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Like a Grinding Stone: How Crowdfunding Platforms Create, Perpetuate, and Value Health Inequities

This article explores how inequities are reproduced by, and valued within, the increasingly ubiquitous world of medical crowdfunding. As patients use platforms like GoFundMe to solicit donations for health care, success stories inundate social media. But most crowdfunders experience steep odds and marginal benefits. Drawing on the problematic figure of the “black box” in health disparities research and technology studies, I offer ethnography as a tool for unpacking often inscrutable and complex pathways through which online platforms amplify inequities. By leveraging both online and traditional research strategies—a platform analysis and paired narratives of crowdfunders’ disparate experiences, drawn from open-ended interviews—this article explores how inequities are created and experienced by users. The analysis highlights how inequities are simultaneously central to the functioning of this marketplace and occluded by its platform design. Consequently, crowdfunding is concealing health inequities while shifting public values about who is entitled to health care, and why. [crowdfunding, health insurance, health inequities, charity, digital technology]

I was rushing to make dinner for my hungry child when Trevor, a single father from Arkansas, texted me about his GoFundMe campaign. “I certainly have data for you,” he explained, “but it isn’t a pretty picture.” Trevor’s campaign was a wrenching archive of bad breaks and financial woes. He had Type 1 diabetes and was recovering from a severe accident, while trying to care for his son and navigate a flatlined labor market. He worried about whether he could provide Christmas for his son and having to choose between buying insulin and keeping their house from foreclosure. I found Trevor’s story bracingly honest, but his campaign was unsuccessful by almost any measure. He hadn’t gotten any donations in over a year, nor even, he later confided, any page views beside my own voyeuristic visits. He was texting to

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make sure I really wanted to interview him. I winced as I tried to explain that I did: “You’re not alone” in having this experience, I reassured him, “But it’s a terrible [situation] to be in.” Nine out of 10 medical crowdfunding campaigns do not reach their goals, and nearly 10% are like Trevor’s campaign, gathering very little, if any, interest (Berliner and Kenworthy 2017). Media portrayals of crowdfunding bombard us with successful campaigns that seem unquestionably deserving of attention. Like many, Trevor had found himself trapped between the ideal and the reality of what GoFundMe calls “the giving layer of the internet” (GoFundMe 2019).

Contemporary life is profoundly shaped by economies of attention, systems of surveillance, and relational labors: new evolutions of old capitalisms that consume and monetize our private lives (Baym 2015; Seaver 2018; Zuboff 2018). But overly simplistic narratives of technologies’ totalizing incursions overlook the inattentions and abandonments of platforms: the experiences of those who are present, but invisible, and who feel bound, but rejected. “It’s nobody’s fault, and certainly not yours,” Trevor texted back to me that evening:

Life is a grinding stone, it either grinds you down, or polishes you up depends on what kind of metal you’re made of. Those of us who fight to survive will always cast a wide net. That or I’m a failure as an individual and I have to beg strangers for extra money while I work 40+ hours a week as a full-time single dad. That’s the struggle in my head anyways. Regardless no one has donated a red cent lol so it doesn’t cut too deeply.

Crowdfunding platforms exemplify what Baym and Boyd (2012) call “socially-mediated publicness,” serving as stages on which dramas of deservingness, debates over entitlements, and competing illness narratives play out. But for people like Trevor, they also produce something like socially mediated abandonment. In this apparently meritocratic, individualistic marketplace of hope, many crowdfunders find “failure” as their “begging” is met with silence. Precarity reinforced by crowdfunding echoes broader political economies of gig work and “crowdwork” that are both necessary and wholly insufficient for financial survival (Gray and Suri 2019; Kneese 2018).

In *Affliction*, Veena Das (2015) asks: “How do the movements between these different thresholds of life carry the marks of suffering endured, of betrayals, as well as small acts of kindness that have made it possible for some to survive while others die?” (p. 2). I approach crowdfunding with similar questions, seeing it as a platformed space where judgment and charity, and abandonment and kindness, coexist and together produce inequities. I adopt Trevor’s metaphor to ask how GoFundMe might be a grinding stone, transforming lives already under pressure. Whereas the original idiom offers a trope of meritocracy—it is the strength we have as individuals that determines our outcomes—Trevor’s experience speaks to the precarity and stress of crowdfunding, how it leaves some lives more polished while many others turn to dust. For whom is crowdfunding an opportunity, and for whom is it a dismantling?

Medical crowdfunding provides an architecture for amalgamating individual assessments of deservingness to determine who will get money to access health care. This architecture, as I show, powerfully amplifies inequities. Crowdfunding

platforms create and rely on these hierarchies to function; inequities have deep economic value for this industry. But companies also conceal inequities beneath an affective veneer of kindness and possibility, attracting users by portraying their platforms as free, democratic spaces. Following widespread critiques of other digital platforms for their role in exacerbating inequities and economic precarities, this article offers one of the first ethnographic forays into a relatively new technology, exploring how inequities are used, produced, and concealed by crowdfunding platforms. My aim is not simply to document how inequities emerge, but to explore how inequities are normalized, occluded, and become valuable for a digital platform that is reshaping how Americans access and perceive charitable support.

In the following section, I use the figure of the “black box” in both public health and technology studies to ask why processes that create inequities online are made invisible, and what their inscrutability means for the ways we understand data and experience. I offer online ethnography as a tool for peering inside such black boxes and for understanding why they exist in the first place. I begin this ethnographic approach with a platform analysis of GoFundMe, focusing on the affects and values it cultivates to uphold and conceal the centrality of inequity to its functioning. I then present several stories of crowdfunders whose campaigns have profoundly different outcomes, exploring how complex social inequities both fuel and are exacerbated by medical crowdfunding. By juxtaposing campaigns for similar causes that have radically different outcomes, it becomes easier to understand the social, technological, and moral forces that produce crowdfunding disparities, and their impacts on users’ lives.

Black Boxes and Online Inequities

Crowdfunding emerged in the immediate aftermath of the 2008 financial crisis, offering users a way to leverage social networks to raise money. Crowdfunding first thrived as a lending- and reward-based model for “consumer-investors” to support business projects they felt had value; subsequently, platforms like Kickstarter and Indiegogo thrived among creative entrepreneurs and fans (Belleflamme et al. 2015). Around 2010, a new set of donation-based, for-profit platforms like GoFundMe and YouCaring appeared, aiming to allow users to fundraise for personal charitable causes and needs (Sisler 2012). While charitable crowdfunding has notable antecedents in personalized humanitarian fundraising—from Victorian aid societies, to child sponsorship schemes, to microlending initiatives—its emergence is uniquely tied to a period of government austerity, economic precarity, and rising health care costs for Americans.

Scholars have ample concerns about crowdfunding’s potential to further exacerbate health inequities. Due to the challenges of collecting robust data from private platforms, only a handful of studies have empirically documented this phenomenon. Studies in both the United States and Canada have found that crowdfunders seek funds to fill common holes in the social safety net, and that campaigns for older people, people of color, and transgender users tend to perform more poorly (Barcelos 2019; Berliner and Kenworthy 2017; Igra 2020; Kenworthy et al. 2020; Lukk et al. 2018). Duynhoven and colleagues (2019) found that Canadian cancer campaigns were more common in wealthier, better educated, urban areas. Berliner and

Kenworthy (2017) found that inequitable and historically rooted notions of moral deservingness shape campaign success; those with the most complex, chronic conditions struggled most in appealing to this ethic. In a qualitative study of funeral crowdfunding, Kneese (2018) described how campaigns were embedded within unequal technological, media, and social environments that heightened inequitable outcomes. Most of these studies focus largely on campaign creation and financial outcomes as metrics for measuring inequality, leaving out questions of how campaigners arrive at, and subjectively experience, unequal outcomes.

Tracing how multiple and overlapping inequities—social, economic, political, health-related—collectively influence outcomes is challenging. Both the fields of technology studies and health disparities research refer to this challenge as a “black box”—a set of “known unknowns” that create inequitable outcomes but whose processes and interactions are opaque. In both fields, scholarship has strived to open these boxes and better understand how inequities are produced. Both fields have also critiqued the problematic figure of the black box as a conceptual trap. Health disparities researchers frequently challenge “black box epidemiology,” which poorly articulates the multicausal pathways that link large social forces to differential health outcomes (Krieger 1994; Nedel and Bastos 2020). Social epidemiology has made theoretical and empirical strides in breaking open black boxes (e.g., Krieger 1994; Williams 2003), but the primary problem of the black box is that it was allowed to exist in the first place, a depoliticizing monolith that masked intentional structural injustices (Nedel and Bastos 2020). Even the term itself draws on racist semiotics of blackness as inscrutable and problematic.

Similarly, much work in critical media and technology studies has critiqued the often closely guarded inputs and outputs of machine learning, artificial intelligence (AI), and platform design. Here, too, it is notable that the mere existence of an impenetrable box is the result of systematic failures to govern and regulate technologies that are profoundly biased (Benjamin 2019; Crawford et al. 2019; Noble 2018; Pasquale 2015). But critical scholarship has also attempted to move away from thinking about technological black boxes as discrete, bounded objects, and instead imagining things like algorithms “as complex sociotechnical assemblages involving long chains of actors, technologies, and meanings” (Christin 2020: 898). Drawing on a fundamental principle from technology studies, it is crucial to examine how users relate to platforms and AI, and how this, in turn, shapes technologies and their societal impacts. The black box is a technoscientific artifice too often stripped of the human dynamics involved in creating and experiencing it. But scholarship must also ask how the mechanisms that create inequity—or even, as Gray and Suri (2019) explore, the labors that drive the new economy—are deliberately made invisible, and what value that invisibility offers to these corporations.

While discussions of the black box in both fields are complex, they share common concerns with how inequalities are, in fact, made, and the methodological challenges of understanding these processes of making. While ever more sophisticated quantitative research in both fields aims to “know” these unknowns, qualitative research is often overlooked, even as narrative data from users often sounds the first alarms about harms, exclusion, and pathways of discrimination. Ethnography can reveal how platforms produce inequities (Christin 2020; Seaver 2017), providing a valuable record of what happens inside processes that are deliberately made opaque.

The factors contributing to this opacity—including corporate interests, power hierarchies, and exclusion of diverse voices—also contribute to the dismissal of narratives as evidence of structural injustices (Benjamin 2019; Daniels 2013). And yet these narratives remain some of our most powerful records of how inequity is both produced and experienced (Das 2015; Sangaramoorthy 2019; Yates-Doerr 2020).

Crowdfunding conceals inequities behind a narrative screen of charitable values, donor sentiment, and apparent meritocracy. These dynamics—charity, sentiment, meritocracy—are created by, and embedded within, hierarchical and punitive social systems, where they are used to justify and normalize structural harms against disenfranchised and marginalized groups (Berlant 2008; Giridharadas 2018; Markovits 2019). Crowdfunding creates an artifice of meritocracy where certain people seem “worth” more or less because of what their campaigns raise, not because of the myriad structural and cultural factors that have influenced the monetary outcome of their campaign. Thus, we cannot focus solely on campaigns’ economic outcomes, but how they end up there, and why. The following section describes how ethnography, attuned to both the platform and its users, can unmask these processes.

Methods

This study joins a growing body of ethnographic work on the lived experiences of social media users and platforms (Airoldi 2018; Coleman 2010; Dalsgaard 2016). Digital ethnography examines how platform architectures and user groups mutually constitute each other as well as documenting individual users’ online lives. In practical terms, this means that in addition to dozens of interviews with crowdfunding users and recipients, I spent six years (2014–2020) studying the technological architecture and moral ecologies of the online crowdfunding marketplace. I viewed, catalogued, and qualitatively coded thousands of crowdfunding campaigns; followed them across social media landscapes; interviewed key informants within the industry; studied the “back end” of sites’ web architectures; and followed news and press releases from crowdfunding companies. I tried, as much as possible, to enter the moral worlds of crowdfunding as a social media environment and marketplace: by following feeds, listening to company podcasts, reading blogs, and following the evolving discourses of campaigners and donors themselves, absorbing what does and does not matter, what is and is not valued and promoted, and how success is measured. My research increasingly focused on GoFundMe as it came to heavily dominate the market, though I also studied YouCaring,¹ Fundrazr, and Watsi (Kenworthy 2018). IRB approval was obtained for this research from the University of Washington Human Subjects Division, and I undertook additional precautions to protect participant data in accordance with Internet research best practices (Markham and Buchanan 2012). Here and elsewhere, I have removed or changed as much identifying data as possible, particularly data or quotations from campaign pages that can be traced back to user identities.

While this is not *in situ* ethnography in its traditional sense, open-ended interviews allowed me to move behind and beyond websites to observe users’ interactions and experiences with them (Berning et al. 2017; Coleman 2010). Moving beyond the website does not mean being unencumbered by it, however. Creating a diverse sample required first auditing how platforms’ algorithms mediated visibility and

returned search results (Sandvig et al. 2014; Seaver 2017). Because algorithms promote successful, “trending,” and geographically proximate campaigns, my sampling strategy involved targeted and specific keyword and zip code searches to identify all possible campaigns. After defining basic sampling criteria, I used purposive quota sampling to increase sample diversity in terms of race, age, gender, religious beliefs, geographic location, and socioeconomic status.

Interviews with 28 campaigners and patients between 2018 and 2020 provided a rare look behind the narratives featured on campaign pages. Crowdfunding is altering the ways illness narratives are created, and for what audiences and purposes they are written. Campaign pages are not simply illness narratives that have been projected onto social media platforms; rather, users often pursue multiple objectives when creating campaign stories. Ethnographic interviews offer an opportunity to move between text (on campaign pages) and experience, to better understand users’ hopes and goals, while also attending to places of disjuncture, discomfort, and dissemblance. As Gonzales (2018) notes, they shed light on how crowdfunders’ own identities and subjectivities shift through their use of the platform. My approach aims to construct a more cohesive story, in collaboration with participants, of a time of profound crisis, grief, and need in both their online and offline lives.

Monetizing Sickness, Self, and Care on Crowdfunding Sites

Before turning to users’ stories, it is necessary to understand how GoFundMe’s platform is carefully designed to help users monetize their needs for a highly inequitable marketplace, while also concealing these inequities beneath a veneer of positive affects. For first-time crowdfunders, GoFundMe offers an innocuous, friendly, introduction. “Welcome! GoFundMe is the world’s largest crowdfunding platform, with over \$9 billion raised so far. With a community of more than 50 million donors, GoFundMe is changing the way the world gives.” These metrics create a sense of possibility, and users are reminded the platform is free, that they “can use GoFundMe for just about anything” (Creating a GoFundMe from Start to Finish N.d.). This narrative of opportunity contrasts with enormous differences in fate that crowdfunders experience. For example, Eliza O’Neill, a young girl with a rare genetic condition, raised more than \$4 million for her care and research, while most campaigns raise only a few thousand dollars (Berliner and Kenworthy 2017).

Though medical anthropologists have recognized online spaces as important sites of patient sociality, subjectivity, and narrative, monetary exchange is an increasingly powerful dimension of online social engagement (Kneese and Merid 2018; Rabinow 1996; Swartz 2020). As Swartz (2020) observes, monetary transactions shape, and enable membership in online communities and economies; GoFundMe represents a particularly active hub for these dynamics. Increasingly, people report that crowdfunding donations are an important obligation within their social networks; similarly, economically precarious workers view a large social network as a crucial safety net (Young 2020). “A millennial savings account is just a twitter account with 10k followers just in case you need to crowdfund for medical bills,” quipped writer Alyssa Keiko on Twitter (2018). These changing social mores are sculpted by social media companies striving to transform users into capital (Swartz 2020). But how

does GoFundMe convince users to put a price tag on their own needs, their social networks, and themselves?

GoFundMe's platform uses normative technological scripting to shape user expectations and help them monetize needs. Campaigns featured on the site's discovery pages are successful and trending, carefully curated to appeal to broad cultural categories of deservingness and identity.² Site algorithms and design ensure casual users rarely encounter an unsuccessful campaign. Jocelyn, a "campaign expert" bot, advises new users to set a very low monetary goal of \$1,000, since that is what most campaigns choose. Setting small goals lowers campaigners' expectations and ensures that more campaigns meet their goals, contributing to increased metrics and feelings of success. Donors, too, are guided by prompts that reveal how deeply the platform monetizes behaviors and networks. After donors navigate away from a campaign, a pop-up window reminds them that sharing the campaign online is "worth" \$37 in expected donations. Sharing a campaign on Facebook "can increase ... donations as much as 350%." GoFundMe employs high levels of cross-platform integration and data sharing, meaning that these shares are worth quite a lot to the company, enabling it to access friend lists, gain exposure, and expand its user base.

Finally, GoFundMe also scripts how users will perceive the platform's own value. Reminding users that GoFundMe is "powered by the kindness of our donors," the quietly for-profit platform charges a tip of 10–20% on each donation (Answers to Common Fundraising Questions N.d.). Soliciting tips as a primary revenue strategy reflects some of the key ethical norms of the platform: freedom of choice in what to support, and how much; and a beneficent guiding principle of "kindness" that appears both apolitical and optional. Yet, tellingly, opting out of the tip is difficult, and when users donate to campaigns, they consent to the use and sale of their data, which may be far more valuable than tips alone.

GoFundMe navigates a tension between making illnesses about money and addressing health care needs by transforming cash into care. Central to this system, and made largely invisible within it, is the hypercompetitive marketplace where donors assign values to individuals according to their identities, needs, and stories. This differential value system is concealed behind the exhaustively positive effects that GoFundMe cultivates. People like Emily, a young woman with leukemia who was on the verge of homelessness and raised just over \$1,000, were nonetheless quite positive about their GoFundMe experiences:

When I first started I didn't think I was gonna get very much. I thought it was a good idea to try to share my story and get it out there. When I started getting money it kind of hit me, like, people actually care. People from high school I'd never even talked to were giving me 50, 60 dollars each month. It was like, whoa, people might not actually show that they care, but they care.

Even those who have not raised much money often report positive feelings about their campaign outcomes, in part because the platform is built on overwhelmingly positive affective engagements—likes, hearts, messages of support, and donations.

Experiences like Emily's echo research that finds online engagement offers young cancer patients a "vital media" that generates a sense of well-being but also demands optimistic illness narratives (Stage et al. 2020). Gonzalez et al. (2018) have found

disclosures of personal information on crowdfunding sites to be a transformative, even reaffirming, experience for patients. However, it seems likely that platform scripting partially fosters these positive subjective experiences—e.g., by encouraging users to set artificially low campaign goals so that they can be met more quickly and elicit feelings of success. As crowdfunders revealed in interviews, these “feel-good” social media sentiments often coexisted with experiences of profound inequality in both campaign process and outcome. The full extent of these inequalities is often difficult to grasp, largely because platform architectures strive to make these inequalities less visible and instead portray a meritorious and optimistic marketplace. To better understand the complex (and invisible) dynamics of inequity that shape campaign outcomes, the following two sections present sets of paired campaign stories—two for car accident victims, and two for people with Type 1 diabetes—that disrupt the narratives projected by GoFundMe’s platform design, revealing how inequity is produced and valued by the site.

A Tale of Two Accidents

Diego

Diego is a 20-year-old Latino college student from a small town in the Yakima Valley of Washington State. The Yakima Valley is a richly productive agricultural region whose economy has been built on steep racial and economic inequalities. A fifth of the population in Diego’s hometown lives below the poverty line, and nearly a third reports fair or poor health status (Washington Department of Health N.d.). Diego’s campaign was created for his 18-year old cousin Mariana, who suffered a permanent brain injury in a car accident. Diego’s family asked him to set up the campaign because, as a computer science major, he is the tech-savvy one in the family. The campaign he set up offered a very brief narrative and a photo of Mariana taken prior to the accident, smiling radiantly. While Diego’s family is very close, his relatives were unwilling to share details of Mariana’s situation via the campaign page. Diego said they didn’t want “to seem like they were just trying to get pity.” It was hard, he observed, “to just balance the things that they didn’t want to share ... and the things that were sort of important to having [in] the campaign, to make sure people knew the seriousness” of the case.

In our interview, Diego filled in the gaps in Mariana’s story in short, nearly emotionless sentences. Mariana was not wearing a seatbelt. She flew through a window of the car and stopped breathing at the site of the crash. She had no health insurance, and the driver had no car insurance. Mariana was pregnant at the time of the crash, and doctors told the family they could either try to save her or try to keep her alive to save the baby. Diego’s family made the agonizing choice to keep her on life support until the baby could be delivered; Mariana eventually died at home, though her baby survived. Her health care costs were astronomical, including more than a month spent in intensive care. “All the financial burden fell on my family,” Diego explained; he’s sure his uncle, an agricultural worker, “will be in debt until he dies.”

Despite Mariana’s care costs, Diego had low expectations for the GoFundMe campaign. “We were just hoping to start at ... a low starting point ... and see where it would go.” Ultimately, they raised \$1,200 toward a \$2,500 goal, which

he thought was “a little more successful than I expected it to be.” The family also hosted community dinners and raffles; many in their community preferred these in-person methods of fundraising because of technological barriers and suspicions about online fundraising. “I think people like seeing the things happening in person,” Diego observed, “[it offers] a sense of reassurance that you aren’t just putting your credit card info on some website.” Eventually, the family soured on GoFundMe after seeing that the platform took “a significant portion of the donations.” “At the beginning, it didn’t feel like such a big deal,” Diego observed, “because I figured they have to run the website somehow. But at the same time, once I ... did the math and everything else, I was like, ‘that is actually a little more significant than just a few dollars.’”

Diego’s story directly contradicts dominant narratives of easy crowdfunding success. His family’s experience reflects multiple ways that crowdfunding platforms can exclude, diminish, and further disenfranchise already marginalized users. Encouraging campaigners to set low goals and lower expectations ensures that even “successful” campaigns cannot cover relatively small medical costs. Thus, the cultivated affect of campaign outcomes—“it was a little more successful than I expected it to be”—coexists with grief and disappointment arising from debt, loss, and silences. Percentage fees charged by websites (a norm when he ran his campaign) can seem most significant in low-earning campaigns where every dollar is precious. Limited trust in technology means campaigners face diminished returns for online labors, and more offline labors to raise money. Finally, there is the type of narrative that families like Diego’s can construct. He notes the care they took not to seem pitiable—and to protect their privacy, likely because of worries about how their family, as immigrants, would be perceived. This echoes a complex history and politics of deservingness in the United States that limits the claims that campaigners from already disenfranchised communities are able to make online (Hagan 2019; Sargent 2012; Watkins-Hayes and Kovalsky 2016). Their reticence in sharing details on the campaign page reveals how disclosure and affective labors of public presentation differ across social hierarchies (Baym 2015; Duffy 2016).

Spencer

The same week that I spoke with Diego, Spencer suggested we meet at a trendy coffeeshop to talk about the campaign he’d set up for his close friends, Mark and Sofia. The couple are married with two children, and both worked as community leaders in Seattle. Sofia is originally from South America and works on immigration issues; Mark is a well-known Christian social entrepreneur. A year prior, they had been involved in a serious car accident while celebrating their anniversary in Mexico. Stranded without travelers’ or rental car insurance, Spencer recalled, “their first fear as they’re trying to survive a near-death experience, their first fear was like, can we pay for this, can we get home.” While they had health insurance, they worried about what it would cover, and their injuries were severe enough to require medical repatriation to the United States. Spencer repeatedly described their situation as “dramatic,” especially their fight to get medical repatriation covered by their American Express card. Spencer also raised questions about the other driver involved

in the accident, calling inconclusive police reports “a pretty classic coverup” and a “shady government deal” to conceal evidence.

After Spencer got Mark and Sofia’s call from Mexico, he worked all night to set up a crowdfunding campaign. He solicited support from other friends, “gathering people in for their skill sets.” Lawyers helped negotiate with the credit card company; others handled media requests. Spencer noted that “all the people on [the] team had either the financial ability to take the time off, or some of them like me, ... [I’m] in charge of my schedule.” They created several social media accounts for the campaign, and online forms to organize volunteers. Within an hour of launching, the campaign reached its initial \$7,000 goal. From his hospital bed, Mark created a hashtag—#fellowshipofcare—to describe their remarkable mobilization.

The campaign, to put it in Spencer’s terms, “blew up.” Friends “basically ran a budget on what all the potential expenses would be,” from childcare to flying in parents for support, to long-term counseling and therapeutic services, and then raised the campaign goal to \$75,000. Early success increased exponentially as YouCaring’s site algorithms made the campaign more visible. “As far as I know, a lot of [our] supporters were just from YouCaring. That happens more with these larger [campaigns] I think, where it just trends on [the site].” This led to considerable media coverage, since the media “just check these sites ... for things that are starting to trend.” In less than two weeks, they met their goal.

Soon, it became clear that their projected costs were grossly overestimated. American Express covered the medical flight, health insurance came through, and friends and family covered other costs directly. “It was a little scary,” Spencer recalled, “we were thinking, can we give the money back if we don’t need it? How does this work?” Platforms provide little way for fundraisers to do this, or for them to redistribute funds to less successful campaigns. Instead, success opened new doors to imagining what care could look like for Mark and Sofia. “That’s what I love about the YouCaring concept, is it can actually help people think ... long term and actually get the funds ... to do that self-care.” Spencer went so far as to credit the platform’s design with their rapid medical recoveries. “What’s beautiful about YouCaring is that it shows all of those supporters ... the design, [with] the funders on the right, where it scrolls down through all the people [who donated] and their little comments ... that is like an additional boost.” He noted that cash donations were evidence that well wishes were “not trite” but showed people were really “there for you.” Mark and Sofia recovered quickly after several surgeries. Left with a vast surplus of funds from the campaign, Sofia quit her “high stress” job and started a community coffee shop in a rapidly gentrifying neighborhood of Seattle.

Spencer was forthcoming about why the campaign was so successful. First, he credited Mark and Sofia’s identities: “they had already established themselves in the world as people who care.” Successful crowdfunders often conflate success with moral goodness: You are successful because you’re a good person; but success also powerfully reinforces perceived goodness. Mark and Sofia benefit from a narrative in which they are blameless humanitarians caught in a situation made worse by non-White, suspicious Others. “It was no fault of their own. ... That’s one of the key pieces for me,” Spencer explained, “Like if I go climb a cliff, and fall off, because I’m stupid, I’m probably going to feel awkward about crowdfunding for that. ... [Mark and Sofia’s] story was so much more powerful. It was dramatic, it was fast,

and it was, like, criminal. And it happened in another country.” Mark and Sofia also benefited from significant social capital, from the many talented friends who leveraged expertise on their behalf, and the benefit of the doubt given to them by media outlets and donors. Their ability to be perceived as “doing good” in the community is deeply linked to classist, racist, and nationalist notions of who provides help, who receives it, and what doing good looks like.

Spencer credits two other successful campaign elements: First, the outcome was unknown, but hopeful, offering the likelihood of a happy ending; second, he was careful to “keep ... any of the desperation” out of their story. One is left wondering whether and how Mariana’s family might have leveraged similar narrative arcs. If successful crowdfunding relies on offering narratives of resilience and hope, for whom are these available? Drawing on Spencer’s frequent invocation of the value of “drama,” we should ask how the dramas of Mariana’s story remain hidden, and even become shameful.

“Stark” is a deeply inadequate descriptor for the disparities between these campaigns, which accumulate along multiple axes of inequity—race, immigration status, class, education, social capital, age. Credibility and deservingness differ not just among campaigners, but within the technology itself. Diego’s neighbors and family, who needed in-person fundraisers and eschewed websites that asked for their personal information, demonstrate different ways that technology is experienced and leveraged across social strata. This results, in part, from the excessive data surveillance, privacy infringements, and digital harm that poorer, immigrant, and non-White communities experience (Benjamin 2019; Eubanks 2017; Petty et al. 2018). Diego’s story resonates with research showing that White users are significantly over-represented on GoFundMe (Kenworthy et al. 2020) and invites us to consider how crowdfunding itself holds different meanings and affordances for users based on their identity and social location.

Short-term Help, Long-term Needs

Not every comparison is as glaring as the one above. To demonstrate more complex dynamics of success, I present a second, shorter set of stories about crowdfunding for insulin. The terrain of deservingness and fault is more complex here: Diabetes is a chronic illness with limited relief, rather than an acute, accidental crisis. Campaigners can offer donors little reassurance of an easy fix or an end in sight. They often face stigma and accusations that poor health behaviors have caused or exacerbated their condition. “Not to quantify it too much,” the wife of one diabetic fundraiser reflected, “but little blond-haired, blue-eyed girls with rare cancer are certainly a bit more popular than ... a beloved father and hardworking person struggling to stay alive because of diabetes.” After a widely publicized story in 2017 of a young man who died while trying to crowdfunding the costs of his insulin (Closson 2017), many public commentators pointed to crowdfunding and insulin pricing as dual pillars of a health system marred by inequity and precarity. Diabetes in America needs a secondary typology beyond Type 1 and Type 2—covered and uncovered.³ Covered diabetes is affordable, manageable, survivable. Uncovered diabetes is unsustainable, unmanageable, and perpetually life-threatening. As these campaigns show, crowdfunding offers little respite from uncovered diabetes, or the structural violence that

causes it. Yet it is still taken up as a survival strategy, even when chances of success are limited.

Chris

Chris, a well-known Chicano musician, ended up in the ICU after falling severely ill while on tour and was diagnosed with Type 1 diabetes. With tens of thousands of social media followers, Chris's GoFundMe campaign quickly raised more than \$15,000. Before we talked, I had hoped that this might be one of the rare diabetes campaigns that finds success. But while Chris's campaign undoubtedly helped him get through a rough patch, he and his family were still struggling to get by when we spoke a year later. Research shows that considerable financial toxicity accompanies diabetes diagnoses in the United States: More than 40% of people with diabetes report difficulty paying their medical bills (Caraballo et al. 2020). Chris's diagnosis came at an especially vulnerable period in his life. He had gotten sober and was finally touring with his band again but had lost his house and was uninsured. After his diagnosis, he had to cancel the tour, which was his only source of income. Campaign donations went to immediate medical costs and debts. "When it first happened ... we're like, 'Wow, this is so much!' [but] once we started adding things up and back rent and bills, and three kids and house and hospital bills ... yeah, it just, it was gone." Chris ultimately borrowed \$13,000 from his record label to stay afloat.

A year later, Chris was still living in a camper with his wife and three children in Minnesota: He said the previous winter had been "really bad." Despite two years of appeals, he was still not on Medicaid, in part because finances from his music career and the GoFundMe campaign were so confusing. Several times, hospital financial counselors accused him of lying about his income after seeing his campaign. He followed-up on doctor referrals from his hospital stay, but without insurance the "bills ... were crazy ... and I got kind of weary of going." Chris hadn't seen a primary care doctor in more than a year and was having serious vision problems. It was hard to get healthy food and cook it, especially relying on food stamps. And despite finding low-cost insulin at Walmart, when we spoke it had been five days since he'd taken one of the two kinds of insulin he needed. Despite these conditions, Chris radiated generosity and what he called the "DIY spirit" of his band—sentiments that echoed the projected ethic of GoFundMe as well. He was proud of his sobriety and his kids. "Everything is looking up," he told me, despite "tough times and tough changes." He noted it had been hard to ask for money, but that he had also questioned whether he should have asked for more. Mostly he was trying to focus on the future. "So, our string of bad luck is definitely gonna, hopefully, be reversed, you know?"

As Chris talked, his voice was frequently drowned out by the inevitable noise of three children, two adults, and several cats living in a small camper. This cacophony of Chris's real life contrasted with the easy success projected by his online campaign and his social media posts, where an adoring mass of followers assumed they were saving his career and his life, oblivious to the silent crises he still faced long after the campaign had ended. This audible disjuncture highlighted the performative demands of the crowdfunding economy and what it implicitly asks campaigners to silence, to make invisible. For a campaign that successfully defied the odds, it

privately failed to offer enough support, and contributed to difficulties enrolling in Medicaid. Crowdfunding, even when successful, can reinforce what Merid (2020) calls “health insurance precarity,” and fail to substitute for yawning gaps in the social safety net. Yet crowdfunding also makes these gaps more invisible, incentivizing users to project positive personal successes rather than deeply entrenched structural abandonments.

Trevor

Trevor, the single father from Arkansas, experienced another way that crowdfunding marketplaces produce silence and occlude inequities. When we finally spoke on the phone, Trevor repeatedly told me his campaign had been “just another line that could be cast into the water.” Living in a state where it was hard to get Medicaid, and where he felt shame about using it even when he did have it, Trevor saw GoFundMe as a possible, but unlikely, source of help. Though he was a part-time web developer, a savvy social media user, and very much in need of financial assistance, Trevor ultimately decided not to share his campaign on social media:

I understand the dynamic to run a successful GoFundMe ... to just get it out on Facebook, make it a huge social media scene ... and I did research to look at other people's GoFundMe pages and I was just like, holy shit. I have no right to be asking for money on this page with some of the [other] stories that I read and what they're going through. So, my fucking story of just being a poor single dad with just bills he can't afford, you know medical bills, that's ... a lot for me to ask. I certainly couldn't go on Facebook and make it some big social media thing where I'm begging for money to pay for insulin. I mean, my pride's worth more than that to me.

So Trevor posted his campaign and never told a soul about it, hoping someone would stumble across it. Trevor did this because the stories that GoFundMe had curated and put into public view reinforced a rhetoric of deservingness centered on individual, unexpected, solvable tragedy—not the grinding, complex tragedy of a poor father who may someday die because he can't afford insulin. Trevor was an astute observer of the complex moral values of this platform, of the hierarchies of deservingness it reinforced. The shame these elicited paralyzed him. And he is not alone; industry experts told me that building but not sharing a campaign is a surprisingly common phenomenon.

Trevor's narrative also reinforces an ethic of personal responsibility for campaign outcomes that crowdfunding marketplaces foster. He attributes his lack of success to his unwillingness to “make it some big social media thing,” rather than a fabricated moral economy that deems him less deserving. But I also wondered whether Trevor's account was entirely true, or whether his aforementioned “pride” had led him to give an account of a campaign made but not shared, rather than the perhaps more shameful story of a campaign shared but wholly unsuccessful. This alternative explanation is only possible because of the invisible shame and self-blame that crowdfunding can foster for those who find little success. To set up a campaign is to buy into the possibility of uniquely individual deservingness and opportunity;

when it does not succeed, users must internalize a sentiment of profoundly personal responsibility for failure.

These campaigns cast doubt on what we can see and understand about crowdfunding from campaign narratives and metrics of success. Chris's highly visible campaign projected social rescue but did not spare him financial suffering; Trevor's campaign's invisibility doubly conceals self-sabotage in the name of pride. Both face continued threats to their welfare that are rendered invisible to platform audiences. Sites like GoFundMe create discursive black boxes by scripting user behavior and narrative, while also leveraging algorithms and platform design to conceal the inequitable dynamics that shape experiences and outcomes.

Conclusion

This article traces how crowdfunding platforms create, value, and hide inequities, examining GoFundMe's platform architecture alongside users' profoundly disparate campaign experiences. These narratives complicate more formulaic and reductionist accounts of what succeeds and what doesn't on crowdfunding sites. Diego's and Spencer's stories highlight how inequalities in class, race, and social and symbolic capital are amplified and reinforced through crowdfunding; the narratives of Chris and Trevor add dimensions of complexity to that dichotomy. Across several narratives, we can see how crowdfunding sites reinforce upper-class taboos against appearances of what Spencer calls "desperation," and working-class taboos against asking for help. Consequently, users with greater needs have less narrative flexibility and often feel more shame about crowdfunding. Returning to Trevor's original metaphor, crowdfunding often appears to grind down those who are already made vulnerable by systems of oppression and health care precarity in the United States. Those it polishes up already benefit from intricate webs of support, privilege, and symbolic capital. These narrative inequities are compounded by platform dynamics and technological barriers that reinforce inequitable outcomes and conceal them from view.

Crowdfunding economies are altering the way that our societies recognize and validate the needs of others, placing a black box around technological and social processes that create and reinforce inequity. Some needs are made invisible as users choose not to create or share content. Other needs are lost in a hypercompetitive marketplace where algorithms shape visibility and attention. These dynamics reinforce an ever-steeper hierarchy of needs, where only the exceptionally tragic, and those with the greatest social capital, have any chance of success. Crowdfunding companies rely on these dynamics for success while projecting a marketplace of opportunity and kindness. In this way, crowdfunding is part of a broader gig economy that promises freedom while delivering abandonment and precarity (Gray and Suri 2019; Kneese 2018). Charity can be as much a part of these processes of economic abandonment as other sectors (Spade 2020). Gig philanthropy (or its byproduct, gig begging) is another side of the same coin, though with a particularly misleading veneer of feel-good sentiment.

It is important to acknowledge that, in presenting these stories, I am inviting—and readers are participating in—exercises of judging and assigning value to campaigns. Though my purpose is to raise questions about fairness and equity, similar

appraisals, rooted in thinly veiled ideas that not all campaigns are equally deserving, are essential to the functioning of crowdfunding platforms. While many see crowdfunding as an unfortunate consequence of a broken U.S. health system, the hierarchies at its core are the same as those embedded in privatized health care solutions. Indeed, it is the notion that communities and corporations should choose who gets care that is the central basis of the most marketized, neoliberal health care alternatives and a cornerstone of opposition to universal health care (Dao and Mulligan 2016; Mulligan and Castañeda 2018; Schwarz 2019). While universal health coverage certainly does not erase these judgments, it privileges collective entitlement over individual appeal.

Finally, the fundamental politics of platforms aims not to “curate” public discourse, but to create it (Gillespie 2010). Crowdfunders often tell me they are pleasantly surprised by how much their campaign raised, even when the sum is paltry. This says less about the effectiveness of crowdfunding and more about how it has changed people’s expectations about what they deserve, what is necessary, and where aid will come from. GoFundMe is the latest iteration in a decades-long expansion of privatized health care markets that have stripped citizens of their sense of health rights and entitlements. As citizens begin to see the value of health in terms of donations, more collective recognitions of their rights within a social contract fade from view. Thus, we must read donations given and received as a reflection of the inevitability of abandonment and debt in our health and technological systems and our collective futility to do any more than offer cash as a temporary and inadequate fix.

Notes

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1. GoFundMe acquired YouCaring in 2018; consequently, my research shifted to focus primarily on GoFundMe.

2. It is difficult for outside researchers to assess whether featured campaigns are curated by humans or automated processes, but the types of campaigns featured have changed in recent years after public critiques of which types of people and causes are featured.

3. I owe this idea in part to Carruth and colleagues (2019), who identified what anthropology can offer to current subtyping efforts in diabetes diagnostics.

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