

Crowdfunding Chemotherapy: Worthiness, Reciprocity, and Community on GoFundMe

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CHAPTER ONE: INTRODUCTION

BACKGROUND

Crowdfunding refers to the practice of raising individually small amounts of money from a large number of people in hopes of financing a project or business venture of some sort. The first well-known crowdfunding platform to gain traction in the United States was ArtistShare, which went live in 2003 and acted as a fan-funded record label for musicians (Freedman and Nutting 2015). By 2010, websites such as GoFundMe and Kickstarter collected donations for individuals and small organizations (Freedman and Nutting 2015). According to GoFundMe, “Crowdfunding harnesses the power of social networks and the internet to give people the means to raise funds, help others overcome hardship, and meet aspirational goals. With crowdfunding, you can help a friend or help an entire community. You can do everything from pay for your own surgery to fulfill a student’s dream of attending college—and so much more.”

In traditional philanthropy, individuals or organizations typically give to a non-specific individual or group, mediated by a charitable organization. For instance, the person who donates \$100 to the ALS Association or Susan G. Komen for the Cure may personally know someone who suffers from ALS or breast cancer, but their donation will not be given directly to that patient; instead, it may be used for a variety of administrative, outreach, or research expenses in addition to providing direct relief to select individuals or families. In medical crowdfunding, donations go directly to a recipient, with only a small cut taken by the mediating digital platform.

GoFundMe was founded in 2010. Its platform provides the digital scaffolding needed to operate crowdfunding campaigns for both individuals and groups. It is technically “free” to start a GoFundMe campaign, but GoFundMe takes 2.9% off the top of every donation for credit

processing fees. Until 2018, GoFundMe also took an additional 5% of every donation for administrative purposes. This change may have been prompted by competition from other platforms that did not take such a large cut of funds raised, such as YouCaring.

GoFundMe regards itself as an “industry leader” in crowdfunding. By 2015, its campaigns had raised a cumulative \$1 billion (Soskis 2017). At the time of this writing, GoFundMe campaigns have raised over \$5 billion. As early as 2014, medical fundraising had become the most popular motivation for new crowdfunding campaigns (Renwick and Mossialos 2017). In 2018, GoFundMe acquired YouCaring, which had until then been its major competitor in the medical crowdfunding market. GoFundMe has also acquired GiveForward and Generosity. Much of the current literature on medical crowdfunding is based on research conducted not on GoFundMe but rather its former competitors; with this project, I am helping to fill the gap in our knowledge of GoFundMe, because GoFundMe’s digital toolkit for campaign organizers and donors is distinct in a handful of key ways. For example, GoFundMe offers a free mobile app, beneficiary management services, and a team fundraising option. GoFundMe has also streamlined integration with other social media platforms, such as Facebook and Twitter, which facilitates the spread of “viral” campaigns.

The scholarly literature on crowdfunding is relatively young but spans a broad range of topics and disciplines, including (but not limited to) ethical quandaries, economic perspectives, sociological and spatial analyses of inequality, narrative and discourse analyses of campaigns, and critical perspectives. Qualitative researchers have also examined the discursive construction of the economic exchange—often referred to by donors and beneficiaries as a “gift” or “blessing”—that is always at the core of crowdfunding exercise, as well as the non-monetary forms of support in which monetary exchanges are embedded. Moreover, the robust

anthropological literature on illness narratives, health inequalities, and “the digital” (however it may be defined) is relevant here even when it does not directly address medical crowdfunding, because we see illness narratives and health inequalities playing out on crowdfunding platforms. Finally, the anthropology of media and journalism provides useful frameworks for my analysis of media representations and reporting on medical crowdfunding.

RESEARCH QUESTIONS

The overarching research question guiding this project is, How do successful medical crowdfunding campaigns mobilize discourses of worth and community to imbue charitable giving with notions of reciprocity or worthiness? From this springs a follow-up question, How do the news media participate in such discursive processes? When a local campaign goes viral or a politician lambasts crowdfunding as a symptom of a broken healthcare infrastructure, journalists report on it, and their commentary contributes to public debates on the role of charity in health funding. Furthermore, to what extent do campaigners, interviewees, and journalists frame these narratives as political ones? Philanthropy—its spoken and unspoken goals, who benefits and who does not, and the relationships between donors and recipients—is always political (Gomberg 2002; Hanson 2015; Katz 2013; Liberman 2019). The managed care model (i.e. health insurance plans that contract services between healthcare facilities and care providers) that structures the provision and funding of healthcare in the United States, and has thus created the need for medical crowdfunding, is also deeply political (Boehm 2005; Dao and Mulligan 2016; Horton et al. 2014; Nelson 2005; Rylko-Bauer and Farmer 2002).

Like any undergraduate thesis, this project must be limited in scope: my analysis is restricted to ten campaign case studies and 130 newspaper articles. Generalization from this

work to the whole of medical crowdfunding is thus impossible. Given the sheer volume of medical crowdfunding campaigns, and the rate at which medical crowdfunding continues to grow in prevalence and monetary value, generalization is likely out of the question even if it were to be judged desirable. However, close examination of this small sample nevertheless reveals some of the important trends in medical crowdfunding and its supporters and skeptics.

In addition to the practical necessity of restricting sample sizes, it was also necessary to restrict the theoretical and topical breadth of this research. Medical crowdfunding campaigns span diverse topics (from cancer treatment to gender-affirming surgery, substance abuse rehabilitation, and assisted reproductive technology), invoke a wide range of moral discourses, and are affected deeply by race, gender, class, religion, and dis/ability. In medical crowdfunding one also sees what Daniel Miller et al. have termed “scalable sociality”: our increasing ability, facilitated by digital technologies, to fine-tune the size of our audience and our expectations of privacy (Miller et al. 2016, 3). In the construction of a campaign, the organizer chooses what medical and financial information to make public, what kinds of digital images and videos to upload, and what crowdfunding platform to use. Each platform has its own ethos and local, national, or international reach. For instance, GoFundMe most commonly hosts American and Canadian campaigns and receives site visitors with American or Canadian IP addresses, but there are other platforms devoted to international humanitarian projects, such as GlobalGiving. Finally, crowdfunding does not exist in a vacuum, but rather in relation to many other digital technologies. Volumes could be written on the figure of the “viral” medical crowdfunding campaign in the public consciousness, its reliance on the scaffolding provided by other digital platforms such as Facebook and Twitter, and the role of non-donor social media users in its dissemination.

Due to constraints of time and resources, this project will focus instead on ten medical crowdfunding campaigns, located in the United States, seeking funds for illness or injury, that for one reason or another gained traction on GoFundMe at one moment in time. I hope that this snapshot helps to elucidate the rhetorical work done by these campaigns within a political-economic context in which many individuals struggle to access the kinds of healthcare they need and want, and the future of public health insurance options through the Affordable Care Act and Medicaid remains uncertain. In the wake of the novel coronavirus pandemic, health inequities and costs have become a global topic of concern at the same time as rising unemployment and medical shortages threaten families in the immediate and long-term. Medical crowdfunding campaigns reflect the economic inequalities, or precarity (Lorey 2015), of the current moment, but they are also generative spaces in which worthy citizens and biopolitical subjects are produced.

OVERVIEW OF MEDICAL CROWDFUNDING

This literature review is divided into five subsections, each suggesting a different perspective from which we can understand medical crowdfunding and summarizing the relevant literature. Medical crowdfunding has been critiqued robustly by bioethicists and clinicians for unfairly allocating scarce resources and complicating the patient-clinician relationship. Narrative theory is crucial to understanding medical crowdfunding, because the narrative of the campaign description is the main vehicle through which claims about worthiness and reciprocity are crafted and communicated to potential donors. Economic perspectives on medical crowdfunding suggest its potential utility and shortcomings, as well as its relation to medical debt and income inequality. Digital anthropology and the anthropology of media offer valuable insights into the

power of mediation platforms (in this case, GoFundMe.com), in addition to the role of public discourse in shaping and challenging such ventures. Finally, the theoretical assumptions that underlie the political orientation of this project are explored and summarized in the final subsection.

Ethical issues

The ethical concerns surrounding crowdfunding that have been explored by scholars and medical professionals alike are too numerous to fully elucidate here, but a brief overview is necessary to situate this project in the current conversation. Ethicists have addressed in turn benefactors, donors, attendant clinicians, and society at large. Some scholars are concerned that leveraging social networks for monetary gain in this way strains kin and other social relationships. For instance, Durand et al. (2018) suggest that potential donors who know the benefactors of campaigns personally may feel pressured to give even when they are unwilling or unable for fear of damaging the relationship. Similarly, in their interviews with campaign benefactors and supporters, Kim et al. (2017) found that donors often described a feeling of “social responsibility” that could be met through donating to a friend’s campaign. Even when a donor had already provided other forms of support, donating money was still important or necessary (Kim et al. 2017).

Doctors have written that they lack ethical and professional guidelines regarding medical crowdfunding and, consequently, are unsure what roles they ought to or may reasonably be expected to play in campaigns, particularly high-profile cases (Young and Scheinberg 2017). For example, are physicians legally or ethically obligated to assist campaign organizers, or to report campaigns that they know to be fraudulent or contain medically inaccurate information (Durand

et al. 2018)? Building on this, what responsibility do donors and potential donors bear in weeding out fraudulent campaigns? Some scholars have suggested that donors bear substantial ethical responsibility in medical crowdfunding and, prior to donating, must evaluate what their donation would be used for, if it is an effective use of money, and if the proposed therapeutic interventions are likely to have significant deleterious effects on the patient-benefactor (Moore 2018). Still others have argued that the continuous surveillance of campaigns by the digital public constitutes sufficient precaution against fraud and misuse of campaign funds (Freedman and Nutting 2015).

The single most pressing ethical concern in medical crowdfunding is the reallocation of resources that it facilitates, and the ways in which these allocations may reinforce pre-existing social inequalities. Berliner and Kenworthy (2017, 240) argue that “U.S. healthcare and social safety-net systems are strongly premised on ideas of deservingness structured by class, race, gender and immigration status; [medical crowdfunding] further legitimizes this logic.” Lukk, Schneiderhan, and Soares (2018) found that not only are “visible minorities” (i.e., people of color) less likely to start medical crowdfunding campaigns, but also that when they do, they raise significantly less money compared to young, white individuals. These disparities are present even in campaigns for benefactors who are further marginalized due to their transgender identities. Barcelos (2019) found that campaigns for gender-affirming surgery were more likely to be successful if they were for white, masculine-presenting individuals, and if the narratives reflected dominant transnormative discourses about gender dysphoria. Access to the internet as well as the technological devices and literacy needed to organize a campaign are also unequally distributed but key to successful fundraising (Berliner and Kenworthy 2017; Durand et al. 2018; Liberman 2019; Paulus and Roberts 2017). Finally, Renwick and Mossialos (2017) point out that

high-profile medical crowdfunding campaigns for extremely rare genetic disorders run the risk of swaying public opinion in favor of “inefficient” priority-setting for biomedical research.

In addition to reinforcing socioeconomic hierarchies, medical crowdfunding also emerges as a means of signaling one’s affiliation with a certain community, class, or identity. Certain behaviors or facets of an individual’s identity can act as markers signaling or preempting compassion and solidarity, and many are tied to discourses of worth or deservingness, such as the question “Did he smoke?” in reference to news of a lung cancer diagnosis (Perusek 2012). Paulus and Roberts (2017) remark that campaigns make “identity claims” about benefactors, and Gerber and Hui (2014) similarly write that signaling one’s shared identity is an important motivation for donation. In sum, ethicists examine medical crowdfunding from several “scales”—individual donors to societal resource reallocation—and are frequently quite critical of the phenomenon at multiple levels.

Economic perspectives

Next, I turn to the literature on exchange theory as well as perspectives by economists. Medical crowdfunding is a form of giving. Legally, it is considered personal giving, unless the campaign partners with a licensed charity, at which time it becomes “charitable giving.” Only charitable giving is tax-deductible. Reduced to its essence, the relationship between benefactor and donor is one of exchange. A viewer, moved by the emotional appeal of a campaign, sends money via PayPal to a beneficiary (be they an acquaintance or a stranger), and in return, the donor can feel that they have done a good deed. If the donor and beneficiary know each other offline, donating may also strengthen their pre-existing relationship. Renwick and Mossialos (2017) argue that there are four main economic benefits to crowdfunding: expanded market

participation in healthcare (which many others see as a problem); broader access to funds for individuals and small businesses; increased awareness for rare diseases; and public engagement (51). They caution that crowdfunding is largely unregulated and poses substantial risk as well, chiefly issues of fraud, inefficiency and lack of transparency and accountability (Renwick and Mossialos 2017).

Economists have tended to regard medical crowdfunding as a means to forestall medical debt and personal bankruptcy. According to 2007 estimates, as many as 62% of personal bankruptcy filings in the United States resulted from medical debt; in 2001, the figure was 46% (Burtch and Chan 2014). Burtch and Chan (2014) found that, at the level of aggregate county-wide populations, personal bankruptcy filings decreased significantly as dollars raised on GiveForward increased. Furthermore, they suggest that there is a substitution effect between medical crowdfunding and public health insurance, providing quantitative evidence to support the claim that medical crowdfunding is acting as a “stop-gap” (Burtch and Chan 2014, 15). They argue, “if \$1,000 were raised in each state within a three-month period, this would reduce between 114 and 136 bankruptcies in the United States per quarter” (Burtch and Chan 2014, 15).

Social scientists have argued that medical crowdfunding also provides an opportunity for benefactors to obtain non-monetary support from existing social connections, such as home visits, phone calls, and private messages (Kim et al. 2017). From their interviews with 83 medical crowdfunding beneficiaries and supporters, Gerber and Hui (2014) found that “making connections” was equally important to campaign organizers as making money. Additional connections may be beneficial because they can be leveraged in future times of need, but this also points to the importance of non-financial motivations in medical crowdfunding.

Elise Andaya writes that a common saying overheard during her fieldwork among doctors in Havana, Cuba, was “Here, nothing can be done, but everything can be resolved” (Andaya 2009, 360). By this, speakers are referring to the mobilization of kinship and other social networks to obtain resources not available through state-sanctioned means (Andaya 2009, 360). Although medical crowdfunding in the United States does not occur in a context of socialized medicine, successful campaigns are an embodiment of similar mobilizations. In both contexts, the “gift” of health—achieved by infusing ostensibly nonreciprocal exchanges with moral meaning—represents the resolving of a perceived imbalance created by economic precarity and medical need. In the absence of state support, kin and other social relationships must be mobilized to support patients and their caregivers.

Hanson (2014) has argued that charity is a ritual of exchange in Western contexts and that the act of charitable giving in a seemingly innocuous, compassionate relationship actually functions as a declaration of power. Traditional philanthropy differentiates between the haves and the have-nots and involves no real financial loss to the philanthropist; nor does it facilitate wealth redistribution on any significant scale (Hanson 2015). Robbins (2006) suggests that the conspicuous compassion of charity helps to reinforce social and class-based hierarchies, when the poor depend on the goodwill of the affluent. Charitable giving through medical crowdfunding is often quite conspicuous. After their donation is processed, donors are urged to comment on the campaign’s website, share the campaign to their personal social media, and to otherwise “spread the word.” Indeed, Durand et al. (2018) found that the number of external shares was strongly correlated with the amount of funds raised. The hypervisibility of medical crowdfunding campaigns, both on social media and in the more traditional media, has important consequences

not only for fundraising success or failure but also for how campaign narratives are constructed and disseminated.

Narrative theory

The central component of any medical crowdfunding campaign is the campaign description and, if present, campaign updates. Although hypothetically any form of text can be uploaded in this section, GoFundMe encourages campaign organizers to “share their story” here, privileging more narrative forms of writing over lists, bullet points, poems or other alternatives. Since the campaign description functions as the primary appeal to donors (Chen, Thomas and Kohli 2016), I focus my narrative analysis here. According to Arthur Frank (1993), medical narrative as a genre originated in the 1970s and is characterized by individualism, an emphasis on self-change, and the making public of what was once designated a private experience. “The illness narrative presents who the ill person has become and stakes a public claim on this new identity” (Frank 1993, 42). The individual experience of suffering must also be distinguished from the mass phenomenon of suffering (Frank 1993). As David Perusek (2012) so eloquently puts it, “How to construct an illness narrative on pages already so full?” (500)

Medical narratives are shaped in large part by the medical conditions they describe. Many medical crowdfunding campaigns are started in response to traumatic injuries that result in brain damage or permanent disability. What narrative devices, then, do campaign organizers use to motivate strangers to donate to the care of patients who are unlikely ever to be “cured”? Indeed, several scholars have found that often those campaigns for the most “hopeless” cases—individuals who require ongoing or lifelong therapeutic intervention and, arguably, need assistance the most—do not receive funding as quickly as campaigns that feature photogenic

individuals or appear to offer patient-benefactors a “quick fix” (Proelss, Schweizer and Zhou 2018; Young and Scheinberg 2017). Nevertheless, there are many notable examples of “viral” campaigns for individuals with severe, incurable conditions, and two of the case studies I will examine for this project involve benefactors facing lifelong paralysis.

In her work among patients with severe brain damage and the medical personnel who care for them, Eleanor Antelius (2007) argues that a different kind of hope becomes essential to the process of clinical meaning-making and the patients’ call to action. Since a cure is likely impossible, discourses of hope do not invoke the idea of a distant future with open horizons—instead, hope is rooted in the present, in short- to medium-term goals and hopes for minor improvement or the prevention of further deterioration (Antelius 2007). Similarly, Lenore Manderson and Narelle Warden (2016) found that midlife and elderly Australian women with chronic health conditions focused primarily on their present lived realities. In rehabilitation facilities, health providers consider it essential for patients with incurable diseases or injuries to remain motivated to participate in physical and occupational therapy; consequently, they shy away from providing direct answers to questions about possibilities for significant future improvement in favor of offering short-term “carrots” (Antelius 2007). It is possible that similar narratives emphasizing hope in the present, despite a sense of foreclosed future possibility, are also at play in medical crowdfunding campaigns, as campaign organizers work to convince potential donors that benefactors with incurable conditions are still “worthy” of financial aid.

The single largest category of medical crowdfunding campaigns is those related to cancer (Berliner and Kenworthy 2017; Lukk, Schneiderhan, and Soares 2018; van Duyhoven et al. 2018). David Perusek (2012) writes that one of the ways in which the sick person is encouraged to frame themselves and their experiences is by positioning themselves in relation to others such

that their positive attributes—in the case of cancer or other illnesses, their “successful attitudes”—are naturalized. Moreover, the attitude of the patient is a matter of public surveillance (Perusek 2012, 496), and this can also be seen in medical crowdfunding. Paulus and Roberts (2017) observe a tension in medical crowdfunding campaigns between the need to communicate the urgency of the situation with the need to present a hopeful attitude. In a similar vein, Durand et al. (2018) found that campaigns with negative overall sentiments performed poorer than campaigns with more positive overtones.

Finally, the overall narrative frame of the campaign matters. Chen, Thomas, and Kohli (2016) found that crowdfunding campaigns that utilized emotional rather than rational frames were more successful on average. They also identified guilt as a particularly significant appeal mode, and suggest that campaigns that emphasize empathy and self-efficacy are more successful because these sentiments tend to elicit guilt in potential donors (Chen, Thomas, and Kohli 2016). For instance, campaigns that emphasize the beneficiary’s poverty may elicit guilt in affluent potential donors. Perusek suggests that militaristic language is used in cancer narratives because it reflects a societal desire to meet the violence of life-threatening illness with violence (Perusek 2012, 497) and even a brief pass through the top medical crowdfunding campaigns on GoFundMe provides plenty of examples of patient-benefactors engaged in biomedical “battles.” Potential donors respond differently to hopeful, strong, or positive campaign narratives than they do despairing or “overly negative” ones.

Digital anthropology and media studies

Media studies can offer many important insights into medical crowdfunding. For one, medical crowdfunding is an industry that relies on media coverage for its stratospheric rise.

Arguably, journalists and news reporters have helped bring medical crowdfunding campaigns to the forefront of public consciousness. Media outlets simultaneously present medical crowdfunding as a highly personal (and sometimes embarrassing) component of the illness experience; as a symptom of systemic issues in the U.S. healthcare system; and as a dangerous space populated by scammers, fraudulent campaigns, and dubious requests. Above all, medical crowdfunding is controversial: it is a site of public discussion and disagreement, as evidenced by the contradictory nature of much reporting as well as a series of high-profile, ethically murky campaigns in recent years. I chose to include newspaper articles on medical crowdfunding in this project because, as S. Elizabeth Bird frames it, an anthropological perspective on journalism offers “a way to explore the nature of news as a form of cultural meaning making—its creation, content, and dissemination” (Bird 2010, 1).

Charles Briggs and Daniel Hallin (2010) extend the concept of biocommunicability to the public sphere. Noting that “information is assumed to be useful because it helps citizens and policy-makers to make collective decisions about the public interest” (Briggs and Hallin 2010, 152), they argue that certain health topics are perceived as more political than others, including health insurance. As I hope to demonstrate in Chapter Four, the scale applied is crucial here, as journalists may elect to focus on individual narratives at the expense of broader institutional critiques. Journalists use these personal stories to frame their articles and “hook” readers. At the same time, sharp distinctions between health versus political reporting are often elusive, because many journalists also draw out clear causal pathways between health insurance policy, financial need and impediments to access, and biomedicalized suffering or death.

Viewing medical crowdfunding through a lens informed by media studies also facilitates my analysis of the relationship(s) between benefactors and donors. How do campaign organizers

imagine their audience, or, what can be inferred about the imagined audience through their campaign materials (e.g., updates)? On the other hand, how does the audience of donors respond to an imagined benefactor, whom they may only “know” through publicly available campaign materials? Eden Litt (2012) writes that the construction and performance of self on social media platforms is complicated by shifting and often unstable relationships to time and space—it is often unclear who is viewing one’s content, and when, given the portability of digital technologies and ever-changing, indeterminate understandings of privacy. Moreover, “while we are dependent on the imagination as a guide during social media use, it is the actual audience on the other side of the screen reacting and judging the performance. Therefore, potential tensions between the two audiences may lead to consequential outcomes” (Litt 2012, 333). In the process of setting up a webpage or posting an update, campaign organizers must make many decisions based on who they imagine their audience to be. If they misjudge their audience, funding is imperiled, and with it, one potential avenue to access healthcare.

Anthropology of insurance and managed care

Medical crowdfunding is linked to issues of healthcare access and inequality, especially health insurance. Horton et al. (2014) write that the Affordable Care Act attempts to reduce the number of uninsured Americans and reform a health system widely regarded as inefficient and broken, but leaves intact the employer-based system of health insurance that treats health as a commodity to be bought and sold. Berliner and Kenworthy (2017) found that a disproportionately high number of medical crowdfunding campaigns were from states that elected not to adopt the Medicaid expansion under the Affordable Care Act. In their spatial analysis of Canadian census zones, van Duyhoven et al. (2018) observe that although rural areas

in Canada face the most severe service gaps, medical crowdfunding campaigns are located disproportionately in urban, higher-income areas. This suggests one additional way that medical crowdfunding can deepen existing health inequalities.

Nevertheless, most campaigns do not explicitly name the systemic injustices promulgated by the current health insurance structure. In Berliner and Kenworthy's (2017) study, although 70% of the campaigns sampled mentioned financial difficulty, only 41% explicitly mentioned health insurance. Discussions of health insurance were typically limited to brief mentions of uncovered costs and high deductibles or copays. Similarly, Lukk, Schneiderhan, and Soares (2018) found that only 95 out of 248 campaigns sampled mentioned either a lack of private health insurance or inadequate public health insurance coverage. This discrepancy highlights the important political work being done by campaigns, in which deeply political issues (including, but not limited to, the Affordable Care Act, Medicaid, and calls for a universal and/or single-payer healthcare system) are partially obscured by a veil of apolitical, neoliberal discourse.

Gomberg (2002) argues, "There is a difference between the ethical obligations imposed on us when we are confronted with an individual in need of emergency rescue and the social problems that arise from pervasive poverty" (40). In his opinion, the "fallacy of philanthropy" lies in the common assumption that random emergencies and pervasive social problems create the same ethical obligations, and that philanthropy is a morally good (or at worst, neutral) response to these obligations. He adds, "There will always be a residue of exceptional unfortunate events that our foresight has failed to prevent, and the exceptionality of emergencies makes it relatively painless to respond to them with a norm of rescue" (Gomberg 2002, 49). Perhaps, then, medical crowdfunding campaigns have become a growing phenomenon because they repackage the mundane suffering embedded within the U.S. healthcare system into stylized

narratives that tell the stories of individualized catastrophes. In Chapter 2, I will pull out the discourses of urgency and emergency seen in many medical crowdfunding campaigns, and in Chapter 5 I will situate these themes in the context of health insurance reform.

Gomberg (2002) argues that successful capitalism inevitably creates poverty. Therefore, allocating resources towards relief organizations deflects from the political work needed to identify and change the structural causes of poverty and its associated forms of suffering. Applying his logic to medical crowdfunding, it could be argued that donating to medical crowdfunding campaigns is counterproductive—it will not solve the issue of systemic health inequality, and may actually make matters worse by propping up our unequal healthcare system. In their critiques of market-based medicine, Barbara Rylko-Bauer and Paul Farmer (2002) argue that the conflict between justice and profit margins so characteristic of medicine in the United States is the inevitable result of allowing neoliberal market ideologies to shape healthcare delivery. Their conceptualization of “medicine as commerce” (Rylko-Bauer 2002) tracks with how access to healthcare is mediated by crowdfunding platforms such as GoFundMe for the economically marginalized.

METHODS

The methodological foundation of this project is the analysis of ten case studies selected on GoFundMe in September 2019, in addition to 130 articles published in major U.S. newspapers between January 2011 and September 2019. Originally, I wanted to collect a random sample of campaigns, but GoFundMe’s algorithm made that impossible. Instead, I selected ten campaigns that were “trending” on GoFundMe at the time of data collection. With regard to the news articles, I noted each article’s general stance towards medical crowdfunding, common

structural characteristics, and emergent themes, with particular attention paid to the presence or absence of explicitly political commentary and recurrent ethical concerns. The news media play an important role in the co-production and dissemination of the discourses of worthiness, individualism, and competition that are inseparable from the phenomenon of medical crowdfunding, meriting their inclusion here. These findings are reported in Chapter Four.

Visitors to GoFundMe can filter medical fundraisers by seven broad categories, and I chose these case studies with an eye to providing a roughly representative sample of the kinds of campaigns site visitors are likely to encounter. From GoFundMe's main page, there are two pages displaying lists of medical fundraisers—one aimed at potential donors, the other curated for visitors interested in starting their own campaigns. All ten campaigns were selected from the former page, <https://www.gofundme.com/discover/medical-fundraiser>. On this page, campaign blurbs are displayed in a grid arrangement, and although it is unclear exactly how the order of the campaigns is determined, I was able to determine that the site visitor's IP address, the amount of money raised, number of shares to external websites, and volume of donations all play a role. It takes hundreds of clicks ("Show More") to reach "unsuccessful" campaigns, and many of the top campaigns are marked by banners that read "trending now." All ten campaigns were chosen from the top of the digital pile, as I am interested in the discursive strategies and notions of reciprocity mobilized in those campaigns that are "successful," "go viral," or attract the attention of the news media. All medical crowdfunding campaigns hold meaning for their organizers, but for the purposes of this research, "trending" campaigns are better examples of larger collective processes of meaning-making due to their greater public reach.

Every campaign has its own webpage on GoFundMe's server. After selecting my case studies, I downloaded each campaign's webpage, including not only the campaign description

but also any campaign updates, videos uploaded by organizers, and the ten most recent comments left by donors. With reference to the literature on crowdfunding, I then developed three coding frames for campaign descriptions/updates (in other words, any text shared by campaign organizers), videos, and comments. Coding was done manually and was based on concepts and clusters of terms. Of primary interest with regards to campaign descriptions and updates were concepts of urgency, need, worthiness, gratitude, spirituality, and reciprocity. For videos, I noted overall emotional affect, setting, number of persons present, and whether they appeared to be professionally edited. When coding comments, I took note of references to offline relationships between benefactors and donors, requests for donations to other fundraisers, and spirituality. Although the bulk of these findings will be shared in Chapters Two and Three, they will also be addressed in Chapter Five, because the individualized narratives publicized in medical crowdfunding campaigns are always linked to the powerful systems and institutions that produce health disparities.

INTRODUCING THE CASE STUDIES

I provide a brief overview of the case studies here to orient the reader, and because some of the similarities and differences between the campaigns I selected will be immediately apparent. “Sladek Strong,” “Kinsley’s Spine & Brain Tumor Treatments,” and “Support Henry & Ruth to Health: Join Team HRJH” all feature patient-benefactors struggling with various cancer diagnoses. “Help for the Olla family,” “Knutson Medical Costs,” and “Critical Car Crash (Ashok and Soujanya)” were created in response to serious car accidents; in the former two campaigns, children were fatally wounded, and entire families involved. In both “Knutson Medical Costs” and “Brian Ortner’s spinal injury recovery fund” an adult receives a spinal injury

resulting in permanent partial paralysis. “Save Yoel and Yael” and “Cowgirl Up for Jaci Hermstad” both attempt to raise massive amounts of money for experimental therapies for rare genetic disorders.

“Amy’s Surgery” is unique among this sample because it has a relatively “happy ending.” Amy and her husband created a GoFundMe campaign to raise \$20,000 for the removal of a cancerous mass on Amy’s thyroid. The campaign surpassed its fundraising goal and, in a final update posted to the campaign website, Amy’s husband writes that Amy underwent a successful surgery to correct her condition, with no further issues expected by her medical team. All of the other campaigns and their narrative trajectories, however, reflect the ongoing uncertainty, pain, and fear wrought by serious medical diagnoses. As I followed these campaigns over the course of my research, I found few happy updates.

All of the campaigns presented in this work are available publicly at the time of writing, and although at least one of the campaigns is now listed as “inactive” or “complete,” most are still collecting donations, posting updates, and receiving comments and shares. I provide links to the campaigns in an appendix if readers would like to reference them. Although several campaign organizers actively continue to recruit media outlets and local charities to their cause, I discourage readers from using their personal social media to publicize the campaigns presented here. Medical crowdfunding raises tricky questions about privacy and the divide between public and private, and since I did not receive permission from campaign organizers to publicize their campaigns, I will refrain from doing so.

CHAPTER TWO: NARRATIVITY

INTRODUCTION

In this chapter, I will analyze these ten campaigns as narratives. What components are common to all campaigns? How are they constructed? Who are the actors? Who is the audience? And perhaps most importantly, what discursive themes emerge? First, I will provide an overview of the “nuts and bolts” of a medical fundraiser on GoFundMe. GoFundMe provides a template (i.e. digital framework) for every fundraiser hosted on its platform, as well as recommendations to boost the likelihood of success. GoFundMe’s algorithm uses geography and recency to sort campaigns, which impacts a given campaign’s relevance and ability to attract donations. When I visit gofundme.com from an IP address in the United States, I see different “trending” campaigns than a visitor whose IP address places them in Great Britain. Some of the highly valued attributes that emerge from my reading of these campaigns are work ethic, bravery, selflessness, humility and gratitude, optimism, and faithfulness. Through narrative, campaign organizers attempt to demonstrate beneficiaries’ possession of these attributes to potential donors, thereby establishing their worthiness. At the same time, organizers also seek to create a sense of urgency: donate now!

Visitors to the site can navigate to an individual campaign by typing [gofundme.com/f/\[campaign-title\]](http://gofundme.com/f/[campaign-title]) into the search bar. Campaign websites are laid out in a simple grid-like pattern. At the top of the page is the campaign title, up to three photographs (if posted by the campaign organizer), the name of the individual(s) organizing the campaign, a progress bar displaying the total funds raised to date, and a list of the most recent donors and amounts donated. Campaigns are “tagged” by GoFundMe and categorized; all of my case studies were

tagged “Medical, Illness & Healing.” Next comes the campaign description, which functions as the primary appeal to donors. Any updates to the campaign follow the campaign description in reverse chronological order, similar to a blog. A button at the very bottom of the page allows visitors to report campaigns they believe to be misleading or fraudulent.

"Cowgirl Up" for Jaci Hermstad

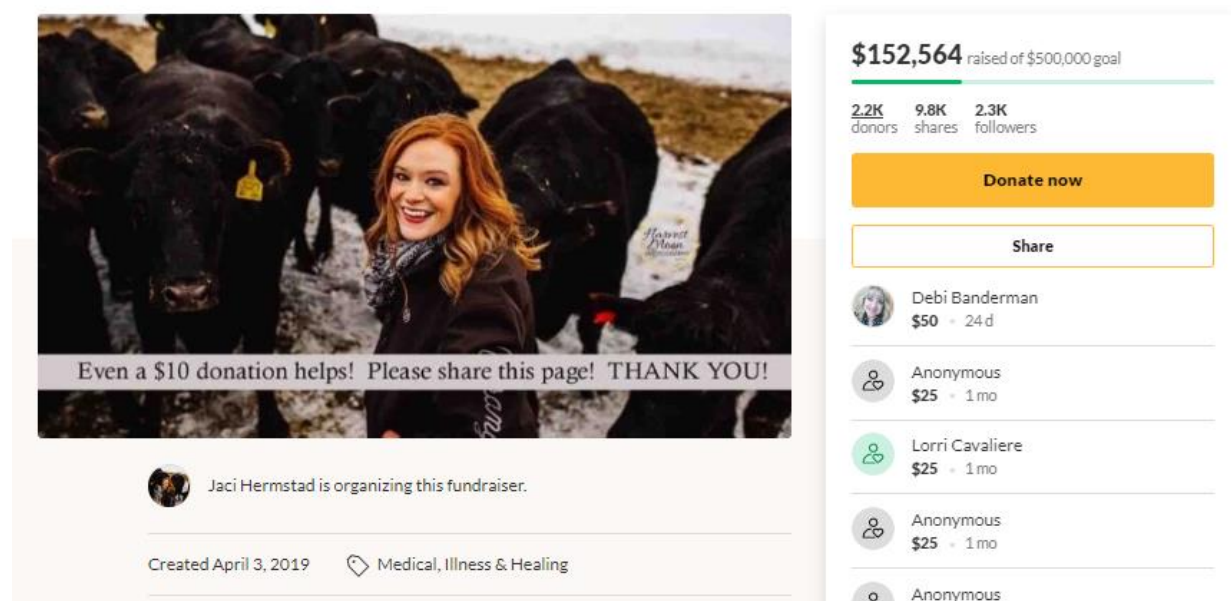


Figure 1. A web screenshot of “‘Cowgirl Up’ for Jaci Hermstad,” one of the case studies.

How are campaigns oriented in time and space? The geospatial location of the campaign is tagged as well. Campaign organizers are required to provide their city and state of residence, allowing GoFundMe to target site visitors with local campaigns first. When I first visited GoFundMe’s homepage, I was on the Mount Holyoke College campus, and I noticed the “Find a GoFundMe near you” feature offered me a dozen different campaigns tagged in South Hadley, Massachusetts, in reverse chronological order from the time of last donation. Since South Hadley is a small college town, there are comparatively few campaigns, allowing me to view campaigns that had not received a donation or been updated in over six months. Visitors whose IP addresses place them in a major city, however, would likely have a very different experience, suggesting

that the experience and meaning of recency on GoFundMe is always relative and unstable, and impacted by population density. This is particularly important because van Duynhoven et al. (2019) have found that most medical crowdfunding campaigns are clustered in urban settings. Rapid turnover means that campaign organizers must craft campaigns that receive a steady stream of donations if they want to remain at the top of the digital “pile.”

In a similar vein, each campaign’s website lists the date of its creation, but all updates and donations appear in reverse chronological order. For campaigns with a great many updates—such as “Brian Ortner’s spinal injury recovery fund,” which at the time of writing has over 200 updates and counting—the relative difficulty of scrolling back all the way to the beginning means that most visitors and donors will potentially only see the most recent updates. Each update must be compelling to potential donors in its own right, because campaign organizers cannot assume that readers have read everything. Moreover, campaign descriptions and updates that exceed a certain length are partly cut off and can only be viewed in full by clicking a pop-up “Read more” button. As such, the beginnings of each update are particularly important because they must “hook” the visitor/reader. This leads nicely to an analysis of the individualizing elements of these campaigns, starting with the creation of a sense of urgency. How do campaign organizers craft a narrative that pulls readers in, compels them to keep clicking and reading, and prompts them to open their wallets?

In theoretical terms, this chapter draws heavily upon Arthur Frank’s work on medical narratives and Ruth Page’s work on embodiment in online narratives. Frank (1993) establishes the medical narrative as a distinct genre of writing. He plots the phoenix-like change of self entailed by narrativizing one’s illness experience, suggesting that the medical narrative tracks an ontological shift from “who I was before” to “who I am now” and “who I might become.” This

change of self begins with an epiphany, “the recognition that illness has *always* been the *medium* of the self” (Frank 1993, 46, emphasis in original). By this, he means that the sufferer comes to realize that who they are is what illness has always been making them into (Frank 1993). In medical crowdfunding narratives, this change of self may be described in the campaign description, or gradually, throughout a series of updates.

I am also influenced by Page’s (2011) analysis of cancer blogs and gendered narratology. Medical crowdfunding campaigns share many similarities with personal blogs, in particular the importance of narrative self-disclosure. Page argues that the narratives found within the personal blogosphere are highly gendered, and I found evidence suggesting that campaign narratives may also be gendered in similar ways. Eight of the case study campaigns were narrated by women, and one was organized by a team of 16 individuals. Only one campaign was narrated primarily by a man, suggesting that the discursive work done by medical crowdfunding narratives is disproportionately women’s labor, although this also needs to be addressed quantitatively. The labor of a medical crowdfunding campaign narrative can thus be thought of as a kind of gendered care work.

CRAFTING INDIVIDUALITY

How do campaign organizers craft narratives that establish the beneficiaries’ need? I first coded my case studies for individualizing elements, defined in this project as those phrases that set apart the beneficiaries’ experiences as something outside the bounds of “normal” illness/medical experience. According to Ian Hacking (2006), new kinds of persons are made when their boundaries and characteristics are changed, and the limits of possibility depend on what we can imagine them to be, which in turn depends on how we describe ourselves and

others. How are worthy beneficiaries made up as persons (to use Hacking's phrase), and how are they distinguished from others? Campaign organizers create worthy beneficiaries in two key ways. First, by emphasizing the random nature of an accident or illness and thereby characterizing the beneficiaries as "unlucky" or the event as "tragic;" second, by referring to "unthinkable" or "unimaginable" circumstances that are otherwise unknowable to those who have not experienced it themselves. The curtain may be partially drawn back by the intimate narratives shared in the campaign, the writer suggests, but still, these experiences are so abnormal, so unfortunate, that they are singularly worthy of financial aid because there is no other way for outsiders to relate.

Medical narratives, according to Frank (1993), "remain open-ended resources of 'see what happened to me,' not closed prescriptive forms of 'this will happen to you'" (49). The medical crowdfunding narrative invites the donor to look, and to care about what is happening to another, but not necessarily to fear for oneself. In this way, medical crowdfunding campaigns are participatory narratives, but that participation also requires a certain distancing of the self from the other. To this end, I also draw on David Perusek's work on cancer experience in the United States. Perusek (2012) argues that the mythology of cancer isolates sufferers by placing their "unimaginable" experiences outside the realm of human imagination and, consequently, beyond the reach of deep empathy and meaningful social connections. I will return to this argument shortly, but first, I will provide some examples of individualizing elements in medical crowdfunding campaigns. By "individualizing elements," I mean the discursive strategies campaign organizers use to set themselves apart from others. How do their stories transform their experiences into something exceptionally tragic or noteworthy to readers (a.k.a. potential donors)?

“Cowgirl Up for Jaci Hermstad,” created on 3 April 2019, is an example of a medical crowdfunding campaign for an experimental treatment. Jaci, both beneficiary and campaign organizer, introduces herself in the campaign description as follows: “I have a rare form of ALS called FUS p525L mutation. The only other person I knew who had this merciless disease was my identical twin sister, Alex. She was diagnosed at age 11 and I watched her die on Valentine’s Day in 2011.” She goes on to explain how the disease progression has affected her daily life, the novel gene therapy treatment she is seeking, and how donations will be spent. These first three sentences of her campaign description are noteworthy because unlike in many other campaigns, she does not identify herself by name, occupation, or with any personal defining characteristics—rather, she identifies herself with the rarity of her genetic disease. Her form of ALS is so unique that the only other sufferer she has ever known was her identical twin, and her experience of this genetic disease so unthinkable that she actually saw her sister die from it.

“Knutson Medical Costs,” created on 28 July 2019, is a very different kind of medical crowdfunding campaign. Organized by a family friend after a car accident resulted in the death of a young girl and the paralysis of her mother, the campaign description begins simply, “This morning, July 28, the unthinkable happened to the Knutson family.” In the first update, posted on 29 July 2019, an uncle writes that only a few days before the accident, the family had gone on vacation and taken several family photos together. “Little did they know it would be the last photos of their precious daughter and family together as they knew it.” Although their motivations are quite different, these two campaigns both use individualizing narrative strategies to demonstrate need and attempt to convey to readers (their potential donors) the severity of their situation. Jaci’s form of ALS is extremely rare; therefore, she can easily make a case for the uniqueness of her experience. The Knutsons, however, are victims of a tragic, but statistically far

more common, occurrence: a fatal car accident. In order to individualize the type of event that occurs multiple times per day in the United States alone, the campaign organizer makes it unthinkable in a different way: unimaginable not because it is so uncommon, but because it is so horrific that we do not want to imagine it.

CRAFTING URGENCY

In addition to impressing upon potential donors the uniqueness of the situation, campaign organizers across all of my case studies also sought to create urgency in their narratives. This could be achieved through direct references to time (e.g. hard deadlines for funding experimental treatments) or indirectly, through references to the “dire” or “critical” nature of a situation. As discussed previously, GoFundMe’s architecture prioritizes recency and novelty—new visitors to a campaign website will see first the three most recent donations and only the most recent updates, unless they intentionally click back to view older posts. The same is true for donor comments as well. Older updates and comments may be “buried” rapidly beneath an onslaught of new digital content in campaigns that are updated frequently or have “gone viral” and received a sudden influx of donations. However, narrative urgency is not merely an accident or inevitable consequence; it is crafted intentionally, particularly in campaign descriptions, for the purpose of conveying need. The implicit question that campaigns seem to be answering is, “Why do you need money now?”

“Sladek Strong,” created on 26 July 2019, is organized by a relative on behalf of a married couple who have both been diagnosed with cancer. After opening with a short story of an interaction between the couple and their young children, she writes, “these are the very real, unimaginable thoughts and daily conversations happening between my sister, her husband and

their five year old twins RIGHT NOW.” She continues, “Now, they are both fighting together, for each other and for their children. This additional cancer diagnosis, surgeries for both of them, lengthy hospital stays, and numerous medications...*they just keep coming*” (emphasis mine). This quote is reminiscent of Lenore Manderson and Narelle Warden’s (2016) argument that chronic health conditions and the resulting chronicity of suffering (not only medical but also financial, emotional, and spiritual) lead to “recursive cascades,” in which many medical factors come together and are compounded in social context. The use of the phrase “they just keep coming” signifies the relentless cascade of medical and financial challenges faced by the Sladeks.

Page (2011) addresses this temporal element in cancer blogs, finding that temporality in storytelling in personal blogs also has a gendered element. Men’s narratives contained more recounts, “a temporal sequence of events where the [reflexive] evaluation is less prevalent and ongoing rather than found in a concentrated climax” (Page 2011, 230). Women’s narratives used more anecdotes, “stories that report a remarkable event, characterized by an evaluative punchline” (Page 2011, 230). Pointing out that anecdotes are more likely to stimulate an affectual response in the reader, she observes that women were also more likely to use this narrative strategy to highlight their emotional responses or thought processes (Page 2011, 231). When campaign organizers—in this sample, most of whom are women—build their narratives with recursive cascades and anecdotes, the events they describe are affectively marked as remarkable and relentless.

“Save Yoel and Yael,” created on 12 December 2018, is quite different from “Sladek Strong.” “Save Yoel and Yael” was created by the parents of Yoel and Yael who, at the time of the campaign’s creation, were just a few months old. Yoel and Yael are fraternal twins who have Canavan disease, a rare genetic neurodegenerative disorder. “Save Yoel and Yael” aims to raise

\$2 million to fast-track the development of an experimental gene therapy and fund NeuroMovement therapy for the twins in the interim until they (hopefully) can receive the gene therapy. The twins' mother explains,

They have only one chance to receive this therapy, and the soonest one is projected to be ready for a human clinical trial in Summer 2019, but requires approximately \$2 million more to reach Canavan patients. We are desperate to expedite funding to bring this gene therapy out of the lab and into the brains of patients like our twins and the handful of other beautiful children awaiting this treatment.

The final sentence of this excerpt also suggests that donating to the campaign will benefit more than just Yoel and Yael, the unnamed "other beautiful children."

"Save Yoel and Yael" has the highest funding goal of all the campaigns I analyzed by far, and other studies suggest that the average medical crowdfunding campaign has a mean funding goal of "only" \$50,000 (Litman-Navarro 2018). The \$2 million goal is justified here by presenting an urgent need to speed up ongoing research. The urgency of the request is further illustrated later: "As with any progressive disease, early intervention is critical. ... Time is brain; the more therapy Yoel and Yael can receive, the more of their brains (and skills) we can save." The claim that "time is brain" is an arresting one. It also parallels the idiom "time is money." Since there are no time limits constraining GoFundMe campaigns, a campaign can be left up indefinitely, and the organizers can continue to withdraw funds as long as donations trickle in. However, the organizers of "Save Yoel and Yael" have imposed their own deadline on the campaign due to the nature of the beneficiaries' illness, and the difficulty of meeting such a high funding goal in a relatively short period of time is perhaps compounded by the sense of timelessness evoked by GoFundMe's structure.

GOD AS ACTOR

Religion also features prominently in almost all of the GoFundMe narratives I analyzed. In these campaigns, only the Judeo-Christian God was invoked, and only Christian and Jewish faith communities were explicitly discussed, although it is very likely that many donors were followers of a different (or no) religion. I found that the Judeo-Christian God (hereafter referred to simply as “God,” because that is the terminology used in many of the campaigns) became an actor in the stories told by campaigners in three major ways. First, campaign organizers might appeal directly to God through prayer, or request that potential donors pray on behalf of the beneficiaries. Second, campaign organizers sometimes suggested that donations were facilitated by God, or that the GoFundMe campaigns were in some way a reflection of divine providence. Finally, campaign organizers sometimes stated or implied that funding success was a direct reflection of beneficiaries’ spiritual deservingness—their “grace,” “treasure in heaven,” or “karmic earnings.” This last point ties into a broader examination of discourses of worthiness on GoFundMe but introduces an element of religiosity that I believe has been under-examined by scholars thus far.

I will pay particular attention to “Amy’s Surgery,” created on 31 May 2019 and organized by Amy’s husband, Rick. Rick identifies himself as a pastor whose church recently closed as he seeks to move his ministry to a new location. However, shortly after closing their church, doctors discovered a tumor in Amy’s thyroid, requiring surgery. Pastor Rick organized the campaign to cover the costs of this “elective” surgery, but this campaign stood out from the many other campaigns for similar procedures that I saw in my search due to its strong religious overtones. The campaign description concludes with a prayer containing many biblical references:

Here is what I declare over Amy every day: Romans 8:1-2, The Law of the Spirit of Life in Christ Jesus has set Amy free from the Law of sin and death. Romans 8:11, the Spirit that raised Jesus from the dead dwelling in her gives life to her body from the crown of her head to the soles of her feet! She is healed by the stripes of Jesus and as a tithing convent family Malachi says that God rebukes the devourer for our sake! He meets all our need according to His riches in glory by Christ Jesus! No weapon formed against us will prosper and every tongue that bring false judgment and accusation will be proved wrong and condemned!

Additionally, I found it interesting that the first photo included with the campaign is an image of Pastor Rick and Amy standing together wearing matching crisp white outfits. It is unclear whether their outfits are intended to signal their affiliation with a particular sect, but given the symbolic importance of the color white in Christianity, such imagery may be intended to convey to potential donors Amy's innocence, purity, or virtuosity. Campaign organizers commonly included written prayers in campaign descriptions and updates. Campaigners might pray for donations or, alternately, request prayers in addition to donations. For instance, in "Knutson Medical Costs," the campaign organizer writes, "More than anything, please pray for comfort and healing for the whole Knutson and Bostrom families."

Prayer requests were also included when a beneficiary's condition took a turn for the worse or when awaiting a diagnosis—in "Brian Ortner's spinal injury recovery fund," Brian's wife, Amy, writes, "Please pray for Brian today for him to make it out of this risky surgery safely, and pray for us all in the future as we learn to deal with this tragedy." Campaign organizers also sometimes offered thanks to God when they received good news. In a similar vein, commenters commonly offered prayers in addition to donations, such as "Continued

prayers for a full recovery and a very positive outcome ❤️” (“Amy’s Surgery”). In return, some campaigners prayed on behalf of donors. In “Amy’s Surgery,” Pastor Rick, writes in an update, “May each of you experience His love and peace, may you know what is the hope of His call and the riches of His inheritance available to us in Jesus!” Sharing religious blessings is one way that campaign narratives become participatory ventures.

Campaign organizers also suggested that successful campaigns, large donations, or “going viral” reflected God’s will. In “Amy’s Surgery,” Pastor Rick writes, “Amy and I have been and continue to trust God in this matter but as the Word says *you have not because you ask not*” (emphasis mine). Applied in this context, the proverb “you have not because you ask not” implies that the faithful need only to ask for donations in a medical crowdfunding campaign, and they shall receive. On the other hand, this statement also heavily implies that those who do not receive donations either did not ask properly or are undeserving. This is reminiscent of the prosperity gospel, the belief among some evangelical Protestants that financial and physical well-being are both under God’s control (Burton 2017). Campaigners also sometimes leveraged the social ties created and maintained within religious communities to encourage donations. For instance, in “Help for the Olla family,” created on 30 May 2019, the aunt of a family whose sons were involved in a fatal car accident writes, “we are strengthened and comforted by all the love surrounding us—reminding us that our Heavenly Father is holding us close.” Similarly, in “Support Henry and Ruth to Health: Join Team HRJH,” created on 18 August 2019 for a mother-and-son duo both diagnosed with cancer, the campaign organizer writes, “[she] embraced her Jesuit community as enthusiastically as they embraced her.”

“Save Yoel and Yael” is a particularly noteworthy example of this leveraging of faith communities through medical crowdfunding narratives. The campaign is partnered with Yoel

and Yael's parents' synagogue, making all donations tax-deductible. Besides mentioning this fact and their Ashkenazi Jewish heritage, the campaigners make no mention of Judaism or spirituality in their campaign description. In the campaign's only update, however, time is marked simultaneously by the twins' condition and the Jewish calendar:

Yom Kippur, the holiest day on the Jewish calendar, is upon us. For most of us in the Jewish community it is a time of introspection, forgiveness, resolve to improve, and prayers for a sweet new year. For our family this time marks the anniversary of Yoel and Yael's devastating diagnosis, one which brought tremendous fear, sadness, anger, grieving and a sense of hopelessness for the future.

Additionally, the campaign organizers maintain a list of links to articles written about their family, several of which were published by Jewish newspapers and magazines (both regional and national). Notably, the campaign description is available in English, Spanish, and Modern Hebrew translations. Comments such as "Bezrat Ha-Shem you will raise the money soon," "Gmar hatima Tova! Hoping for good news in the new year!" and "May they both live and grow healthy Ad 120 Bezrat Hashem!" make it clear that although the intended reach of the campaign is beyond the family's own Jewish community, their local and religious connections are still important to their fundraising success.

Campaign organizers were occasionally even more explicit in their linkage of spiritual devotion and funding success. In the campaign description, Pastor Rick writes, "I have been a pastor for over 22 years and I have responded to the needs of many over the years and ask you to consider helping us in this time. We believe because we have laid up our treasure in store in heaven that God can and will bring in to us in our hour of need." The metaphorical treasure he has accumulated through his faith, he suggests, will translate directly to a wealth of donations on

Earth in his wife's time of need. Again, a clear link is established between faithfulness and worthiness. In a video uploaded with "Amy's Surgery" titled "Amy Needs Surgery," he reiterates, "I am not a beggar, but I know I have a store in heaven. I have laid up treasure in heaven for years, as a tither, as a giver, as one who has responded to the needs of many other people in 22 years of ministry and 30 years since I have recommitted my life to the Lord I have really sold out to the things of God." It is important for him to clarify that he is hard-working and does not "beg" or ask for much, signaling the deservingness of this request. It is equally important, he suggests, that he has been "a giver" in his life and ministry, reinforcing the importance of (perceived) reciprocity in my case studies. This theme will be explored in greater detail in the following chapter.

DISCOURSES OF WORTH

What makes any given beneficiary worthy of donations, and how to portray that to potential donors? Given that fewer than 10% of campaigns are estimated to meet their funding goals (Berliner and Kenworthy 2017), this is a pressing issue for campaign organizers. It is important to note that what campaign organizers might believe makes beneficiaries worthy does not necessarily overlap fully with what they choose to include in their campaign narratives. For example, campaigners might believe that all people deserve healthcare no matter their ability to pay, but other studies have found that very few medical crowdfunding campaigns explicitly call out the injustice of the American healthcare and health insurance industries in their campaigns, opting instead to focus on individualized concerns (Berliner and Kenworthy 2017; Paulus and Roberts 2017; Snyder et al. 2017). Campaign organizers were sometimes explicit in describing beneficiaries' worthiness, but much of the work of establishing worthiness is implicit. Across

these ten campaigns, beneficiaries tended to be characterized as hard-working individuals facing their health issues with courage and the “right” attitude. They also demonstrated ample gratitude and were frequently humble and prayerful.

Work ethic and gratitude

An ethic of hard work is essential to the characterization of most of the beneficiaries in these ten case studies. Paulus and Roberts (2017) found that campaigners make “identity claims” about beneficiaries, telling potential donors that they are hard-working and valued members of their communities and thus, deserving of help. In “Amy’s Surgery,” Pastor Rick assures potential donors that he and his wife have not taken their campaign lightly: “We believe the laborer is worthy of their wage and are not asking for anything for free. We have however exhausted every means to get this done and time is becoming critical.” The family on the receiving end of “Support Henry & Ruth to Health: Join Team HRJH” are described as follows: “Gratitude is a core value for this family. With every curve ball, medical twist, and crazy bad piece of luck, this family focuses on the generosity and beauty of their community. They know that it is this tremendous outpouring of love and support that will once again see them through.” Writing of the Sladeks, the campaign organizer assures potential donors that “they appreciate every single thing that is done for them, more than I can express.”

Bravery and battle metaphors

Another way that campaign organizers portrayed beneficiaries as worthy of donations is by calling attention to their courage, strength, or mental fortitude in their “battle” or “fight” with illness or in recovery. “Kinsley’s Spine & Brain Tumor Treatments” was created on 23 April

2019 by the mother of a young girl, Kinsley, who was recently diagnosed with several tumors. In one of the first updates to the campaign, she writes, “[Kinsley] is doing great and is being so brave. The radiation does make her sleepy and feel a little nauseous, but she is powering through and continues to amaze us everyday with her strength. ... Kinsley is going to kick cancers [sic] butt!” In a later update, she writes, “Hats off to this little fighter!” In “Brian Ortner’s spinal injury recovery fund,” Amy writes in an early update, “It was great to see him powering through. You know the guy is in pain with broken ribs, scapula, back surgery that left him with 9 inch rods, and yet he powers through. Pain meds help, but that Ortner stubbornness and I am gonna do it myself attitude helps alot [sic] too.” Finally, in “‘Cowgirl Up’ for Jaci Hermstad,” Jaci writes in her campaign description, “I have hope. I have one life and I want to fight for it with everything I’ve got.” These examples are just a handful among many, present in all ten case studies, demonstrating the importance of the “battle” metaphor in American illness narratives (Perusek 2012). Bravery and courage are often tied to faithfulness as well, as in “‘Cowgirl Up’ for Jaci Hermstad”: “We are all trying to be brave and faithful, but it’s still challenging.”

Selflessness, compassion, and gender

In campaigns that featured adults as their intended beneficiaries, compassion, kindness, and selflessness were frequently emphasized by campaign organizers. In “Sladek Strong,” Kate’s sister writes that “at times when others are supposed to be comforting Kate, she comforts others.” Kate is “the most wonderful, caring, selfless person I know.” Henry is described as “a loving, kind, and generous friend,” and his mother, Ruth, as “a single mom who is the sole caregiver for Henry 22, Joe 20, Helen 17, and two dogs - Chloe 13, and Lola 4.” In an update, Ruth explains, “Fortunately, my current treatment allows me to focus on caring for my family.”

It is interesting to consider the ways in which these portrayals of beneficiaries are also likely to be influenced by gender norms. Although I did not review enough campaigns to justify broad statements about the role of gender in medical crowdfunding, I noticed that Brian (from “Brian Ortner’s spinal injury recovery fund”) and Brian (from “Sladek Strong”) were not described in the same way. Whereas female beneficiaries were often described as both kind and strong, male beneficiaries were more often described simply as strong, with the notable exception of Henry (who is a loving, generous friend) from “Support Henry and Ruth to Health.”

In her work on illness narratives in personal blogs, Page (2011) argues that gender shapes participation in both form and content. She found that women bloggers write more than men when the topic is oneself, whereas men write more on external happenings (Page 2011, 222). She also observed that women left more comments on other women’s blogs than men’s blogs, and vice versa, suggesting that online illness narratives contain gendered appeals to a shared experience (Page 2011, 226-227). Furthermore, women’s cancer blogs contained, on average, more links to other personal blogs than did men’s cancer blogs (Page 2011, 228). Page (2011) suggests that digital communities of bloggers are made up of highly gendered networks, and my preliminary findings on gender in medical crowdfunding narratives indicate a need for further research in this regard. I will also return to the topic of gender and comments in the next chapter.

“Paying it forward” and future generosity

The notion of “paying it forward” also came up in two of the campaigns and is related to the theme of selflessness and generosity. In “Amy’s Surgery,” Pastor Rick explains that extra donations will “make a difference in some lives... We know we’re not the only ones, but we would like to take pressure off as many as we can as we get to the other side of this.” In “Sladek

Strong,” the campaign description includes the plea, “if any family is deserving and will pay it forward when they are able, it is the Sladeks.” Campaign organizers also sought to demonstrate their authenticity by including promises, such as “please continue to share and donate if you are able. *I promise you*, it could not go to a more deserving family” (emphasis mine). Such claims further individualize beneficiaries by quite literally setting them apart from others; the Sladeks are more deserving of your donations than any other families you might see on GoFundMe. By characterizing donations to a medical crowdfunding campaign as a form of goodwill that will eventually be “paid forward” by the beneficiaries, the campaign organizer presents the campaign narrative as an ongoing one stretching forth indefinitely into the future. Accordingly, donating to a medical crowdfunding campaign also represents an investment in an ongoing relationship, in which the successful recipient will ideally go on to give to others.

Childhood innocence

Four of my campaign case studies feature children or infants as their intended beneficiaries, and while analyzing these narratives, I found that campaign organizers tended to emphasize themes of innocence. Kinsley is described as “sweet” and “beautiful,” and when her mother posts an update, she signs off as “Kinsley’s Mommy.” The Olla family is described as “beautiful” and their sons (the victims of the car accident) are described as “sweet” and “beautiful gifts.” Yoel and Yael, their mother writes, are her “most precious loves.” The Knutson children are also described as “sweet,” “precious,” and “dear.” Taken together, these examples from four different campaigns suggest that when children are key actors in medical crowdfunding narratives, their perceived childhood innocence is a defining characteristic.

Innocence, however, is not apolitical (Ticktin 2017); and the decision to use these terms in a fundraising campaign must therefore be considered a strategic one. Ticktin (2017) points out, “while innocence can compel responses to important events... it can also create a distinction between worthy and unworthy victims in these same events” (577). The “event,” in medical crowdfunding, is an environment in which people do not have the funds to pay for healthcare. She argues that innocence, as freedom from sin, is “a state of *moral and epistemic purity*” (Ticktin 2017, 578, emphasis in original). Although potential donors may judge that an adult is unworthy of their money because he does not appear to be hardworking or responsible enough, child beneficiaries cannot be evaluated by the same standards—they are freed from some of these expectations by virtue of their innocence.

Positive mindsets

Perusek (2012) argues that the perceived power of positive thinking is an important component of the American cancer mythology. Although most of the campaigns I analyzed were not related to cancer, I found that an ethos of optimism was common to all ten campaigns. In “Support Henry and Ruth to Health,” Ruth writes in an update, “Believe it or not, even during these cancer-filled days, life is good. There is an inexplicable joy that comes with being present during the big and small moments of everyday life and paying attention to the beauty and love that cancer cannot defeat.” In “Brian Ortner’s spinal injury recovery fund,” Amy writes, “If you can’t get inspired out here you are crazy. There is inspiration around every corner.” Positive thinking may also be infused with spirituality. For instance, in “Amy’s Surgery,” Pastor Rick writes, “We are expecting a good report Monday, faith denies the circumstance to remain and

God is faithful to move through compassion to help His children as we look to Him as the Ultimate and Only source that will never let us down.”

Worthy faithful

Finally, as discussed earlier, discourses of worthiness commingled with discourses of religiosity and faithfulness. In “Amy’s Surgery,” Pastor Rick writes, “we stand in faith as always for God's provision and healing. But faith moves and acts, we are taking a step of faith today to save Amy's life!” By presenting their decision to start a GoFundMe campaign as one motivated at least in part by religious conviction, they may reduce the likelihood of their narrative being interpreted by potential donors as suspect or greedy (i.e. unworthy). Additionally, the inclusion of the caveat “faith moves and acts” serves as an implicit admonishment of those faithful individuals who do not take action. Similarly, in “Critical Car Crash (Ashok and Soujanya),” created on 24 July 2019, the campaign organizer and colleague of the beneficiaries writes, “We are praying for their speedy recovery and they are in dire need of financial support... They strongly need our prayers and financial support to get back to normalcy.” Again, the line between spiritual and financial support is intentionally blurred. In the next chapter, I will delve deeper into the notion of support: who offers what (and why) and the extent to which these exchanges might be considered reciprocal.

CHAPTER THREE: RECIPROCITY

INTRODUCTION

In the previous chapter, I discussed several of the key ways in which campaign organizers construct narratives that establish their status as worthy recipients of charitable giving. These discourses of worthiness, however, make up only half of the story. Equally important is how campaign organizers justify individual fundraising goals with reference to budgets and highly technical biomedical explanations of illness, injury, and intervention. One consequence of the latter is a diffusion of specialized knowledge through the phenomenon of medical crowdfunding. Furthermore, the identity work being done by campaign narratives—in other words, positioning subjects as hardworking, upstanding members of their communities—does not end with donation. In all of my case studies, I found evidence of imagined and/or desired reciprocal ties between donors and recipients. Idealized reciprocity is inscribed in discourses of worthiness as campaign organizers strive to demonstrate their gratitude and humility and donors, appearing in comments, continue to perform altruism after the donation itself has been processed.

This is reminiscent of the kinds of relationships established through organ transplantation. For instance, Margaret Lock (2001) suggests that in the contemporary United States, the “gift of life” as a metaphor for organ transplantation functions as a way of reasserting control over a tragic accident. In the case studies presented here, I found that the “gift of the successful campaign” was also narrativized as a way in which beneficiaries could begin to make sense of their experiences. In the comments section of campaigns, donors expressed similar sentiments, indicating their desire to help the beneficiary regain some financial and medical

control over their situation. Lock (2001) argues that the disruption created by fatal accidents is partially corrected through the sacrificial altruism of organ transplantation. In medical crowdfunding, it is the cumulative impact of many smaller financial sacrifices on the part of strangers that helps to repair the disruption created not only by medical tragedy, but also by financial precarity.

OBJECTS OF EXCHANGE

Establishing financial “need”

The median fundraising goal on GoFundMe is approximately \$50,000 (Litman-Navarro 2018), but in my sample, the median was \$175,000 and the mean was \$354,000 (skewed by “Save Yoel and Yael,” which has a goal of \$2 million). When I remove “Save Yoel and Yael,” the mean is approximately \$170,000. This is partly due to the fact that campaigns commonly raise their fundraising goals when they reach or surpass their initial goal, presumably to encourage new donors to keep giving. For instance, “Sladek Strong” began with a goal of \$25,000, which was increased to \$50,000 within 24 hours; the goal was increased again to \$100,000 within three days and once more to \$200,000 over a month later. Other times, campaigners ask for non-monetary donations in conjunction with an ongoing campaign, such as when Kinsley’s aunt in “Kinsley’s Spine & Brain Tumor Treatments” provided a link to an Amazon wish list in an early update, qualified with, “Several folks have asked ‘What ELSE can I do to help?’ so we’ve created an Amazon wishlist [sic] of items that we believe will help Kinsley during/after her radiation treatments.” However, campaigners must also respond to the unspoken question, “Why so much?” It is not enough to simply persuade potential donors that you are a

worthy recipient; you must also persuade them that your intended use of those donations is justified.

These “practical” justifications of the campaign tended to follow a basic pattern. First, the initial ask must be reasonable, and any changes to the fundraising goal must be explained. What counts as “reasonable” is always a negotiation between the needs and wants of the intended recipient, and the cultural norms that influence behaviors seen as appropriate versus inappropriate for someone asking for charity. Given that financial hardship has historically been seen as a personal failing in the United States (Katz 2013), it is critical that campaigners can provide a reasonable explanation for how they intend to use donated funds, or they risk being perceived as greedy or dishonest. Such a misperception would undermine the work done elsewhere in the campaign narrative to present beneficiaries as honest and hard-working. Accordingly, there must be at least a rough breakdown of costs, or even a budget of sorts. This is particularly salient for beneficiaries who intend to use donations for purposes other than paying medical bills. Finally, and perhaps most importantly, it is insufficient to simply say, “I need money to pay for chemotherapy.” Campaign narratives provide a wealth of highly specialized biomedical terms and concepts with detailed explanations, suggesting that technoscientific detail may itself act as a legitimizing factor in medical crowdfunding campaigns.

“Support Henry & Ruth to Health: Join Team HRJH” provides an excellent example of this pattern in action. The campaign organizer, a friend of the family, succinctly establishes the legitimacy of the financial ask and provides a breakdown of costs both medical and non-medical. She begins, “While Henry was fighting cancer, Ruth took a non-paid medical leave. The family then lost their only source of income.” Since Ruth sustained this loss of income due to the need to care for her son, the family’s lack of income is presented as unfortunate but inevitable and is

likely to be sympathetic to many. She returns to work eventually, but this is not enough:

“Although Ruth has health insurance for her family, their out of pocket medical expenses with deductibles and co-pays will far exceed what her sole income can absorb.” She has also done the responsible thing by obtaining health insurance for her family, but again, through no fault of her own, it is not enough.

Next, she explains where the money is going. The explanation is sufficiently detailed that it is unlikely to arouse suspicion as a possible fraudulent campaign, and the expenses listed are substantially large such that it “makes sense” that she has set a fundraising goal of \$120,000:

Between chemo treatments, and for several months after transplant, Henry will require medical monitoring at home that Ruth will not be able to provide. She must fight her own battle with cancer, get her daughter to college, and care for Joe, the bone marrow donor.

In addition to the crippling medical expenses, your donation will provide funds for home health care, household assistance and increased daily living expenses.

It is worth mentioning here that any one of these listed expenses—one patient’s cancer care, home health care, and another patient’s recovery from donating bone marrow—could make up a campaign of its own; indeed, there are countless examples of such campaigns on GoFundMe. This folding of several huge expenses into one campaign is emblematic of several of my case studies. For example, “Save Yoel and Yael,” which has the highest fundraising goal by far (\$2 million), is seeking funds not only for a therapeutic intervention not covered by insurance but also to fast-track the release of a novel gene therapy currently under development.

This “stacking” of expenses may represent an intentional (although not necessarily conscious) strategy to convey the severity of a need partly through an eye-catching goal, one that piques a potential donor’s interest if for no other reason than its somewhat shocking nature.

However, the outcomes of such a strategy are highly variable, given that the vast majority of campaigns never meet their fundraising goals and also, that donors are more likely to give more when theirs is the donation that will put a campaign “over the edge” (Klinowski, Argo and Krishnamurti 2016). Consequently, one might imagine that campaigns with very high goals are unlikely to meet them, and from a statistical perspective they would be correct. These case studies suggest that it is possible, but perhaps also that success hinges not only on a great deal of luck but also a sophisticated narrative strategy, one that makes use of shock value and recursive cascades (see Manderson and Warden 2016) that tell of financial hardship.

Medical jargon and the diffusion of specialized biomedical knowledge

Tanaka and Volda (2016) argue that the legitimacy of a medical crowdfunding campaign is established in part by offering high-quality information to potential donors. For transnational medical crowdfunding campaigns with humanitarian aspirations, one study has shown that highly technical language is negatively correlated with funding speed, possibly because jargon-filled narratives are less readable (Proelss, Schweizer and Zhou 2018). However, it is unknown if this statistical association holds true for domestic medical crowdfunding. In each of my case studies, campaigners provided detailed descriptions of diagnoses and prognoses, rare genetic disorders and catastrophic spinal injuries, chemotherapy regimens and novel gene therapies. I have a background in the biological sciences in addition to my anthropological training, but as I read and reread these campaigns, I came to learn more than I ever expected to know about Canavan disease, amyotrophic lateral sclerosis (ALS), and C4 spinal injuries. Campaign narratives were not limited to abbreviated “WebMD”-style descriptions, but frequently included in-depth explanations of the mechanisms of action of certain therapeutic interventions, as well as

information on the research and development process as it pertained to alternative or experimental pharmaceuticals or techniques.

For this section, I return to “Support Henry & Ruth to Health: Join Team HRJH.” The original campaign description contains only a brief overview of the medical conditions facing Henry and Ruth, but the updates are much more explicit. In an update posted on 8 October 2019, Ruth describes the series of procedures to transplant healthy bone marrow stem cells from Henry’s brother, Joe, to Henry:

Henry goes to the hospital on October 11 (Day -8) to begin his pre-transplant conditioning that will destroy his bone marrow with high-dose chemo and radiation. On October 14, Joe will take a pause in his college life to begin daily, outpatient treatments that will boost his stem cell growth. The donation procedure is a long, but non-surgical, blood draw into a machine that separates and collects stem cells before returning the reconstituted blood back into Joe’s body. On October 18 (Day 0), Henry will receive Joe’s freshly collected stem cells by an infusion that typically lasts no more than an hour. This begins a critical time, waiting and watching for Joe’s transplanted stem cells to make a happy home in Henry’s depleted bone marrow, producing a new and cancer-free immune system.

This excerpt is particularly rich because it demonstrates a common interweaving of medical jargon with simple—perhaps even black-boxed—explanations (see Yates-Doerr’s 2015 description of medical black-boxing). Readers are introduced to complex concepts including (but not limited to) stem cells, blood reconstitution, and immune system regeneration. Enough background information is provided that potential donors can deduce that stem cells have something to do with the immune system, but the molecular mechanisms by which a stem cell

transplant “takes hold” in the recipient’s bone marrow is black-boxed behind the metaphor of “making a happy home.”

Without interviewing Ruth, it is impossible to say if she chose to include this information in an update because she wanted her campaign description—the direct appeal—to be as readable and accessible as possible, or if she simply did not want or think to share this information with site visitors until after the campaign had been created. Intentional or not, however, the result is that the updates to her campaign act as a site for the diffusion of specialized biomedical knowledge and medical jargon. With enough time spent browsing GoFundMe, the “educated layperson” can obtain a working knowledge of variety of ailments, from the tragically common to the extraordinarily rare. It is equally easy to imagine, however, that potential donors with little to no working knowledge of medical science could be alienated by the pervasiveness of technoscientific discourse on the site. In this way, the strategic deployment of medical jargon, clarified with the appropriate amount of background information, may function as a social signaling factor a la Paulus and Roberts (2017), signifying the beneficiary’s status as an educated member of the public who is, in turn, enculturating potential donors into biomedical discourses.

RECIPROCITY IN MEDICAL CROWDFUNDING

Overview

On the surface, charitable giving might appear theoretically and practically distinct from reciprocal exchange. The thesis of Marcel Mauss’ famous argument in *The Gift* (1990 [1925]) is that the most important characteristic of a gift is the obligation to return it, but it is not immediately clear how the beneficiary of a medical crowdfunding campaign might be expected to do so. In its simplest form, charity is a unidirectional flow of money, from one person or

organization to another. As discussed in the previous chapter, charitable giving is also inextricably linked to discourses of worth. Katz (2013) writes that the category of the “undeserving poor” can be seen in who does and does not receive financial assistance in their time of need. The acceptance of such a financial “gift” does not necessarily constitute an end to the exchange, and recipients of financial aid may also be expected to act in certain ways. In my experience, it is generally considered rude to impose explicit limits on the use of one’s charitable gift, but this is not a universal presumption. With organ transplantation, who can and cannot receive an organ is tightly regulated by clinicians, and transplant recipients are expected to manage their health afterwards in ways that protect the medical integrity of the transplant. Expectations may also be more hopeful than demanding, such as the donors I observed who left comments requesting further updates, or photos of the beneficiaries.

Crowdfunding further challenges these more traditional conceptions of reciprocal exchange because its stated aim is to connect a single beneficiary and/or project with a stream of donors, many (if not most) of whom will be strangers. Other forms of charitable giving that bring strangers together predate crowdfunding via digital platforms—for example, patrons of a small-town diner tossing their spare change in a donation bucket for a local family whose child has cancer. What makes crowdfunding noteworthy is not the presentation of a small number of recipients to a large number of unrelated donors, but rather the weakened influence of geography and, with it, the increased ease with which campaigners can solicit donations from distant individuals they are unlikely to ever encounter offline. Although the restaurant patrons in the above example may not personally know the beneficiary, the likelihood that they share distant kin or “a friend of a friend” is much greater. In contrast, crowdfunding campaigns that “go viral” rely heavily on “a friend of a friend of a friend of a...” and so on, thereby entailing the creation

of a high number of new, imagined relationships, in which the possibilities and pressures of reciprocity must be negotiated. This aligns nicely with Paul Rabinow's concept of biosociality, in which new identities circulate and are taken up in the process of self-production and regulation. The result is the creation of biosocial communities, as "individuals sharing certain traits or sets of traits can be grouped together in a way that not only decontextualizes them from their social environment but also is nonsubjective" (Rabinow 1996, 100). Medical crowdfunding campaigns facilitate the creation of biosocial communities oriented around a common goal: to get someone the medical care they need.

Imagining and enacting reciprocity

First and foremost, donors offer recipients a charitable gift. GoFundMe allows campaign organizers to "cash out" at any time, and they are not bound by any time constraints on their campaigns. As soon as a donation has been processed by GoFundMe's third-party vendor, the full available balance of a campaign can be withdrawn by the campaign organizer (or any individual or organization they have authorized to withdraw funds on their behalf). Importantly, this will not affect the fundraising goal or total displayed on the campaign's webpage (GoFundMe). Donations are only refundable in the event of fraud, so it is crucial that potential donors act cautiously when evaluating campaigns. The specter of fraud shapes public perceptions of the relationship between donor and recipient in ways that I will explore in greater detail in the next chapter, but for now it will suffice to say that the legitimacy work done by campaign organizers as they craft their narratives is but one response of many.

Other scholars have called attention to the ways in which family and friends may be implicitly or explicitly obligated to contribute to campaigns. Durand et al. (2018) suggest that the

leveraging of reciprocity facilitated (and potentially deepened) by medical crowdfunding is a critical ethical issue for organ transplant recipients as well as their medical caregivers. This resonates with Kim et al.'s (2017) finding that close relatives and friends of recipients report feeling pressured to donate even when they have already provided non-monetary support. Notably, in their study of projects hosted on Kickstarter's platform, Chen, Thomas and Kohli (2016) found that guilt was the single most effective appeal mode. Although they did not investigate the meaning(s) and implications of guilt for donors with preexisting relationships to beneficiaries, related topics have been addressed in the social sciences of medicine. In her discussion of the "tyranny of the gift" as it relates to organ transplantation within kinship networks, Scheper-Hughes (2007) argues that living organ transplants within kin networks can transform medical needs into automatic claims on another's bodily resources. Monetary gifts may be less extreme, but medical crowdfunding nevertheless raises questions about the interplay of obligation and altruism.

Medical crowdfunding is sometimes portrayed by supporters and industry spokespeople as a fundamental or "bare" form of altruism. In these corporate imaginings, kinship and other social ties are stripped away. The relationship of the beneficiary to each individual within an imagined audience of strangers is reduced to a unidirectional gifting of funds that entails no future obligations on either end. According to this story, donations from strangers are distributed according to the merit of each campaign, with the quality of the narrative being one key component by which campaigns are evaluated. The simple fact that quantitative research has shown that medical crowdfunding does not fairly distribute donations according to most metrics of "need," however, is still not adequate to fully dispel the GoFundMe mythology. To do so

requires analysis of longer-lived connections forged between donors and beneficiaries as well as the non-monetary forms of support mobilized by the most successful campaigns.

What else do related and unrelated donors alike offer recipients? Through comments left behind on the campaigns, donors offer recipients and their loved ones emotional and spiritual support. A donor to “Support Henry & Ruth to Health: Join Team HRJH” wrote, “we wanted to help in a monetary way, but also to send our positive thoughts and prayers to their family.” This comment suggests that the valuation of monetary compared with non-monetary support in medical crowdfunding is perceived as flexible. In my case studies, it was also common for religious blessings to be coupled with secular well-wishes. Equally common were comments that encouraged beneficiaries to “stay strong” and “keep fighting,” or implored their loved ones to “not lose hope.” For instance, two commenters to the same campaign wrote that they were sending “strength” along with their positive thoughts. This ties in nicely with the broad cultural expectation in the United States that individuals view serious medical maladies as enemies to be battled and, hopefully, overcome (see Perusek 2012).

Medical crowdfunding campaigns also become a venue for the distribution of non-monetary material support through the organization of volunteer labor and pooling of “the crowd’s” knowledge. As mentioned before, an Amazon wish list is linked to “Kinsley’s Spine & Brain Tumor Treatments.” In “Knutson Medical Costs,” a friend of the family writes in a late update, “I have a favor to ask... if any of you know someone who can get us a good deal on a diesel Sprinter van, please let me know.” She explains that once Mary Ann—who was paralyzed from the neck down in an accident—is ready to leave the hospital, she will need a vehicle that can accommodate her wheelchair. She also writes later to express her gratitude for the many people who have visited Mary Ann in the hospital to keep her company during her extended stay.

Finally, in “Support Henry and Ruth to Health: Join Team HRJH,” a man named Ken even offers Henry a job: “Henry.. finally found a bigger building to support the co growth.. move probably after first of new year.. an office will be waiting for you to fill it!! God Bless you and your family.” These examples showcase just a few of the ways that the effects of medical crowdfunding can ripple out into “offline” life.

What do recipients offer donors in return? As discussed in the preceding section, recipients offer donors specialized biomedical knowledge. Moore and Brown (2007) use the traveling *Body Worlds* exhibit as a case study in which to trace the ever-evolving line between voyeurism and education, and suggest that it deepens Western conceptualizations of body-as-machine. In a similar vein, I argue that the deployment of graphic medical imagery and narrative, as found in many medical crowdfunding campaigns, evokes voyeurism in the hopes that the potential donor’s gaze will translate to the beneficiary’s financial gain. Personal blogging and the digital sharing of illness narratives predate but continue to be popularized by medical crowdfunding. This is especially pertinent since GoFundMe requires campaigners to use their real names, whereas bloggers have the option of sharing intimate stories under a pseudonym. To fundraise on GoFundMe, the beneficiary must accept a certain degree of intrusion into their medical histories and relinquish a significant deal of privacy—at least, as much they deem necessary to construct a compelling narrative.

Recipients also commonly use the updates section of their website to offer donors a peek behind the curtains into the hardships and triumphs of their private everyday lives. Perhaps nowhere is this better demonstrated than the case of “Brian Ortner’s spinal injury recovery fund,” organized by Brian’s wife, Amy. To date, Amy has posted over 300 updates to the campaign, averaging one update per day, chronicling the accident that left Brian paralyzed, his

recovery, and the family's grief and journey towards collective healing and acceptance. For instance, she provides personal, detailed updates on Brian's physical condition, such as "It was a 10 hour surgery, he lost a liter and a half of blood, he has 2-9inch rods in his back with 12 inch incisions." She also shares comments on his psychological state, although these are less frequent. Given that many people enjoy reading and learning about others' lives for the sake of it, this cannot be discounted as a reciprocal offering. It is difficult, however, to disentangle the creation of this kind of digital intimacy from the legacy of medical voyeurism.

These updates also include intimate photos of the family together in Brian's hospital room as well as Amy's musings on next steps as she organizes Brian's medical care and attempts to maintain stability for their two young children. For instance, after Brian's doctor recommends a residential treatment facility in another state, she reflects on the decision she will have to make: "the thought of not moving and that being the wrong decision for Brian long term is terrifying. The thought of uprooting my children from their support system is sickening especially my [daughter]. I don't want to do it. I don't want to adult anymore but there is no pause button now. It is forward fast." She mentions at one point that her friend recommended she write a book, which raises the question, how exactly can we categorize and understand this vast narrative she has already produced and published (in an informal online manner)? I struggled with the decision to include this campaign in my thesis because reading and taking notes on this family's story sometimes felt like an invasion of privacy. I often had the sense that I was reading Amy's diary. However, I believe that my emotional response to this narrative (among others) speaks to the importance of a critical analysis of the work being done in this space, because it is just such an emotional response that campaigners hope will elicit donations.

Finally, and I argue most importantly, recipients offer donors profuse gratitude and declarations of affinity that, together with the aforementioned window into their private lives, encourage the formation of nascent digital communities on GoFundMe. Sometimes these projects of community-building are aided by a shared or assumed religiosity. For instance, in “Amy’s Surgery,” Pastor Rick declares his love and gratitude for the donors who helped fund his wife’s surgery while at the same time praying over them in return: “May each of you experience His love and peace, may you know what is the hope of His call and the riches of His inheritance available to us in Jesus! We love and appreciate you, again, Thank you! We call you loved and blessed!” Gratitude is a way of reassuring donors that they donated to a deserving person or family. Gratitude that takes the form of blessings or secular well-wishes also allows recipients to engage in a reciprocal exchange with the messages left behind in the comments by many donors. Accepting a donation may incur a debt, but thoughts and prayers can at least be returned equally.

I close this section with a brief reflection on altruism and gratitude as demonstrated in my case studies. “Rather than celebrate the ‘altruism’ of women worldwide, we ought to be paying attention to the social pressures exerted on them to be living donors” (Scheper-Hughes 2007, 508). Although Scheper-Hughes was thinking of organ transplantation when she wrote this, I argue that the social pressures implied by altruism are applicable to medical crowdfunding as well, albeit in a less extreme manner. Charitable giving through digitally-mediated platforms such as GoFundMe is a public act—everyone can see the first name and last initial of the four or five donors who have given most recently, and how much; and optional donor comments attract additional public attention. Other scholars have described the social pressures placed on individuals close to beneficiaries in “real life” to donate even when donating incurs financial hardship (Durand et al. 2018; Kim et al. 2017). Celebrating uncritically the altruism of donors on

GoFundMe, as the company's Chairman and CEO Rob Solomon has in recent interviews (Monroe 2019), helps obscure the reality of the limited and biased resource reallocation that is taking place against the backdrop of a broken health funding system.

Challenging reciprocity in the comments section

The previous analyses notwithstanding, I occasionally witnessed behavior by donors that challenged any initial, more straightforward understandings I had of reciprocity on GoFundMe. Donors, after giving, leave comments asking viewers to help them with their own needs or projects, unrelated to the campaign whose webpage they are commenting on. Although this does not appear to be the norm, it occurred in at least two of the ten campaigns I analyzed, so it is probably not rare, either. For instance, in "Help for the Olla Family," one commenter writes, "Guys please donate to our charity so that we can decrease the poverty by providing food shelter and clothes to the poor people around the world." Another writes, "Hello Good Angels, This campaign is almost funded. Now please help me Any amount you can, because gofundme doesn't support my country Bangladesh yet :(To help, Please email: Shamsul.kayes@gmail.com Thank you." In these examples, neither campaign organizers nor other commenters publicly responded to such requests.

Such requests and comments may simply represent desperation on the part of campaign organizers whose campaigns have, for whatever reason, failed to garner sufficient funds, as well as individuals who do not have active crowdfunding campaigns but have an urgent need. Hypothetically, some of them might represent attempts by scammers, although this strikes me as unlikely given that only individuals who have already donated to a campaign are allowed to post comments. I suggest that attempts to redirect potential donors from highly successful campaigns

to other charitable ventures (whether those are less successful campaigns or direct money transfers through Venmo or Cash App) also constitute attempts to leverage reciprocity in the digital networks created through one campaign to the benefit of another. “Now that you have the money you need,” they suggest, “you ought to help me raise the money I need.” Although I will not dwell on this further, the negotiation of reciprocity in digital fundraising is one exciting venue for future research.

GoFundMe’s role as a digital mediator

GoFundMe brags that it is the only free fundraising platform. While it is true that neither donors nor recipients pay a platform processing fee (which other crowdfunding platforms charge), GoFundMe still takes a cut of each donation: 2.9%, in addition to \$0.30 for credit processing. Although this may not sound like much, it adds up. For example, if “Save Yoel and Yael” were to achieve its \$2 million fundraising goal, GoFundMe would be entitled to \$58,000; a \$50,000 campaign would yield \$1,450 for the company. Since its inception, it has raised over \$5 billion, and in 2016 it reportedly earned \$100 million in revenue for the company (Monroe 2019). Since fees are taken out of each individual donation rather than the sum total of funds raised, everyone who donates to a campaign is also giving a small portion of their funds to GoFundMe.

Donors enter into an economic relationship with GoFundMe by virtue of using its platform to start a campaign webpage. However, the relationship is more nuanced than a simple summary like this might suggest. GoFundMe uses successful campaigns, referred to as “success stories,” to advertise and recruit new individuals and groups considering starting their own campaigns (see <https://www.gofundme.com/c/success>). As far as I could tell, GoFundMe does

not need to obtain permission from campaign organizers or recipients to use their narratives in this way. Of course, one possible beneficial outcome of this is an uptick in new visitors to featured campaigns, leading to more donations. Consequently, although GoFundMe generally takes a very hands-off approach to campaigns, placing the onus on organizers to attract supporters and on potential donors to verify the legitimacy of suspicious campaigns, extraordinary campaigns are occasionally selected for increased publicity in this way. An attention-grabbing campaign that spurs others to start campaigns with GoFundMe thereby boosts company profits as well.

CONCLUSIONS

What purpose does a rhetorical emphasis on reciprocity—whether expressed explicitly as “giving back” or implied through exclamations of gratitude—serve for beneficiaries and donors? In my case studies, I observed that beneficiaries and donors alike expressed a longing for the creation of community (both digital and offline) around the ill or injured person(s) and their loved ones. In medical crowdfunding, “supporters are motivated to participate in crowdfunding to expand their social networks—supporters who provide monetary, informational, and social support to creators can feel they are a part of a special community, an outcome that satisfies deep human needs for belonging” (Gerber and Hui 2014, 23). When supporters are hoping to raise funds for their own projects, the expansion of social networks made possible through crowdfunding can have tangible gains.

The window into the patient’s medical history and personal life provided by medical crowdfunding narratives may also foster feelings of connectedness between beneficiaries and donors. When Amy from “Brian Ortner’s spinal injury recovery fund” mentions a passing desire

to publish a longer volume of her family's experiences in the form of a book, a commenter replies enthusiastically "I had been thinking the same thing," and another writes that they are "struggling right along with you." Moore and Brown (2007) observed that many visitors to *Body Worlds* exhibits reported feeling a greater sense of community with others, particularly those of different races, after viewing white and non-white bodies, with their skin removed, side-by-side. This raises questions about the power of purposeful medical voyeurism to foster a sense of closeness, but given the continued funding inequalities present on GoFundMe, it is unclear that this is true in medical crowdfunding. Metzl (2004) writes, "a voyeur nation's compulsion with the actions of others tirelessly protects against awareness of the fragility of the self" (419). Reading medical crowdfunding narratives as unique accounts of tragedy and need can also obscure the injustices of the U.S. healthcare system.

At other times, social ties were proposed on the basis of shared narratives of illness, injury, or healing, creating microcosmic communities of commonality. These biosocial communities (à la Rabinow) are also reminiscent of Rose and Novas' (2005) theory of biological citizenship at the level of individual projects. Individuals who possess certain biological characteristics in common (e.g., AML) become part of a community through medical crowdfunding and can leverage these ties to access care. A commenter on "Sladek Strong" writes: "A very brave man who I understood battled so hard to beat AML. How can you NOT support all that he was fighting for - life with his family. We celebrate his memory & extend our hearts to his family. We too celebrate everyday our loving Father & Husband... who fought the AML battle to the very end - [he] made us all that much better." This comment challenges other site visitors to donate, thereby signaling their support of a life worth fighting for: life with one's

family. Such a community should also, they suggest, celebrate those who responded to their diagnoses in certain socially sanctioned and gendered ways (i.e. fighting).

Finally, despite the rarity of Canavan disease, “Save Yoel and Yael” reached strangers who forged connections with the family on the basis of motherhood, shared baby names, and the experience of raising twins. “In honor of our own daughter Yael, and our daughter Orli who is achieving the same milestones your beautiful children are.” This comment is particularly affecting due to the unique disease progression of Canavan disease, which results in milestone regression (i.e. the loss of previously-gained developmental abilities) as neurodegenerative processes escalate. By linking Orli’s development to Yoel and Yael, whose development is in jeopardy, this parent calls attention to their shared identities. A second commenter writes: “I am a mom of twins myself, and my heart goes out to you and your beautiful babies. May they be well, and may you bring in all the resources and support you need to care for them.”

Reciprocal ties imagined by beneficiaries and donors alike are of material importance. The creation of these ties relies upon biosociality and identity work performed by both campaign narratives and commenters. Although donating to a campaign may appear to be a unidirectional exchange, I have demonstrated in this chapter that beneficiaries offer several things in return: biomedical knowledge, intimate self-disclosure, gratitude, and religious blessings, among others. These reciprocal ties are real to many donors, as demonstrated by the commenters who attempt to leverage their network ties for their own benefit. In my next chapter, I will “zoom out” and explore how connections created and strengthened on GoFundMe do (or do not) map onto news media representations of medical crowdfunding.

CHAPTER FOUR: MEDIA REPRESENTATIONS

INTRODUCTION

Media coverage of medical crowdfunding can be roughly divided into two main categories: the presentation of individual medical crowdfunding campaigns, or commentary on medical crowdfunding as a phenomenon. Coverage of individual campaigns is often accompanied by a degree of commentary, which can make it difficult to classify the odd article as either/or. Nonetheless, op-eds and think pieces on GoFundMe and other medical crowdfunding platforms are increasingly common. In her work on Palestinian border protests, Amahl Bishara (2010) observes that journalistic reporting is not (although it typically purports to be) a mere objective rendering of the facts as they exist “out there”: rather, it helps make up our shared understandings of people, places, and events. Media representations and commentary on medical crowdfunding play an important role in the creation and cultivation of public sensibilities regarding such behavior.

There are several reasons why media outlets publish articles that focus on individual medical crowdfunding campaigns. Campaigns for local residents may “go viral” on social media, making them appealing candidates for human interest stories. Campaigns may be for prominent residents of a community. The organizers of a campaign may approach media outlets with their story—in fact, GoFundMe encourages this. At a deeper level, however, medical crowdfunding campaigns are also opportunities to reinforce community norms, ignite public debate, or offer critiques of the political-economic context in which they are situated. I found that news articles that focused on individual medical crowdfunding campaigns were likely to report on campaigns in ways that reproduced certain moral discourses and codes of conduct. The following quote

from one interviewee-benefactor is illustrative: "‘I didn't want to ask people for money—it goes against everything I was taught,’ Allen said. ‘My parents didn't raise me to live at home and live off of Social Security. I was expected to be independent. But I was desperate, so I put my pride aside and tried it’" (Takahashi 2013).

This chapter takes up a series of questions. Which campaigns are publicized, and what justifications (if any) are offered by journalists for these choices? When highlighted campaigns are accompanied by editorial commentary, what themes emerge? Similarly, what patterns emerge in commentaries on medical crowdfunding as a phenomenon? When journalists criticize medical crowdfunding, what aspects of it are they critiquing? What ethical concerns (if any) are expressed by journalists in their coverage of medical crowdfunding as a phenomenon? Are articles that focus on crowdfunding as a phenomenon more likely to approach the issue from a critical angle than articles that focus on individual campaigns? I find that articles focusing on individual campaigns tend to present medical crowdfunding in a positive-to-neutral light using morally and religiously inflected rhetoric.

Commentary on the phenomenon of medical crowdfunding, however, often strikes a different tone, taking a more balanced or even overtly critical stance. These articles were more likely to present medical crowdfunding as an unfortunate, if unsurprising, response to issues of healthcare access and the cost of health insurance in the United States. To this end, I ask how media coverage of crowdfunding fits within a broader journalistic context in which private health insurance reform, Medicaid/Medicare and the Affordable Care Act, and the 2016 presidential election are also topics of concern. Is medical crowdfunding identified as a problem, a symptom of other problems, or a potential solution, and what justifications are offered?

METHODS

An advanced search of ProQuest US Newsstream for the terms “crowdfunding” and “health” together shows that national newspapers first began reporting on medical crowdfunding in the beginning of 2011. On February 26, the South Florida Sun Sentinel reported on the charitable activities of the Fort Lauderdale-based MicroGiving Foundation, which linked locals in need with generous benefactors (Streeter 2011). On March 20, the Chicago Tribune reported on two local crowdfunding platforms designed for personal projects—33needs and EduLender—as well as a local woman’s GiveForward campaign to raise money for her younger sister’s cancer treatment (Wong 2011). However, the first media mention of GiveForward was on December 5, 2008, in an article published by the Chicago Tribune that simply listed it as one among many local possibilities for holiday charitable giving (Geraci 2008). GiveForward.com was launched on August 14 of the same year but later merged with YouCaring.com, which has since merged with GoFundMe.com. GoFundMe, which was founded in 2010, first appeared in a national newspaper on July 12, 2010.

The articles presented here for analysis are neither exhaustive nor representative of all news articles focusing on individual medical crowdfunding campaigns. Indeed, one of my major findings was that perspectives on crowdfunding in the media are diverse and nuanced. Having said that, several themes emerged from my brief review of national news coverage since 2011, around which journalists’ opinions and habits tended to coalesce. Chief among them were certain tonal patterns (inasmuch as tone can be inferred solely from the written word), common structures framing their arguments, limited appreciation for the ethical concerns surrounding medical crowdfunding, and highly individualized narratives not unlike those created within the campaigns themselves. Observations and insights gleaned from 48 news articles focusing

specifically on individual medical crowdfunding campaigns published between 2011-2019 are discussed.

Next, I analyzed an additional 82 articles focusing on the *phenomenon* of medical crowdfunding published in the same period. As with articles focusing on individual medical crowdfunding campaigns, this small sample is neither exhaustive nor fully representative of the diversity and forcefulness of opinion surrounding the crowdfunding industry's recent boom. Rather, these articles were chosen for analysis with an eye to presenting a spread of opinion across the political spectrum from 2011-2019. For a recent and thorough analysis of media coverage of crowdfunding, see Murdoch et al. (2019).

In their content analysis of 336 news articles on medical crowdfunding published between 2015-2017, Murdoch et al. (2019) found that it was equally common for journalists to portray crowdfunding positively or neutrally. However, less than 5% of articles surveyed portrayed crowdfunding in a negative light (Murdoch et al. 2019). They chose to survey articles that focused on individual medical crowdfunding campaigns, and tone was determined through the development of a coding frame. Articles that predominantly mentioned the benefits of crowdfunding were coded as positive, whereas those that predominantly mentioned problems with crowdfunding were coded as negative. Articles that mentioned both benefits and problems were coded as negative.

Unlike Murdoch et al., I was more interested in the tone of editorial commentaries on medical crowdfunding as a phenomenon. While implicit and sometimes explicit endorsements of medical crowdfunding certainly play an important role in shaping public discourse, the role of persuasive editorials aiming to convince their readers to think and feel a certain way about the phenomenon is at least as important. Furthermore, editorials on medical crowdfunding appear

more apt to explicitly mention the U.S. healthcare system, health insurance reform and the pharmaceutical industry. As an undergraduate with limited time for data collection and analysis, analyzing the news is a way for me to get at how medical crowdfunding is imagined in the public sphere. Furthermore, by extending my discourse analysis to news articles, I aim to uncover how media coverage affirms, extends, or challenges the forms of speech and action undertaken by medical crowdfunding narratives.

My sample size was not large enough to perform any statistically significant or particularly rigorous analyses in this regard, but that was not my intention; rather, I hope to show that the general thrust of the coverage of medical crowdfunding by major newspapers in the United States is complicated and frequently contradictory. My findings in this regard are indicative of possible trends since 2011 and may point to several major themes and areas for future research. The overall tone of each article was classified as positive, negative or neutral, according to the same criteria set by Murdoch et al. (2019). Basic descriptive statistics revealed that of the 82 articles I selected for analysis, 16 were positive (19.5%), 34 were neutral (41.5%), and 32 were negative (39%). More interesting, however, are the shifts in positive and negative coverage over time seen in this sample. In 2015, there was an uptick in articles discussing the phenomenon of crowdfunding, as seen both in my sample and in ProQuest News' search results for "crowdfunding AND health" by year. 2015 was also the first year where I began to see articles explicitly discussing systemic problems with the phenomenon of medical crowdfunding. Of the 20 articles dating from 2015 in my sample, three (15%) were positive, ten (50%) were neutral, and seven were negative (35%). This trend appears to crystallize in 2018 and 2019. In 2018, only one article was positive whereas eight were negative. In 2019, of 15 articles sampled, 11 were negative and four were neutral—none were predominantly positive. As I will explain

next, however, these articles were frequently structured such that criticisms were softened by extended reference to individualized accounts of suffering.

KEY FINDINGS

Tone

When considering the tone or emotional resonance of an article, I considered the article's goal(s). Are journalists choosing to present individual medical crowdfunding campaigns to attract more donors, present advice for readers interested in starting their own campaigns, share a warning story, or illustrate a broader discussion of the phenomenon of medical crowdfunding? Evaluating articles in this way can be difficult because journalists often do not explicitly state their reasons for choosing certain campaigns to highlight, but certain patterns can be inferred when articles are considered as part of a trend in media coverage spanning 2011-2019.

Many campaigns are clearly chosen in the hopes that publicity will attract more donors to the cause. When this is the case, articles typically appear in local or regional newspapers and conclude with links to campaign websites or information on other ways to reach out and provide assistance. For example, in "Community lifts SJ family" (2016), published in Cherry Hill, New Jersey's *Courier Post*, journalist Matt Flowers shares the story of a local woman with a brain tumor whose friends set up a GoFundMe page to raise money to offset the costs of her ongoing treatment. The article concludes by reemphasizing the campaign recipient's status in the community as a mother. Similarly, in "County paramedic fighting for his life after years of saving others" (2016), journalist Jorge Milian emphasizes the benefactor's status as a "West Palm Beach native who needs a little help," who "has delivered babies, brought overdose victims

back to life and performed other similar miracles during 18 years as a Palm Beach County paramedic.” Consistent with my findings from campaign narratives, an individual’s social status in their community can be leveraged in times of need. At the same time, there is an implicit undercurrent of worthiness—none of the articles analyzed presented campaigns for individuals described as being on the fringes of their communities or marginalized in some way (although it could be argued that by virtue of needing to crowdfund medical expenses, all campaign benefactors are financially marginalized to some extent). I will return to this “felt absence” of the multiply marginalized in my final chapter.

Articles juggled two conflicting tendencies while reporting on individual campaigns. Detailed biomedical diagnoses, concepts and explanations were frequently graphic and painted a grim picture of the interviewee-benefactors’ prognosis. At the same time, much of the reported interview transcripts emphasized optimism, “strong” spirits and discourses of hope. It was common for an article to shift between these tonalities on a paragraph-by-paragraph or sentence-by-sentence basis. For instance, in “Crowd-funding sites help pay medical bills” (2013), journalist Zenovia Campbell writes, “A squamous cell tumor that is wrapped around her mandible and the nerve that controls tongue movement prevents Keira Boswell Beadle from speaking.” This is immediately followed up with, “But her spirit is strong and envelops the cozy living room of a rented home in Gilbert where she spends most days in a plush chair surrounded by friends and loved ones, the family dog, Gizmo, at her feet” (Cambell 2013). In “Analy grad fighting to survive,” both discourses are brought together in a single sentence: “[Benefactor’s doctor] said she can’t administer anticoagulants to reduce the blood clots because the vasculitis that causes [interviewee-benefactor]—‘a sweet, sweet young lady’—to bleed internally could turn fatal as her blood thins” (Smith 2015). Here, a detailed explanation of a potentially fatal

condition is contextualized with assurances that the patient is “sweet” and a “lady.” Similarly, in “Bravely breathing” (2014), journalist Allison Griffin toggles between paragraphs titled “Living with pain,” “God’s work,” and “The fight continues.” Even a brief perusal of the article shows that “pain” is a rather superficial description of the interviewee-benefactor’s medical condition, and the article’s angle is clearly religiously motivated.

Although lists of crowdfunding “do’s and don’ts” more commonly accompanied articles that focused on the phenomenon of crowdfunding rather than individual campaigns, interviewee-benefactors sometimes offered technical advice for readers interested in starting their own campaigns. More often, however, interviewee-benefactors urged readers to be open to asking for help. In “10-year-old inspires new fundraiser to help dad's fight with cancer,” a woman whose husband is facing a terminal cancer diagnosis advises, “What I learned from this whole situation is you ask for help and accept that help” (Davis 2015). In “A focus on healing,” an interviewee-benefactor states that she “[doesn’t] like sympathy” but “[my nurse] made me feel like maybe there's nothing wrong with accepting help at this time” (Burger 2018). Finally, in “Child’s illness has Lowell family struggling,” an overview of the medical and financial realities that have motivated a family to crowdfund their son’s surgery ends with “In spite of the rough few years, it's been difficult for her family to ask for help” (Allen 2013). As discussed earlier, the performance of stoicism and an ethic of hard work do important work in the construction of benefactors as worthy recipients of charitable giving. When interviewed by journalists, benefactors tend to emphasize these values while at the same time urging like-minded people to ask for help when needed. Although a reluctance to ask for help is not explicitly praised, it is worth asking why such statements—or, perhaps, assurances—are a recurrent theme. Interviewee-benefactors also appear to be responding to an assumption that one ought to learn something

from experiences of suffering. This connects to the work of meaning-making performed by campaign narratives, as discussed in Chapters Two and Three.

Moreover, interviewee-benefactors occasionally offered critiques of various aspects of crowdfunding, including specific platforms, the process of publicizing the campaign and trying to attract donors, or the U.S. healthcare system at large that has created this need. For instance, in “Child’s illness has Lowell family struggling,” journalist Samantha Allen (2013) writes, “Though the family has health insurance, their bill for the surgery comes out to about \$10,000.” This critique of out-of-pocket costs is implicit, but others are explicit: “I’d ... like to put into perspective just how much it cost(s) to keep a child with cancer essentially alive. This new drug I spoke of that will be used in the clinical trial alone cost \$178,000” (Carroll 2017). Here, healthcare costs are named as a barrier to caring for a child with cancer. A third family explains to the journalist, “We’ve definitely taken a business approach [with the campaign]” (Keshavan 2017). Medical crowdfunding is a labor of care, but it is also a labor of bureaucracy and economic strategy.

Structuring the media coverage

The titles of articles that focus on individual medical crowdfunding campaigns reflect certain kinds of rhetoric that emphasize bravery, militarized metaphors of “fighting” illness, worthiness, and bootstrap narratives. In this regard, media narratives of medical crowdfunding agree with campaign narratives, as discussed in Chapter Two. “Bravely breathing” (Griffin 2014), “Online drive aims to help disabled New London man get rolling again” (Baldelli 2014), “Story of cancer fight goes viral” (Goodwin 2014), and “Analy grad fighting to survive” (Smith

2015) are only a handful of examples. Titles may also emphasize the kindness and generosity of supportive communities and social networks: “Community lifts SJ family” (Flowers 2016), “Crowdfunding to save a life” (Keshavan 2017), “With 'a little help from his friends - and a few strangers' - he's ready to walk again” (Vitez 2014), and “Friends see support swell when using crowdfunding site to help families in need” (Moore 2015). Finally, quotes taken directly from interviews with the organizers and benefactors of medical crowdfunding campaigns may also form the title of an article. These quotes most often emphasize the severity of an illness or injury or the urgency of the need, such as “It's enough to make you cry” (Spencer 2015), “I’m not ready to leave my kids” (Tice 2018), and “‘It couldn't be': Keene parents confront a new reality, their daughter's leukemia” (Engel-Smith 2018).

In contrast, articles that focused on the phenomenon of crowdfunding, rather than individual campaigns, tended to possess less emotionally evocative titles, with the exception of those articles that portrayed crowdfunding in a predominantly negative light. For instance, “Acts of kindness, and the underlying rot” (Fortin 2019), “Crowdfunding raises huge sums for ‘pure bunk’ homeopathy cancer treatments” (Perry 2019), “That heartwarming story about a kid crowdfunding for his infant brother defines what's wrong with U.S. healthcare” (Hiltzik 2018) and “The moral crime of relying on GoFundMe for health care” (Pitts 2015) take strong stances on the ethical and/or political context of medical crowdfunding that are clear in their titles. Articles that portrayed crowdfunding in a positive or neutral light typically featured neutral, descriptive titles, such as “Online fundraising becoming more common” (Falchek 2015), “Medical costs spur online fundraisers” (Tucker 2015) and “A growing number of patients turn to crowdfunding sites to defray medical costs” (Mayer 2013).

Many of the articles that focused primarily on the phenomenon of medical crowdfunding opened with a spotlight on one or two campaigns for local individuals or families. These articles frequently ended by refocusing on the aforementioned campaigns and providing links to campaign websites for readers interested in donating. Commentary on medical crowdfunding and/or the U.S. healthcare system was effectively sandwiched between individualized accounts of physical, emotional and financial suffering. For instance, the article “Crowdfunding sites help Boulder County residents raise money to pay for treatments” begins with the following quote from an interviewee-benefactor: “The thing about giving—it feels good... I hope people feel good about [this campaign] and don't feel burdened” (Bear 2017). What follows is a brief overview of the current state of crowdfunding that touches on the Affordable Care Act, income disparities, undocumented immigration, and the election of Donald J. Trump, and their links to the rise in medical crowdfunding (Bear 2017). And yet, the article ends not with a decisive statement forming an explicit connection between these powerful institutions and individual suffering, but with a quote about gratitude: “It's very humbling... I'm so full of gratitude for all the support I've been given. It's really quite touching” (Bear 2017). Providing firsthand accounts of medical crowdfunding may make the concept more relatable for some readers. At the same time, the line between acknowledgement and endorsement is unclear, especially when the accompanying commentary takes a middle-of-the-road stance.

Several articles from 2017 and 2018 reported on Berliner and Kenworthy’s sociological study of medical crowdfunding narratives. “Looking Under the Health Care Safety Net” (2017) reports their findings that the vast majority of campaigns fail (meaning that they do not meet their fundraising goals) and campaigns originate disproportionately from states that opted out of the Medicaid expansion made possible through the Affordable Care Act. However, much of the

article's focus is on the interdisciplinary nature of the research, and it also advertises the University of Washington Bothell's health studies programs. "Crowdfunding for medical bills band-aid, not a cure-all, UW Bothell study finds" (2017) also reports their major findings, but presents an overall more robust critique of the phenomenon of medical crowdfunding by including extensive quotes from the researchers themselves. It concludes, "The most dangerous consequence of the rise of medical crowdfunding, the authors argue, is the way it trains us to see health care as a personal good to be earned, rather than a universal human right" (2017).

Finally, a handful of articles presented a meta-commentary on the news media's coverage of medical crowdfunding. These articles tended to be sharply critical of both media representations of medical crowdfunding and the phenomenon of crowdfunding itself. One article reported on Murdoch et al.'s review of media representations of medical crowdfunding campaigns, "Media often ignore ethical concerns about medical crowdfunding, study finds" (Perry 2019). Journalist Susan Perry (2019) concludes, "we need to ask questions about the campaign, particularly about the evidence behind the treatments for which the money is being raised. Who will the money be benefiting—the patient or the clinic or company selling the treatment?"

Ethical concerns

The ethics of medical crowdfunding were a site of divergence between articles that focused on individual campaigns and those that focused on medical crowdfunding writ large. Of the 48 articles that focused on individual medical crowdfunding campaigns, few presented any ethical concerns with crowdfunding. On the contrary, several presented crowdfunding as an

ethical solution to issues of healthcare access and equity, and the generosity of acquaintances and strangers was presented as an unequivocal good. For instance, “Crowd-funding sites help locals with medical bills” (Voorheis 2014) ends with the following quote from the interviewee-benefactor: “You can change the world with five bucks.” Journalists usually mentioned whether an interviewee-benefactor had health insurance (and if so, public or private), worked full-time, and had children. These articles broach the possibility for structural critiques of the U.S. healthcare system, but these are left to the reader rather than elaborated.

Unlike those articles that focused on the phenomenon of medical crowdfunding, which were very concerned with scams or otherwise “questionable” campaigns, none of the 48 articles focusing on individual campaigns addressed issues of fraud or suggested that fundraising for experimental or unproven therapeutic interventions was inherently problematic or dubious. One article, “Bangor boy to get experimental stem cell therapy to treat his autism,” relays the story of a local mother seeking funds to bring her autistic son to Panama for an unproven stem cell therapy that will reduce the “symptoms” of his autism (Bayly 2015). Journalist Julia Bayly discusses the controversy surrounding this treatment, which is discouraged by the Maine Medical Association and at the time of writing, not approved by the FDA (Bayly 2015).

Although Bayly explains some of the controversy surrounding novel stem cell therapies, she ends by refocusing on the mother’s hopes for her son: “With takeoff just weeks away, Rachel is optimistic—and realistic. ‘I am not delusional and thinking he will be cured 100 percent, because the reality is Connor will still be autistic at the end of the trial,’ she said. ‘If what we are doing is a step forward in curing autism, that is very exciting’” (Bayly 2015). By focusing on the promise of hope and neglecting to mention the activist work done by autistic individuals and

communities to stop presenting autism as something that ought to be cured, this article also reproduces stereotypes of autism.

One other article is worthy of special consideration here because it directly addresses some of the ethical and political issues that can arise with medical crowdfunding, taking the ultimately unsuccessful campaign for Charlie Gard as its case study. After Charlie Gard, a young boy with a rare terminal illness, was denied an unproven treatment by the National Health Service in Britain, his parents attempted to crowdfund the treatment in the United States. In “‘For Charlie, it’s too late’: Parents of British baby abandon legal fight to get treatment in U.S.” (2017), Christina Boyle and Alexandra Zavis, writing for the *Los Angeles Times*, take a neutral stance on a case that captured the attention of the international media. Opinions from physicians and medical ethicists on both sides of the debate are presented. Additionally, Boyle and Zavis observe that Charlie Gard’s story—and the crowdfunding campaign that raised over \$1.7 million—gained so much media traction in part because it became a rallying point for U.S. pro-life lobbying groups, adding fuel to the fire of an already-raging debate over personhood, parental rights, and proposed changes to the Affordable Care Act (Boyle and Zavis 2017).

Nevertheless, this article is structured like most of the others such that a purportedly balanced presentation of two opposing ethical stances becomes secondary to the strong emotional appeal of the campaign benefactors and/or organizers—in this case, Charlie Gard’s parents. The article begins with the “Quiet sobs” of his parents as they read a prepared statement and ends with the following: “‘We are so sorry that we couldn’t save you,’ Yates said. ‘We had the chance, but we weren’t allowed. Sweet dreams, baby boy. Sleep tight, our beautiful little boy’” (Boyle and Zavis 2017). Thus, although the intention of the journalists may have been to present a balanced overview of a controversial case with global implications, the end of the

article is emotionally evocative and leans towards the crowdfunding model in which patients with financial resources should be allowed to choose treatments for themselves or their minor children.

Among the 82 articles concerning the phenomenon of medical crowdfunding, of chief concern were scams, fraudulent campaigns, and campaigns for highly experimental, unproven, unapproved or so-called “alternative” medical treatments. In “Scams plague fundraising efforts” (2016), journalist Steven Petrow suggests that GoFundMe and other popular platforms are fundamentally flawed because there is no internal mechanism for verifying the authenticity of campaigns; that work is left to potential donors. Furthermore, he adds, “even ‘good’ campaigns raise very tough questions about funding medical costs this way. How do we decide who is worthy of our donations? Do we help fund unproven treatments? Does an individual's previous history matter in determining whether we support them?” (Petrow 2016) In her op-ed for Chicago’s *Inquirer*, Adrienne Gonzalez (2018) writes that she has taken matters into her own hands, by starting a website called GoFraudMe.com that names and shames suspected fraudulent campaigns. Nevertheless, she is wary of dissuading potential donors, concluding:

Although I believe GoFundMe is dismissive in its stance on fraud and doesnt [sic] do enough to educate donors on the risks, my work is focused on pointing out the risks so donors can feel safer about giving. For every Johnny Bobbitt, you have countless campaigns that never appear in the news connecting individuals to the help they need through the power of the crowd. Dont [sic] let the bad deeds of a few individuals scare you away from giving. Take GoFundMes advice and stick to people you know and trust. (Gonzales 2018)

The “power of the crowd” is always dangerous because it can be manipulated by scam artists, but if people properly regulate their donations, she suggests, it can also be a force for good.

In “Evil Intermediation Platforms” (2017), anthropologists Athina Karatzogianni and Jacob Matthews summarize what they view as “the exploitative character of the sharing economy that has thus far been employed to sustain a capitalist order in crisis.” They name crowdfunding platforms as one of many features of the digital economy and sharing economy, which are characterized by both “zombie capitalism” and “hypercapitalism” (2017). Zombie capitalism is the drive to accumulate even when it is no longer possible to generate additional profit (Karatzogianni and Matthews 2017). Hypercapitalism, which refers to the growing reach of the processes of commodification (Karatzogianni and Matthews 2017), is an occasional implicit critique of medical crowdfunding seen in op-eds and other commentaries. This may manifest as laments over the commodification of kin and social ties (although this is not unique to crowdfunding by any means) or expressions of discomfort by those asked to donate to campaigns for friends or coworkers.

One illuminating example of public resistance to hypercapitalism, captured in the news media, can be found in a Dear Abbey column titled “Funding for patient seems brazen” (2016). The anonymous complainant, referred to as “TIGHTWAD IN CANADA,” writes, “people I’ve spent only a few hours of my life with asking for money for luxuries seems nervy to me. Am I a tightwad, or is a financial donation necessary to express condolences?” They clarify that the benefactor is a young woman with terminal cancer and has health insurance through their employer. Of concern here is the fact that “The proceeds will be donated to fulfilling a ‘cancer bucket list,’ which includes pampering, trips and other luxuries” rather than “real financial need.” This Dear Abbey column makes use of two moral discourses, which medical

crowdfunding is seen to be at odds with: first, that charity ought to be reserved for the “truly” needy (however that may be quantified and qualified); and second, that the act of asking coworkers for donations to a personal fundraiser violates certain social norms and expectations of workplace propriety.

Individualizing elements

Many of the articles emphasized the luck involved in meeting one’s fundraising goals, either the journalist themselves or the individual(s) interviewed. Luck or randomness may be referred to as luck, a miracle, a blessing, or God’s will, among others. In “Bravely breathing” (2014), Allison Griffin’s interviewee states that “God’s hand really began to appear” when she received news that a set of transplant lungs were available for her teenage son with cystic fibrosis. In “Britta Wolfarth’s health challenges include getting insurance coverage” (2017), David Templeton’s interviewee states, “You get mad, but God would not give me something that he didn’t think I couldn’t handle,” the implication being that medical crowdfunding offers a possible way for him to handle God’s challenge. In “Community lifts SJ family” (2016), Matt Flowers’ interviewee states, “It is really sad that often the worst of things happen to the best of people.” Finally, in “It’s enough to make you cry” (2015), Jon Spencer’s interviewee states, “Now God’s made it possible through [my campaign organizer]. The sky’s the limit now.”

Many, if not most of the articles that focused on medical crowdfunding as a phenomenon also emphasized the element of luck or randomness involved in successful medical crowdfunding campaigns. In “Have crowdfunding requests become the new lottery ticket?” readers are asked to compare the case of two local campaigns: one for an elderly woman who

needs to build a wheelchair access ramp for her house, and one for a sick dog (Davich 2017). Noting that the sick dog raised thousands of dollars while the elderly woman raised only \$75, journalist Jerry Davich poses the rhetorical question, “Why do some social media or crowdfunding efforts take off into viral success while others languish in obscurity?” He suggests that perhaps “a little luck or divine blessing” is at work in the fulfillment of some requests (Davich 2017). Finally, many articles presented the potential drawbacks of medical crowdfunding alongside lists of suggestions for how to maximize one’s chances of success. Success is therefore individualized, much as medical and financial hardship is individualized in campaign narratives.

Institutional critiques

Medical crowdfunding campaigns are situated at the intersection of two competing tensions. On the one hand, these campaigns only exist because of the financial hardship imposed by the current U.S. healthcare and health insurance systems. On the other hand, interviewee-benefactors also must demonstrate their worthiness as recipients of charitable giving. In short, benefactors must be needy, but not *too* needy—their need must be the result of tragedy or unfortunate happenstance rather than systemic discrimination or institutional failings. In media coverage of individual campaigns, this plays out through assurances that interviewee-benefactors did all the “right” things first before turning to charity, including (but not limited to) paying for private health insurance; exhausting the benefits provided by Medicaid, Medicare or Supplemental Security Income (SSI); asking for private loans to cover their expenses; and turning to their family and close friends first before asking their broader social networks for financial assistance.

Commentaries on medical crowdfunding writ large frequently drew attention to the precarious state of healthcare funding. “Though Coleman is covered by insurance, the expenses associated with his care and the transplant have been tremendous” (Griffin 2014). This example aligns with trends observed in campaign narratives; both emphasize the inadequacy of the current system, but explicit critiques are rarer. Sometimes simple misfortune was presented as the problem, rather than any clear policy failure: “Huber's temporary insurance policy ended in November. She planned to sign up for a new plan on the health care exchange for January” (Voorheis 2014). In a final example, crowdfunding was presented as a necessity for paying for care not covered by insurance: “So far, Beadle said his wife's conventional medical care has totaled \$445,000, with insurance covering 80 percent. Her integrative-care treatments have cost about \$130,000, but their insurance plan covers only 10 percent” (Campbell 2013). By extending the discourse of worthiness that takes shape in medical crowdfunding narratives, media coverage of medical crowdfunding also reproduces naturalized and normalized inequalities in the contemporary United States. In the final chapter, I situate both media and campaign narratives in conversation with the anthropology of insurance, scholars of precarity, and critiques of managed care.

CHAPTER FIVE: CRITICAL MEDICAL ANTHROPOLOGY AND CONCLUSION

INTRODUCTION

In the preceding chapters, I have analyzed the discursive techniques that shape campaign narratives and influence the relationship between donors and beneficiaries of medical crowdfunding campaigns on GoFundMe. I have also analyzed several trends in the news media representation of medical crowdfunding since 2011, focusing on the extent to which the coverage is critical or uncritical and how journalists also participate in the discursive construction of worthy beneficiaries. I now turn my attention to some of the larger-scale structures that have allowed medical crowdfunding to emerge as a seemingly necessary and reasonable solution for paying for medical care in the first place. I am influenced by the perspective of critical medical anthropology, which looks “upstream” at the systems and institutions that impact (access to) health.

The ten campaigns presented here as case studies have many important differences, but they are also characterized by several striking commonalities. Financial need is justified through appeals to circumstances outside of the individual’s control, as well as the establishment of the intended beneficiary as a worthy, productive subject. Optimism and gratitude emerge as key discursive elements and are frequently (though not always) linked to religious faith. All but one of the beneficiaries are white, and most of the campaign organizers are women. My intent in this final chapter is to situate these themes in broader political-economic context. Many scholars have convincingly argued that life in the contemporary United States is characterized by precarity (along multiple axes) and increasing socioeconomic inequality (Katz 2013; Lorey 2015; Rylko-Bauer and Farmer 2002). Financial insecurity can intersect with, compound, and drive health

inequities; this is visible on GoFundMe and, arguably, exacerbated by the phenomenon of medical crowdfunding.

For this chapter, I chose to focus on the idea of precarity as a form of political marginalization; the anthropology of insurance, with particular attention to public health insurance and the battle over the Affordable Care Act; and those who are excluded from medical crowdfunding either partially (through reduced likelihood of success) or altogether (through lack of access). I hope that this work can contribute to critical medical anthropology by shedding light on medical crowdfunding as an emergent form of digital sociality and the kinds of discourse it reproduces. By “zooming out” in this way, it is possible to understand medical crowdfunding narratives as forms of gendered and racialized affective labor that are not only responding to, but also participating in, inequitable healthcare and insurance systems.

PRECARITY, POLITICAL MARGINALIZATION AND GOVERNANCE

Cultures of optimism

Ehrenreich (2009) argues that the United States has adopted positive thinking as an ideology, inseparable from capitalism and nationalism. By positive thinking, she means the “practice, or discipline, of trying to think in a positive way” (Ehrenreich 2009, 4). Positive thinking is a key component of consumer capitalism, as industries envision potential for unlimited market growth and consumers internalize the belief that “they deserve more and can have it *if they really want it and are willing to make the effort to get it*” (Ehrenreich 2009, 8, emphasis mine). She suggests that systematic positive thinking also has the power to distract Americans from growing inequality through its emphasis on personal responsibility. It is your

responsibility to think positively, work hard and not complain. Her portrayal of the dual nature of positive thinking in the American psyche as a force both rational and irrational is also noteworthy here. Some scientific research suggests that there are tangible health benefits to thinking positively, but she argues that equally important is the sense “that our thoughts can, in some mysterious way, directly affect the physical world” (Ehrenreich 2009, 5). Such “magical thinking,” in her words, enables us to reject the thought that our world might be getting worse, because to “give in” to such negative talk might actually make the world a little bit worse.

Positive thinking intersects with health in many ways, including through poverty and bootstrap imperatives, but it can also be seen in the culture surrounding cancer diagnosis and treatment. Reflecting on her own experience with breast cancer, Ehrenreich (2009) argues that breast cancer in the American context constitutes a rite of passage, making women into “survivors” and promising the opportunity for creative self-expression and reinvention. Moreover, she and Perusek (2012) point out a common myth: that a positive attitude can help treat cancer, or even prevent it entirely, supposedly by “boosting the immune system, empowering it to battle cancer more effectively” (Ehrenreich 2009, 34). This is because positive thoughts are widely perceived as the antithesis of stress. In a similar vein, Ehrenreich (2009) writes that the adoption of a growth mindset, to which positive thinking is essential, is also commonly advocated for and by women with breast cancer. Cancer therefore becomes a vehicle for personal and spiritual growth.

This is doubly insidious for cancer patients because not only is the practice of positive thinking celebrated, failure to do so is often perceived as a moral and social failing. According to Ehrenreich, “the failure to think positively can weigh on a cancer patient like a second disease” (43). Subtle victim-blaming rhetoric abounds in the American cancer mythology—if you have

cancer, your negative thinking habits must have worn out your body, and you will need to correct course if you want to win the battle. Perusek (2012) writes of the isolation experienced by many other cancer patients as a result of the social mandate to put a positive spin on experiences that can be psychologically devastating, confusing, or frightening. He terms cultural responses to cancer diagnosis and treatment “antiresources,” cultural frames that harm more than they help. For instance, as he cared for his brother, who was dying of lung cancer, he struggled to explain to friends and acquaintances why his brother had chosen to “give up” by foregoing a planned operation: “such talk weighed like an accusation of guilt repeated and amplified again and again” (Perusek 2012, 492). Even the affectionate branding of his brother by others as a pessimist or skeptic became an antiresource. “Conversations among extended family openly—if always compassionately—acknowledged the likelihood of a connection between Ted’s personality and his disease” (Perusek 2012, 492).

What does this mean in the context of medical crowdfunding? Mattingly (2010) has described the construction of hope as a narrative process set into motion by the clinical encounter. Hope, as Ehrenreich (2009) is quick to point out, is not the same as positive thinking—she positions hope as genuine and positivity as artificial. Mattingly (2010) elaborates on Ehrenreich’s identification of hope as an existential problem or crisis, explaining that hope is a moral project (like positive thinking), and yet it is always already bound up with despair. She writes, “I will consider dreaming that comes when you might least expect it, the terrifying nightmares that serious illness or tragedy can precipitate. Even more, I will consider what may be done with such nightmares, the work to make them habitable” (Mattingly 2010, 4). I suggest that the ten campaigns I analyzed can be understood as a way of dreaming against both medical tragedy and impending financial disaster. At the same time, campaign narratives espouse positive

thinking above all else. Durand et al. (2018) have shown that the words “death,” “dying,” and “fear” are associated with reduced funding, whereas “hope” and “gratitude” are associated with greater funding success. The positive thinking and/or hope on display in medical crowdfunding narratives do not exist in a vacuum, but rather a space in which to misspeak, to accidentally cast oneself as a cynic or pessimist, has real economic consequences.

Precarity and personal bankruptcy

What is precarity, and why does it matter to my discussion of medical crowdfunding campaigns, particularly given that campaign narratives often seek to be apolitical? According to Tsing (2016), “precarity is the condition of our time” (20), a defining aspect of late industrial capitalism. According to Lorey (2015), precarity can be thought of as an intentional social order that manages insecurity and risk to the benefit of neoliberal governance and consumer capitalist market ideologies. “Precarity involves social positionings of insecurity” (Lorey 2015, 12), and it affects politics and the economy in addition to interpersonal relations. Because medical crowdfunding is an economic enterprise that is eminently social, emerging in the past decade in the aftermath of economic recession, it is fitting for an analysis informed by precariousness. The economic consequences of the ongoing pandemic, projected to dwarf the 2008 recession, make such analysis all the more timely.

One consequence of precarization is the neoliberal undermining of labor organizing (Lorey 2015). Precarity affects everyone, but in individualized and individualizing ways, and as such it becomes difficult or impossible to represent laborers as a collective. Lorey (2015) writes, “The many precarious are dispersed both in relations of production and through diverse modes of

production, which absorb and engender subjectivities, extend their economic exploitation, and multiply identities and work places. It is not only work that is precarious and displaced, but life itself” (9). The precariousness of life itself is demonstrated vividly on GoFundMe. Campaigners craft narratives that are at once individualizing—making the case for why you should donate to them instead of someone else—and deeply embedded in existing and imagined social networks both on- and offline. And yet, the existence of thousands of medical crowdfunding campaigns has not led to systemic changes to healthcare and health insurance in the United States. Campaigners in my case studies did not organize in expressly political ways, nor call for their supporters to do so, despite the substantial emotional and technological work they invested in their campaigns. One way of understanding this is by thinking about the naturalization and normalization (through precarization) of financial and medical insecurity.

Precarity can be understood as a condition that motivates some individuals to create medical crowdfunding campaigns. In this context, it is perfectly rational to invest one’s time and energy into the construction of a campaign that is unlikely to succeed. When accessing and paying for healthcare is commonly a fragmented, uncertain process reliant upon multiple insecure actors and institutions, why not explore another uncertain option? GoFundMe is high-reward and appears on the surface low-risk (although this is contested, as I have discussed in the preceding chapters). As many campaigners say themselves, GoFundMe is frequently a last resort. Burtch and Chan (2014) remind us that medical debt is the leading cause of personal bankruptcy in the United States. The specter of being forced, by tragedy or random chance, to file for bankruptcy is one of many ways that all but the wealthiest households live precariously, and this precarity is amplified at lower income brackets and/or for those who live with, or care for someone with, a serious or chronic illness.

Writing against precarity

Although the existence of medical crowdfunding reflects and perpetuates precarious conditions, the construction of campaign narratives may constitute one way in which campaigners and beneficiaries (re-)establish a sense of control over their lives. Although campaign narratives generally emphasized the random, unpredictable nature of the tragedy that had befallen beneficiaries, they also presented their campaign's success as a means by which some modicum of order or normality could be restored. For instance, Ruth from "Support Henry & Ruth to Health: Join Team HRJH" writes, "Believe it or not, even during these cancer-filled days, life is good. There is an inexplicable joy that comes with being present during the big and small moments of everyday life and paying attention to the beauty and love that cancer cannot defeat. This joy is possible thanks to you all – to the help provided by the GoFundMe community [among others]."

This aligns with Page's (2011) description of the reflective anecdote. By emphasizing emotional disclosure over strictly fact-based linear accounts, campaign narratives elicit affectual responses from potential donors, as discussed in Chapter 2. However, writing and sharing reflective anecdotes also functions as a way for the writer to make order and meaning out of a chaotic set of experiences. Campaign organizers can thereby be said to write not only in response to precarity (because financial instability is their prime motivation), but also against precarity. Reaching a fundraising goal and then paying off one's medical bills is one way of restoring material order to life.

Private health insurance

Dao and Mulligan argue that health insurance is of critical importance for anthropological inquiry. “Insurance prices and redistributes risk; it promises security against life’s calamities; and its web of contracts constitutes networks for the provision of care” (2016, 6). They ask, “Will health insurance facilitate the right to health or merely the right to purchase health?” (2016, 8) In their study of diabetes management, Hunt et al. (2019) found that patients expressed equal frustration with public and private health insurance in the Canadian two-tiered system; regardless of how they were insured, the kind of care they received was dictated more by insurers than their clinicians. Thinking along these lines, I ask if medical crowdfunding democratizes access to healthcare funds or if, instead, digital technologies such as crowdfunding platforms merely democratize access to unlikely opportunities to receive such funds. Statistical analyses of medical crowdfunding campaign successes and failures strongly support the latter (Durand et al. 2018).

Continuing the preceding section’s discussion of risk and security, GoFundMe redistributes risk in a manner similar to but distinct from that of health insurance. The financial burden is distributed across a beneficiary’s network, lightening the load on any one individual or family. The social network mobilized by successful campaigns is not unlike the “web of contracts” embedded in health insurance. Although campaigners are unlikely to meet their fundraising goals, many people in the United States do not receive the funds they need from health insurance either. Success on GoFundMe may only materialize for 10% of campaigns (Durand et al. 2018), but it would also be inaccurate to characterize the current health insurance system as one in which patients and families can count on all their needs being met. Given the prominent role of corporate logics in healthcare and the ways in which clinicians’ prescribing

powers are constrained by the pharmaceutical industry and the health systems that employ them (Hunt et al. 2019), this is unsurprising.

It was common for campaigners to talk about health insurance in superficial ways. This supports a growing body of literature suggesting that campaigners frequently name inadequate health insurance as a motivating factor (Berliner and Kenworthy 2017; Lukk, Schneiderhan, and Soares 2018). If they did not have health insurance, they explained why; for instance, Pastor Rick and Amy from “Amy’s Surgery” do not have health insurance because they are in the process of moving their congregation to a new church and cannot afford to pay for it. In keeping with Snyder et al.’s (2017) and Paulus and Roberts’ (2017) findings, none of the campaign narratives directly addressed or even alluded to the injustice of needing to seek out charity in order to supplement their health insurance coverage. Instead, the inadequacy of the current state of healthcare financing is presented as an inevitability. In this sense, medical crowdfunding can be described as depoliticizing.

Medicare, Medicaid, and state expansions

Public health insurance in the United States is run by a complex bureaucracy, and its inadequacies have led clinicians and patients to seek alternative means of funding. In her ethnographic fieldwork of federally qualified health centers (i.e. community health clinics) in New Mexico, Boehm (2005) found that the implementation of managed care models as a Medicaid “safety net” has shifted public funds in ways that parallel GoFundMe. She argues that the culture of managed care privileges neoliberal notions of efficiency and questions the oft-unspoken assumption that private healthcare can stand in for public care for the poor and

undocumented. Thinking back on critiques of medical crowdfunding that lament its inefficient resource reallocation, perhaps some of the opposition to medical crowdfunding reflects a neoliberal distrust of the public “crowd,” whose donations are seen as wasteful or irrational. However, her analysis of Salud!, New Mexico’s Medicaid managed care alternative “lauded as the panacea for public health ills” (Boehm 2005, 49), is also reminiscent of claims by proponents and corporate representatives that medical crowdfunding is, similar to community health clinics, a “safety net of the safety net.” In community health clinics and on GoFundMe alike, insufficient reimbursement or coverage by Medicaid leads to the shouldering of medical costs by alternative public sources.

Likewise, Dao and Mulligan (2016) highlight the cost-shifting strategy employed by both public and private health insurers. In cost-shifting, growing proportions of total cost for services are offloaded onto patients (through reduced coverage and systematic denials of coverage) and the insured population as a whole (through increased deductibles, among others). This complements Boehm’s (2005) observation that community health clinics through Medicaid managed care are required to negotiate ever-increasing administrative costs at the same time as they struggle to meet the needs of a growing patient population, leading to an increase in charity-funded care. Following the passage of the Affordable Care Act, Medicaid payments to hospitals were restricted, because the expansion of Medicaid was supposed to make such “disproportionate” payments redundant (Horton et al. 2014). However, Horton et al. (2014) write that in states that opt out of the Medicaid expansion, safety net hospitals have been hit by a dual funding crisis: “They will lose out on the prospect of newly insured patients even as they face restricted—not stagnant—Medicaid funding” (7).

None of the campaigns that I analyzed stated that they currently or had in the past received public health insurance. As mentioned earlier, Berliner and Kenworthy (2017; see also Liberman 2019) found that medical crowdfunding campaigns originate disproportionately from states that did not adopt the Medicaid expansion under the Affordable Care Act. Hunt et al. (2019) point out that the impact of managerial care—and its underlying corporate logics—on health and health inequities can only be expected to increase over time, as mergers and acquisitions by huge health systems wipe out independent practitioners. The human cost of managed care is felt by patients, which Amy, Brian’s wife from “Brian Ortner’s spinal injury recovery fund,” vents about in one of her updates:

Brian's doctor here said that 5-10 years ago patients with Brian's other injuries (shoulder and rib fractures) used to come to a rehab facility for a short time, learn how to survive at home, be sent home for a month to a month in a half, and then come back to rehab. Asshole insurance companies started denying people from coming back so they stopped doing that and people like Brian have to just power through.

However, it is unclear what kind of health insurance her family has or used to have.

Nelson (2005) points out that the growing decentralization of health services in the United States can mask the political and economic power relations that affect care for Medicaid recipients. She compares the forces at work in Medicaid managed care in New Mexico to those that shape foreign aid. Both forms of aid, she writes, convey a hierarchical relationship between the wealthy giver and the impoverished recipient. Insurance systems are depoliticized when problematic bureaucratic processes are endlessly augmented by stop-gap technological intervention, rather than fixed at the root. Medical crowdfunding is an excellent example of a

technological stop-gap response to an inequitable healthcare system, and I argue it is similarly depoliticized by both campaign narratives and media representations.

Passage of the Affordable Care Act

Horton et al. (2014) argue that one critical task of an anthropology of insurance is to challenge and unpack the assumptions underlying notions of profit, cost, and risk. Explaining that the goal of the Affordable Care Act was to expand both the private health insurance industry and Medicaid, they argue that what is enshrined through its passage is not the right to healthcare but the right to health insurance. The high cost of deductibles and copays means that even individuals who have insurance may struggle to afford care. Health funding is thus a fruitful juncture to think with structural violence. Both public and private health insurance plans are structured such that pay-ins are maximized and pay-outs are minimized, with real human consequences. Rylko-Bauer and Farmer (2002) argue that any healthcare system structured according to market ideology will eventually be forced to “manage inequality” rather than provide care. By this, they mean that the numbers of uninsured and underinsured can be expected to continue growing, as will the rationing of care, increased privatization (such as that seen in Medicaid managed care), and increased health inequities for the low-income and minorities. At the same time, efforts to address growing inequality will be inadequate because they are rooted in cost effectiveness rather than compassion and equity (Rylko-Bauer and Farmer 2002).

The Affordable Care Act has been subject to attacks and reform by Congressional Republicans ever since its inception, and the past three years have seen additional attacks by President Trump’s administration. Furthermore, the upcoming presidential election in November

2020 has the potential to reshape the health insurance industry. Progressive Democratic candidates have called for Medicare for All and/or a single-payer system, whereas more moderate candidates have proposed expanding the reach of the Affordable Care Act. No matter what, changes to the bureaucratic management of care in this country will be felt by patients and their families, probably in unpredictable ways, and medical crowdfunding will almost certainly persist. The ongoing pandemic also stands to place an unprecedented strain on our healthcare and insurance systems.

Falling through the cracks

Any characterization of GoFundMe as a democratizing or equitable (if unlikely) stopgap measure or option of last resort misses the mark. Not only is fundraising success biased in favor of white, relatively affluent, and technologically skilled individuals who are embedded in preexisting offline social networks, but also, the most marginalized individuals are less likely to even make it onto GoFundMe's website in the first place. In order to start a campaign, you must have access to a computer or smartphone connected to the internet. If you are not literate, you will have to find someone who is to write and publish your campaign. You need a bank account linked to your campaign to withdraw the funds. Without at least a few family or friends who can share your campaign, the chances of it ever attracting wider attention are slim to none. Even when all these conditions are met, you are unlikely to turn to the internet for financial assistance if your life experiences have taught you that you cannot trust or rely upon others. Outcomes are demonstrably unequal on GoFundMe, and yet even the selection of campaigns available to potential donors is unlikely to reflect the true range of need in their local communities, because many populations are underrepresented or excluded entirely.

My goal in drawing attention to this gap is not to negate or minimize the urgent healthcare needs and profound economic inequality made visible by medical crowdfunding. On the contrary, I want to highlight the extent to which the suffering of some continues to be rendered invisible at the same time as others, who have more societal privileges but are still left in desperate need of medical and financial relief, compete for donations from a similarly-precarious public. Medical crowdfunding is not a viable alternative method of financing healthcare in the United States. It is also not an egalitarian (if dystopian) lottery, because fundraising success is not truly random, as some have suggested. The same social hierarchies that restrict access to healthcare offline continue to play out on GoFundMe, and this is felt in both the disproportionate failure of campaigns for minorities (Barcelos 2019; Lukk, Schneiderhan, and Soares 2018; Young and Scheinberg 2017) and the weighty absence of certain others entirely.

In order to theorize the limited representation of people of color, especially Black people, on GoFundMe, I have looked to the work of scholars of critical Black studies and the digital humanities. The barriers to funding experienced by campaigns for racial minorities can be explained at least in part by systemic racism, but the reason for the paucity of Black campaigns in the first place is complicated. Sharpe (2016) argues that the chronic violence enacted against Black bodies in the United States “in the wake” of American chattel slavery is also played out in healthcare clinics, where Black patients such as her brother are less likely to have their pain taken seriously. Pervasive disregard for or misrecognition of Black suffering suggests one possible reason why Black beneficiaries are less likely to succeed on GoFundMe. In his study of crowdfunding campaigns for gender-affirming medical care, Barcelos (2019) found that white binary transgender beneficiaries were more likely to receive donations than non-white and/or

nonbinary beneficiaries. He also found that the most successful narratives, statistically, were those that reinforced transnormative stories about gender identity and expression, and certain kinds of gender-affirming surgeries (e.g. bilateral mastectomy). This adds further evidence to suggest that medical crowdfunding reproduces widespread stereotypes of certain minority subjects.

The slipperiness of “success”

In this project, I focused exclusively on ten campaigns that might be considered highly successful. Even though several have not reached their fundraising goal at the time of writing, all have secured tens of thousands of dollars in donations. Given that fewer than 10% of campaigns are estimated to meet their goals, and as many as 30% will not receive a single donation (Durand et al. 2018), this is a great achievement indeed. And yet, what are we to make of a campaign such as “Save Yoel and Yael,” which has raised hundreds of thousands of dollars but still not enough to obtain the experimental gene therapy needed to give Yoel and Yael a chance at survival? What about “Sladek Strong,” which met its goal several times over but ultimately could not save one of its beneficiaries? The very concept of “success” begins to break down in this context. Success becomes even more of a slippery concept when we consider the types of non-monetary support mobilized by medical crowdfunding, as discussed in Chapter Three. If “Save Yoel and Yael” fails to meet its fundraising goal but succeeds in bringing together a digital community of parents of children with Canavan disease, is that enough? And what of the potential therapeutic value of chronicling a family’s medical journey, as in “Brian Ortner’s spinal injury recovery fund”? I cannot answer these questions now, but they are potential avenues for future research.

MEDICAL CROWDFUNDING AS AFFECTIVE LABOR

This labor is individual. Much scholarship has been devoted to the “social contract of health” and the ways in which the American debate on health insurance emphasizes personal responsibility rather than health as a public good and/or collective responsibility. The mandate to purchase health insurance implemented by the Affordable Care Act “further entrenches an atomized, individualized approach to public policy” (Horton et al. 2014, 12). These corporate logics of efficiency and individualism are also on display in charitable giving. In medical crowdfunding the onus is on the campaigner and/or beneficiary to “sell their story” to an imagined audience of potential donors in order to access health funds. Should their campaign fail, the implicit message is either that they were not deserving of donations in the first place, or that they did not work hard enough to make their campaign succeed. The responsibility is on the campaigner to craft a compelling narrative, through which they might obtain the money they need, just as individuals are expected to purchase health insurance but can only hope that it will fully meet their needs.

This is also a highly gendered form of labor. It would be interesting to have more quantitative data on gender in medical crowdfunding, although some scholars have found that women may be more likely than men to receive funds (Proelss, Schweizer and Zhou 2018). Given my small sample size, I cannot assume that this is true across all medical crowdfunding campaigns, but it is noteworthy that almost all of the campaign organizers in my case studies were women. Moreover, certain components of the narrative style of these campaigns—namely, the heavy use of the reflective anecdote—are gendered in ways akin to those of personal blogs (Page 2011). My findings suggest that some of the most successful medical crowdfunding

campaigns on GoFundMe are characterized by sophisticated narrative strategies that rely partly on gendered, affective labor.

CONCLUSION

In this project, I have drawn upon the narratives of ten medical crowdfunding campaigns and 130 news articles in an attempt to understand the discursive work being done by campaigners and journalists. In conversation with the literature on narrativity, exchange theory, precarity, health insurance, and managed care, I arrive at a series of conclusions. First, and most importantly, medical crowdfunding campaign narratives affirm and reproduce discourses of worthiness and need. This is accomplished through a discursive emphasis on work ethic, bravery, humility, positive thinking, innocence, and faithfulness, which creates urgency, sympathetic victims, and inherent competition between beneficiaries. News media coverage of medical crowdfunding extends this discourse of worthiness and reciprocity.

These narratives also constitute a kind of gendered affective labor, performed disproportionately by women on behalf of family and loved ones. Campaign narratives rely heavily on the use of reflective anecdotes that seek to elicit emotional responses in readers. This affective labor relies largely on an aspirational reciprocity between beneficiaries and donors as well as the establishment of biosocial communities. Finally, the precariousness of health funding in the United States is reflected in (and perpetuated by) the individualizing elements of campaign and media narratives. Additionally, my analysis supports findings by other scholars that the discourse of worthiness figures centrally in campaign narratives and broader journalistic commentary; that campaign narratives perform “identity work,” by positioning beneficiaries as

honest, upstanding community members; and that social hierarchies are replicated on medical crowdfunding platforms such that minorities are less likely to meet their fundraising goals.

As I finished my writing for this project, the SARS-CoV-2 pandemic swept across the United States and the world, forcing schools and businesses to close and resulting in massive disruptions to everyday life. As I write this, the pandemic is also placing an unprecedented strain on our healthcare infrastructure and precipitating a global economic recession. By mid-April, I have already seen countless crowdfunding campaigns for medical bills, daily expenses such as rent and utilities, and continued online education. Several health insurance providers and hospital systems have opted to cover care related to SARS-CoV-2 at no cost to patients, raising many questions about the future of health funding. I believe that ethnographic research at the intersection of health and economic precarity is needed now more than ever, and this global emergency has informed my plans for graduate study and future research directions.

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