Medical Crowdfunding and Disparities in Health Care Access in the United States, 2016-2020

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See also Snyder, p. 357.

Objectives. To assess whether medical crowdfunding use and outcomes are aligned with health financing needs in the United States.

Methods. We collected data on 437 596 US medical GoFundMe campaigns between 2016 and 2020. In addition to summarizing trends in campaign initiation and earnings, we used state- and county-level data to assess whether crowdfunding usage and earnings were higher in areas with greater medical debt, uninsured populations, and poverty.

Results. Campaigns raised more than \$2 billion from 21.7 million donations between 2016 and 2020. Returns were highly unequal, and success was low, especially in 2020: only 12% of campaigns met their goals, and 16% received no donations at all. Campaigns in 2020 raised substantially less money in areas with more medical debt, higher uninsurance rates, and lower incomes.

Conclusions. Despite its popularity and portrayals as an ad-hoc safety net, medical crowdfunding is misaligned with key indicators of health financing needs in the United States. It is best positioned to help in populations that need it the least. (Am J Public Health. 2022;112(3):491-498. https://doi.org/10.2105/ AJPH.2021.306617)

nline crowdfunding is increasingly perceived as an ad-hoc social safety net in the United States. GoFundMe controls more than 90% of the US donation-based crowdfunding market, where more than one third of campaigns are for medical needs. 1,2 More than 250 000 health-related campaigns are initiated yearly, raising more than \$650 million. Patients and families typically use medical crowdfunding to solicit financial donations from social networks for individual health and medical expenses. The average campaign raises a modest amount of money—several thousand dollars—to provide financial help for needs ranging from emergency and chronic care costs to routine out-of-pocket costs and

financial needs secondary to illness, such as lost wages.^{3,4} Medical crowdfunding has often been portrayed in the popular media as an ad-hoc safety net for patients in the United States, particularly in states where insurance coverage is low and medical debt and out-of-pocket costs are high. Many campaigners use crowdfunding to address health needs in the absence of more robust health coverage.³⁻⁵ But less attention has been paid to a key test of crowdfunding's efficacy as a "safety net": whether, and how well, it provides support to populations with the highest health financing needs.

More comprehensive research on the scope of US medical crowdfunding and its alignment with existing safety

net systems is needed to inform health policy decisions amid significant financial and health precarity. To date, little research has captured large-scale data on medical crowdfunding campaigns in the United States. A recent research brief assessed the medical conditions addressed and association with statelevel charitable giving among nearly 300 000 medical crowdfunding campaigns. 6 A large cross-sectional study of US cancer campaigns found that they raised less in areas with higher neighborhood deprivation, and those with existing socioeconomic advantage found more success. A similar study found that underinsured cancer campaigners "seek but do not receive higher donation amounts."8 Studies in

the United Kingdom and Canada found substantial evidence that campaigns are being used to fill gaps in health coverage. ^{3,5} Lee and Lehdonvirta complement these findings with a small but comprehensive study demonstrating that crowdfunding is used where formal and informal safety nets fail, but that success is harder to achieve in these areas. ⁹

This is the first large study in the United States to examine crowdfunding's effectiveness as an ad-hoc safety net by assessing how its use, earnings, and outcomes align with populationlevel health financing needs. We gathered a cross-sectional data set of US medical crowdfunding campaigns from 2016 to 2020 to examine use, rates of success, and inequalities in returns. Given persistent concerns with crowdfunding inequalities, including its potential to be most successfully leveraged by people with already high levels of social, cultural, and economic capital, 7,10-13 we utilized state- and county-level data to assess whether crowdfunding use and outcomes align with the areas of highest health financing and health coverage needs.

METHODS

Our cross-sectional study aimed to capture the largest possible set of publicly available US GoFundMe campaigns in recent years (2016–2020). Researchers have faced persistent difficulties in accessing platform-controlled data and generating representative samples of campaigns from available data. GoFundMe algorithms tend to prioritize more successful and geographically proximate campaigns in search results, which can bias samples. Many studies have relied on subsamples focused on specific medical conditions, using

targeted keyword searches. Others have relied on convenience sampling strategies, pulling data from top search results or platform-curated discovery pages, which likely replicates algorithmic biases toward more successful and trending campaigns. ^{9,14} Several recent studies have used GoFundMe's site index to generate lists of campaign pages⁷; however, we have found that the site index does not include all campaigns, especially those that are less successful.

To gather a more comprehensive set of campaigns, we created searches for each US zip code on GoFundMe in November 2020. GoFundMe search engines return results first for the searched zip code, and then nearby areas, up to 1000 individual campaigns. We found that 99.9% of zip code searches returned fewer than 1000 unique campaigns for that area, indicating that this is a strong strategy for generating a comprehensive set of available campaigns. Given evidence (discussed subsequently) that many low-performing campaigns are systematically removed from the GoFundMe Web site after 1 year, we performed our primary analysis on the subset of campaigns created in 2020. However, we summarized 5 years of data for comparison purposes. We identified 3 571 101 unique campaigns, of which 2360899 were US-based, with publicly accessible data; 504 790 were in the "medical, illness, and healing" category. Our data set was limited to 447 112 campaigns created after January 1, 2016. We excluded campaigns started less than a month before data collection (n = 9481), as these were more likely to have lower returns. In addition, we excluded 35 campaigns with average donations of \$25 000 or more from unverified "offline" donations: large

"offline" donations, which are not monitored by GoFundMe, typically indicate joke or fraudulent activity. ¹⁵ This left a sample of 437 596 US medical campaigns, 196 955 of them from 2020.

Data on campaign outcomes (goal, dollars raised, donations, shares), location (city and state), and date of campaign creation were automatically scraped from campaign pages. We first summarized key indicators of campaign performance by year. Analysis focused on 2 dependent variables: campaign prevalence, measured as the number of campaigns per 100 000 residents, and campaign earnings, typically measured as the amount of money raised. We measured correlations between state-level health financing needs, and campaign prevalence and earnings, by using data on proportions of state population with medical debt (from the 2018 National Financial Capability Survey)¹⁶ and percentage of population uninsured (from the 2018 US Census Small Area Health Insurance Estimates).¹⁷ Following earlier research indicating that cancer crowdfunding is less successful for marginalized populations in the United States⁷ and in areas with lower education and income in Canada, 18 we assessed whether similar patterns exist in states with higher health financing needs. To test for further associations with economic inequities at a county level, we used a quintile analysis to assess crowdfunding use and earnings at different per-capita income quintiles, using 2018 US Census data. 19

RESULTS

Of the campaigns in the "medical, illness, and healing" category on GoFundMe in 2016 to 2020, 437 596 met sampling criteria. These campaigns

raised more than \$2 billion from 21.7 million donations, toward a collective goal of more than \$8.45 billion. As shown in Table 1, median campaign earnings were small, raising \$1970 toward a \$8000 goal, from 24 donors. Variation between successful and unsuccessful campaigns was vast: the top campaign raised \$2.4 million from more than 70 000 donors, while 16.1% of campaigns were entirely unfunded, raising \$0. Half of campaigns reached 25% of their goal; a third reached 50% of their goal; a fifth reached 75% of their goal; and less than 12% fully reached their goal.

Table 1 shows steady declines in median returns, goals, donations, and

shares yearly, with steeper declines in 2020. This trend is likely attributable in part to the persistence of more successful campaigns over time, whereas unsuccessful campaigns are more likely to be deleted. However, the growing popularity of GoFundMe may also be contributing to a more competitive environment. In 2020, we observed a much larger proportion of unfunded campaigns—33.8%—indicating that unfunded campaigns were removed by users or site moderators after a year. Tellingly, the 4.1% of campaigns unfunded in 2019 were almost all from the last 2 months of the year, within a year of when we gathered our data. Notably, when we excluded unfunded

campaigns in 2020, poorer campaign outcomes persisted on all indicators compared with earlier years. While 2020 data reflected the impacts of COVID-19, which may have increased campaign creation, we can also observe increased inequalities in returns. In 2020, the top campaign earned more than twice that of previous years, with 3 times the number of donations, while a large number of campaigns went unfunded. Competition and inequality among campaigns is very high, while likelihood of success is quite low, especially in 2020.

Because 2020 offered the most comprehensive data set, we analyzed 2020 data in subsequent tests while offering

TABLE 1— Summary of Medical Campaign Characteristics by Year, 2016–2020, and Subset of 2020 Not Including Unfunded Campaigns: United States

	2016	2017	2018	2019	2020	2020 (Excluding Unfunded)	Total
No.	37 824	53 453	61 393	87 971	196 955	130 364	437 596
Goal, \$							
Median (IQR)	10 000 (5 000–20 000)	10 000 (5 000-20 000)	10 000 (5 000–20 000)	7 500 (3 500–15 000)	5 000 (2 000–12 000)	5 000 (2 750–15 000)	8 000 (3 250-15 000)
Range	1-1 000 000 000	1-150 000 000	1-987 654 000	1-1 000 000 000	1-1 000 000 000	1-758 000 000	1-1 000 000 000
Raised, \$							
Median (IQR)	4 150 (2 405-8 801)	3 530 (2 158-6 905)	3 400 (2 023-6 890)	2 135 (560-4 966)	265 (0-2 000)	1 125 (275–3 775)	1 970 (200–4 775)
Range	0-457 160	0-935 955	0-932 952	0-1 058 490	0-2 402 960	1-2402960	0-2 402 960
Donations							
Median (IQR)	49 (30-88)	41 (25-72)	39 (22–71)	26 (9-55)	5 (0-27)	17 (5–46)	24 (4-54)
Range	0-14943	0-24029	0-26330	0-19306	0-73 385	0-73 385	0-73 385
Shares							
Median (IQR)	380 (195–710)	284 (145–541)	236 (113-462)	147 (6-383)	0 (0-120)	45 (0-262)	116 (0–362)
Range	0-100 586	0-46 128	0-38 191	0-48 864	0-117997	0-117997	0-117 997
% raised of goal, %							
25	73.8	71.6	69.9	54.8	31.1	47.1	49.9
50	48.9	45.7	45.3	35.1	20.0	30.3	32.2
75	30.3	27.9	28.1	21.9	12.7	19.2	20.1
100	16.8	15.6	15.8	12.8	7.8	11.8	11.6
Unfunded, %	0	0	0.1	4.1	33.8	0	16.1

Note. IQR = interquartile range.

comparisons for other years in supplemental files. To assess how medical crowdfunding aligned with health financing needs, we tested the association between state-level campaign indicators and levels of medical debt and uninsurance. Figure 1 presents

scatterplots of campaign prevalence (number of campaigns per 100 000 residents) and earnings (median \$ raised) alongside proportions of residents with medical debt and without insurance by state. There were positive associations between campaign prevalence and

medical debt ($R^2 = 0.14$; P < .01) and between campaign prevalence and percentage of uninsured ($R^2 = 0.51$; P < .001), indicating that citizens in states with higher medical debt and uninsurance were turning more often to crowdfunding, as would be

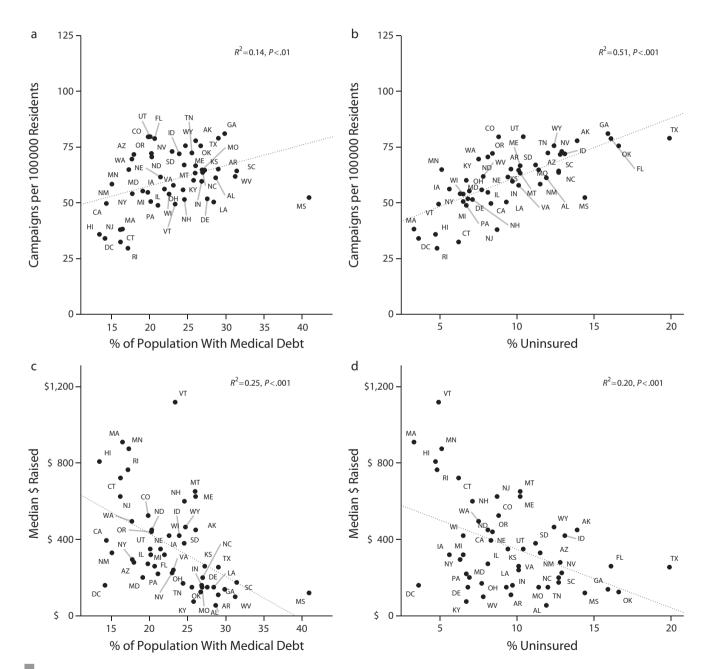


FIGURE 1— Scatterplots of State-Level Campaign Prevalence (per 100 000) and Median US Dollars Raised by Percentage of Residents (a, b) With Medical Debt and (c, d) Without Health Insurance: United States, 2020

Note. Fitted regression line and R^2 depicted on each plot. *Source.* Medical debt data from National Financial Capability Study¹⁶; health insurance data from 2008 to 2018 Small Area Health Insurance Estimates.¹⁷

	Median Income, \$	Campaigns, No. (%)	Donations, No. (%)	Amount Raised, \$ Million (%)
Quintile				
1	19 264-47 045	39 091 (19.9)	868 977 (13.3)	70 (12.6)
2	47 045-53 739	41 742 (21.2)	1 117 137 (17.1)	92 (16.5)
3	53 742-60 716	42 915 (21.8)	1 498 954 (23.0)	119 (21.5)
4	60 739-72 330	38 175 (19.4)	1 399 942 (21.5)	122 (22.0)
5	72 337-129 558	34740 (17.7)	1 630 282 (25.0)	152 (27.3)
Total		196 663	6 515 292	555

Note. Each quintile represents one fifth of the US population. Quintiles 1 and 2 overlap for median income because 2 counties had the same median income. Data exclude 0.15% of campaigns in which county-level census income information was not available for campaign zip code.)¹⁹

expected. In terms of campaign earnings, however, we observed a strong negative association between median campaign earnings and both medical debt ($R^2 = 0.25$; P < .001) and percentage of uninsured ($R^2 = 0.2$; P < .001; Figure 1). Thus, while medical crowdfunding is more common in states with lower insurance coverage and higher medical debt, campaigns in those states raised less money.

In Figures A through D (available as supplements to the online version of this article at http://www.ajph.org), we present similar analyses for other years—2016 to 2019—and 2020 excluding unfunded campaigns. Associations for campaign earnings remained similar and significant for all other years, indicating that crowdfunding earnings were consistently lower where needs were highest. There was a small but growing association between campaign prevalence and uninsurance over time, but this effect was particularly strong in 2020. For associations between prevalence and medical debt, 2020 was an outlier, and all other years showed no significant relationship. When we excluded unfunded campaigns for 2020, the relationship also all but disappeared, indicating that unfunded campaigns accounted for the association between campaign creation and medical debt. This may reflect the difficulties of leveraging crowdfunding to pay off medical debts rather than prevent them.²⁰

Given these state-level dynamics, we further explored how economic inequality might be associated with campaign prevalence and earnings at a smaller spatial level. Table 2 presents data on campaign prevalence, number of donations, and total amount raised by campaigns sorted by income quintile. Campaign location data were used to create equalpopulation quintiles according to county median income. There were fewer campaigns in the high- and lowincome quintiles and the greatest density of campaigns in the middleincome level. By contrast, both number of donations and overall amount raised by campaigns were lowest in low-income guintiles and increased noticeably in higher-income quintiles. This indicates that campaigns initiated in the highest-income areas of the United States will have the greatest likelihood of success. This effect remained similar for 2016 to 2019 as shown in Figure E (available as a supplement to the online version of this article at http://www.ajph.org).

DISCUSSION

This article provides one of the first large-scale assessments of medical crowdfunding in the United States, showing its use and outcomes are misaligned with key indicators of health financing needs. Medical crowdfunding is undeniably popular, but the \$2 billion raised by campaigns is small compared with the \$3.8 trillion spent on health care in the United States in 2019 alone.²¹ With more than 26 million individual donations, medical crowdfunding's impact on public attention and engagement far outpaces its contributions toward health expenditures. This finding is supported by survey data indicating that 20% of US households have contributed to a medical crowdfunding campaign.²² Despite growing popularity, rates of success were low, especially in 2020, with a large proportion of unfunded campaigns. These inequalities are compounded by stateand local-level inequities. While increased financial needs can align with more campaigns, campaigns have the lowest earnings where needs are highest. Income is associated with campaign success, whereas campaign earnings are worst at the lowest income levels. These results align with

recent research on cancer crowdfunding.^{7,18}

Several interwoven forces contribute to these effects. Because most crowdfunding campaigns rely on donations from social networks, and networked wealth can vary by socioeconomic status, campaigners from lower socioeconomic status groups have fewer networked resources on which to draw.¹³ Medical debt and uninsurance in communities leads to poorer overall health, higher care burdens, and higher income inequality, compounding inequalities in likelihood of crowdfunding success. 23,24 And barriers to entry and success for crowdfunders correlate with these independent variables, such as literacy, education status, or technology access.4 Thus, medical crowdfunding can both fuel, and be fueled by, growing disparities in health care systems.²⁵

Is crowdfunding serving as an ad-hoc safety net? Lee and Lehdonvirta refer to crowdfunding as an "entrepreneurial safety net," noting that this competitive environment rewards the same "characteristics and endowments" as the broader market economy. 9(p20) Drawing on the cliff analogy for addressing social determinants of health,²⁶ we view safety nets as intended to equally catch those who fall off the cliff of good health. For a lucky and privileged few, crowdfunding offers not a net but a trampoline, launching them toward significant financial support. For the rest, the net is riddled with holes. There is an urgent need to understand crowdfunding as a driver of disparities in health care financing and access.

Digital platforms do not preserve data well, and users, who have a "right to be forgotten," can also delete their campaigns, removing crowdfunding data from the site.²⁷ We found a large

proportion of unfunded campaigns in 2020 that was not apparent in earlier vears, with indications that unfunded campaigns are being removed from the site. It is hard to discern whether removals are user- or platforminitiated. Like much retrospective online data, comparisons across years should be handled carefully because of this survival bias. We observed largely consistent trends across 2016 to 2020 in terms of misalignment with health financing needs, indicating that medical crowdfunding has consistently been least effective for those with the highest financial needs and, if anything, is worse than reported here because of selective deletion of unfunded campaigns.

Limitations

This study had several limitations. It was exploratory, and further research is needed to elaborate on these dynamics. By relying on zip code searches, a very small number (0.1%) of zip codes with very high population density may not have yielded comprehensive data. Data from 2020 likely included impacts of COVID-19 on crowdfunding, which other studies have noted increased overall campaign creation and lowered success because of growing competition and economic impacts of the pandemic. 28,29 Here we found that associations in data were more pronounced, but not fundamentally different, between 2020 and previous years, with the exception of associations between medical debt and crowdfunding prevalence.

Public Health Implications

Crowdfunding is a disruptive technology that is reshaping how patients

finance health care in the United States. While popular and frequently cited as an ad-hoc safety net, its protection is limited and inequitable. Campaigns raise a median of \$1970, which can certainly offer relief for some users from the cost burdens of care, but largely does so for those who need it least.²⁰ These minimal positive impacts come with steep social and health equity costs. Health policy researchers and policymakers must recognize this sector's impact on health care access and health and social inequities, particularly as a growing body of research demonstrates inequities in crowdfunding by race, gender, socioeconomic status, and, now, health care financing needs. 7,10,13,18,29 Our preliminary analysis shows that crowdfunding's use and outcomes are misaligned with needs, making it neither an effective nor a fair means of filling safety net gaps. Further analyzing these trends requires public access to anonymized crowdfunding data, particularly for unfunded and deleted campaigns. Crowdfunding is symptomatic of broader financial toxicities and health inequities in the United States, conditions from which crowdfunding companies directly profit. Thus, crowdfunding is unlikely to effectively ameliorate these conditions and may well contribute to them.

Therefore, we offer 3 preliminary policy recommendations. First, there is an urgent need for more transparency in crowdfunding data: policymakers and researchers should call on companies like GoFundMe to publicly share data to enable better research and policymaking and support legislative efforts to mandate company disclosures of how user data are collected and sold. These data should be used to better inform policymakers and the public about the limited benefits—and

significant inequities—of crowdfunding use for health coverage needs. Second, public health researchers should join calls for public transparency and accountability in company algorithms, which, in this case, may shape the visibility and success of campaigns, contributing to inequities. Finally, and most importantly, expanding more universal health coverage and social assistance would alleviate reliance on such inequitable and misaligned digital "safety nets." AJPH

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CONTRIBUTORS

N. Kenworthy led the conceptualization and writing. M. Igra collected the data and conducted the data analysis. Both authors contributed to revising and editing.

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CONFLICTS OF INTEREST

Neither author has any known conflicts of interest to declare.

HUMAN PARTICIPANT PROTECTION

This study was national in scope and used public secondary data as well as data collected from publicly available sources. The University of Washington Human Subjects Division determined that institutional review board approval was not required for this study because it used publicly available data and did not involve interactions or interventions

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