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## The politics of health mobilization in the United States: The promise and pitfalls of “disease constituencies”

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### ABSTRACT

A critical review of recent literature on U.S. social movements concerned with matters of health and illness prompts reconsideration of the prevailing conception of such movements as necessarily isolated and particularistic. With a focus on disease-constituency-based mobilization—presently the most potent model of efficacious activism to be found in the domain of health and illness in the United States—I argue that such activism may tend in two directions: a specific response to an imminent disease threat, and a bridging of collective action frames and identities that can lead to connections across differences and broader mobilization. Case studies have demonstrated how patient activism has affected the management of illness, attitudes and practices of health professionals, research practices, processes of innovation, state policies, and corporate behavior. Through close analysis of patient group mobilization and its distinctive orientation toward knowledge and expertise, I argue that patient groups in practice may connect with or influence one another or a range of other forms of mobilization in relation to health, and I examine the “linkage mechanisms”—spillover, coalition, and frame amplification—by which this can occur. Rather than imagine a stark opposition between particularistic, single-issue health politics, on the one hand, and universalistic efforts to transform the meaning and practice of health and health care in the United States, on the other, I propose closer attention to the potentially Janus-faced character of many health movement organizations and the ways in which they may look either inward or outward.

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In their introduction to a volume on social movements and the transformation of U.S. healthcare, [Levitsky and Banaszak-Holl \(2010, 3\)](#) described a paradoxical clash in scholarly perceptions. In the eyes of many analysts of health politics, health-related collective action is to be found practically everywhere one looks in the United States—perhaps especially so, compared to other places—and has been a potent force for many decades. Social movements have surfaced in campaigns to promote occupational health, oppose racially segregated hospitals, challenge gender bias in medicine, promote antismoking measures, and advance many other causes besides (see also [P. Brown et al., 2011](#); [Hoffman, 2012](#); [T. M. Brown and Fee, 2014](#); [IOM, 2014](#)). Meanwhile “a second perspective, in striking contrast, despairs of the absence of collective action” and laments that “there has never been, nor does there appear to be now, a large-scale, grassroots movement seeking fundamental transformation in the American health care system” ([Levitsky and Banaszak-Holl, 2010, 3](#); see also [J. S. Quadagno, 2005](#)).

[Levitsky and Banaszak-Holl](#) resolve the paradox by distinguishing between particularistic demands and universalistic initiatives:

While the United States has seen successful movements on behalf of particular social groups or around specific issues, these demands have not coalesced into a movement for more comprehensive reform, and by some accounts may have actually *impeded* efforts to achieve large-scale reform of the American health care system ([Levitsky and Banaszak-Holl, 2010, 3](#) (emphasis in the original)).

[Taylor and Zald](#) made a similar point in their conclusion to the same volume, arguing that “aspects of the larger socio-political context create the efflorescence of movements and at the same time have restrained the possibilities of developing a comprehensive welfare state” ([Taylor and Zald, 2010, 301–302](#)).

In this essay I propose setting aside this bifurcated conception of the space of political possibilities in relation to health and health care in the United States—the highly particular versus the fully universal—and replacing it with a more nuanced appreciation of

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real and potential pathways of influence across, and cooperation among, social movements of various sorts. Elsewhere in this special issue, authors reflect on the opportunities and impediments involved in promoting a conception of health as a collective good—what Robert Wood Johnson Foundation President Risa Lavizzo-Mourey (2014) has described recently as the goal of building a “Culture of Health.” Invocations of “culture” in relation to health merit scrutiny (Hall and Lamont, 2013; Aronowitz et al., 2015), and, as I will describe, I prefer to speak of the prospect of promoting diverse *cultures* of health, in the plural. Nonetheless inspired by a consideration of the challenges involved in furthering what Lavizzo-Mourey (2014, 14) calls the crucial recognition that “we are all in this together,” I take this opportunity to draw on the academic literature on social movements and health activism to consider the possibilities and risks that may inhere in various forms of political mobilization, and how those possibilities and risks may either promote or impede the formation of new forms of solidarity in relation to health promotion and health care.

My starting point is the significant body of scholarship in fields such as science and technology studies (STS), sociology, and anthropology that has documented and analyzed the proliferation of patient groups or “disease constituencies”—groups that mobilize around specific illness states or health vulnerabilities to demand various forms of biomedical and political action or redress. AIDS activism (Epstein, 1996; Treichler, 1999; Gould, 2009; Colvin, 2014) and breast cancer activism (Anglin, 1997; Kaufert, 1998; Klawiter, 1999; Myhre, 1999; Kolker, 2004; Gibbon, 2007; Klawiter, 2008) are only two of dozens of examples of this kind of mobilization, which has become increasingly prominent in the United States in recent decades but which is also evident around the world. Case studies have demonstrated how such activism has affected the management of illness, attitudes and practices of health professionals, research practices, innovation processes, state policies, and corporate behavior (for an older review see Epstein, 2008). Commentators have sometimes been critical of such advocacy groups, but few have denied their impact. In the United States, it is safe to say that this disease-constituency-based mobilization is presently the most potent model of efficacious activism to be found in the domain of health and illness.

By studying activism that is sparked by an imminent disease threat, what lessons can be gleaned for projects that seek to forge connections across differences and mobilize individuals who may not live under the shadow of a particular disease? At first glance, disease-based activism almost necessarily pits advocates of specific illnesses against one another as they vie for attention and their “piece of the pie” in the form of funding allocations from Congress and research grants from the National Institutes of Health (NIH) (Best, 2012). As suggested by a recent news article in *Science* called “What Does a Disease Deserve?” (Kaiser, 2015), debates about illness-specific activism—especially in the United States—tend to position the various distinct patient groups as engaged in competition that is inevitably zero-sum. Furthermore, it is plausible to argue that a narrowed focus and singular mission is precisely what permits such groups to mobilize effectively, establish a coherent collective identity, and frame their agendas in ways that resonate. Thus the disease-based model of mobilization seems immediately to raise legitimate doubts about the prospects for opening up broader conversations, not only among those who confront different health challenges, but also between those who are healthy and those who are well.

Yet there are reasons to question this assessment, not least because recent empirical research suggests that as many as 30 percent of “patient groups” in the United States transcend a single-disease focus, for example by emphasizing more than one disease or advocating for the more general health concerns of specific

sociodemographic subgroups (Keller and Packel, 2014). Furthermore, clear distinctions between states of health and disease are themselves increasingly blurry: new technologies are rendering more and more people as “patients in waiting,” at risk of specific diseases (Timmermans and Buchbinder, 2012), or as suffering from disease risk itself (Fosket, 2010; Aronowitz, 2015), while other healthy individuals increasingly see themselves as “not yet sick.” Such developments not only underscore the potential broader significance of patient group organizing but also suggest that conceptions of a strict divide between disease-response activism and health-promotion activism may prove increasingly less tenable.

In what follows I mine the existing literature on social movements in health and emergent forms of “biocitizenship” to argue: that the study of disease-specific advocacy has much to offer scholars concerned with other sorts of health mobilization, such as campaigns of health promotion; that the tactics of disease constituencies may be relevant to such efforts; and that what we think of as “patient activism” is often relatively hybrid and fluid, with manifold goals and potentials for connection with other advocacy groups and movements of various sorts. I argue for the importance of three specific “linkage mechanisms”—spillover, coalition, and frame alignment—in sometimes broadening the outlook of patient groups, bridging the gaps between them, and/or connecting them with other sorts of health movements. Therefore the analytical objective is to displace overly-rigid notions of an opposition between single-issue, disease-based health politics and more universal health politics. This analysis is a first step toward identifying the internal characteristics and external pressures that prompt Janus-faced health movements to focus either inward or outward.

## 1. Scholarship on patient groups and health movements

The past two decades have seen a significant rise in scholarly interest in the broader phenomenon of social movements active in the domain of health. Over time, such research has embraced a capacious understanding of the varieties of health activism in the United States. In a recent review, historians of public health Brown and Fee pointed out that “social movements in health have been persistent and regularly renewed sources of motivation for population health advances in Europe, the United States, and other parts of the world since at least the early 1800s,” including “movements focused on urban conditions and health, on children and health, and on behavioral and substance-related determinants of health” (T. M. Brown and Fee, 2014, 386). Other scholars have emphasized the historical intertwining of health movements with movements addressing other concerns, such as work, the environment, gender, and race (P. Brown et al., 2011). Indeed, important scholarship—of which Nelson’s (2013) study of the Black Panther Party is exemplary—has caused us to view well-known social movements in a new light when refracted through the prism of health concerns. Still others have taken different approaches to the general theme of health movements, including calling attention to the role of “consumer movements” in health (J. Quadagno and McKelvey, 2010; Rodwin, 2011; Baggott and Jones, 2014) or examining the role of social movements in transforming institutionalized aspects of healthcare domains (Banaszak-Holl et al., 2010). In addition, Hoffman has provided a comprehensive “rights-based” re-reading of U.S. healthcare politics to reveal the tight imbrication of health movements with various strands of political mobilization to expand rights over the course of the twentieth century (Hoffman, 2012).

Amidst this growing concern with social movements active in the domain of health, a significant body of scholarship has examined what have been variously termed patient groups (Epstein, 2008), patients’ associations (Rabeharisoa and Callon, 2002),

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