



# Producing a worthy illness: Personal crowdfunding amidst financial crisis



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## ABSTRACT

For Americans experiencing illnesses and disabilities, crowdfunding has become a popular strategy for addressing the extraordinary costs of health care. The political, social, and health consequences of austerity—along with fallout from the 2008 financial collapse and the shortcomings of the Affordable Care Act (ACA)—are made evident in websites like GoFundMe. Here, patients and caregivers create campaigns to solicit donations for medical care, hoping that they will spread widely through social networks. As competition increases among campaigns, patients and their loved ones are obliged to produce compelling and sophisticated appeals. Despite the growing popularity of crowdfunding, little research has explored the usage, impacts, or consequences of the increasing reliance on it for health in the U.S. or abroad. This paper analyzes data from a mixed-methods study conducted from March–September 2016 of 200 GoFundMe campaigns, identified through randomized selection. In addition to presenting exploratory quantitative data on the characteristics and relative success of these campaigns, a more in-depth textual analysis examines how crowdfunders construct narratives about illness and financial need, and attempt to demonstrate their own deservingness. Concerns with the financial burdens of illness, combined with a high proportion of campaigns in states without ACA Medicaid expansion, underscored the importance of crowdfunding as a response to contexts of austerity. Successful crowdfunding requires that campaigners master medical and media literacies; as such, we argue that crowdfunding has the potential to deepen social and health inequities in the U.S. by promoting forms of individualized charity that rely on unequally-distributed literacies to demonstrate deservingness and worth. Crowdfunding narratives also distract from crises of healthcare funding and gaping holes in the social safety net by encouraging hyper-individualized accounts of suffering on media platforms where precarity is portrayed as the result of inadequate self-marketing, rather than the inevitable consequences of structural conditions of austerity.

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## 1. Introduction

“Why do I support universal healthcare paid for with our taxes?” asked a progressive political meme that circulated in August 2016. “Because I don’t want to live in a country where people have to set up a GoFundMe page just so they don’t die.” This meme reflects a remarkable emerging phenomenon within U.S. health care: the use of charitable crowdfunding sites such as GoFundMe (GFM) to address financial burdens arising from illnesses, disabilities and

accidents, crises exacerbated by unfilled gaps in the social safety net. Increasingly, Americans are using crowdfunding strategies to draw attention to their illness stories, in order to solicit support in the form of donations and “shares” on social media, and to ameliorate the extraordinary costs of uncovered or poorly covered health care (Sisler, 2012).

Crowdfunding has rapidly become institutionalized as part of the health care financing landscape: medical institutions such as hospitals counsel patients to set up campaigns, and starting campaigns for friends and family members has become a popular form of caregiving (Vance, 2012). GFM, a for-profit company founded in 2010, raised over \$470 million in campaigns by 2014; by 2016,

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yearly fundraising exceeded \$2 billion (Hurst, 2015; Gofundme, 2016). Medical and health campaigns consistently comprise GFM's most popular funding category, claiming 17% of total donations in 2012 (Barclay, 2012). By 2015, GFM had hosted more than 1.8 million campaigns for medical causes (Mac, 2015). GFM charges a 5% fee on all funds raised which makes it an extremely profitable venture, earning hundreds of millions of dollars each year from charitable campaigns hosted on its site.

The rise of medical crowdfunding emerges from two intertwining phenomena: fiscal crises in the American health care and social assistance systems, combined with the emergence of “sharing” and “crowd” economies that promote hyper-individualized and largely unregulated entrepreneurship. As such, medical crowdfunding campaigns provide a living archive of Americans' struggles to cope with illness in a neoliberal health system and in the wake of the 2008 global financial crisis, using a range of social media literacies to promote their appeals. Contexts of austerity encourage needy individuals to market their illness experiences and basic health care needs (Beckman, 2010; Lorey, 2015). We argue that the promotion of self-marketing for financial survival requires crowdfunding campaigners to learn and demonstrate media literacies across multiple domains in order to establish credibility, attract donors, and evoke a sense of deservingness. As discussed below, this is coupled with pre-existing social mores about deservingness and social assistance that penalize already disadvantaged groups. Taken together, we suggest that these phenomena increase the likelihood that crowdfunding for healthcare is exacerbating severe population health disparities.

Despite the growing popularity of medical crowdfunding, very little research to date has explored its usage and consequences (Snyder et al., 2016). Due to the paucity of research on this topic, we open with an explanation of how austerity in the U.S. healthcare system intersects with the rise of crowdfunding as a neoliberal economic system. We then report on the results of an exploratory inquiry into medical crowdfunding campaigns, examining how they reflect a prevailing politics of deservingness (Sargent, 2012) and reinforce social and health inequities in the U.S. We first present quantitative data on the characteristics of 200 randomly-sampled campaigns, and then provide an in-depth textual analysis of selected campaigns that explores the binds campaigners face in representing financial distress on crowdfunding platforms.

## 2. Background

### 2.1. Austerity and affordability in the U.S. Healthcare system

Health care in the U.S. relies on a privatized, market-driven financing model that has undergone repeated austerity measures since the 1980s (Bodenheimer, 1989; Navarro, 2009). Austerity policies generally worsen health outcomes (Basu and Stuckler, 2013), but they also reinforce systems of care that deepen financial instability and social inequities (Pfeiffer and Chapman, 2010). 62.1% of all bankruptcies in the U.S. are medical, making medical debt a major source of financial insecurity for Americans (Himmelstein et al., 2009). Inadequate public insurance coverage and costly private insurance plans contribute to high uninsurance rates, which exacerbate the financial burdens of health care. Prior to the implementation of the Patient Protection and Affordable Care Act (ACA), an estimated 37 million adult Americans were uninsured (Schoen et al., 2011). Yet “safety-net providers,” who shoulder the bulk of care for uninsured populations, are insufficient to fill gaps in the system and unintentionally exacerbate health inequities (Becker, 2004, 258).

The ACA has made considerable strides in addressing some of these problems: The uninsured population has dropped to 9.1%,

and Medicaid expansion significantly reduced medical debt, particularly in low-income areas (Barnett and Vornovitsky, 2016; Hu et al., 2016). Political opposition to the ACA, however, has limited Medicaid expansion, often in states where Medicaid is already poorly funded and has the most stringent qualification criteria (Brooks et al., 2015). In addition, the ACA has not protected Americans against other kinds of financial vulnerability caused by the private insurance system. By relying on private insurance “marketplaces” in which consumers purchase plans according to their ability to pay, the ACA has reinforced an underclass of consumer-citizens who cannot afford the costs of care (Horton et al., 2014). Americans are paying an increasingly large portion of their salaries into insurance premiums, deductibles, and co-payments, which leaves already poor households in financial distress (Claxton et al., 2015). At the same time, many Americans have purchased cheaper policies that leave them underinsured. While the number of underinsured Americans was rising steadily prior to the introduction of the ACA (Schoen et al., 2011), many experts acknowledge that the ACA has not improved underinsurance nearly as much as expected (Collins et al., 2014).

Thus, though the ACA was aimed at reversing the tide of austerity measures related to health in the U.S., its reliance on privatized solutions and states' expansion of Medicaid has produced a two-tier system of health care access for most Americans. Those who retain access to high-quality plans, either through their employers or their individual purchasing power, remain more insulated from financial crises related to illness, while those who do not have access to Medicaid, or can only afford inadequate plans, face an unsustainably high cost of insurance punctuated by severe financial distress when health care crises arise. With an estimated 23% of adults in the U.S. underinsured, a significant portion of the population occupies this lower tier (Collins et al., 2015). For this population in particular, crowdfunding is a crucial financial survival strategy. The 2016 elections, however, have all but guaranteed that those insured under the ACA (and, potentially, Medicaid and Medicare) will face threats to their continued access to care. Thus, it is extremely likely that even larger portions of Americans will turn to crowdfunding to supplement inadequate health coverage in the coming years.

### 2.2. Contextualizing crowdfunding

Online crowdfunding is a direct outgrowth of crowdsourcing, which is an open call for labor, once performed by employees, to be fulfilled by a large group of individuals (Howe, 2006). Crowdsourcing exists in almost every facet of our information society, with notable examples in business, such as Amazon.com's Mechanical Turk, which pays consumers to complete small tasks that can only be done by humans (Ross et al., 2010); journalism, in which sites like Reddit.com compile information contributed by “citizen journalists” (Allan, 2009; Castells, 2011), and medicine, with sites such as Crowdmed (2016) enabling users to work together to “solve difficult medical cases online.”

For enthusiasts of the crowdsourcing model, the ability to collaborate across geographies and mobilize online networks and resources represents the potential for social revolution (Howe, 2006) and the democratization of formerly centralized sites of knowledge production (Benkler, 2006). Yet for others, crowdsourcing is viewed as an extension of existing forms of exploitation, in which those with income stability profit from other's amateur production and leisure (Bannerman, 2013, 5). The debate over participants' agency and autonomy extends into the realm of crowdfunding.

Crowdfunding involves what Belleflamme et al. (2014, 4) define as “an open call mostly through the Internet, for the provision of

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