



# 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

financial resources either in form of donation or in exchange for some form of reward and/or voting rights.” Like crowdsourcing, crowdfunding promotes collaboration across shared interests and mobilizes personal and institutional ventures that have not had access to traditional financing (Otero, 2015). This is particularly useful for fund-seekers who don’t necessarily have an established track record of success in business ventures (Van Wingerden and Ryan, 2011).

Crowdfunding rose to popularity first as a mechanism for the “consumer-investor” to support incubator businesses and entrepreneurial ventures (Van Wingerden and Ryan, 2011, 5), and then as a way for the public to support underfunded creative arts ventures through sites like Kickstarter, indiegogo and Sellaband. Crowdfunding has also been mobilized in response to national tragedies, such as in support of survivors of The Pulse nightclub shooting in Orlando, Florida (Equality Florida, 2016) and has been utilized as a form of activism and awareness-raising. Crowdfunding for healthcare and health research has emerged in tandem with these other uses. Campaigns to support exploratory and experimental medical research allow researchers to circumnavigate the often competitive and slow channels for institutional support, by enabling consumer-supported research. Health-related campaigns on charitable crowdfunding websites like GoFundMe and YouCaring request funds for individual patients (Sisler, 2012); in this paper we focus on this form of crowdfunding rather than fundraising for consumer-supported medical research projects (Otero, 2015).

A significant percent of the U.S. population has participated in crowdfunding: according to the Pew Research Center (Smith, 2016), 22% of adults have contributed to a crowdsourced online fundraising project, and 3% have created their own crowdfunding project. Typically, crowdfunding users have contributed to a handful of projects, with most making relatively small contributions. The majority (68%) of campaigns Americans are contributing to are for someone in need; most donated to a friend or an acquaintance (Smith, 2016).

Online crowdfunding for healthcare arises in the post-2008 economic context, in which economic austerity has met with an equally fervent increase in the use and accessibility of mobile digital media and social media platforms. Similar to Craigslist, AirBnB, and Uber, businesses that subvert more formal and regulated systems of entrepreneurship, crowdfunding for healthcare mobilizes the citizen-entrepreneur. Participation on crowdfunding sites is not structured purely by social networks and interactions, but, as Feminist studies of digital infrastructure and human-computer interaction have emphasized, is shaped by the configurations of the Internet platforms on which they exist. These platforms perform cultural work by structuring how social networks are formed and articulated online (Irani, 2015a; Ross et al., 2010), advancing a cultural shift toward individual and atomized practices of participation and the performance of new forms of what Lilly Irani calls “entrepreneurial citizenship” (Irani, 2015b). The burden of representing a campaign’s viability or worth is a condition of successful participation that takes urgent precedence over diagnosing failures in the social safety net and disrupts possibilities for collective action.

### 2.3. Demonstrating deservingness

Crowdfunding for healthcare represents an intersection of two economic and social systems whose neoliberal values reinforce a politics of deservingness in which those who are deemed “less meritorious...are marginalized from the body politic” (Sargent, 2012, 855).

For centuries, health care has been allocated based on assumptions of the moral worthiness of individuals and populations

(Daniels, 2008; Hoffman and Rebecca, 2013; Tanenbaum, 1995). More broadly, social assistance policies are routinely crafted according to assessments of which social groups are more or less deserving (Katz, 2013). As Fraser (1993, 9) notes, the “political imaginary of social welfare” is based in the construction of social identities, and assumptions about their moral worth. Because social policies are most concerned with the poor and needy, decisions about social policy are often distilled into discussions about the deficiencies of the poor (Katz, 2013). Dominant discourses in the U.S.—such as those regarding a “culture of poverty” or “welfare queens”—have, over many decades, “denigrated” the undeserving “for presumed moral laxity” (Sargent, 2012, 855). Most often, social categories of undeservingness are thrust upon marginalized groups that face significant discrimination, such as communities of color, single mothers, immigrants, drug users, the formerly incarcerated, and unemployed, able-bodied men (Bourgeois, 2003; Katz, 2013). Though questions of deservingness have been extensively studied in social assistance programs, scholars have noted the need for more social science research into how deservingness is crafted, perceived, and institutionalized within specific health care systems (Willen, 2012b).

The rise of neoliberalism, with its ideological focus on personal responsibility, further enshrined deservingness as a foundational criterion of assistance. This had the effect of deepening and normalizing social inequalities, and, consequently, health inequities (Navarro, 2009). More recently, as Willen (2012b, 805) notes, “global recession, retreating welfare states, and skyrocketing health care costs” have made questions of deservingness all the more fraught. As Becker (2004, 260) observed in studies of uninsured populations more than a decade ago, “deservingness is related to productivity, and hence, to wealth—in short, to the ability to find the financial resources to pay for medical care.... The effect has been to further marginalize those who are poor.” It is likely that this value system is reinforced on crowdfunding platforms, where more affluent campaigners often have social and cultural resources that help them appeal to criteria of deservingness (Snyder, 2016, 38). Such criteria, when taken at face value, undermines and erodes more rights-based approaches to health that recognize equitable entitlements to accessible and affordable care (Ruger, 2010; Willen, 2012a).

To date, social science research on crowdfunding has attempted to measure and assess perceptions of campaign credibility as a key factor of success (Kim et al., 2016), rather than discourses and norms of deservingness. Similarly, media coverage has largely focused on questions of campaign credibility and episodes of potential fraud (Simon, 2016). Despite the social salience of these concerns about credibility, however, we find that perceptions and portrayals of deservingness are a key factor in how campaigners design their sites and are judged by social networks. By reinforcing deservingness as moral criteria for resource allocations in a hyper-individualized economy, we argue that crowdfunding has the potential to influence social norms and hierarchies in health care more broadly.

### 3. Methods

In order to better understand how, and under what circumstances, Americans are utilizing crowdfunding for health care, we conducted a mixed-methods study of a randomized sample of 200 GFM campaigns between March and September of 2016. GFM, founded in 2010, was chosen for the study because it is recognized as the world’s largest crowdfunding platform, based on both funds raised on the site and the number of backers participating in campaigns (Mac, 2015). Campaigns on GFM are organized into 21 categories. The sample for this study was drawn from GFM’s

“medical” category, which attracts the largest number of campaigns (Sisler, 2012). Though health-related campaigns are occasionally posted to other categories, the medical section of GFM includes the vast majority of such campaigns.

It is difficult to estimate the overall number of campaigns on the GFM site or in the medical category at any one point in time; population size fluctuates as campaigns are added and removed. To determine an accurate sampling frame, a computer program was developed to search GFM’s medical category by zip code. This generated a list of up to 500 campaigns within and nearby each zip code; duplicate campaigns in the search results were subsequently deleted from the list. This process, completed in July 2016, generated a list of 165,925 medical campaigns. From this list, a randomized sample of 222 campaigns was selected; 22 campaigns were eliminated because they did not meet the sampling criteria, as described below.

Sampling criteria stipulated that a campaign’s primary purpose should be either: 1) to fund medical- or health care-related costs; or 2) to address a health or medical condition identified by the campaigners. In many cases, campaigns sought to fund both medical and non-medical expenses, and cases were not removed for including non-medical costs. Campaigns were, however, excluded if they only solicited funds for funeral costs. To be included, campaigns had to be fundraising for a person (not a pet), and not primarily for research efforts, medical mission work, non-profit organizations. Because of our interest in the contexts of health care austerity in the U.S., it was also stipulated that campaigns should be based in, and fundraising for, a person residing in the U.S. Finally, we made an explicit methodological decision not to assess or evaluate the worthiness or necessity of stated needs, or intended medical or healing procedures as part of the sampling criteria, because of the potential for introducing social and cultural biases and value judgments. Of the 22 campaigns excluded from the sample based on these criteria, 4 (18.2%) did not have a primary focus on medical costs and were not motivated by a medical condition; 5 (22.7%) were fundraising for a medical mission trip or non-profit organization; 4 (18.2%) were fundraising for pets; 4 (18.2%) were for people not residing in the U.S.; and 2 (9.1%) were fundraising for funeral costs. In 3 (13.6%) cases, campaign pages were shut down or the campaign was cancelled during the two-week data collection period.

Mixed-methods approaches were used to gather and analyze data about each campaign. First, basic quantitative data was collected on the characteristics and success of campaigns in the sample. This included the campaign’s monetary goal and total amount raised, as well as the numbers of shares, likes, donations, photos, updates, comments, videos, and days the campaign had been running. Two-tailed Pearson correlation tests were used to assess the relationship between certain campaign characteristics and the amount of money raised. The insurance status of recipients (if stated) was also recorded as a categorical variable. Descriptive data analysis of these indicators was conducted to identify trends and common characteristics. The city and state of each campaign was also recorded, and a chi-square test was used to assess whether campaigns were disproportionately located in states that did not adopt the ACA Medicaid expansion. Sociodemographic information about either campaigners or recipients was much more difficult to gather, as most campaigns lack explicit descriptions of race, ethnicity, age, or socioeconomic status. Because gathering such data would have relied heavily on (likely inaccurate) assumptions made by the researchers based off of photos and textual evidence, we decided not to collect or report these indicators.

Initial quantitative data provided a baseline for a more detailed discourse analysis of the 200 campaigns. Screenshots, text, and photos were captured from each campaign within a two-week

period and coded according to emergent themes and trends. Initial codes were based on research questions and a review of the existing literature on crowdfunding, and included: insurance and financial status indicators; medical circumstances that prompted the campaign; disease, injury and syndrome categories; socioeconomic status descriptions of campaigners or recipients; target audience; and campaign goals. Codes were revised and expanded during the analysis to accommodate emerging themes, and data was then recoded.

Finally, an in-depth textual analysis was conducted to examine selected campaigns, as well as advice from GFM to campaigners, to explore how a moral economy of deservingness was constructed, reinforced, and appealed to throughout these sites. Using approaches from both media studies and ethnography, we examined campaign sites as dynamic and interactive spaces in which campaigners, patients, donors, and onlookers were all participating in the construction of narratives about illness, need, deservingness, hope, and suffering. In the final section of this paper, we analyze how key literacies in two campaigns impact health equities.

The University of Washington Human Subjects Division determined that Institutional Review Board approval was not required for this study because it used publicly available data and did not involve interactions or interventions. Nevertheless, additional efforts were undertaken to protect the identity of those whose campaigns we examined: no last names are reported, most demographic data are not discussed individually, nor are photographs utilized. Though campaigns examined are likely still discoverable on GFM, these measures insure that, once removed, campaigns and patients’ medical information are difficult to identify through the published research.

## 4. Results

### 4.1. Characteristics of crowdfunding campaigns

Quantitative data underscore the enormous diversity among campaigns in terms of their goals, relative success, and social media capabilities. As shown in Table 1, the randomized sample of 200 crowdfunding campaigns revealed considerable variability across almost all indicators. Campaign goals – the stated monetary amount which campaign organizers hoped to raise – ranged in size from \$310 to \$100,000 (mean \$12,505, SD 16950.03). Taken together, campaigns in the sample raised over \$600,000, earning GFM over \$30,000 in fees. Despite this apparent success, however, 90% of campaigns did not meet their goal, and on average netted just over 40% of their goal. (Unlike other sites, GFM does not require campaigners to meet their funding goal in order to receive the funds they have raised.) The range of amounts raised was striking: the top campaign netted nearly \$20,000, but 7 (3.5%) campaigns raised no funds, and 14 (7%) raised less than \$100. Similarly, campaigns showed wide variation in donor behavior. Campaigns had a mean of 36 donors contributing an average of \$80.47. While 40 (20%) campaigns had less than 10 donors, the top campaign had 247. The average amount donated (mean \$80.47, SD 75.15) and the largest donation (mean \$482.53, SD 779.18) to each campaign also showed remarkable variability. Most campaigns in the sample had been running for long periods of time, with 112 (56%) having run for a year or more. These results indicate that crowdfunding success – measured as either reaching one’s goal or a sizeable amount of funding raised – is hardly guaranteed, and that many campaigns fall far short of campaigners’ expectations, even after running for long periods of time.

GFM encourages campaigners to engage in two primary efforts to attract and retain donors: first, sharing their site widely to gain social media spread; and second, engaging campaign visitors



**Table 1**  
Characteristics of GFM campaign pages.

	Mean	SD <sup>a</sup>	Q1 <sup>b</sup>	Q3 <sup>c</sup>	N
Campaign goal (\$)	12505.44	16950.03	3000.00	14975.00	200
Money raised (\$)	3033.96	3997.72	692.50	3355.00	200
Progress towards goal (% of goal raised)	41.10	63.78	9.04	53.05	200
Campaign length (# days)	407.66	291.04	150.00	570.00	200
# donors	35.62	41.12	11.00	41.00	200
Top donation (\$)	482.53	779.18	100.00	500.00	200
Average donation (\$)	80.47	75.15	49.55	89.85	200
# friends	560.98	703.08	194.75	649.50	198
# shares	249.23	252.43	72.25	327.25	200
# hearts	34.02	40.10	11.00	40.00	200
# comments	0.89	1.61	0.00	1.00	200
# campaign updates	4.60	6.37	1.00	5.00	200
# campaign photos	3.02	3.85	1.00	3.00	200
# campaign videos	0.04	0.262	0.00	0.00	200

<sup>a</sup> Standard Deviation.<sup>b</sup> First Quartile.<sup>c</sup> Third Quartile.

through photos, videos, and frequent updates. As predicted, campaigners' ability to engage in such tactics varied widely. Though the mean numbers of Facebook friends (560.98, SD 703.08) and shares on social media (249.23, SD 252.43) were quite high, the enormous variability among campaigns was notable. Furthermore, the mean number of shares for campaigns was nearly 7 times the mean number of donations, indicating that social media spread did not directly result in donations. On GFM, visitors can also engage by "hearting" a campaign (clicking on a heart icon, similar to "liking" a post on Facebook); or by posting a comment. Campaigns had an average of 34 hearts (SD 40.10) and less than 1 comment (mean 0.89, SD 1.61); variability here, too, was sizeable. Finally, campaigns varied in their engagement with visitors and followers through updates (mean 4.60, SD 6.37), photos (mean 3.02, SD 3.85) and videos (mean 0.04, SD 0.262). Though experts strongly recommend using videos in crowdfunding (Brigman, 2016), only 6 campaigns (3%) did so, indicating that technical and social media literacy may be a considerable barrier for many GFM users.

As shown in Table 2, many activities intended to increase campaigns' appeal show statistically-significant correlation with the amounts of money raised. But we caution readers against presuming causality here: it is conceivable that donations to campaigns elicit further campaign activity (updates, photos, videos) rather than vice-versa. **In-depth analysis with a larger sample is necessary to quantitatively assess the effects of campaigner behaviors here.** Instead, we focus on more qualitative assessments of how campaigners attempt to articulate deservingness.

A wide variety of medical concerns, illnesses, and conditions motivated the campaigns captured in our sample. These ranged from acute illness events and unexpected accidents; to numerous chronic diseases like cancer, diabetes, and musculoskeletal disorders; to a range of disabilities and congenital malformations. The most common medical problem described in the sample was cancer, in 31% of campaigns (N = 62). The severity and urgency of conditions also varied considerably. Though many conveyed a considerable sense of urgency, others requested funds for long-delayed but largely elective care or procedures. Despite the variety of these motivating conditions, nearly all campaigns endeavored to demonstrate deservingness, justify appeals, and raise funds in a competitive funding environment where success was not guaranteed. Additional studies are needed to assess how campaign objectives may influence fundraising success.

Finally, a much larger proportion of campaigns than expected were based in states that chose not to adopt the Medicaid expansion under the ACA. In these states, uninsured patients face a

**Table 2**

Results of two-tailed correlation tests of relationship between certain campaign characteristics and amount of money raised.

Campaign Characteristics	Correlation coefficients (r) (n = 200)
# updates	0.226**
# photos	0.182**
# videos	0.256**
# comments	0.175*
# shares	0.489**
# hearts	0.853**

\*P &lt; 0.05; \*\*P &lt; 0.01.

double bind in accessing insurance coverage: first, it is much more difficult to qualify for Medicaid coverage because they do not fall under the more stringent poverty level guidelines; second, they often do not earn enough to be entitled to government subsidies under the ACA that would help them pay for private health insurance (Brooks et al., 2015). Notably, whereas about 54% of our sample came from states without the Medicaid expansion, only 39% of the U.S. population resided in these states in 2015 (U.S. Census, 2015). After removing campaigns that began prior to the enactment of the ACA, the difference in proportions was statistically significant,  $\chi^2(1, N = 188) = 9.638, p = 0.0019$ . Given that Medicaid expansion has provided an important protective buffer against medical debt and bankruptcy in states that have adopted it, these findings indicate that financial distress and underinsurance may be motivating factors in a large proportion of campaigns.

#### 4.2. Narrating financial distress

As noted above, it is difficult to systematically assess other socio-demographic indicators that might impact on deservingness, such as race, social class, and gender, given available data. But qualitative analysis of the 200 sampled campaigns allowed us to assess the frequency of expressions of socioeconomic vulnerabilities, including overwhelming medical expenses, underinsurance, and generalized financial distress. Overwhelmingly, this analysis confirmed that financial strains were the most consistent and prevalent concerns among campaigners, reflecting some of the most pernicious effects of austerity politics in the U.S. health system. In many cases, campaigns were explicitly directed at ameliorating the financial burdens caused by exorbitantly high healthcare costs, insufficient or expensive insurance coverage, lack of

insurance, and the additional social and monetary costs of care-taking and illness.

Financial hardships were repeatedly discussed: more than 70% (N = 143) of campaigns mentioned some form of financial difficulty, and 35% (N = 70) discussed medical bills. Many described the stress of watching bills “pile up,” “mount,” or “keep coming in”: “The winter months are coming in on us now and so are the bills piling up,” wrote one campaigner in an update. “We can no longer have yard sales due to weather conditions therefore we have no extra income to help pay the bills. Any and all help will be graciously appreciated” (M1119). Many campaigns also mentioned the dual struggles of lost wages due to illness or the demands of caretaking (N = 57, 28.5%), the high costs of care (N = 54, 27%), and unpaid debts (N = 12, 6%). “If I can beat cancer, I can beat bill collectors,” one campaigner asserted (M1128). Others wrote in more specific terms about debts owed and strategies for financial survival. “The hospital bills are way beyond what we can pay. The payments they want are way beyond what we can pay. We tried for all their financial services and they all say we make too much. That’s tragic because we are both on disability. The worse part is there is still more to come,” wrote one campaigner (M1115). Finally, many campaigns noted that non-medical expenses mounted during lengthy treatment and recovery periods (N = 15, 7.5%), including the costs of travel to far-flung facilities and childcare. These findings are presented in further detail in the [supplementary online Table 3](#).

The effects of insufficient and expensive health insurance coverage were also evident in accounts of medical costs that were not covered (N = 37, 18.5%), high deductibles (N = 12, 6%), high co-pays (N = 10, 5%). Notably, however, less than half of campaigns explicitly discussed insurance (N = 82, 41%). Of those, 10% (N = 8) had private insurance; 17% (N = 14) had public insurance, which included Medicaid, Medicare, and other government-run programs; 22% (N = 18) had no insurance; and 51% (N = 42) did not specify the type of insurance they had. No campaigns mentioned the ACA or Obamacare by name. Troublingly, the use of crowdfunding can also imperil entitlement to public benefits based on income and poverty levels because any funds raised qualify as income. Thus, success in crowdfunding can in fact undermine, rather than buttress, the financial stability of impoverished campaigners.

What we see in this data, then, are widespread experiences of financial distress and vulnerability related to health care costs. Furthermore, campaigners do not seem to feel that it is necessary to explain insurance status in order to demonstrate deservingness or credibility, indicating that Americans are well-acquainted with the inadequate financial protections offered by insurance, and the unavoidable, extraordinary medical expenses that characterize serious illness or disability within contexts of healthcare austerity in the US. Donors and commenters across the sampled campaigns did not question the veracity of financial distress, and only one campaign sought to justify costs by posting material evidence of hospital bills (M1128). It seems likely that with a normalization of financial distress and austerity contexts in health care, campaigners do not feel as much pressure to demonstrate credibility and deservingness in financial terms, as financial distress appears normal within their social networks and audiences. Rather, as we will show in the following sections, campaigns’ deservingness is evaluated through more visual, symbolic, and narrative criteria.

#### 4.3. Crafting appeal, communicating deservingness

Research has shown that social networks have value in building identity, community and culture (Castells, 2011; Papacharissi, 2010), but accessing and mobilizing the value of networks requires specific capabilities—including adept self-expression and a familiarity with multiple forms of literacy. Because contemporary

sociality in the digital age is organized by a networked connectiveness that favors weak and latent ties (Christakis and Fowler, 2009; Van Dijck, 2011; 2013), campaigners must work to appeal to their imagined audiences (Marwick, 2011; Litt, 2012). As with other forms of social media, GFM is a platform that acts as technology of the self (Van Dijck, 2013, 201) in which users engage in both “unconscious self-expression” and “conscious self-promotion.” Social media literacies are also critical to ensuring campaign success and establishing deservingness. Those who are social media literate know that storytelling and narrative self-presentation through both text and images helps to ensure the spreadability of their campaigns, inspiring viewers to pass them on to their personal networks (Jenkins et al., 2013). Additionally, strong reading and writing literacies act as important markers of social capital, as are the technical literacies that are needed to take full advantage of GFM’s resources and link to the various social media sites that can help to promote campaigns. Campaigners must also possess medical literacy – forms of patient “expertise” (Dumit, 2012, 27) that enable them to translate complex medical information, navigate health systems, and understand insurance and billing.

As we argue below, each of these literacies reflect neoliberal values in which campaign success, spreadability, and even forms of care become the responsibility of individuals and their personal networks. As Snyder (2016, 38) notes, crowdfunding’s focus on “personal appeal or social standing” as a criteria of deservingness “[rewards] those already in a privileged socioeconomic position.” We believe that multiple literacies, which reflect social and economic privileges, are very likely to enhance campaigns’ potential success, and, in turn, beget additional advantages. Thus, crowdfunding has the potential to exacerbate social and health inequities, though it is often portrayed as a meritocratic system that rewards hard-working and morally deserving campaigners.

A brief look at GFM’s advice to campaigners provides insight into the importance of particular design choices and demonstrations of media literacies to craft appeal and communicate deservingness. Best practices and guidelines for successful crowdfunding abound, and increasingly are dedicated to helping people seeking personal funds (Briggman, 2016). But campaigners need not look beyond the GoFundMe site itself for support. Beyond the expected technical support, GFM’s blog and website offer tips on how to promote and improve campaigns’ impact. In “6 steps to a Successful Campaign,” GFM advises users on circulation strategies, and aesthetic and content norms. This advice enmeshes the technical, social, and emotional factors that lead to campaign success, underscoring that campaign spreadability is not solely determined by the number of shares, but a constellation of signifiers that position campaigns as deserving of funds within specific value systems.

Social networking is at the center of GFM’s suggested strategies. GFM strongly encourages campaigners to share their link with friends and family via Facebook, email, text, and other social networks, noting that this media is “the absolute best way to reach those closest to you,” for these are the people most likely to donate and promote the campaign. This advice requires that users possess not only social media accounts, but the necessary time and media literacy to maneuver and maintain them so that they appropriately link to GFM.

In addition to practical considerations, GFM advises campaigners to make their sites “compelling” using text and images. Campaigners are encouraged to include personalized messages with frequent updates and “catchy and descriptive” titles. Textual choices are presented as common sense. “Which title sounds better?” they ask. “‘I Need Money!’ or ‘Julie’s Rally Against Cancer’.... the second one, right?” Here no explanation is given as to why the latter title “sounds better,” rather the implication is that a personal

“rally” against a specific illness is more compelling than an exclamation of financial need. Similarly, GFM encourages campaigners to make their pages “look their best” by including a “great photo or a video” that will “create a strong reaction like ‘Wow’ or ‘Awe’ or ‘I need to know more about this’” from potential donors. For emphasis, GFM presents two campaign homepage images for comparison. The first portrays an infant dressed in thick glasses and colorful clothing that matches the pink and white text the campaigners have chosen, which reads “Grace Anna’s Bedroom Addition.” The campaign is shown to have earned \$17,585 of its original goal of \$15,000. The second campaign utilizes a stock illustration of a perspiring man holding a dumbbell that is weighted down on the side and has the word “BILLS” written on it. The title of this campaign, written in green font, is simply “Medical Bills.” It appears to have raised only \$240 of its \$4500 goal. Similar to the earlier comparison of campaign titles, once again GFM implies, rather than explicitly states, that even though both campaigns seek funds to address secondary needs arising from medical crisis, “Grace Anna’s Bedroom Addition” is more compelling. The suggested appeal of the campaign can be attributed to its use of self-produced visual content and its organization around a specific problem (building a bedroom) that donors can feel they are helping to solve (Fig. 1). Notably, GFM does not address any questions about fairness—whether, for example, donating to medical bills rather than house renovations might be a more equitable use of scarce resources. Across the advice and examples GFM provides, the reality of financial burden and attendant structural issues is shrouded in optimism and a disavowal of overwhelming need in favor of discrete and marketable requests.

#### 4.4. Domains of success in two campaigns

In what follows, we explore two campaigns in depth in order to understand how dominant social mores and various media literacies shape their perceived deservingness, and thus relative success. We argue that the values promoted through crowdfunding further exacerbate deep-rooted health inequities.

The “Team SuperVan” campaign has not only taken, but arguably gone beyond, the steps that GFM advocates, demonstrating a mastery of crowdfunding by effectively utilizing social media, posting a plethora of images, and creating what is essentially a unified and marketable brand—SuperVan—around 6-year old Van and his team of supporters. It is one of the top-earning campaigns in our sample, having gained 153 donors, 200 shares, and \$13,450 of its \$50k goal in 17 months. Van’s 17-month fight with Stage 3 Rhabdomyosarcoma is heavily documented by his mother: 20 updates containing photos and text tell the story of his diagnosis, treatment and eventual remission. Through the initial text on the homepage and throughout the very detailed updates, contributors are encouraged to join a “team” in which their prayers, thoughts, and of course, financial contributions make them a part of the Johnson family’s journey. In its many pages, this campaign relays a human interest story that only briefly mentions “financial burden.”

Conversely, one of the less successful campaigns in our sample, “Family in Need,” struggles to mobilize the necessary media literacy skills for effective self-marketing. By media literacy we again refer to the campaigner’s ability to adeptly navigate and utilize the capacities of social media platforms, and to demonstrate standard reading and writing competencies. It has garnered only 15 donors in 10 months despite 124 shares, and has earned \$550 of its \$10K goal. Created by a husband and father of four sons, the campaign story describes how his family “has been struggling with our bills” due to chronic health issues and surgeries that related to familial adenomatous polyposis, and the autism diagnosis of two of his sons. The campaign consists of just one image, a brief introduction to the

situation, and a few short updates that simply reiterate need.

The campaigns take very different approaches in how they address financial need. “Team SuperVan” provides detailed information about the specific costs that funds will help defer, including particular medical treatments as well as “trips to the hospital, parking, deductibles, co-pays, and other out-of-pocket expenses.” “Family in Need,” on the other hand, references more generalized problems. They claim that “bills have stacked up” and that their home is at risk of going back into foreclosure. While the latter family’s needs are arguably more acute, their lack of specificity undermines the sense that they can be effectively alleviated.

The discrepancy in the demonstrations of media literacy between the two campaigns is apparent. It is clear that the “Team SuperVan” campaigners and potential donors possess extensive media literacies, leveraging the campaign across media platforms by including a link to a robust and frequently-updated Facebook page, and deploying the hashtags #Justbeatit, #Cancersux, and #SuperVan. It also includes several photographic memes that have legibility and, most importantly, spreadability with potential donors who use social media. For instance, one photo of Van on a stretcher in the hospital includes black typeface that reads “No hair, don’t care.” Meanwhile, the “Family in Need” creator appears to be struggling with even the basic functionality of the site, claiming he had to set up a second campaign because he had trouble changing his bank on the first one he set up. To boot, the text is rife with spelling and grammatical errors that detract from clarity.

Utilizing symbolic language and images is central to campaign marketability. “Team SuperVan” presents itself as a unified brand, one that refers to the heroism of both the patient and his team of supporters. It even includes a tagline: “sometimes real superheroes live in the hearts of small children fighting big battles.” Van is described as a “super child,” “our hero” and as having “super strength,” and is even depicted as a superhero, with two images of him dressed in a cape that have been edited to seem as if he is flying. Van’s team of family and friends also appear in SuperVan apparel, with one shirt reading, “Van has super powers and he can defeat anything!” Van’s superheroism is supported by descriptions of his optimism and strength during trials. One photo shows him smiling with the caption “even after chemo he’s all smiles!” The superhero motif is powerful and popular, and legible across a variety of literacies and tastes. It also plays into neoliberal dogmas regarding self-branding, independence, and the super-human skills needed to navigate medical and economic systems while working against potential narratives of vulnerability that would make these socio-economic dynamics more visible.

Whereas “Team SuperVan” uses text and images to tell a story about a specific medical tragedy motivating their campaign, the “Family in Need” site is very sparse, with only one dark photograph that depicts the six family members sitting on a couch together, with the youngest son frowning while holding a newborn baby. Besides this photo are 12 brief text updates of two or three lines. Unlike “Team SuperVan,” where needs are described and explained across several pages of writing and accompanying images, here potential donors must work to determine a hierarchy of needs. What the updates make clear, however, is that the family is struggling and in a state of increasing desperation:

“Things still have not gotten any better. I don’t know where else to turn anymore. Got denied for food stamps and still haven’t gotten the kids on ssdi. If I didn’t have bad lu k (sic) I’d have no luck. For my kids sake, my family’s sake, please help.”

As their needs and desperation mount, it becomes more difficult to identify specific needs; rather, the campaign appears to seek some amelioration of the family’s extreme financial distress.

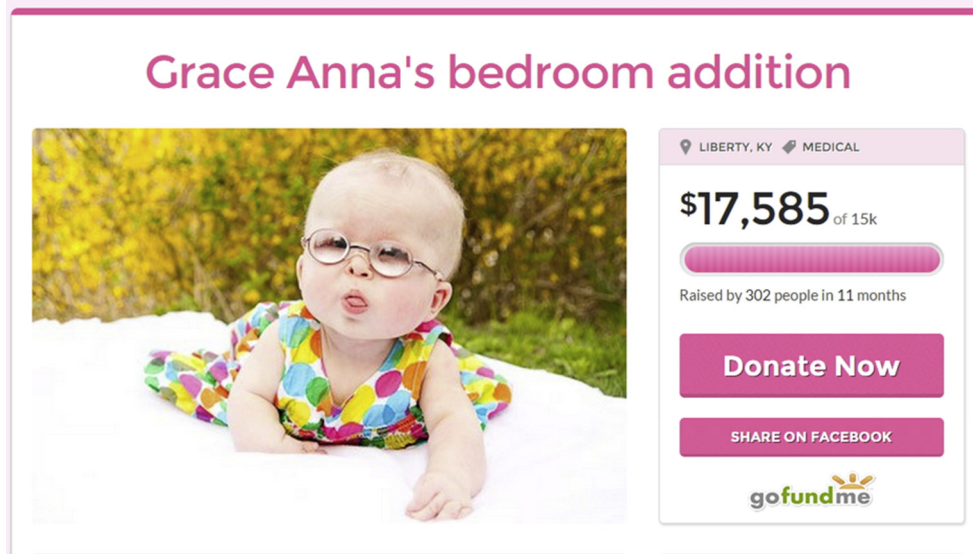


Fig. 1. Producing a worthy illness 27.

Donor comments also demonstrate the relative media literacies of the campaigners' social networks and reinforce the worthiness of the cause. "Team Supervan" contains dozens of donor comments that typically reiterate the campaign's message and branding tactics, such as "Continuing the prayers and well wishes for our little Super Hero #supervan." "Family in Need," on the other hand, has no donor comments, and over half of all donors remain anonymous. While campaigners do not have control of donor participation, the comments reflect the tone of the campaigns, and possibly impact its overall effectiveness.

Like most sharing economies, GFM privileges a set of literacies that become markers for deservingness; thus campaign failure becomes a reflection of individual worth. In comparing these two campaigns, the double bind of the poor on GFM becomes apparent: by virtue of being more needy, they may appear less deserving or as having needs that exceed what a campaign can address. To wit, the more generalized one's distress or the more complex one's needs, the more difficult they become to represent. When the narrator is able to promote a few discrete needs (such as an MRI or drug treatment) that promise a possible solution to the medical problem, the campaign itself becomes more marketable and compelling. While discrete needs can be represented as the by-product of a broken healthcare system that is out of the control of the campaigner, generalized financial distress is too difficult to attribute outcomes to specific gaps in care, and thus the appeal for potential health improvement is limited. Thus, the particular sharing economy that GFM presents, combined with healthcare austerities, produces an environment in which discrete and solvable problems are the most marketable and thus most likely to be shared and successfully funded. Nevertheless, numerous campaigns use GFM to express and attempt to ameliorate broader financial distress caused by austerity in the United States, as shown above. The entrepreneurial discourse that fuels successful narratives is inherently at odds with the potential for compelling claims to deservingness, making it more difficult to establish rights-based claims to care. It is likely that other dimensions of deservingness are equally relevant, such as gender, ethnic and racial disparities as well as stigmatized health conditions. These are difficult to assess with the data available, but merit further investigation.

## 5. Conclusion

This paper offers findings from the first stage of a multi-stage research project that will include more long-term, face-to-face ethnographic inquiry. In this way we seek to fill an important gap in the scholarship that examines the use of crowdfunding to meet individual healthcare needs. The data distilled from sites like GFM has inevitable limitations. For instance, it is difficult to assess demographics of campaigns without introducing bias. In addition, we are unable to observe: how campaigners and their donors interact offline; the relationship of campaigns to outside fundraising efforts, financial aid, or caregiving; more complex aspects of illness experience over time; and how donors make decisions about contributing to campaigns. All of this points to the need for further face-to-face ethnographic research, which will add depth and complexity to the findings presented here.

These results, however, offer compelling evidence of the realities of crowdfunding, including wide variability in campaigns' engagement with their audience, ability to garner social media spread, and resulting financial success. While some campaigns show significant, even surprising, financial successes, most fall far short of targets. GFM campaigns offer an important record of Americans' struggles to cover the costs of medical care, and those associated with illness and caregiving. The high proportion of campaigns located in states that refused the ACA Medicaid expansion underscores an emerging divide between Americans experiencing more or less severe contexts of austerity in public health insurance coverage. Geographic inequities are compounded by the social, technological, cultural, and media literacies required to develop successful GFM campaigns. U.S. healthcare and social safety-net systems are strongly premised on ideas of deservingness structured by class, race, gender and immigration status; GFM further legitimizes this logic.

Our findings reveal a crucial paradox in the use of crowdfunding for health care. Although it may be most financially critical as a tool for those most vulnerable in the U.S. healthcare system, crowdfunding platforms are constructed in ways that can further marginalize these populations. The importance of certain literacies and forms of social capital on GFM reproduces inequities and



reinforces a hyper-individualized system of choosing who is and who is not deserving. Moreover, the narrative form and discourses produced by GFM works to redirect public attention away from persistent conditions of austerity, deep gaps in the social safety net, and growing health inequities in the U.S. Finally, we anticipate that these trends will become more acute as the incoming Trump administration takes steps to repeal existing health care coverage, and crowdfunding becomes an even more important but inequitable tool for accessing healthcare.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2017.02.008>.

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