clinical trials and exercising voting rights on all ACTG committees (Epstein, 1996).

Equally significant, but perhaps less obvious, changes occur in an activist group and its members as they evolve through the struggles and successes of the movement (W. A. Gamson, 1992). While engaged in the social processes of activism (i.e., planning and implementing actions, as well as managing relationships and identity), some members develop skills, knowledge, and values that they previously did not have or need. For example, as noted earlier, the need to engage in debate with experts has led activists to educate themselves about virology, pharmacology, and other pertinent scientific topics; develop social skills; and practice these skills through collective action. Moreover, three activist and self-advocacy values are promoted among members of ACT UP: (i) educating themselves about treatments and illness allows them to engage in more productive dialogs with experts (including scientists and health care providers), (ii) learning to be assertive helps them to confront paternalistic or authoritarian interactional styles sometimes exhibited by these experts, and (iii) being willing to not adhere to the advice of authorities leads them to negotiate treatments and care better suited to their needs (Brashers, Haas, et al., 2000). Taken together, the skills, knowledge, and values evident in collective action suggest important interactional influences that can promote change for people living with HIV or AIDS.

Comparing activist and nonactivist people living with HIV or AIDS

The current study compares people who belong to an activist group with those who do not. Establishing differences between activist and nonactivist

individuals living with HIV or AIDS is an important step toward developing explanatory models of the effects of activist group membership. We have two reasons to expect such differences: (i) there likely are behavioral and psychological predisposing factors that lead to membership in an activist group, and (ii) the educational and motivational environments established through the relationships of activist group members (i.e., the social tasks of the collective) are likely to lead to changes in individuals. We focus on four dimensions in this comparison to highlight individual factors that may either influence or be influenced by interactions within an activist group: demographic and health characteristics, social network integration, coping behaviors, and knowledge of HIV-treatment information sources. Each of these four elements, which are central to the social tasks of the collective as well as the individual experience of coping with illness, are examined.

### **Demographic and health status characteristics**

People may be differentially willing or able to join activist movements, perhaps due to such personal characteristics as age, education, or time constraints (e.g., family or work responsibilities). For people living with HIV or AIDS, participation in ACT UP also may be related to such factors as health status (e.g., people who are more ill may be less able to participate), diagnosis (i.e., HIV versus AIDS), or the experience of debilitating symptoms, which may limit activity (e.g., fatigue). To investigate the association of personal characteristics to activist group membership, we asked the following research question:

*RQ1:* Are there differences in demographic and health status characteristics of activist and nonactivist individuals living with HIV or AIDS?

### **Social network integration**

One characteristic that we expect to be important in an individual's experience with collective action is integration into social networks (i.e., the degree to which they are connected into networks of others living with HIV or AIDS). Interpersonal ties (i.e., knowing someone in the movement) and membership in related organizations (which might generate more interpersonal ties) may be associated with the likelihood of joining a movement (McAdam & Paulsen, 1993). In contrast, people who have fewer connections to these social networks may find collectives or activist groups unfamiliar and less available than those with denser networks (Marwell & Oliver, 1993). For example, some people with HIV or AIDS may have social networks that include others who are infected (e.g., those in the gay community; see Hart, Fitzpatrick, McLean, Dawson, & Boulton, 1990), which may lead to even greater social integration; for others, the lack of connection to other people who are HIV infected may decrease the likelihood that they will join an activist group. In addition, people may *develop* denser social networks through relationships formed and maintained in an AIDS

activist group. Given that people who participate in collective action may be more likely to have and to develop denser social networks, we advanced the following hypothesis:

*H1:* Activists will have greater social network integration in HIV and AIDS communities than will nonactivists.

### **Coping preferences**

Researchers who study coping have described how individuals with HIV or AIDS use various social and psychological strategies to cope with illness-related stresses (e.g., Fleishman & Fogel, 1994; McCain & Gramling, 1992). Lazarus and Folkman (1984) described two such general strategies as *problem-focused coping* (i.e., active cognitive or behavioral efforts to manage stress through changing behaviors or environmental conditions) and *emotion-focused coping* (i.e., cognitively managing affective states through the regulation of distressing emotions). We expected that involvement in activism would likely be mirrored in more general coping behaviors; specifically, activism implies a problem-solving approach that is reflected in the use of more behaviorally oriented coping strategies and is reinforced through collective action (cf. Chesney & Chesler, 1993). Emotion-focused coping (e.g., detachment or escape-avoidance) possibly precludes engagement with a collective that might generate the emotion being regulated or suppressed (i.e., people who want to avoid thinking about HIV might avoid interacting with others living with HIV or AIDS; see Moore et al., 1998, for a related idea). Therefore, we proposed the following hypothesis:

*H2:* Activists will be (i) more likely than nonactivists to use problem-focused coping and (ii) less likely than nonactivists to use emotion-focused coping.

### **Knowledge of HIV-treatment information sources**

Differences in familiarity with HIV-treatment information sources may be related to membership in an activist organization. As part of coping with their illness, individuals living with HIV or AIDS may seek and receive health information from a variety of sources, including the media, health care professionals, family and partners, friends, and other people living with HIV or AIDS (Lovejoy, Morgenroth, Paul, Freeman, & Christianson, 1992). Activists also are likely to use such information sources to develop expertise for engaging in dialogs with scientists and policy makers (Brashers & Jackson, 1991). Because individuals who are members of an activist group are more likely to have a self-advocacy orientation (Brashers, Haas, et al., 2000), actively engage in health care decision making at collective and individual levels, and participate in collective attempts to reduce uncertainty, they should demonstrate a greater awareness of sources of HIV-treatment information than nonactivists. Thus, we proposed the following hypothesis:

*H3:* Compared with nonactivists, activists will have a greater knowledge of HIV-treatment information sources.

Finally, we speculated that there may be differences in the types of HIV-treatment information sources described by activist and nonactivist individuals. For example, if activists indeed have a greater awareness of sources in general, they will likely know more about lesser used HIV-treatment information sources (i.e., less traditional sources). To investigate these differences, we asked the following research question:

*RQ2:* Will activist and nonactivist individuals with HIV or AIDS list different sources of HIV-treatment information?

Addressing these research questions and hypotheses will provide evidence for the connection between engagement in a collective and individual behaviors. Specifically, the relationships of activist group members provide a basis for establishing a connection between the social aspects of collective action and the individual aspects of coping with HIV infection or AIDS.

## Method

### Participants

This sample of 174 adults with HIV or AIDS was obtained from organizations from throughout the U.S., including 2 AIDS service organizations ( $n = 33$ ), 10 AIDS activist organizations ( $n = 31$ ), and an AIDS clinical trials unit at a large Midwestern teaching hospital ( $n = 110$ ). Questionnaires were left at each organization for interested participants to take. The sample that resulted was composed of 155 males (89.1%) and 16 females (9.2%). (Some demographic categories do not equal 100% because of missing data.) Participants self-identified as White ( $n = 133$ ; 76.4%), Black ( $n = 22$ ; 12.6%), Hispanic ( $n = 10$ ; 5.7%), or from other ethnic backgrounds ( $n = 9$ ; 5.3%). Participants reported their sexual orientation to be gay ( $n = 128$ ; 73.6%), lesbian ( $n = 1$ ; < 1%), heterosexual ( $n = 25$ ; 14.4%), or bisexual ( $n = 14$ ; 8%). Participants in this sample self-identified as being HIV positive ( $n = 79$ , 45.4%) or as having AIDS ( $n = 92$ , 52.9%); their CD4 counts (a major marker of immune system function) ranged from 0 to 1440/mm<sup>3</sup> ( $M = 281$ /mm<sup>3</sup>,  $SD = 291$ /mm<sup>3</sup>).

### Measures

All measures were administered as part of a larger study of people living with HIV or AIDS. A survey questionnaire was used to collect data; the instrument consisted of demographic questions, items answered using a 5-point Likert-type scale, and several open-ended questions. Only measures relevant to the present study (i.e., activism, demographic and health status characteristics, social network integration, coping behaviors, and knowledge of HIV-treatment information sources) are described here.

**Activism.** We focused on two measures of activism: membership in an activist organization and self-advocacy orientation. To assess activist group membership,

participants were asked a single question that was answered yes or no: 'Do you belong to an AIDS activist organization?' Thirty participants answered yes to that question, which represented 97% of the questionnaires from ACT UP chapters (i.e., one person who completed a questionnaire through ACT UP reported that he was not a member of that group). Because our primary concern was to determine differences between those who belonged to an activist group and those who did not, we chose to include the 30 participants who reported membership in an activist organization in the first group and the remainder in the second.

A second measure of activism was utilized to assess individuals' tendency toward self-advocacy, a central feature of activist action (see Brashers, Haas, et al., 2000). Specifically, Brashers, Haas, and Neidig (1999) found that members of activist groups differed from nonmembers on the Patient Self-Advocacy Scale (PSAS), which is composed of 12 items that measure (i) education about illness and treatments (e.g., 'I actively seek out information about my illness'); (ii) assertiveness in health care interactions (e.g., 'I frequently make suggestions to my physician about my health care needs'); and (iii) potential for 'mindful' non-adherence (e.g., 'Sometimes there are good reasons not to follow the advice of a physician'). These three dimensions form the basis for the overall construct of self-advocacy. For analyses in this study, we used the overall scale, which had a Cronbach's  $\alpha$  of .79. Higher scores on this scale represent a greater tendency toward self-advocacy.

**Demographic and health status characteristics.** Although there are an indefinite number of possible personal characteristics that might be different between activists and nonactivists, we sampled from the major categories of demographic and health status variables. First, participants were asked to report *demographics* of age, highest education level completed (high school or less, two-year college, four-year college, master's degree, or a doctoral or professional degree), and whether or not they currently were employed. Second, they were asked to report *health status* indicators of CD4 count, HIV or AIDS diagnosis, time since diagnosis, and experience of fatigue (a frequently debilitating subjective symptom).

**Social network integration.** To estimate the degree to which study participants were involved in communities of people living with HIV or AIDS, they were asked questions (answered yes or no) about whether or not they (i) participated in support groups, (ii) received services at an AIDS service organization, and/or (iii) volunteered at an AIDS service organization. Each of these measures was analyzed separately as a dichotomous variable. We also asked those who attended support groups to report the number of times per month they attended a support group.

**Coping behaviors.** Participants responded to items from the Ways of Coping Checklist (WCCL; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986) that were selected as applicable to a population of people living with HIV or AIDS. Participants were asked to what degree they used various methods of coping on a Likert-type scale ranging from 1 (*not used*) to 5 (*used a great deal*). *Problem-focused coping* was measured with seven items that specifically focused on the WCCL concepts of planful problem solving and positive reappraisal (e.g., 'I made a plan of action and followed it' and 'I changed or grew as a person in a good way'). *Emotion-focused coping* also was measured

with seven items that addressed the WCCL concepts of wishful-thinking, detachment, and escape-avoidance (e.g., 'I went on as if nothing had happened' and 'I wished the situation would go away or somehow be over'). Cronbach's  $\alpha$  was .87 for the problem-focused coping scale and .78 for the emotion-focused coping scale. Scores were averaged across the items with higher scores representing greater likelihood of use.

**Knowledge of HIV-treatment information sources.** To investigate differences in the knowledge of resources between activist group members and nonmembers, we focused on their knowledge of HIV-treatment information sources, a fundamental concern for most people living with HIV or AIDS. To measure their knowledge of these sources, participants were asked to read the following brief scenario, in which they were asked to imagine that they were seeking information about an experimental treatment: 'You recently heard of a new treatment that is not yet widely available. The treatment is still experimental, but you would like to obtain more information about it.' They were then instructed to list as many possible sources of information about the treatment that they could imagine and to rate the likelihood that they would use each of the sources that they listed on a scale of 1 (*very unlikely*) to 5 (*very likely*).

A category scheme of treatment information sources for people living with HIV or AIDS was developed through an inductive process. Participants' responses were sorted into conceptually similar groupings by two of the authors. Relatively narrow categories were first developed by matching responses that were considered substantively similar (e.g., *New York Times* and *Washington Post* were classified as newspapers); these categories then were collapsed to form broader categories (e.g., newspapers and television were classified as media). After development of the coding scheme, one of the authors and a person trained to use the scheme each coded all of the 872 sources of information listed by participants. Coding the data into the major categories and sub-categories occurred simultaneously. Intercoder reliability was high (Cohen's kappa = .91), and disagreements subsequently were resolved through discussion between the coders until agreement on all coding was reached.

As shown in Table 1, we categorized sources of treatment information into 14 superordinate categories (with 49 sub-categories identified; details are available from the first author). Respondents reported both mediated and interpersonal sources for gathering treatment information. Media sources included literature from various organizations (e.g., AIDS service organization newsletters, government agency publications, and local and county health department literature) and mass media (e.g., magazines, newspapers, and television) as means of gathering HIV- and AIDS-related information. Interpersonal sources included seeking information through interaction with such people as health care workers (e.g., physician, nurse, and social worker), family, or friends with HIV or AIDS.

## Results

Research questions and hypotheses were answered with a variety of statistical tests, most commonly with a comparison between participants who were members of an activist group and those who were not. For all tests of significance, alpha was set at .05. We also included effect size estimates (e.g.,  $r$  for  $t$ -tests or the odds ratio for  $\chi^2$ -tests).

**TABLE 1**  
**Comparing treatment information sources for activist and nonactivist individuals**

Source	Activist <i>n</i> (% of total)	Nonactivist <i>n</i> (% of total)	Odds Ratio
Health care Worker	34 (15%)	146 (23%)	0.61*
Community Health / ASO	54 (24%)	111 (17%)	1.53*
Media	27 (12%)	120 (19%)	0.60*
Government Health Agency	27 (12%)	79 (12%)	0.99
Friend	17 (8%)	38 (6%)	1.31
Gay or HIV Media	13 (6%)	33 (5%)	1.14
Library	5 (2%)	39 (6%)	0.35*
Telephone Hotline	13 (6%)	19 (3%)	2.03
Support Group	6 (3%)	11 (2%)	1.58
Family Member	5 (2%)	10 (2%)	1.45
Internet	7 (3%)	7 (1%)	1.61*
Grapevine, Word-of-Mouth	5 (2%)	9 (1%)	1.61
Pharmaceutical Company	6 (3%)	5 (1%)	3.51*
Other (Not mentioned above)	6 (3%)	20 (3%)	1.25
TOTAL	225 (100%)	647 (100%)	

Overall  $\chi^2$  (13,  $N = 872$ ) = 33.33,  $p < .001$ .

\* $p < .05$  based on a binomial test.

### Demographic and health status characteristics

Research question one asked whether personal characteristics of activist group members are different from those of nonmembers. Education level was significantly associated with activist group membership,  $\chi^2(4, N = 170) = 13.67$ ,  $p < .01$ , with a Spearman rank-order correlation of .28,  $p < .001$  (indicating a positive linear association between activism and education level). The mean time since diagnosis for the sample was 57 months (range = 1 to 156 months,  $SD = 40.59$  months), with activist group members having been diagnosed longer ( $M = 72.1$  months,  $SD = 39.7$ ) than nonmembers ( $M = 53.7$  months,  $SD = 39.9$ ),  $t(164) = 2.66$ ,  $p < .05$ ,  $r = .20$ .

There was no significant difference detected between the age of activist group members ( $M = 37.3$  years,  $SD = 6.3$ ) and nonmembers ( $M = 36.5$  years,  $SD = 7.4$ ). There was no significant association detected between activist group membership and working: of those reporting employment status, 11 (37.9%) activist group members and 70 (51.5%) nonmembers were employed. There was no association detected between activist group membership and diagnosis: 20 (66%) activist group members and 71 (51%) nonmembers reported an AIDS diagnosis. There was no significant difference in CD4 count between members of an activist organization ( $M = 276/\text{mm}^3$ ,  $SD = 308/\text{mm}^3$ ) and nonmembers ( $M = 283/\text{mm}^3$ ,  $SD = 291/\text{mm}^3$ ). Finally, there was no significant association between activist group membership and fatigue: 24 activist group members (85.7%) and 96 nonmembers (68.1%) experienced fatigue.

### Social network integration

Hypothesis 1 predicted that activists would have greater social network integration than nonactivists. Being a member of an activist group was associated

with receiving services at an AIDS service organization,  $\chi^2(1, N = 171) = 4.46$ ,  $p < .05$ , with 18 (60.0%) of the activist group members and 55 (39.0%) of those who were not activist group members reporting that they received such services. Activist group members also were more likely to volunteer at an AIDS service organization ( $n = 20$ , 66.7%) than those who were not members of an activist organization ( $n = 40$ , 28.4%),  $\chi^2(1, N = 171) = 15.93$ ,  $p < .001$ . Activist group membership was not associated with participating in a support group: 14 (46.7%) activist group members and 45 (31.9%) nonmembers attended support groups. However, participants who attended support groups had higher self-advocacy scores ( $n = 59$ ,  $M = 4.06$ ,  $SD = .47$ ) than those who did not ( $n = 113$ ,  $M = 3.59$ ,  $SD = .52$ ),  $t(170) = 5.77$ ,  $p < .001$ ,  $r = .40$ , and the frequency of support group attendance was positively associated with self-advocacy ( $r = .48$ ,  $p < .01$ ). (All  $t$ -tests conducted to test the research hypotheses were one-tailed independent groups tests). Individuals who volunteered at AIDS service organizations also had higher self-advocacy scores ( $n = 60$ ,  $M = 3.95$ ,  $SD = .55$ ) than those who did not ( $n = 112$ ,  $M = 3.64$ ,  $SD = .52$ ),  $t(170) = 3.58$ ,  $p < .001$ ,  $r = .26$ , and individuals who received services at AIDS service organizations had higher self-advocacy scores ( $n = 73$ ,  $M = 3.93$ ,  $SD = .46$ ) than those who did not ( $n = 97$ ,  $M = 3.60$ ,  $SD = .57$ ),  $t(168) = 4.09$ ,  $p < .001$ ,  $r = .30$ .

### **Coping preferences**

Hypothesis 2 predicted that, compared to nonactivists, activists would be more likely to use problem-focused coping strategies and less likely to use emotion-focused coping strategies. A  $t$ -test demonstrated that activist group members ( $M = 4.33$ ,  $SD = .56$ ) were more likely than nonactivists ( $M = 3.50$ ,  $SD = .93$ ) to use problem-focused coping,  $t(68.5) = 6.33$ ,  $p < .001$ ,  $r = .34$ . (Separate variance estimates were used because of unequal variances of the groups on the problem-focused coping measure.) Activist group members ( $M = 2.53$ ,  $SD = .79$ ) were also less likely than nonactivists ( $M = 3.08$ ,  $SD = .93$ ) to use emotion-focused coping,  $t(168) = -3.03$ ,  $p < .01$ ,  $r = .23$ . In addition to these findings, self-advocacy was correlated positively with problem-focused coping,  $r = .41$ ,  $p < .01$ , and negatively with emotion-focused coping,  $r = -.27$ ,  $p < .01$ .

### **Knowledge of information sources**

Hypothesis 3 predicted that activists would have greater knowledge of HIV-treatment information sources than would nonactivists. Of the 174 participants, 138 (79%) completed the sources-of-information task: 25 of the 30 activist group members (83%) and 113 of the 144 nonmembers (78%). A one-tailed  $t$ -test showed that individuals who belonged to an activist organization listed more HIV-treatment information sources ( $M = 8.76$ ,  $SD = 2.59$ ) than individuals who did not belong to an activist organization ( $M = 5.83$ ,  $SD = 2.72$ ),  $t(136) = 4.92$ ,  $p < .001$ ,  $r = .39$ . Self-advocacy also was significantly associated with the number of information sources listed,  $r = .35$ ,  $p < .001$ .

Research question 2 asked about differences in information source utilization between activists and nonactivists. On the basis of data shown in Table 1, a chi-square test demonstrated that there was a significant association between types of information sources named and activist group membership,  $\chi^2(13, N = 872) = 33.33$ ,  $p < .001$ . Follow-up binomial tests were conducted to determine which specific information sources contributed to this effect. The number of information sources listed overall for each subgroup was used to calculate expected values for the binomial tests (26% activists and 74% nonactivists). As shown in

Table 1, members in an activist organization were less likely than nonactivists to list media, library, and health care workers as sources of information, and more likely than nonactivists to list community health or AIDS service organizations, Internet, telephone hotlines, and pharmaceutical companies. Odds ratios, which describe the relative odds of an event given group membership (e.g., the odds of an activist group member naming 'media' as an information source divided by the odds of a nonactivist naming 'media' as an information source) are reported as an effect size measure in Table 1 (see Haddock, Rindskopf, & Shadish, 1998). If the odds are equal (e.g., activist group members are as likely as nonmembers to name 'media' as an information source), then the odds ratio equals one.

## Discussion

AIDS activism has become an important social and political component of the lives of people living with HIV or AIDS. Membership in an activist group is likely to reflect a desire for social and personal changes in coping with HIV illness. People come to social movements, such as ACT UP, with skills and resources that are employed in encounters with others inside and outside the movement. Interacting with others through collective action also can change people in a variety of ways (Klandermans, 1992), including psychological empowerment (Zimmerman & Rappaport, 1988). As W. A. Gamson (1992) noted, 'Participation in social movements frequently involves an enlargement of personal identity for participants and offers fulfillment and realization of self' (p. 56). Our study supports the contention that there are substantive differences between activist and nonactivist individuals living with HIV or AIDS. In particular, activism and a self-advocacy orientation were both associated in this study with coping preferences, knowledge of HIV-treatment information sources, and social network integration, as well as some demographic and health status characteristics.

Evidence from the present study suggests that activism is part of a more general active orientation that involves cognitive and behavioral attempts to change circumstances. Compared with nonmembers, members of activist organizations reported greater likelihood of using problem-focused coping and less likelihood of using emotion-focused coping. In addition, self-advocacy was positively associated with the likelihood of using problem-focused coping and negatively associated with the likelihood of using of emotion-focused coping. Thoits (1994) argued that individuals who are 'psychological activists' tend toward problem-solving orientations in an effort to actively confront situational challenges. In a study of relationships in which couples were dealing with everyday problems, she found that individuals who attempted to change their circumstances had higher levels of self-esteem and lower psychological distress than individuals who did not try to change their circumstances, even when those efforts to change were unsuccessful. We might expect, then, that encouraging active coping strategies might improve psychological outcomes for individuals with HIV or AIDS. In addition, working to conquer the challenges of HIV infection – including making decisions about treatments,

negotiating the health care system, and maintaining interpersonal relationships – may lead to positively valued identity attributes, such as perceiving oneself to be an active problem solver (Thoits, 1994), collective identification as an activist (Simon et al., 1998), and/or feelings of high personal and collective efficacy (Bandura, 1997). Enacting an activist role also might combat feelings of helplessness or loss of control that accompany being labeled as 'ill' or 'a victim of AIDS.'

An additional dimension on which activists differed from nonactivists was knowledge of HIV-treatment information sources. In exploring the influence of an activist orientation on these sources of information reported by people living with HIV or AIDS, we found that belonging to an activist organization was associated with reporting a greater number of sources and that self-advocacy was positively correlated with the number of sources listed. These findings support Brashers, Haas, et al.'s (2000) contention that a defining feature of activism and self-advocacy for people living with HIV or AIDS is increased attention to information seeking. They found that people who were self-advocates placed greater importance on information seeking to discover the most recent illness and treatment information, whereas those who were not self-advocating tended to be more passive about acquiring information for health care decision making. It may be that those who belong to activist organizations, in comparison with those who do not, are regularly exposed to and familiarized with more diverse sources of HIV-treatment information from their association with other activists. In particular, the need to engage experts in debate may lead activist group members to be more aware of available information sources, whereas non-members may have less exposure to (and, therefore, less knowledge of) possible sources of HIV- and AIDS-related information.

There were differences not only in the number, but also the types of HIV-treatment information sources listed by our study participants. Nonactivists were more likely to list traditional sources (e.g., health care providers and media), whereas activists were more likely to list nontraditional sources (e.g., Internet sources and pharmaceutical companies). Although the number of participants reporting use of these sources was small in this study, activists were more likely than nonactivists to list computer-mediated information sources. The World Wide Web, listserves, and newsgroups have evolved rapidly as important means of providing individuals with health information. Many teaching hospitals, clinics, and research institutes have developed websites that include patient education bulletins, research articles, and information about specific programs (e.g., information about health care delivery or clinical trials participation). Listserves and newsgroups provide channels for sharing data and social support among people with similar illnesses and medical conditions. Together, these sources provide an easily updated and maintained system for delivering facts about health and treatments in an environment in which (i) information changes rapidly and (ii) the need for the latest information often is critical for participating in individual and collective action, accessing quality health care, and making effective treatment decisions.

Activists also differed from nonactivists on social network integration. Activists were more likely to participate in AIDS service organizations through volunteering and receiving services. In addition, self-advocacy was higher for those involved in AIDS service organizations, as well as for people who participated in support groups. Research indicates that people with particularly stigmatizing illnesses may seek out similar others for support (e.g., Davison, Pennebaker, & Dickerson, 2000), which may create important opportunities for social network development. Moreover, Hays, Chauncey, and Tobey (1990) demonstrated that these opportunities for mutual support (e.g., involvement in support groups or community associations) were correlated positively with psychological well-being, leading the authors to hypothesize that being able to assist others decreased feelings of dependence and helplessness. Membership in a collective, therefore, also might promote individual self-esteem (i.e., how a person values himself or herself on the basis of perceived personal attributes) and collective self-esteem (i.e., the value a person places on himself or herself on the basis of social group membership) (Crocker & Luhtanen, 1990). Both may be positively affected by engagement in AIDS activist groups, either through opportunities to interact with similar others or because of individual and group successes of collective action.

Because people may be differentially willing or able to be active participants in collective and individual action (e.g., those who are more ill may be less inclined to desire control over their treatments; see De Haes & Molenaar, 1997), we need to know more about which characteristics are associated with increased willingness and ability to participate in activist movements. In addition to differences in coping preferences and knowledge of HIV-treatment information sources, we found that members of activist groups (compared with nonmembers) tended to have higher levels of education and a longer time since diagnosis. Other factors associated with activist group membership that should be investigated (e.g., motivations and barriers to collective action; see Klandermans, 1997; Klandermans & Oegema, 1987) include the personal, social, and cultural contexts in which potential members are situated. For example, cultural or political inhibitors may prevent some people from joining activist groups, including social norms against confrontation or legal sanctions for civil disobedience. For instance, some people have criticized ACT UP actions as inappropriate. Protests against the Catholic Church in New York interrupted services at St. Patrick's Cathedral, and posters of Cardinal John O'Connor pictured beside a condom carried the message 'Know Your Scumbags' in protest of his public opposition to safer sex education promoting condom use. These actions brought criticism from those outside the movement (even among the group's sympathizers) and drew added attention from the local police to subsequent actions by ACT UP at the church. Either issue might prevent potential members from joining the activist organization.

Other people living with HIV or AIDS may avoid such collectives as ACT UP, AIDS service organizations, or peer support groups because they need to maintain uncertainty about their illness. Brashers, Neidig, Haas, et al.

(2000) reported that individuals living with HIV or AIDS sometimes avoid situations in which they are likely to encounter negative information (e.g., support groups in which other members may become sick or die) so that they can maintain hope. Participants in their study also reported taking 'holidays' from information when it became too negative, overwhelming, or both. Haas (1999) similarly found that gay male couples coping with HIV or AIDS sometimes avoid talking about the illness as a way of maintaining normalcy in their relationships. Finally, Taylor and Armor (1996) argued that coping with adversity can be accomplished through maintaining positive illusions. These findings suggest that we should not be quick to dismiss emotion-focused coping as a dysfunctional form of managing the stresses of illness. Further research should be conducted that (i) examines how people manage uncertainty, hope, and positive illusions and (ii) explores the ways in which those variables are connected to health outcomes.

Future research also should help determine other influences on individual and collective motivations and behaviors. For example, in addition to more instrumental purposes, social movements may be a mechanism for the expression and management of a variety of emotions. Jasper (1998) noted that 'emotions exist or arise in individuals before they join protest groups; others are formed or reinforced in collective action itself' (p. 397). People living with HIV or AIDS and their supporters may feel solidarity or love for one another, anger and fear about the potential consequences of the disease, shame about having contracted the disease, and/or hope for maintaining health. Participation in an activist organization's activities and interactions among its members may provide outlets for emotional expression. Meyers and Brashers (in press) argued that emotional components of ACT UP's actions (the use of slogans and chants, vilification of opponents, expressions of anger, and use of visual images) both complement and stand in contrast to the 'rational' argumentation that occurs in meetings with government and industry representatives. Others have found that anger expression in AIDS activist protests can be both a motivating and cathartic experience (Ariss, 1994; Brown, 1997). The experience and expression of emotion in collective action subsequently may affect the overall mental and physical health of people living with HIV or AIDS.

Future studies should be designed to include a variety of other outcome measures to assess the association between membership in a collective and such variables as psychological distress, quality of life, and related constructs. There has been considerable interest in how individuals with HIV or AIDS cope with stress (e.g., Folkman, 1997; Krikorian, Kay, & Liang, 1995). Being able to predict coping behaviors (including activism and self-advocacy) may be important because of the implications of coping preferences for such health-related outcomes as quality of life (Friedland, Renwick, & McColl, 1996), depressive symptoms (Fukunishi et al., 1997), compliance with medication regimens (Singh et al., 1996), clinical progression of HIV disease (Mulder, Antoni, Duivenvoorden, Kauffmann, & Goodkin, 1995), survival time (Reed, Kemeny, Taylor, Wang, & Visscher, 1994), and increased risk of such unhealthy behaviors as smoking, drinking,

and engaging in unsafe sexual behavior (e.g., Folkman, Chesney, Pollack, & Phillips, 1993; Thompson, Nanni, & Levine, 1996). Coping effectiveness training (e.g., M. Chesney, Folkman, & Chambers, 1996) or interventions for increasing people's participation in health care decision making (e.g., Peerbhoy, Hall, Parker, Shenkin, & Salmon, 1998; Socha-McGee & Cegala, 1998) may need to account for the social nature of coping strategy development for people diagnosed with HIV or AIDS. Understanding how activist and self-advocacy philosophy and skills are encouraged through interactions with others may help us to assess the means by which people learn to involve themselves in their own health care and to determine the efficacy, efficiency, and patterns of adoption of self-care behaviors.

### Limitations

This study helped to establish differences between activist and nonactivist individuals living with HIV or AIDS. It does not, however, allow us to determine how these differences came about. For instance, it is not clear whether individuals who participate in collective activism are attracted to it because of the orientation they have toward their health care (e.g., focusing more on problem-solving and integrating themselves into social networks of individuals living with HIV or AIDS) or if they develop these values because of the educational and motivational practices inherent in activist groups' social activities (i.e., through planning and implementing social action and through managing identities and relationships). We believe that both factors contribute to these differences. Future studies that follow individuals from diagnosis through activist group membership should be designed to examine these processes in a more temporal fashion.

This study also is limited by the size and composition of the convenience (i.e., volunteer) sample used in this study. The sample size was small, which might explain some nonsignificant results (in particular, in the demographic and health status research questions). Studies that include larger samples of activist and nonactivist individuals are needed. In addition, most participants in the study were White, gay, and male; therefore, we are not able to generalize across sex, race, and sexual orientation in the population of people living with HIV or AIDS. Women, heterosexual males, and members of racial minority groups may be more or less likely to join activist groups than are White gay males. For example, a recent study by Stein et al. (2000) demonstrated that women are more likely than men to delay seeking health care for themselves because of their need to care for members of their families. Similarly, women may be less likely to engage in activism if it competes with their sense of obligation to family members.

### Conclusion

Social activism has become an important part of the lives of people living with HIV or AIDS. Participating in social activist groups and organizations

may be attractive for people who perceive that individuals working alone are inefficient change agents, perhaps because of the need for diverse social skills and expertise in a variety of complex subjects. Members of activist groups and organizations bring skills and resources to that site that they share with other members and they seek out skills that they lack. Both individual and collective self-esteem may be positively affected by engagement in AIDS activist groups, either through opportunities to interact with similar others or because of individual and group successes of collective action. Differences between members and nonmembers are, at least in part, attributable to the social relationships and interactions that occur within activist action. Social activism is an important direction for studying the social and personal relationships of people living with HIV or AIDS.

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