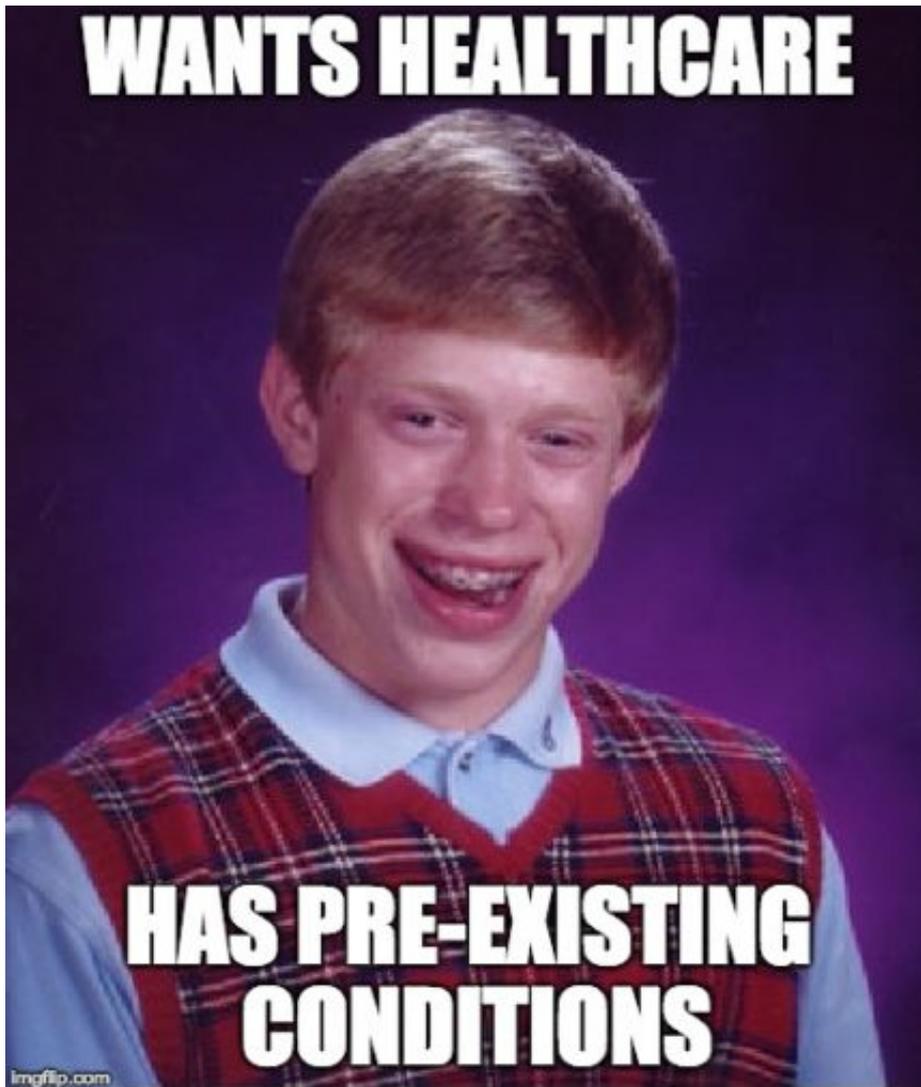


<http://somatosphere.net/2018/06/health-activism.html>

## Is Health Activism a Collective Responsibility?

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By Beza Merid



During the tumultuous “repeal and replace” frenzy in the spring and summer of 2017, the US House of Representatives and Senate moved quickly to consider bills intended to either eliminate the Patient Protection and Affordable Care Act (ACA) or restrict its various provisions. The American Health Care Act (AHCA) in the House and the Better Care Reconciliation Act (BCRA) in the Senate and their respective amendments were assembled with haste, often leaving little time for debate and public response before the prospect of a vote. As draft versions of these bills leaked and the details of their proposals spread, [Americans](#) in the United States (U.S.) [protested](#), and called and emailed their representatives and

senators to voice their alarm about new legislation that would strip away vital health insurance provisions—like protections for individuals with “pre-existing conditions”—that keep them alive. Many also shared intimate illness narratives (Kleinman 1988) in town hall meetings to personalize the stakes of this legislation. For individuals with pre-existing conditions, the prominent burdens of this legislative move are twofold, combining the already high cost of health care with the [constant and looming fear](#) of potentially being deemed *uninsurable* without a federal mandate for coverage. These collective and individual acts were instances of health activism, and they made health-related political organizing a topic of frequent, national discussion. As protesters and activists participated in sit-ins, faced arrest, and spoke of their confrontations with the specter of premature death as a consequence of health insurance precarity, they raised an important question: *is fighting for access to health care only the responsibility of those directly affected by its inaccessibility, or is it a responsibility shared by all?*

This focus on individuals with pre-existing conditions, in particular, is a fascinating and vital entry point into what is a broad and ongoing conversation about health and responsibility. A pre-existing condition, according to a [2017 Issue Brief](#) from the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health & Human Services, is “a health condition that predates a person applying for or enrolling in a new health insurance policy.” These conditions are part of the lives of millions of people from the United States, who are sometimes born with these afflictions and other times develop them throughout the course of life. The ASPE brief reports that as many as 133 million non-elderly Americans in the U.S. (about 51% of the non-elderly population) may have a pre-existing condition, including 67 million women and girls and 66 million men and boys (2). Prior to the ACA and its establishment of a federal policy on providing care for conditions that predated the start of an insurance plan, health insurance companies were able to define which conditions could be defined as a “declinable” pre-existing condition and, if an insurance policy were to be extended, how much care the plan would cover.

A [2016 Issue Brief](#) from the Kaiser Family Foundation reports that these declinable conditions, which varied state by state, included diagnoses affecting millions of Americans in the U.S. Among the most common conditions were high blood pressure (46 million people), asthma and chronic lung disease (34 million people), heart conditions (16 million people), and cancer (11 million people). These chronic conditions often place lifelong burdens on patients and caregivers that extend far beyond the significant financial costs of medical care. They place strains on personal and professional lives by fostering endless worry. They require patients and caregivers to become experts in both the bureaucracy of

health insurance policy (Parthasarathy 2010) and the nuances of their diagnoses and prognoses. The threat of inaccessible health care, of being told that one's health is too costly to insure, places embodied and ever-shifting limitations on the kinds of lives patients and caregivers can live, and those they may hope to someday experience.

While millions of people in the U.S. live with pre-existing conditions that indelibly shape their lives, for countless others in the U.S. with secure, high quality health insurance, these worries may exist only in abstraction. In truth, these burdens could come for any of us. What happens if health insurers are not required to cover patients with pre-existing conditions and, say, your child is born with a congenital disease? Who should be responsible for securing care? What happens when the cost of care for that child meets a lifetime cap on coverage in their first years of life? How might patients and caregivers facing this precarity survive, and what could they do to make the urgency of this legislative question plain to the many for whom these stakes may be less urgent and personal?

Questions about who is responsible for health are entrenched in longstanding political, legal, philosophical, and cultural debates about what it means to be a 'good citizen' (Galvin 2002). These debates are framed as a clash between two positions: one that highlights the importance of individual responsibility for health as an empowerment of individuals to make behavioral and lifestyle changes to promote health, and another that recognizes the importance of understanding individual responsibility within a social context that may not always enable 'responsible' self-action (Minkler 1999; Guttman and Ressler 2001). In historicizing this tension, these debates trace the codification of the 'individual responsibility thesis' to policy and health promotion documents like the so-called Lalonde report, *A New Perspective on the Health of Canadians*, in 1974, and the US Surgeon General's report, *Healthy People*, in 1979 (Minkler 1999; Galvin 2002; Wikler 2002). They also articulate the potential ethical pitfalls of overemphasizing the role of either personal or collective responsibility as part of this tension. The 'good citizen,' it seems, can thrive in an environment that keeps these two positions in balance. Striking that balance, unsurprisingly, is and remains a vexing problem.

I posed these questions to my students at the University of Michigan this semester in a class I teach on health and the media. The course considers how ideas about health, health maintenance, and illness are made socially meaningful through the technologies and media practices that fill our everyday lives. I was particularly interested in how my students would respond to the prevalence of pre-existing conditions, and how the fear of uninsurability can come to take over your life. Through an examination of media such as scripted and medical reality television shows, health education films, and intimate illness narratives in newspaper op-eds and

on YouTube, we discussed how health institutions and individuals circulate ideas about health as a personal and collective responsibility. I challenged my students to think critically about the lived experiences of illness, and how the media that pervade our lives express and shape our ideas about health and responsibility. Frequently returning to the notion of the pre-existing condition, we debated the merits of valuing health as either an individual or collective responsibility, considering what these values and their expression in the media we consume reveal about, say, our nation's commitment to equal protection under the law.

We spent a lot of time talking about how the stories we share about our illnesses—especially intimate stories about illness shared in public—can have a transformative quality about them. The labor of sharing these narratives, on illness blogs (McCosker and Darcy 2013) or in town halls with political representatives, for example, can provide a measure of relief and some semblance of control for patients and caregivers who may feel their lives are otherwise spiraling just out of their reach. They can offer instruction to the newly diagnosed or individuals who have no personal connection to a specific illness experience, providing rich detail that can foster empathy and a specific understanding of others' precarity (Butler 2004). By centering this appreciation of precarity in others, these narratives can also establish compassion for others as a prompt for collective, political, and legislative action. For the most part, my students seemed very open to the argument in favor of a collective fight for access to health care as a social obligation. This, I believe, was due in large part to our sustained conversation about and exposure to reading and viewing these kinds of affecting, personal narratives.

Our health media landscape, or healthscape (Clarke et al. 2010), is comprised of the health media we consume *as well* as the health media that we produce. I prompted my students to think about the kinds of illness narratives, technologies, and media practices we might create to communicate more effectively the urgency of these questions. We considered how the architectures of sites like YouTube and GoFundMe (Berliner and Kenworthy 2017) and the communication practices of social media accounts run by institutions like the American Cancer Society could be used to represent structural barriers to health equity, and prompt support for systemic change. We discussed how [Jimmy Kimmel's health insurance monologues](#) not only conveyed an emotional narrative about pre-existing conditions, but also made recommendations about how viewers could engage urgent policy debates. We set out, in short, to do the work of imagining a better healthscape by identifying our large-scale problems and conceptualizing interventions that directly addressed them.

Heather M. Zoller (2005) argues that a necessary condition of health activism is that it challenges order and power structures that impede

health promotion or otherwise influence health negatively, focusing on improving health conditions and health care policies. Throughout the semester, we debated the merits of labeling various media objects as instances of health activism, considering whether or not they met this threshold rather than, say, ‘raising awareness’ about existing social problems without advancing structural solutions. One such discussion focused on the explosion of health care memes during the “repeal and replace” months, considering whether the production and circulation of image macros could reasonably be called an activist intervention. As part of this exercise, I had my students make health care memes in order to consider what an investment in collective action should demand from us. After an entertaining class session distilling the ideological critique against the rationing of health care into the structured communication of a meme, we decided that while health care memes could use incisive humor to address [hypocrisy in the actions of political figures](#), they didn’t quite meet Zoller’s standard. And while these memes are sufficient to keep structural critiques about the inaccessibility of health care alive, my students suggested, they didn’t have the emotional appeal and political potential of intimate patient and caregiver illness narratives to sustain such a critique.

What kinds of mediated health activist interventions, then, would effectively frame the fight for broad access to health care as a collective obligation? How might the media we consume and produce be used to call on individuals who *don’t* live with pre-existing conditions to push for structural, policy-based change? This remains an open question, and one I ask my students to consider in the health and disease contexts most meaningful to them.

Imagining how the healthscape will continue to evolve, with emerging technologies and media practices potentially meeting and satisfying the changing health communication needs of myriad populations, encourages an investment in the speculative futures of media production and health activism to which we can all contribute. Through these discussions, we explored how the needs of vulnerable populations—including the need to access affordable care, information about health care, and emotional support for patients and caregivers—could go unmet under a paradigm that framed health maintenance as a strictly personal obligation. This paved the way for discussions about how the healthscape could not only foster expressions of need *by* individuals and disease constituencies, but also expressions of care *by* others *for* these individuals and disease constituencies. By centering this work and the recognition of others’ precarity as a cultural ideal, this course illustrates how the politics of health and health care pervade our media landscape and reflect ongoing tensions about what it means to be a responsible patient.

As reports circulate about a new round of repeal and replace efforts

coming later this year, this conversation is one my students and I will continue to engage.

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