Health Activism: Communication Theory and Action for Social Change

This article argues that “health activism” as a concept has been overlooked as an important element of health communication and situates the concept in relation to key areas of research in the field, including health citizenship and community organizing. The author presents theoretical frameworks for comparing and contrasting health-related social action based on issue focus and political orientation that facilitate communication-based contributions to multidisciplinary research. This contribution is discussed in more detail by theorizing communicative processes associated with health activism. It is then argued that the study of health activism can benefit from adopting critical perspectives that focus on issues of power and conflict and on multisectoral views of health that examine activist efforts related to a broad array of the determinants of health, including political, economic, and environmental issues.

Use of the term health activism is not particularly common in either popular or academic discourse, especially when compared to the ubiquity of the term environmental activism. We are more likely to hear discussion of AIDS activism or breast cancer activism than we are to hear the covering term “health activism.” By referring to activists one disease or health issue at a time without reference to the more encompassing concept, many scholars and the public may overlook important commonalities (and differences) among activist efforts that focus on a range of issues related to health. Initially defined in terms of efforts, often grassroots, to change norms, social structures, policies, and power relationships in the health arena, health activism includes actions related to patient activism, health care reform, disease prevention, illness advocacy, physical disability, environmental justice, public safety, and health disparities in populations such as women, minorities, gays, and lesbians, among others.
Health activists at times have achieved significant influence over social norms and policies in public health and medicine. These achievements include the grassroots work of Black women health activists in the late 1800s and early 1900s who pursued social justice in health, putting in place an infrastructure that formed the basis for state-level public health efforts for African Americans (Smith, 1995). In the 1960s and 1970s, women’s health activists placed women’s health on the national agenda, encouraged self-empowerment, and challenged medical definitions of disease (Eckman, 1998). Civil rights groups, unions, and organizations for retired persons successfully fought for Medicare legislation in 1965 (Hoffman, 2003). Beginning in the 1970s, multiple antitobacco groups including Action on Smoking and Health, Americans for Nonsmokers’ Rights, Group Against Smokers’ Pollution (GASP), along with the health voluntaries such as the American Heart Association, fought for health warnings, restrictions on smoking, and significant changes in public attitudes toward smoking (Wolfson, 2001). At the same time, environmental health activists worked to create the Clean Air Act (1970), the 1972 Clean Water Amendment, the Occupational Health and Safety Administration, and the Environmental Protection Agency (Faber & O’Conner, 1993). In the 1980s and 1990s, activists worked to reduce stigma associated with AIDS, to spur research into treatments, and to promote accessibility to those treatments (Christiansen & Hanson, 1996). Activists also have raised funding and visibility for breast cancer research and treatment (Klawiter, 2002).

This influence illustrates the importance of examining health activism as a major form of health communication. The article provides conceptual definitions and theoretical frameworks that facilitate comparisons among a wide array of health activist efforts in order to develop a more coherent body of theory and research about communication in health activism than currently exists in the field. I would argue that health communication can benefit in the study of activism by adopting critical and multisectoral lenses that focus, respectively, on issues of power and inequality and linkages among multiple social domains that influence health. As such, these lenses encourage attention to relationships between activism and sociopolitical and economic influences on health status at local and global levels.

The article begins with a discussion of existing treatments of activism in health communication, followed by a discussion of important conceptual definitions in the arena of health and social change. The next section provides theoretical frameworks for the study of health activism based on issue focus and political orientation. I then describe potential contributions of health communication research to interdisciplinary research by examining communication processes related to activism. The
article ends with discussion of how studies of health activism can expand health communication theorizing by engaging the complexities of human health.

**Activism and Health Communication Studies**

Activist efforts help to construct (and are constructed by) the discursive contexts of the key research foci in health communication, including the meaning and experience of illness, provider–patient interaction, prevention campaigns, community organizing, medical and pharmaceutical issue management, mediated health depictions, health policy, and health care access debates. Despite this influence, health activism receives relatively limited attention in the health communication field. For example, the *Handbook of Health Communication* (2003) does not contain a chapter explicitly addressing activism, and some textbooks largely overlook the issue (e.g., du Pre, 2000). This may be because the field places greater emphasis on traditional health campaigns and provider–patient interaction.

Most communication research that emphasizes collective action for health focuses on community organizing and development (Diop, 2000; Ford & Yep, 2003). Among those areas that focus specifically on activism, AIDS and breast cancer receive the most attention, leaving other forms of health activism undertheorized. Additionally, much of the work done in the area of activism related to health is conducted by rhetoricians and cultural theorists (Fabj & Sobnosky, 1995; Pezullo, 2003), whose interest in theoretical issues of the public sphere and argumentation provide very valuable insights, but whose research is not yet fully integrated with the theories and interests of health communication. As I will demonstrate, sociologists, psychologists, and social movement scholars have developed a base of literature that also has yet to be integrated with communication theorizing and research.

Consequently, the concept is not well defined. When invoked in health literature, the term activism or even health activism often goes undefined. Brashers et al. (2000) defined *social activism* as “persuasive communication behaviors of a collective that are intended to serve the common interest” (p. 375). Usefully, Geist-Martin, Ray, and Sharf (2003) informally define health activism in terms of taking responsibility for individual health, working to improve health conditions for a group, and making efforts to change and improve policies for large groups of people. The authors include activities ranging from demonstrations, lobbying, and fundraising to helping friends and keeping health records. They also situate health activism as a form of health citizenship.
Rimal, Ratzan, Arntson, and Freimuth (1997) argued that the concept of patient should be understood in terms of “health citizenship,” which involves “an active citizen involved in individual and collective decision-making” (p. 61). These authors argued that the role of the researcher is to “increase citizen’s health decision-making competencies” (p. 63) and that research to improve individual health should consider multiple arenas, including health policy, access to medical care, and community activism. Community activism is described as part of health citizenship, defined in terms of community groups who mobilize for collective action.

However, I would argue that the preceding perspectives do not adequately distinguish health activism as a concept from health citizenship, in part because they do not theorize issues of power and conflict. In the next section, I describe how doing so provides a means of distinguishing among health-related efforts.

**Conceptual Definitions**

In this section, I provide some conceptual distinctions among terms that I believe would allow communication scholars to address activism with greater clarity by accounting for key contextual issues, including power and conflict. This conceptualization acts as both a review of existing research and a prescription for useful ways to proceed in a communication-based study of health activism. I describe relationships among the terms health activism, health social movements, community organizing, and community development (see Appendix).

*Health activism* implies, at some level, a challenge to the existing order and power relationships that are perceived to influence some aspects of health negatively or to impede health promotion. This is the case because activism involves attempts to change the status quo, including targets such as social norms, embedded practices, policies, or the dominance of certain social groups. If we look at the activities Geist-Martin, Ray, and Sharf (2003) list as activism, this definition would favor demonstrations and lobbying over helping friends and keeping health records. Those elements of health citizenship (Rimal et al., 1997) that focus on social change and challenges to existing power relations would be considered health activism.

Brown et al. (2004) contrast activism with health *advocacy*. According to these authors, health advocacy focuses on education and works within the existing system and biomedical model. Advocates tend to rely on expert knowledge rather than insert lay knowledge into expert systems. Activist-oriented groups, in contrast, tend to engage in direct action, challenge the medical paradigm, and insist on democratic participation in knowledge production.
Of course, many activities are not so clear-cut. For example, the phenomenon of celebrities (such as Michael J. Fox) testifying before Congress to increase funding for a particular disease can be seen as attempting to shift research priorities within the existing medical model. On the other hand, such actions can be seen as activism to the degree that they challenge medical control over the funding and prioritization of research. Thus, questions of power and conflict must be accounted for when invoking the concept of activism rather than assumed a priori. Nevertheless, the distinction between education-based and resistance-based approaches is an important one in the field of health communication, where existing social structures are often taken for granted (Lupton, 1994).

Conceptualizing activism also involves contextual questions of scope and time. Specifically, scholars in health psychology, sociology, and other allied health fields often investigate activism using the term social movement and related theoretical concepts. Della Porta and Diana (1999) argued that social movements involve (a) informal networks with (b) shared beliefs and solidarity, (c) collective action focusing on conflicts, and (d) use of protest. The authors note that movements differ from other political groups because they act outside institutions, engage in unconventional actions, and often use protest. These characteristics can be understood to apply to collective activism as well.

However, the authors also argue that social movements differ from isolated protest events because they have vision, identity, a sense of linkage, and ongoing action. Single organizations may be a part of social movements but are not movements in themselves. Given that the term social movement implies activism on a large scale and existing over time, activism can be separate from, precede, follow, or include social movement activity. Thus, health social movements (HSMs) can be understood as a form of activism. My focus in this article on the more inclusive term activism versus social movement reflects a desire at the theoretical level to include as broad a range of resistance efforts as possible, including isolated protest events and the actions of single organizations.

Brown et al. (2004) provided a relatively useful definition of health social movements as “collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organizations, supporters, networks of co-operation and media” (p. 52). However, the term medical may encourage a narrow reading of the term by focusing on medical policy (as the provision of health care) versus broader health policies that include public health infrastructures, public safety, disability, environmental quality, and other issues (for a communication perspective on public health and medical distinctions, see McKnight, 1988). The authors themselves noted that HSMs address a range of issues related to public health and medicine.
Therefore, I would replace the term medical with health in this definition of HSMs, to read: collective challenges to health policy and politics, belief systems, research and practice.

Distinctions among these terms do not reflect preexisting ontologies and should not be reified into inflexible categories. Rather, discussion demonstrates the interrelationships among these concepts. Indeed, from a communication perspective, it is vital to understand how participants themselves perceive their actions and choose to label them. For example, Wolfson (2001) argued that antitobacco activism constitutes a social movement in part because it has attempted to create structural change beyond the individual level and in part because participants consider it to be one.

Aside from social movements, scholars also address activism by studying community organizing. Using the activism lens I describe here requires us to distinguish among the multitude of community approaches in order to better understand how they relate to existing systems of power. First, community organizing is often referred to as a specific process of empowering individuals and building relationships and organizations to create action for social change at the community level. Loue et al. (2003) defined bottom-up (versus elite or top-down) community organizing as grassroots activism. In a bottom-up approach, design and implementation of programs or policies are driven by community memberships. Grassroots efforts often draw from Saul Alinsky or Paulo Freire to create critical dialogue about the status quo that acts to mobilize groups for change (Minkler & Wallerstein, 1997). This dialogue is expected to lead to improved individual health behavior and changed collective identity.

Although community organizing could be distinguished from grassroots activism based on the target of action (local community or broader social issue), Minkler (1997) complicated this by noting that “community” can be defined in terms of geography, collective identity, shared characteristics, special interests, or patterns of social interaction. Fisher (1997) further blended the distinction by describing the “social action community organization” such as Citizen Action, a grassroots, conflict-based, direct action-based group working for the disadvantaged with a focus on redefining power relationships. Minkler also noted that such organizations may work locally on issues of national concern (e.g., pollution).

In elite/top-down approaches to community organizing, efforts may be instigated and led by an outside organizer (Loue et al., 2003). Community development projects generally involve the physical development of impoverished communities by elites, often addressing jobs, housing, and safety. Stoecker (2002) argued that community development projects often involve disconnected, discrete efforts that fail to address impor-
tant barriers to “self-help.” The author argued that many community development projects create no bargaining power, so that advocates must beg elites for resources, often leaving a community worse off. Such efforts can be distinguished from activism to the degree that they are led by elites, work within existing structures, and fail to address power relationships.

Without getting overly mired in classification, we can understand health-related community organizing to be a form of health activism that focuses on a particular community (however defined). Questions related to community organizing and community development as forms of health activism would focus on the degree to which an effort is directed from the outside versus a bottom-up approach and the degree to which an effort engages with significant changes in the status quo, including political, cultural, and economic changes. As I discuss later, organizing that focuses on community self-empowerment can be helpful in reducing dependencies, but may justify the retrenchment of public services and support in ways that support neoliberal governance models, the effects of which exacerbate inequities in health for disadvantaged groups (Campbell & Murray, 2004; Petersen & Lupton, 1996).

The discussion of each of these terms—activism, social movements, and community organizing and development—.touches on the issue of the political focus among activists and activist groups. In the following section, I describe ways to theorize different activist efforts.

---

**Theoretical Approaches to Health Activism**

There are a variety of theoretical schemes designed to compare and contrast activism, social movements, and HSMs in particular. Here, I describe some of the advantages and drawbacks of these systems for studying collective action in health and propose a framework for comparing (a) issue focus and (b) political orientation that may be useful for building a coherent body of research in communication studies, as well as in other disciplines.

**Issue Focus**

First, health activists are concerned with a variety of issues within the rubric of “health,” and they can be classified in terms of this focus in order to understand their commonalities and differences. Brown et al. (2004) divided HSMs into “health access movements,” which focus on access to medical care; “constituency based health movements,” which focus on health inequalities among groups and “embodied health movements,” which focus on disease and illness experience, addressing “eti-
ology, diagnosis, treatment and prevention” (p. 50). The authors acknowledge that these categories may blur; for example, they argue that environmental justice movements are both embodied and constituency based because they are constituted by people with an illness or fear of illness, but also address inequality. Also, it is conceptually difficult to differentiate between these two categories because many embodied health movements (disability, mental health, AIDS) are focused on inequalities among different constituencies as they address disease diagnosis, treatment, and prevention.

Clearly, any categorization system will not be mutually exclusive. However, some important elements of health activism may be overlooked by using Brown et al.'s (2003) scheme. One is that this categorization largely rules out what Stewart (2001) referred to as “other-directed movements,” or those efforts that are intended to help others. The scheme does so by placing everyone either as a constituent promoting the health of their own group or as someone with a particular illness. This is evident when the authors state that “a health social movement needs some degree of a shared illness experience in order to organize in the first place” (p. 454). Yet, as an example, some people work for gun control measures for the safety of the general public without personal experience of gun-related injury or death. Other activists may work on behalf of those whose illness or disability prevents self-advocacy. Another issue is that the categorization system may obscure the work of public health prevention by locating prevention within the embodied health movement. This move may lead us to overlook work that focuses on the roots of multiple health problems across various sectors, for example, the control of toxics or the effects of global economic policy.

So, although constituency and embodiment are highly useful concepts, I would propose a modification to this system that divides health activism into three issue-focused categories: (a) medical care access and improvement, (b) illness and disability activism, and (c) public health promotion and disease prevention activism (see Table 1).

The medical care access and improvement concept focuses on efforts to expand access to medical care and health insurance, along with movements to improve the quality of medical care delivery and communication. This category would include medical care reform activism such as labor campaigns (Wages, 1994). Additionally, medical care workers often take up activism in order to protest changes in care delivery, such as the Australian nurses who protested the privatization of community health services (Serghis, 1998). Also in this area is patient activism to improve doctor–patient interactions (Brashers et al., 2000) and identity-based advocates who work for improved medical sensitivity for groups such as gays and lesbians (Epstein, 2003).
Illness and disability activism focuses on bringing attention to particular diseases, developing research and treatment, and altering public perceptions and norms related to illness and disability. For example, Michael J. Fox’s public advocacy for research into Parkinson’s disease (Geist-Martin et al., 2003) is an example of illness activism, as are disability rights organizations. Breast Cancer Awareness Month activities that focus on early detection of breast cancer fit into this category (Klawiter, 2002). Illness activism includes women’s resistance to the medicalization of women’s health issues, such as menopause, childbirth, or menstruation (Tiefer, 2001). Another example is DNA patenting by patients to challenge corporate medical patenting that impedes research into cures for their disease (Allen, 2001).

Public health and disease prevention activism focuses on removing the causes of disease and barriers to good health. This would include public safety issues such as gun violence and tobacco (Nathanson, 1999), drunk driving (Morris & Braine, 2001), and environmental sources of cancer-causing agents (Klawiter, 2002). As I will discuss, significant activist efforts in this area may focus on the roots of health concerns across multiple sectors, including income disparity, education levels, social prejudice, and resource availability.

This categorization system is also blurred because of significant overlap between illness advocacy and disease prevention (for example, AIDS and asthma activism works for treatment for the ill as well as social preventive measures). However, the distinction is intended to differentiate between activism primarily focused on bringing attention and funding for the cure of disease or changed cultural attitudes toward illness,
and activism aimed toward removing the causes of disease, inequity in health status, and barriers to good health.

**Political Orientation**

A second theoretical issue related to activism involves orientations toward social change. Because activism involves some level of resistance or challenge to the status quo, research must address explicitly the issues of power. Generally, theorists place activists or social movements on a continuum from reformist to revolutionary. However, Wilson (1973; see also Scambler, 2002) provided additional points on the continuum by comparing locus of change—individual versus social—and amount of change.

To begin, *alternative efforts* aim toward partial change of the individual, countering conventional norms in favor of sustainable lifestyles and personal betterment. These efforts may include activism to promote alternative healers and “green consumer” lifestyles that involve sustainable purchasing among environmentalists. *Reformative efforts* aim toward partial social change, offsetting existing injustices or inequalities. Reformative health activism includes Medicare/Medicaid reformers, disability rights activists, and groups like MADD that promote accident prevention through individual responsibility.

*Redemptive efforts* aim toward radical change but focus on individual and personal betterment. Although rarer than other forms, examples may include movements for self-care and faith-based healing. Wellness movements focused on the promotion of individual psychological, physical, and emotional well-being may qualify when they focus on transformation of the individual. Finally, *transformative efforts* aim for fundamental change in broad-based social structures, such as universal health care, social norms related to disability, or poverty. Although Wilson (1973) added that radical change involves violence, it should be noted that many transformative groups, such as the peace, civil rights, and global justice movements, prize nonviolence as both value and tactic (see Table 1 for comparisons.)

This theoretical scheme provides a useful heuristic for developing research and praxis related to communication and health activism. However, communication scholars should be as grounded as possible when making claims about relationships between activism and social change because there are multiple perspectives through which activist efforts can be interpreted, and the purpose and scope of such actions may change over time. For example, there is the potential for reformist groups to prevent transformational politics by blunting public pressure for changes in more fundamental issues related to health. As Ray (1993) noted, alternative efforts such as green consumerism may depoliticize critical issues of environmental policy, leaving problematic structures such as in-
dustrial practice intact. On the other hand, Scambler (2002) noted that reformative movements may enhance the chance for greater changes later, such as is the case when alternative self-help groups act transformatively to fight off the colonization of the lifeworld by medical expertise and create joint narratives that later form the basis for collective action. Similarly, redemptive movements alter individual values, which may contribute to structural change.

Given this concern with issues of power and social change, critical perspectives can provide an important lens for analyzing the political orientations of health activists. Critical and cultural approaches in health communication consider both hidden conflict and apparent conflict and their relationship to power and ideology (Lupton, 1994; Waitzkin, 1991). In particular, critical-interpretive communication studies focus on how communication constructs ideology, taken for granted assumptions about reality that structure social decision making and everyday life in ways that systematically reinforce the interests of dominant groups. Critical-interpretive scholars are interested in multiple forms of hegemony, including dominance of biomedical models of medicine as well as ideologies related to gender, race, and class. Because hegemony can be understood as a dialectical tension of control and resistance (Mumby, 1997), critical scholars also examine the role of agency in resisting and transforming dominant power relations. This perspective is relatively rare in health communication, and existing work may be faulted for inattention to concrete methods of resistance and social change. Critical studies of health activism may help to remedy both of these issues.

**Communication Processes and Health Activism**

Ultimately, activists’ orientation toward change influences and is influenced by the communicative context for collective action related to health. When health activists pursue health-related change, they engage in multiple symbolic, interpretive, and interactional processes. As Morris and Braine (2001) argued, the central goals of movements are to bring about cultural change, “to convince people to see things differently, to interpret social reality differently” (p. 21). The same can be said for health activism. This section illustrates that a variety of disciplines and research perspectives (sociology, psychology, rhetoric, cultural studies) can be brought to bear on the study of health activism. Furthermore, a communication perspective, particularly health studies, adds to extant literature in the area by theorizing processes of symbolism, meaning construction and interpretation, social interaction, and power and influence. Communication processes related to health activism include, but
are not limited to, identity construction, the interpretation of illness causation, the choice and articulation of solutions, the development of public appeals, and the implementation of methods and tactics, as well as forms of organizing. The choices made in each of these areas influence and are influenced by activists’ issue focus and political orientation along with potentially unique contextual factors associated with the socially constructed environments in which they are embedded.

Here, I describe these communication processes in relation to extant research. I explain how health communication, and critical perspectives in particular, can add insight to this multidisciplinary literature as well as practice, and chart areas for future research.

Identification
First, both individual and collective activism rely upon the development of identification with an issue, and collective activism in particular requires the development of some degree of common identity among participants. The communication discipline highlights the symbolic processes through which individual and collective identities develop and how they interrelate to develop a sense of commonality (Cheney & Christensen, 2001).

Moreover, multiple perspectives in health communication can investigate identity issues related to gender, ethnicity, and class in health activism. Gibbs (2002) noted that women have largely organized the grassroots network of environmental health activism. When such activists find disease clusters, the fact that they are women is often cause to dismiss them as “hysterical housewives” (p. 104). Bullard (1990) has written extensively about environmental racism and the environmental justice movement, and there is a continued need to examine the role of ethnicity and class in both health disparities and activist attempts to address them.

Additionally, health communication can add to our knowledge of identity issues related to health activists’ management of illness-related stigma. Existing research illustrates how both AIDS and asthma activists focus in part on changing social perceptions of a disease (Brown et al., 2003; Elwood, 1999). Indeed, identity may be the primary subject of activism, such as when activists focused on the medical depictions of women’s sexual needs (Tiefer, 2001). On the other hand, health communication research can help us to understand how health activists who do not share an illness identity or some other shared characteristic such as ethnicity or gender work to achieve a common identity.

Morris and Braine (2001) argued that activism requires the development of oppositional consciousness that contests dominant ideologies and provides “symbolic blueprints for collective action and social change” (p. 26). Oppositional consciousness directs attention away from personal explanations and “identifies dominant groups and their structures
of domination as the source of oppression” (p. 27). Brown et al. (2004) developed a linkage to health through the concept of the “ politicized collective illness identity,” which creates common bonds among illness sufferers that link illness to structural inequalities and power differences. The field is well situated to examine how groups develop injustice frames, define us–them dichotomies in defining oppression, and articulate their own positions in terms of morality (Cheney & Tompkins, 1987). Critical perspectives in particular can investigate the degree to which individuals develop oppositional consciousness as they engage in activism. Doing so allows us to distinguish between grassroots activism and elite-based issue management (known as “Astroturf”) that adopts “activist” identities for defensive purposes. The restaurant industry’s attempt to discredit advocates of healthier food at www.consumerfreedom.com is an example.

**Health and Illness Causation**

Second, activists articulate their interpretation of health and illness causation. Although causality in health may be taken for scientific fact, I argue that this is best considered an interpretation for at least two reasons. One is the issue of scientific uncertainty. Given the difficulty of establishing causation in the realm of human biology, there will be different levels of public and scientific knowledge of and agreement about the origins of health problems. For example, Nathanson (1999) argued that growing scientific and public agreement about tobacco-induced illness assisted the antitobacco movement, whereas the gun control movement faces disagreement about whether guns or humans themselves cause health problems. The second reason is that activists must make value-laden choices from among multiple levels of causation that may operate together. For example, reformist groups such as the Susan G. Komen Foundation support research into individual-level changes such as diet and smoking, whereas the transformative efforts of the Toxic Links Coalition of the San Francisco Bay Area support environmental and political causation theories including those surrounding corporate toxic production (Klawiter, 1999). Some asthma advocates pursue a multicausal approach that addresses individual, political, and environmental sources of illness (Brown et al., 2003).

Health communication can contribute to our understanding of activists’ interpretive choices surrounding health and illness causation. The field can apply existing research about risk communication and the rhetoric of causality (Kirkwood & Brown, 1995; McKnight, 1988) to the study of activist discourses so as to improve the practice of health activism. Additional research could examine relationships between illness narratives (Sharf & Vandeford, 2003) and activism, which would provide unique insight into how activists discursively construct health itself and how this discourse may change over time.
Critical research in health communication (Dutta-Bergman, 2004; Lupton, 1995; Zoller, 2003) has investigated the political implications of different theories of causation, and such research can shed light on activism. It is helpful to investigate the theories of health offered by reformist, redemptive, transformative, and alternative groups and their relation to social change. Furthermore, an important part of what health activists do is focus public attention on who has the power to define health, illness, risk, and causality. For example, patient activists must work to include patient perceptions of illness causation into medical encounters (Brashers et al., 2000).

**Constructing Solutions**

Third, often linked to their interpretation to causation, activists articulate and pursue solutions as they choose targets for change. Based on their orientation toward change, groups may choose individual, governmental, institutional, or broader social and political solutions. Reformative efforts are more likely to call for improved government funding, altered medical practice, or changed policy. Transformative efforts may ask for broader changes in social norms, industrial and economic practices, or the medical care system. As discussed earlier, these choices are not static and may evolve over time. Hoffman (2003) noted that health care reform activists often begin by promoting reformative changes in the existing medical care system but move to calls for comprehensive medical care reform based on their experiences.

Health communication studies have much to contribute to our understanding of how activists choose various targets for change and how they articulate their justifications. For example, McLean (1997) described how community organizers on an Indian reservation chose projects based on the needs of residents as articulated during dialogue. The communicative implications of different goal choices should be compared across different types of activist groups, including grassroots and top-down approaches, as well as health care reform groups, illness activism, and public health and prevention efforts. Additionally, the field can expand its research into health policy construction as a symbolic, negotiated process (Sharada, Venkataramana, & Nirupama, 2001; Sharf, 1999) and a power-laden activity (Conrad & McIntush, 2003; Dejong & Wallack, 1999) by understanding the role health activists play in the process. Furthermore, critical perspectives can broaden our understanding of policy to areas of power and influence beyond the state, including nongovernmental actors such as the WHO and the UN, and private organizations such as national and international corporations.

**Public Appeals**

Fourth, activists articulate theories of causation and solutions using different forms of public appeal. These appeals may take the form of aware-
ness messages, pleas for social responsibility, or appeals to fear, sympathy, morality, respect, or social justice, along with a variety of other approaches. Activists rely on persuasive appeals to connect with the public to change attitudes and encourage action. Indeed, environmentalists have found that human health itself is a powerful form of appeal, as calls for action tied to health problems may mobilize the public more than appeals to ecology will (Brandon, 2003). Communication researchers can contribute to theory and practice by understanding how groups can link public appeals to targeted audiences. For example, antismoking activists found that calls for policy and normative changes were more successful when aimed at the risk of passive smoke to nonusers than when fear appeals focused on the risk to smokers themselves (Nathanson, 1999).

The development of collective identity may influence the appeals activists employ. For example, the deaf community tends to see itself as a cultural group like an ethnic group and, similar to the appeals of the civil rights movement, often makes appeals for respect and equality of access. Deaf activists, on the other hand, tend to identify as disabled and make appeals in terms of special needs (Groch, 2001).

Also, activists’ political orientation will influence the rhetorical burden that they face and the strategies they employ to face it. Elite-based, reform-oriented activists often have greater access to political decision-makers and may face greater public acceptance of their goals. Yet, as Hoffman (2003) argued, a technical approach common to elite groups may impede grassroots mobilization. The author attributed the failure of groups in the United States to coalesce into a serious grassroots movement for national health care access to elites’ use of technical language that failed to capture the imagination of the public. On the other hand, the AMA appealed successfully to the masses, particularly by using fear appeals related to “socialized medicine.”

Existing communication research at the crossroads of rhetoric and health addresses the role of communication appeals in AIDS activism, including the use of humor (Christiansen & Hanson, 1996), visual symbols (Sobnosky & Hauser, 1999), and argumentation (Fabj & Sobnosky, 1995). Public relations and issue management research has been used to analyze campaign appeals, and it can be used by scholars to assist activist groups in articulating their message (for example, Condit & Condit’s [1992] study of antitobacco activists successful use of “incremental erosion” provides understanding of what may be a useful strategy for other health activists).

Critical and cultural perspectives would facilitate investigation of the degree to which activist appeals create change for those outside White and middle-class groups. Nathanson (1999) noted that U.S.-based anti-
smoking activists have been successful in reducing smoking acceptance among White and educated groups, but have done little to penetrate attitudes among minorities and the working class. Furthermore, critical perspectives can draw attention to the degree to which activist appeals address health disparities between developed countries and those in the global south.

**Methods and Tactics**

Fifth, public appeals are closely related to the communication methods and tactics deployed by activists to gain attention for their issues. The same appeal by groups such as AIDS activists for social justice might be expressed using different methods, from direct action to public protest to Internet-based education. Common activist tactics include public education and advocacy; entertainment media such as the movie *Supersize Me*; direct mail and Internet sites such as the Center for Science in the Public Interest or notmilk.com; public participation events such as Race for the Cure; protests that include public melodrama such as Act Up!; and lesser known street protests such as the Boston healthcare providers’ Boston Tea Party, which involves throwing overboard annual reports of for-profit health care firms (Stoecker, 2002). Methods also include legal strategies such as filing litigation against the tobacco industry and the use of negotiation and dialogue by local community organizers (Ford & Yep, 2003).

Existing studies of health-related media coverage (Kline, 2003) provide practical insight for activist groups (which rely heavily on media coverage to reach broad audiences), including the development of alternative media, as AIDS activists did in Gillette’s (2003) study. Lacey and Llewellyn (1995) noted that media coverage itself can encourage and shape public activism about certain health risks such as the Alar pesticide scare.

Critical studies can employ the political orientations in the preceding section to understand how methods are employed to meet different goals. For example, transformative activists may be more likely than reformative activists to use direct action and protest as techniques that gain attention for issues outside mainstream public opinion.

**Forms of Organizing**

Sixth, the development of common approaches among activists—the kind that lead to sustained activism, community organizing, coalitions, and social movements—requires coordination. Thus, choices of different forms of organizing will influence how a group develops an identity, communicates among members, and speaks with the public. Groups may adopt bureaucratic and top-down organizing methods, or they may use grassroots and feminist organizing approaches. Choices of organizational form and decision making will influence who can participate and whose interests are reflected in decision making (Medved et al., 2001; Zoller,
Community organizations may attempt to work by consensus in order to achieve full participation, often believing that participation is itself good for health. The health voluntaries have adopted a bureaucratic form of organizing that is associated with a more conservative approach to social action (Smith, 1995).

Further, the development of networks and coalitions are key strategies in achieving change for many grassroots groups. Coalitions may involve temporary, strategic alliances (Della Porta & Diani, 1999) or long-term strategies (see, for example, Ford & Yep, 2003). Lammers, Duggan, and Barbour’s (2003) institutional perspective on health care organizations can be applied to an array of health organizations to add insight into how medical, public health, and health voluntaries and grassroots activist groups interact. For example, Wolfson (2001) noted that partnering with nonprofits and governmental organizations brings important resources but also restricts the political activity of those involved.

Critical perspectives can study the growing development of radical coalitions, which signal a shift in transformative activist organizing strategy that is increasingly global in scope, perhaps best exemplified by the network organizing of activists in various affinity groups aimed at changing global economic issues. AIDS activism sprang from connections with the movements for gay rights and against apartheid (Sawyer, 2002), and Act Up! members are now developing broader alliances with global groups to fight transnational corporate practices such as those related to pharmaceutical profits and international financial institutions that contribute to the poverty that fuels the spread of AIDS (Shepard, 2002). The development of coalitions crosses multiple social sectors such as environmentalists, women’s rights groups and peace advocates.

New methods of organizing, including those that eschew hierarchy for overlapping group membership, temporary alliances, and Internet-based methods, merit attention for their implications for health. Rosenau (1994) argued that postmodern coalitional movements such as Act Up! have strengths, including realism, respect, and individuality, but are limited in effectiveness because they have no attention span and are concerned only about things that affect participants. Future research can address how radical coalitions are formed and sustained, and the degree to which these organizing methods influence policies related to the health status of multiple groups. A critical approach to communication in health activism would highlight conflicts among groups about appropriate tactics, such as those between direct-action groups like Earth First! and institutional consensus groups like the Sierra Club (Faber & O’Conner, 1993).

This list is not intended to be exhaustive of the communicative processes involved in health activism. It also should be noted that these communication processes are not isolated. Research is necessary to
understand dynamic relationships among identity formation, causal attributions, rhetorical appeals and communication methods, organizational forms, and outcomes. Delineating these issues for discussion, however, allows us to examine how a communication perspective, particularly a health communication perspective, can add to existing research to provide insight into health activism. Although it may be difficult to assess outcomes related to activism, given that outcomes may occur in unpredictable ways and appear long after efforts have ended (Fitzgerald & Rodgers, 2000), the field of communication can investigate outcomes related to different strategies through contextualized research.

Discussion: Health Activism and the Broadening of Health Communication Theorizing

This article illustrates that focusing on health as a modifier of “activism” requires some theorizing not found in general social movement research. It also demonstrates that the field of communication has much to contribute to interdisciplinary work in the area. I would also argue that engaging the complexities of health and social action can broaden health communication theorizing. Health activists must engage at the practical level with the complexities of health and, as a result, they ask theorists to do so as well. Some of these complexities arise from the fact that health status is multisectoral, meaning that health status depends on multiple systems ranging from health care delivery, to education, and to governmental regulation. Health also crosses national borders and is tied to issues of socioeconomic and cultural power. Consequently, our theorizing of health activism must address multisectoral and global efforts and be situated within material and symbolic power arrangements.

First, many public health prevention activists focus on the numerous, interconnected economic and social roots of health inequalities, and these efforts may be overlooked by existing conceptions of illness activism related to single health issues. Multisectoral approaches address social relationships among poverty, race, and gender, along with health care access, work relationships, environmental standards, quality of life, and more. So, for example, antipoverty activists may not immediately appear to be health activists, but reducing poverty levels can be considered public health prevention activism because it would arguably have a greater impact on health outcomes than many other forms of health care spending (Anderson, 2000; Christopher, England, Ross, Smeeding, & McLanahan, 2003). The field can expand theorizing through attention
to multisectoral coalitions such as environmental justice groups and public health movements that are “[w]orking to build a multiracial, multi-issue movement” (Hofrichter, 1993, p. 89).

Second, the study of health activism can broaden our theorizing by further engagement with the global interconnectedness of health. Activists challenge policies emanating from the state, corporate advocates, and networks of global organizations. A significant movement of transformational activism involves the array of forces often referred to as the movement for “globalization from below” (Falk, 1999), aligned to reject, counter, and reformulate existing economic policies known as “free trade” or “neoliberalism.” Although these groups frequently do not use the label “health activists,” by addressing policies related to the ability of states to provide health care and social safety-net programs, adopt the precautionary principle in protecting the public health from industrial harms, or make decisions about intellectual property rights related to pharmaceuticals, they represent a significant force for improving health status and reducing health inequities. Global economic policy is central to health communication but is often ignored in favor of individually oriented campaign research.

Third, and closely related to the previous two points, activists often find their efforts linked to larger political issues. Thus, studying health activism asks communication theorizing to engage more deeply with the material and symbolic elements of health related to socioeconomic status and cultural power. Throughout the article, I have emphasized how critical and cultural approaches to health communication can contribute to theory and practice by questioning the relationship of reformative, alternative, redemptive, and transformational activism to contexts of power and inequality. Much existing work in health communication addresses community empowerment in terms of self-help in individual neighborhoods or physical communities. Some of this research risks reinforcing the logic of individualism and ignoring the power-laden context in which communities and individuals make decisions. Community empowerment understood as an alternative to medical and public services can be problematic, such as in Rimal et al.’s (1997) claim that through community-oriented health promotion, “Citizens can discover that they have the power and capacity to improve their health rather than to depend on health professionals to fix them” (p. 69). Although a vital issue, without attention to issues of power, self-reliance risks reinforcing the logic of neoliberal global economic policies that undercuts the notion of health as a public good and support for social safety nets. Studying health activism encourages communication scholars to address the relationship of activism, and of their own research, to larger social contexts.
Conclusion
Health activism is a site for interdisciplinary research at the crossroads of health, communication, sociology, social movements, and cultural studies to name a few areas. The purpose of this essay is to encourage the potential of health communication studies to contribute to research and practice in the area. Health activists influence health status through changes in public norms, policies, and social structures. Their actions help to constitute the health contexts that health communication researchers examine. This influence merits the placement of health activism on the communication research agenda on par with health promotion campaigns, doctor–patient interaction, and other significant forms of health communication research.

Attention to health activism as a concept allows us to understand commonalities and differences among efforts in ways that may be overlooked by focusing separately on “asthma activism,” “breast cancer activism,” and so on. Such a focus helps us to forge a better understanding of the discursive role that the concept of health itself plays in motivating public debate, social action, and public policy on a local and global scale. The conceptual and theoretical frameworks are intended to facilitate health communication’s contribution to this area of study by organizing extant research and drawing attention to theoretical–practical issues that can be developed using health communication perspectives.

This article also calls for greater attention to issues of power and resistance related to health activism. I argue that such attention necessitates a broader conceptualization of health and its determinants that addresses activism related to socioeconomic and political roots of health status. Taking a multisectoral approach to health brings to light a wide array of activists involved in health-promoting behavior, activists who might otherwise be ignored in the study of health activism. In particular, health communication should not overlook the opportunity to examine the immense impact of global market policies on health and the growing movement of local and global activists who target this economic infrastructure.

A strength of the communication discipline, and health communication in particular, is the fusion of theory and praxis. This productive capacity can be employed to understand, critique, and even promote health activist efforts.

Appendix: Conceptual Definitions

**Health citizenship:** “An active citizen involved in individual and collective decision-making” (Rimal et al., 1997, p. 61).

**Health activism:** A challenge to existing orders and power relationships that are perceived to influence negatively some aspects of health or
impede health promotion. Activism involves attempts to change the status quo, including social norms, embedded practices, policies, and power relationships.

*Health advocacy:* Health-related promotion efforts that operate within the existing system and biomedical model, usually with a focus on education (Brown et al., 2004).

*Health social movements:* Collective challenges to health policy and politics, belief systems, research, and practice, which may include numerous formal and information organizations and networks that develop over time with ongoing action, often organized from the bottom up.

*Community organizing:* A process of empowering individuals and building relationships and organizations to create action for social change at the community level; it may be led by outside organizers or by community members themselves.

*Community development projects:* Such projects generally involve the physical development of impoverished communities by elites, often addressing jobs, housing, and safety.

Heather M. Zoller (PhD, Purdue University) is an assistant professor in the Department of Communication at the University of Cincinnati. The author wishes to thank Steve Depoe, Gail Fairhurst, and Shiv Ganesh for helpful assistance in reviewing the manuscript. Address correspondence to the author at Department of Communication, University of Cincinnati, Cincinnati, OH 45221-0184; zollerhm@email.uc.edu.

1 This includes health experts who led the 1920s Committee on the Costs of Medical Care, labor leaders in the 1940s who campaigned for Wagner-Murray-Dingell, and industry groups involved in planning for Clinton’s health care reform proposal.

2 These organizational decisions may reflect the influence of the social and business elites who often sit on the boards of such organizations as the American Cancer Society, which consistently discounts the role of the environment in cancer causation and whose board is made up of executives from some of the largest polluters in the U.S. (Epstein, 1999).


Wages, R. (1994, October 20). *Health activism*. Address by the president of the Oil, Chemical, and Atomic Workers Union to the Labor and Single Payer Rally, Oakland, CA.


