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A cross-sectional study of social inequities in medical crowdfunding campaigns in the United States

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Abstract

Americans are increasingly relying on crowdfunding to pay for the costs of healthcare. In medical crowdfunding (MCF), online platforms allow individuals to appeal to social networks to request donations for health and medical needs. Users are often told that success depends on how they organize and share their campaigns to increase social network engagement. However, experts have cautioned that MCF could exacerbate health and social disparities by amplifying the choices (and biases) of the crowd and leveraging these to determine who has access to financial support for healthcare. To date, research on potential axes of disparity in MCF, and their impacts on fundraising outcomes, has been limited. To answer these questions, this paper presents an exploratory cross-sectional study of a randomized sample of 637 MCF campaigns on the popular platform GoFundMe, for which the race, gender, age, and relationships of campaigners and campaign recipients were categorized alongside campaign characteristics and outcomes. Using both descriptive and inferential statistics, the analysis examines race, gender, and age disparities in MCF use, and tests how these are associated with differential campaign outcomes. The results show systemic disparities in MCF use and outcomes: people of color (and black women in particular) are underrepresented; there is significant evidence of an additional digital care labor burden on women organizers of campaigns; and marginalized race and gender groups are associated with poorer fundraising outcomes. Outcomes are only minimally associated with campaign characteristics under users’ control, such as photos, videos, and updates. These results corroborate widespread concerns with how technology fuels health inequities, and how crowdfunding may be creating an unequal and biased marketplace for those seeking financial support to access healthcare. Further research and better data access are needed to explore these dynamics more deeply and inform policy for this largely unregulated industry.
Introduction

Populations in the US and around the world are increasingly turning to online, donation-based crowdfunding platforms to solicit financial help for health care expenses.\cite{1-4} On platforms such as the popular site GoFundMe, patients, family members, and supporters can build fundraising campaigns using text, photos, and video, and then easily distribute financial appeals to their extended social networks using emails, texts, or social media platforms. Medical campaigns make up more than a third of all fundraising efforts on sites like GoFundMe, raising more than $650 million a year.\cite{5,6} GoFundMe has grown rapidly to control more than 90% of the donation-based crowdfunding market in the US: the total amount fundraised on the platform jumped from $1 billion to $4 billion between 2015 and 2017.\cite{7,8} While crowdfunding is also used to fundraise for medical research and to support broader charitable causes, this paper will focus on its most common use—soliciting donations to cover personal medical and health-related costs, often referred to as medical crowdfunding.\cite{9}

Medical crowdfunding (MCF) is a rapidly expanding and largely unregulated industry that is changing how Americans secure social and financial support in the midst of chronic and acute health crises. Many turn to MCF when other forms of healthcare coverage and social safety nets fail: Kenworthy and Berliner’s 2017 study of a randomized sample of US MCF campaigns found that they were disproportionately prevalent in states that had not accepted Medicaid expansion under the Affordable Care Act.\cite{3} In the US, where 45% of adults are ranked as inadequately insured,\cite{10} MCF can provide an important source of immediate material and social support. Despite common perceptions of crowdfunding as an easy way to raise capital, research has shown that only 10% of crowdfunding campaigns reach their financial goals, and many fall far short of success.\cite{3,11} Numerous questions have been raised about how crowdfunding may exacerbate inequities by creating a competitive marketplace where only a few succeed. Many scholars have highlighted the likelihood that education, social class, demographic characteristics, attractiveness, type of medical condition, and size of social network could all impact the success of campaigns, and thus access to healthcare.\cite{2,12–14} Yet with a few exceptions, empirical research on how these characteristics shape MCF access or success has been very limited.\cite{3,15–17}

Scholars have voiced widespread ethical concerns about MCF, in particular its potential impacts on health disparities.\cite{2,12–14,18,19} However, empirical research to help answer these questions and inform future policy regarding the industry is limited. A 2019 paper by van Duynhoven et al. spatially assessed the geography of Canadian cancer campaigns, finding that they were most common in urban areas with higher levels of income, home ownership, and education.\cite{15} Lukk et al. studied a relatively small sample of Canadian crowdfunding campaigns for individual education and health needs, and found that older adults, women, and “visible minorities” had poorer fundraising outcomes than other demographic groups.\cite{16} Barcelos studied 410 crowdfunding campaigns for transition-related medical care for transgender people, and reported that the majority of campaigns were for white, transgender men seeking chest surgery, underscoring the importance of future intersectional analyses of crowdfunding inequities.\cite{20} As Barcelos notes, these dynamics reflect the dominance of more privileged identities within the crowdfunding marketplace, and the likelihood that barriers to entry limit access to the marketplace as well as success within it.\cite{20} In a mixed-methods analysis of 200 US MCF campaigns, Berliner and Kenworthy found that campaigners with the most severe and complex needs often struggled to create compelling campaigns that attracted donors.\cite{3} These observations indicate that crowdfunding may be best suited to those who are higher in social hierarchies and experiencing simple, solvable problems;
similarly, crowdfunding may present significant barriers to entry and market disadvantages to those who experience complex health and social issues.

Crowdfunding users are routinely told by experts and crowdfunding platforms themselves that they can improve their campaign outcomes by extensively engaging with networks and sharing compelling, multimedia narratives about their illness experience.[21–23] Yet given dynamics of inequity on platforms and the highly competitive market that MCF users face, it is likely that identities may play an equal, or larger, role in campaign set-up and outcomes. The approach herein follows the conceptualization of Noble and Tynes,[24] recognizing the internet as “a system that reflects, and a site that structures, power and values” (p. 2, emph. original). It is hypothesized that race and gender inequities are embedded into, and measurable at, several different parts of the crowdfunding process: 1) associated with use, measured as disparities in who is represented on crowdfunding sites; and 2) associated with outcomes, measured as disparities in campaign fundraising outcomes. Additional campaign characteristics, such as whether recipients are adults or children, and relationships between campaigners and recipients, are assessed for their association with campaign outcomes. As a counterpoint to this analysis, measures of social engagement between crowdfunders and donors / visitors are evaluated to assess for significant associations with campaign outcomes, and the strength of these variables compared to gender and race in contributing to campaign outcomes.

To date, research on inequities in MCF has faced several methodological challenges. The first challenge regards sampling: platforms like GoFundMe will not release their data to the public, so researchers must rely upon the platforms’ search and categorization tools to develop samples. This introduces a number of potential sources of bias, because platform algorithms are designed to prioritize specific content in making it visible to users. Typically campaigns that are more popular, that started more recently, and that are geographically proximate are more likely to appear earlier in search results. The second challenge is one of analysis. Because users are not asked by sites to list basic demographic information—including gender, age, race, or indicators of socioeconomic status (SES)—these indicators must be coded either by hand or machine learning. Both approaches, as discussed below, introduce potential errors and biases into the very data researchers are able to gather. Therefore, the ability to systematically measure demographic disparities in crowdfunding access or success has been limited.

This paper addresses these challenges to present the first known analysis of how race and gender impact crowdfunding access and campaign outcomes using a randomized sample of medical campaigns in the US. As the analysis is presented below, a wide array of technological, social, and health-related factors of disparity that may contribute to these results are discussed and referenced. The following section briefly outlines existing research on how technologies fuel social and health inequities. In a separate publication, Kenworthy elaborates a more comprehensive model of how these disparities may impact the crowdfunding process, to which readers are referred for deeper conceptual analysis of these dynamics.[25]

**Potential sources of bias and disparity in crowdfunding**

Extensive research has now shown that online social networks, platforms, algorithms, technologies, and even Silicon Valley corporations themselves are designed in ways that disproportionately disadvantage women, people of color, and other marginalized groups.[26–32] Ruha Benjamin has described this web of new technologies as a “subtle but no less hostile form of systemic bias,” and one that often is disguised by common perceptions of technology as objective, open, and non-biased.[30] Research has documented systemic biases across many online technologies: search engine algorithms which reinforce racism and sexism online;[27] the collection, sale, and use of increasingly enormous troves of online data that disproportionately
punish and surveil the poor and people of color and reinforce social hierarchies; and social media sites and online algorithms that reduce racial empathy and reinforce and spread extremism and hate against marginalized groups. Given the complex and compounded axes of inequality and power that operate online, it is important to take a multidimensional approach to understanding both the hierarchies that produce technology, and the hierarchies that technology creates and reinforces. As a number of scholars note, the default identity that creates and structures the culture and systems of the modern internet is white, male, and capitalistic.

Feminist scholars have also shown how the internet is changing (and often reinforcing) forms of labor that are often deeply feminized—including affective, relational, and emotional labor. And while the internet has expanded the diversity of who does such labor (including, for example, a large number of men), it has not altered the dominant perceptions of such labor as feminine, or the ways in which such labor reinforces gendered care responsibilities both on- and offline. Precarity in these new labor markets further accrues along lines of race as well as gender, with women of color and black women particularly burdened by these new labors, and in contexts where they are least protected.

Additional dimensions of inequity require attention as technologies evolve, including along hierarchies of age, socioeconomic status, geography, and ability/disability. Because different technologies and platforms operate uniquely and cultivate different online cultures, disparities along these lines can be harder to predict or track, but are no less important. For example, many older adults struggle to acclimate to new tech infrastructures, while young people, who often master new technologies quickly, are also subject to exploitation within new online marketplaces such as YouTube due to their young age and limited industry regulation.

It is unlikely that crowdfunding would be immune to these dynamics, though research on the topic to date has been scarce. In fact, platforms like GoFundMe are so integrated with other, more widely researched systems like Facebook and Google that it would be difficult for MCF to even separate itself technologically from sources of bias and discrimination on other platforms. Furthermore, GoFundMe is impacted by the existing internet cultures, hierarchies and exclusions described above. These shape how people engage, assess each other, build relationships, accrue status, and leverage various forms of capital online. On similar platforms like Airbnb, patterns of bias manifest in measurable discrimination against non-white hosts and guests, as well as a self-discounting effect for non-white hosts. Similar dynamics have been documented on entrepreneurial, rewards-based crowdfunding platforms like Kickstarter, with studies finding that African American men receive less funding and their projects are perceived as lower quality; that minority producers face price discounting; and that visually-identifiable race in Kickstarter campaigns impacts the probability of success.

Disparities also extend to gender on these platforms, with Greenberg and Mollick finding that women are under-represented on these sites, receive less funding, and yet, with all other things being equal, would be expected to outperform men in their campaigns—a set of dynamics that also mimics workplace standards in more traditional industries.

Finally, but no less importantly, crowdfunding platforms are embedded in broader social worlds where existing and historical disparities and biases can alter people’s experiences of crowdfunding. Health system inequities and existing health disparities drive people toward crowdfunding; but people with less social, economic, or educational capital may find it harder to crowdfund, and thus may be less represented on the platform. As described by Berliner and Kenworthy, successful crowdfunding requires multiple literacies and forms of expertise—digital, medical, social—as well as robust social networks with expendable capital. MCF campaigns also appeal to, and reinforce, dominant social ideas of who is and is not deserving of charity. In the US in particular, these social mores are deeply rooted in histories of racial
and gender oppression, whereby specific populations have been routinely classified as less deserving of social support, charitable assistance, and safety net programs—and have been publicly shamed for needing or asking for such assistance once it is available.[52–56] Existing social inequities also compound the stigma of particular illnesses, causing those with marginalized identities to be more often seen as responsible for their conditions.[57,58] All of this contributes to the likelihood of differential access and outcomes in medical crowdfunding campaigns. This study, which offers the first cross-sectional analysis of social inequities and their relationship to MCF campaign use and outcomes, is a much-needed first step in examining these dynamics.

Methods

In order to conduct a more reliable assessment of who crowdfunds and how social factors are correlated with MCF campaign outcomes, a randomized sample of US MCF campaigns from GoFundMe, the most popular and widely used crowdfunding site in the US, was created and analyzed.[8] To create a randomized sample of campaigns, it was necessary to develop a robust and accurate sampling frame of all known US medical campaigns on GoFundMe at a single point in time. To do this, a computer program was developed to search all medically-categorized campaigns on the site using US zip codes in July 2016. For each zip code searched, the site returned 500 campaigns closest to that zip code; this was done for every US zip code and duplicate campaigns were removed from the results. This process generated a known population of 165,925 US medical campaigns. From this list, a randomized sample of 822 campaigns was created for further analysis. Campaigns that were not primarily motivated by a medical cause or healthcare costs in the US or for a US resident were excluded. So, too, were campaigns for veterinary care, research efforts, medical volunteer work abroad, or fundraising on behalf of non-profit organizations. Out of 822 campaigns, 135 were excluded for failure to meet the inclusion criteria. An additional 47 campaigns were removed from GoFundMe by the time of data analysis (July 2018), likely because campaigners had shut them down. In line with ethics guidelines for internet research,[59] these cases were not used since it was likely that the campaigners did not intend for their information to remain public and online. The remaining sample included 640 campaigns that met criteria and were still online by July 2018. Finally, 3 campaigns that had run for less than 30 days from when data were originally collected were removed from the sample so as not to skew results; ongoing qualitative research from this project suggests that most campaigns see the bulk of their donor activity in the first month, with steep declines in engagement and donations after that point in all but the rarest of cases.

The University of Washington (UW) Human Subjects Division determined that Institutional Review Board approval was not required for this study because it used publicly available data and did not involve interactions or interventions. Nevertheless, additional efforts were undertaken to protect the data collected. All data was stored on password-protected, encrypted drives and de-identified prior to data analysis. Furthermore, the current publication presents only population-level statistics and not any individual or identifying data. All persons working with identifiable data in the study analysis completed ethics training provided through the UW Office of Research.

Variables were created for primary characteristics on each campaign page. These included: outcome measures such as monetary goal, money raised, number of donations, largest single donation, average donation, and percent of goal reached; campaign characteristics such as length (in days), city and state where campaign was located, and the number of updates, photos, and videos; and social engagement measures such as shares, likes, comments, and campaigner’s number of Facebook friends.
Additional demographic variables were identified and coded based on information from campaign pages. The perceived gender of both the MCF campaign organizer (the ‘campaigner’) and the intended recipient of the campaign funds (the ‘recipient’) were coded. Sometimes these were the same person, but often someone was fundraising on behalf of another person. Gender was determined using three sources of data: first, pronouns, gender descriptors, and stated relationships (i.e., ‘mother,’ ‘son,’) in a campaign’s text; second, user names, which were compared with the US Census baby names list by gender; and finally, user photos. If there was disagreement among these three sources of information, or if insufficient information was available to make a conclusive judgement, the gender was marked as ‘unknown.’ Non-binary gender descriptors were coded using users’ own terminology, and transgender identities were coded as such when self-identified in the data. In recognition of trans people’s self-identification of gender and the fact that many may pass as cisgender and/or not reveal their status as transgender due to safety or privacy concerns, all campaigns were coded according to participants’ stated gender as men, women, or genderqueer. Narratives were also coded for the relationship between the campaigner and recipient and whether the recipient was an adult (18 or older) or a child (under 18). These variables were only coded based on explicit, written information on the campaign page (for example, “My twelve-year old son...”); when information was not available these variables were coded as “unknown.”

Finally, the perceived race of the campaign recipient was coded using three categories: 1) white; 2) black; 3) non-black person of color. While these are broad and imperfect categories that cannot capture the diversity or complexity of racial identification, experience, or discrimination in the US context, even simplistic racial binaries have been shown to map onto significant social and health inequities in the US.[60,61] There is no gold standard for assessing race online, although some strategies have been shown to be more objectionable than others: the use of facial recognition technologies in studies of social media is particularly problematic given embedded racial biases in those technologies and broader questions about how race can be defined from facial appearances alone.[62–64] For this project, perceptions of race by potential contributors to MCF campaigns are more relevant than how campaigners might identify themselves. Consequently, three raters from different racial backgrounds coded for race using visual and textual information drawn from campaign pages. Most often, there was not enough data on campaign pages to also assess the race of the campaign organizer, so only the race of campaign recipients was recorded. Using a fully crossed design, all raters assessed all campaigns. Intraclass correlation (ICC) was measured using the ICC two-way random test in SPSS.[65] This yielded an ICC score of .819, which is considered excellent for inter-examiner levels of agreement.[66]

The analysis aimed to answer two sets of questions: First, what are the demographics of MCF campaigners and recipients, and are there inequities in who is using, and providing the labor for, MCF and its intended beneficiaries? Second, are different demographic groups—including recipients with different gender, race, and age—associated with different campaign outcomes? In order to assess these questions, it was necessary to undertake two preliminary tasks. The first was identifying the best variable(s) for measuring campaign outcomes from the data available. While many people are concerned with ‘success’ in crowdfunding, this is difficult to measure given that all campaigners set different goals, and often have different expectations of what might constitute success. Thus, this project identifies fundraising ‘outcomes’ as a less value-laden measure of how campaigns performed. Possible variables for campaign outcomes included the total amount of money raised, the percentage of the goal reached, the average donation amount, and the number of donations. Measures of whether a goal was met, or the percentage of goal reached, are only valid if goal-setting is consistent among campaigners, which it is not. Many confounding factors, including the severity of illness and medical costs, may impact the goal that fundraisers set. Data from ongoing qualitative research also indicates
that fundraisers set goals based on what they think they can reasonably ask for, not their actual financial need. Thus, using a percentage of the goal reached for campaigns may be more reflective of how campaigners set goals than of how successful their campaigns were. Goals themselves may impact the total amount of money campaigns raise by setting donor expectations and creating cut-off points for when campaigners may be compelled to stop campaigning—thus total amounts raised are also likely to be unreliable as measures of outcome.

Consequently, this analysis relies on two other dependent variables which represent the overall financial commitment a campaign generates: 1) the number of donations and 2) the average donation amount (calculated as total amount raised divided by the number of donations). These two measures do have some drawbacks, though they are less significant than those for other dependent variables. Average donation amount may not adequately capture popular campaigns’ spread if they have many small donations, whereas the number of overall donations does not measure donation amounts. However, used side-by-side, these variables together provide a measure of both social network engagement with a campaign and the ways that donors are ‘valuing’ the campaign in the size of their donations.

The second preliminary task was assessing other campaign characteristics which might impact outcomes. In particular, campaigners are often told to engage extensively with their audience in order to boost the visibility and success of their campaigns. Thus, the analysis aimed to assess how social engagement between campaigners and potential donors—measured by updates, photos, videos, comments and hearts—corresponded with, and contributed to, campaign outcomes. If they did not show significant correlation with, or contributions to, campaign outcomes, this would lend credence to the hypothesis that demographic factors might play a larger role than others have predicted.

To carry out these analyses, data were compiled in SPSS and then further analyzed using R. Descriptive statistics on campaign characteristics and the demographics of campaigners and recipients were compiled. Chi-square goodness of fit tests were used to assess how demographics of crowdfunding campaigns and recipients compare with the US population at large. Descriptive statistics of campaigners’ social engagement were also compiled, and Spearman’s ranked correlation tests were used to assess the independence of these variates to inform the building of regression models to test the hypotheses that gender and race impact medical crowdfunding use and outcomes. Generalized linear models were then used to adjust for potential confounding variables, using the glm function in R. Regression models were then used to assess the relationship between various demographic characteristics and two dependent variables for campaign outcomes: the number of overall donations and the average donation amount. Linear regression was used for the average donation amount (since it is a continuous variable), and a series of Poisson regression models were used to assess contributing factors to the number of donations (a discrete variable).

Results

Campaign characteristics and social engagement

Medical crowdfunding campaigns in this study show a wide variability in terms of campaign outcomes and social engagement. These basic descriptive results underscore how competitive the field of MCF is for crowdfunders, and how unequal MCF experiences and outcomes can be. They also indicate that the sample captures much more variability than would be seen if the analysis focused on top search results from the GoFundMe website, where algorithms prioritize successful and ‘trending’ campaigns. As shown in Table 1, campaign goals—the total amount campaigners hoped to receive—ranged from $150 to $300,000 (mean 14753.06; SD 25278.14). This shows both the diverse purposes to which MCF is being put—from minor
needs to major, high-cost interventions—and the wide range of outcomes on the platform. As other studies have found, [3,67] reaching financial goals is quite rare: only 9.2% of campaigns met their stated financial goal, and on average, campaigns reached less than half of their goal (mean 41.75%; SD 58.10%). There is repeated evidence of extreme disparities in terms of outcome when measured as the total amount raised (min 0; max 45,000), largest single donation (min 30, max 10,480), or % of goal raised (min 0; max 864.50). Disparities are less acute, and show fewer outliers, when using the chosen outcome measures of number of campaign donations (min 0; max 883) and average donation amount for each campaign (min 0; max 718.50). Some campaigns find considerable financial success and engagement—even from single donors giving truly exceptional amounts of money—while other campaigns find little traction, with 2.3% netting no donations at all. Finally, many campaigns have been online for a long period of time (mean 458.14 days; SD 307.25), indicating not necessarily that they are active for this entire time, but, as is more likely, that they are left online after activity declines—possibly because campaigners forget about them, because taking campaigns down is more complex, or because pages archive a powerful moment in campaigners’ lives. More research is needed into campaigner motivations and decision-making in this regard.

Alongside measures of financial success in campaigns, broader engagement between campaigners and potential donors can be measured through media and updates posted by campaigners, and shares, likes (on GoFundMe these are ‘hearts’), and comments by visitors. Here, too, there are wide disparities (Table 1): shares ranged from 0 to 3600 (mean 316.92; SD 380.85); hearts ranged from 0 to 919 (mean 41.42; SD 64.10); and comments ranged from 0 to 16 (mean 1.12; SD 2.01). It is worth noting, however, that these levels of engagement, even for the most successful campaigns in the sample, still fall far short of what is seen for truly viral campaigns by which campaigners may be inspired or even set expectations. As a point of comparison, one of the most successful and long-running medical campaigns on GoFundMe, “Saving Eliza,” had, as of July 2019, 56,000 shares, 30,000 likes, and 260 comments. [68]

### Table 1. MCF campaign outcomes, social engagement, and other characteristics.

|                         | Mean   | Std. Dev | Min   | Max     |
|-------------------------|--------|----------|-------|---------|
| **Outcomes**            |        |          |       |         |
| Campaign goal ($)       | 14753.06 | 25278.14 | 150.00 | 300000.00 |
| Amount raised ($)       | 3731.04 | 5812.46  | 0.00  | 45000.00 |
| % of goal raised        | 41.75  | 58.10    | 0     | 864.50  |
| Donations (#)           | 43.05  | 66.19    | 0     | 883     |
| Average donation ($)    | 83.73  | 67.68    | 0     | 718.50  |
| Largest donation ($)    | 588.19 | 1008.97  | 0     | 10480.00 |
| **Social engagement**   |        |          |       |         |
| Comments (#)            | 1.12   | 2.01     | 0     | 16      |
| Updates (#)             | 7.80   | 47.12    | 0     | 1200    |
| Photos (#)              | 3.89   | 9.35     | 1     | 191     |
| Videos (#)              | .07    | .45      | 0     | 6       |
| Shares (#)              | 316.92 | 380.85   | 0     | 3600    |
| Hearts (#)              | 41.42  | 64.10    | 0     | 919     |
| **Other characteristics** |       |          |       |         |
| Campaign length (days)  | 458.14 | 307.25   | 30    | 1950    |

Descriptive statistics of MCF campaigns from a randomized sample of 637 US medical crowdfunding campaigns on the site GoFundMe.com.

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In addition to how potential donors engage with campaigns, campaigners engage with their publics through stories, updates (posts written after the campaign has launched), photos and videos. While campaigners are often told by sites like GoFundMe that such elements are essential to campaign success, there is little evidence to support this assertion, and some research shows that the use of photos, videos, and updates by users is more limited. A study by Xu, for example, has shown that these elements are underused by campaigners, and similar results are shown here, particularly when it comes to videos. Only 4.3% of campaigns included videos, for example, and while all campaigns had at least one photo, there was wide variation in how many photos and updates were posted (Table 1).

To identify the mutual independence of covariates included in our models, a Spearman's ranked correlation test was used to test the independence of each campaign feature used. Spearman's ρ is used instead of Pearson's r for two primary reasons: it is less sensitive to a few outliers in the sample whose removal would potentially impact later tests; and it performs better for ordinal variables, of which there are quite a few among the campaign characteristics. Contrary to findings from previous studies, the heatmap shows very low levels of correlation between many campaign characteristics such as updates, photos, videos, number of Facebook friends (of the campaigner) and time since campaign was started. Hearts, shares, and to a lesser extent, comments by campaign supporters were positively associated with the number of donations, as is to be expected given that these likely contribute to positive campaign outcomes. However, these are likely less robust and relevant measures of campaign outcome than number of donations or average donation size, as social engagement does not always translate into monetary results which are key to healthcare access for MCF users.

Who uses medical crowdfunding?

In order to answer the question of who uses MCF, both crowdfunding campaign organizers and intended recipients were coded for demographic characteristics whenever possible. In some cases, a person with a health issue or need builds a crowdfunding campaign for themselves, but more often, friends, family members, or neighbors start campaigns on behalf of patients who may be too incapacitated by illness to build their own campaigns or who feel too much shame about asking for financial help. Given that these social relationships are leveraged to attract donations from others in a social network, and often help to lend campaigns significant credibility, it was important to better understand campaigner identity as well as the relationship between campaigners and recipients. As shown in Table 2, only 20.41% (n = 130) of campaigns were self-organized; 9.26% (n = 59) of campaigns were organized by parents of the recipient; 22.29% (n = 142) were organized by other immediate family members of recipients (siblings, spouses, grandparents, and children); 16.8% (n = 107) were organized by friends or distant relatives; a handful were organized by unmarried partners (.47%, n = 3); and in about a third of cases the relationship was not explicitly stated (30.77%).

The gender of both recipients and campaigners was coded using techniques described in the methods section above. The results are shown in Table 2. Among campaign recipients, data showed a relatively equal gender balance, with 47.1% men (n = 300), 49.92% women (n = 318), and .16% genderqueer (n = 1). Only 2 campaigns explicitly revealed transgender identity—both of them self-organized campaigns for transgender men. Given the popularity of crowdfunding for transgender health needs, including for gender confirmation treatments, it is worth highlighting that transgender campaigns were a very small population in the overall sample (n = 2), comprising less than 1% of all cases.
Despite the relative gender balance among male and female identified campaign recipients, there were acute gender imbalances among campaign organizers. Among those campaigning for themselves, about 67% (n = 85) were women, and among those campaigning on behalf of others, nearly 80% (n = 400) were women (see Table 2). As shown in Table 3, chi-square goodness of fit tests were conducted to compare the means for recipient and campaigner gender with the US population at large, drawing from the 2017 American Community Survey estimates. These tests confirmed that while there was no statistical difference between the gender balance of recipients and that of the population at large, there were highly statistically significant (p = .000) differences among campaigner gender, for those self-fundraising ($X^2 = 13.993$) and, particularly, for those fundraising for others ($X^2 = 192.998$). As discussed below, these gender imbalances indicate a strong gendered labor component to crowdfunding that has not yet been explored in the literature.

### Table 2. Characteristics of crowdfunding campaigners and recipients.

| Campaigener-Recipient Relationship | N   | Percent |
|-----------------------------------|-----|---------|
| **Self-fundraising**              | 130 | 20.41%  |
| Parent                            | 59  | 9.26%   |
| Immediate family member           | 142 | 22.29%  |
| Friend or distant relative        | 107 | 16.8%   |
| Unmarried partner                 | 3   | 0.47%   |
| Unknown                           | 196 | 30.77%  |
| **Gender of recipient**           | 637 |         |
| Man                               | 300 | 47.10%  |
| Woman                             | 318 | 49.92%  |
| Genderqueer                       | 1   | 0.16%   |
| Unknown                           | 18  | 2.83%   |
| **Gender of campaigner-self-fundraising** | 127 |         |
| Man                               | 41  | 32.28%  |
| Woman                             | 85  | 66.93%  |
| Genderqueer                       | 1   | 0.79%   |
| Unknown                           | 0   |          |
| **Gender of campaigner-fundraising for others** | 510 |         |
| Man                               | 86  | 16.86%  |
| Woman                             | 400 | 78.43%  |
| Genderqueer                       | 0   |          |
| Unknown                           | 24  | 4.71%   |
| **Race of recipient**             | 637 |         |
| White                             | 495 | 77.71%  |
| Black                             | 52  | 8.16%   |
| Non-black POC                     | 66  | 10.36%  |
| Unknown                           | 24  | 3.77%   |
| **Age of recipient**              | 637 |         |
| Adult                             | 524 | 82.26%  |
| Child                             | 113 | 17.74%  |

Demographic characteristics of crowdfunding campaigners and recipients, including gender, race, and age, as well as relationship between campaigner and recipient, if specified in the campaign.

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Using similar methods, the race of recipients was also examined, using 3 broad categories for perceived racial identity: 1) white; 2) black; 3) non-black person of color (POC). White people accounted for more than 75% of campaign recipients overall (77.71%, n = 495), while black people represented 8% of recipients (n = 52), and non-black POC represented 10% (n = 66) (Table 2). As can be seen in Table 3, these proportions also show significant ($X^2 = 18.980, p = .000$) differences from the US population at large, with people of color significantly under-represented and whites over-represented across the board. Racial disparities are particularly notable here given research showing that people of color, particularly African Americans, are more likely to be uninsured;[73] have higher rates of chronic disease, premature death, and many types of injury;[60] and carry more medically-related debt[74]–factors which would increase the likelihood of conditions and financial needs which might cause people to crowdfund.

Given considerable evidence that disparities accrue most significantly among women of color,[24] it was important to use an intersectional frame to investigate gender and race representation together. Table 4 shows a breakdown of MCF users (n = 554) by gender and race, with those with unknown race or gender removed. While white women are over-represented, under-representation is particularly acute for black women, who make up less than 7% of women in the sample. This resonates with numerous accounts of black women’s marginality in online spaces, and is particularly striking given the health disparities and medical debts they face.

Finally, the proportions of recipients who were adults or children were assessed (Tables 2 and 3). The majority of recipients (82.26%, n = 524) were adults, a statistically larger proportion than the US population at large ($X^2 = 9.608, p = .002$). While there have been many high-

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Table 3. Means comparison of demographic characteristics between crowdfunding and US population at large.

|                      | N      | Percent | US Population at large (%)* | Comparison of means ($X^2$) | P value |
|----------------------|--------|---------|-----------------------------|-----------------------------|---------|
| **Gender of recipient** |        |         |                             |                             |         |
| Man                  | 300    | 48.54%  | 49.2%                       | .107                        | .744    |
| Woman                | 318    | 51.46%  | 50.8%                       |                             |         |
| **Gender of campaigner–self-fundraising** |        |         |                             |                             |         |
| Man                  | 41     | 32.54%  | 49.2%                       | 13.993                      | .000**  |
| Woman                | 85     | 67.46%  | 50.8%                       |                             |         |
| **Gender of campaigner–fundraising for others** |        |         |                             |                             |         |
| Man                  | 86     | 17.70%  | 49.2%                       | 192.998                     | .000**  |
| Woman                | 400    | 82.30%  | 50.8%                       |                             |         |
| **Race of recipient** |        |         |                             |                             |         |
| White                | 495    | 80.75%  | 73%                         | 18.980                      | .000**  |
| Black                | 52     | 8.48%   | 12.7%                       |                             |         |
| Non-black person of color | 66   | 10.77%  | 14.3%                       |                             |         |
| **Age of recipient** |        |         |                             |                             |         |
| Adult (18+)          | 524    | 82.26%  | 77.1%                       | 9.608                       | .002**  |
| Child (under 18)     | 113    | 17.74%  | 22.9%                       |                             |         |

Means comparison between demographics of crowdfunding campaigners and recipients and US population at large. Unknown and genderqueer cases removed for the purposes of this analysis.

*Source for US population data: US Census Bureau, American Community Survey[72].

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profile crowdfunding campaigns for sick children, and children are often perceived as particularly deserving cases on the site, it is notable that they make up a smaller proportion of campaigns than might be expected.

Disparities in crowdfunding success

In addition to assessing under-representation of specific groups and the over-representation of female labor in MCF campaigns, disparities in campaign outcomes among different groups can also be measured. Two key measures of campaign outcome—the number of donations and the average donation amount—were assessed. The primary aim was to measure the associations between race, gender, and age of campaign recipients and campaign outcomes, though in several models we include a variable for social network size as a potential moderating variable. The relationship between campaigner and recipient was also included, because it can impact the perceived credibility, and thus potential outcomes, of campaigns. Throughout these models, variables for non-monetary campaign outcomes—social media shares, comments, likes—are not included, as the intention is to focus on monetary outcomes of campaigns, which in turn impact access to health resources.

First, a linear regression analysis of the effect of recipients’ gender, race, age, and campaigner-recipient relationship on the average donation amount was conducted (Table 5). The relationship between campaigner and recipient did not have any significant association, nor did the gender of the recipient. However, significant effects were seen for both race and age factors. Being black was associated with a recipient receiving on average about $22 less per donation (β = -22.223, p = .030). Being a non-black person of color was associated with about $12 less per donation, but this finding was not statistically significant (p = .178). Surprisingly, being a child was also associated with a lower donation amount, a loss of about $18 per donation (p = .022).

Second, a Poisson regression analysis of the relationship between recipients’ gender, race, age, and campaigner-recipient relationship on the number of donations to the campaign was conducted (Table 6). Recipients who were people of color were likely to receive significantly fewer donations. Those for whom gender could not be determined given the available information were also associated with fewer donations, though this may be a reflection of the general paucity of information or unclear narratives in those campaigns. Similar to the findings for gender and average donation above, there was a small (but significant) difference between men and women in terms of the number of donations received, with women earning fewer
donations. Those whose immediate family members, parents, or friends were campaigning on their behalf received more donations, as expected. More surprising is that children appear to attract a smaller average donation size but significantly more donations overall. Interpretations of this seeming paradox are discussed below.

It is possible that the relationships seen above are attributable, in whole or in part, to the size of crowdfunding users’ existing social networks. Existing disparities in access to, or safety on, internet platforms might impact the size of one’s online social network. If this effect is strong enough, it could account for most, if not all, of the disparities seen in crowdfunding outcomes. To assess the impact of this potential moderating variable, two additional tests were conducted. In the first (Table 7), a Poisson regression analysis measures the relationship between campaigner demographic variables (as above) and the size of their online social network, measured as the number of Facebook friends they have. As is seen in Table 7, men, adults, those campaigning for themselves, and white campaigners all have a larger number of Facebook friends, though in campaigns for children and people of color the effect is small (and in the case of children, not significant).

To test the strength of the number of Facebook friends as a moderating variable, a final Poisson regression model was used, which included the number of Facebook friends as a covariate alongside demographic factors in analyzing their impact on the number of campaign donations. Table 8 shows very similar results to those shown in Table 6, indicating that while the number of Facebook friends influences campaign outcomes, the significant relationships between demographic characteristics and number of donations still hold. One exception is

| Table 5. Linear regression of demographic effects on average donation amount. |
|------------------|------------------|------------------|
|                  | Estimate         | 95% Confidence Interval | P-value |
| (Intercept)      | 66.494           | (-22.131, 155.119)     | 0.142   |
| **Relationship to Recipient** |                  |                  |        |
| Self (Reference) |                  |                  |        |
| Parent           | 13.086           | (-10.148, 36.320)    | 0.270   |
| Immediate Family Member | 7.151       | (-8.761, 23.063)     | 0.379   |
| Unmarried Partner | 14.864          | (-60.774, 90.502)    | 0.700   |
| Friend or Distant Relative | 13.03      | (-4.143, 30.204)     | 0.139   |
| Unknown Relationship | 6.264          | (-9.003, 21.530)     | 0.422   |
| **Gender**       |                  |                  |        |
| Male (Reference) |                  |                  |        |
| Female           | -2.738           | (-13.310, 7.833)     | 0.612   |
| Genderqueer      | 27.074           | (-103.654, 157.802)  | 0.685   |
| **Race**         |                  |                  |        |
| White (Reference) |                  |                  |        |
| Black            | -22.223          | (-42.266, -2.179)    | 0.030*  |
| Non-Black POC    | -12.1            | (-29.693, 5.493)     | 0.178   |
| **Age of Recipient** |                |                  |        |
| Adult (Reference)|                  |                  |        |
| Child            | -18.124          | (-33.655, -2.593)    | 0.022*  |
| Log of Number of Residents in State | 1.287      | (-4.155, 6.730)      | 0.643   |

Linear regression analyzing the relationship between gender, age, race, and campaigner-recipient relationship and average donation amount to MCF campaigns.

*** = < .001
** = < .01
* = < .05

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that for women campaigners the small effect observed in the previous model is no longer significant. It is worth noting, however, that race and age effects remain significant in this model.

Discussion

Proponents of crowdfunding have repeatedly emphasized that it is a way of using social media to democratize charity and philanthropy, expanding who has access to charitable giving and who can participate in it as donors.\[75,76\] By contrast, this research indicates that the crowd dynamics brought to these platforms are not the dynamics of a social democracy–wherein all citizens have shared, equal rights and protections–but of an aristocratic oligarchy, where an elite few succeed, and the majority of users struggle, facing multiple scales of hierarchy and inequity. Data on the demographics of crowdfunding users indicates that there are significant inequities in representation which may reflect issues in the accessibility of the platform or sociopolitical dynamics that make people with various marginalized social identities feel unwelcome or unlikely to succeed. Given the evidence of rampant disparity, discrimination, and bias across internet spaces, technologies, and social media platforms discussed previously, it is likely that some dynamics carry over from other internet spaces, while others are forged anew on crowdfunding platforms. Technological disparities are likely compounded by social biases which users bring to the platform, including expectations of who can and should be crowdfunding, and whose cases are the most trustworthy and deserving.\[3,16,71\] The impacts of these biases can be seen in the disparities in campaign outcomes by race, in particular, but also by gender and age.

| Table 6. Poisson regression of demographic effects on number of donations. |
|---------------------------------------------------------------|
|                                                              |
| Estimate  | 95% Confidence Interval | P-value  |
|---------------------------------------------------------------|
| (Intercept)        | 3.358   | (3.321, 3.395) | <0.001*** |
|                   | Parent  | 0.341   | (0.285,0.396) | <0.001*** |
|                   | Immediate Family Member | 0.580   | (0.540, 0.647) | <0.001*** |
|                   | Unmarried Partner | 0.098   | (0.107, 0.302) | 0.350 |
|                   | Friend or Distant Relative | 0.375   | (0.331,0.420) | <0.001*** |
| Relationship to Recipient                                      |
| Self (Reference)                                               |
| Relationshop to Recipient                                      |
|                      | Male (Reference) |                  |
|                      | Female          | -0.027           | (-0.050, -0.003) | 0.026* |
|                      | Genderqueer      | -1.508           | (-2.310, -0.706) | <0.001*** |
|                      | Unknown          | -0.237           | (-0.316, -0.158) | <0.001*** |
| Age of Recipient                                              |
| Adult (Reference)                                             |
| Race                                                          |
| White (Reference)                                             |
| Black              | -0.058           | (-0.104, -0.012) | 0.013* |
| Non-Black POC       | -0.179           | (-0.222, -0.135) | <0.001*** |

Poisson regression analyzing the relationship between gender, age, race, and campaigner-recipient relationship and number of donations to MCF campaigns.

*** = < .001
** = < .01
* = < .05

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Gender and race disparities among MCF users constitute a base layer of inequities in terms of representation on the site. The disproportionate number of crowdfunding recipients who are white likely reflects both technological and sociopolitical disparities which might deter people of color, particularly black women, from appealing for charity using these platforms. These disparities are even more striking when considered in light of the disproportionately large numbers of people of color, particularly African Americans, who are sicker, less insured, and more medically indebted. Those with marginalized identities experience at times acute discrimination and harassment online which has consequences ranging from emotional burn-out to profound unsafety.\[43,77\] It can lead people to avoid particular internet sites due to the social dynamics encountered there. Similar dynamics may also exist on MCF sites and impact who feels safe and welcomed on the platforms. For example, while GoFundMe has been used as a space for organizing in support of racial justice, and to memorialize and bring awareness to racial injustice,\[78\] the platform has also been widely associated with prominent campaigns in support of nationalist or anti-black activism. This includes campaigns to support armed militia unlawfully policing the US-Mexico border, and police officers responsible for the deaths of unarmed black people. While GoFundMe has later moved to shut down such campaigns, they continue to appear regularly on the site. GoFundMe’s past reluctance to shut down such campaigns was read by many as tacit endorsement. This, alongside observations that GoFundMe directly profits by playing host to such causes, has led to campaigns such as the #dontfundhate campaign, protesting fundraising in support of Darren Wilson, the officer who killed Michael Brown.\[79\] Incidents like these may lead to communities of color feeling excluded from, under-represented by, or unsafe on, such platforms.

Table 7. Poisson regression of demographic effects on number of Facebook friends.

|                           | Estimate | 95% Confidence Interval | P-value |
|---------------------------|----------|-------------------------|---------|
| (Intercept)               | 6.374    | (6.365, 6.383)          | <0.001*** |
| **Relationship to Recipient** |          |                         |         |
| Self (Reference)          |          |                         |         |
| Parent                    | -0.480   | (-0.497, -0.462)        | <0.001*** |
| Immediate Family Member   | -0.084   | (-0.094, -0.073)        | <0.001*** |
| Unmarried Partner         | -0.124   | (-0.175, -0.074)        | <0.001*** |
| Friend or Distant Relative| -0.117   | (-0.128, -0.105)        | <0.001*** |
| **Gender**                |          |                         |         |
| Male (Reference)          |          |                         |         |
| Female                    | -0.126   | (-0.133, -0.119)        | <0.001*** |
| Genderqueer               | -2.922   | (-3.269, -2.576)        | <0.001*** |
| Unknown                   | -0.362   | (-0.384, -0.339)        | <0.001*** |
| **Age of Recipient**      |          |                         |         |
| Adult (Reference)         |          |                         |         |
| Child                     | -0.004   | (-0.014, 0.006)         | 0.427   |
| **Race**                  |          |                         |         |
| White (Reference)         |          |                         |         |
| Black                     | -0.014   | (0.002, 0.027)          | 0.028*  |
| Non-Black POC             | -0.096   | (-0.107, -0.084)        | <0.001** |

Poisson regression analyzing the relationship between gender, age, race, and campaigner-recipient relationship and number of Facebook friends.

*** = < .001
** = < .01
* = < .05

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Disparities in representation on GoFundMe are compounded by disparities in outcome—evidence here that shows people of color are likely to raise less money on the platform, measured by both the number of donations and the average donation amount. Notably, being black was associated with earning $22 less per donation in comparison with white crowdfunding donors. These racial biases show effects even when the size of one’s online social network is taken into account. Differences in social network size do also contribute to crowdfunding outcomes, likely reflecting the existing biases and disparities that more vulnerable groups face on other social media platforms. Alongside limited but compelling research showing evidence of systemic racial biases on platforms like Airbnb and Kickstarter,[47–50] there is good reason to suspect that charitable crowdfunding platforms offer new spaces for existing racial biases to be enacted. These platforms may also exacerbate existing biases by exposing charitable appeals to a broader audience or subjecting campaigns to platform algorithms which might be biased against particular kinds of users. These inequities compound already acute social and health system disparities which limit access to, trust in, and equitable outcomes from, healthcare for people of color, particularly black women.

Alongside these racial inequities are unequal gender dynamics. It is notable that there are not significant differences in campaign outcome between men and women, except for in number of donations (see Table 6). However, these outcomes may mask a number of social dynamics and biases which are influencing MCF—such as gendered and racialized social mores about who should be entitled to social assistance (typically in the US this has been women and
More overt disparities are at work among non-cisgender crowdfunding users, with very few overall represented on the site (despite research showing that crowdfunding is a popular option for fundraising for transgender medical care); and with much poorer outcomes among non-binary users, though the n of 1 is very small. These findings resonate with those of Barcelos, who found that transgender crowdfunding campaigns raise on average a much smaller amount of money than has been found in research on general medical campaigns.[20]

The stark gender imbalances among campaign organizers represents a new frontier of gendered care labor which is being undertaken online and across digital social networks. Whether online or in person, gendered care labor often comes at the expense of self-care and the maintenance of one’s own social network ties, which may be represented in the disproportionate number of women who are self-campaigning as well. Data here confirms that the vast majority of campaigns do not go viral, and thus the ‘crowd’ with whom crowdfunders are interacting is often an intimate, densely connected social assemblage. This may increase the gendered aspects of the labor involved in campaigns, as much of it involves managing intimate relationships among family, friends, neighbors, and co-workers, and repeatedly interacting with this network both collectively and individually over time as the campaign unfolds. This represents a new domain of gendered, digital care labor, which underscores how both digital labor and care labor are deeply feminized within contemporary social and economic realms. This finding resonates with ample work in digital media studies showing how relational and affective labor is crucial to many practices and economies online, from the work of musicians engaging with fans, to the management of community forums, to the liking of status updates on Facebook.[40,41] Thus, crowdfunding platforms represent an amalgamation of various forms of often (unfairly) feminized labor, including work to: sustain relationships; catalogue, remember and manage exchanges within gift economies; keep information flowing among friends and family; manage emotions (of self and others); capture and share images; and foster and sustain empathetic connections.

Lastly, these results suggest interesting though unexpected dynamics of inequity between children and adults on crowdfunding platforms. The general under-representation of children within this sample contradicts the visibility of campaigns for children within the popular press and imagination, which may be driven by rare but highly viral campaigns such as “Saving Eliza”. [68] Several other factors might contribute to the under-representation of children, including the reticence of parents to post private information about their children online, the relatively larger number of social and charitable support programs available to sick children, or the fact that children tend to face fewer hospitalizations and chronic illnesses than adults. [80,81] A seeming paradox in campaign outcomes emerges: children’s campaigns attract more donations, but of lower average amounts. This may reflect a dynamic whereby children’s campaigns spread more widely through social media, perhaps because they elicit broad sympathy, but attract lower average donations as the donors contributing to their campaigns may not be as closely related to the family and thus willing to give less money. Thus, sympathy may not be synonymous with success on crowdfunding platforms—a dynamic that merits much more intensive analysis, particularly in terms of what motivates donors and how they decide what to give to specific campaigns.

**Conclusion**

This exploratory research presents the first known analysis of how basic demographic characteristics such as age, race, and gender are represented in MCF, and how these characteristics...
are correlated with crowdfunding outcomes. The data point to systemic disparities in terms of crowdfunding use and outcomes. It highlights how inequities can affect crowdfunding in different ways, such as the significant burden of digital care labor that falls on women, even while women and men have relatively similar campaign outcomes. The data also point to the likelihood of intersectional dynamics by which race, gender, age, and other disparities compound one another within the crowdfunding environment. Overall, this article provides essential evidence that crowdfunding is playing host to, and potentially exacerbating, social biases related to perceived deservingness; however, much more research is needed to better understand how these disparities are created, and the social and technological mechanisms through which they are sustained and compounded.

Data presented here indicate that existing technical and sociopolitical disparities act as barriers to entry for some people and affect the success of certain campaigns once they are set up. What this means is that people from marginalized groups may face two sets of inequities, both of which produce disparities in MCF, and which, taken together, compound each other. It is also likely that there is a feedback effect at work: if a person sees others in their demographic who are not successful in their MCF campaigns, they are probably less likely to turn to crowdfunding themselves when a need arises; conversely, if one sees others like them succeeding at crowdfunding, they may be more likely to use it themselves. Thus, outcomes among others in a social class or group may influence future use and success. Much more research is needed, however, to explore these dynamics in more detail, including the affective and personal dimensions of what it means to inhabit MCF spaces while coming from marginalized identities and backgrounds.

There are several limitations to this study. The first (and most prominent) relates to the data researchers are able to access from GoFundMe, which does not share data publicly. It is likely that GoFundMe collects much more robust information on users' demographics and geographic locations, but without access to this data, researchers must rely on coding methods like those described above, or facial recognition technologies, which present a host of methodological and ethical issues, particularly when used with racially diverse populations. The demographics that can be assessed from the data available are limited. A more nuanced measure of age would strengthen the analysis considerably and enable assessments of whether dynamics like ageism are impacting campaign outcomes. Also notably absent from the data are measures of socioeconomic status and class, which are important variables on which research has been limited. Future research exploring how different medical conditions impact campaign outcomes will be important as well. A larger data sample overall would also enable a more robust intersectional analysis and exploration of transgender and non-cisgender campaigns and their outcomes. Our sample also does not capture data from people who intended to set up crowdfunding campaigns but were not successful in doing so, due to a range of potential social and technological barriers. However, disparities in who is represented on crowdfunding sites are evident in the data and lend credence to the idea that these barriers prevent certain people from crowdfunding.

Variables for campaign outcome present several drawbacks, as discussed above. Without adequate measures for the severity of need across campaigns or for the number of views each campaign page received, it is difficult to develop a single robust outcome variable. Ideally, future researchers would be able to access an indicator of how many page views each campaign gets, so as to then compare various outcome measures against this. The analysis does not focus extensively on non-monetary measures of campaign outcome, including shares, likes, and comments. It is possible that by leaving these out, the analysis has not adequately captured the engagement of broader audiences who do not donate but do share, like, or comment on campaigns. This impact might be more acute for campaigns appealing to networks with less
financial capital and would be worth examining more closely in future studies. Finally the analysis uses the number of Facebook friends of the campaigner as a rough measure of online social network size, but this excludes other social media platforms that may be important to campaign outcomes and which may be preferred by different groups of users, as research suggests.[24]

Social media platforms are often designed and managed with little attention to how they may create or exacerbate disparities, and attention to disparities may be occluded by platform companies’ insistence that they are providing a public good. Given that MCF platforms are directly impacting patients’ ability to access and afford healthcare, it is essential that these dynamics be further examined. Given that much of the effect here may be due to social “crowd” dynamics, it is likely that any platform which enables healthcare access through crowdfunding is likely to create and exacerbate, rather than address, inequities and precarity. This is similarly true of platforms such as Uber, Airbnb, and Mechanical Turk—key players in a “gig economy” that contribute to economic precarity for user-employees, exacerbate broader social problems, and are difficult to regulate.[83,84] Thus, policymakers should aim to both address disparities within MCF and also (and more importantly) ensure broader healthcare entitlements and social safety net systems that would ease Americans’ reliance on MCF in the first place. A first step towards the former effort would be to encourage public access to MCF data and better transparency from crowdfunding companies. To work toward the latter, it is necessary to recognize that crowdfunding is wholly at odds with, and will never be a replacement for, a rights-based system of care which enables all people, regardless of identity, to access necessary healthcare.

Supporting information

S1 Fig. Heatmap of correlation of campaign features, social engagement and number of donors. Based on Spearman’s ranked correlation test used to test the independence of each campaign feature used in tests.

(PNG)

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References

1. Sisler J. Crowdfunding for medical expenses. Can Med Assoc J. 2012 Feb; 184:E123–4.

2. Snyder J, Mathers A, Crooks VA. Fund my treatment!: A call for ethics-focused social science research into the use of crowdfunding for medical care. Soc Sci Med. 2016 Nov; 169:27–30. https://doi.org/10.1016/j.soscimed.2016.09.024 PMID: 27665200

3. Berliner LS, Kenworthy NJ. Producing a worthy illness: Personal crowdfunding amidst financial crisis. Soc Sci Med. 2017 Aug; 187:233–42. https://doi.org/10.1016/j.soscimed.2017.02.008 PMID: 28274601

4. Bassani G, Marinelli N, Vismara S. Crowdfunding in healthcare. J Technol Transf [Internet]. 2018 Apr 20 [cited 2019 Jan 21]; Available from: http://link.springer.com/10.1007/s10961-018-9663-7

5. Medical Fundraising [Internet]. gofundme. 2018 [cited 2019 Jan 21]. Available from: https://www.gofundme.com/start/medical-fundraising

6. Cerullo M. Their twins’ medical costs total $750,000—each. They and thousands of others are counting on GoFundMe. CBS News [Internet]. 2019 Jan 28 [cited 2019 Jul 1]; Available from: https://www.cbsnews.com/news/crushedy-medical-bills-many-americans-go-online-to-beg-for-help?flag=CNM-00-10aag7e

7. Gofundme. A Universal Desire to Help: How GoFundMe Reached 40 Million Donors [Internet]. Medium. 2019 [cited 2019 Feb 5]. Available from: https://medium.com/gofundme-stories/a-universal-desire-to-help-how-gofundme-reached-40-million-donors-fe1c32b04dcc

8. Harris A. GoFundMe keeps gobbling up competitors, says it’s “very good for the market” [Internet]. Fast Company. 2018 [cited 2019 Jan 21]. Available from: https://www.fastcompany.com/40554199/gofundme-keeps-gobbling-up-competitors-says-its-very-good-for-the-market

9. Matthew J. Renwick, Elias Mossialos. Crowdfunding our health: Economic risks and benefits. Elsevier.

10. Collins SR, Bhupal HK, Doty MM. Health Insurance Coverage Eight Years After the ACA [Internet]. The Commonwealth Fund; 2019 Feb [cited 2019 Jul 1]. Available from: https://www.commonwealthfund.org/publications/issue-briefs/2019/feb/health-insurance-coverage-eight-years-after-aca

11. Helhoski A, Simons V. Seeking Medical Debt Relief? Crowdfunding Rarely Pays Off the Bills [Internet]. NerdWallet. 2016 [cited 2019 Jan 21]. Available from: https://www.nerdwallet.com/blog/loans/medical-debt-crowdfunding-bankruptcy/

12. Snyder Jeremy. Crowdfunding for Medical Care Ethical Issues in an Emerging Health Care Funding Practice, Hastings Cent Rep. 2016;(Nov–Dec):36–42.

13. Vox Ford, Folkers Kelly McBride, Caplan Arthur. Medical Crowdfunding’s Dark Side [Internet]. Health Affairs. 2018 [cited 2019 Jan 21]. Available from: https://www.healthaffairs.org/do/10.1377/hblog20181019.834615/full/

14. Young MJ, Scheinberg E. The Rise of Crowdfunding for Medical Care: Promises and Perils. JAMA. 2017 Apr 25; 317(16):1623. https://doi.org/10.1001/jama.2017.3078 PMID: 28334321

15. van Duynhoven A, Lee A, Michel R, Snyder J, Crooks V, Chow-White P, et al. Spatially exploring the intersection of socioeconomic status and Canadian cancer-related medical crowdfunding campaigns. BMJ Open. 2019 Jun; 9(6):e026365. https://doi.org/10.1136/bmjopen-2019-026365 PMID: 31227531

16. Lukk M, Schneiderhan E, Soares J. Worthy? Crowdfunding the Canadian Health Care and Education Sectors: Health Care and Education Crowdfunding. Can Rev Sociol Can Sociol. 2018 Aug; 55(3):404–24.

17. Durand WM, Joh, Adam E. M. Eltorai, Alan H. Daniels. Medical Crowdfunding for Patients Undergoing Orthopedic Surgery.
18. Jeremy Snyder, Peter Chow-White, Valorie A Crooks, Annalise Mathers. Widenin g the gap: additional concerns with crowdfunding in health care. Lancet Oncol. 2017 May; 18:e240. https://doi.org/10.1016/S1470-2045(17)30259-0 PMID: 28495286

19. Dressler G, Kelly SA. Ethical implications of medical crowdfunding: the case of Charlie Gard. J Med Ethics. 2018 Jul; 44(7):453–7. https://doi.org/10.1136/medethics-2017-104717 PMID: 29728452

20. Barcelos CA. Go fund inequality: the politics of crowdfunding transgender medical care. Crit Public Health. 2019 Feb 11:1–10.

21. Ortiz RA, Witte S, Gouw A, Sanfilippo A, Tsai R, Fumagalli D, et al. Engaging a Community for Rare Genetic Disease: Best Practices and Education From Individual Crowdfunding Campaigns. Interact J Med Res. 2018 05; 7(1):e3. https://doi.org/10.2196/ijmr.7176 PMID: 29402763

22. Briggsman S. Crowdfunding personal expenses: Get Funding for Education, Travel, Volunteering, Emergencies, Bills, and more! Briggsman; 2016.

23. 6 Steps to a Successful Campaign [Internet]. GoFundMe. [cited 2019 Jul 20]. Available from: https://support.gofundme.com/hc/en-us/articles/203604494-6-Steps-to-a-Successful-Campaign

24. Noble SU, Tynes BM, editors. The intersectio nal Internet: race, sex, class and culture online. New York: Peter Lang Publishing, Inc; 2015. 278 p. (Digital formations).

25. Kenworthy N. Crowdfunding and global health disparities: An exploratory conceptual and empirical analysis of donation-based medical crowdfunding around the world. Glob Health. in press;

26. Eubanks V. Automating inequality: how high-tech tools profile, police, and punish the poor. First Edition. New York, NY: St. Martin’s Press; 2017. 260 p.

27. Noble SU. Algorithms of oppression: how search engines reinforce racism. New York: New York University Press; 2018. 229 p.

28. Pitti SJ. The Devil in Silicon Valley: Northern California, Race, and Mexican Americans. Princeton, NJ: Princeton University Press; 2018.

29. O’Neil C. Weapons of math destruction: how big data increases inequality and threatens democracy. First edition. New York: Crown; 2016. 259 p.

30. Benjamin R. Race after technology: abolitionist tools for the new Jim code. Medford, MA: Polity; 2019.

31. Daniels J. Race and racism in Internet Studies: A review and critique. New Media Soc. 2013 Aug; 15 (5):695–719.

32. West SM, Whittaker M, Crawford K. Discriminating systems: Gender, race, and power in AI [Internet]. AI Now; 2019 Apr [cited 2019 Jul 1]. Available from: https://ainowinstitute.org/discriminatingsystems.pdf

33. Zuboff S. The age of surveillance capitalism: the fight for a human future at the new frontier of power. First edition. New York: PublicAffairs; 2018. 691 p.

34. Petty T, Saba M, Lewis T, Gangadharan SP, Eubanks V. Our Data Bodies: Reclaiming Our Data [Internet]. 2018 Jun [cited 2019 Jan 21]. Available from: https://www.odbproject.org/wp-content/uploads/2016/06/ODB.InterimReport.FINAL_.7.16.2018.pdf

35. Gangadharan SP, Eubanks V, Barocas S. Data and discrimination: Collected Essays. Open Technology Institute; 2014 Oct.

36. Tufekci Z. Algorithmic harms beyond Facebook and Google: Emergent challenges of computational agency. Colo Technol Law J. 2015; 13(2):203–17.

37. Noble SU. Teaching Trayvon: Race, Media, and the Politics of Spectacle. Black Sch. 2014 Mar; 44 (1):12–29.

38. Kendall L. Hanging out in the virtual pub: masculinitie s and relations hips online [Internet]. Berkeley: University of California Press; 2002 [cited 2019 Jul 18]. Available from: https://doi.org/10.1525/california/9780520230361.001.0001

39. Brock A. Life on the wire: Deconstructing race on the Internet. Inf Commun Soc. 2009 Apr; 12(3):344–63.

40. Baym NK. Connect With Your Audience! The Relational Labor of Connection. Commun Rev. 2015 Jan 2; 18(1):14–22.

41. Jarrett K. The Relevance of “Women’s Work”: Social Reproduction and Immaterial Labor in Digital Media. Telev New Media. 2014 Jan; 15(1):14–29.

42. Adair C, Nakamura L. The Digital Afterlives of “This Bridge Called My Back”: Woman of Color Feminism, Digital Labor, and Networked Pedagogy. Am Lit. 2017 Jun; 89(2):255–78.

43. Maragh RS. “Our Struggles Are Unequal”: Black Women’s Affective Labor Between Television and Twitter. J Commun Inq. 2016 Oct; 40(4):351–69.
44. Brockes E. Parents are exploiting their children on YouTube for fame and easy money. The Guardian [Internet]. 2019 Mar 22 [cited 2019 Jul 28]; Available from: https://www.theguardian.com/commentisfree/2019/mar/22/parents-exploiting-children-youtube-fame-easy-money

45. Fisher M, Traub A. On YouTube’s Digital Playground, an Open Gate for Pedophiles. The New York Times [Internet]. 2019 Jun 3 [cited 2019 Jul 28]; Available from: https://www.nytimes.com/2019/06/03/world/americas/youtube-pedophiles.html

46. Edelman B, Luca M. Digital Discrimination: The Case of Airbnb.com. Harv Bus Sch Work Pap No 14–054. 2014 Jan;

47. Kakar V, Voelz J, Wu J, Franco J. The Visible Host: Does race guide Airbnb rental rates in San Francisco? J Hous Econ. 2018 Jun; 64(7):3269–87.

48. Younkin P, Kuppuswamy V. The Colorblind Crowd? Founder Race and Performance in Crowdfunding. Manag Sci. 2018 Jul; 64(7):3269–412.

49. Younkin P, Kuppuswamy V. Discounted: The effect of founder race on the price of new products. J Bus Ventur. 2019 Mar; 34(2):389–412.

50. Rhue L, Clark J. Who Gets Started on Kickstarter? Racial Disparities in Crowdfunding Success. SSRN Electron J [Internet]. 2016 [cited 2019 Jul 18]; Available from: http://www.ssrn.com/abstract=2837042

51. Greenberg J, Mollick E. Leaning In or Leaning On? Gender, Homophily, and Activism in Crowdfunding. Acad Manag Proc. 2015 Jan; 2015(1):18365.

52. Hagan A. How Medicare For All Challenges our Ideas of Black Deservingness [Internet]. Somatosphere. 2019 [cited 2019 May 28]. Available from: http://somatosphere.net/2019/how-medicare-for-all-challenges-our-ideas-of-black-deservingness.html/?fbclid=IwAR320v20kHDS3UmkQ6f3yvTHI02IB-X82TAKwCd4hml7yMO50x0U

53. Sargent C. Special Issue Part I: ‘Deservingness’ and the politics of health care. Soc Sci Med. 2012 Mar; 74(6):855–7. https://doi.org/10.1016/j.socscimed.2011.10.044 PMID: 22245382

54. Hoffman BR. Health care for some: rights and rationing in the United States since 1930. 2013.

55. Tanenbaum SJ. Medicaid eligibility policy in the 1980s: Medical utilitarianism and the “deserving” poor. J Health Polit Policy Law. 1995; 20(4):933–54. https://doi.org/10.1215/03616878-20-4-933 PMID: 8770758

56. Katz MB. The undeserving poor: America’s enduring confrontation with poverty. Second edition. Oxford: Oxford University Press; 2013. 353 p.

57. Parker RG, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Soc Sci Med. 2003; 57:13–24. https://doi.org/10.1016/s0277-9536(02)00304-0 PMID: 12753813

58. Stangl AL, Earnshaw VA, Logie CH, van Braak L, Simbayi L, Barré I, et al. The Health Stigma and Discrimination Framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Med. 2019 Dec; 17(1):31. https://doi.org/10.1186/s12916-019-1271-3 PMID: 30764826

59. Markham A, Buchanan E. Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee [Internet]. Association of Internet Researchers; 2012. Available from: https://aoir.org/reports/ethics2.pdf

60. Communities in Action: Pathways to Health Equity [Internet]. Washington, DC: National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on Community-Based Solutions to Promote Health Equity in the United States; 2017 Jan. (Baciu A, Negussie Y, Geller A, editors. National Academies Press). Available from: https://www.ncbi.nlm.nih.gov/books/NBK425844/

61. Williams DR, Mohammed SA. Discrimination and racial disparities in health: evidence and needed research. J Behav Med. 2009 Feb; 32:20–47. https://doi.org/10.1007/s10865-008-9185-0 PMID: 19030981

62. Buolamwini J. Gebru T. Gender Shades: Intersectional Accuracy Disparities in Commercial Gender Classification. In: Friedler SA, Wilson C, editors. Proceedings of the 1st Conference on Fairness, Accountability and Transparency [Internet]. New York, NY, USA: PMLR; 2018. p. 77–91. (Proceedings of Machine Learning Research; vol. 81). Available from: http://proceedings.mlr.press/v81/buolamwini18a.html

63. Chinoy S. The Racist History Behind Facial Recognition. The New York Times [Internet]. 2019 Jul 10; Available from: https://www.nytimes.com/2019/07/10/opinion/facial-recognition-race.html

64. Roth WD. Methodological pitfalls of measuring race: international comparisons and repurposing of statistical categories. Ethn Racial Stud. 2017 Oct 21; 40(13):2347–53.

65. Hallgren KA. Computing Inter-Rater Reliability for Observational Data: An Overview and Tutorial. Tutor Quant Methods Psychol. 2012; 8(1):23–34. https://doi.org/10.20982/tqmp.08.1.p023 PMID: 22833776
66. Cicchetti DV. Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. Psychological Assess. 1994 Dec; 6(4):284–90.

67. Helhoski A, Simons V. Seeking Medical Debt Relief? Crowdfunding Rarely Pays Off the Bills [Internet]. NerdWallet. 2016 [cited 2019 Jan 21]. Available from: https://www.nerdwallet.com/blog/loans/medical-debt-crowdfunding-bankruptcy/

68. O'Neill G. Saving Eliza [Internet]. GoFundme. [cited 2019 Jul 1]. Available from: https://www.gofundme.com/ElizaO'Neill

69. Xu LZ. Will a digital camera cure your sick puppy? Modality and category effects in donation-based crowdfunding. Telemat Inform. 2018 Oct; 35(7):1914–24.

70. Taylor JMG. Kendall’s and Spearman’s Correlation Coefficients in the Presence of a Blocking Variable. Biometrics. 1987 Jun; 43(2):409. PMID: 3607205

71. Barcelos CA. ‘Bye-bye boobies’: normativity, deservingness and medicalisation in transgender medical crowdfunding. Cult Health Sex. 2019 Feb 14;1–15.

72. US Census. American Community Survey, 2013–2017 American Community Survey 5-Year Estimates, Table DP05 [Internet]. US Census; [cited 2019 Jul 1]. Available from: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

73. Cohen RA, Terlizzi EP, Martinez ME. Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey, 2018 [Internet]. National Center for Health Statistics; 2019 May. (National Health Interview Survey Early Release Program). Available from: https://www.cdc.gov/nchs/data/nhis/earlyrelease/insur201905.pdf

74. Wiltshire JC, Elder K, Kiefe C, Allison JJ. Medical Debt and Related Financial Consequences Among Older African American and White Adults. Am J Public Health. 2016; 106(6):1086–91. https://doi.org/10.2105/AJPH.2016.303137 PMID: 27077346

75. Assadi D. Crowdfunding: democratizing networking, financing and innovation. J Innov Econ. 2018; 26(2):3.

76. The World Bank. Crowdfunding’s Potential for the Developing World. InfoDev;

77. Rentschler CA, Thrift SC. Doing feminism: Event, archive, techné. Fem Theory. 2015 Dec; 16(3):239–49.

78. Kneese T. Mourning the Commons: Circulating Affect in Crowdfunded Funeral Campaigns. Journal of Social Media + Society. 2018; (Jan-Mar):1–12.

79. Zara C. GoFundMe Critics Raise Billboard In San Diego, Launch #Don’tFundHate Over Officer Darren Wilson Campaign. International Business Times [Internet]. 2014 Oct 9 [cited 2019 Jul 1]; Available from: https://www.ibtimes.com/gofundme-critics-raise-billboard-san-diego-launch-dontfundhate-over-officer-darren-1702134

80. Summary Health Statistics: National Health Interview Survey, 2017 [Internet], Centers for Disease Control; 2017 Oct. Report No.: Table P-10a. Available from: https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2017_SHS_Table_P-10a.pdf

81. Schor EL, Cohen E. Apples and Oranges: Serious Chronic Illness in Adults and Children. J Pediatr. 2016 Dec; 179:256–8. https://doi.org/10.1016/j.peds.2016.08.098 PMID: 27671116

82. van Duyhoven A, Lee A, Michel R, Snyder J, Crooks V, Chow-White P, et al. Spatially exploring the intersection of socioeconomic status and Canadian cancer-related medical crowdfunding campaigns. BMJ Open. 2019 Jun; 9(6):e026365. https://doi.org/10.1136/bmjopen-2018-026365 PMID: 31227531

83. Gray ML, Suri S. Ghost work: how to stop Silicon Valley from building a new global underclass. Boston: Houghton Mifflin Harcourt; 2019.

84. Irani L. Difference and Dependence among Digital Workers: The Case of Amazon Mechanical Turk. South Atl Q. 2015 Jan 1; 114(1):225–34.