

Public Engagements with Health and Medicine

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Abstract This introduction to the special issue on “Medicine, Health, and Publics” argues that a rhetorical understanding of publics offers conceptual, methodological, and practical benefits to health and medical humanities scholars.

Keywords Health and medicine · Publics theory · Rhetoric · Rhetoric of health and medicine

Around the globe, citizens employ a diverse array of rhetorical practices while participating in biomedical and health processes. HIV-positive citizens in China initiate online conversations concerning their medical challenges. Citizens in India create Facebook pages in response to the moral and health crises surrounding rape. International foundations supply resources for people with contested illnesses such as Gulf War Syndrome or Morgellons, including organizing research projects with sympathetic health care practitioners. Meanwhile, thousands “Race for the Cure” or contribute to the global “One Billion Rising” campaign against sexual violence. Assisted by the Internet, others supply rapid feedback to health professionals about the official definitions of conditions affecting them or their loved ones. For instance, during a 6-week comment period in mid-2012, patients and their families, health care professionals, and advocates generated more than 13,000 comments and 12,000 emails in response to the American Psychiatric Association’s proposed revisions to the diagnostic criteria of the *Diagnostic and Statistical Manual of Mental Disorders* (APA 2013). Still other citizens join advocacy groups, serve on health-policy decision-making bodies, sound off in online fora, or write health-related editorials for the local newspapers. As they join in dialogue about the health and medical matters that mutually affect them, these citizens form publics in attempts to transform their social worlds (see Asen 2000; Hauser 1999; Warner 2002).¹

Recognizing this vibrant multiplicity of public engagements with health and medical processes and seeking to extend ongoing scholarly conversations about the coevolving relations among biomedicine, health, and publics, this special issue highlights what a rhetorical understanding of publics contributes to the medical and health humanities. Analyzing public engagements with health and medicine is important for health and medical humanities scholars for two primary reasons. First, in an era punctuated by persistent calls for “public

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participation,” “patient participation,” “public engagement,” or “user involvement” in biomedical and health processes (Braun and Schultz 2010; Irwin 2001; Resnik 2001; Wilson, Wynne, and Stilgoe 2005), we need to assess the multiple ways that publics already interface with biomedical and health knowledge formation, contestation, decision making, and practices. Second, in a time when medicine and health play an increasingly prominent role in shaping the contours of our collective, networked and global life, we need to understand how citizens, institutions, and movements increasingly organize around biological, medical, and health matters. In so doing, we can better account for the vital roles that publics play in shaping the contours of biomedicine and health.

The essays in this volume share the assumption that a rhetorical perspective on publics offers conceptual, methodological, and practical advantages to scholars in the health humanities. On a conceptual level, a rhetorical understanding of publics foregrounds the multiplicity of relations that form around issues of common concern (Asen 2000, 2004, 2010; Brouwer and Asen 2010; Doxtader 1995; Edbauer 2005; Hauser 1999; Pezzullo 2003). In popular parlance, it is not uncommon to hear “the public” hailed as a homogenous mass. We might read an essay about the public’s response to pandemic influenza or listen to a radio program about the general public’s attitude toward health care rationing, as if there existed either a uniform public or an easily apprehensible public response. By contrast, a rhetorical perspective on publics replaces the vision of *the* public as a monolithic totality with a view of multiple, overlapping, and interrelated groups whose members engage one another in dialogue about matters of mutual interest (Hauser 1999; Warner 2002). A rhetorical perspective on publics thus advances a participatory, dialogic model wherein citizens self-organize around issues of interdependent concern in a public sphere that need not be limited to geographical space. Emphasizing mutual spheres of influence and interchange, such a perspective encourages us to consider the “rather fluid network of exchanges” shaping health and medical knowledge and practices (Edbauer 2005, 19). From this perspective, we can appreciate biomedical and health discourses and practices as the result of complex sets of interacting rhetorical performances that bridge public, private, institutional, and technical concerns.

On a methodological level, attending to publics encourages health humanities scholars to shift the unit of analysis from the official texts of biomedicine to the practices that various groups use in contributing to and altering biomedical and health practices (see Hauser 1999; Pezzullo 2003). This methodological turn therefore implies that traditional rhetorical hermeneutics and close textual reading might profitably benefit from including participant observation, ethnography, interviewing, and other social science methods in order to capture the complex texture of public action and understanding. The resulting shift from elite representation to public performances and enactments mirrors recent calls to examine multiple health practices (Mol 2003) rather than focusing exclusively on the competing epistemologies of medical institutions, experts, and publics. These methods are not discrete, however, and they often overlap. For example, a number of the essays in this volume demonstrate the benefits of blending humanistic textual analysis with social science methods in order to access public opinions in the places they are formed, while other essays use the standard rhetorical toolbox to show the potentials and perils of public engagements with biomedicine and health. Although rhetoricians of health and medicine have room for improvement in this area, studying the publics that organize around health and medical matters compels us to engage more meaningfully with the stakeholder groups affected by our scholarship (see Frey, Pearce, Pollock, Artz, and Murphy 1996). In this way, taking publics seriously calls for a shift from “the rhetorical situation to rhetorical ecologies,” necessitating examination of the broader “context of interaction” (Edbauer 2005, 9) in which health and medical issues are discussed, challenged, enacted, and curtailed.

On a practical level, attending to publics honors the roles that various stakeholders play in shaping the coevolution of publics, institutions, biomedicine and health research, practices, and understandings even as it can reveal the places where public participation is curtailed or prohibited. By shifting attention from official biomedical texts to the roles publics play in shaping biomedical and health discourses and practices, rhetoricians and health and medical humanists can better map existing patterns of influence and identify places and strategies for rhetorical intervention in matters of public health and wellbeing. By uncovering both the opportunities for and the barriers to public participation in health and medical processes, health humanities scholars can advocate for better systems and practices. In short, a rhetorical model of publics presents an inclusive vision of health and medicine as networked, public exchange and encourages us to see participants in health and medical processes as more than consumers, clients, and patients. Acknowledging the complex work of publics in health and medicine therefore reinforces the health and medical humanities' concern for the humane—and distinctly human—dimensions of health and medicine.

By exploring the possibilities for a rhetorical understanding of public engagements with health and medicine, this special issue furthers the conversation initiated by an earlier volume of the *Journal of Medical Humanities*, edited by the University of Pittsburgh rhetorician of science John Lyne. In “Contours of Intervention: How Rhetoric Matters to Biomedicine,” Lyne called attention to a growing transdisciplinary field, the rhetoric of health and medicine (2001, 3). Rhetoric has long been concerned with public life, the public good, with the *nomoi*, *logoi*, and *ethoi* through which people come together to make decisions. Extending this tradition, Lyne's recommended rhetorical approach shares with the health humanities a broad interest in the socio-cultural, ethical, aesthetic, and historical dimensions of health and medical practice yet foregrounds the symbolic and material practices that shape meaning and judgment in health and medical matters (see also Berkenkotter 2008; Derkatch & Segal 2005; Keränen 2010a, b, 2014; Lyne 2001; Segal 2007, 2009a, b; Scott, 2003a, b). The essays in Lyne's special issue supply a framework for understanding health and medicine as deeply affected not only by the to and fro of public arguments about health and medical matters but also by a host of other rhetorical performances and enactments.

Existing rhetorical scholarship on publics (Asen 2000, 2004, 2010; Brouwer and Asen 2010; Doxtader 1995; Edbauer 2005; Hauser 1999; Pezzullo 2003) has drawn from and elaborated the work of a broad collection of thinkers, including Hannah Arendt (1958), Seyla Benhabib (1996), John Dewey (1927), Nancy Fraser (1992), Joseph Gusfield (1981), Jürgen Habermas (1989), and Michael Warner (2002), each of whom attempted to theorize the character, constraints, and possibilities of public life. While drawing inspiration from this broader set of authors, rhetoricians have tended to take as specific points of departure Habermas's (1989) *Structural Transformation of the Public Sphere*, feminist critiques of the notion of a bourgeois public sphere (e.g., Fraser 1992), and articulations of the pluralities and tensions in the interplay of publics (e.g., Warner 2002). Rhetoricians have explored the constitutive role of discourse in citizenship and public life (Asen 2004), the importance of vernacular or everyday rhetoric in shaping public opinion (Hauser 1999), the difficulty of untangling relations between publics and counterpublics (Asen 2000; Pezzullo 2003), and the metaphors through which we understand publics (Brouwer and Asen 2010). Publics theory has thus supplied a rich lexicon for analyzing how publics form, maintain, complicate, and challenge the status quo, and it opens up potential avenues of investigation concerning biological citizenship, around which emerging subjectivities and social movements can coalesce (Rose and Novas 2005).

Although publics theory does not appear within studies of health and medicine to the same degree that it does in rhetoric studies more broadly, rhetoricians who focus on health and

medicine have laid the groundwork for analyses of public engagements with biomedicine and health. They have done so by tracking the trajectories of controversies that lie at the intersection of public and technical knowledge (e.g., Boyd 2002; Fabj and Sobnosky 1995; Keränen 2005, 2010b; Paroske 2009), by analyzing public discourse about biomedical and health topics (e.g., Segal 2007), and by plumbing how public or lay meanings differ from dominant biomedical understandings (e.g., Condit 2001). In one notable study, Phaedra Pezzullo (2003) analyzed how the San Francisco-based Toxic Links Coalition's (TLC) annual "Stop Cancer Where It Starts" tour challenges dominant public understandings of breast cancer. Another promising early line of work initiated by Valeria Fabj and Matthew Sobnosky (1995) has shown how ACT-UP AIDS disrupted the barriers between the technical, public, and private spheres of argument and translated their HIV/AIDS concerns into public issues, thereby promoting a "rejuvenation of the public sphere" (163). Moreover, scholars in the rhetoric of science, which shares an intellectual lineage with the rhetoric of medicine, have long examined the interplay between public and technical rhetorics (Goodnight 1982; Lynch 2011), even as some authors have challenged the boundaries between them (Boyd 2002; Keränen 2005). These studies suggest places of potential rhetorical invention for scholars who wish to examine the interplay among publics, health, and biomedicine. Indeed, the essays in this volume build upon this literature while demonstrating a range of conceptual, methodological, and practical contributions to our understanding of public engagements with biomedicine and health.

In the first essay, Heidi Y. Lawrence, Bernice L. Hausman, and Clare J. Dannenberg analyze the consequential world of flu vaccination, focusing on the implications of locality in the study of vaccine hesitancy. Their discussion theorizes the notion of a *local public*, utilizing data from a study of two communities and their uptake of H1N1 and seasonal flu vaccination in 2009–2010. Identifying three primary framings of vaccine resistance, Lawrence and her co-authors situate vaccine hesitancy in the local, familial context of health decision making. They find that individuals' views of vaccination have much to do with their perceptions of family health and ideas about immunity and less to do with national preoccupations with the dangers of vaccination.

Philippa Spoel, Roma Harris, and Flis Henwood similarly employ a vernacular perspective alongside theories of environmental and health citizenship to investigate what the government's role in healthy living means for older adults in the U.K. and Canada. Their analysis of 55 interviews reveals that although a majority of participants articulate the ideal of the individually responsible health citizen, a number also use techniques of dissociation to critique the government's role in healthy living. They conclude that the participants in their study transcend passive, compliant recipient roles and reveal complex modes of enacting health citizenship.

Having seen how publics can resist dominant health configurations in Spoel, Harris, and Henwood's essay, we also see how professional discourse can influence the terms of "public" discussion. Demonstrating what fine-grained discourse analysis can offer the study of publics and medicine, Patty Kelly analyzes five instances of reported speech on the *DSM-5* draft diagnostic criteria for the classification Posttraumatic Stress Disorder. Kelly reveals how textual standardization positions a community of speakers beyond the APA as exemplary speakers, writers, and revisers of the professional style, thereby facilitating the cultural portability of the *DSM-5* diagnostic criteria, the "common language," and merging public and professional discourse. Moreover, she shows how reported speech, ostensibly derived from patients, becomes transformed into medically actionable data.

Just as professional norms may subtly shape public discourse, institutional norms also affect the contours of public discourse, sometimes undermining it. Christa B. Teston, S. Scott

Graham, Raquel Baldwinson, Andria Li, and Jessamyn Swift offer a three-pronged rhetorical-qualitative analysis of how public voices were incorporated yet muted in the FDA's 2011 hearing, which considered the fate of Avastin as an approved breast cancer drug. Offering an example of a hybrid forum that blended technical and lay perspectives, the Avastin hearing ostensibly included public representation. The authors' combination of analytical moves, ranging from stasis analysis through the application of multiple ontologies theory, highlights the many ways that the Avastin hearing fell short of its goal of public inclusion. Teston and her co-authors conclude by offering suggestions for making hybrid fora more inclusive.

Huiling Ding turns her attention to the work of international publics in a comparative study of transnational quarantine rhetorics. Using SARS and H1N1 as extended examples, Ding examines the interplay between official and public mobilization in China, Canada, and U.S. Chinatowns. She finds that grassroots efforts, online surveillance, and citizen initiatives played important roles not only in shaping public perceptions of the pandemics but also in curtailing their spread. Important for the purposes of this issue, Ding shows how Chinese netizens influenced perceptions of and responses to quarantine. Ding concludes that future public health measures must meaningfully engage publics if they are to be successful in minimizing epidemic spread.

Jennifer Malkowski examines academic strategies of containment of a controversial medical counterpublic called *bug chasers*, the label used to denote gay men who actively seek HIV. Malkowski analyses eight peer-reviewed social science articles about bug chasing to explore how scholars frame bug chasing amid a larger U.S. public health agenda. She finds that academic explanations tend to contain bug chasers using prevention rhetoric and thereby miss the ways bug chasing invites reconsideration of the goals of public health. Her analysis offers a study of discourse at the interface of counterpublics, academe, and biomedicine and thus reveals how perceptions of counterpublics can mobilize characterizations that limit public health responses. She concludes with a set of recommendations for engaging counterpublic rhetoric in cases of "risky" health practices.

J. Blake Scott's afterword, "Elaborating Health and Medicine's Publics," reflects on the essays in this special issue in light of the imperatives for studying public engagements with health and medicine. Scott concludes with two questions for further investigation: "How do discursive constructions of publics and more specific instantiations of embodied experiences mutually shape each other?" and "What do the infrastructures of health and medical users look like and involve in their enactment?" In so doing, Scott asks us to transcend traditional approaches to the rhetoric of medicine by more fully accounting for embodiment and infrastructure.

Special issues are mercifully never produced in isolation; this one has been buoyed by a vibrant community of health and medical rhetoricians. The idea for this volume formed in the summer of 2011, where participants assembled at a Rhetoric Society of America (RSA) summer workshop in Boulder, Colorado, to address "Medicine, Health, and Publics." J. Blake Scott and I led a team of scholars at various career stages in formulating medical rhetoric research projects; together, we molded dissertations, journal articles, and book proposals. As a follow-up to that session, I organized a "Medicine, Health, and Publics" meeting of the Association for the Rhetoric of Science & Technology (ARST), held in conjunction with the biennial meeting of the RSA in Philadelphia, Pennsylvania, in May of 2012. Here, more than 30 scholars from across North America gathered to share their research on topics related to how publics interface with biomedicine and health. Authors of the top submissions to the preconference were invited to revise their work for inclusion in this special volume. It was my intent to produce a volume that could be used by health humanities scholars and others in the humanities to teach students about how publics interface with biomedicine and health, and so

the final pages of the volume offer a discussion guide for use in the classroom and by reading groups.

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Endnotes

¹ To enhance the readability of the opening paragraph, I elected to relegate most citations to this endnote. For more information about online and televised forums for discussing HIV/AIDS and SARS in China, see Yu (2007). For one example of a Delhi Rape Protest facebook page, see <https://www.facebook.com/groups/DelhiRapeProtest>. For more information about One Billion Rising, touted as the "The Biggest Mass Global Action To End Violence Against Women & Girls In The History Of Humankind," see www.onebillionrising.org. Fair (2010) and Keränen (2014) discuss competing medical claims in Morgellons. For more information about the Susan Komen Foundation's "Race for the Cure," see <http://www5.komen.org/> and King (2006).

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