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THE VALUE OF YOUR LIFE BY THE NUMBERS

CROWDFUNDED MEDICAL DEBT

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This paper on medical crowdfunding and social value synthesizes and discusses findings surrounding demographic differences in performance when crowdfunding, particularly on GoFundMe. Using this data and Judith Butler's idea of grievability, the paper suggests that medical crowdfunding, through the analysis of social interconnectivity, can be used as a metric to understand who is and isn't grievable in the US. The paper then ultimately concludes that both a radical overhaul of the American medical system and a more comprehensive welfare system are necessary in order to foster a happy, healthy and socially connected America.

INTRODUCTION

Following a recent spinal cord injury, my partner took the liberty of creating a GoFundMe campaign to assist me and my family in paying for my care. Many of my friends, family, teammates, and classmates heard about this campaign through word of mouth, texts, social media, or posters and donated to or shared it. They interact or have interacted with me, whether it is in class, on the field, or just seeing me around. Despite the massive help to my family, my campaign, like many others, didn't reach its goal. In that regard, my campaign is not in the minority. Rather, me and my family were lucky to even get it off the ground. The fact of the matter is, most GoFundMe campaigns fall far short of their goal, or in other words: fail.

Despite this, GoFundMe, the largest medical crowdfunding platform in the United States, has increasingly, and worryingly, come to supplement and supplant the American healthcare system for many Americans. While the American system is known to have brought about great innovations in health such as insulin, corrective heart surgery, and kidney transplants,¹ it is also the very same system that has monetized them, putting these medications and procedures outside the reach of many who need them.² Medical costs have put tens of millions of Americans into financial destitution³ over problems that they had no way to avoid. Injury and sickness, while sometimes predictable, are most often spontaneous, leaving most Americans in a constant state of precarity, one accident away from financial ruin. Even after the contributions of our health insurance, my family was stuck with over $7,000 in medical debt. Among my friends in rehab, I was considered lucky

for that sum.

While many injured and sick Americans do have health insurance, that is certainly no guarantee that one is safe from the financial ramifications of this broken system; many insured Americans still struggle to cover their monthly insurance bill or the cost of care after insurance.⁴ Covering these costs can obviously be difficult, and as a result, many Americans turn to their friends, family, and neighbors for help through crowdfunding. In doing so, they are playing on their grievability, or their perceived social value, to raise money. This trend has continued and intensified in recent years, with medical campaigns on GoFundMe growing in 2020 to over 5 times their number in 2016.⁵ While the reasons for this trend are up for debate, Americans’ growing medical debt,⁶ a shrinking economy and the growing popularity of the platform⁷ are all likely explanations.

Using GoFundMe, I will demonstrate how one’s grievability is connected to and dictated by social interconnectedness and apply that to the cases of my own crowdfunding experience as well as crowdfunding as a whole in America to demonstrate differential grievability among demographic groups. I argue that the surge in the use of crowdfunding to supplement and supplant health insurance is a larger issue of the social value of your life and can be used as a metric to understand who is considered grievable and, more importantly, who is not. Crowdfunding’s attractive capability to relieve Americans’ medical debt in a shrinking economy has expanded in recent years, all while putting both a face and an identity to whom Americans give their money. Crowdfunding, rather uniquely, possesses the ability to reify and measure grievability.

**MEDICAL CROWDFUNDING: HOW IT OPERATES AND ITS NECESSITY**

Crowdfunding has become an integral part of the means to attain care. While not every American who has an experience in the American medical system is put into a situation in which they feel GoFundMe is needed or helpful, a significant chunk have either turned to GoFundMe as a last resort or used it to take the edge off of what could otherwise be a financially crippling sum.⁸ Due to the inability of many Americans to pay exorbitant (and inflating) medical bills, the market opens up for sites like GoFundMe, simultaneously individualizing the issue and taking responsibility away from the failing medical system. The American system’s death spiral of privatization and subsequent failure has carved out the niche for GoFundMe, shifting the blame off of the privatized American system, and onto unsuccessful campaign organizers. The feel-good story of people helping their friends and neighbors is nice, but do not let that fool you; this is a very problematic phenomenon. While health insurance may not mean one can be certain of financial coverage, and their failure is a reason for many of GoFundMe’s patronage, coverage from health insurance is far more likely to cover the costs of a brush with the American medical system.⁹ But the false hope, or cruel optimism, to use the words of Lauren Berlant, of one being able to cover their medical debt through crowdfunding, creates a vexing issue of growing reliance

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⁶Yabroff et al., “Prevalence and Correlates of Medical Financial Hardship in the USA.”
⁷Lee, “Most GoFundMe Campaigns For Medical Bills Fail, Less Than 12% Reach Goals.”
⁸Lee.
⁹Lee.
upon crowdfunding.¹¹ On top of the American population that can’t afford insurance in the first place, insured Americans pressed for cash may now think that they can eliminate their health insurance for that money and rely upon crowdfunding when they become injured or sick. Thus greater exposure to precarity is felt by the American populace on a given day, a trend that will be discussed later.

This paper will operate largely on statistics and arguments particularly concerning GoFundMe. Essentially, GoFundMe and websites like it provide the tools for just about anyone to set up a campaign on their website, and in exchange, they take a 2.9% + 30¢ fee¹² off of every donation. This fee means that setting up a campaign is completely free to the organizer, and the cost is footed by those who choose to donate. Once the campaign has been created, the creator is able to create a link to it to share all over websites like Instagram or Facebook and create QR codes for posters. GoFundMe largely relies upon being used in tandem with social media platforms like Instagram, Facebook, and YouTube. The social media piece is how a lot of campaigns source the bulk of their funds. Rather than living solely on GoFundMe’s website, where it is unlikely to attract any significant attention, social media has a “pushing” effect.¹³ This is exactly why many crowdfunding websites recommend (for their own benefit and the campaign’s) that the creator puts it onto their social media page(s),¹⁴ exposing the campaign to people who care about the injured/sick person and to those who are not actively looking for causes to donate to. This effect has revolutionized the way Americans, and people around the world, crowd fund. Campaigns that use social media to spread the word not only end up bringing in a great deal more money,¹⁵ but also take out a lot of the legwork and costs of otherwise needed crowdfunding events, meaning they net a higher amount for the actual cause.¹⁶ But this reliance upon social media, and thus one’s social network, creates an interesting demonstration of value that will be discussed in the application of the concept of grievability.

GRIEVABILITY, SOCIAL INTERCONNECTIVITY, AND SOCIAL VALUE

In the introduction to her book Frames of War, Judith Butler notes that most people are familiar with grief as a function of a life ended or lost,¹⁷ but not so familiar with grievability as a concept. In her words: “grievability is a condition of a life’s emergence and sustenance”¹⁸ that she argues leads to its recognizability, or ability to be read as, a life. To be without grievability, Butler argues, is to be “something living that is other than a life.”¹⁹ Grievability is lent to people by their ability to be legible as a life. As such, it is, to some degree, a function of perspective and position. My particular campaign was effective and people donated because of my proximity to them, or our shared circles of social interdependence. I argue that while “success” may be an idea subject to people’s perspectives, there are people who are understood to be more grievable than others. Grievability is, in some ways, contingent on how interconnected you are. A larger social circle and online social presence, the more one’s absence will be felt. So through my circle’s unconscious obligation to notice and feel my absence, I know that I am grievable to those people. That lack of my presence is noticed; as Butler puts it, “only

¹¹Lee, “Most GoFundMe Campaigns For Medical Bills Fail, Less Than 12% Reach Goals.”
¹⁴Huang et al.
¹⁵Huang et al.
¹⁶Huang et al.
¹⁸Butler, 15.
¹⁹Butler, 15.
under conditions in which loss would matter does the value of the life appear.” Inversely, then, in conditions in which loss doesn’t matter, life is not perceived as valuable. Imagine the same injury that I suffered, but if it had happened to someone none of us knew. To my friends and family who donated, they would never have known the person was injured. This isn’t their fault, nor is it the fault of the person who was injured, but their grievability, or their social value, isn’t felt by my donors. This is an inherent limitation of human socialization; not only can we not know everyone, but even if we did, not everyone makes a noticeable difference in our lives. So while this injured person may have the same injury and costs, their story doesn’t ever make it to my donor’s ears, meaning that they are not perceived as grievable by my donors. On their end, this person has their own circle, and within their circle, they have people who find them grievable and not me. Grievability, then, must be understood as a condition that is experienced subjectively.

Social interconnectivity, or interdependence, is like a measurable piece of theory that can be used to understand grievability through crowdfunding data. Social interconnectivity is an attempt to measure one’s integration, reliance upon, and contribution to their community. It is somewhat well understood by those who study social interconnectivity that typically, as a function of economic class, social interconnectivity is lower among impoverished Americans. In Nicole Stephens, Jessica Cameron and Sarah Townends’ study, Lower Social Class Does not (Always) Mean Greater Interdependence, they demonstrate this fact, and go on to explain that the reason that this trend is created and maintained may be due to the economic pressures that come with poverty and the greater level of precarity, or proximity to destitution, one finds themselves in when in poverty. An example given in the conclusion of the study explains this phenomenon best: “if individuals encounter an unexpected challenge, such as losing a job, and lack the social connections (e.g., a job referral) necessary for finding a new job, their economic position may deteriorate more than it would have in the presence of greater social resources.” Even if the social resources aspect of poverty didn’t come into play, Stephens et. al argue that the lower interconnectivity brought on by poverty also worsens people’s psychological well-being and mental health, leaving them less able to cope with adversity and stress. The bottom line is this: social interconnectivity, or rather the lack thereof, is a weapon with which impoverished people are kept in precarity.

Butler, 14.


Stephens, Cameron, and Townsend, “Lower Social Class Does Not (Always) Mean Greater Interdependence.”

Stephens, Cameron, and Townsend.

Stephens, Cameron, and Townsend, 1070.

Stephens, Cameron, and Townsend, 1070.

Stephens, Cameron, and Townsend, 1070.

Stephens, Cameron, and Townsend, 1070.
SOCIAL INTERCONNECTIVITY AND CROWDFUNDING

Americans kept impoverished through their lack of social interconnectivity, among other things, will inherently experience a higher level of precarity when it comes to their health. Unlike their middle and high-class counterparts, they have fewer financial resources to pay for health insurance or medical debt. This lack of resources leads to them having a higher reliance upon crowdfunding as discussed earlier, due to the necessity of it as a last resort to pay for care. While reliance upon crowdfunding is already a worrying trend, that compounds with the fact that impoverished and poor Americans, who need help the most, show far lower metrics of success on GoFundMe and websites like it. In a study by Nora Kenworthy and Mark Igra²⁹ on the disparities of who receives money on GoFundMe, they found that, from over 400,000 campaigns studied, those originating from the poorest quintile of American counties were in fact the least likely to meet their goal, and had the fewest donations and least money raised³⁰ when compared to the 4 richer quintiles.

One of the most glaring explanations for this trend is that GoFundMe, being donation based, relies heavily upon the social net people are surrounded by. Having more friends, or even just more people who consider one grievable, should, on average, naturally lead to a higher amount of donations, as they should be the people who directly value one’s health. In the case of my own campaign, and mirrored in GoFundMe campaigns' typical heavy reliance on social media, the bulk of people's donations come from the people around them; their friends, family, coworkers, and teammates. Being more socially interconnected,

³⁰Lee, “Most GoFundMe Campaigns For Medical Bills Fail, Less Than 12% Reach Goals.”

and thus having more people around you, should lead to a higher success rate among those campaigns. In reality, the richest quintile of American counties shows the highest success across all three of these categories, despite not having high social interconnectivity. This is because crowdfunding doesn’t have to be as simple as sourcing donations from your friends and family. Richer people and especially richer families have, through an inherent byproduct of their money, more fluid schedules.³¹ Money gives them the ability to take extended breaks from work and still be able to support themselves. Along with this money are financial resources that can be used to better their campaign. To complete the recipe for success, rich Americans also have a tendency to have richer friends,³² meaning more disposable income in their circles and thus greater donation size. Through a mix of these, the rich are able to offset their lower social interconnectivity through more working hours on their campaigns, richer donors, and money that can go into getting the word out. All the while, impoverished Americans are without these resources and typically hold lower social interconnectivity than the rich. Without these factors to offset their lack of interconnectivity, campaigns from impoverished Americans are left to wither on the vine. Additionally, these impoverished Americans who experience lower rates of success in crowdfunding disproportionately include members of minoritized identities, which will be discussed in the following section.³³ ³⁴

³¹Stephens, Cameron, and Townsend, “Lower Social Class Does Not (Always) Mean Greater Interdependence.”
³³Lee, “Most GoFundMe Campaigns For Medical Bills Fail, Less Than 12% Reach Goals.”

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ANALYZING DISPARITIES AMONG MINORITIZED AMERICAN POPULATIONS

While it may seem obvious to some, it should be explicitly stated that American institutions, including the American medical system, have long shown biases against members of racial, sexual, and gender minorities.³⁵ These biases compound to place these minoritized groups in a higher level of precarity than their White, straight, and cisgender counterparts, which also creates a higher need for medical crowdfunding. Despite this, members of American racial minorities are actually less likely to create a campaign,³⁶ which could be due to the lower likelihood of success and lack of access to the internet among communities of color.³⁷ Whatever the reasoning, this finding aligns with other existing trends of lower numbers of campaigns being launched from poorer counties.³⁸ Black, Hispanic, and Asian American families all hold far less average wealth than their White counterparts.³⁹ This means that these families experience a higher average need for money from crowdfunding, but are also far less likely to have successful campaigns. Being publicly oriented, crowdfunding will inherently express the biases of the American populace. For example, in a study on crowdfunding it was found that Black organizers receive, on average, $22 less per donation.⁴⁰ This aligns with the trend of impoverished Americans receiving lower donations and also shows how that unequally affects people of color.

Queer and trans people see a difference in their performance on GoFundMe as well. Although I was not able to find as comprehensive of data on the subject as for members of racial minorities, it would seem the difference in performance for LGBTQ Americans is more tied up in the methods than the results. Transgender Americans, for example, have different medical needs in that they often seek gender-affirming care, and members of all gender and sexual minorities actually hold a higher reliance upon existing online groups.⁴¹ This is probably partially due to their lower likelihood to have medical insurance,⁴² but also a difference in the acceptance of their identity. This will be discussed later, but being a heavily politicized group, LGBTQ Americans seeking care often need to go further to find it, resulting in a heavier reliance on social media. While not a traditional form of social interconnectivity, online friends and affinity groups are absolutely means by which one can be socially interdependent. To some degree, the congregation of LGBTQ Americans into online communities may in fact be a transcendence of social interconnectivity, finding community outside their own physical space. Re-

³⁵Hanks, Solomon, and Weller.
³⁸Lee, “Most GoFundMe Campaigns For Medical Bills Fail, Less Than 12% Reach Goals.”
³⁹Hanks, Solomon, and Weller, “Systematic Inequality - Center for American Progress.”
Regardless, this higher reliance on social media reflects the social isolation felt by many queer and transgender Americans.

These differential results are an issue that plagues crowdfunding websites, no matter the cause (medical, business, charity, etc.)43 These differences are a natural expression of the implicit biases held by American donors as well as long-term systemic isolation. Furthermore, especially when it comes to transgender Americans, the politicization of medical needs leads to an interesting conversation of palatability and social acceptance.

PALATABILITY, POLITICIZATION, AND PUBLIC INTIMACY

Medical crowdfunding is clearly different from other forms of crowdfunding. It is deeply personal, requiring the re-telling of a possibly traumatic story to hundreds, if not thousands, of people. In my own experience, I often pondered the implications of this. I still experience post-traumatic stress under certain situations that remind me of my injury six months later. Even just telling one person about my own injury can bring me discomfort. When Americans are refused free healthcare and the poor are forced into reliance upon crowdfunding, the American system is forcing this same retelling upon hundreds of thousands of Americans.

Not only can this result in undue pain, but it also creates a prioritization of stories. When trying to get people to donate, what one is essentially doing is playing to become grievable to the reader. While to this point I have focused upon success as a function of how many people a campaign reaches, actually getting the people one reaches to donate is arguably just as important. This is why successful campaigns will have not only an introduction to the injured person, but will be fleshed out with pictures of major life events and hobbies, regular and frequent updates, and an explanation of their condition. Campaigns that have large text explanations of the situation show far higher metrics of success43 than those that don’t, and optimizing a campaign’s use of pictures has the same effect.44 The degree to which one can make their campaign more complete, attractive, and aesthetic has a high correlation with its success. While this isn’t necessarily fair, this is how one relays grievability. The more completely a person is portrayed through a campaign, the more attached potential donors become to the campaign, the safer donors feel with spending their money and ultimately, the more likely they are to donate. This creates a distinct monetary incentive for one to synthesize a publicly palatable story, one that can be read and interpreted in a positive light by as many people as possible. This means people are forced to hedge some of the truths of their story, omit details or generally soften up their experience. This incentive means people have to choose between telling the entire truth of their experience or optimizing their palatability to potential donors. On top of this, the people writing the descriptions of the campaigns are most often the ones who are receiving medical treatment.45 While GoFundMe is here to help, it incentivizes people to focus on and retell the pain they have endured while already in an incredibly painful time in their life.

Furthermore, this palatability applies heavier constrictions upon those in minoritized groups. Given that crowdfunding relies upon the American public, a member of a minoritized group seeking care will have to fight not only to create a palatable campaign but also against people’s preconceived notions or opinions about the group they belong to. For example, transgender people seeking care in the US will have a harder time securing funding because of their generally lower cultural acceptance in America. Not only do they need to convince people that they are a worthy cause to donate to, they need to do so from lower

44Zhang, Lyu, and Luo, 188.
45Zhang, Lyu, and Luo, 188.
perceived grievability to start with. Someone with more cultural grievability though, such as a white cisgender male, will have an easier time being legible to more people as a life deserving of one’s donation.

Palatability also extends to the type of medical situation the campaign is made to support. Campaigns that are made to support procedures or conditions that are perceived as “resolvable”⁴⁶ will, on average, show higher metrics of success. This would include something like a broken arm, torn ligament, or other more acute injuries. On the other hand, conditions that are less “resolvable,” including things like cancer, long-term rehabilitation, or a spinal cord injury, see less success. This is because people want to feel like their money is going somewhere, and one way to get that is through a quick turnaround. Investment in longer-term injuries forces people to stay tuned to feel that payoff which can be a greater emotional investment. Similarly, emergency cases tend to grab more cash as well.⁴⁷ In order to maximize one’s grievability one requires either great luck in their medical situation or the willingness and ability to exaggerate or mute certain details. These aren’t things everyone possesses or has the time or resources to learn. The American system forces people to not only spend more on their own care than they would in other developed countries,⁴⁸ but to pay out of pocket for their fellow Americans who cannot afford care.

SOLUTIONS AND CONCLUSION

The issue I’ve laid out in this paper goes beyond just a problematic healthcare system. The system is so flawed, so useless, that it forces people into charity and/or financial ruin.⁴⁹ In that charity, donors with limited resources themselves, must choose who “deserves” care more, which, when done by the whole American population, demonstrates differential grievability through the social value of different people’s health. Medical crowdfunding, and its inevitable failures, are a measurement by which we can understand social value and how it is attributed. People “earn” grievability through their social interdependence and efforts to maximize it. So, assuming that our issue is creating an equitable healthcare system to demonstrate the extension of social value to all Americans, we have a few options.

Any solution for the current situation will require massive undertakings, so while some could be less radical than others, they are necessarily structural and large in scale. The first solution is to deliver financial assistance to those in need. This would include people who struggle to afford to live in this country, regardless of their employment status, housing status, or other oft-used methods of denial of benefits. The idea is to give everyone a baseline to live off of. This would include things like a place to live, food, power, water, and access to transportation. These benefits would not come in the form of a blank check, but rather as a system set up to grant housing, food, water, etc. directly to the people in need. That way the money the government spends on this program is used how it was meant to be used. It is worth mentioning that the U.S. Government does have some of these programs in place, with programs like Food Stamps, housing assistance, and reduced public transportation fares. Regardless, the American Government’s attempts at welfare are as unsuccessful as they are disingenuous and underfunded. While the logistics of these programs and their expansion aren’t perfect, there can be methods by which it can be determined where these resources need to go. This should both make it more palatable to otherwise-opposed voters and make it more faithful to its purpose.

Alternatively (or maybe in tandem), we could

⁴⁶Huang et al., “Explaining Donation Behavior in Medical Crowdfunding in Social Media,”
⁴⁷Zhang, Lyu, and Luo, “What Contributes to a Crowdfunding Campaign’s Success?”
⁴⁹Yabroff et al., “Prevalence and Correlates of Medical Financial Hardship in the USA.”
undertake a massive reconstruction of the American medical system to guarantee medical care to all. At the moment, anyone who has dealt with the American system can tell you it is absolutely broken. Not only do Americans get lower quality health care than other comparable countries, but we also pay more.⁵⁰ This new system, if modeled and executed correctly, would be cheaper for the everyday American, by eliminating the “middlemen” of health insurance, and having people communally pay, through taxes, for each others’ healthcare.⁵¹ While it wouldn’t be perfect, and would still have some of the pitfalls of inequity in today’s system, it’s a start. Both of these systems would be built to guarantee healthcare and prosperity to Americans, but also to create happier lives for people. If executed in conjunction, Americans would be richer on average, have access to better healthcare, and hold greater social interconnectivity, creating greater social value. The benefits of these programs far outweigh the costs, both numerically⁵² and socially. While I have largely focused on the practical aspects of these benefits, it needs to be stated too that a more socially interdependent America is a happier America. People who hold more connections in their community typically feel happier in their lives,⁵³ and being able to show that we, as a country, mutually care for each other is a benefit that would also create more trust in each other and the government.

The current system of American healthcare has failed us. It unnecessarily forces upon people more suffering, hardship, and strife, while at the same time implicitly telling them that they do not hold societal value. Grievability, or expressed social value, is attributed to social interconnectivity, and this can be both demonstrated and measured by the state of medical crowdfunding in America. Not only does medical crowdfunding demonstrate who is grievable on an individual scale, but when compiled, it shows how we value people as a society. Groups who experience demonstrable gaps in their societal value are in need of help. They need not only help to survive but also help to be humanized. In the words of Judith Butler, they need help to be “legible as a life.”⁵⁴

REFERENCES


⁵⁰Schneider et al., “Mirror, Mirror 2021.”
⁵¹Schneider et al.
⁵²Schneider et al.
⁵³Stephens, Cameron, and Townsend, “Lower Social Class Does Not (Always) Mean Greater Interdependence.”
⁵⁴Butler, Frames of War, 84.


