TOGETHER, WE CAN: AN EXPLORATORY ANALYSIS OF PATIENT-CENTERED CROWDFUNDING

By

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DEDICATION

To Mom and Dad – I couldn't have made it half this far without you guys.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

LIST OF TABLES

ABSTRACT

TOGETHER, WE CAN: AN EXPLORATORY ANALYSIS OF PATIENT-CENTERED CROWDFUNDING

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Patient-centered crowdfunding is a new, disruptive innovation that is changing the way that many patients are paying for the cost of medical treatment. GoFundMe, the leading patient-centered crowdfunding platform, uses social media-like features to help patients tell personal stories about their health situations and collect donations to help pay for care. This mixed method dissertation is the result of three interrelated exploratory research studies conducted on patient-centered crowdfunding effectiveness; that is, the reasons why some campaigns succeed, and others fail. Rogers (2003) Diffusion of Innovations (DOI) framework was utilized during the project's conceptualization phase. The interrelated studies conducted found donors prefer campaigns with hopeful outcomes and a clear plan, that real-life support networks play an important role in successful health crowdfunding, and that individual-level characteristics such as e-health literacy can influence donor behavior. This dissertation is intended to be a reference for further study on patient-centered crowdfunding and to assist patients and campaign managers who are currently using online crowdfunding platforms to pay for healthcare expense

CHAPTER ONE
WHY STUDY PATIENT-CENTERED CROWDFUNDING?

<u>Introduction</u>

Entrepreneurial crowdfunding platforms such as Kickstarter, IndieGoGo or

Patreon probably come to mind when most people think of crowdfunding. However,

while these crowdfunding websites have proven successful for raising capital, not every

crowdfunding site has a commercial aim (particularly websites dealing with health-

related issues). Patient-centered crowdfunding platforms such as GoFundMe are

changing patients' lives by offering a means of running altruistic crowdfunding

campaigns to assist with the cost of medical care and logistical support for the patient.

While entrepreneurial and patient-centered crowdfunding sites function by soliciting a

large "crowd" of people for small donations to reach fundraising objectives, their specific

techniques, communication, and goals are very different.

Currently, there is an imbalance in the crowdfunding literature with most of the

resources and research focusing on entrepreneurial crowdfunding efforts such as

launching start-ups or pitching new products (Epstein, 2017; Rich, 2014; Wilson, 2012).

Far less research has examined the use of crowdfunding to assist with covering the costs

of treatments for patients. With crowdfunding becoming an estimated multi-billion-

dollar industry annually (Statista, 2018), it is reasonable to say that crowdfunding

methods are becoming more mainstream (Reid, 2017). Patient-centered crowdfunding is

an important new topic to study within the health communication discipline. It combines elements of e-health, health communication campaigns, social/digital marketing, social network activation, disclosure of health information via digital platforms, and privacy management. These topics are generally studied by health communication researchers, making patient-centered crowdfunding a potentially fruitful area of inquiry for those interested. Through studying patient-centered crowdfunding, one could learn how digital media, entrepreneurial methods, and effective health communication intersect to provide relief to patients going through a personal health crisis. The purpose of this research study is to learn more about the patient-centered crowdfunding ecosystem on GoFundMe to offer patients guidance in navigating the dynamics of running a personalized, social media-integrated health communication campaign. This project focuses on patient-centered crowdfunding campaigns rather than large scale, single issue campaigns (diabetes, breast cancer, etc) as patient-centered campaigns make up the majority of health-based crowdfunding efforts on GoFundMe.

The project provides 1) one of the first descriptive data analyses of important communication characteristics of crowdfunding sites, 2) an exploration of donors' underlying motivations to participate in crowdfunding, 3) communication strategies employed to assist with crowdfunding efforts and 4) insight into other relevant aspects of patient-centered crowdfunding. This project is, to my knowledge, the first of its kind to explore health-focused crowdfunding using a mixed-methods approach. This is an important area to study from both a research and practice perspective because it not only focuses on a major disruptive innovation within the healthcare payment field, but also

research on crowdfunding can lead to better outcomes at the individual level for patients

by helping them secure resources and support for treatment.

CHAPTER TWO
DISTINCT FEATURES OF CROWDFUNDING AND ANALYSIS OF THIS
PHENOMENON THROUGH THE LENS OF COMMUNICATION

<u>Commercial Crowdfunding Overview</u>

While the idea of pooling community funds together to accomplish a collective

task is not a new one, digital crowdfunding platforms with social-media integration are

changing the ways that entrepreneurs, start-up companies, and even more established

businesses go about securing capital from investors and bringing new products or

services to the marketplace (Kuti & Madarász, 2014). Companies like Kickstarter,

Indiegogo, Patreon, and others have helped crowdfunding become a multi-billion dollar

industry since becoming established during the late 2000's. These companies rely on

innovative products, participatory marketing with investors and potential consumers,

robust rewards systems for donors, viral marketing, and diffusion through social

networks to become widely supported (Lagazio & Querci, 2018). Although there are

many factors that influence an entrepreneurial crowdfunding campaign's success, giving

donors partial "ownership" of the creation process, providing specific and personalized

rewards, and leaning on established, innovative adopters that already exist in the

network/marketplace can oftentimes lead to a commercial crowdfunding campaign

achieving the best outcome (Rich, 2014).

To understand how campaign donors feel like partial "owners" of an innovation, one must first understand their role as stakeholders in the process. Kuti and Madarász, (2014) called this process as "equity-based crowdfunding" and described it as "the [usually inexpensive] issuance of shares through the internet, where investors can acquire stock in corporations for a small amount of money, with a claim over the company's future cash flow [or products]" (p. 355-356). In cases where there is an ownership element to future cashflow, the transaction resembles purchasing a stock, albeit more informally. However, many platforms opt to deliver goods, services, or other perks in lieu of surrendering parts of their cashflow. This choice is made by those running the campaign. By giving both their financial support and social support (in terms of publicly supporting the innovation), the donor becomes a stakeholder in the campaign's outcome. As a stakeholder, the donor not only provides the upfront financial investment, but continues to be emotionally invested in the campaign as it progresses. This emotional investment may cause donors to pay attention to updates about the campaign post-donation and will increase the likelihood that they will circulate information about the campaign to other people on their network who might not otherwise be invested (Snyder, 2016). This process of outcome ownership is powerful for entrepreneurial crowdfunders because, over time, it creates an organic network of supporters that can be activated based on the campaign's actions.

Another set of motivating factors for many donors are the rewards associated with donation. Kuti and Madarász (2014) defined reward-based crowdfunding as a system where "funders receive either real products or services in exchange for their donation.

This process of reward-based crowdfunding is started by the project initiators when they post all relevant information and is continued by giving sales incentives" (p. 356). Nearly all commercial crowdfunding campaigns provide different tiers of rewards for donors depending on the size of their donation. The size of the rewards is oftentimes reflected by the size of the donation – this means that individuals who provide smaller donations will likely receive a smaller reward (such as a t-shirt, mug, hat, etc.), while individuals who provide larger donations will likely receive a larger reward (such as reduced-cost copies of the product/service being crowdfunding, producer credits for creating the product, naming rights for certain products, or even flights/tours of the facilities that are being crowdfunded). Many crowdfunding entrepreneurs credit creative and/or attractive rewards as the catalyst for commercial crowdfunding's recent success (Stegmaier, 2015). This is what distinguishes crowdfunding a business endeavor from a stock offering. These rewards are indeed motivating for many, but the tangible benefits of donation are not the prime appeal for all donors. Some donors are attracted to innovative ideas, which are bountiful in the crowdfunding marketplace.

Rogers (2003) found that roughly 2.5 to 3.5 percent of the population belong to a group known as the innovators. This consumer group is exceptionally committed to trying new, cutting-edge products and services as soon as they are introduced into the marketplace and before many of the other individuals on their personal networks try them. These innovators are the same people who would wait outside for days for the new iPhone, preorder a new type of television a full year before it comes out, or go out of their way to be at a new restaurant on opening day. Their need for newness is a perfect fit for

the entrepreneurial crowdfunding marketplace, because nearly every product in the market would be classified as either a new innovation or an improvement on a previous innovation. Thanks to commercial crowdfunding, innovators can now log into a single website and view thousands of cutting-edge products through which to invest their money. This is a critical point for the entrepreneurs themselves and presents a great opportunity to ensure their campaign's success; while innovators are driving towards the products, entrepreneurs are seeking motivated individuals that like their products who can also help the products diffuse through social networks.

If entrepreneurs can determine which innovators will be drawn to their products, they can make efforts to get their products into the hands of the innovators, thus speeding up the diffusion process. This could mean that the product is sent to an identified innovator at a reduced price, for free, or on a trial basis. The critical point is that the innovator has enough time to spend with the product to become excited about it enough to want to tell the non-innovators on their social network about it (Gould, 2017). Furthermore, the crowdfunding process expands the role of innovators by pulling them into the innovation development process, meaning that they have a greater influence on the innovation during the pre-diffusion, pre-release process. Therefore, crowdfunding gives individuals in the innovator group a chance to build a stronger connection to the innovation that extends beyond ordinary diffusion. Another potentially relevant innovator subgroup motivated to participate for altruistic reasons could include family members, pastors, neighbors, and anyone else who feels the urge to make a positive difference in another person's life. Members of these groups might be more likely to

create and/or share GoFundMe pages for others and work to spread the message. Opinion leaders are often central for helping an innovation diffuse successfully due to their established credibility around the topic (Esslimani et al., 2010), and GoFundMe provides some of this similar credibility to patients looking to fundraise for their healthcare.

Discrepancies between Patient-Centered and Commercial Crowdfunding

Patients who are suffering from severe illnesses, injuries, or other debilitating conditions face numerous challenges on their journey towards better health. Crowdfunding tools have helped many patients cope with the financial challenges associated with having a health crisis, but this benefit does not come without a cost. Crowdfunding relies on strategic communication about a niche topic, through a digital medium, that becomes widespread as it diffuses through the medium to donors and, later on, through the donor's networks. Unlike with commercial crowdfunding, the goal is not to bring a new product or service to market, but rather to offer support to those who do not have the means to support themselves. Rather than marketing a product, the platform "markets" someone's well-being. The transactional nature of the platform is likely a reflection of its creator's worldview – As Spender (2018) writes,

> Silicon Valley has its own set of rules, -- or at least it thinks it does. I've written about tech culture before – the worldview that literally everything is a problem able to behacked and that even the most complex social or cultural

constructs…can be deconstructed and sorted into neat algorithms, then taught to a computer (p.1).

There are additional ethical concerns associated with patient-centered crowdfunding that are not as apparent with commercial crowdfunding. First, patient-centered crowdfunding must keep the patient's privacy and humanity in mind (something that does not need to be considered as often in commercial crowdfunding). Second, patient-centered crowdfunding does not provide tangible rewards for support (although it does provide a more intrinsic reward), and third commercial crowdfunding typically follows an all-or-nothing (AON) model in which they must reach their goals to receive the funding. In contrast, in patient-centered crowdfunding, each donation makes its way to the patient within 24 hours usually regardless of the amount or the campaign's progress.

Rewards

As previously mentioned, the rewards system is one of the most interesting and dynamic components of commercial crowdfunding. However, patient-centered crowdfunding has no such system, and instead seemingly rely on altruistic rewards to help motivate donors. Rather than trying to gain support through presales or products, donors to patient-centered crowdfunding campaigns receive fewer tangible benefits. While these rewards might not necessarily motivate everyone, patient-centered crowdfunding's continued growth each year (Paynter, 2018) indicates that there is something appealing to participation on these platforms. For example, GoFundMe has

created a system in which donors can directly link their Facebook page to the donation site. As users donate, they have the option to share the information about the campaign and their donation to their own private Facebook pages. Although some have condemned publicly sharing information about donations as virtue signaling, or the process of engaging in altruistic behaviors for self-serving purposes such as increased attention/social capital from peers (Duff, 2012), this public sharing can create social desirability around donation behavior and therefore activate more individuals on the network to follow through on donating. Additionally, another step that may enhance diffusion of crowdfunding messages is that a link to the campaign is embedded in the Facebook post, meaning that others, upon seeing a donation, can donate their own resources within a few clicks.

Diffusion of Innovations Theory

The Diffusion of Innovations model was developed by Everett Rogers in the early 1960's during his work as an agricultural sociologist. While the theory was initially intended to study the adoption of agricultural innovation by farmers, Rogers soon realized that the process of diffusion that the farmers participated in was very similar to the diffusion or adoption process that most individuals face whenever they encountered any new technology, idea, or other commercial/social phenomenon. Since its inception, Diffusion of Innovations has been used to study a wide variety of topics. These topics have included defense, healthcare, social policy, technology, and many others (Aubert & Hamel, 2011; Easley & Kleinberg, 2010; Ghoshal & Bartlett, 1988). The model itself its

straightforward: Diffusion of Innovations identifies the ways in which innovations spread through society via peer-to-peer networks and communication channels over various periods of time until enough of the population either accepts or rejects the innovation, which then determines whether the innovation is adopted and becomes more mainstream, or whether it fails to spread (Rogers, 2003).

Despite websites such as GoFundMe, Kickstarter, or Patreon existing for a little less than a decade, crowdfunding has already established itself as a disruptive innovation that has launched a multi-billion dollar a year global industry (roughly $9.37 billion dollars at the time of writing this; Statista, 2018). Though the innovation is still growing in popularity and adoption, it is becoming clear social-media integration with conventional fundraising objectives has revolutionized the way that many individuals participate in charitable giving. Diffusion of Innovations is an ideal theory for research into the current patient-centered crowdfunding ecosystem. This is because Diffusion of Innovations Theory offers insights into: 1) the ways that potential adopters (i.e. donors) organize in society based on their likelihood to adopt; 2) the factors of an innovation that make it attractive for potential adopters, and 3) the process of diffusion through which an innovation's validity is confirmed by friends and acquaintances via peer-to-peer networks (Rogers, 2003). Diffusion of Innovations Theory provides deeper understanding into the social and cognitive process behind altruistic giving on patient-centered crowdfunding platforms.

Diffusion of Innovations' Relevance to Crowdfunding

The three critical features that are most relevant to the topic are 1) the adopter categories, 2) the factors influencing the adoptability of an innovation, and 3) insights into the diffusion process. This section will analyze how each is relevant to studying diffusion within the context of patient-centered crowdfunding. Rogers (2003) highlights five distinct adopter categories in Diffusion of Innovation. As one group adopts the innovation, it validates the innovation's worth for the next group in the curve and so on. The five adopter categories are: Innovators (3.5%), Early Adopters (roughly 12.5%), Early Majority (34%), Late Majority (34%), and the Laggards (roughly 16%). The innovators are the first group to want to try a new innovation, and they will try it simply because it is new. To the innovators, the point of trying a specific innovation is not nearly as important as trying something that is new. This group will always be the first to adopt an innovation, and they play an important role in the innovation's long-term success despite their small percentage size compared to the other groups.

Innovators are typically the ones who create and initially share the innovation, allowing its initial success. In the case of crowdfunding, the innovators are the individuals who would donate to GoFundMe when it was first established in the late 2000's. Early adopters are the second group to adopt an innovation, and they rely on seeing the innovators have success with the innovation to become motivated to try it. The next group, the early majority, is extremely important for an innovation's widespread adoption. Diffusion of Innovations scholars generally agree that having success with the early majority is a good sign for an innovation's long-term success (Gould, 2017; Burke,

12

2014, Rogers, 2003). The late majority is the fourth group and is motivated both by seeing the early majority have success with the innovation, as well as attempting to distance themselves from the laggards (who are sometimes viewed as untrendy or behind-the-times). The laggards are the last group to adopt and they typically only adopted out of necessity; that is, they have no choice but to adopt the new innovation because it has essentially replaced the older innovation used by laggards.

The second important component of Diffusion of Innovation used to study patient-centered crowdfunding is the framework that Rogers (2003) establishes for "more adoptable" innovations. According to Rogers (2003), innovations that have greater compatibility, perceived advantage, trialability, and observability while being less complex are more likely to become adopted than the innovations that do not have these qualities. The following section provides a more detailed explication of these components.

Application of Diffusion of Innovation

The Diffusion of Innovation Model suggests, as previously mentioned, studying crowdfunding using DOI needs to be divided in three different sections to study each dimension of the innovation. The first section must focus on trying to understand the specific components of the innovation itself and their functions. That is, to analyze the crowdfunding campaign pages, the academic literature on crowdfunding, and integration on social media to fully elucidate the ways in which patient-centered crowdfunding offers its adopters higher perceived advantage, compatibility, observability, trialability, and less

13

complexity. The second section of a Diffusion of Innovations study on crowdfunding would focus on understanding the donors, their behavior, their motivations for donation, the factors that led to their adoption of patient-centered crowdfunding donation behaviors, and relevant demographic information (to see the effects of sociodemographic/cultural factors on crowdfunding adoption). The final section would be the diffusion itself, meaning that efforts should be made to determine 1) the types of peer-to-peer communication/exposure that leads to the adoption of patient-centered crowdfunding behaviors and 2) the types of peer-to-peer communication/exposure that causes individuals to not want to participate in crowdfunding.

Perceived advantage refers to the improvement that an innovation has over its predecessor (Rogers, 2003). In the case of crowdfunding, its predecessor could be viewed as conventional fundraising. Conventional fundraising methods rely on slower forms of communication, such as mail, phone calls, television commercials, and radio advertisements. Crowdfunding has a clear advantage over these tactics because of its immediacy: it is fully integrated with social media, available on anyone's phone or tablet, and made credible through the observed actions of other donors on the platform. Some patient-centered crowdfunding organizations even use their own iPhone and Android apps to create the most efficient user experience. Major charitable organizations such as the Red Cross, The Bill & Melinda Gates Foundation, WaterAid, and others have also begun to utilize digital tools to improve their own effectiveness; this raises the question of whether these expanded digital media efforts are a result of competition that has arisen out of the emergence and rapid growth of crowdfunding.

The next factor, compatibility, refers to how well the innovation can be integrated into the user's lifestyle (Rogers, 2003). With many Americans living a modern lifestyle involving smartphone and social media use, digitally integrated charity platforms could have a significant advantage reaching people in a lifestyle-compatible fashion. While this factor is largely dependent on the individual user's routine and behaviors, one can still make the argument that patient-centered crowdfunding is more compatible with people's lives because it makes charitable giving more personal. That is, rather than donating to a large organization and not knowing how the specific donation is being used, crowdfunding users get to see a more personalized influence that their donation makes. In this regard, donating to a crowdfunding platform is more compatible with the human experience of helping a friend or neighbor rather than donating to a conventional organization.

Trialability refers to a potential adopter's ability to try out the innovation to see if it would be a good fit for them (Rogers, 2003). Patient-centered crowdfunding has trialability function in that it allows users to support a campaign without a monetary commitment. This is possible through sharing the campaign on integrated social media, telling others on one's personal network about the campaign, and even communicating with the campaign manager to see if there is any other non-monetary assistance that can be offered. Through taking any of these actions, potential donors can do a support "trial" to see if they enjoy the feeling of providing support. While larger organizations have opportunities for people to volunteer (such as FEMA, the Red Cross, etc.), these trial commitments can take time and become more costly than a donation to some volunteers.

Additionally, platforms like GoFundMe allow donors to make contributions for as little as a few dollars, making crowdfunding's barrier to entry significantly smaller than other campaign commitments.

The fourth factor, observability, refers to an individual's ability to witness others having success by engaging with the innovation (Rogers, 2003). GoFundMe and other sites have made great efforts to mimic social media platforms, which means that they often publicize the actions of nearly everyone involved on the platforms. Donors can see what other donors are giving or saying about the campaign, how many donors have participated, what the campaigners are saying in response to the donations, etc. This degree of transparency makes patient-centered uniquely observable when compared to other types of charitable giving. While it is difficult to observe the positive feeling that a donor might receive by supporting a campaign, there is an observable reputational benefit to donors. Peers that are linked via social media witness the positive action taken by the donor, as do other donors who are networked to the same campaign.

Complexity refers both to how difficult the innovation is to learn how to use and how difficult it is to continue using (Rogers, 2003). With Facebook and Twitter becoming established several years before digital crowdfunding, the crowdfunding platforms had the advantage of being able to build on a format familiar to users. More specifically, the text tools, picture/video editing suite, social components, and donation system all mimic technologies that the vast majority of potential donors are already familiar with. As such, it is reasonable to say that patient-centered crowdfunding is likely one of the least complex forms of charitable giving on a mass scale. In recent years,

GoFundMe donations have even become tax-deductible and automatically email the filing forms of the year's donations to the donors.

Using Rogers' (2003) Diffusion of Innovations theory highlights the important components of patient-centered crowdfunding that have caused it to rise in such popularity over the last decade. There is currently little data available on how widespread crowdfunding is, but it is reasonable to assume that it has moved beyond the innovator stage outlined by Rogers (2003) . To become more widespread, crowdfunding, like all innovations, will have to continue to diffuse through social networks until it reaches the early-majority of users and begins to form the S-shaped adoption curve (Rogers, 2003). If patient-centered crowdfunding platforms continue to improve on their strengths while adapting to the needs of their users, it is likely that patient-centered crowdfunding will continue to grow and further establish itself as a widely adopted innovation for helping others in need.

Suggested Implications from Diffusion of Innovation

There are several critical implications that Diffusion of Innovation theory suggests about patient-centered crowdfunding. These implications include that patient-centered crowdfunding platforms should: 1) rely on diffusing through computer-mediated social platforms (such as Facebook) to find clusters of individuals who would feel motivated to donate; 2) possess all of the qualities that an innovation needs, as outlined by Rogers (2003), to become attractive to potential users and become more widely-adopted; 3) update to meet the demands of new adopters on the network, and 4) give

access and support to individuals and communities who might not otherwise have the knowledge, skillset, or means to solicit widespread donations. Diffusion of Innovation provides a lens through which these implications can be further examined. Patient-centered crowdfunding is a complex, multi-faceted innovation that is continuing to change the ways that many individuals are seek financial stability while handling health crises. While patient-centered crowdfunding has done much for many people to help them cover the costs of health care, the innovation is still relatively in its infancy. Therefore, this study attempts to understand the functions, capabilities, and responses to patient-centered crowdfunding, as described by donors and campaign managers who have used the platform, with the purpose of providing actionable information that may increase overall crowdfunding effectiveness.

Limitations of Diffusion of Innovation

Diffusion of Innovation theory provides a useful framework for study the crowdfunding, but it has its limitations. Diffusion of Innovation tends to examine bigger units of analysis. That is, it focuses on innovation at the societal level and looks at adoption/diffusion in terms of different groups. While this is an effective perspective to have for studying segments of the population, less of the focus is on studying individuals within the population. The individual-level unit of analysis is important for the study of crowdfunding because it is often the personal, direct nature of the appeals that help campaigns succeed. Therefore, additional theories and literature are used in this study of patient-centered crowdfunding that provide insights into the individual-level

communication patterns and other behaviors of patients, particularly while engaging on digital platforms.

E-Health Overview

Della Mea (2001) described e-health as the incorporation of technological innovations (oftentimes electronic, computer-mediated means) in health care for the purpose of improving patient outcomes and optimizing processes within the system. While scholars have proposed many different operationalized definitions of e-health communication (Hans et al., 2005), nearly all of them share one primary trait; e-health research focuses on the intersection of technological innovation and health care (Ball & Lillis, 2001; Donoghue & Herbert, 2012). More specifically, these researchers explore the ethical, social, economic, and personal influences of health technologies, to determine how new health innovations or behaviors are adopted. As such, this body of literature is built on understanding both emergent health technologies and how individuals engage with those technologies (Ahern et al., 2001;Eysenbach, 2001; Pagliari et al., 2005); this research is useful to build upon while studying patient-centered crowdfunding.

Scholars have described patient-centered crowdfunding as a potentially disruptive innovation due to its continually growing reputation for providing life-changing assistance to patients experiencing health crises. Ozdemir et al. (2015) explain that "[disruptive innovations] are groundbreaking ideas/products that seem to appear out of the blue and can lead to newer technologies or overturn markets, sometimes in short order. True disruptive [innovations are] a combination of vision, serendipity, knowledge,

and a willingness to think horizontally about multiple future outcomes and applications…the automobile, semiconductor electronics, and the internet are examples of [disruptive innovations] that revolutionized economics and society" (p.267-268).

Exploring the ways in which crowdfunding has disrupted the more conventional avenues of fundraising is useful for understanding the overall function of patient-centered crowdfunding. Prior to the establishment of platforms like GoFundMe, patients without the financial means, education, or efficacy to navigate the healthcare system might find themselves having to pay for expenses, relying on financial aid/loans, or hoping to be selected for a charity or program that would cover health care costs (KFF, 2018). Those who celebrate these sorts of disruptive technologies would argue that crowdfunding provides individuals with a low-cost, social media integrated alternative that empowers patients and their trusted supporters with the ability to secure resources for treatment through effective health communication. However, having a purely optimistic view of emergent technologies can be inadvertently dangerous because it could cause someone to miss or overlook their potential drawbacks.

To understand how a "silicon valley mindset" could damage crowdfunding efforts and reinforce inequality, one must first understand the technology that governs the platform. GoFundMe is intentionally designed to be a social platform, and therefore mimics the traits of other established, popular platforms. Social media platforms are designed to propel well-trafficked content to the top of users' feeds, giving them a chance to socially engage with the others who interact with the post. The algorithms cause certain posts to go viral, and this virality comes at the cost of driving other content lower

on the feed, making it less visible to users. While it's debatable whether this is an acceptable practice on standard social media platforms such as Facebook, Twitter, Instagram, etc., this viral dynamic can have negative consequences for those crowdfunding medical expenses. Patients turn to GoFundMe because they are likely in desperate situations and hope to lean on the public's goodwill to meet their financial needs. While this might sound straightforward, not every GoFundMe receives equal attention on the platform because of the way that the campaigns are displayed; as with other social media, the content that gets the most traffic gets driven straight to the top. This means that those who don't receive early, frequent attention, or lack a group of real-life friends and family to donate could see their campaigns buried on the platform under more successful campaigns.

This inherent competition reflects how its designers believe the platform should operate The emphasis is placed on rewarding competition, rather than putting an emphasis on need. This could be the result of the "true aims" of a Silicon Valley innovator, described by Silverman (2018) "[Silicon Valley's] products are organized less around improving lives than around occupying as much of their users' attention as possible" (p .1) Rather than fixing the real problem – individuals in need trying to allocate the resources to solve problems – the GoFundMe platform instead can make fundraising even more difficult for those who already lack a real-life network of people to help them during their treatment and recovery by funneling traffic to already popular campaigns.

Dynamics like these can be particularly difficult to overcome as technology becomes more deeply woven into people's daily lives and continues to prove itself

essential for most common functions. Users are developing habits on the platform, which are, in part, influenced by the platform's inherit structure. As people become more reliant on these technologies, they are forced to surrender a certain level of control, which further empowers these companies to establish a higher level of social dominance. As Hui (2014) writes "…the Internet has a strange tendency toward monopoly, with corporate giants such as Amazon, eBay, Google, and Netflix dominating their respective markets. In light of Facebook claiming over one billion monthly active users, [some describe] social networking as the commercialization of the once unprofitable art of conversation" (p. 1).

Patient-centered crowdfunding technologies function by combining methods of conventional, grassroots fundraising with via digital/social media integration. The result is a set of personalized campaign-styled messages delivered to potential donors on a broad scale. This innovation provides patients, friends, and family members with the tools to operate an e-health-based fundraising campaign designed around reaching patient-specific outcomes on a vetted platform with an established userbase. Research into the role of communication in health care cost crowdfunding efforts builds upon the scholarly literature about e-health communication in two ways: This research: – 1) expands what is understood about e-health campaign communication by introducing new information about an emergent technology (with commercial crowdfunding being roughly 10 years old), and 2) provides deeper insight into the ways that individuals manage their communication during health crises when open public disclosure is in their

financial best interest.

Privacy Management

There are numerous benefits to having deeper understanding of patient-centered crowdfunding. Whether it comes to training patients to become better communicators, optimizing the platform interface for an easy user experience, or determining the best practices in applied health campaign communication for crowdfunding, further study of patient-centered crowdfunding could eventually help many patients turning to crowdfunding methods have the best experience on the platform. Aside from the direct benefits for patients, there are academic benefits to studying patient-centered crowdfunding. These academic benefits include: – 1) a chance to explore applied communication privacy management in the context of a patient-centered health communication campaign (with its own set of challenges and circumstances that make it unique from traditional privacy management), and 2) a new context in which to explore the ethics of patient-focused communication.

Communication Privacy Management theory (or CPM theory) explains how individuals manage their private information, create rules for it, share it with others, and conduct maintenance when privacy boundaries have been violated (Petronio, 1991). The theory assumes that humans are (1) rule makers, (2) rule followers, and (3) decision makers that own their private information. In the context of patient-centered crowdfunding, the patient is the principal owner of their private situational knowledge. As such, it is the responsibility of the patient to decide what information is shared, who it

is shared with, and the conditions in which the information is to be treated with by others (Petronio, 1991).

This theory is often used by e-health scholars because of the insights that it provides into how individuals manage their privacy online. Patients who are not running their own crowdfunding campaign must be especially mindful of the sorts of information that their campaign managers share about their situation by setting strict rules about what is communicated. Patients and managers need to exercise their role as "rule-makers" early on in their campaign to establish what is and what is not permitted during the campaign. What is acceptable is not only limited to written language (such as page updates, specific details about surgeries/medications/treatments, updates on rehabilitation work, etc.), but it can also include visual components (such as pictures, videos, or other artwork).

Conversely, the patient and manager(s) will also need to coordinate and create pre-approved content for the pages so that the campaign messaging remains consistent and on schedule during its operation. Campaign managers will need to establish certain "pre-approved" permissions as to what they are permitted to share during the campaign. Using this method would help to streamline the process of connecting the patient to the audience on the crowdfunding page. An effective way of gaining this "pre-approval" to share private information is through boundary linkage. That is, patients determine ahead of time who they wish to co-own and co-manage their private information during the campaign, and they link boundaries with these individuals. This means that the individuals can act more freely with their knowledge, as long as they adhere to the rules

that were set out by the patient during the rule-making stage.

Another important component of Petronio's (1991) CPM theory is that it assumes that humans are not static. That is, individuals and the situations surrounding them are constantly changing, which means that new boundaries or rules will need to be established and old ones will need to be checked on and adjusted during the campaign. For example, a patient might not initially object to their campaign managers photographing them in their hospital room or taking short videos for the campaign page. However, patients' attitudes might change if they must go through a procedure that causes them to feel fatigued, needing rest, or requiring quiet privacy. Patients sometimes feel differently about being photographed or video-recorded in their new state despite giving prior permission to the co-owners of their private information. This situation could potentially cause internal turbulence among the information managers despite a rule not being explicitly broken. Therefore, it is advisable for patients and managers to conduct routine boundary maintenance whenever they believe there could be a drastic change in the patient's daily life (such as a new treatment or procedure).

Ethics and Etiquette

Studying the ethics and etiquette of crowdfunding is also a worthwhile goal; if more is understood about the best practices and behaviors on the platform, then users can be guided to act with those in mind. While there are many reasons to be optimistic about crowdfunding, not everyone benefits from the platform in the same way, nor are there any safeguards in place to prevent certain groups from receiving preferential treatment

over others on the platform. Young (2017) writes "…in considering the equity of [patient-centered crowdfunding] methods, it is important to recognize the potential for unfairly advantaging those with the means to engage with online tools and tap into large social networks, which may lead to an underrepresentation of cases with greatest need in which patients lack the tools to coordinate effective crowdfunding campaigns. Analogous criticism has emerged in evaluating the case of patients with end-stage organ dysfunction traveling domestically for transplant listings in multiple regions or traveling internationally to leverage black market organ sales; such methods have been widely criticized given that they are particularly accessible to well-off patients" (p. 1,623). Young (2017) writes that:

> "Another issue with crowdfunding research is that there are no set standards on crowdfunding etiquette or formalized practices of crowdfunding to reference – "Apart from the issue of equity, there are currently no guidelines to aid clinicians in navigating the sometimes-difficult requests made by patients or families to participate in crowdfunding efforts. Are clinicians professionally obligated to support patients crowdfunding efforts by, for instance, furnishing routine clinical updates to be posted online? May a clinician justifiably request not to be named in crowdfunding efforts? How should clinicians respond if they discover information being used in crowdfunding is medically false or misleading? Should crowdfunding platforms require that physicians verify medical supplications, or

ensure that all relevant information may reasonably inform donors decisions

provided?" (p. 1623-1624).

The answers to these questions are critical for crowdfunding's sustained success

because they highlight current barriers to more widespread adoption of the innovation.

Crowdfunding is still in its infancy and must overcome several hurdles to become more

widely-adopted in society. One of the first steps towards wider adoption would be for e-

health scholars to highlight the fact that crowdfunding exists for more than just business.

Misinformation

Fraud and misinformation pose ethical concerns for crowdfunding platforms

because they create mistrust among users, redirect funds away from patients who need

them, and diminish the overall reputation of crowdfunding. Snyder (2016) wrote that "the

actual number of fraudulent medical crowdfunding campaigns is difficult to know, as

many of these cases will go undetected by website administrators and law enforcement

officials…while medical crowdfunding websites have the advantage of giving potential

donors access to a wide range of individuals in need of help, this technology also means

that potential donors may have to accept the user's description of her medical situation at

face value or take on the task of determining which campaigns are trustworthy" (p. 36-

37). Although patient privacy laws might make specific details about the patient's health

all but inaccessible, trust could be built with potential donors by providing transparency

in other aspects of the treatment. For example, social media/networking functions of crowdfunding make sharing "proof of payments" possible.

Patients and those campaigning on behalf of patients must make efforts to avoid appearing fraudulent; while this might sound unlikely, crowdfunding users who are in desperate situations might unintentionally exaggerate details about their state to engender a greater donor response. As Snyder (2016) notes, "…Outside of cases of deliberate fraud, crowdfunding users have a strong incentive to sensationalize or embellish their stories to receive donations. Because these websites allow and encourage users to reach beyond their existing social networks to solicit donations from strangers, their stories of medical need have to stand out from those of others using these websites to be successful" (p. 37-38). Carefully taking notes of symptoms and situations as they arise could help reduce hyperbolic language later on in campaigns. That step will assist campaigners in providing accurate descriptions of the incidents based on firsthand accounts.

Inequality

Equality of use is an ethical concern for crowdfunding platforms. Snyder and Chow-White (2017) argues that "…although a formal charity is more likely to distribute resources according to need, crowdfunding is much less equitable in disbursing funds. Individuals most likely to be successful in meeting their fundraising goals are those with large social networks, a sympathetic story to tell, or contacts in the media to help promote their campaigns. Although all individuals legitimately seeking crowdfunding are in a position of vulnerability, crowdfunding tends to favor those in a relative position of

privilege in their communities" (p. 1). Patients should attempt to connect with social

media users who have broad networks to help cope with potential inequality issues;

Facebook or Twitter users that have many friends or followers could be considered to

have a substantial following. Currently, there is no available data on the "ideal" follower

count; future research should consider examining how the spread of a campaign (measure

in social media "shares") affects the campaign's success in reaching its goal. Efforts

should be made to deploy social media tracking tools such as SproutSocial or Hootsuite.

Crowdfunding websites rarely provide tips on how to become established on

external social media platforms. While some might argue that it is not the crowdfunding

company's responsibility to teach users how to utilize Facebook or Twitter, it is in the

company's own best-interest to have informed, empowered users on social media to be

more effective at soliciting donations. Crowdfunding almost purely relies on integrated

social media to establish a strong donor network, and the user's success on external social

media sites is directly correlated with the crowdfunding company's success. Banner

(2013) writes that "requests [in crowdfunding campaigns] rely heavily on integrated uses

of other participatory media, such as Facebook and Twitter, to get the word out. This

raises questions of how crowdfunders use media advocacy strategies to promote their

messages to their intended audiences. As such, the success of crowdfunding campaigns

relies on the mobilization of existing community" (p. 59). Users who wish to utilize

crowdfunding but lack social media will need to make a concentrated effort to become

established on social networks. Many crowdfunding platforms are completely integrated

on social media and joining them opens new levels of access to donors who might not otherwise discover the campaign.

<u>Digital Communication and Crowdfunding</u>

Prior e-health research into crowdfunding has been rather limited due to the newness of the innovation. However, a few scholars have begun to uncover some themes and patterns of the crowdfunding ecosystem through their work. To date, research has illustrated that one of the biggest challenges that narrative-driven, patient-centered campaigns face is making a positive impression on the audience – "Campaigns must disclose extremely difficult personal circumstances, an act that risks creating a negative impression of the person in need and possibly resulting in adverse audience reaction (in this case, failure to donate money)" (Paulus & Roberts, 2017, p. 67). E-health researchers have previously studied disclosure on digital platforms, which is a central construct for narrative building during the crowdfunding process. During this process, the user is challenged with telling the story of the patient in need but must navigate the fine line between disclosing enough information to warrant assistance but not enough to paint an undesirable image that could push away potential donors. Barekt-Bojmel Moran, and Shahar (2016) suggest two tactics for *positive self-positioning* that can make a difference in how a campaign is perceived. First, users must establish the worth or merit of the cause they are promoting in a way that is culturally relevant to the members of their network and 2) place requests for funding or donations until the very end of the presentation (p. 793). Furthermore, Davidson and Poor (2015) noted that "people generally do not want to burden families and friends with crowdfunding requests, yet studies show that it is

30

through support of existing networks that campaigns succeed…this creates a problem for the person in need and may explain why so many [crowdfunding campaigns] are run by third parties" (p.129).

E-Health Literacy

The other major component of e-health research important for the study of patient-centered crowdfunding is the concept of e-health literacy. Scholars have described e-health literacy as a sort of efficacy in navigating the tools, systems, and jargon of digital or computer-mediated health platforms (Norman & Skinner, 2006). E-health researchers have established methods to research e-health literacy in the population. These methods include exploring stakeholders' literacy with digital media, identifying relevant skills that increase individual-level media literacy, and observing participants' abilities to apply newly acquired skills on e-health platforms (Brainen & Neter, 2017; Brainen & Neter, 2012; Miller & West, 2007). Within the context of patient-centered crowdfunding, e-health literacy skills would include 1) the ability to access and use all of the technical features of the platform (having a phone/computer, having access to the internet, access to email, skill in using the interface); 2) a support system that will assist in the crowdfunding process and co-own/manage private information in a responsible way through the campaign page; and 3) the efficacy to engage with the platform in an ethical, responsible, and consistent way to have sustained success and build towards reaching a long-term goal.

Proposed Axioms of Inequality

This study proposes six axioms of inequality based on aggregated descriptions of equality-related issues that recurrently appear within the crowdfunding literature. These axioms can be helpful for anyone studying patient-centered crowdfunding and should be kept in mind while conducting research on the subject:

i) Technological Inequality – Not every patient will have the computer skills or social media literacy necessary to fully engage with crowdfunding platforms in the most effective manner. Crowdfunding services, while lacking an upfront cost for their use, still require the user to have a relatively updated, reliable device with internet connectivity (such as a phone, tablet, or computer) to participate. While these devices are becoming more commonplace, there is still a high cost associated with them. This cost can be exclusionary to some individuals who are already likely to be facing other financial challenges.

ii) Inequality of Illness – Different conditions solicit different responses from donors, meaning that certain illnesses or injuries could be over/underrepresented in terms of need versus actual donations received.

iii) Inequality of Patient – Donations collected through crowdfunding run the risk of favoring certain patients over others due to factors beyond need. This means

that age, gender, social class, ethnicity, sexual orientation, or any number of other personal factors outside of the illness or injury could influence whether a campaign is supported.

iv) <u>Inequality of Efficacy</u> – Patients will have varying confidence levels while with crowdfunding platforms, which will affect their participation on them as well as influence whether campaigns are maintained and regularly updated in the correct manner.

v) <u>Inequality of Support</u> – Not every patient will have the same support system around them in real life to assist with campaigning. While many campaigns are managed by a friend, family member, or colleague, sometimes the burden of running a crowdfunded e-health campaign will fall directly onto the shoulders of the patient or researcher. In these cases, the success of the campaign could be hindered by the subject's vulnerable physical, mental, and/or emotional state.

vi) <u>Inequality of Knowledge/Exposure</u> – Many patients and researchers simply are unaware of crowdfunding's potential as a means of garnering financial support. Without much knowledge of or exposure to crowdfunding, these individuals will likely never consider these avenues as a means to reaching their goals.

Social Networks Overview

Social network researchers study the communication that occurs on social networks between members and how that interaction influences aspects of the individual's personal and social lives (Otte & Rousseau, 2002). The concept of a social network is based on the idea that everyone within a communication environment is "networked" to the other individuals that they interact with because of their interactions (DeAndrea et al.; 2009; Grandjean, 2016), and that various messages can spread through the networks and influence the members of the networks to take on various behaviors, adopt new styles, or give their attention to new causes (Nasrinpour et al.., 2016). Riquelme et al (2016) explained that social network researchers work to classify individuals within various social networks based on their potential to act within the network and work to understand how different members of networks self-organize. There are numerous practical applications for conducting social network research – these applications include research into marketing, health communication, epidemiology, public relations, sociology, e-health, computer science, security, and many others. The social network analysis literature is related to the growing body of literature in patient-centered crowdfunding because both phenomena rely on understanding how messages travel through networks across channels, and that activating important members of those networks is critical for the overall success of the idea, product, or campaign that is being promoted.

The social networks literature also provides insights into communicating on networks useful for the study of patient-centered crowdfunding. Currently, some applied

research scholars have begun to study the best practices of crowdfunding in the context of using narratives on social networks. This body of research has found that, in addition to developing the storytelling skills necessary to craft compelling campaign messages, users should also strive to be competent with social media and have established social media profiles to benefit from dispersing the narrative to broader groups of potential donors. Banner (2013) wrote that "requests [in crowdfunding campaigns] rely heavily on integrated uses of other participatory media, such as Facebook and Twitter, to get the word out. As such, the success of crowdfunding campaigns relies on the mobilization of existing communities" (p. 63) Users who wish to utilize crowdfunding but lack social media will need to make a concentrated effort to become established on social networks – many crowdfunding platforms are completely integrated on social media and joining opens new levels of access to donors who might not otherwise discover the campaign.

Social Networks and Crowdfunding

A primary function of social network analysis is to assess communication, develop strategies, and test message effectiveness (Corlew, 2015). Furthermore, this type of analysis centers on understanding who the key figures are in a network, how community leaders function on the network, and how they can be reached and convinced to pass along communications in the network (Rogers & Kincaid, 1981). Researchers have developed sophisticated operationalizations for describing common network arrangements. These include items such as connectedness, integration, diversity, and openness (Rogers & Kincaid, 1981). Despite the clear use of social media integration in

crowdfunding platforms, there has yet to be a social network analysis conducted on patient-centered crowdfunding platforms such as GoFundMe.

Social network analysis is a good fit to study patient-centered crowdfunding because the very nature of crowdfunding relies on social network success; Facebook, Twitter, and Instagram have adapted their platforms to seamlessly integrate with GoFundMe so that users can share information about patient-centered crowdfunding campaigns on their own personal networks with minimal effort. As a result, some patient-centered crowdfunding campaigns tend to go "viral" – that is, to become widely popular due to some inherent trait in the video that causes rapid, widespread sharing on social media. As mentioned, studying the patterns, qualities, and motivations behind network activation is one of the prime interests of social network scholars, and exploring this gap in the crowdfunding literature could also address a gap in the social networking literature regarding network activation for charitable purposes or in the context of personal health crises.

One of the most useful pieces of research from the social networks/campaign communication literature that can be used to inform the academic study of crowdfunding is Rogers and Storey. Rogers and Storey (1987) conducted research on successful communication campaigns that rely on large social networks to bring about specific outcomes. The authors found that there are several recurring components of communication campaigns that allow for them to successfully activate social networks and bring about the campaign's desired outcomes. The nine traits of successful communication campaigns are:

1) use a communication tool that allows messages to be sent to a wide audience

2) utilize mass media channels to raise awareness about the cause/issue so that participants will organically start issue-oriented conversations

3) reinforce behavior change by encouraging communication through peer networks

4) use credible, established sources

5) routinely conduct research on network members to determine the most effective forms of messaging

6) make appeals that are emotionally "close" to the audience and avoid making appeals that they will not identify with

7) emphasize positive consequences of participation/adoption during the campaign

8) divide network members into separate groups so that they can be targeted more effectively

9) communicate on multiple levels (that is, they use intra, inter, network, community, and other forms of communication at the same time to reach different network members)

Research Questions

Diffusion of Innovations is an appropriate theory for this study due to its examination of how different groups engage with new and disruptive innovations (such as crowdfunding platforms). Rogers' (2003) insight into the innovation and audience

influencers for adoption is useful for understanding crowdfunding's success, as well as Diffusion of Innovations' perspective on barriers to adoption or why particular innovations fail. Communication Privacy Management Theory provides a robust description of the interpersonal, social processes behind privacy management. Having a framework for privacy management conversations is invaluable for understanding the ways that patients communicate with their caregivers and campaign supporters about their conditions. CPM theory serves as an outline for understanding the choices that patients and patient-centered campaigns make with their messaging to supporters.

The social networks literature provides insight into how campaign messaging through interpersonal and social media networks influence a campaign's outcome. Patient-centered crowdfunding could not exist or thrive in its current capacity without high levels of engagement from donors. As such, understanding social network activation and engagement is a central aspect of this study. Research questions should focus on understanding and gathering descriptive data on the techniques that campaigns use to solicit a response from their networks and expand to new networks. The commercial crowdfunding literature is also useful. While the goals of commercial crowdfunders are very different from those of patient-centered crowdfunders, both groups go through similar processes in terms of network engagement, to reach their goals. Understanding the differences and similarities between these two approaches is important because it allows them to be examined as two separate constructs.

The following section presents the fundamental research questions of this study, organized based on their connection to the theories, themes, and questions identified

through reviewing the literature. These questions are focused on (1) innovation, (2) donor perspectives, (3) campaign manager perspectives, (4) e-health, (5) social media/networks (6) personal characteristics, (7) communication and privacy, (8) and other potentially important themes surround patient-centered crowdfunding campaigns. This study poses the following research questions:

- **RQ1: What are the relative advantages of patient-centered crowdfunding? Put another way, what qualities of the innovation make it preferable to users over similar alternatives?**
- **RQ2: What qualities are consistently present in successful patient-centered crowdfunding campaigns?**
- **RQ3: What motivates donors to adopt the particular innovation of patient-centered crowdfunding?**
- **RQ4: What role does a patient's communication play in a campaign's overall level of success?**
- **RQ5: What features of patient-centered crowdfunding are attractive to potential donors?**
- **RQ6: Do crowdfunding campaigns exacerbate existing health disparities and inequalities of access? If so, how?**
- **RQ7: What efforts are being made to promote equality on crowdfunding platforms?**
- **RQ8: How do personal characteristics (happiness, self-efficacy, altruism, and e-health literacy) influence donor behaviors?**
- **RQ9: Are there any cultural or socio-economic/technological barriers that influence crowdfunding participation?**
- **RQ10: What are the differences between campaigns with high levels of network activation/participation and campaigns with low levels of network activation/participation?**
- **RQ11: What are the effects of high/low social media shares on a campaign's success?**
- **RQ13: What are the consistent traits of messages (in a patient-centered crowdfunding context) that travel through social networks?**
- **RQ14: How does a patient's condition influence the way that donors respond to the campaign?**
- **RQ15: Does the patient's disclosure of their challenges help or hinder the crowdfunding campaign? If so, how?**

CHAPTER 3
METHOD OF DATA COLLECTION

<u>Research Design Overview</u>

Patient-centered crowdfunding is a complex, multi-dimensional phenomenon that combines emergent technologies, charity, e-health communication, health campaign communication, and individual-level social psychology. As such, this dissertation utilizes multiple methods to provide a well-rounded, representative set of descriptive data. This study leans on perspectives from both quantitative and qualitative research methodology to understand 1) the critical aspects of the innovation itself and 2) the interpersonal/motivational factors that cause individuals to donate to/succeed/fail with crowdfunding campaigns. To accomplish this goal, a survey, content analysis, and in-depth interviews were utilized. This chapter describes the specific research methods used for data collection in this study. Campaigns included in this study were limited to those occurring in the United States because GoFundMe is a United States entity is largely used by those with ties to the United States. Moreover, healthcare is treated more like a commodity in the United States rather than right; this means that services like GoFundMe have a niche role in America that it might not have in nations with nationalized healthcare systems.

Due to the sheer size of the available data, sampling methods were used to scale the dataset to a manageable amount in the content analysis for a single researcher and

additional coder (for ICR, or intercoder reliability). This study utilizes multiple sampling strategies to account for this issue. The first strategy was to set a specific, unchanging range of dates in which to analyze crowdfunding campaigns. The other sampling strategy used was to select a predetermined number of campaign pages. While this method might have neglected some of the lesser-known or supported campaigns, it led to an organic picture of the types of campaigns typically receiving traffic on GoFundMe. The pages were randomly sampled from GoFundMe's website, with every other row of campaigns being displayed selected for coding. The only criteria required for selection was the campaign be displayed on GoFundMe's platform

Reliability is a major concern for all researchers, especially when dealing with new and/or exploratory research such as that of patient-centered crowdfunding (Drost, 2011). In the case of this exploratory study, triangulation methods were used to strengthen validity. Triangulation is the process of addressing the same research goal or question using multiple research methods; this study utilized triangulation in the form of the three separate methods on the same topic to increase confidence in the results. This was achieved through discovering similar sets of patterns across differing forms of data collection (i.e., phenomena noticed in the content analysis were also studied in the survey and interviews to increase confidence in the themes identified). The following subsections provide deeper detail into the three different data collection techniques utilized.

<center>**Content Analysis**</center>

Patient-centered crowdfunding campaigns publish a large amount of data about the subject of each campaign on the campaign's home page. These pages were valuable for assembling a descriptive dataset about crowdfunding trends and practices. The codebook collected descriptive information about the campaigns themselves, including the level of donations, number of donors, social media influence, goals, and other relevant factors. (See the Content Analysis Codebook in Appendix 1). The codebook was largely original because, to this investigator' knowledge, there has never been a content analysis conducted on patient-centered crowdfunding campaigns. However, there was a business crowdfunding content analysis codebook (for IndieGoGo) written by Logazio and Querci (2018) that was helpful in developing the initial codebook for this study.

Logazio and Querci (2018) provided several useful descriptive data categories for conducting content analysis on commercial crowdfunding (p. 318). While these researchers' intent was to study businesses reaching out to potential buyers via IndieGoGo, their analytical approach to understanding the relevant components of crowdfunding was adapted for patient-centered research. Logazio and Querci's (2018) categories work for the purpose of understanding patient-centered crowdfunding. **Table 1** includes the adapted categories.

Table 1. **Descriptive Variables (Adapted from Logazio and Querci, 2018)**

Dataset Structure	Measures

Descriptive Operationalizations
    Amount Received — Amount of money raised by the campaign (USD)

    Backers (Donors) — Total number of individuals who contributed

    Average funds — Amount received/number of funders (USD)

    Campaign Success (DV) — Hit goal? Y/N

Campaign Operationalizations
    Sector (Illness/Injury) — Type of illness or injury

    Funding type — Flexible, Partial, or All-Or-Nothing?

    Project Target — Amount of money requested by fundraiser (USD)

    Duration — Fundraising time window, in days

    Team Members — Number of individuals helping to manage/assist with the campaign directly

Communication Operationalizations
    Video — Is their pitch video designed to quickly describe the campaign? Y/N

    Length — Text word count

    Language — English-only? Multi-lingual?

    FB Shares — Number of shares of Facebook

    Twitter Shares (New for GoFundMe) — Number of shares on Twitter

    Updates — Number of updates posted on the campaign page

    Comments — Number of comments from donors/potential donors

    Websites — The existence of links to external websites where potential backers can find more information on the project

Survey

The survey was an effective way to understand the perspectives and motivations of donors and potential donors in patient-centered crowdfunding. Information regarding individuals' behaviors, motivations, and personal characteristics was collected through the survey. Kreps (2011) wrote that "the use of online surveys has received a lot of attention in recent years in health communication and health promotion research literature. Conducting surveys via email and the internet can save researchers a great deal of time and expense, [and] evidence suggests that response rates for online surveys are at least as good as for the telephone and through-mail surveys, oftentimes even better" (p. 286). The survey was distributed to individuals via social media who have previously encountered crowdfunding campaigns to understand the factors that influenced their decisions of whether to donate. More specifically, survey respondents were permitted to take the survey as long as they were at least familiar with GoFundMe and had time and computer access to take the survey. They did not have to have donated previously – while this might seem like an odd decision, one of the goals of the study was to determine the differences in perspectives between donors and non-donors. Most of the participants had previous donated, but roughly one-fifth of the respondents had not; this allowed for a few interesting comparisons between groups that will be shown in the results chapter.

The survey relied on digital methods of recruitment; these methods included a convenience sampling among individuals already networked to the researcher, as well as sharing the link to crowdfunding related platforms, social media pages, and websites.

Links to the survey were sent through conventional social media channels (Facebook and Instagram) to different campaign message threads in the comments sections. The reasoning behind this approach was twofold – individuals who found the link on Facebook 1) were likely to have the digital efficacy skills to be able to click through a survey and 2) their time on social media likely exposed them to GoFundMe campaigns previously. This recruitment method was also a convenient way to reach a potentially large number of participants.

The questionnaire used several multiple-choice options about past donation behavior, validated scales, closed-ended questions, and participant demographics. Participants also provided answers to questions from four different, established scales to get a sense of their individual-level personality traits potentially influencing their participation (or lack thereof) in crowdfunding efforts. These scales include 1) the General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995), 2) the Self-Reported Altruism Scale (Rushton et al., 1981), 3) the Subjective Happiness Scale (Lyubomirsky & Lepper, 1999), and the E-Health Literacy Scale (Norman & Skinner, 2006). Explanations of why these characteristics could shape decisions to participate and crowdfunding and their connections to theories/literature in earlier chapters are provided in the subsections below:

General Self-Efficacy Scale

Due to crowdfunding being a new, disruptive innovation (outlined by DoI) that is internet-based, individuals who feel more efficacious with technologies could be more likely to engage with them. Moreover, LaRose and Eastin (2001) found that user's internet self-efficacy is positively influenced by previous positive experiences and outcomes through successful internet usage. In the context of patient-centered crowdfunding, this means that individuals with higher efficacy could be more likely to view, and perhaps donate to, campaigns. The scale was included in the study to determine whether donation behavior is influenced, in part, by perceived self-efficacy such that donors are likely to be those who are confident in their ability to use this innovation. The GSE was developed by Schwarzer and Jerusalem (1995) during their work studying health psychology. Higher scores on the scale indicate an individual with higher self-efficacy, which translates to higher levels of work satisfaction, more stable emotions, and a more optimistic outlook (p. 36). Conversely, lower self-efficacy is found to lead to burnout, stress, depression, anxiety, and a number of other negative complications (Schwarzer & Jerusalem, 1995, p. 36-37). The scale ranges from 10 to 40, and is provided in Table 4.

Table 2. General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995)

	Not at all true (1)	Hardly true (2)	Moderately true (3)	Exactly true (4)

1. I can manage to solve difficult problems if I try hard enough

2. If someone opposes me, I can find the means and ways to get
what I want

3. It is easy for me to stick to my aims and accomplish my goals

4. I am confident that I could deal efficiently with unexpected
events

5. Thanks to my resourcefulness, I know how to handle
unforeseen situations

6. I can solve most problems if I invest the necessary effort

7. I can remain calm when facing difficulties because I can rely
on my coping abilities

8. When I am confronted with a problem, I can usually find
several solutions

9. If I am in trouble, I can usually think of a solution

10. I can usually handle whatever comes my way

Self-Reported Altruism Scale

The literature review raised questions about whether individuals donate to
GoFundMe for altruistic/intrinsic reasons and whether real-life social networks play a
role. This scale was included to determine whether people who self-identify as being
more altruistic tend to donate to GoFundMe campaigns. Other personal factors such as
knowing the patient, being familiar with the patient's condition, being frequently exposed
to campaigns on social media, etc., could influence one's decision to donate.
Consequently, collecting altruism data permitted significance testing between response

item scores and prior donation behaviors. The Self-Reported Altruism scale was developed by Rushton et al. (1981) and it seeks to determine an individual's level of altruism based on the frequency in which they engage in several charitable acts. The questionnaire has 20 questions, each of which is asked on a 5-point Likert-type scale. Higher scores on the questionnaire are indicators of higher levels of altruism. Individuals with higher levels of altruism are generally considered to be more likely to continue engaging in altruistic acts compared to those with lower scores (Rushton et al., 1981). The scale ranges from 20 to 100 and is presented in Table 5.

Table 3. Self-Reported Altruism Scale (Rushton et al., 1981)

	Never	Once	More than once	Often	Very often
I have helped push a stranger's car out of the snow.					
I have given directions to a stranger.					
I have made change for a stranger.					
I have given money to a charity.					
I have given money to a stranger who needed it (or asked me for it).					
I have donated goods or clothes to a charity.					
I have done volunteer work for a charity.					
I have donated blood.					
I have helped carry a stranger's belongings (books, parcels, etc.).					
I have delayed an elevator and held the door open for a stranger.					
I have allowed someone to go ahead of me in a lineup (at photocopy machine, in the supermarket).					
I have given a stranger a lift in my car.					
I have pointed out a clerk's error (in a bank, at the supermarket) in undercharging me for an item.					
I have let a neighbor whom I didn't know too well borrow an item of some value to me (e.g., a dish, tools, etc.)					

I have bought 'charity" Christmas cards deliberately because I knew it was a good cause.

I have helped a classmate who I did not know that well with a homework assignment when my knowledge was greater than his or hers.

I have before being asked, voluntarily looked after a neighbor's pets or children without being paid for it.

I have offered to help a handicapped or elderly stranger across a street.

I have offered my seat on a bus or train to a stranger who was standing.

I have helped an acquaintance to move households.

Happiness Scale

Park et al (2017) established a link between being happy and being exposed to generous behavior through a series of fMRI scans of fifty participants. Their study raises the question of whether happy individuals are more likely to donate or donating to a cause can make someone happier. As such, this study sought to determine participants' happiness through self-reported measures to learn whether happiness-induced generosity impacts GoFundMe participation. The subjective happiness scale is a short, four-item scale that seeks to determine happiness based on responses to different sentence regarding mood or outlook (Lyubomirsky & Lepper, 1999). Lyubomirsky and Lepper (1999) developed this scale through an in-depth literature review and found that it was correlated with other measures of subjective happiness (p. 147). The scale ranges from 4 to 28.

Table 4. Happiness Scale (Lyubomirsky & Lepper, 1999).

	Lowest Score						Highest Score
In general, I consider myself…	1 not a very happy person	2	3	4	5	6	7 a very happy person
Compared to most of my peers, I consider myself…	1 less happy	2	3	4	5	6	7 more happy
Some people are generally very happy. They enjoy life regardless of what is going on, getting the most out of everything. To what extent does this characterization describe you?	1 not at all	2	3	4	5	6	7 a great deal
Some people are generally not very happy. Although they are not depressed, they never seem as happy as they could be. To what extent does this characterization describe you? (This item is reverse-coded)	1 not at all	2	3	4	5	6	7 a great deal

E-Health Literacy Scale

The e-health literacy scale was included as a part of the survey because it assesses how effective a person is at navigating e-health technologies. This factor is related to the

adoption criteria outlined by Rogers (2003) in that perceiving advantages, less complexity, more compatibility, etc., with patient-centered crowdfunding technology could lead to someone being more likely to participate and donate to a campaign. Additionally, the e-health literature indicates that there is a certain level of technical understanding associated with the use of digital health technologies. As such, this instrument was used to look for correlations between donor status and e-health literacy. The e-health literacy scale is a ten-item scale that seeks to determine an individual's 1) perceived skill level at using information technology for healthcare, and 2) to aid in determining "goodness of fit" between e-health programs and their targeted consumers. (Norman & Skinner, 2006). Norman and Skinner (1999) developed this scale though working with various members of the population who engage with e-health tools at different levels of competency. The scale ranges from 10 to 50, with higher scores indicating a higher likelihood that the person will be competent with using e-health technologies.

Table 5. E-Health Literacy Scale (Norman & Skinner, 2006)

Question	1	2	3	4	5
How useful do you feel the Internet is in helping you in making decisions about your health? (1=Not Useful at all, 5=Very Useful)					
How important is it for you to be able to access health resources on the Internet? (1=Not Important at all, 5=Very Important)					

I know what health resources are available on the Internet (1=Strongly Disagree, 5=Strongly Agree)

I know where to find helpful health resources on the Internet (1=Strongly Disagree, 5=Strongly Agree)

I know how to find helpful health resources on the Internet (1=Strongly Disagree, 5=Strongly Agree)

I know how to use the Internet to answer my questions about health (1=Strongly Disagree, 5=Strongly Agree)

I know how to use the health information I find on the Internet to help me (1=Strongly Disagree, 5=Strongly Agree)

I have the skills I need to evaluate the health resources I find on the Internet (1=Strongly Disagree, 5=Strongly Agree)

I can tell high quality health resources from low quality health resources on the Internet (1=Strongly Disagree, 5=Strongly Agree)

I feel confident in using information from the Internet to make health decisions (1=Strongly Disagree, 5=Strongly Agree)

In-Depth Interviews

The purpose of the interviews was to sit down one-on-one with individuals who have engaged with crowdfunding platforms in the past. Most interviewees were donors. Their status as donors was a function of donors being a larger group than patients or recipients of campaign funds. Gill et al. (2008) wrote,

"…interviews consist of several key questions that help to define the areas to be explored, and also allow the interview/interviewee to diverge in order to pursue an idea or response in more detail…the flexibility of this approach [allows] for the discovery or elaboration of information that is important to participants but may not have previously been thought of as pertinent by [the researcher]" (p. 292).

These interviews sought to understand the 1) challenges (refers to the obstacles to patient-centered crowdfunding participation), 2) motivations (refers to the specific factors that motivate individuals to donate or consider donating on crowdfunding pages.), and 3) ethical perspectives (refers to the character, beliefs, and principles of the participant) of both the patients/campaign operations and the donors. As such, two separate in-depth interview guides were used (one for each group). Interviews with patients/campaign managers also focused on support, defined as the system surrounding the patient beneficiary who is the focus of the patient-centered crowdfunding campaign. The interview protocols are listed in Appendix 3.

Efforts were made to connect with interviewees on social media and through GoFundMe comments sections. Purposive sampling was utilized to locate known donors and campaign managers (Tongco, 2007). Additionally, a snowball sampling strategy was used. Often one donor would know other donors to the same campaign and asking for references to other potential interviewees proved to be an effective means of gathering data. GoFundMe was also contacted regarding the project to assist with recruitment, but

there was no response from them on multiple attempted contacts. Some suggest that directly contacting gatekeepers can be an effective way to gain access to difficult or hard-to-reach populations (Atkinson & Flint, 2001), but this method proved unsuccessful through reaching out to GoFundMe.

Chapter Review

The first goal of the study was to create useful descriptive data for building a long-term research agenda around patient-centered crowdfunding. Establishing this dataset provides a baseline for future research around the patient-centered crowdfunding ecosystem by showing relevant themes, relationships between patterns of donation and personal characteristics, and establishing existing dynamics on the platform. It also provides future crowdfunding users with an overview of how the innovation functions and the sort of results that other users have achieved. Specific quantitative metrics that describe what goes into a successful campaign are presented. Descriptive data are included on the donors so that crowdfunding practitioners may become more aware of the types of people to whom they are making appeals.

CHAPTER FOUR
RESULTS

Overview

This chapter contains the results of the qualitative and quantitative data collection methods outlined in the previous chapters and includes explanations for the analysis choice along with results that tie into the earlier-mentioned research questions. This chapter also includes the participant demographics, tables to describe relevant parts of the descriptive data set, connections between the in-depth interview guide and the analysis, details about the coding, intercoder reliability calculation, and thematic analyses conducted to construct this data set. Three data collection methods were used: (1) in-depth interviews, semi-structured, recorded, transcribed, analyzed); (2) a survey (70 questions, multiple choice/Likert-type with short response), and (3) a content analysis of crowdfunding pages, subject profile, and thematic analysis. The data were analyzed at multiple levels: (1) campaign, (2) individual, donor, and (3) individual; recipient. Efforts were made at each level of analysis to collect and organize the data based on the theories and research outlined in the literature review. Data were collected until saturation was achieved, illustrated by the appearance of meaningful trends in the data that can be explored in future research. The next section describes and reports the final instruments, recruitment, and sample assembled through each data collection method.

QUALITATIVE: THEMATIC ANALYSIS

Sample and Recruitment: In-Depth Interviews

Twenty-four ($n = 24$) participants were interviewed for the study. The participants were sorted into one of two categories based on their past experiences with patient-centered crowdfunding platforms: (1) donors ($n = 19$) or (2) campaign managers ($n = 5$). While there is a clear imbalance in the sample, it is not a problem within this dataset as there are significantly more donors than campaigns on *GoFundMe.* The population is relatively young, with the average participant in their early thirties ($m = 32.5$; $sd = 15.1$). This is younger than the current average age of the U.S. population ($n = 38$) (Jeffrey, 2018). The majority of the sample is white ($n = 20$; 83.3%); the second largest group is Hispanic ($n = 2$; 8.3%), with the remainder of the sample being African American ($n = 1$; 4.1%) and Asian ($n = 1$; 4.1%). The majority of the sample is female ($n = 14$; 58.3%).

Participants were recruited initially through social media and word of mouth; it was later discovered that both crowdfunding donors and campaigners likely knew other people who have donated to a campaign. Therefore, snowball recruitment became a reliable method for finding additional participants. In other words, current participants, if they were willing, would recommend other participants to be interviewed for the study. Participants who agreed to be interviewed met with the researcher at a mutually determined time and public location. If this option was not feasible, recorded phone calls were offered as an alternative. All of the interviews were recorded using an iPhone 6+ along with an auxiliary microphone to boost the quality of the capture. Due to file storage constraints, these files were transcribed soon after their recording to make room for future

interviews. The transcriptions were later analyzed to uncover themes and isolate quotes that are detailed in this chapter. Participants were recruited from the end of January until the beginning of March, when data collection ended. There was not an explicit, targeted number for interviews but rather a goal to reach saturation with the themes being sought by the in-depth interview guide.

Participants were interviewed using one of two in-depth interview guides based on whether they were a donor or a campaigner on *GoFundMe.* While the phrasing of the questions was different in these guides, they both shared the common focus of connecting the experiences and worldview of the participants to the relevant themes outlined in the literature review. These themes include: (1) user experience (diffusion theory), (2) networking/social media, (3) ethics, (4) attitudes/motivations, (5) future uses, (6) privacy management, (7) obstacles, and (8) process improvements. Transcripts were analyzed using NVivo 11, and the work was finished using Nvivo 12 due to a mandatory software upgrade mid-project. This did not have an impact on the researcher's ability to analyze the data. The following section will organize the qualitative data based on the themes uncovered during the analysis.

Transcripts were read several times, and the data were organized using a semi-open coded approach. More specifically, certain top-level codes (the themes identified in the literature review) were incorporated into the qualitative codebook. Additions were then made to the codebook as new themes emerged over the course of the analysis. Each transcript was read at least three times, with the final transcript being read alongside the finalized codebook. Finally, for the quotes used in the remainder of this project, the

abbreviation **CM** will indicate that the quote is from a *campaign manager* and the

abbreviation **D** will indicate that the quote is from a *donor*. This portion of the analysis

seeks to assemble data to answer the following research questions posed in earlier

chapters:

- **RQ1: What are the relative advantages of patient-centered crowdfunding? Put another way, what qualities of the innovation make it preferable to users over similar alternatives?**

- **RQ2: What qualities are consistently present in successful patient-centered crowdfunding campaigns?**

- **RQ3: What motivates donors to adopt the particular innovation of patient-centered crowdfunding?**

- **RQ4: What role does a patient's communication play in a campaign's overall level of success?**

- **RQ5: What features of patient-centered crowdfunding are attractive to potential donors?**

- **RQ6: Do crowdfunding campaigns exacerbate existing health disparities and inequalities of access? If so, how?**

User Experience

The biggest distinction between users was the way the campaign was presented on

social media. Some donors mentioned seeing "sponsored" posts where those running the

campaign paid some of their own money to boost the chances of others seeing it. These

promoted posts usually only cost a few dollars a week and had mixed results. This raises

the issue of equality, because some patients are likely in no position to be able to pay

extra money for a paid advertisement campaign. Most participants described the process

as an "organic, grassroots" movement where motivated individuals share the campaign for no personal benefit. None of the campaign managers who participated in this study admitted to using paid or promotional techniques through social media.

Grassroots support on social media seems to be an effective way of expanding a campaign's network and introducing new donors to the crowdfunding process. One participant echoed this sentiment by saying:

D: I only trusted [GoFundMe] because I know [the participant's brother] isn't the type to get scammed on the internet. I don't know technology that well, but I trust it if he trusts it. So, when I saw [the patient] get sick and my brother share his page, I felt like I could donate because I knew that it was safe.

Seeing trusted peers having success with a new innovation is one of the key elements for successful diffusion of innovations adoption (Rogers, 2003). Potential donors verify the authenticity of *GoFundMe* campaigns by watching others have success with the behavior. This theme coincides with Bandura's (1977) Social Learning Theory, which states that adopted behaviors come through observed peer success.

Outcome attachment motivates donors to support after the initial donation. Another interesting element identified through the user experience questions was that donors continued to offer communication support to campaigns post-donation by utilizing the comment/share tools provided on social media. Specifically, donors often used their

own private social media to provide links to the campaign's donation page, resulting in new potential contributors being exposed to the campaign. This is important because it (1) increases the likelihood of additional financial donations amount from individuals willing and able to help and (2) provides those without the means to donate with an option to still support the goal of raising awareness about the campaign. On a more personal level, campaign managers felt encouraged and supported when they noticed acquaintances and distant friends going the extra mile to rally support. One campaign manager summarized this theme by saying:

> **CM:** I was blown away by how heartfelt the support was. People we hadn't talked to or seen since our wedding were sharing our story. Like...my ex from high school even donated and shared our page. And that was 20 years ago we dated…We don't have a lot of money. We're comfortable but weren't ready for the cost of all of those surgeries. We don't know a lot of rich people, so it really helped that a whole lot of people saw and supported. We made over twenty thousand dollars with a hundred bucks being the biggest [donation]!

Also, donors feel connected to the campaign's result. Their financial and time commitment allows them to experience a sort of personal success; if a campaign reaches its goal, the donors feel like their contributions made a difference in someone else's life. This is reflected in one participant's comment:

D: It makes you feel like you did something that matters. I remember when I got the follow up email months later when [the patient's] campaign hit its goal. Five grand wasn't a huge amount, but the fact that everyone who knows and loves [the patient] could come together and help them out in just a few weeks…it was cool. I've donated two or three more times to other campaigns but see that first one succeed so hard convinced me that *GoFundMe* is a good thing. It's kind of sad when they don't work out because I'm thinking, why are the person's family not helping?

Donations to strangers can occur when the campaign or patient strikes a sympathetic, personal chord, even when the donor does not have a real-life interpersonal connection to the patient. Some donor's personal experiences of various conditions seems to impact their donation behavior. Some interviews illustrate how important sympathetic connections are for patient-centered crowdfunding success. Some donors felt inspired to give when they felt an indirect connection to a stranger whom they shared some commonality with, such as a value, personal experience, or traumatic event. Even if the donor does not directly know the patient, the donor might have strong feelings about the patient's condition based on their perception of the kind of person the patient is due to similarities in their own lives. One participant cited military experience as a connection to a campaign, and said:

D: I wasn't in combat ever, but I was friends with guys at [a military base] who were. What those dudes go through is just unbelievable. People say they appreciate [the service], but I don't think a lot of people really get how bad it is. So, I didn't know the guy, but saw how combat would have him in a wheelchair and I just had to help. If that was [a former military friend] and he got shot up, I'd want people to help him. They didn't even ask for that much. I can't remember what it was, but he got it. I felt good about that.

While this donor did not explicitly say it in the interview, the donor made it apparent that their prior personal experience interacting with members of the armed forces was a determining factor in their decision to donate to the campaign. It is impossible to say whether this donor would have donated to the campaign if they did not have this personal experience, but the donor would have had to at least find a different motivating reason to do so. It is likely that the campaign would not have stood if the participant had not had these experiences.

For their part, other participants cited health-based sympathetic experiences which created a connection to the patient or campaign:

D: I had to quit my job for a little bit when my dad got [Alzheimer's]. He needed around the clock care and I was living out of state. I used a chunk of my savings to move. We eventually got him moved to a home, and I was lucky because I had a good job, and it was still really expensive. And stressful on the family. I try to

donate when I see someone who's going through what I went through. They

didn't have GoFundMe and stuff twenty years ago when that all was happening.

Would've been nice, but we did fine.

Witnessing a family member struggle with a debilitating illness like Alzheimer's

can be a severely traumatic experience that changes the way that one views the disease

and others who are experiencing a similar struggle. In fact, this participant was so

impacted by their personal experience that the participant claimed to seek out

Alzheimer's patients for online donations. This personal connection with strangers is an

interesting dynamic that could be a particularly appealing feature that is nearly unique to

crowdfunding – conventional donation methods to major charities do not provide the

same level of choice in selecting who is benefiting from a donation, and some donors

likely find it appealing to send support to patients on the basis of a shared experience that

resonates with them emotionally.

Campaigns tend to have the best results when they start well. Campaign

managers who operated successful campaigns explained that gaining early support or

traction is critical for long-term success. More specifically, having many donors in the

early stages of the campaign helps to legitimize the cause to other donors and shows that

a campaign has upward trajectory. One manager provided details helpful for

understanding this theme by saying:

CM: The first day or two, we didn't get much response. I was discouraged. Then we got twenty dollars here, ten dollars there, and we ended up getting almost four hundred dollars by the end of that fourth day. We were over fifteen hundred by the end of the week! The first hundred seemed like it took as long as the rest, but things took off once a few people primed the pot.

This participant's comment indicating a strong start is critical is reminiscent of an s-curve and Rogers' (2003) concept of critical mass. Once a small percentage of participants donate, this activity legitimizes the campaign to other potential donors. Not only is attracting donors early on monetarily beneficial to patients, but it can also give donors peace of mind that the campaign is legitimate and not a scam or fake profile. One of the donors hinted at the psychology behind seeing a campaign with donation momentum versus one without it:

D: Sometimes those new [campaign pages] that go up look a lot like scams at first. They have one picture and no one has donated. I get people are stressed, but they also have to try to let us know they're legit or else they're not going to get a lot of donations. Personally, I like to give to campaigns that are almost at the goal so I can help push em over the top.

Appearing legitimate is important at all phases of fundraising, but this comment highlights how many potential donors could feel when they see a sparsely populated

campaign page, especially at the beginning of the campaign. While this lack of content

might have a good explanation. Perhaps the campaign manager is still coping with the

initial shock of the patient's condition. Launching a campaign without the necessary,

sometimes tedious, steps of adding compelling content could harm the campaign.

Networking/Social Media

There were two sets of three questions centering around networking and social

media in the in-depth interview guides. The purpose of these questions was to understand

the participants' perspectives of the impact that social media has on the patient-centered

crowdfunding process. Donor questions focused on the influence of social media on

campaign participation and process. Manager questions sought to determine how social

media influences the capabilities, outcome, and process of patient-centered crowdfunding

campaigns.   **Table 2** illustrates how the different questions approach this theme:

Table 1: Donor/Campaign Networking/Social Media Questions

Donors	Campaigns
Q5. How has social media influenced your participation in crowdfunding?	Q5. How has social media influenced your campaign's outcome?
Q6. Do you think social media makes the overall crowdfunding experience better or worse?	Q6. Do you think social media makes the overall crowdfunding experience better or worse?
Q7. Are you more likely to donate to a crowdfunding campaign that you see on social media as opposed to email or word-of-mouth?	Q7. How would crowdfunding be different without social media?

Social media seems essential for patient-centered crowdfunding. All

participants mentioned social media use in their daily lives in some capacity. Donors

utilized Instagram, Facebook, and Twitter without a clear age or gender pattern. All

participants seem to have at least average competency in utilizing social media on their

tablets or smart devices. Every participant engaged with crowdfunding campaigns that

they found through social media with the exception of two. The two participants who did

not initially discover crowdfunding through social media still used an electronic medium

(email marketing by GoFundMe). The email marketing method still incorporated

elements of social media, as explained by the participant:

> **D:** I don't go on Facebook a lot. Can't even remember the password. So, I have to
>
> use the iPad that's got it saved. I used to get a lot of update emails from Facebook
>
> though. I saw that [the patient] was GoFunding on Facebook because it was the
>
> most trending post among my friends that week. I probably wouldn't have noticed
>
> it otherwise. Glad I did though.

The previous quote shows how interwoven social media has become in people's

lives, and how far the reach can be when a campaign utilizes a variety of communication

delivery methods. Someone who claimed to not even log into their Facebook often

received an email notification from Facebook that a person he knew was sharing a

GoFundMe campaign. This means that the message was created on GoFundMe, was

introduced to a network on Facebook, shared by someone on that network, and an

algorithm automatically distributed the updated to personal email addresses simply because two people were designated as "friends" on Facebook. One manager offered an interesting perspective on how impactful social media can be for a patient-centered crowdfunding campaign's success:

> **D:** The world has gone digital. We do everything on our phones now – I have a 3-year-old niece who can unlock [her mother's] phone in seconds. And I don't even think she knows her numbers yet. So people started using phones and technology from the time they're little, and they're going to grow up really comfortable with it. So, it makes sense to me that social media makes [crowdfunding] better. People are comfortable on Facebook, so if GoFundMe can be on Facebook people would feel better about it.

As this participant notes, social media platforms have deeply penetrated everyday social life. As such, GoFundMe's presence on social networks and the tools that its developed to make sharing and promoting on other platforms are likely to continue making it an attractive, recognizable option. Familiarity can breed trust, and the more that GoFundMe accounts can be present and showcase genuine legitimacy, the more likely it will be for people to accept the technology. This dynamic relates back to Rogers' (2003) concept of observability. That is, the more a innovation can be observed in operation by others, the more likely it is to diffuse. However, to some potential donors, more campaigns appearing asking for donations could create an environment in which

scamming becomes more commonplace (if proper measures are not taken).

Social media could make scamming easier. While no participants acknowledged they were victims of GoFundMe scams, many believe that social media makes it easier for people to try to scam money because (1) it has a lower barrier of entry than other types of crime/scam, and (2) it's new and therefore many people are still unfamiliar with the way that scammers operate. The following statements encapsulate these two sentiments:

(1) Lower Barrier to Scam

> **D:** I think that people don't take online crimes as seriously as other crimes. I illegally downloaded music with Limewire and Napster as a kid, but I really don't think I was hurting anyone. I mean maybe the music industry but they're already rich. Still, I wouldn't even scam on GoFundMe but I think some people would view those sort of things as being the same because they both happen on computers or the internet.

This participant raises an interesting point. Online crimes do not provide the same proximity to the victim and might likely leave the scammer with less guilt or shame associated with taking advantage of another person. This donor's reference to stealing music from Limewire and Napster as a youth highlights the fact that some crimes appear to me more "victimless" due to their online nature. Additionally, there are likely far fewer law enforcement resources being dedicated to catching these sorts of crimes compared to

speeding, stealing, or violent crime. GoFundMe scams, when caught, appear to be so infrequent that they are even considered newsworthy:

> **D:** It's way harder to get caught for something like that. I can only think of one case recently in the news where that couple teamed up with that homeless veteran, but that was a really elaborate scam with the news involved and everything. If that's what it takes to get busted, then a lot of the scammers are just going to keep scamming. Maybe they're going after these people, but I don't really know how I'd know if they were.

True or not, the sentiment that some of these crimes go unpunished or even uninvestigated could potentially be damaging for GoFundMe's long-term success and take away opportunities from legitimate patients who could use the help. Other participants shared this sentiment, with one theorizing that the relatively low-stakes of some campaigns is enough to avoid heavy scrutiny from those who might otherwise investigate them and, while potentially time-consuming, faking injuries to abdicate responsibilities/garner sympathy as been going on for far longer than GoFundMe has been around. In one exchange, a participant outlined how easy it could be to run a scam just by purchasing a prop:

> **D:** The thing is that scams could be for small amounts and it's easy to fake. Anyone can go buy some crutches and ask for five hundred bucks online. Who

checks it out? I don't know – that's why I donate to people that I know so I can follow up with them on the phone or with a text or something. The only people who get caught doing that shit are people who raise a million dollars or something.

These problems seem to only be fixed by increasing the criteria for beginning a GoFundMe campaign, yet one of the most attractive components of GoFundMe is the ease-of-use. This fits with Rogers' (2003) concepts of perceived advantage and compatibility. It is far easier and less expensive to start a GoFundMe than start to create a 501 c3 charity. The exchange is that the charity is likely to be much more vetted, and there is an avenue for serious, actionable recourse for those who would abuse a 503 c3 charity for personal gain. Without going through additional hurdles and making GoFundMe harder to use, the other option for reducing scamming would be to have a more informed base of donors. As with many innovations, additional time will likely breed a higher degree of familiarity and make donors more competent at detecting scams on the platform.

(2) Newness

Several participants cited lack of familiarity as reason that they could potentially be scammed. First-time donors or donors that are myopically focused on making their single donation and logging out could be particularly at risk. One participant who gave her first ever GoFundMe donation to a rescue animal that needed an operation did not

seem to worried about their money going to waste. She also brought up the fact that they did not spend much time or effort verifying the legitimacy of the campaign:

> **D:** I've been using the site for about a year just giving a little here and there when I see a beagle up there. Beagles look alike a lot of the time and if someone tried hard, I bet they could scam people like me that don't really look into things too much. I'm really not on there enough to keep up with updates and news and all that. I figure if someone takes money I'm trying to do something good with, at least I tried and the bad juju is on them.

While it is admirable that this donor is so trusting and would not be overly upset to see their money taken, this mindset could unwillingly cause a substantial amount of damage to GoFundMe in that scamming could become more commonplace. Since user safety is ultimately the platform's responsibility, users should be careful about how they go on the platform in order to reduce the likelihood that they'll be taken advantage of. If users were more vigilant about the campaigns they donate to and make efforts to verify the campaigns they donate towards, then scammers could might eventually become far less common on the platform. Other participants supported the idea of new, less vigilant donors being a target for scamming:

> **D:** I think that first time donors probably get scammed the most if they're giving money to a stranger. I don't know how many people that is, because again I think

that most people give to the people they know, but that seems like when it'd be the most likely to happen. I don't know. It seems easy for a charitable person to give to a really needy-looking person without really looking into it if they have the money.

Social media use does not translate to automatic success. While social media is clearly central to crowdfunding, campaign managers cite several challenges to crowdfunding that are caused by social media. Two of the most commonly-cited challenges include (1) time commitments and (2) network activation:

(1) Time (from Campaign Managers)

Nearly all campaign managers cited lack of time as a problem when running their campaign. While digital and social media tools are designed to make the user experience easier by saving time, it increases the social expectation of communication – the immediacy culture of social media and streaming-enabled devices have created an environment in which there is a certain expectation that campaigns actively communicate with their participants. Although there is no rule or mandate that this must occur, campaigns that under communicate with donors or rarely respond could risk losing legitimacy and support. One campaign manager addressed both points in her response:

CM: We felt like we were constantly having to update and respond to every little comment we got everywhere. It took so much time. I don't want to sound

71

ungrateful for all of the money and support we got, but it was really exhausting

having to constantly be logged in to talk to people. That's what it takes, so we did

it. I think that's why you see a lot of campaigns not work out…there's 2 updates

in a month and they don't respond to comments. I get that it's scary. We were

scared too. But, if people are going to spend their money then you got to at least

say thanks.

Time can also be a problem for campaign managers due to their other life

expectations. In most cases, campaigns were being managed by a close friend or family

member of the patient, meaning that whoever was running the campaign likely had to

juggle a family life, job, bills, and other personal responsibilities while dealing with the

GoFundMe page. GoFundMe's digital tools might make it easier to manage mass

communication, but better tools still cannot account for the exterior obligations of the

campaign managers. One manager compared the experience to working several jobs:

CM: Looking back, I wish I could've hired an assistant or something. It felt like

having two full time jobs. Well, three because of the other two kids. So, between

being a working dad and having a kid recovering in the hospital, I spent a lot of

my time just reading the comments and trying to catch up on all of the messages

we got. [The participant's wife] went back to work too, so we were both having to

juggle making time for each other.

While it is difficult to offer solutions to time-related problems as they vary from person-to-person, engaging towards donors and producing quality materials for the campaign can help the campaign reach its goals. The longer a campaign manager procrastinates on this due to other time commitments, the more the campaign manager risks reducing traffic on their campaign pages. Therefore, campaign managers should try to establish a workable routine for posting new content and responding to comments/questions on the pages. By committing a few minutes every day, campaigns managers might be able to reduce instances of feeling overwhelmed by campaign-related work.

(2) Network

Activating and mobilizing social networks successfully is at the head of GoFundMe success. From the outside, one might think that patient-centered crowdfunding is about going viral and getting extensive mass media exposure, but earlier themes identified in this analysis illustrate how getting off to a strong start seems to be one of the most important steps a campaign can take. The most effective way to get a strong start with an online campaign is to lay the groundwork with one's personal network (either face-to-face or through social media) to try to influence their participation during the early stages of a campaign:

> **CM:** Pretty much all of our first donors – like our first five or six at least – were all people who knew about the campaign already and reached out. I think they just

did their donation so it would show up on the algorithm or whatever. My husband is an engineer and he knows more about that part of it than I do. You can ask him about that when you talk to him. But any way, we got that initial bump from our first few donations and then people from years ago and even a few total strangers started to chip in.

Not only does recruiting real-life supporters help the campaign launch, but it can also spread the message to unknown or unlikely supporters and garner additional donations or other assistance for the campaign. This method could circumvent some of the innovation participation barriers and potentially create opportunities for those who have not yet been exposed to GoFundMe (i.e. the late majority and laggard groups, as defined by Rogers (2003). A participant describes a moment like this when a particularly generous (and likely wealthy) person learned of a campaign through a family member, and would have otherwise never made a donation because this person was unaware of GoFundMe:

> **D:** [The participant's father-in-law] hates computers and never would've known about [the patient's] campaign, but their grandchildren go to high school together and are really good friends. He used to come down to Lake Anna with us in the summer and stay at the house down there. We told [father-in-law] about what happened, and he went straight to his checkbook and told us to give $5,000 to the boy's parents. I don't know if that counts for going to GoFundMe me because I

still don't know if he knows what it is, but he made the check out to us so we

could deposit it then put it through the website.

Personal network activation can be an advantage or disadvantage depending on

the affluence of the network; if someone is fortunate to have wealthy friends, family, and

neighbors, they have a richer network from which to solicit donations from. Conversely,

those who are networked with more economically depressed or less fortunate people will

not have the same advantage for soliciting financial support from their direct

interpersonal relationships. A participant provided a good example of affluence on

networks when she described being family friends with several lawyers:

D: I think that [the patient's family] was lucky because they had insurance, but

their dad also had a lot of friends from law school that did well for themselves. So

when friends can cut several thousand dollar checks without blinking, it somehow

makes the fundraising go a lot smoother.

It is hard to say what can be done to help those who do not have affluent personal

networks account for lack of initial financial backing during the beginning stages of the

campaign. These individuals will likely need to increase the breadth of their initial

support by soliciting more people that they know personally to engage with the

campaign. Although an extensive word-of-mouth effort for promoting a campaign seems

unrelated to GoFundMe, it might be the only recourse that some individuals have when

they cannot find momentum.

Oversaturation of GoFundMe campaigns on social media is a new challenge.
With the growing popularity of GoFundMe, the platform runs the risk of oversaturation
and a decrease in the net effectiveness of crowdfunding measures due to the sheer
number of people campaigning. Not only does oversaturation decrease the likelihood that
a campaign will gain as much visibility, but it also creates an environment in which sick
people are indirectly competing with one another, sometimes for their very survival. This
morally questionable dynamic raises serious concerns about the type of system that
creates this sort of competition:

> **CM:** It feels like a really weird, sort of sick competition. While we were
> campaigning for [the patient], we had to do better than the other patient's family
> and friends or else they would get the money and we wouldn't. I hated it. It was
> probably my least favorite part of the process behind [the patient] actually being
> sick. I think that's what our culture has become though. If someone doesn't
> outwork everyone else, they don't deserve anything. Those people better hope
> they always have their health.

The most striking part of this campaign manager's response is the passage "I
think that's what our culture has become though. If someone doesn't outwork everyone
else, they don't deserve anything." This ties directly back to the literature review

discussion of Silicon Valley culture's potential influence on the platform. Many of the technology multinationals that have molded tech culture hold very distinctive libertarian values, such as hard work making one deserving of success, competition for resources, and fierce individualism. While these values have led to many positive innovations, they have come at the cost of often pitting vulnerable individuals against each other for scarce resources in sometimes dire situations. This value system seems to not draw the line at healthcare funding, but rather reinforces competitive norms in the content of patient-centered crowdfunding. Participants cited problems in the American approach to healthcare as an explanation for why patient-centered crowdfunding platforms are gaining popularity:

> **D:** I think that it goes to show how much need there is for better healthcare. It'd be a perfect world if no one needed GoFundMe, but it seems more and more people are getting on it every year.

Other participants pointed out how the growing popularity of GoFundMe is making it more difficult for individual campaigns to stand out:

> **D:** Sometimes it can be overwhelming. For every person you help there are ten more that need help. I don't know if it's because more people are hopping on because they hear "free money" or if the economy or price of insurance are

making more people have to use it. It seems a lot more crowded than it did in 2014 when I first used it.

Oversaturation becoming an issue raises the question of whether there is growing need for services like GoFundMe, or if there is instead an influx of new users running campaigns on the platform because they believe that it's a good way to make money. While many campaigns are justified, there are many that are for less-worthy causes than preserving life and wellness, a point summarized nicely by one campaign manager:

CM: It's so easy to make one, that people are making them for everything. For selling shirts, going on vacations, making art projects. Everything. And think 'there are people over here fighting for their lives and futures, and other people are taking up space to make a buck. Unbelievable.

This frustration is likely to be felt more acutely by campaign managers than it is donors because the managers have more severe repercussions to suffer from campaign oversaturation on GoFundMe. The clearest solution seems to be to limit the options that a person can crowdfund for, or at the very least have stricter guidelines and campaign placement practices that would allow for display on the website to be based on need rather than traffic.

Honesty, transparency, and communication. Participants made it clear that lying or misleading donors is a bad tactic for someone trying to run a successful crowdfunding campaign. It discourages donors from contributing to a campaign and could potentially deter them from ever engaging with the platform in the future.

Participants offered insight into the impacts of dishonesty as well as the importance of transparency and effective communication; multiple managers discussed weighing privacy concerns with the need to maintain honesty and transparency. In some ways, proving oneself to be honest in a patient-centered crowdfunding context should mimic good honesty practices on other forms of social media and offline. Being transparent and clear with one's intentions, having specific stated goals and following through on them, and avoiding exaggeration or intention misleading are all generally good ways of maintaining and improve credibility. One participant shared opinions on these issues:

> **D:** Lying on GoFundMe is about the worst thing I can think of. It takes money away from people who need it and it makes money for thieves. I'm always really careful about who I donate to, but there's still a level of trust. At the end of the day, it's still the internet. If someone lies on GoFundMe and they get caught, I think they get in legal trouble now. Even if they didn't, it'd probably ruin their reputation on the site forever and it could come back to bite them if they ended up actually needing the service at some point.

This participant's comment that GoFundMe is "still the internet" implies that there is an inherit discomfort or distrust with using digital platforms. When compared to real life interaction, there is no doubt that the inability to see/hear directly from someone without a computer screen adds a degree of credibility. Building trust, in this context, is the responsibility of both parties. Donors should try to make well thought out decisions regarding their donations and general interactions on the platform. While not all participants had equivalent digital efficacy skills (as will be discussed later in this analysis), nearly everyone is capable of doing at least a minimal amount of vetting before making the decision to give a donation. For campaign managers, voluntarily exhibiting transparency could establish credibility with donors. Campaign managers described several methods for being transparent, with one particular respondent offering a nice summary that encapsulated much of the general sentiment:

CM: It's hard to prove that you're not lying. Someone can say 'I'm not lying' but that's what a liar would also say. I think the best thing that we did to be honest was we showed as many receipts and paperwork items as we could. We obviously crossed out our address and private info, but we showed photographic evidence of the dollar amounts we were up against, and people didn't seem to raise questions about whether or not we were a real campaign.

One of the risks associated with being transparent is that too much transparency could lead to the mishandling of personal information and could result in a boundary

violation, as described by Petronio (1991) As a result, the co-owners of the patient's private information (the campaign managers) should be very intentional about the way they construct and distribute campaign messages. One of the best ways for campaign managers to navigate this delicate situation is to, when possible, include the patient in conversations about the campaign. Not only will this avoid boundary turbulence and prevent awkwardness or resentment between parties, but campaign managers will likely feel better knowing that they are able to operate without having to worry about the patient's perspective on the campaign. One campaign manager described this scenario by saying:

CM: What made the transparency hard is that we had to make sure [the patient] was okay with us putting her business out there. She's a private person. But she never really raised a fuss about GoFundMe. I think it's because we were doing most of it, and she didn't really have to see it or think about it. Still, her endorsement to do it our way made us feel like we could operate without worrying about stepping on her toes or doing something that would make her upset.

Other managers utilizing the method of including the patients in planning sessions were able to establish guidelines for how the private information would be treated, as well as setting ground rules for the kind of content that would be shared:

CM: I think that the only rule we came up with is that [the patient] wanted me to check with him before I put up any pictures of him recovering. I think it's more of a teenager thing with him than a patient thing though – kids want every hair to be perfect. We kept that rule though, and we didn't have issues.

Some campaigns that had multiple managers or were living at a distance from the patient utilized other technologies to work collaboratively. These participants cited Dropbox, Skype, and GoogleDocs as the primary tools used. Campaigns with multiple managers would assign a workflow where different people would take on different tasks:

CM: We decided very early on that we would all need to be okay with what was posted. We started a google drive so that we could all see and edit the document. The same person always posted it, but everyone had to give their approval through the chat. I think that the biggest benefit to doing it that was is that no one got upset about anything after the fact.

This section illustrated some of the reasons why trust, both inside and outside of the campaign, is important for the campaign's overall success. Internal trust dynamics include clear communication between the campaign manager(s) and the patient, as well as routine privacy management and maintenance measures while creating campaign content. Externally, campaigns must make themselves transparent to donors by speaking candidly, showing confirmable evidence of honest campaign practice, and responsibly

managing the funds that are received

Poorly written content and/or disorganized pages. Donors want clear communication free from clutter and exaggeration. There are a variety of reasons behind this. The following subsection will explore this theme.

GoFundMe campaigns must strike a delicate balance between informing the donors by making heartfelt appeals without excessive wordiness and hyperbolic, language. While GoFundMe provides a few guidelines (using completed sentences, checking for spelling/grammar, reading text out loud before posting, etc.) they are not necessarily helpful in providing actionable advice on generating quality content. As a result, many campaign managers have to rely on their own skillsets and perceptions of what quality strategic communications writing entails. This leads to a lack of consistent content between campaigns, and donors often find themselves navigating campaigns that either 1) do no provide the correct details, 2) are too sparse on content, 3) contain too much content, or 4) contain so many grammar/spelling errors that donors move on to other pages. One donor described his frustration this way:

> **D:** Some people are too wordy when they write about the [GoFundMe] pages. I don't know, it just seems like they're trying to make things a big deal more than they're trying to just tell me what happened and why I should donate. There's less substance. If I'm going to give money, I want to know, in simple terms, what happened, what's the plan, and how my money can help make that plan happen.

Period. If they can do that, then I think this whole process gets easier for

everyone.

As stated earlier, having a lot of content does not automatically qualify a

campaign as being well put together; there are other ways of damaging credibility aside

from having an essentially empty page. Campaign pages that are sloppy in appearance,

error filled, and disorganized harm campaigns. Donors notice these flaws, as indicated by

some of their responses during the interviews:

> **D:** It's clear when a GoFundMe page is quickly thrown together. It just looks bad.
>
> There are grammar mistakes, there are really few pictures. When they look like
>
> that, it makes me wonder if they'll have the same level of care with the donations.
>
> I want to help, but I have to know the help is actually going to help and not just
>
> get misspent because of poor organizational skills or something.

These dynamics highlight the potential need to produce additional training

materials or writing templates to give users greater creative guidance. While some might

argue that it is not GoFundMe's job to train its users on how to structure their content,

there are clearly certain criteria that donors are looking for in the content. Therefore,

GoFundMe should take the initiative to work with their users (the campaign mangers) to

determine ways of making them more effective content creators on the platform. Not only

would this elevate the quality of the communications on the GoFundMe pages, but it

could also lead to campaigns seeing greater success in meeting their goals and ultimately benefit the GoFundMe organization itself through this process.

Some donors seem unaware of equality problems. There are distinctive differences in perceptions of equality among this study's participant group. This could be due to a variety of reasons. The question asked of all 24 participants was "Do you believe that GoFundMe is an equal platform?" and they were then asked to explain their answers. Some participants who did not understand the question were asked a rephrased version of the question such as "Is there anything about GoFundMe that promotes or impedes equality, in your opinion?" There was a very interesting array of responses to this question. Some participants had answers that were potentially reflective of social class, which can manifest itself in the form of racial inequality.

One of the most apparent distinctions that is possibly contributing to this issue is the lack of diversity within the sample (83.3% white). However, this lack of ethnic diversity in the sample could potentially be more reflective of the ethnic reality of GoFundMe (more so than having 4-5 equally sized participant samples from different ethnic groups). Still, the overconcentration of certain worldviews/perspectives could be unintentionally impacting campaign successes and failures on GoFundMe. Here is what several participants in the larger sample group (83.3% white) had to say about equality issues on GoFundMe:

D: I feel like a lot of poor people feel more equal to one another. People don't seem to care as much about broad social justice/racial problems when they're hungry, and I feel like in a weird way struggle can bring people together. I was really poor in college, but I remember not having as many problems as I do now that I'm doing better financially. I think a lot gets political too. Equality gets shoehorned into a lot of things. So, I don't think that there's an equality issue even though people might try to make it seem like there is one. Just because I'm white doesn't mean I'll only donate to white people.

While the previous respondent did not say that she was offended by the question or the idea of inequality on the platform, this participant did seem a little defensive in answering it. The transcript does not capture the respondent's tone, but the answer was given in a slightly incredulous way, as if the idea of social inequality on a charitable platform was a ridiculous notion. This respondent also brought race into the conversation without being prompted in the response above. The same participant provided this statement:

D: I think people donate to who they trust, and they're more likely to trust people they know. I know mostly white people so that just happens to be who I trust, but I don't donate to them just because they're white. It's a coincidence, but I don't really see a connection to inequality.

Other participants answered the equality question more through the lens of class rather than race, and some mentioned race and class. One such participant cited media influence for conditioning people to view inequalities more readily than they might otherwise:

> **D:** I think if there is inequality, it has to be more about poor versus rich more than any racial stuff. I think that's a lot of media hype, personally. Just people looking for something to be outraged about. I've given to non-white people on GoFundMe. I think we're a bigger part of the population, so it makes sense that there would be more of us on GoFundMe.

There was an interesting underlying certainty among nearly all white participants that equality issues either were not on the platform, or perceptions of inequality were exaggerated. These responses are likely reflective of the participants' previous experiences and worldview. Inequality is less of a concern for those who enjoy privileged or advantaged end of it. Individuals with higher degrees of affluence may be more likely to have the time, access, and personal skills required to launch a successful crowdfunding campaign than those who are less affluent. Although this imbalance can exist irrespective of ethnicity, ethnicity and social class are often tied together in the United States. As such, the pattern of Caucasians reporting little inequality or not perceiving them could be symptomatic of this greater underlying theme.

Interestingly, this analysis uncovered distinctively different results on this question from the non-white respondents in the study. The following statements come from less represented racial groups in the sample (16.7% non-white):

D: I feel like there are some equality problems, but not in an earth-shattering way. I can't help but notice a good amount of the unfunded GoFundMe's are for people that look like me. I don't think it's intentional, I just think white people have more money a lot of the time and they just spend it however they choose. I don't have numbers on any of this, but I've been donating for a few years now and I feel like white kids usually get their GoFundMe money before anyone else.

This response can be connected back to the notion of network affluence (Schradie, 2012), the idea that one's personal network can be a heavy contributor in getting exposure on social media. This particular respondent was Hispanic and this person described how many of his friends or family abroad only spoke Spanish. He was not sure whether they could engage with GoFundMe, even if they wanted to, for a variety of reasons. Social contexts of this sort inherently put some users at a disadvantage by not giving them the same freedom to activate their network (as an English speaking Caucasian would), then this is a nearly textbook example of passive inequality (Bowles, Loury, & Sethi, 2014). While both groups, in theory, have the same potential to use the platform towards the same end, uncontrollable personal characteristics are putting one person at a disadvantage. Additionally, earlier parts of this analysis highlighted the fact

that GoFundMe implicitly puts patients in competition with one another for donors' attention and resources. Inequality of opportunity to take full advantage of the platform further stacks the deck against people with less training, access, or personal connections. Participants echoed these sentiments in different ways, with one mentioning the connection between real-life affluence and digital impact:

> **D:** It's hard for me to outright say 'it's not a fair set up' but…it's not a fair set up. The same advantages and disadvantages people have don't just magically disappear because we go digital. Affluence is affluence in real life, on Facebook, on GoFundMe, all of that. So, communities with more money like [Caucasian communities] will take their money online when they go online. The members of my community that have a lot of money, I don't think any of them know what GoFundMe is or have interest in it. So our affluence doesn't show up for our people the way it could I think.

These responses are illuminating in that they contextualize some of the problems likely being felt on a broader scale across the platform. These problems are reflective of issues that are broadly present in American society and will likely take efforts beyond the means of GoFundMe campaigns to fix. However, broader awareness of inequality is one of the critical first steps in being able to effectively address it. GoFundMe should turn its attention towards this class inequality issue and attempt to take measures to highlight campaigns that might otherwise not get as much attention for a variety of reasons. In the

era of big data and emerging AI, it is becoming progressively easier to handle large datasets and look for recurring patterns. If individuals from lower socioeconomic communities are indeed struggling to make progress with GoFundMe, it should be easy for the company to internally data to confirm it. If this is the case, then greater efforts must be made for all GoFundMe campaigns to have a fair shot at meeting their goals.

Attitudes/Motivations

Questions were asked about attitudes and motivations for engaging in GoFundMe campaigns or donating to them. This line of questioning yielded some of the longer responses from participants. However, many of the answers were told in stories or the conversation led to being off topic. Concentrated efforts were made to select salient answers identifying the participant's attitudes and motivations. The donor group questioning was based largely on their personal impression of the campaign, while the manager questioning focused on their perception of how donors respond to the campaign/situation. **Table 4** illustrates how the different questions approach this theme.

Table 2: Donor/Campaign Attitude/Motivation Questions

Donors	Campaigns
Q11. Is there a certain medical condition or situation (cancer patients, hurricane victims etc.) that you are more likely to donate to based on your past experiences?	Q12. Do you think that there was something about your situation that made it more likely that people would feel motivated to donate?"
Q12. Is there anything discouraging about	Q13. Is there anything discouraging about

crowdfunding?	crowdfunding?
Q13. Would you consider using GoFundMe if the appropriate situation presented itself? Why or why not?	Q14. Would you recommend other people use GoFundMe if they encountered a situation in which it would be helpful?

Donors seem concerned with positive impact/trajectory of the patient more often than with a specific illness or injury. Many donors believe that crowdfunding directly helps the patient; the ability to see improvement in the patient can be a powerful motivator. Some participants explained that it was easier to give to someone that they know had a strong chance of recovery. Seeing campaigns without a clear strategy or specific goals was viewed negatively by donors, with some going as far to say that they feel like those campaigns appear to be scams. The following donor suggests that a chance for recovery is an important factor in making her donation decision:

> **D:** I'm a waitress at [redacted] so I'm not rich. But I was raised to tithe, and I started making my 10% charity GoFundMe, which means that I'm on the site at least twice a month. It's only seventy dollars a paycheck. But I want it to go to good use…so I research the pages to make sure the story is believable, and the money will help. I feel bad for people fundraising for funerals. But that just doesn't help as much as like a cancer kid or something. I want my donation to be a part of what gives someone more life.

In addition to having a chance for recovery, respondents also said that having a plan and sharing that plan with potential donors makes the campaign more appealing. This theme is in agreement with the earlier discussions on campaign transparency; that is, campaigns that are more transparent (i.e. sharing a well-developed plan) are more compelling to donors and trusted more than campaigns that lack a clear explanation of the patient's difficulty and the needed solution. There are several reasons for this, with one of the most important being that clarity and specifics build donor trust; they help donors feel their resources will be responsibly managed, as described by the following participant:

> **D:** I'm skeptical to donate if there's no plan. What am I giving money for? I don't know if that's too harsh, but it's like people just want the money and don't say how it gets spent. If one person tells me where the treatment money goes and someone else doesn't, then the first person gets my donation.

Having a timetable was important for one donor, who noted that as the primary reason for his repeated donations. Timetables might include weekly or bi-weekly messages that keep donors informed, written using the GoFundMe blogging tools. GoFundMe automatically sends the update to donor email addresses. This step has a secondary benefit to campaigns because it provides previous donors two opportunities to help the campaign: 1) by sharing the new update on their own social media, and 2) to potentially donate again if they are feeling motivated to do so. Some repeat donors cited following the routine updates and being engaged with the content as motivating

influences for them, as summarized by this participant:

> **D:** [The patient's] family was really great about giving these weekly updates every Monday. It was a quick little phone video, but we got to see the healing each week. I started   looking forward to them and it even got me to donate later when they were so close to hitting the goal.

While these methods seem to be promising ways of improving campaign performance, they do come at a cost. Not everyone has the time, skillset, and energy to be able to produce high-quality, well produced content on a weekly. Those with the capabilities to make a weekly video have a certain baseline level of resources that not everyone can access; dynamics like these create inequality on the platform, as discussed earlier in this chapter.

Donors are less engaged with crowdfunding, in general, when the patient of the campaign does not survive. There are a significant number of crowdfunding campaigns that help survivors deal with funeral expenses and income shortages as a result of unexpected or tragic loss. With that said, the primary function of GoFundMe is to assist patients with their expenses to ease their recovery process. In the unfortunate circumstance in which the patient does not survive, the money can be used to assist with funeral expenses. However, many campaigns that seek to cover funerals from the start

have the additional challenge of donors feeling more motivated to give to living patients:

> **D:** I wish I had enough to give to everyone on [GoFundMe], but since I can't do
> that I want my dollar to go to help a patient who has a chance of recovering. It's
> discouraging to see the funeral GoFundMe's mixed in with the living patients
> who are fighting for their lives. I don't know. Something just seems
> psychologically off about doing it that way or something. I haven't donated to a
> funeral [GoFundMe campaign], but I've only been using it for like 2 years.

While this donor clearly cares and wants to help, her personal objective of donating to the patient most likely to survive rather than the patient who needs the donation the most (based on severity of condition and distance from reaching the crowdfunding goal), is an example of illness inequality, as discussed as a proposed axiom in the literature review chapter. This sort of inequality causes certain conditions or injuries to be favored over others due to an inherent bias or predisposition within the donor. Other concerns about the condition impacting donations are less about the trajectory of the patient and more about their donation being put to good use. This concern is almost reminiscent of the business notion of return-on-investment (ROI) and raises questions of whether the donation being "money well-spent" is a result of the inherent transactional nature of the platform. One respondent who mentioned money being will spent did not admit that he was bothered with losing it, but expressed general frustration with the process:

94

D: I donated to a campaign where [the patient] died the day after I made my

donation. I wasn't really even mad about the money not helping. It took so long

for me to find out it was even happening, and I was more mad about that. If

everybody who donated gave that money in the first few days [the patient]

could've ended up different.

Another respondent was more blatant about feeling upset that a donation was

made to a patient who did not survive:

D: [The patient] got sick again less than a year after they beat it the first time.

They tried starting another GoFundMe, but I think that most people weren't as

impacted by it because the first one had a lot more success. I don't know if people

were out of money, or didn't care enough to give, or just numb to how tragic it all

was. It made all of it feel like a waste of time and money when they died. That

counts as discouraging. I still feel for the family.

That donors may avoid campaigns that appear unlikely to succeed is an intriguing

observation for several reasons. This observation suggestions: 1) donors assume their

donations will lead to a patient surviving, 2) donors are avoiding campaigns where the

patient's survival is unlikely, and 3) these attitudes may cause divisions among patients,

campaign managers, and donors. These three dynamics combined could be directly

responsible for the success of some campaigns and other campaigns' inability to pay for

treatment.

Extra duties and expenses can have a negative impact on campaign manager. Campaign Managers struggle with many factors, including long hours, lack of sleep, constant socialization, transportation issues, personal finance problems, and several others. The following manager summarizes these:

> **CM:** I had to quit my job to take care of [the patient] for the first few months until he got back on his feet. We got into a lot of credit card debt. Almost done paying it off though. The GoFundMe money helped, but we had a bunch of other expenses too. But we're not ungrateful.

Even with raising a five-figure amount, the cost of treatment coupled with the loss of an income due to needing a stay-home caretaker resulted in the family incurring several thousand dollars of credit card expenses. Even if the patient is able to secure payment for treatment, this example shows how several secondary factors can merge to present an additional wave of challenges to the patient's support system. It is likely that the family's social class and level of affluence impacts their ability to shoulder these additional burdens, once again raising questions about how GoFundMe exacerbates preexisting inequalities. Even those who are unable to quit working still exhibited the necessity to change their working patterns to accommodate the patient, as described by the participant below:

CM: Work got mad at me because I was late to almost every shift while [the patient] was sick. They knew my situation and promised that my job wasn't in trouble because of you know. But my coworkers were passive aggressive about the leniency that I was getting. I understand that on some level too, but they didn't know my situation. I'm glad I don't work there anymore.

Someone who has the resources to handle additional expenses might be less likely to have a negative arrangement with their employer over a schedule changes and might even find themselves in a position where they can afford not to work. Some campaign managers could not even afford accommodations near the location of the patient's hospital:

CM: They wouldn't let me sleep in the hospital room, so I parked my car at the Walmart nearby and tried to sleep. I could've gotten a hotel but those are $160 or $170 dollars where [the hospital] was. I slept bad. I think I would've slept bad in a hotel too.

Even if someone decides to sleep in a car instead of a hotel due to a patient being out of town, the person is inevitably having to pay for gas. These expenses might seem far removed from the needs of the patient but having strong support nearby can make a

meaningful difference. Even so, expenses such as gas for transportation can add up over time, and often remain overlooked,

> **CM:** The hospital that [the patient] was staying at was two towns away. People don't think about the gas for driving two hours a day every day of the week. We were spending hundreds of dollars a month on just that, and health insurance companies don't think about that stuff.

It might be a more difficult "sell" to make public appeals to support the campaign managers, but if their participation is essential for success, they have a meaningful way to justify using some of the donated money. However, this could be a major expectancy violation to donors if they do not know that the campaign managers will be using some of the funds for the inherent expenses that caregivers will incur. As such, and as recommended several times in this chapter, being transparent about where the money is going can go a long way in preserving a positive, trusting relationship with donors.

Campaign managers feel the demands of running a campaign. Managers cite the difficulty of balancing their personal well-being with the progress of the campaign, with several of the reasons being provided in the previous section. While there is an inherent amount of stress with any management position, GoFundMe campaigns are oftentimes being managed by someone without professional communication management experience, who has an emotional attachment to the subject on some level, is dealing with

a large number of donors, and has a chance of being responsible for money that is quickly acquired. These situational factors likely contribute to the high stress of managing a patient-centered crowdfunding campaign. Managers provided interesting details about this dynamic. The following participant described how just being in and out of the hospital was a draining experience in itself,

> **CM:** I hate the hospital now. I didn't have strong feelings before, but I hate it now. We were in there for what seemed like forever. It was under a month, but it was the longest month ever. I felt drained whenever I went in there. We were there all day, but I'd feel completely exhausted after the first hour of being there. I don't know how people work in hospitals their whole career without going crazy.

In addition to being exposed to unfamiliar environments, campaign managers can find themselves dealing with situations that they are unaccustomed to and can be scared of or frustrated by the experience. A participant referenced this theme when she described dealing with more money than she usually handled:

> **CM:** I'm personally not great with money, so I think I was intimidated by the fact that I was responsible for a five-figure amount of cash. I'm not broke, but I'm bad at saving. That was more than my salary and I had to move it around. I obviously wouldn't steal it ever or anything, but I was scared I'd put it in the wrong account

or it'd get stolen or I don't know. It was a lot to suddenly be responsible for, for me at least.

New tasks can also be socially exhausting. Managers who are not used to or dislike interacting with lots of people can find themselves in the stressful situation of having to be in near-constant communication with donors and others who are assisting with the campaign. This likely distracts the managers from typical routines and social interactions, leaving them with less time and energy for personal socialization. Coupled with the stress of having a sick or injured loved one, campaign managers could grow somewhat resentful of the constant interaction,

CM: I was getting really tired of having to constantly type the thank you messages. They were all basically the same thing, but they had to be personalized enough to sound sincere. My mind was just focused on [the patient]. I feel like I was just phoning it in writing on social media. I didn't want any of that to happen so even the thank you's made me mad.

If possible, campaign managers should share the communication burden with other trusted associates. This will reduce the draining feeling of constant social media interaction and hopefully reduce instances of burnout. The downside to this approach is that it requires extra vigilance in establish communication norms and privacy boundaries

and there must be clear communication in between those who are co-managing the campaign.

Managers are surprised with how difficult it is to step away. Participants who ran GoFundMe campaigns develop a sense of responsibility for the patient. As the patient's condition improves, so does the manager's sense of well-being. As a result, campaign managers have indicated that it can be difficult to step away. This was indicated by several managers:

CM: Even when you're not there with [the patient], you're still *there*, you know? It's really hard to separate yourself at any point when someone you really care about is suffering. I just had to remember to tell myself that healing just takes time and that me hovering and stressing everyone else out isn't going to be helpful.

The sincerity of this statement reflects the psychological proximity that managers hold the patients in, in some cases. Even trying to step away for a little bit can be difficult because there is a genuine sense of caring for the beneficiary. Another campaign manager even said that she turned down a generous gift that was intended to help them create some psychological distance between themselves and the situation:

CM: Someone bought my husband and I a weekend away at ocean city as a gift, but we ended up secretly giving it away because we didn't want to be out of town and away from [the patient] for even one night.

There is a distinctive change in how campaign managers lived their lives during the campaigns. Avoiding travel in order to stay with the patient was a common theme:

CM: The only vacation we took in that fifteen-month recovery window was when [a family member] had their wedding. We went for two nights – I think we actually spent longer in the airport and planes than we were actually at the wedding.

Not only was travel impacted, but many managers discussed how they felt less joyous in their daily activities. Several admitted to no longer doing activities they enjoyed because their focus became almost exclusively about the health and wellbeing of their loved ones,

CM: When all you want is for someone to get better, it sucks the joy out of a lot of things that you normally like. So even though I guess I could've technically gone hiking or do whatever, I spent most of my time visiting in the hospital, reading, and waiting. It sounds bad, but it wasn't all bad.

Resolving these harsh dynamics is likely beyond the capabilities of GoFundMe –

however, GoFundMe may consider networking campaign managers together on its

platform in a sort of support group. Not only would managers have a chance to network,

ask each other questions, and pool expertise, but they also find meaningful social support

among others who are sincerely going through similar situations.

Process Improvements

The obstacle category was only asked of the campaign managers as they possess

distinctive insights into the functions of the *GoFundMe* campaign interface. User/patient-

centered design has become a common practice in information technology and health

because it allows a platform to be tailor-made to fit the needs of users. As such, campaign

managers were asked a few questions about their perspective on ways to improve

GoFundMe for future campaign managers. **Table 7** illustrates how the questions

approach this theme.

Table 3: Process Improvement Questions

Donors	Campaigns
N/A	**Q19.** What advice would you give GoFundMe on improving its platform?
	Q20. What were the most and least helpful tools for constructing the GoFundMe home page of your campaign?
	Q21. What was the best advice you

	received from the people at GoFundMe?

Support materials for those who struggle with writing, video production, or photography. User literacy or skillset has an important influence on a campaign's success. Those who struggle with writing content or responding, using social media tools, and editing photos and videos will likely have a more difficult time crowdfunding. These problems were not widespread – only two of the campaign managers brought attention to them. Still, exploring these participants' insights into the challenges of crowdfunding content creation could lead to the development of better training tools or guidelines for future campaigns. These perspectives are summarized by the following excerpts:

> **CM:** I feel like I'm not a dumb person, but I haven't had to write a whole lot
> since attending [a local community college]. I can do it. I finished the associates,
> but I work on cars man. I don't do a lot of writing at my job, and that in
> combination with taking care of [the patient] made the writing process seem really
> hard. It took me days to bring myself to write a page or two. I wish they would
> have like a few templates or pre-made body paragraphs that we could pull from. It
> might not sound super genuine, but I think it would help more than it'd hurt.

This statement illustrates how social and educational inequalities can create challenges that might be more difficult to notice for some people. Some users will need

more help in getting acclimated with public communications. Offering templates or other resources would be a step towards reducing inequality. GoFundMe could reap an additional benefit from providing these tools, as these measures could lead to more widespread success on the platform., increasing its attractiveness to potential users. Another way that GoFundMe can provide assistance is to make the graphic production (of photo or video) as easy as possible for people who do not feel comfortable in producing such graphics:

> **CM:** More tools to help with pictures. That, for sure, would've been nice. I'm terrible at taking pictures. I think my Facebook profile picture is seven years old or something. Doesn't even look like me anymore. So when [the patient] got sick, I had to learn how to be a better documenter of things with my phone. It's already hard to take good pictures, and hospitals are always sort of dreary. If GoFundMe had better guidelines and maybe like an easier way to post older photos online. That could help. That could help me at least.

These suggestions from the participant are valid, but they do not account for the fact that some people might not even have a working phone or internet-connected device from which they can monitor content on the GoFundMe pages. While there are public computers available at many libraries and even some hospitals, someone without access to the technology might also lack the skills required to utilize it. This is perhaps one of the most puzzling problems with GoFundMe; while many possess adequate skills for

running these campaigns, the most vulnerable (i.e., the ones who likely need the most help on GoFundMe) could very well be the ones with the least capability of using it.

Subsection Conclusion

The themes identified through the in-depth interviews provide clear insights into some of the key dynamics at play in the patient-centered crowdfunding ecosystem. As in other arenas of communication, establishing credibility with the targeted audience is extremely important for long-term success and being able to achieve one's goals. This portion of the analysis uncovered several ways to establish credibility, including 1) being transparent and honest, 2) communicating frequently, 3) providing personalized, engaging messages, 4) avoiding the appearance of being unorganized or not having a plan, 5) being proactive, and 6) tapping social networks/connections to assist with the campaign when possible.

This portion of the analysis also uncovered several instances where inequality is at play in the patient-centered crowdfunding ecosystem and has the potential to harm an untold number of campaigns. Due to the fact that inequality issues can manifest subtly and be difficult to spot due to the exist of more easily definable problems, these issues stand a chance of continuing to exist without concentrated efforts on the part of the platform. GoFundMe should conduct a self-audit and look for distinctive similarities in campaigns that fail on its platform to determine whether there are certain sociocultural similarities among campaigns that struggle to meet their goals.

QUANTITATIVE: SURVEY

Sample and Recruitment

A total of one hundred and seven ($n = 107$) participants were included in the final sample of the survey. While there were several different ways to divide the dataset into multiple groups during the analysis, many of the comparisons look for differences in the descriptive data between those who have donated to patient-centered crowdfunding platforms ($n = 90$) and those who have not ($n = 17$). It is unclear whether this imbalance is reflective of the broader population, as it is unlikely that people who have donated to crowdfunding campaigns would severely outnumber those who have not – despite the fact that the survey was anonymous, some participants who have never donated might have felt guilty providing a response indicating that status. While there is no way to verify this due to the anonymous nature of the data collection, it is something to be aware of while reviewing this portion of the analysis. The reason this imbalance could potentially pose issues is because having one group be so small ($n = 17$), it makes determining significance between groups more difficult.

The survey was constructed using Qualtrics and distributed using a direct link to the survey. The link was distributed through several means, including Facebook, Instagram, Twitter, and word-of-mouth promotion. Recruitment was initially slow but began to pick up as others were encouraged to share the link. Additionally, paper copies of the survey were made available on request – anyone who responded using a paper copy would have their responses later entered into the computer and the paper copy would be destroyed. Data was collected from the middle of January 2019 until the

beginning of March 2019. All responses that were initially recorded using Qualtrics were exported into Excel, where they were cleaned and checked for completeness. There was no explicit targeted goal for participant recruitment because the purpose of this exploratory study is to establish broader themes based on descriptive data; the ideal sample size could not be known until at least some data were collected. All participants read an informed consent form which provided key information about their rights as a participant, the purpose of the study, the potential benefits/harms to participants, and contact information for the researchers should the participants have any questions.

The survey questions were based on both the literature identified earlier by this project as well as the qualitative themes that emerged from the interview process that was previous described in this chapter. The phrasing of questions changed due to the nature of the instrument, but many of the themes that the survey addressed were closely related to those that emerged in the interview. These survey themes include: (1) Donor Behavior, (2) Perceived Benefits of GoFundMe, (3) Perceived Harms of GoFundMe, (4) Evaluations of Worthiness, (5) E-Health Literacy, (6) General Self-Efficacy, (7) Self-Reported Altruism, and (8) Happiness. This portion of the analysis will use survey data to illuminate how these themes present themselves in the context of patient-centered crowdfunding, and how these themes change between frequent/recent donors and infrequent/non-recent donors. This portion of the analysis seeks to provide data to answer the following research questions posed in earlier chapters:

- **RQ2: What qualities are consistently present in successful patient-centered crowdfunding campaigns?**

- **RQ10: How do personal characteristics (happiness, self-efficacy, altruism, and e-health literacy) influence donor behaviors?**

- **RQ11: Are there any cultural or socio-economic/technological barriers that influence crowdfunding participation?**

- **RQ7*: Do crowdfunding campaigns exacerbate existing health disparities and inequalities of access? If so, how?**
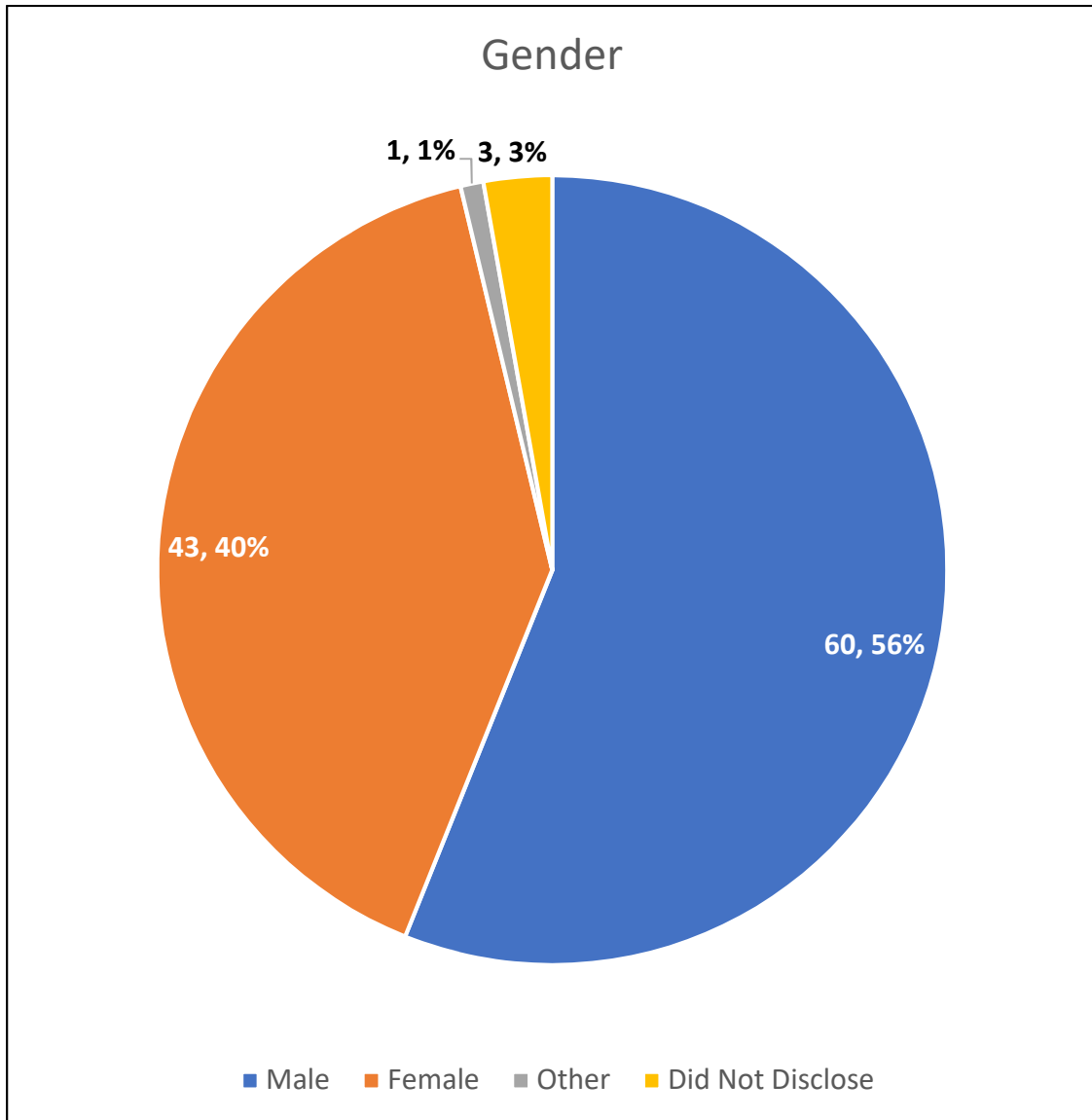
Figure 1: Participant Gender

There was a moderate majority of male participants ($n = 60$) compared to female participants ($n = 43$); there was a small group in the sample that indicated 'other' ($n = 1$) as their gender or that they did not wish to answer that question ($n = 3$).
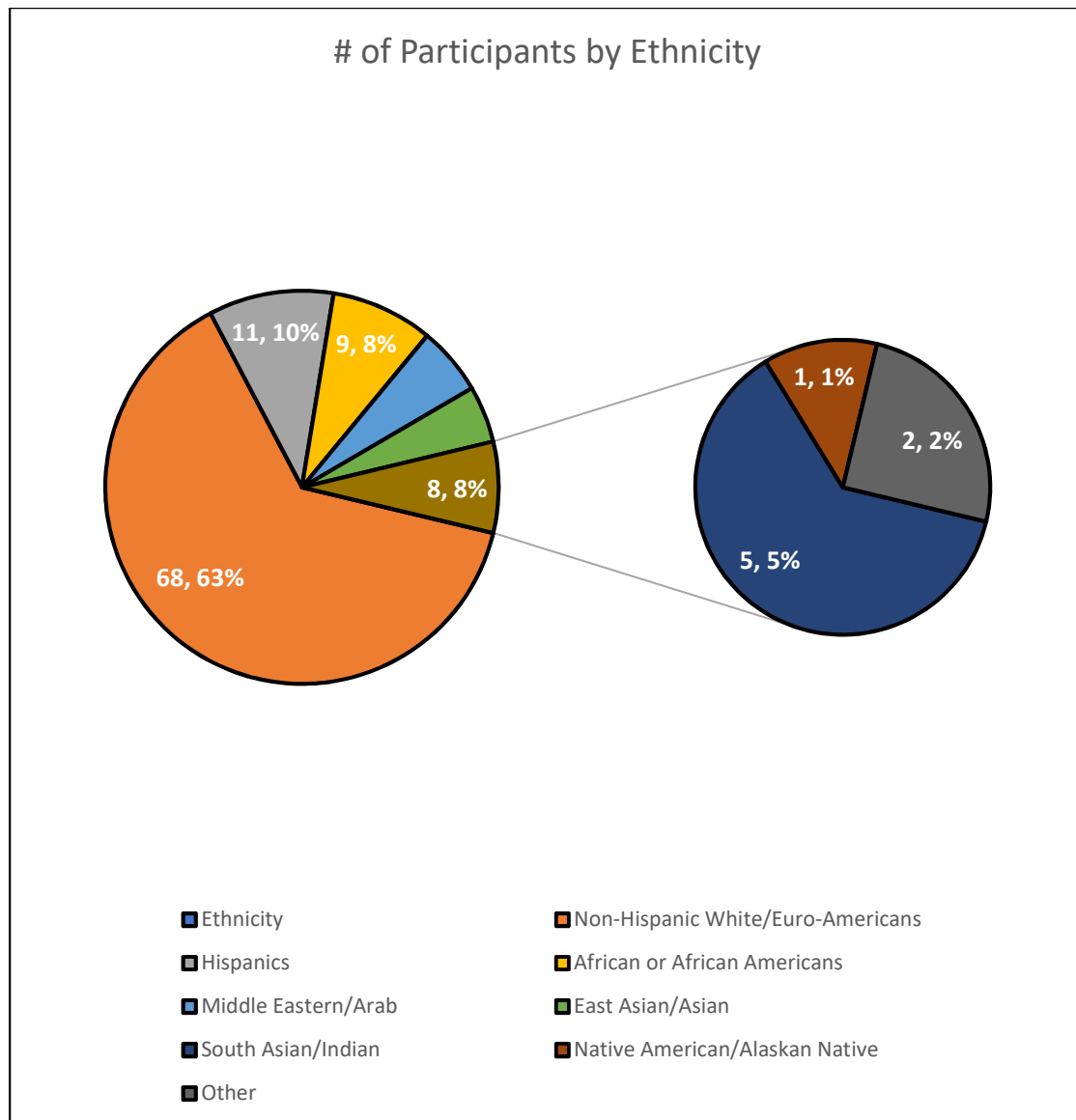
Figure 2: Participant Ethnicity Breakdown

Non-Hispanic White/Euro-Americans were the largest group in the sample (n = 68), followed by Hispanics (n = 11), African Americans (n = 9), and Middle Eastern/Arab (n = 6). The remaining participants identified as East Asian/Asian (n = 5), South Asian or Indian (n = 5), Native American or Alaskan Native (n = 1), and Other (n = 2).
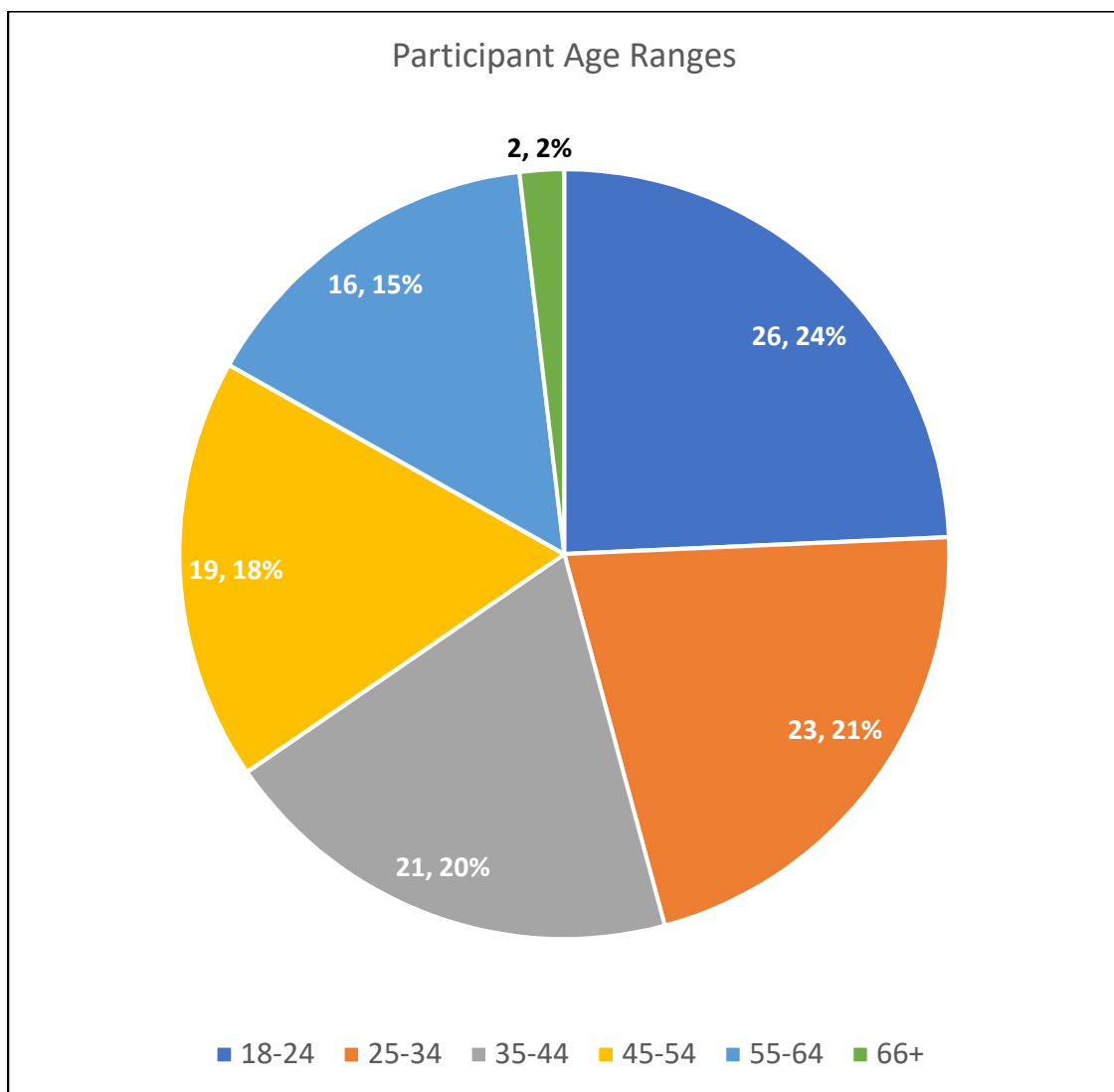
Figure 3: Participant Age Ranges

Participants between the ages of 18-24 made up the majority of the sample ($n =$ 26), but there was a fairly even distribution of ages across the sample – 25-34 was the next largest group ($n = 23$), followed by those 35-44 ($n = 21$), 45-54 ($n = 19$), 55-64 ($n =$ 16), and with a few over the age of 66 ($n = 2$).
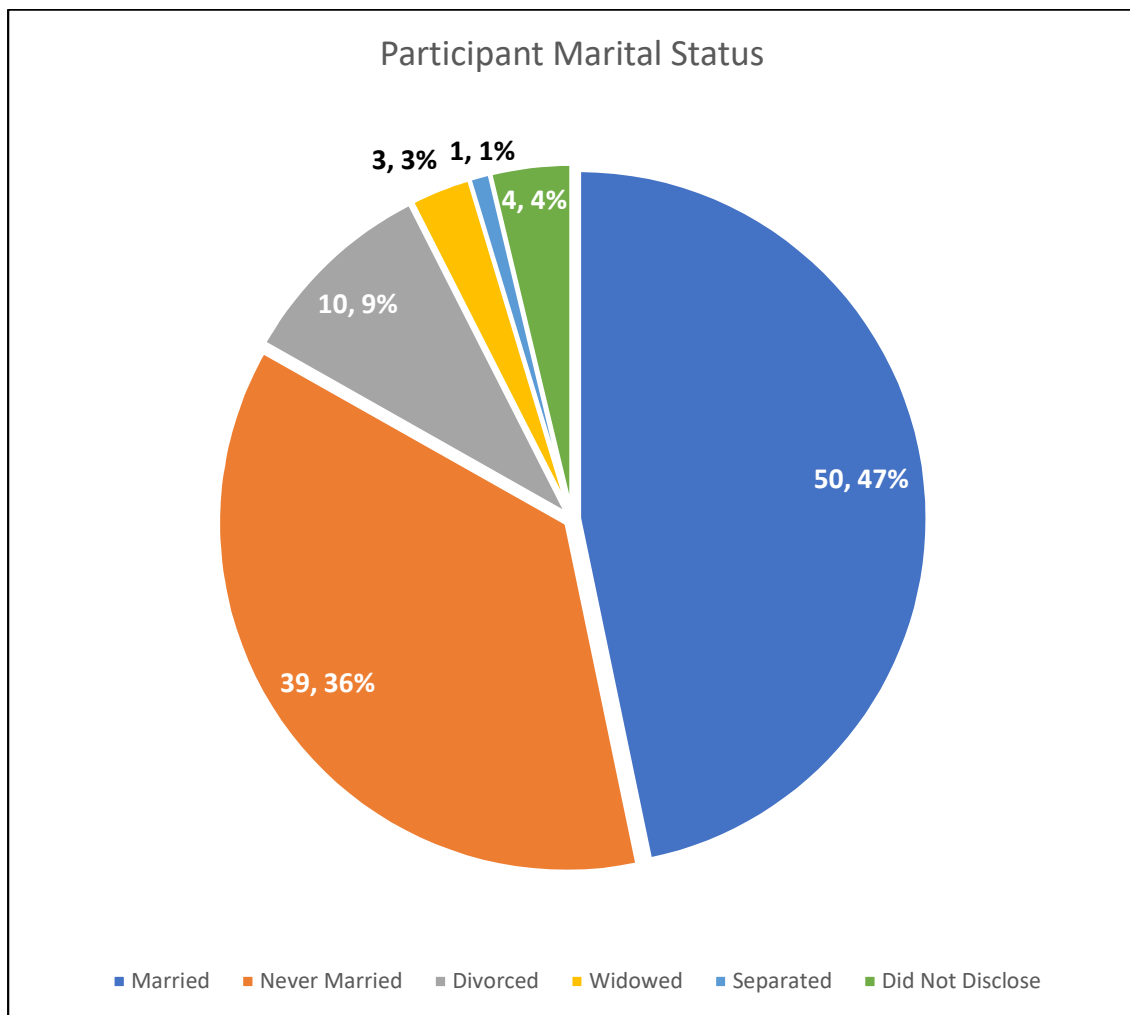
Figure 4: Participant Marital Status

The majority of the sample identified as married (n =50), followed by those who were never married (n = 39), divorced (n = 10), widowed (n = 3), separated (n = 1), and with a few who did not wish to disclose (n = 4). There was a slight majority to those who did not have children (n = 49) compared to those who did (n = 47), but there were a fair amount who did not wish to disclose this detail (n = 11).
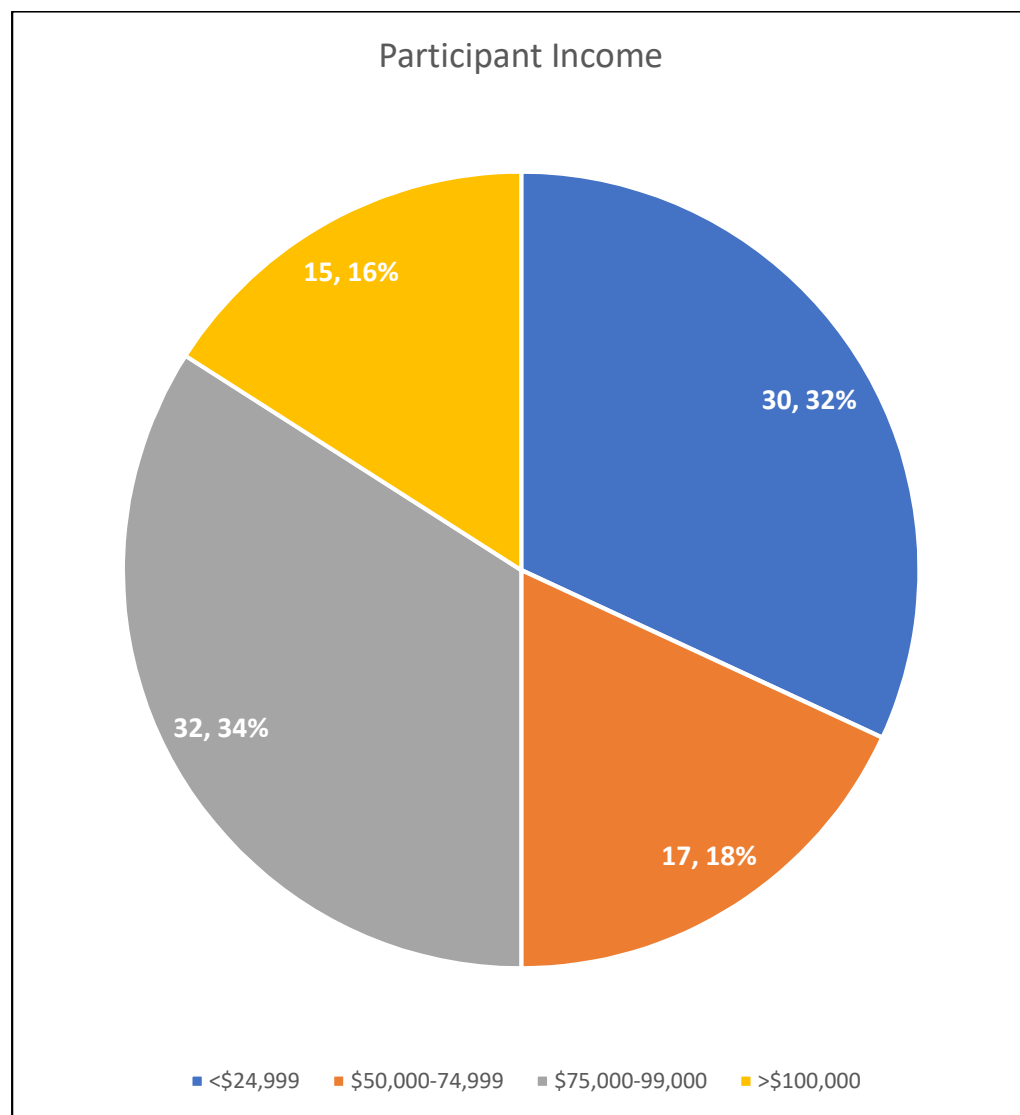
Figure 5: Participant Annual Income

There was a wide amount of variance in the sample's income range – the majority of the sample reported an income of $75,000-99,999 (*n* =32), followed by those who make less than $24,999 annually (*n* = 30), those who make between $50,000-74,999 (*n* = 17), those who make over $100,000 (*n* = 15), and with those in between $25,000-49,999 as the smallest group (*n* = 13).
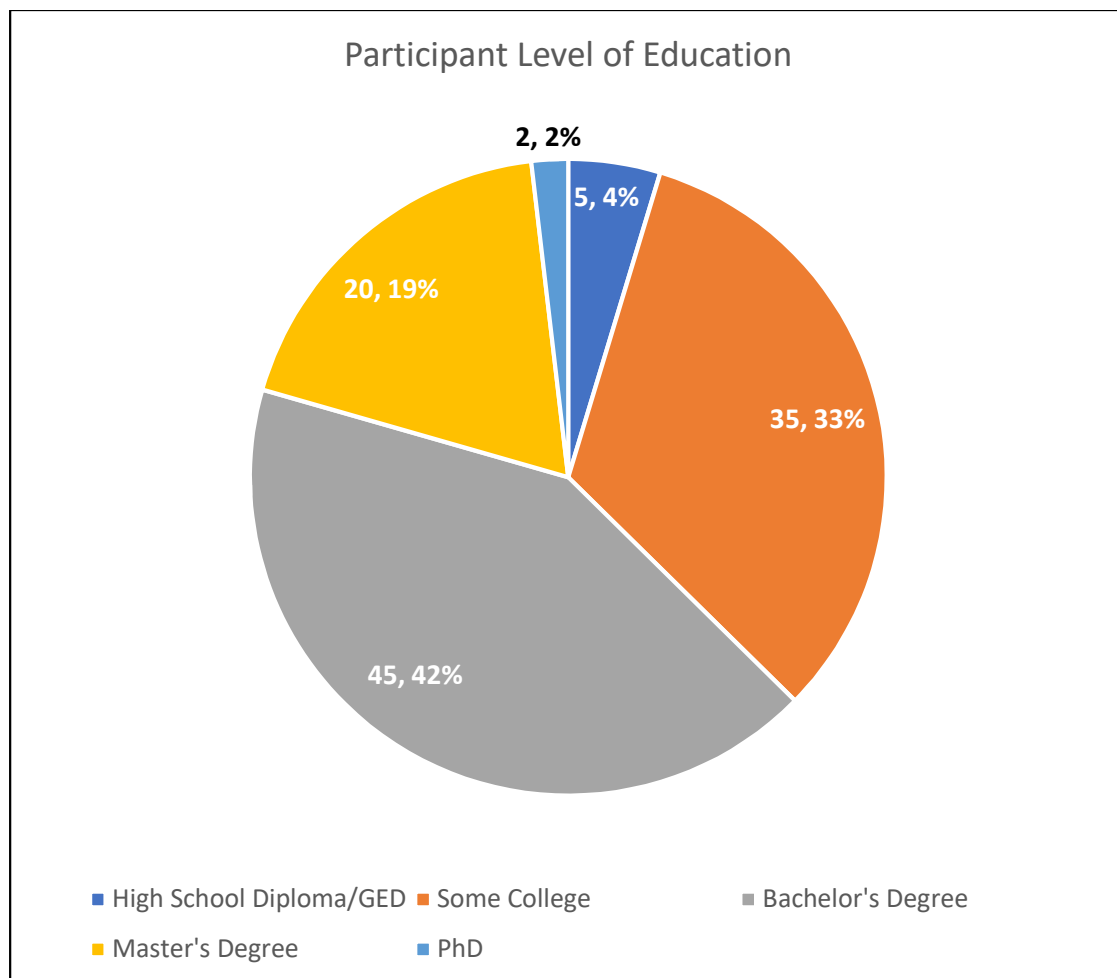
Figure 6: Participant Education Level

Educationally, the largest group in the sample were those with a Bachelor's degree (*n* = 45), followed by those with some college (*n* = 35), a Master's Degree (*n* = 20), High School Diploma/GED (*n* = 5), and with PhDs being the smallest group (*n* = 2).
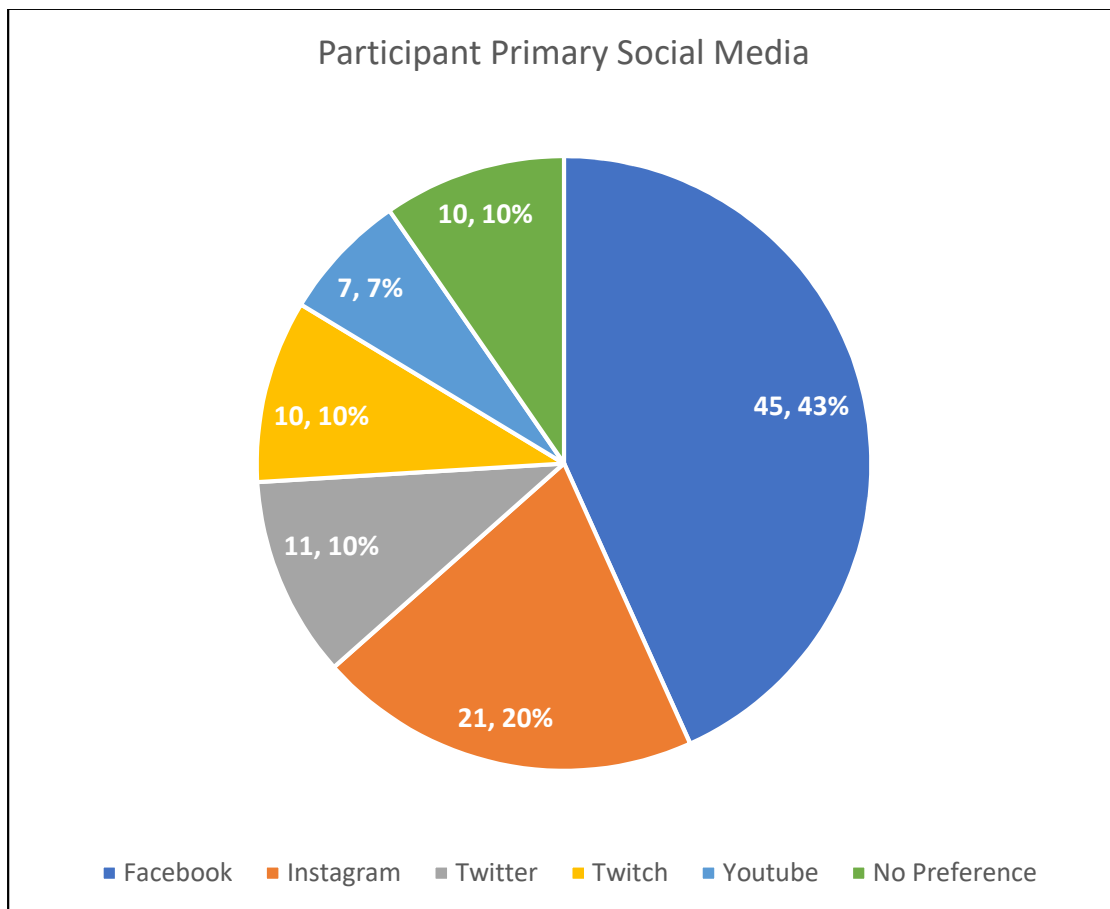
Figure 7: Participant's Primary Social Media Platform

Facebook was the most popular social media platform among participants ($n =$ 45). The second most popular platform was Instagram ($n = 21$), followed by Twitter ($n =$ 11), Twitch ($n = 10$), YouTube ($n = 7$), and 'other' platforms being the least frequent.

Donor Behavior

There is a fairly even distribution in the number of campaigns supported, with the largest group giving to somewhere between one and three campaigns. While the majority of respondents donated to one to three campaigns ($n = 31$), large groups of participants also donated to four-to-six campaigns ($n = 24$) or seven-to-nine campaigns ($n = 22$). A small portion of the participants claimed to have donated to ten or more campaigns ($n = 13$), while others did not donate to any ($n = 17$). While it is impossible to tell whether these participants answered truthfully, it admittedly seams off that roughly 4/5ths of the sample had previous donated; it is questionable how reflective this number is of the broader population. **Figure 1** demonstrates participant's history of donations to crowdfunding campaigns.
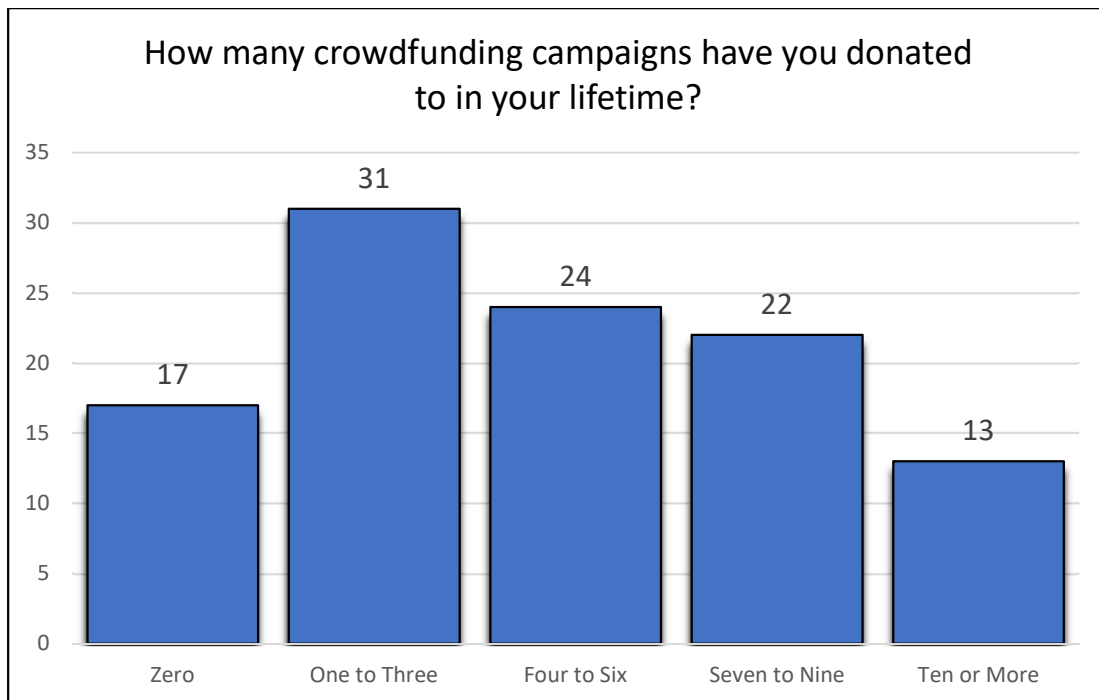
Figure 1: Number of Campaigns Supported

Smaller donations of \$10-20 were the most common 'small donations' in the sample. The participants who have donated to crowdfunding campaigns were asked to identify the lower range of their donation size. Most of the sample donated between \$11-20 as their smallest donation ($n = 38$). The second largest group were those who donated between \$21-30 ($n = 22$), over \$41 ($n = 11$), and \$31-40 ($n = 10$). Those who donated less than \$10 made up the smallest group within this sample ($n = 9$). **Figure 2** provides a visual example of minimum donation size distribution across the sample.
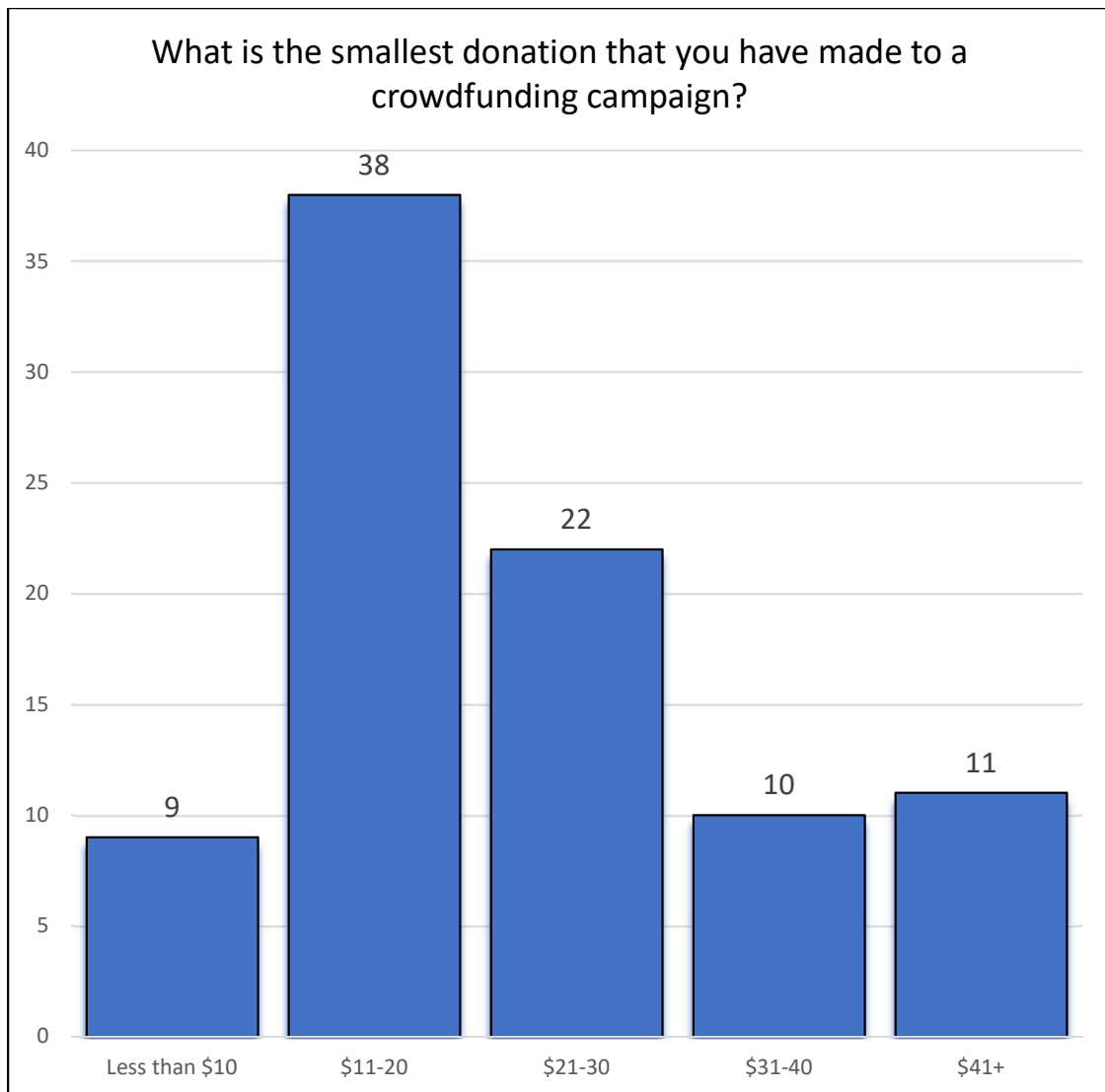
Figure 2: Smallest Donations

Large donations over $100 were the most common 'large donations' in the sample. Participants were asked to indicate the largest donation that they had ever given to GoFundMe. Donors gave large donations of over $100 ($n = 25$) more often than any other amount. It would be ideal to compare this data to average donations on GoFundMe,

but the platform does not makes it data readily available to the public, and there was no response to inquiries about this data despite numerous requests. The second closest large donation group were those who gave between $76-100 ($n = 22$), followed by those who gave $51-75 ($n = 21$), $26-50 ($n = 14$), and with the smallest group being those who gave less than $25 ($n = 8$). **Figure 3** provides illustration for this distribution.
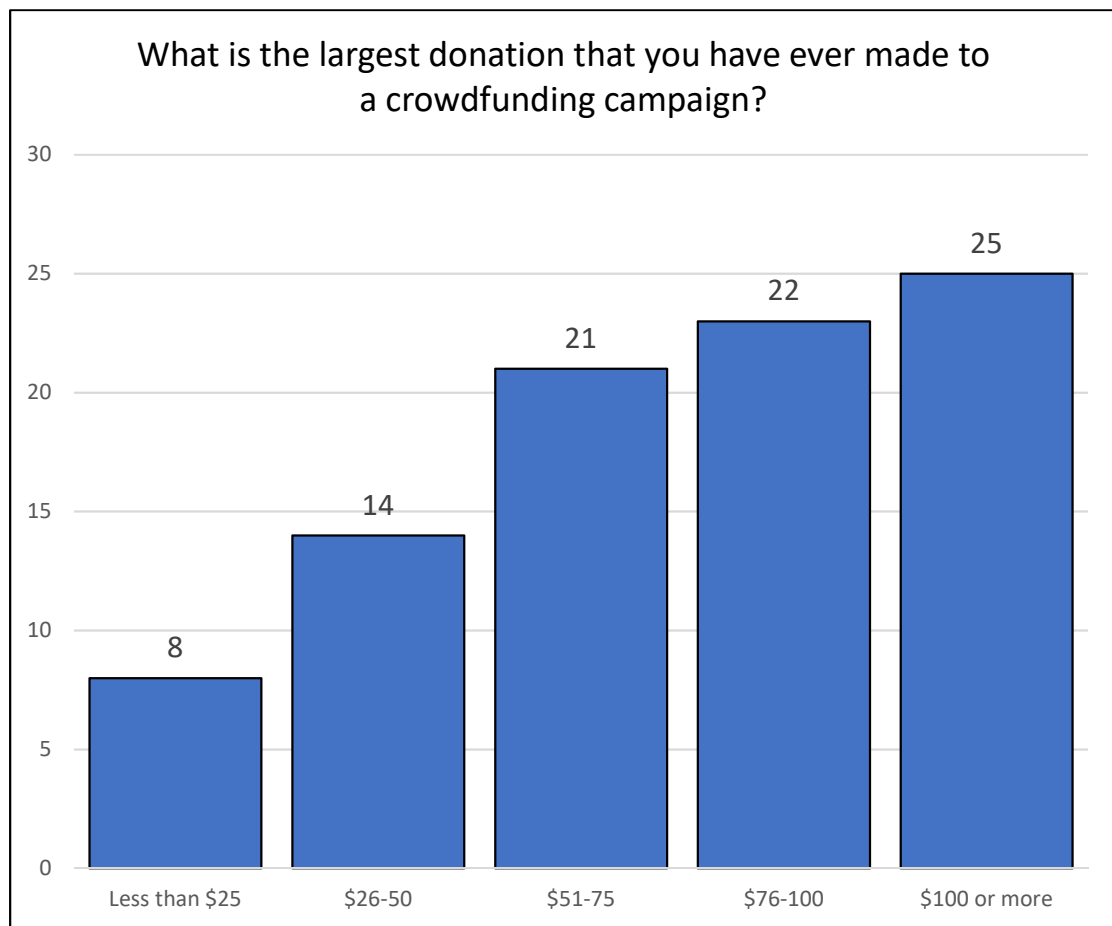
Figure 3: Largest Donation Size

GoFundMe was the most commonly-supported platform by donors.

Participants were provided a list of eight different crowdfunding platforms and asked to identify every platform that they had donated to in the last year. Participants were permitted to select as many of the options as they wished. The most popular platform for donors was *GoFundMe* ($n = 85$), followed by Kickstarter ($n = 29$), Patreon ($n = 17$), IndieGoGo ($n = 4$), and Other ($n = 1$). No participants indicated that they had donated to Crowdrise, Rockethub, or Razoo. **Figure 4** demonstrates these differences.
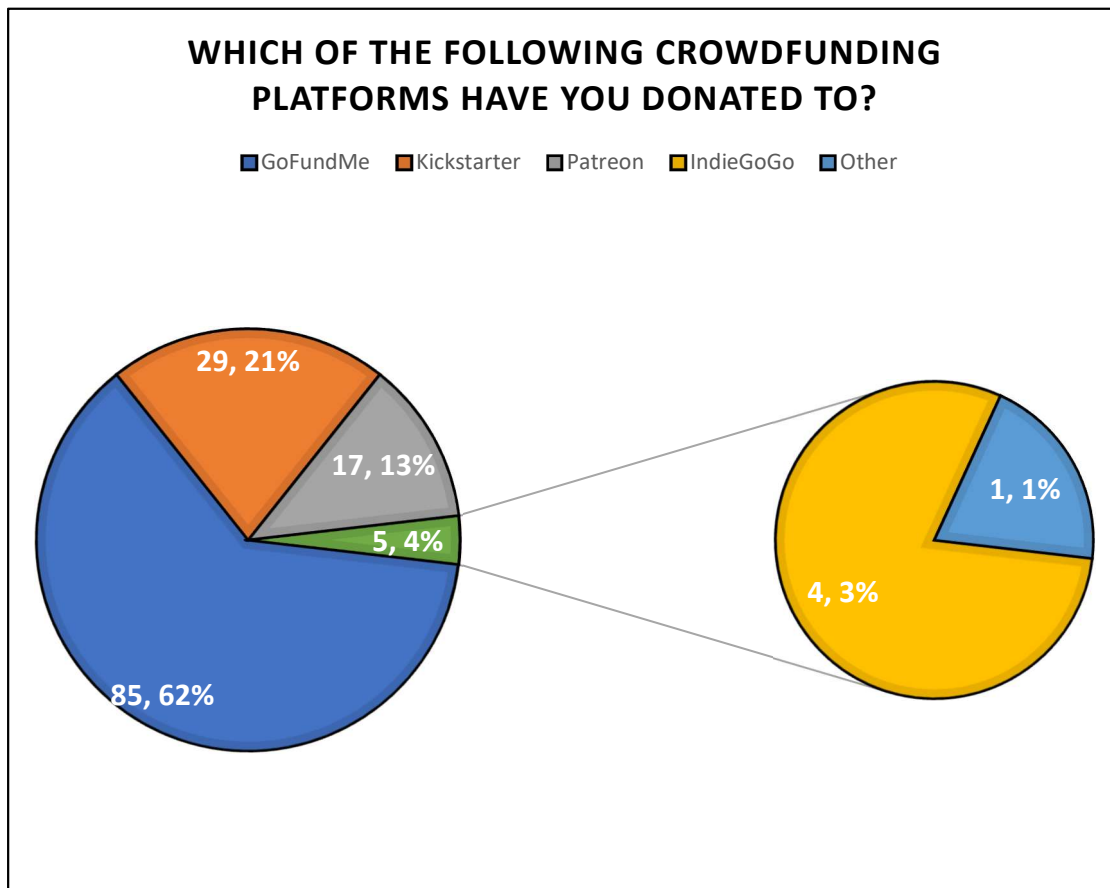
Figure 4: Where Participants Are Donating

The majority of crowdfunding donors give money on a quarterly basis. Participants were asked to identify how often they donated to crowdfunding pages based on one of five time categories. Quarterly donations were the most common ($n = 43$), followed by bi-annual donations ($n = 25$), annual donations ($n = 18$), and monthly donations ($n = 4$). No one in the sample indicated they made weekly donations, so this category was omitted from the figure. **Figure 5** shows the distribution of these responses.

How often do you donate to crowdfunding pages?

■ Every Year   ■ Every Six moths   ■ Every Three Months   ■ Every Month

18, 20%

4, 4%

43, 48%

25, 28%
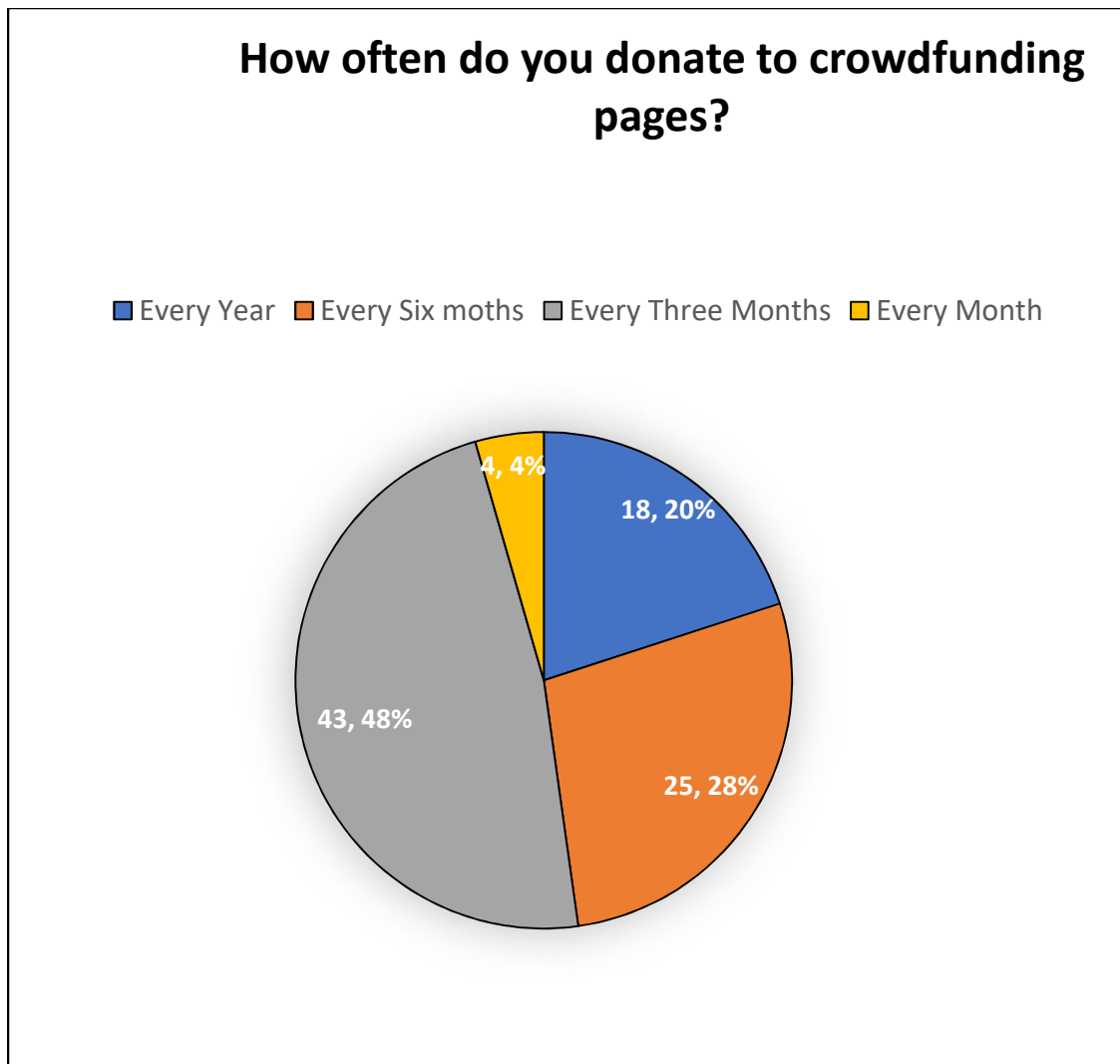
Figure 5: Frequency of Crowdfunding Donation

The majority of crowdfunding donors have given money to pet campaigns.
Participants were asked whether they had donated to a campaign that was for a pet or
animal –**Figure 6** demonstrates this distribution.

Have you ever donated to a GoFundMe campaign that was created for a pet or animal?

39, 43%

51, 57%

■ Yes ■ No
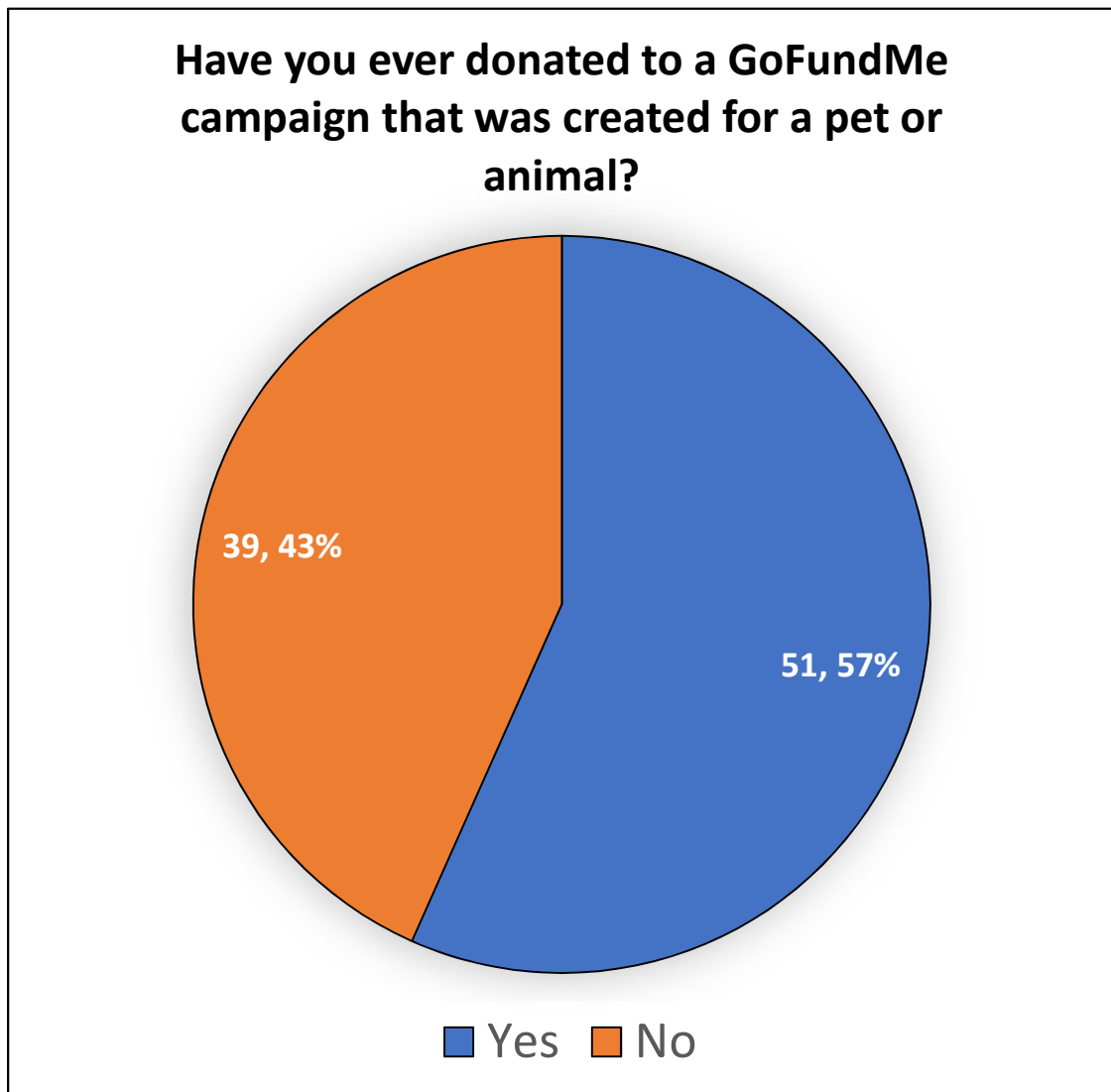
Figure 6: Donation Behavior Towards Non-Human Patients

Most donors in the sample have given money to a crowdfunding campaign within the last year. Participants were asked whether they had donated to a

crowdfunding campaign within the last year.. **Figure 7** illustrates this data.

Have you donated to a crowdfunding campaign within the last year?

18, 20%

72, 80%

■ Yes ■ No
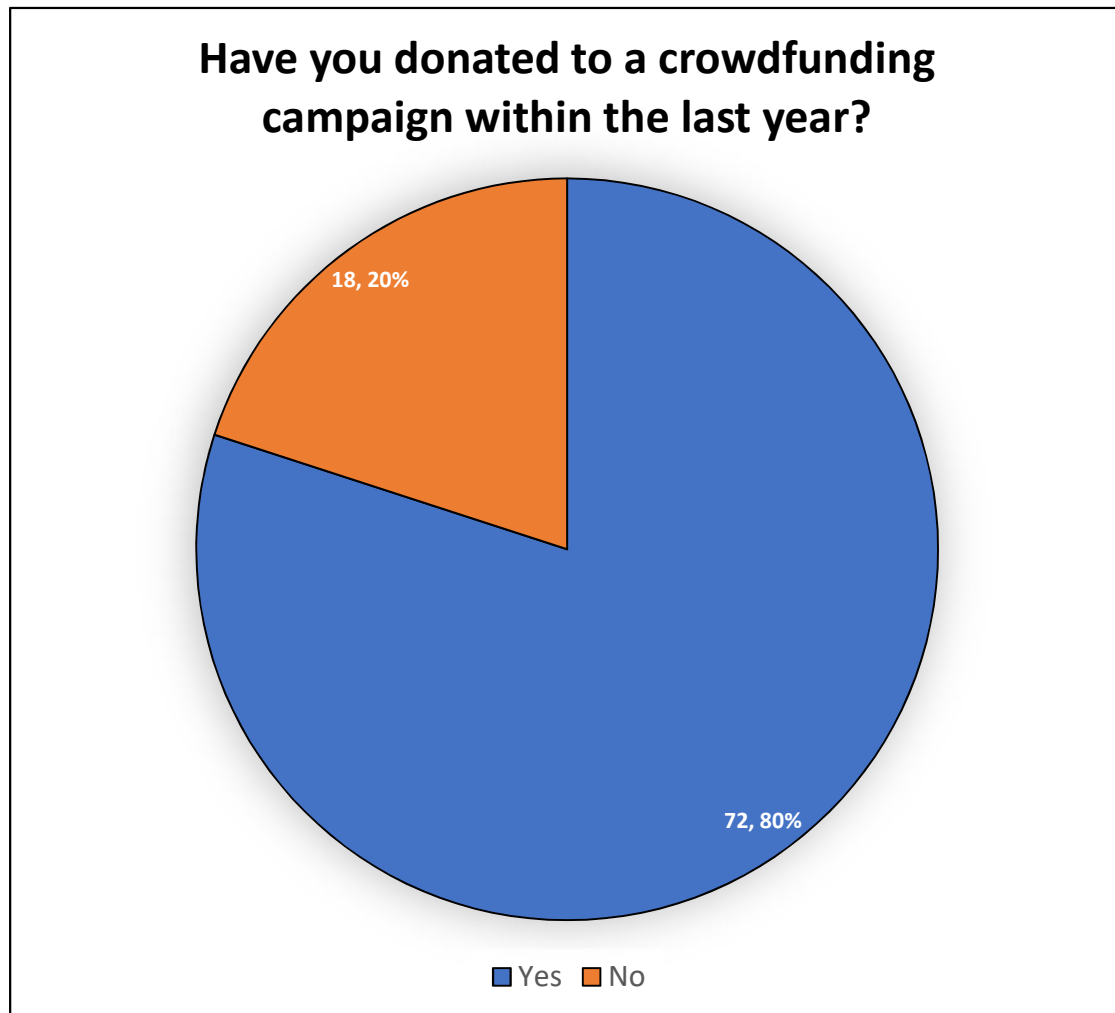
Figure 7: Donations within the last year

Most donors give to a mixture of patients who are suffering from illness and injuries rather than focusing on one or the other. Participants were asked to identify

the affliction that was behind the patient(s) need to crowdfund. The options were (1) Illness, (2) Injury, (3) Both, (4) Can't Remember/No Answer. Most participants donated to campaigns that effected both the sick and injured ($n = 61$), followed by those who exclusively donated to campaigns centered around illness ($n = 20$), injury ($n = 5$), and those who did not disclose ($n = 4$). **Figure 8** shows this distribution:
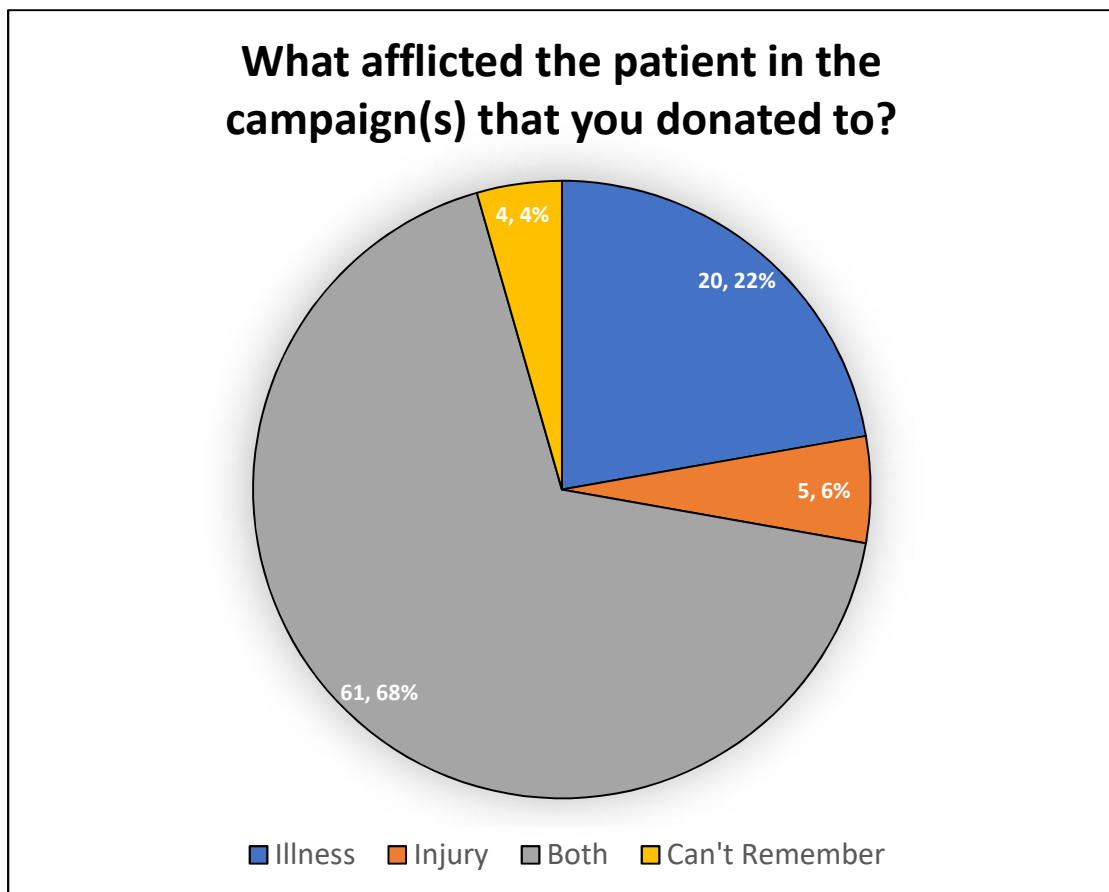
Figure 8: Affliction Behind Campaign Donation

Perceived Benefits of GoFundMe

Participants were presented a series of short statements in order to determine their perception of GoFundMe's benefits. Participants were asked to indicate their level of agreement using a 7-point Likert-type scale. Those who donated to crowdfunding campaigns were separated from those who did not, and the mean score for each group was calculated. These mean scores can be viewed in **Table 1a** below, along with the average of means. A series of t-tests were used to determine whether there was a significant difference in crowdfunding participation (those who have donated to campaigns and those who have not) and whether they perceived benefits to using GoFundMe; the results of these t-tests can be viewed on **Table 1b.** Those who had not donated were asked to answer asked to respond as best as they could based on their perceptions of the innovation.

Table 1a: Perceived Benefits of GoFundMe

Statement	Group	Mean	Standard Deviation
GoFundMe is an excellent option for all patients who are struggling to pay for their expenses.	Donors	5.76	1.60
	Non-Donors	3.35	1.73
GoFundMe is simple and easy-to-use.	Donors	5.83	1.40
	Non-Donors	3.06	1.75
	Donors	5.95	1.35

Crowdfunding is an effective alternative to traditional fundraising.	Non-Donors	3.20	1.90
Donating to GoFundMe campaigns gives/would give me a good feeling.	Donors	5.91	1.33
	Non-Donors	3.71	1.69
I feel like my donation is making more of a different when I donate on GoFundMe compared to conventional fundraising methods (auctions, charity dinners, mailed donations, etc.)	Donors	5.76	1.51
	Non-Donors	3.50	1.95

Table 1b: Donation Behavior x Attitudes Towards GoFundMe

Statement	*t-Test Result*
GoFundMe is an excellent option for all patients who are struggling to pay for their expenses.	t(103) = 5.59, *p* <. 001
GoFundMe is simple and easy-to-use.	t(103) = 7.17, *p* <. 001
Crowdfunding is an effective alternative to traditional fundraising.	t(103) = 6.80, *p* <. 001
Donating to GoFundMe campaigns gives/would give me a good feeling.	t(103) = 5.94, *p* <. 001
I feel like my donation is making more of a difference when I donate on GoFundMe compared to conventional fundraising methods (auctions, charity dinners, mailed donations, etc.)	t(103) = 5.48, *p* <. 001

The results of the t-tests on **Table 1b** indicate that positive attitudes towards patient-centered crowdfunding are significantly related to participation on the platform.

Perceived Harms of GoFundMe

Participants were presented another series of short statements that sought to determine their perception of the potential harms/downside of using GoFundMe. Participants were asked to indicate their level of agreement using a 7-point Likert-type scale. As with the benefits statements, donors and non-donors were separated into two different groups. Mean scores were calculated for each group's responses to the statements, along with the average of means. **Table 2a** provides the mean responses, and **Table 2b** provides t-tests for a significant relationship between the response and one's donation behavior (Donor/Non-Donor).

Table 2a Perceived Harms of GoFundMe

Statement	Group	Mean	Standard Deviation
I'm worried that some GoFundMe campaigns could be a scam	Donors	3.56	1.98
	Non-Donors	5.53	0.94
GoFundMe takes too high of a percentage of the donations	Donors	2.52	1.76
	Non-Donors	4.62	1.50
I think GoFundMe needs to spend more	Donors	2.64	2.05

time vetting the people who choose to use the platform.	Non-Donors	5.30	1.56
I feel like many of the campaigns that I see on GoFundMe are exaggerating their claims.	Donors	2.69	1.94
	Non-Donors	5.71	1.31
GoFundMe success is mostly random	Donors	2.62	1.91
	Non-Donors	5.88	1.17

Non-donors perceived greater potential harm/problems with GoFundMe than those who had previously donated . The problem perception among non-donors was higher for each statement than the donor responses.

Table 2b Donation Behavior x Negative Attitudes Towards GoFundMe

Statement	*t-Test Result*
I'm worried that some GoFundMe campaigns could be a scam	$t(103) = 3.97, p < .001$
GoFundMe takes too high of a percentage of the donations	$t(103) = 5.49, p < .001$
I think GoFundMe needs to spend more time vetting the people who choose to use the platform.	$t(103) = 5.43, p < .001$
I feel like many of the campaigns that I see on GoFundMe are exaggerating their	$t(103) = 6.13, p < .001$

claims.

GoFundMe success is mostly random	$t(103) = 6.77$, $p < .001$

The results of the t-tests on **Table 1b** indicate that negative attitudes towards patient-centered crowdfunding are significantly related to participation on the platform.

Evaluations of Worthiness

One portion of the survey sought to gather both quantitative and qualitative data by providing respondents with the opportunity to select from multiple options to questions and provide a short explanation in text form. Before answering, participants read three separate, anonymized scenarios from real-life GoFundMe pages. Participants were then asked to select the campaign that they were the most likely to donate to, the campaign that they were the least likely to donate to, and finally provide explanations for each. To be more specific, participants read and selected from the following scenarios:

#1) "**Jamie was diagnosed with stage IV pancreatic cancer on September 2018. To say we are devastated is an understatement…**

Jamie is a proud graduate of the University of San Diego and after graduation, he enlisted in the United States Airforce. From 2004-2012 Jamie served on active duty, spending much of his time in the distinguished US Airforce 82nd Airborne.

Jamie sacrificed greatly to serve our country with multiple tours in Iraq and Afghanistan. Today, Jamie continues to serve as a member of the San Diego fire department as a volunteer while he works as an IT contractor during the day. This brave, stoic, yet fun-loving father of two young boys, now needs our help. As you can imagine, the medical bills are starting to come in and as Jamie is currently a contract worker, his income may become unstable during his arduous treatment. Please help us raise money for this soldier, father, son, and brother. We can help ease some of the stress that comes with difficult treatment and the bills that go along with them.

#2) **"Stop recidivism...help Gregg get on his feet after serving his time**

On Tuesday morning, June 26th, Gregg was released from Red Onion State Prison after serving 16 years for an undisclosed crime. Gregg has had issues with homelessness and substance abuse in the past, and we're worried that he'll end up back on the street or in prison if he doesn't find a way to financially support himself. As friends of Gregg's, we are asking for people to consider reaching into their hearts and donating what they can to help this good man (who has served his time) stay on the right course. Thank you for your consideration.

#3) **"Andy, 16 years old, of Grigson, New Hampshire, was an unfortunate burn victim in the Hooksett bonfire accident on April 3rd, 2018…**

Andy is currently at Springfield Medical Center Burn Unit on life support. He

sustained 3rd degree burns to the majority of his body, especially to his face.

Doctors have him in a medically induced coma. He has undergone multiple

surgeries so far to relieve pressure in his face and arms. Andy has a long road

ahead of him! He will require countless surgeries, facial reconstruction, therapy,

rehabilitation, etc. Please help support him and his family so he can get the

treatment he desperately needs.

"

After reading these options, participants selected the campaign that they felt they

would be the *most likely* to donate to as well as selecting the campaign that they would be

the *least likely* to donate to. The results of these responses can be seen in **Figure 9** below.
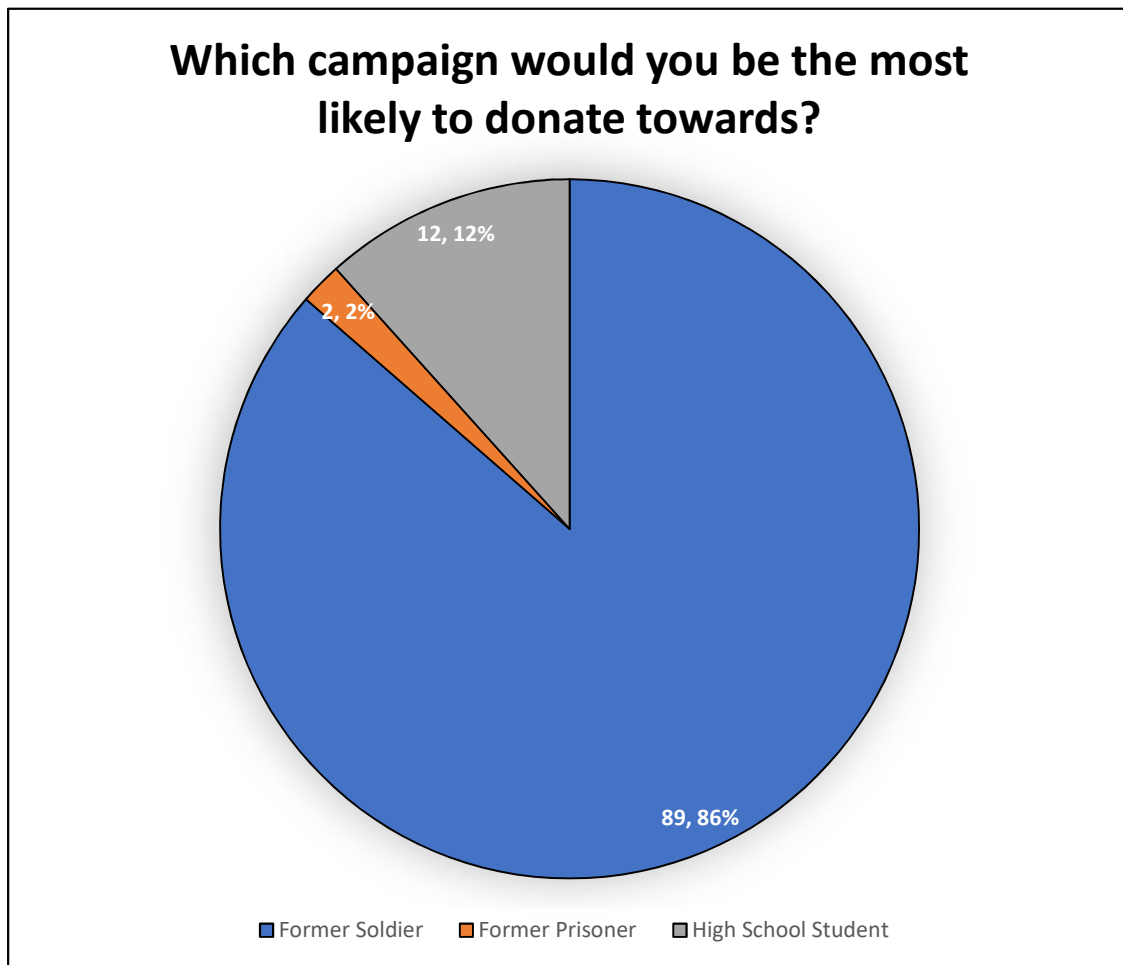
Figure 9: **Participant Support Choice**

The majority of participants said that they would donate to the sick father/retired veteran ($n = 89$), followed by the teenage burn victim ($n = 12$), with the released convict in last ($n = 2$). The following are excerpts from the short responses that help contextualize this quantitative distribution:

Military support, family appeal are important factors for the veteran patient.

People who serve already have to be away from their children and I think that providing extra money for care to the veteran so he can live and be with his kids makes up for the lost time he used to serve our country. I have kids so that makes me want to donate too.

I come from a military family and I am usually inclined to donate or assist when I know it supports the military and those who have served.

My husband was in the military. We have insurance, but we haven't always had great experiences at the veteran's hospitals. Neither of us have ever needed anything serious done, but I worry about having to rely on the military healthcare system. The extra money for the military person would make sure that they could go see specialists more easily, and I think the people who serve really deserve the public help. "

"I'd give my money to the former soldier because he has a family that depends on him. A lot of people would be impacted in a bad way if he died.

Sympathy for the youth; 'long life ahead of him'

Andy is a young man, an average 'Joe' who was hit with an unfortunate circumstance so young in life, he is young and without proper treatment will spend almost the entirety of his life with life altering injuries. He is also at an age where he is developing his sense of self, without generosity he is likely to become disillusioned. Next, Jamie served the country and also works at a fire dept, he will most likely get plenty of support and has already come far in life, he doesn't need my help. Lastly, Gregg may need to be in a more stable situation and find some sort of support group, before he could properly handle money.

The third campaign was chosen because I believe it requires the most external funding to support the most critical situation out of the three options. The VA and Fire Department should already have some aid for Jamie, and Gregg has (hopefully) access to other [services].

I almost gave my money to the military person, but I have children and I couldn't imagine what it would feel like to have that happen to any of them

Former prisoner viewed as unworthy for help when compared to the other two.

Gregg needs more support before he could use money in a self-empowering way. While seeming somewhat callous, throwing money at someone who struggles with an addiction is unlikely to solve anything. If it was apparent that he was

working with a support group, church, shelter, etc., Then I would be more likely

to donate, since he is actively trying to keep himself on the up and up. The fact he

was an ex prisoner doesn't weigh into my decision much, we all deserve a second

chance.

The crime that carried a 16-year sentence would most likely be violent or a

violation of human rights. Based on this alone, I would argue that they had 16

years with access to substance abuse programs and still has not made meaningful

progress and therefore are the least deserving of fundage.

Using drugs and committing crimes as a result of the drug use is a poor life choice

decision. I agree that public services are necessary to assist with parolees and drug

users but I don't believe giving money via a campaign is the best use of money as

I'm not sure how the money will be spent.

We don't know what his crime was and I'd feel really horrible if Gregg did

something to someone once 'he got back on his feet'

I feel like the prisoner has done the most harm to society of the three, so should

society should seek to make the assist the people who didn't harm society first

The two respondents that would choose the prisoner over the others cite lack of post-prison resources

Prisoners don't have as many resources once they get out.

[The former prisoner] is the only one who probably doesn't have insurance

There is a lot of information to unpack with the responses to this question. One of the most surprising findings was that there was an overwhelming amount of support for the military man. Upon further examination though, this makes sense – while the military man provides that distinctive status as an attention grabber, there are far more details provided in his summary paragraph compared to the other two. As the in-depth interviews established earlier on in the analysis, providing descriptive details about the patient can give more people a reason to support that patient. For example, readers of the soldier's profile will know that, in addition to being a soldier, he 1) is a graduate of the University of San Diego, 2) has roots/connections to California, 3) serves his community as a fire fighter, 4) has an aptitude for technology, illustrated by his IT day job, 5) has two young sons, 6) a less than steady income due to his work as a contractor, and 7) has a brother that is invested in his well-being.

Comparing all of these reasons to the other two options, it becomes more clear why donors felt such a strong connection to the soldier – while there was an argument to be made for both the teen and the former prisoner, those two messages did not have the same level of transparency nor did they provide as many opportunities to relate to the

patient. While the teen had the second most votes, nearly all of the reasons given were related to the teen's age and them having the most time ahead of them. The prisoner unsurprisingly received the least support, which is likely symptomatic of United States' passive, dispassionate stance towards those who have broken the law.

E-Health Literacy

With GoFundMe being purely computer-mediated, it is reasonable to assume that there those who participate on the platform must have a certain minimum level of proficiency with technology. Moreover, the discussion of complicated health topics on GoFundMe requires that viewers are familiar enough with health topics and/or have the technical proficiency to search for the health information that they do not possess in order to make informed decisions about their donation behavior. As such, this portion of the analysis explores participant's literacy on digital health platforms and tests to see whether the measurement items significant correlate with donation behavior.

Participants were presented with a series of statements about the internet and health decisions in order to determine their e-health literacy score; respondents were sorted into donor and non-donor groups to see whether there were any distinctive differences between the two groups. The responses were scored using 7-point, Likert-type scales and included the average of means for each group. The responses to these statements can be seen in **Table 3a** below, as well as tests of significance between Donors/Non-Donors and their reported e-health literacy score on **Table 3b**:

Table 3a: E-Health Literacy of Donors and Non-Donors

Statement	Group	Mean	Standard Deviation
The Internet is important in helping you in making decisions about your health	Donors	5.75	1.42
	Non-Donors	3.76	1.71
It is important to be able to access health resources on the Internet	Donors	5.89	1.29
	Non-Donors	3.65	1.73
I know what health resources are available on the Internet	Donors	5.80	1.40
	Non-Donors	3.63	1.77
I know where to find helpful health resources on the Internet	Donors	5.84	1.32
	Non-Donors	3.47	1.94
I know how to find helpful health resources on the Internet	Donors	5.86	1.32
	Non-Donors	4.00	1.55
I know how to use the Internet to answer my questions about health	Donors	5.72	1.30
	Non-Donors	3.56	1.31
I know how to use the health information I find on the Internet to help me	Donors	5.77	1.28
	Non-Donors	3.59	1.58
I have the skills I need to evaluate the health resources I find on the Internet	Donors	5.70	1.50
	Non-Donors	3.71	1.69
I can tell high quality health resources from low quality health resources on the Internet	Donors	5.69	1.35
	Non-Donors	3.88	1.69

| I feel confident in using information from the Internet to make health decisions | Donors | 5.86 | 1.37 |
| | Non-Donors | 4.06 | 1.48 |

Those who have donated to GoFundMe show as having higher e-health literacy when compared to the non-donor group.

Table 3b: Donation Behavior x E-Health Literacy

Statement	*t-Test Result*
The Internet is important in helping you in making decisions about your health	$t(103) = 5.09, p <. 001$
It is important to be able to access health resources on the Internet	$t(103) = 6.17, p <. 001$
I know what health resources are available on the Internet	$t(103) = 5.80, p <. 001$
I know where to find helpful health resources on the Internet	$t(103) = 6.21, p <. 001$
I know how to find helpful health resources on the Internet	$t(103) = 5.58, p <. 001$
I know how to use the Internet to answer my questions about health	$t(103) = 6.09, p <. 001$
I know how to use the health information I find on the Internet to help me	$t(103) = 6.14, p <. 001$
I have the skills I need to evaluate the health resources I find on the Internet	$t(103) = 4.90, p <. 001$

| I can tell high quality health resources from low quality health resources on the Internet | $t(103) = 4.83$, $p < .001$ |
| I feel confident in using information from the Internet to make health decisions | $t(103) = 4.88$, $p < .001$ |

The results of the t-tests on **Table 3b** indicate that participants' e-health literacy scores are significantly related to participation on the platform across every measurement item.

General Self-Efficacy

Self-efficacy (a central construct in Social Cognitive Theory) is an important personal trait that contributes to an individual's ability to reach their goals (Bandura, 1982). Higher self-efficacy can lead to individuals' overcoming obstacles more quickly and can help them cope with negative situations, and vice versa. With this relationship in mind, this portion of the analysis seeks to determine whether there is a difference in mean self-efficacy score between donors and non-donors, and then looks for significant correlations between the self-efficacy measure statements and the participants' donor group status. The GSE scale had participants illustrate their level of self-efficacy by responding to a series of statements using a 4-point scale. Participants were sorted into donor and non-donor categories. Their average responses were calculated, along with the average of means for each group. The t-tests revealed that only one item in this question block was significantly different between donors and non-donors. That item was *"That's to my resourcefulness, I know how to handle unforeseen situations."* The t-test results for

this item can be viewed in **Table 4** below:

Table 4: Self Efficacy x Donation Behavior				
Statement	Group	Mean	Standard Deviation	t-Test Result
Thanks to my resourcefulness, I can handle unforeseen situations	Donors	3.05	.80	t(103) = 2.20, p = .02
	Non-Donors	2.59	.71	

Self-Reported Altruism

Some might view donation to GoFundMe as an altruistic, selfless act where one

donates to a person in crisis in order to help them recover. While this dynamic appears

fairly straightforward, information in the content analysis and in-depth interviews

brought attention to the fact that many people donated due to a prior established

relationship rather than personal feelings of altruism. This raises the question of whether

being highly altruistic is significantly related to donation behavior. This portion of the

analysis separates participants into donor and non-donor groups, compares their

responses on the self-reported altruism scale, and compares these mean response scores

to donation behavior to look for significant relationships with response options (altruistic

behaviors).

The self-reported altruism scale seeks to determine how altruistic a person is by

assigning a numeric value to the frequency at which someone does an altruistic deed. The SRA scale is a 7 point scale, with a higher score indicating that the act in question is done more frequently and a lower score indicating that the act in question is done less frequently. The total scores were calculated for each response, and participants were sorted into donor and non-donor groups to organize the responses. The series of t-tests did not yield significant results for any of the twenty items, indicating that a person's self-identified level of altruism is likely not related to one's decision to participate on patient-centered crowdfunding platforms. This could lend credibility to the notion that GoFundMe success is less about finding altruistic people to solicit donations from, and could potentially have more to do with the prior established relationships in the patient's personal social networks. Additionally, this raises the question of whether online donors are more altruistic than offline donors.

Self-Reported Happiness

Dunn et al (2014) found that "thinking about money may propel individuals towards using their financial resources to benefit themselves, but spending money on others can provide a more effective route to increasing one's own happiness" (p. 1687). Happy people could feel less attachment to their money and be more at-ease with parting with it for the right reason. Because of this fact, this portion of the analysis is designed to determine whether there is a difference in self-reported happiness people donors and non-donor groups and to test for significant relationships between the response items and the group status. The happiness scale is a 7-point, Likert-type scale that ask respondents four

questions about their level of happiness. Two of the response items indicated a significant difference between donors and non-donors. **Table 6a** below provides individual's self-reported happiness scores, and **Table 6b** provides significance scores for the self-reported happiness score and prior donation behavior.

Table 5a: Self-Reported Happiness of Donors/Non-Donors

Statement	Group	Mean	Standard Deviation
	Donors	5.34	1.41
I consider myself happier than most of my peers	Non-Donors	4.18	1.38
	Donors	3.19	1.56
I'm never as happy as I could be	Non-Donors	4.17	1.33

Table 5b: Donation Behavior x Self-Reported Happiness

Statement	*t-Test Result*
I consider myself happier than most of my peers	t(103) = 4.83, *p* <. =.002
I'm never as happy as I could be	t(103) = 4.83, *p* = .01

Subsection Conclusion

The survey yielded several interesting results about individual characteristics, donor perceptions, and donor behaviors that are relevant to the patient-centered crowdfunding ecosystem. Self-efficacy and altruism were not significant attributes for donors. Instead, donors typically held a positive perspective towards GoFundMe and a higher level of e-health literacy. Further exploration of these specific traits should aim to determine how someone develops a positive opinion of GoFundMe, as well as examining how a person develops the positive e-health literacy skills that cause someone to engage with crowdfunding. The question comparing different patient scenarios indicates that donors do make considerations of the patient's background, needs, and assumed character when deciding where to donate. The sample for this exploratory study was not large despite several different avenues of recruitment, but the data still provides a starting point for future research surrounding donors and digital, health-related fundraising platforms.

QUANTITATIVE: CONTENT ANALYSIS

Sample and Reliability Overview

The dataset for the content analysis were collected through the official GoFundMe website. Campaigns were selected based on the criteria of 1) having a human patient, 2) still having the campaign listed as "active" (i.e. still collecting donations), and 3) containing enough content to fill out the codebook. This third criteria was added shortly after the beginning of the analysis in order to omit campaigns that had minimally-filled or blank text boxes, missing pictures, no listed goals, or any number of other missing critical data. A random sample of more than 200 campaign pages were coded by the initial coder, and then a random subsample of 104 campaigns was taken from the original 200 sample and coded by a separate coder in order to calculate intercoder reliability. Some parts of the codebook required the researcher to manually input descriptive data (the campaign goal amount, the number of donors, number of updates, etc.). These descriptive data entry items were not calculated as a part of intercoder reliability; instead, the Cohen's Kappa was used to code the nominal-scaled codes from the two separate coders who coded the same 104 campaign sample. The average calculated percentage agreement between the two coders was $k = .798$.

The content analysis codebook was constructed using Qualtrics. Due to the sheer volume of campaigns and the length of time required to code each campaign, data collection for the content analysis began in November 2018 and concluded in early February 2019. There was no need for recruitment or consent forms since the data were being collected from a publicly-available source (www.GoFundMe.com). The final

sample of 104 reflects only those pages that were doubled coded. The notable patterns that emerged by the end of the content analysis will be identified in the subsections of this chapter and discussed more broadly in the next. The subsections include (1) patient demographics, (2) patient condition and funding, (3) social media and networking, (4) communication content, and (5) patient circumstances. For portions of this analysis, campaigns were sorted into two different categories based on whether they reached their goal (reached, not reached). Finally, this analysis seeks to collect data to answer the following research questions posed in earlier chapters:

- **RQ2: What qualities are consistently present in successful patient-centered crowdfunding campaigns?**

- **RQ12: What are the differences between campaigns with high levels of network activation/participation and campaigns with low levels of network activation/participation?**

- **RQ13: What are the effects of high/low social media shares on a campaign's success?**

- **RQ14: What are the consistent traits of messages (in a patient-centered crowdfunding context) that travel through social networks?**

- **RQ4: What role does a patient's communication play in a campaign's overall level of success?**

- **RQ9: What efforts are being made to promote equality on crowdfunding platforms?**

- **RQ15: How does a patient's condition influence the way that donors respond to the campaign?**

- **RQ16: Does the patient's disclosure of their challenges help or hinder the crowdfunding campaign? If so, how?**

<div align="center">**Description of Sample**</div>

Figure 1 indicates that, of the 104 campaigns in the sample, there were more male patients ($n = 59$) than female patients ($n = 45$).

Patient Gender

45, 43%

59, 57%

■ Male   ■ Female
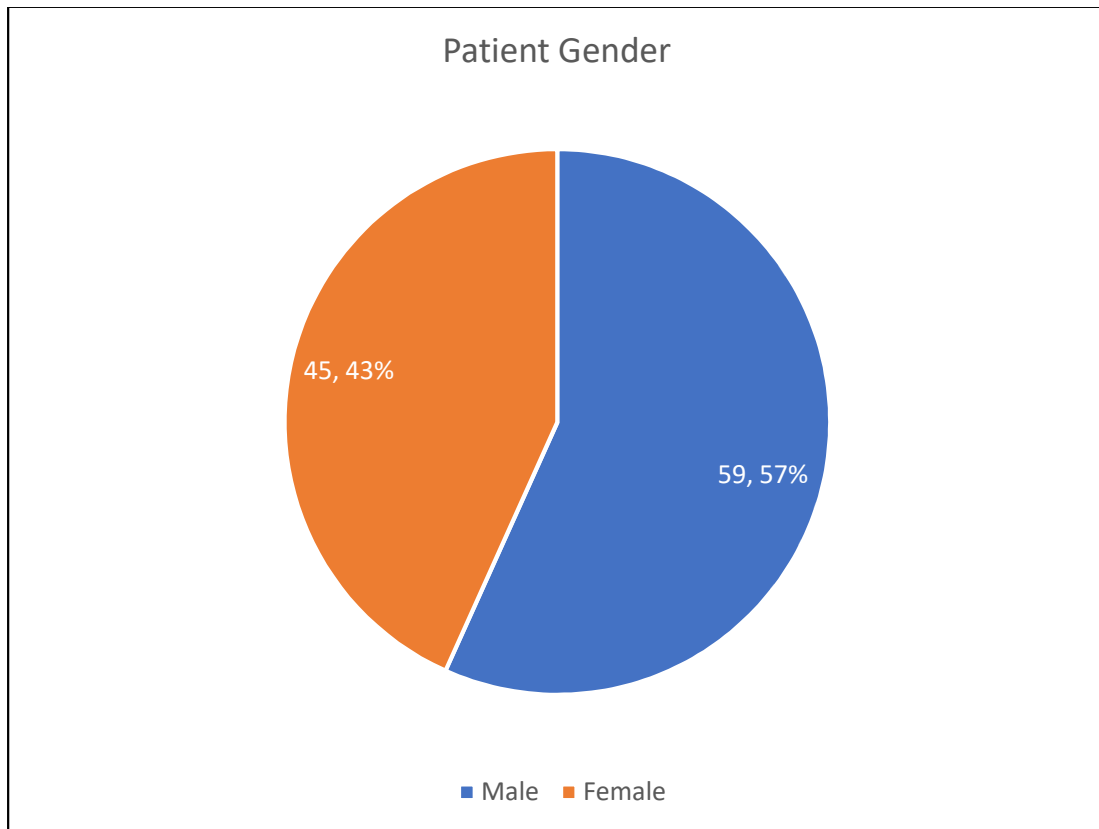
Figure 1: Patient Gender

Figure 2 shows that non-Hispanic White/Euro-Americans were by far the largest group of patients in the sample ($n = 76$), followed by South Asian/Indians ($n = 9$), East

Asian/Asians (*n* = 8), Latino/Hispanics (*n* = 6), African American/Black (*n* = 2), Middle

Eastern/Arab (*n* = 2), and Other (*n* = 1). There were no participants of Native American

or Alaskan Native heritage in the sample.

Patient Demographics

76, 73% · Non-Hispanic White/Euro American
9, 8% · South Asian/Indian
8, 8% · East Asian/Asian
6, 6% · Latino/Hispanic
2, 2% · African/African-American
2, 2% · Middle Eastern/Arab
1, 1% · Other
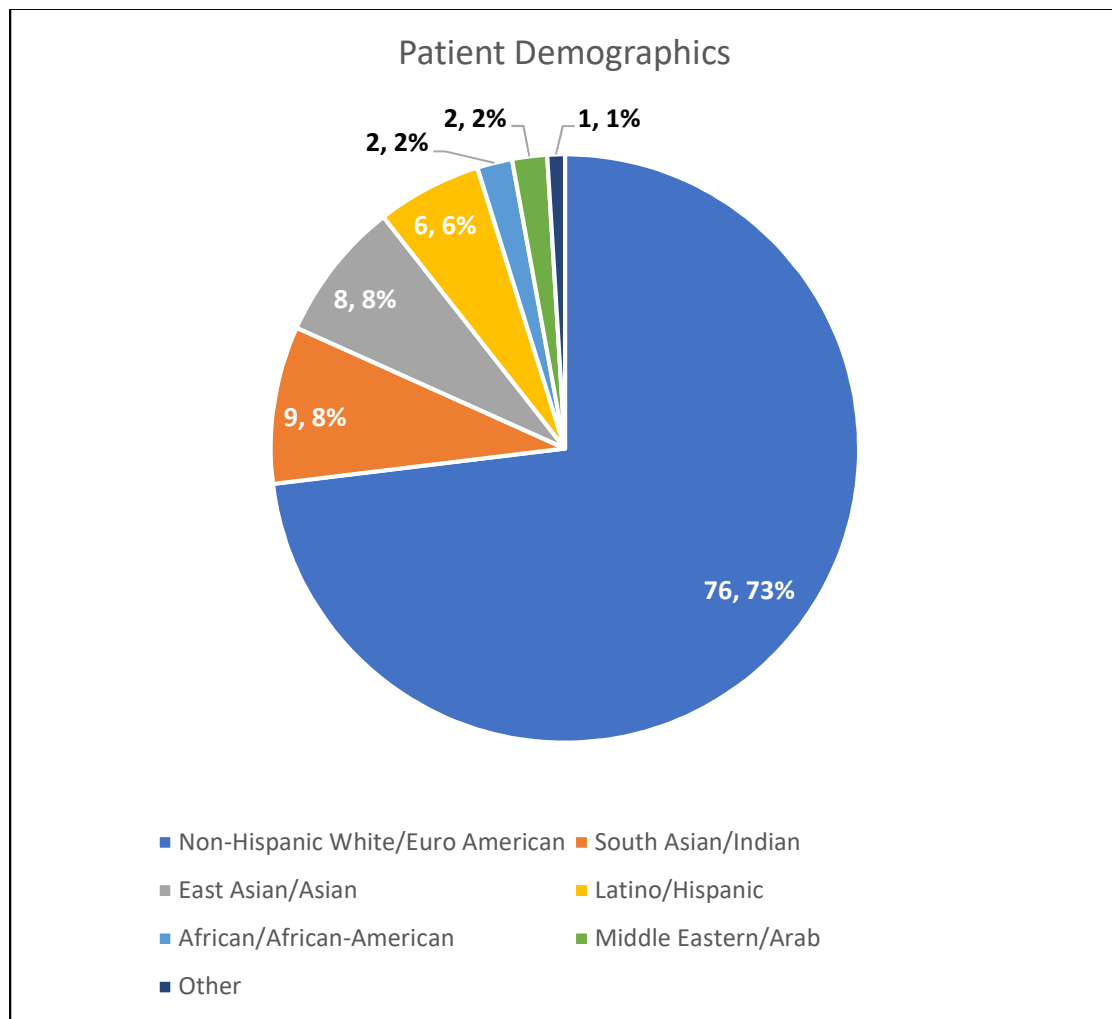
Figure 2: Patient Demographics

Participants were sorted into three broad age categories due to challenges of trying to quantitatively measure individuals ages based on observation. These three age groups included (1) minors (those who appear to be 17 years of age or younger), (2) adults (those who appear to be 18 years of age or older, but do not appear to be senior citizens), (3) senior (those who appear to be retired or of 'retirement age'). **Figure 3** illustrates that, based on these criteria, adults were the largest group in the sample ($n =$ 68), followed by minors ($n = 23$), and seniors ($n = 13$).
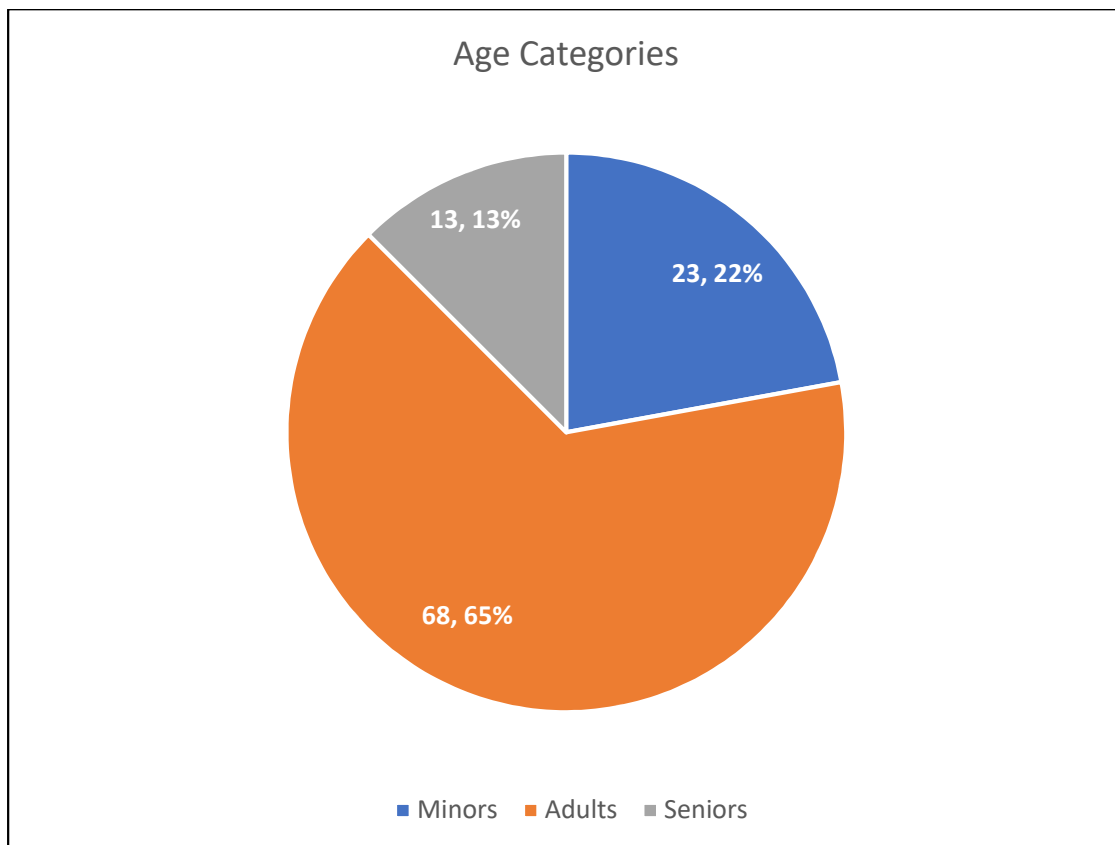
Figure 3: Age Groups

Figure 4 shows that more of the patients who were crowdfunding were doing so because of an illness ($n = 81$) compared to an injury ($n = 23$).
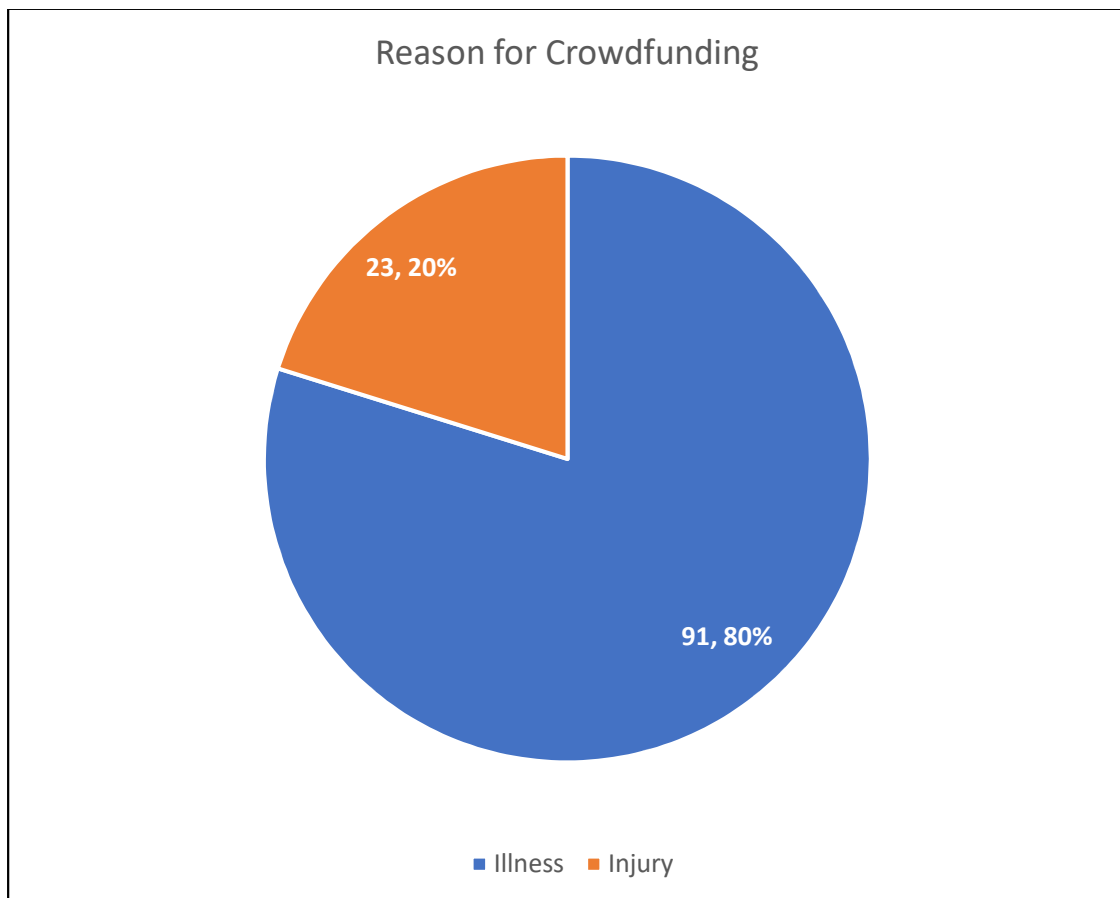
Figure 4: Reason for Crowdfunding

One of the first items on the codebook was to record the campaigns goal in USD along with how much the campaigns raised and the number of donors that contributed.

The average campaign goal was $77,380.14 and had raised a total of $62,257.31 at the time of the data collection. The campaigns averaged receiving donations from 616 donors. Longer campaigns generally hit their goals more frequently that shorter campaigns. At the time of the data collection, the majority of campaigns had reached or exceeded their goals ($n = 68$) compared to the campaigns that had not yet reach their goals ($n = 36$). **Figure 5** below illustrates the distribution of campaign longevity:
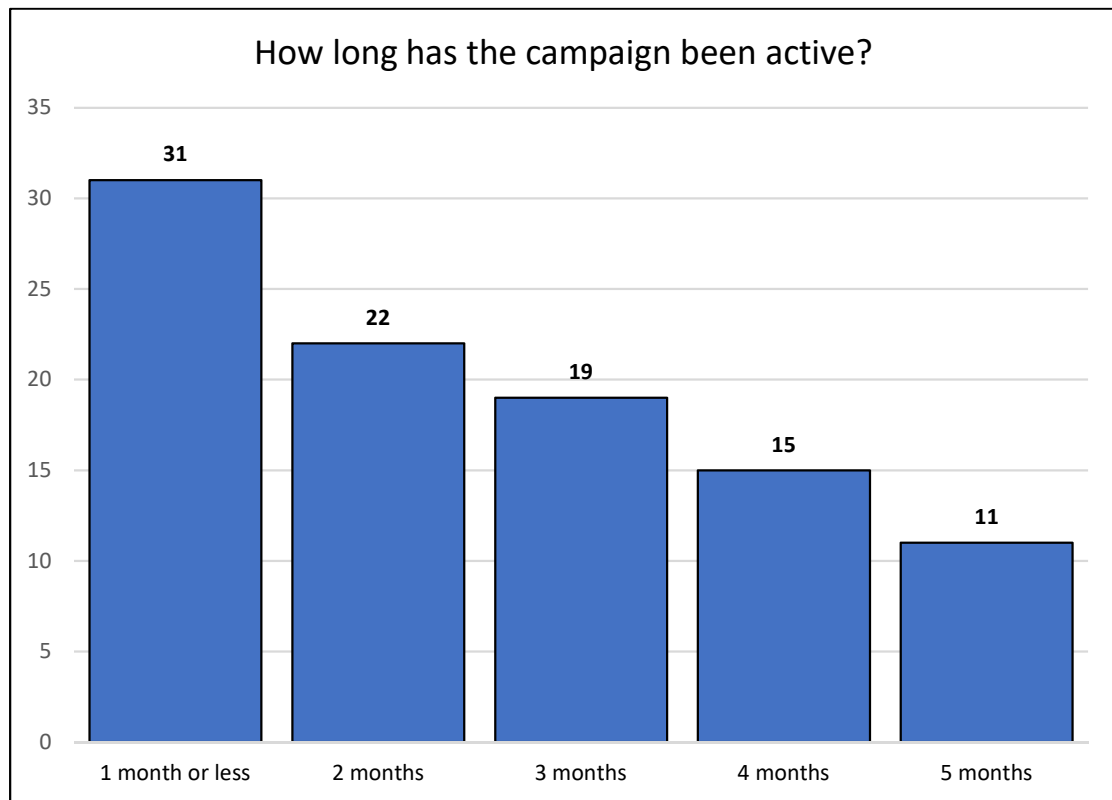
Figure 5: Campaign Length

Patient/Campaign Communication

GoFundMe campaigns provide three primary communication tools to campaign managers through which they can make appeals to their targeted audiences. These tools include (1) text editing features that create blog-style posts similar to those in standard word documents, (2) the ability to post an uncapped amount of pictures surrounding the campaign, and (3) the ability to post videos about the campaign, provided that they are produced and edited using third-party software. This portion of the content analysis investigated how these tools are being used by campaign managers. Campaigns that met their goals were separated from those who had not in order to determine if there were any distinctive differences.

Table 1 shows the results of the chi-square tests between campaign outcome (meeting goals vs. not meeting goals) and the various communication methods used.

Table 1: Chi Square Tests of Communication Methods x Campaign Outcome

Campaign Communication Method	*Chi Square Result*
Text Language	$\chi^2 (3, 103) = 14.18, p < .001$
Pictures	$\chi^2 (2, 103) = 1.05, p = .79$
Videos	$\chi^2 (3, 103) = 6.55, p = .09$
Comments/Responses	$\chi^2 (2, 103) = 11.79, p = .01$

Campaigns that met their goals utilized positive language in greater instances ($n =$ 39; 57.3%) than campaigns that did not reach their goals ($n =$ 8; 22.2%). **Table 2** below illustrates how the emotional tone of the campaign's language differs across the sample.

Table 2: Campaigns Text/Language and Outcomes

	Met goal	Did not meet goal
Positive -- campaign language is optimistic and contains little-to-no negativity	39	8
Mixed -- campaign contains both positive and negative language	21	19
Negative -- campaign language is pessimistic and contains little-to no positivity	1	4
Neutral -- the campaign avoids emotional language	7	5

Every campaign in the sample included at least one picture of the patient. While there are many ways to depict a patient on a GoFundMe page, this analysis utilized the categories (1) Healthy (pictures of the patient never show them as sick or injured), (2) Mixed (pictures of the patient show them healthy and sick/injured), and (3) Infirmed (pictures of the patient are exclusively of them sick/injured). The majority of campaigns utilized exclusively healthy pictures of the patient rather than showing a mixture of healthy/sick images or exclusively sick images. The largest group were campaigns who met their goals that used exclusively health images ($n = 48$). **Table 3** below shows the sample's response in all three categories:

Table 3: Campaign Pictures and Outcomes

	Met goal	Did not meet goal
Healthy -- shows pictures of the patient before the illness/injury or in a state where they do not appear afflicted	48	22
Mixed -- shows a mix of healthy and infirmed images of the patient	18	13
Infirmed -- shows images of the patient while they are sick or injured	2	1

While every campaign is offered the opportunity to post video(s) of the patients to assist in crowdfunding efforts, very few people take advantage of this feature. The analysis determined that the majority of campaigns, both those who met their goals and those who did not, opted to not use a video (met goal, $m = 56$; did not meet goal, $m = 34$). The largest group of campaigns that chose to utilize videos were those who showed the patient as healthy (met goal, $m = 9$; did not meet goal, $m = 1$). The results of this analysis can be seen on **Table 4:**

Table 4: Campaign Videos and Outcomes

	Met goal	Did not meet goal
Healthy -- shows video(s) from before the illness/injury and/or the patient in an unafflicted state	9	1
Mixed -- shows a mix of healthy and infirmed videos of the patient	3	0

	Met goal	Did not meet goal
Infirmed -- shows video(s) of the patient while they are sick or injured	0	1
No Video(s) -- shows no video(s) of the patient	56	34

The total number of Facebook and Twitter shares was collected during the content analysis. Campaigns, on average, were shared 2,013 times. Campaign managers averaged providing five significant updates to the content of the campaign's page over the course of the campaign, not including any additional comments that the managers made to donors in the chat/comment sections. **Table 5** provides details into the comments and responses in campaigns that met their goals as well as those who did not:

Table 5: Social Media Comments/Responses and Outcomes

	Met goal	Did not meet goal
Specific Comments -- comments from donors are generally personal; donors appear to have a connection to the recipient beyond wanting to provide assistance	60	22
Mixed -- comments from donors are an even mixture of specific and non-specific	6	13
Non-specific comments -- comments from donors are generally not personal; donors do not appear to have a connection to the recipient beyond wanting to provide assistance	2	1

These findings are significant and relate back to the idea of a well-managed, competent campaign with clear communication being an important factor for determining success. Managers who invest their time/energy into the campaigns by providing specific updates foster healthy communication with donors and were rewarded for it – campaigns that had specific messaging succeed more frequently that those who did not. While managers in the IDIs complained about the emotional drain caused by near-constant social interaction through the campaign pages, this expenditure of energy seems like it pays off for those willing to put in the work.

Patient v. Friend/Family Management

The content analysis tracked the number of campaigns that were self-managed (managed by the patient) versus those who were managed by a family member or friend of the patient. Nearly every campaign in the sample was managed by a friend or family member ($n = 100$) compared to those that were self-managed ($n = 4$). Two-thirds of the campaigns managed by a friend or family member had reached their goals by the time of the analysis ($n = 67$), while only one-fourth of self-managed campaigns could make the same claim ($n = 1$). The results of this analysis can be seen on **Figure 2** below:
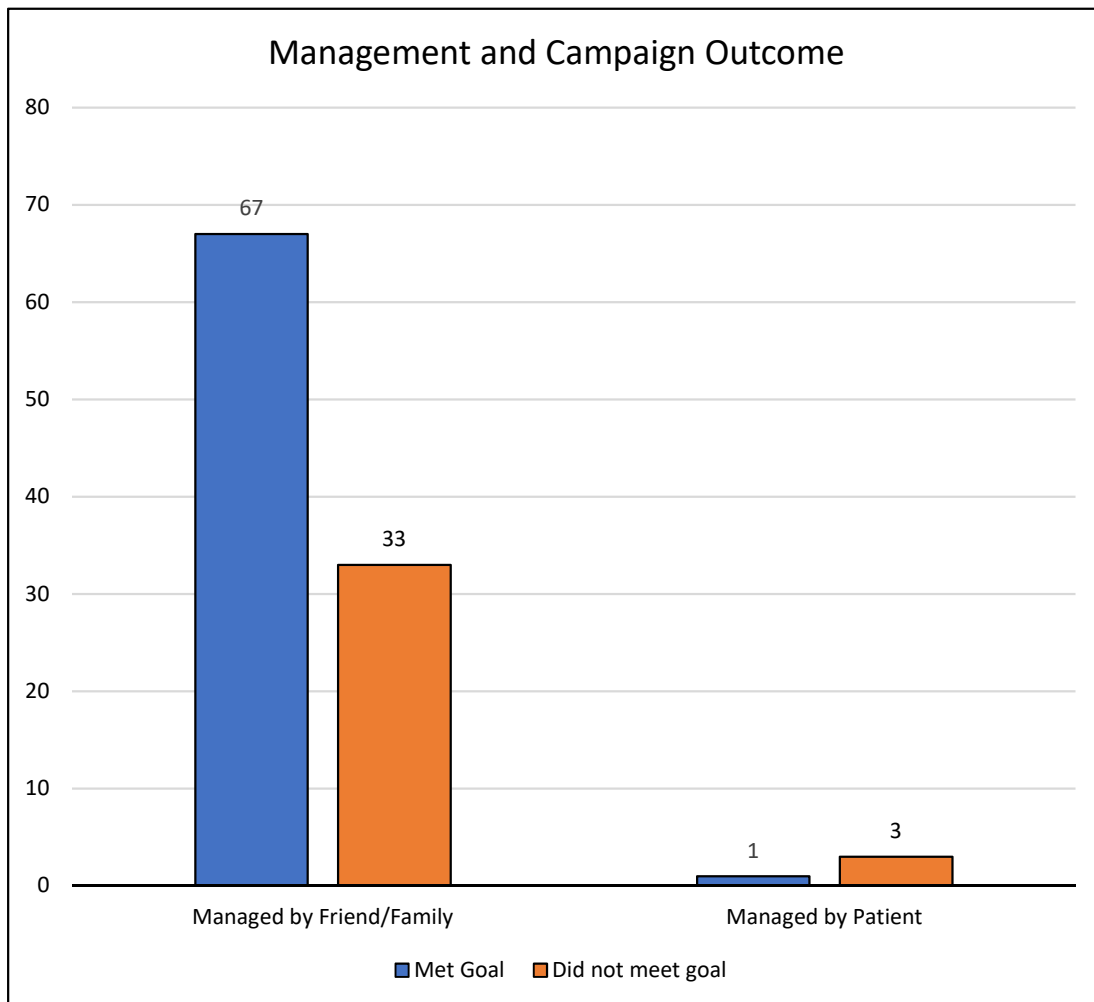
Figure 6: Management Type and Campaign Outcome

Circumstance

The content analysis sought to determine whether certain life circumstances described on the campaign had a significant influence on whether a campaign was able to reach its goal. To test this, data were collected on four different life circumstances that

were made apparent through reading the body text of the campaigns. Campaigns were separated into one of two categories based on whether they had reached their goal by the time of data collection. These circumstances were chosen due to their frequent mention on real-life GoFundMe pages. These circumstances were coded using the following questions (1) Does the patient have dependents? (2) Does the campaign mention secondary problems beyond the treatment of the illness or injury? (3) Does the campaign say how the money will be specifically spent? and (4) Is the campaign managed by someone other than the patient? **Table 6a** provides a crosstabulation of the two campaign categories and the four circumstances.

Table 6a: Campaign Outcome and Personal Circumstance

Did the campaign reach or exceed its goal at the time of data collection?		Yes	No	Total
Does the patient have dependents?	Yes	39 (72.22%)	15 (27.78%)	54
	No	29 (58.00%)	21 (42.00%	50
	Total	68	36	104
Does the campaign mention secondary problems beyond the treatment of the illness or injury?	Yes	52 (73.24%)	19 (26.76%)	71
	No	16 (48.48%)	17 (51.52%)	33
	Total	68	36	104
Does the campaign say how the money will be specifically spent?	Yes	56 (77.78%)	16 (22.22%)	72
	No	12 (37.50%)	20 (62.50%)	32

		68	36	104
	Total	68	36	104
	Yes	67 (67.00%)	33 (33.00%)	100
Is the campaign being managed by someone other than the patient?	No	1 (25.00%)	3 (75.00%)	4
	Total	68	36	104

A large majority of the campaigns that reached their goals (1) mentioned a secondary problem beyond the treatment of illness or injury ($n = 52$), (2) was clear about how the donation money would be spent ($n = 56$), and (3) had the campaign being managed by someone else. Campaigns that did not reach their goal only had a strong majority of campaigns being managed by someone else other than the patient and were more divided in the other categories. Campaigns centered around patients with children ($n = 39$) met their goals in higher instances than campaigns that centered around patients without children ($n = 29$). Chi-square tests were used to further understand the relationships between these life circumstances and crowdfunding success. **Table 6b** provides the results of a series of chi square tests between these circumstances and whether a campaign had reached or exceeded its goal. There were statistically significant results for Q2 and Q3, and results that are close enough for Q1 and Q4 to potentially warrant further exploration with a different and/or expanded sample in the future.

Table 6b: Campaign Outcome x Circumstance Chi Square

Campaign circumstance	*Chi Square Result*
Does the patient have dependents?	χ^2 (1, 103) = 2.32, p = .13
Does the campaign mention secondary problems beyond the treatment of the illness or injury?	χ^2 (1, 103) = 6.10, p = .01
Does the campaign say how the money will be specifically spent?	χ^2 (1, 103) = 15.88, p = .001
Is the campaign being managed by someone other than the patient?	χ^2 (1, 103) = 3.00, p = .08

These results further suggest that future campaigns must be clear with how they will use the donation money as well as providing other details into secondary issues associated with the campaign. Once again, lower transparency seems to be an attractive quality that leads to campaign success. While the sample size is relatively small, the recurrence of this theme through multiple forms of data collect point towards transparency through communication as being one of the key, critical factors in determine patient-centered crowdfunding success. Future campaign managers should make concentrated efforts to remain transparent where possible.

Conclusion of Chapter 4

This chapter contains the results of the mixed quantitative and qualitative data collections, provides analysis to these results, and builds on the previous important

themes that were established by the literature review in the earlier parts of this dissertation to address the fundamental research questions. While the three methods used in this chapter seem diverse in that they collect data in distinctive ways, they all seek to address separate components of the crowdfunding process and contribute to what is understood about the social, technological, and circumstantial factors that contribute to patient-centered crowdfunding success.

The in-depth interviews that provided qualitative data brought attention to several important areas to study within the crowdfunding ecosystem including (1) user experience, (2) networking/social media, (3) ethics and privacy management, (4) attitudes/motivations, (5) future use, (6) obstacles, and (7) potential process improvements. The survey collected data on (1) donor behavior, (2) perceived benefits/harms of crowdfunding, (3) donor evaluations of worthiness, (4) e-health literacy, (5) general self-efficacy, (6) self-reported altruism, (7) happiness. Finally, the content analysis provided insight into (1) patient/campaign communication style, (2) social media comments/responses, (3) patient v. family/friend campaign management outcomes, and (4) life circumstances that could potentially influence whether a campaign reaches its' goal. This chapter analyzed the data in order to provide a baseline dataset for which future crowdfunding research can build. The next chapter, **Chapter V: Discussion**, will expand on the findings in this analysis by offering context, identifying limitations of the current study/dataset, discussing opportunities for future research on this subject, and outlining the next planned steps for this dataset.

CHAPTER FIVE

DISCUSSION

This chapter interprets the data outlined in the previous chapter to examine the implications of the findings for patient-centered crowdfunding. The analysis focuses on each of the 15 research questions outlined by this study to illustrate how the design and data collection process can answer these questions. Over the course of this chapter, this approach will (1) outline the study's findings, (2) explain why they are important, (3) relate the findings to other research/theories, (4) propose alternative explanations for the data, (5) state the theoretical importance of the findings, (6) state the limitations of the research questions, (7) propose solutions for these limitations, and (8) make suggestions for future studies surrounding patient-centered crowdfunding. Discussion summaries can be found below under each research question subsection.

RQ1: What are the relative advantages of patient-centered crowdfunding? Put another way, what qualities of the innovation make it preferable to users over similar alternatives? (In-depth Interviews)

Participants that were interviewed during qualitative data collection cited several advantages to GoFundMe over other alternatives to paying for medical costs and/or making donations to support patients in crises. Rogers (2003) wrote that perceiving an

advantage of an innovation inherently increases the likelihood that someone will engage

with and potentially adopt that innovation; this component of Diffusion of Innovation

Theory could explain why most interviewees mentioned numerous specific advantages to

GoFundMe. These advantages include (1) integration into social media, (2) ability to stay

updated on campaign progress, and (3) likelihood of activating networks of old

friends/acquaintances.

Social media integration is important for both donors and campaign managers. In

2019, nearly everyone utilizes an internet-connected smart device; whether it is a

smartphone or tablet, anyone with such a device can, at no additional cost, use the

GoFundMe application or mobile website to monitor, share, and update campaigns.

Additionally, multiple campaign managers can share the workload by allowing different

users to access the administrative tools, taking the burden off of any one person from

directing the campaign in its entirety. The ability to "dial in" remotely may prevent

campaign managers from having to relocate or quit their jobs in order to dedicate

extensive time to the campaigns.

The internet and social media integration have also provided donors with a high

degree of utility, post-donation. Campaign updates, including the net progress towards

hitting the goal, are sent directly to the email inbox or cellphone (via SMS) to the donor.

This provides donors with a degree of outcome attachment to the campaign – some

interviewees described this as feel like they "have a stake in what happens" and find

themselves "checking [their] email for the updates." Many campaign managers described

old friends and acquaintances that they had not had recent contact with showing support

for the campaigns. Likewise, donors said that they gave to people that they use to know in order to show the recipient they still respect and care on some level.

RQ2: What qualities are consistently present in successful patient-centered crowdfunding campaigns? (In-depth Interviews, Survey, Content Analysis)

Being transparent via campaign updates was a common technique used by campaign managers on crowdfunding pages. Successful campaigns were those that put the patient at the center of the story and attempted to humanize the situation by providing numerous updates, interacting with donors/potential donors through the page, and including extra details about the patient's life and status. Campaign managers should invest the time into routine posting, provide details of where the money is going/how it will be used, and make sure that content is well-written/presented for maximum results.

RQ3: What motivates donors to adopt the innovation of patient-centered crowdfunding? (In-depth Interviews)

Donors did not offer a lot of information on this question. This could be due to the private, sensitive nature of a patient going through a hard time and/or the cultural taboo surrounding the discussion of a person's financial troubles. Still, the in-depth interviews provided some context to what motivates donors to pay money on GoFundMe. Some say that it is a more convenient way of supporting a good cause, while others feel a sense of guilt/relief that they are not the ones facing a health crisis and show their support out of sympathy for the patient. Most donors cited some sort of personal connection to the

campaigns that they supported, while also saying that they found out about the campaign through of social media (Facebook, Instagram, or Twitter). This could mean that many of the campaigns, even those created by a friend or family member, are discovered through social media sharing rather than interpersonal or face-to-face small group communication. As such, social media is likely to be a key diffusion channel for the crowdfunding innovation. Future research on this topic should collected data on whether individuals first discovered GoFundMe (and/or other crowdfunding platforms) through social media sharing and advertisement. Still, having a personal connection, either in real-life or through a shared experience such as military service, lifestyle, or facing similar circumstances could potentially be major factors in motivating individuals to donate.

RQ4: What role does a patient's communication play in a campaign's overall level of success? (In-depth Interviews, Content Analysis)

Clear, effective, and consistent communication are all important factors in patient-centered crowdfunding success. Not only does regular communication create legitimacy surrounding the campaign, but it also personalizes the patient, so they are viewed as a person instead of a charity case. The personalization is one of the greatest strengths of GoFundMe; the platform looks, feels, and interacts with users in the same way that many of the familiar social media websites do. Through the platform patients are able to not only relay their personal stories but also communicate with donors. The patient can tap into a personal support network, vent frustrations, ask for money, information, and/or recommendations on where to seek care. Additionally, GoFundMe provides a forum

where it is okay to ask anyone for donations. While this might not seem like an important factor, American cultural norms around money discussions have made asking for financial help taboo – GoFundMe provides a culturally-acceptable channel in which people are not belittled or questioned heavily when they have a financial need. Petronio's (1991) CPM theory emphasizes the importance of privacy rules and specific channels existing for the disclosure of certain information – one could argue that GoFundMe has created a specific set of channels where the cultural privacy norms surrounding money are suspended and the turbulence that normally surrounds financial conversations evaporates.

RQ5: What features of patient-centered crowdfunding are attractive to potential donors? (In-depth Interviews, Content Analysis, Survey)

Donors seem to be attracted to the platform through a combination of compelling patients to donate to as well as the ease of donating. Once a donation is made, participants become a part of that campaign's ingroup and continue to receive automatic email and SMS updates from the campaigns they have supported. These updates provide donors with the latest information surrounding the campaign goal, patient health/recovery, new challenges, major breakthroughs, and other relevant information. This technique makes the campaign seem like an ongoing, evolving effort rather than a "one-time financial transaction" made by the donors. Because of the personal touch, donors may be inclined to share the campaign on their own social media and promote it to their person networks. Some donors may even be motivated to make an additional

contribution as indicated by the following donor response:

"I donated again when I saw [the patient] was in $500 of hitting their goal. I donated fifty bucks because I thought 'that's 10% of what they need…if 9 more people give fifty bucks, they're there!' I only gave ten bucks the first time too, so giving fifty made me feel better about that"

Many businesses that facilitate e-commerce exchanges (i.e. digital transactions of money for goods/services online) generate revenue by adding additional charges to the transactions. Charging add-on fees is commonplace in various industry sectors such as concert ticket vendors, online stores, and, in particular, credit card companies or e-payment companies like PayPal. GoFundMe has utilized this business model since its inception but has recently changed their stance as of 2018 – GoFundMe no longer takes an additional charge of $1-3 per transaction or an additional added percentage charged to the card; instead, they include the 2.9% credit card processing fee and allow campaigns to collect all of the donated money after that point. This means that GoFundMe's current business model focuses on gathering and selling user data to third parties, potentially leading to further discussions about ethical business practices and user privacy. However, GoFundMe's profitability as a business is not the focus of this analysis but could warrant further exploration at a later time.

RQ7: Do crowdfunding campaigns exacerbate existing health disparities and

inequalities of access? If so, how? (In-depth Interviews)

Many participants did not notice or report inequality issues. However, the sample was not very diverse. Furthermore, many participants discussed equality in terms of race rather than socioeconomic class, or they blended the two together base on their personal perspectives on inequality. The campaign managers interviewed had managed successful campaigns, and most of the donors interviewed supported campaigns that were launched by someone that they already knew. This means that individuals without strong real-life support networks could potentially struggle when trying to launch a patient-centered crowdfunding campaign. Additionally, individuals in a lower socio-economic range might not have personal networks with enough money to provide meaningful support (even if the desire to support is there). It is difficult to know what GoFundMe is doing to address these disparities without having an insight into the organization's perspectives on the issue. However, there are not any clearly-defined parts of their platform that exist with the aim of addressing potential inequalities on the site. One possible solution would be for GoFundMe to provide a specific section on their website for campaigns that are far behind their goals and/or have gotten very little traction in terms of social media support. This would help bring attention to underserved campaigns and give the option to meet the needs of the less supported campaigns. It is unlikely that this solution will completely fix the problem as most donors are drawn to the platform to help people that they already know, but it could at least alleviate some of the pressure for those managing campaigns that have barely gotten off the ground.

RQ11: Are there any cultural or socio-economic/technological barriers that influence crowdfunding participation? (Survey) RQ9: What efforts are being made to promote equality on crowdfunding platforms? (In-depth Interviews; Content Analysis)

This study proposed six different axioms of inequality on crowdfunding platforms in the literature review section. These axioms are important for identifying and categorically organizing different types of inequality in the crowdfunding data. This section of the discussion will briefly review these six axioms and describe how they manifested themselves in the dataset during analysis.

1) Technological Inequality – refers to the imbalance in individuals' computer skills, social media literacy, and ownership of internet connected devices -- these are all necessary items for effective GoFundMe participation because the platform can only be accessed digitally. The widespread significant scores from the t-tests regarding e-health literacy demonstrates that there is a marked difference between the ways that donors and non-donors view e-health technology.

2) Inequality of Illness – refers to the fact that different patient conditions (illness/injury) could solicit different responses from donors. While the data did not specifically point to any particular illness having precedent over others, there were clear sentiments in the in-depth-interview data that indicated respondents were more sympathetic when the situation was dire compared to when it was not. While data did not specifically point to this axiom existing for the previously

mentioned reasons, discussions on pages 87-88 of the analysis section brought to light the idea that severe/potentially life-threatening conditions with a grim outlook can be a major turnoff for donors.

3) Inequality of Patient – refers to the idea that certain patients might be favored over others due to personal factors that extend beyond need and condition. These factors could include age, gender, ethnicity, sexual orientation, and a number of other personal factors. The open-ended survey question centered around donation worthiness (the solider, the student, and the prisoner) also provided insight into how different life circumstances can cause patients to receive donations, which makes the donation decision process extend beyond simply the content of the illness/injury. The samples collected by the three different methods all had a majority group of white adults. While this made it challenging to make meaningful cross-comparisons of patients, it did highlight the fact that there are heavy proportions of certain ages/ethnicities on GoFundMe that could be perpetuating a system of passive bias. Future researcher should aim to collect even samples on GoFundMe to see if funding/support disparities actually do exist due to the patient's personal traits.

4) Inequality of Efficacy – refers to different patient's confidence in their ability to engage with crowdfunding in a meaningful, successful way. This axiom could not be confirmed because the different data collection methods produced different

results. While interviewees described encountering campaigns that were poorly executed, this poor execution could be due to factors beyond self-efficacy. Furthermore, the t-tests on page 127 illustrate little significance in efficacy influencing people's decision to engage with crowdfunding; this further reinforces the idea that familiarity with the platform and the associated technologies could be a more important factor

5) Inequality of Support – refers to the patient's support system. While most campaigns in the samples were managed by someone other than the patient, there were a few campaigns that were self-managed. These self-managed campaigns succeeded far less often than those that were managed by a friend or family however, the interviews were able to determine that there is a high level of stress associated with running a campaign, meaning that those who are facing a life-threatening situation might not be able to take advantage of crowdfunding tools. More research with a broad sample of self-managed campaigns is needed in order to provide a better idea of the stressors of self-management on a patient

.

6) Inequality of Knowledge/Exposure – refers to the lack of awareness and research around patient-centered crowdfunding. There are very few external resources that campaigns have to rely on in terms of books, academic articles, etc. As a result, many campaign managers are having to organically learn the practices of GoFundMe, and sometimes make otherwise avoidable errors. Others might

believe that crowdfunding success is rigged or random and feel like they cannot engage with the platform effectively enough to warrant giving it a shot.

RQ10: How do personal characteristics (happiness, self-efficacy, altruism, and e-health literacy) influence donor behaviors? (Survey)

Some personal characteristics had a notable influence on donor behaviors and warrant more in-depth exploration in future work. E-health literacy, positive/negative perspectives on GoFundMe, and some of the self-reported happiness measures showed as being significantly related to a participant's decision to use crowdfunding. Interestingly, self-efficacy and self-reported altruism were not significantly related to crowdfunding participation. These measures not showing as significant could be due to a variety of reasons and warrant further exploration – future research could try these same scales with a larger sample size to determine if sampling issues were behind these results. However, these results, in concert with the significant findings on personal perspectives and e-health literacy, hint that being a donor might have more to do with 1) feeling positively toward the GoFundMe platform, and 2) having a higher degree of e-health literacy.

E-health literacy is an important personal characteristic because of its focus on an individual's ability to (1) navigate digital health platforms (like GoFundMe), (2) have a certain level of confidence that they can parse through the health information and (3) have the confidence to make informed, correct decisions. Individuals with higher e-health literacy are likely to feel that they understand the campaigns they are donating to more so than individuals with low e-health literacy – for example, a campaign that provides vivid

details complicated treatment plans could be affirming for donors possessing the e-health literacy level needed to understand the plans and this affirmation could encourage the potential donor to support. Potential donors with low e-health literacy might become confused by the plans or not know how to research the treatment options to verify the legitimacy of the campaign's claims; this could cause the donor to not offer support.

There was a marked difference in self-reported happiness levels between donors and non-donors in the survey sample. People who had donated before also reported higher happiness scores, while those who had not donated reported lower scores. This finding raises questions about the degree to which someone's personal happiness influences their decision to donate to charitable causes. The relationship between happiness and donation behavior has the potential to be incredibly nuanced; therefore, a separate study should take additional happiness measures into account and attempt to qualitatively contextualize why being happy could lead someone to donating.

RQ13: What are the consistent traits of messages (in a patient-centered crowdfunding context) that travel through social networks? (Content Analysis)

Campaigns that reached their goals used positive language in their messages at much higher rates than those who did not reach their goals. Much of the time, these positive communications update supporters on the condition of the patient, specific plans for future treatment, statements of faith and well-wishes, and other forms of typical health campaign communication. Another interesting tactic that a few campaigns have employed is to let the patient communicate directly to the donors through some sort of prepared statement or video. These statements from patients tended to be non-specific,

but rather provide a direct line between patient and whomever is listening. One patient began a blog post using this direct style of communication of their thankfulness:

"Gratitude. A couple days ago I was outside in my wheelchair with my good friends, Matt and Wendy. It was a chilly day. However, we were lucky enough to have found the perfect spot where the sun was shining on my face like a spotlight. It felt so amazing and I was extremely grateful. The question is, would I have enjoyed this moment as much a few years ago? Back then, I was always running from one task to the next and it seemed that I seldom stopped to smell the roses. I'm sure I did occasionally, but now more than ever, I am able to slow down and enjoy these precious moments in time."

Communicating negative or bad news can be a messaging challenge for many campaigns because (1) communicating the details about medical issues/treatment can include complicated language, (2) donors indicated that negative campaigns do not inspire donations as effectively, and (3) the patient/manager could be preoccupied with the health problems in front of them rather than feeling like engaging with donors through GoFundMe. Some of the effective strategies for framing negative updates include (1) delivering messages of hope or positivity alongside the negative news and (2) emphasize the fact that the road to recovery is a team effort, and that the efforts of the donors and supporters are going to good use. The same campaign that provided the earlier except (p. 135) perfectly demonstrated how to use these framing strategies by

writing:

"It's coming up on almost one month since my last stem cell treatment and I wish
I could say that I'm 100% healed and ready to run a marathon. Unfortunately, I
can't say that. However, I can say that I'm more optimistic now than I have ever
been during this journey. In fact, on a recent doctor's visit I was told that my
oxygen levels were at 99 which is phenomenal. So, with that said, I see every day
as a blessing. I have an amazing family, an incredible team of helpers, and a
loving, supportive group of friends. In   addition, I have my almighty God
that loves me as one of His children and promises a complete healing. "And by
His stripes, we were healed."

Thank you all for your love, support and prayers.
God bless"

**RQ14: How does a patient's condition influence the way that donors respond to the
campaign? (Content Analysis)**

The specific condition of the patient did not seem to be as important of a factor
for garnering support when compared to other factors. While some donors indicated that
having a loved one suffer an illness/injury made them more sympathetic to current
patients on GoFundMe, there is a confluence of other influencing factors that lead to a
person's decision to donate. Some donors likely donate because of their history or are

familiar with the condition, but these same donors are influenced by the same presentation, personal characteristics, obstacles, financial, and technological factors that influence all other potential donors. Therefore, it is reasonable to say that, while a patient's condition does influence the way that donors responds to a campaign, it is not the sole motivating factor that influences most donors' decisions to contribute. Further research on this topic should focus on the degree to which a personal connection to the patient influences donation behavior compared to the other influencing factors.

RQ15: Does the patient's disclosure of their challenges help or hinder the crowdfunding campaign? If so, how? (In-depth Interviews; Content Analysis)

Disclosure of difficulties on GoFundMe is not an inherently good or bad tactic, but rather comes down to how effectively the patient can make the appeal in a not completely negative way. Campaign managers have control of the campaign's emotional tone and are therefore able to frame challenges in a more positive or neutral manner. Donors indicate that they are less likely to support a campaign that seems futile or if it seems unlikely the patient is going to survive, so managers that use this sort of presentation style to solicit donations could be working against their own interests. This study was not able to provide a more concrete answer to this question due to the varying directions that the disclosure of challenges can go. A study that follows fewer campaigns during their full lifecycle (from inception to completion) might be able to provide a clearer perspective into how audiences respond to news of challenges/personal disclosers of illness by the campaign. This method could be more effective because (1) the

supporters/donors would be more-or-less the same group, and (2) it would allow the researcher to better understand the personal characteristics of the patient/manager and how those characteristics influence the way that patient-centered crowdfunding campaigns develop their disclosure strategies.

Conclusion

Crowdfunding methods provide users with the tools to collect relatively small amounts of money from large groups over a long period of time in order to achieve their goals. These goals can vary – businesses, private organizations, non-profits, professional societies, and individual people have all enjoyed great successes with crowdfunding. This study directs its efforts towards investigating patient-centered crowdfunding due to the lack of established, published research on the topic. Despite the fact that patient-centered crowdfunding is now a billion-dollar annual industry, most research around crowdfunding focuses on non-medical areas (business startups, disaster relief, travel, bringing new products/ideas to market, etc). The final chapter of this dissertation will (1) restate the findings, problems, and potential solutions in light of the analysis and discussion that has been stated throughout previous chapters, (2) outline the specific limitations of this study, (3) provide opportunities and directions for future research, and (4) provide summarizing, concluding remarks.

Key Findings, Problems, and Solutions

Many interesting pieces of data were collected during the interviews, survey, and content analysis. A big challenge for a singular researcher working with a dataset as large as the one collected for this project is that there are numerous directions for analysis. That, compiled with the fact that there is relatively little published research on patient-centered crowdfunding, presents a difficult question to the researcher: what is the most effective way to organize the data to provide meaningful, actionable insight that could potentially improve the ways donors and campaign managers engage with patient-centered crowdfunding platforms? The purpose of this subsection is to provide data-driven insights that could lead to process improvements for all people who choose to use GoFundMe.

Systematic Issues

It is important to establish the fact that there are certain inherent issues with the healthcare system that run deeper than the crowdfunding platform. It is unlikely that people are turning to GoFundMe as their first option for managing healthcare costs. While many Americans are fortunate to have quality health insurance, there are millions whose life circumstances have put them in a position to where they either have no health insurance, or that the coverage/associated costs are too great for them to cover on their own. It is oftentimes the people in this second group that turn to GoFundMe. The issue of health insurance in the United States has been intensely politicized, and this dissertation will not attempt to unpack the argumentation over the reasons behind healthcare inequality. However, problems in the general healthcare industry have created a demand for services like GoFundMe, who, as an organization, lack the capacity to change the

broader healthcare industry. Awareness of the underlying issues that drive people to GoFundMe is important because it helps to frame the sort of problems that are solvable and unsolvable with crowdfunding.

Proposed 'Tiers of Need'

This study helps to confirm that the needs of all patients' on GoFundMe are not equal – while some patients are simply trying to pay their bills until a broken limb heals, others are facing life-threatening diagnoses that impact every facet of their lives. While both of these examples can justify a level of assistance, both have different levels of need. This study proposes implementing a classification system as an option on the platform that designates different campaigns into different categories based on the predetermined level of need of the patient. Doing this would allow new donors to see individuals who are up against the most dramatic circumstances, others who are in serious but not life-threatening conditions, and all the way down to those who just need a few hundred bucks to help with copays – this system would give donors the option to make a donation based on need rather than popularity, familiarity, or any number of other motivating factors. Others might decide to support an underfunded campaign. There is not an easy answer for determining need as several measurements would likely need to be piloted by GoFundMe. The findings in this report would suggest that a combination of socioeconomic status, lack of campaign progress, lack of real-life sport, and/or lack of the necessary skills for running a campaign could be broad categories for determining need.

Still, there is likely to be issues with almost any way of trying to a plan a standard to non-standardized situations.

Proposed 'Diffused Donation' Method

Individuals donate to GoFundMe because, on some level, they want to improve the lives of others. It is a noble act, but it sometimes has unintended negative consequences, such as those described in earlier sections. In order to prevent a high concentration of the funds from going to a small group of donors that vastly exceed their campaign requirements, GoFundMe should consider implementing a partially "diffused" donation system. That is, a system where a predetermined amount of the donation (ideally less than 10%) goes to a community pool that GoFundMe distributes based on need. While this idea would likely be attractive to many, donors have also cited the fact that the donation money going "straight to the patient" is one of the biggest appeals of patient-centered crowdfunding. However, GoFundMe could delicately explain the problem they are trying to solve through diffused donations in an effort to give context for why some of the donated money is being siphoned off. A compromise could be that excessive donations (donations that exceed the campaigns original goal) could pay into the <10% diffused donation pool. Like with any individual-run campaign, GoFundMe would need to make concentrated efforts to be transparent. All of the funds would need to find their way to the patient, or else donors might be resistant to the prospect of diffused donations. Using this approach would be risky, as other platforms that do not charge this community fund could advertise themselves as giving 100% of donations to the specified patient.

Establishment of 'Dire Need' Category

Early campaign success and being able to activate one's personal networks are critically important for patients who are trying to raise money on GoFundMe. However, not every patient will have the means or personal connections to get these campaigns off the ground. GoFundMe should provide a "Dire Need" designation to some campaigns that fit this description and include a section of the home page meant for drawing attention to them. This option provides GoFundMe with a degree of flexibility in that the subject of the campaign does not have to be suffering from a particular condition or circumstance; their inclusion into the dire need category would be based purely on their campaign's success. If this idea works, then patients would be quickly removed from the dire need list as their personal campaigns took off, which would then make room for other patients to go on the list. The biggest drawback to using this approach is that it might encourage patients to not try as hard and game the system so that they can appear on the dire need list.

Proposed 'Certified Legitimate' Designation

Donors were cautious of the legitimacy of some campaigns. No one reported paying money to a scam campaign, but several participants acknowledge that they saw campaigns that they believed to be fraudulent or exaggerated. GoFundMe provides tools for donors to report suspicious campaigns, but their effectiveness is undetermined. This study proposes that GoFundMe create a "Certified Legitimate Campaign" badge that goes at the top of every campaign willing to undergo addition vetting. This vetting process should look similar to other distance-vetting processes such as signing up for

auto insurance online or becoming an AirBnb host – campaign managers could provide a social security number, paperwork proving the patient is at the hospital, paycheck stubs, utility bills, or any number of personal identification documents. The badge would provide legitimacy to donors, who would be given assurance the campaign had been vetted. One drawback to this approach is that the added vetting/steps could add additional stress and make it more difficult for some individuals on GoFundMe to take full advantage of the platform, potentially reinforcing inequality on the platform.

Transparency, User-Centered Design by the Platform

If GoFundMe enacts some or all of these changes, it would be in their best interest to communicate proactively with their uses, explain why the changes are occurring, and emphasize transparency during and after the transition. This study identified several potential improvements by partnering with donors and campaign managers on the platform to collect data; if the scope of this study could identify several improvements with its limited sample, GoFundMe could likely determine several critically important areas to fix taking a user-centered design approach to their research as well. Platforms like GoFundMe can always find room to improve when designed in partnership with users and with the end user in mind. Additionally, taking a user-centered design approach could make GoFundMe more aware of any underlying equality issues that are on the platform.

Study Limitations

While this study aimed to collect a variety of data on patient-centered crowdfunding ecosystems, there were certain limitations to the study that could hopefully be overcome in the future with additional researchers, resources, and time. This portion of the conclusion will outline how (1) time, (2) manpower, (3) sample size, (4) lack of prior data and (5) scope all presented challenges for the direction of this project.

Time

While this project began in earnest in September 2018, the amount of time required to research the topic, propose/design the study, defend the proposal, obtain human subjects research approval from the institutional review board, collect three forms of data, analyze it, and write the report creates a very full schedule for a lone research, leaving little room for error or disruption. The order of data collection was critically important for this project's success – quantitative content analysis does not require IRB approval, so beginning that form of the analysis shortly after the October 2018 proposal defense was a key decision which kept the project moving on time. The quantitative content analysis was concluded in time to build the survey and flesh out the in-depth interview guides. Interviews were scheduled weeks in advance, with multiple interviews being conducted to occur in the same day, one at a time. The survey was launched simultaneously to the interviews so that survey data could be collected while the researcher was gathering qualitative data. Despite the fact that data collection took much longer than anticipated, data were still collected within a timeframe allowing for the

analysis of data and the writing of the report.

Sample Size

The greatest downside to using three separate data collection techniques is that it resulted in less time available to dedicate to any one particular method. This method was chosen due to the fact that there is so little data published on patient-centered crowdfunding effectiveness. Had there been a wider variety of strong foundational literature, then the researcher would have considered dialing in on one of these methods in more detail instead of all three. The sample sizes could potentially have an impact on this study's findings because the total number of participants recruited is but a tiny fraction of the overall user population that the sample was designed to represented. While several interesting themes and datapoints came out of this study, their application for broader GoFundMe users should be confirmed with additional study on larger sample sizes. The current sample sizes limit the number of tests that can be run. Additionally, there were no datasets to reference on this topic or studies to model, so making a comparison to a standard sample was not possible.

Prior Data

The lack of prior data on patient-centered crowdfunding is likely caused, at least in part, by the fact that GoFundMe has only existed for roughly a decade and has only gained substantial popularity over the last five or so years. There are some researchers who are studying crowdfunding, but they tend to study it from the perspective of their

discipline (engineers study the technology, business scholars study broader applications, etc.). As such, there was not a straightforward, largely descriptive piece that could serve a as foundational research "snap shot" of the patient-centered crowdfunding industry.

Future Research Directions

Future research can go down divergent paths, depending on the researcher's personal interest with crowdfunding. Whether someone prefers qualitative, quantitative, or mixed methodologies, there is a veritable goldmine of publicly-available data to be collected on these pages. For those who prefer qualitative methods, the text can be copied into NVivo or other analysis software, and managers/donors can be contacted directly though the platform for interviewing and survey purposes. If given enough time, social media integration with Facebook and Twitter could likely be leveraged effectively to recruit research participants on this topic. With all of this in mind, this dissertation proposes the following directions for future research on this topic to explore:

- **How do GoFundMe user experiences differ when evaluating a campaign?**
- **What are the specific differences in a campaign that is run by someone with high social media efficacy versus someone without it?**
- **How do donors respond when they come across fraudulent information on GoFundMe?**
- **What are the differences in attitudes/motivations among highly motivated donors?**
- **How will patient-centered crowdfunding technology change over time?**
- **What obstacles do donors see to patient-centered crowdfunding?**
- **What tactics do campaign managers employ to cope with stress?**
- **How do people of different ethnic and socio-economic backgrounds evaluate the worthiness of a patient?**
- **What immediate process improvements could be made to bolster fundraising efforts?**
- **What are donor's perceptions of transparency on GoFundMe?**
- **How do campaign managers determine what the fundraising goals will be?**

- **How does the use of mobile technology impact campaign outcomes?**
- **How much does the patient's background and non-medical history impact a donors decision to offer support?**

Additionally, one of the most intriguing dynamics that warrants further exploration is the different personal characteristics between donors and non-donors. While donating money to a charitable cause is generally considered an altruistic action, the altruism scale in the survey indicated that none of the items were significantly correlated with being a donor – donorship seemed to be more reliant on understanding GoFundMe and having higher e-health literacy. Using additional altruism measures (such as Vaux et al's Compassionate Altruism Scale, Sawyer's Altruism Scale, etc). This dive into altruism and patient-centered crowdfunding could also point to a new explication of altruism within the context of digital charity; this new explication would need to account for the barriers to altruistic action (such as knowledge of the charitable platform and the skill set to navigate that platform).

Interviewing additional campaign managers, perhaps having a focus group of campaign managers, and recruiting active campaigns for field observations would be other additional steps that could lead to deeper understanding of this group. While many managers shared similar experiences on a broad level, the specific details of their experience were largely influenced by factors outside of their control (proximity to the patient, the type of illness/injury, the financial situation, the level of support, etc). This group is different enough from the donor group to warrant a separate, additional study of the personal characteristics and circumstances of campaign managers. Finally, further efforts should be made to bring GoFundMe into the conversation. Future research could

aim to partner with GoFundMe to study their internal communication and processes. This could lead to a greater understanding of the platform's inequality dynamics, business model, and operational actions.

Concluding Remarks

This piece began by highlighting the fact that there is a problematic imbalance in the crowdfunding literature; not nearly enough research going towards assisting patients with their crowdfunding efforts compared to the amount of time being spent on helping businesses. This study's purpose was to understand more of what there is to know about the patient-centered crowdfunding ecosystem to learn more about how the innovation works, who is using it, and how to provide guidance on achieving the best outcomes on the platform. While this dissertation had mixed results in fully answering every question that it set out to explore, it provides a valuable source of data that other interested researchers could use to direct future work in studying patient-centered crowdfunding. Like any relatively new innovation, there will be growing pains.

Scammers and dishonest people could try to profit off of the platform. People who honestly deserve the help might see their campaigns fall short. People will lose their lives in the process of crowdfunding. In spite of these shortcomings, GoFundMe has positively impacted the lives of tens of thousands of people and will continue to help more as time moves forward. GoFundMe provides a channel to harness something powerful that has existed much longer than the innovation of patient-centered crowdfunding – goodwill from one person together. GoFundMe illustrates that, if given the opportunity, many

people will contribute to help others in need. While problems might seem catastrophic, people show up for one another when there is need. GoFundMe illustrates the powerful impact of intentional, collective, collaborative effort.

APPENDIX ONE: CONTENT ANALYSIS CODEBOOK

C1 Condition – refers to the illness, injury, or other situation that has resulted in the

patient turning to crowdfunding (A subnode of XXXX will be replaced by new

conditions as they are observed in the analysis; cancer, stroke, car accident, etc.)

    C1 Illness – the patient has turned to crowdfunding because they became sick

    C1 Injury – the patient has turned to crowdfunding because they were hurt

    C1 Mixed – a combination of illness/injury

F1 – Funding

    F1 Goal – refers to the overall targeted dollar amount that the campaign is

    seeking to raise. The exact dollar goal of each campaign should be documented.

    F1 Total Raised – refers to the actual dollar amount that the campaign was able

    to raise at the time of the content analysis. The exact dollar amount should be

    documented.

    F1 Number of Donors – refers to the number of people who donate

F1 Average Donation Size – refers to the average donation size, per donor, that a campaign raises. The exact dollar amount should be calculated for each separate campaign.

S1 Social Media

S1 Facebook Shares – refers to the number of times that a campaign is "shared" on Facebook

S2 Twitter Shares – refers to the number of times that a campaign is "retweeted" on Twitter

S1 Comments – number of comments on the campaign's official GoFundMe page

S1 Non-Specific Comments – comments from donors are generally not personal; donors do not appear to have a connection to the recipient beyond wanting to provide assistance

S1 Specific Comments – comments from donors are generally personal; donors appear to have a connection to the recipient beyond wanting to provide assistance.

R1 Responses – number of responses to campaign comments by the patient/the patient's support team

R1 General Response – responds to donors a whole; does not reference any specific person or donation.

R1 Specific Response – mentions one or more individuals/donations specifically by name and/or amount during their response

R1 Mixed Response – responds to donors as a whole while referencing one or more specific cases by donation amount.**R1 No Responses** – the campaign did not respond to any of the comments that were made on their page.

M1Media

M1 Pictures – campaign uses pictures to help share the patient's story.

M1 Picture Status – refers to how the patient is depicted in the campaign's pictures

M1 Healthy – shows pictures of the patient before the illness/injury or in a state where they do not appear to be afflicted.

M1 Infirmed – shows images of the patient while they are sick or injured

M1 Mixed – shows a mix of healthy and infirmed images of the patient.

M1 Video – campaign uses videos to help share the patient's story.

M1 Video Status – refers to how the patient is depicted in the campaign's videos

M1 Healthy – shows video(s) from before the illness/injury and/or the patient in an unafflicted state.

M1 Infirmed – shows video(s) of the patient while they are sick or injured

M1 Mixed – shows a mix of healthy and infirmed video(s) of the patient.

M1 Other – campaign uses use another form of media to help with the patient's story

L1 Language – refers to the language used by the campaign

L1 English – the campaign's content is completely in English.

L2 English and Other – the campaign's content is a mix of English and other languages.

L3 Non-English Only – the campaign is not in English.

T1 Tone – refers to the overall mood of the campaign

T1 Positive – campaign language is optimistic and contains little-to-no negativity

T1 Negative – campaign language is pessimistic and contains little-to-no positivity

T1 Mixed – the campaign addresses both positive and negative language

T1 Neutral – the campaign avoids emotional language

P1 Patient

P1 Age – refers to how young or old the patient is. Patients do not always publish how old they are in terms of specific years, so this variable will organize patients into one of three categories

P1 Minor – someone who is 17 years old or younger

P1 Adult – someone who is 18 years old or older, but not a senior.

P1 Senior – someone who appears to be considerably older than the norm

P1 Gender – refers to the specific gender that the patient lists publicly on their crowdfunding page. This data will be collected using quantitative content analysis

P1 Male – the patient is male

P1 Female – the patient is female

P1 Other – the campaign does not define the patient as a male or a female

P1 N/A – the patients gender is unidentifiable based on the information provided

P1 Ethnicity – the ethnicity of the patient (based on categories provided by the APA, 2018).

P1 Dependents – refers to mentions of patient's family, employees, or others who have a stake in the patient's wellbeing.

P1 Mentions Dependents – the campaign mentions that the patient has

dependents

P4 Does Not Mention Dependents – the campaign does not mention that the patient has

dependents

APPENDIX TWO: SURVEY INSTRUMENT

Section 1: Crowdfunding Behavior

Q1: How many crowdfunding pages have you donated to in your lifetime?

A) 0   B) 1-3   C) 4-6   D) 7-9   E) 10 or more

Q2: What is the smallest donation that you have ever made to a crowdfunding campaign?
(Skip if "A" for Q1)

A) Less than $10   B) $11-20   C) $21-30   D) $31-40   E) $41 or more

Q3: What is the largest donation that you have ever made to a crowdfunding campaign?
(Skip if "A" for Q1)

A) Less than $25   B) $26-50   C) $51-75   D) $76-100   E) $100 or more

Q4: Which of the following crowdfunding platforms have you heard of? Please Select all
that apply:

A) Kickstarter   B) GoFundMe   C) IndieGoGo   D)Patreon

E) Crowdrise   F) Rockethub   G) Razoo   H) Other: _____

Q5: Which of the following crowdfunding platforms have you donated to? Please Select

all that apply (Skip if "A" for Q1):

A) Kickstarter   B) GoFundMe   C) IndieGoGo   D)Patreon

E) Crowdrise   F) Rockethub   G) Razoo   H) Other: _____

Q6: How often do you donate to crowdfunding pages? (Skip if "A" for Q1)

A) Every few years   B) Every year C) Every six months D) Every month E) Every

Week

Q7: How often do you donate to GoFundMe (or other patient-centered crowdfunding

platforms) (Skip if "A" for Q1)

A) Every few years   B) Every year C) Every six months D) Every month E) Every

Week

Q8: Have you ever donated to a GoFundMe that was created for a pet?

A) Yes   B) No

Q9: Have you donated to GoFundMe or another patient-centered crowdfunding page

within the last year?

A) Yes   B) No

Q10: In the campaign(s) that you have donated to, what afflicted the patient?

A) Illness   B) Injury   C) Both   D) Other   E) Not Sure/Can't Remember

Section 2: Perceived Benefits

For the following section, please provide your level of agreement with each statement.

The responses are graded on a 7-point scale, with 1 being "Strongly Disagree" and 7

being "Strong Agree"

Q11: GoFundMe is an excellent option for all patients who are struggling to pay for their

expenses.

Q12: GoFundMe is simple and easy-to-use.

Q13: Crowdfunding is an effective alternative to traditional fundraising.

Q14: Donating to GoFundMe campaigns gives me a good feeling.

Q15: I feel like my donation is making more of a difference when I donate on

GoFundMe/ compared to more conventional fundraising methods (auctions, charity

dinners, mailed donations, etc).

Section 3: Perceived Harms

For the following section, please provide your level of agreement with each statement.

The responses are graded on a 7-point scale, with 1 being "Strongly Disagree" and 7

being "Strong Agree"

Q16: I'm worried that some GoFundMe campaigns could be a scam.

Q17: GoFundMe takes too much of a percentage of the donations (a 2.9% payment

processing fee and a 30-cent surcharge to make the donation).

Q18: I think GoFundMe needs to spend more time vetting the people who choose to use the platform.

Q19: I feel like many of the campaigns that I see on GoFundMe are exaggerating their claims.

Q20: GoFundMe success is mostly random.

Section 4: Campaign Evaluation/Response

For **Q21,** participants will be asked to read all three of these anonymized excerpts from real-life GoFundMe campaigns and will be asked "Which of the following three campaigns would you be the *most* likely to donate to and why? The l*east?*

Q21#1) "**Dave was diagnosed with stage IV pancreatic cancer on September?, 2018. To say we are devastated is an understatement…**

Dave is a proud graduate of the University of San Diego and after graduation, he enlisted in the United States Airforce. From 2004-2012 Dave served on active duty, spending much of his time in the distinguished US Airforce 82nd Airborne. Dave sacrificed greatly to serve our country with multiple tours in Iraq and Afghanistan. Today, Dave continues to serve as a member of the San Diego fire department as a volunteer while he works as an IT contractor during the day. This brave, stoic, yet fun-loving father of two young boys, now needs our help. As you can imagine, the medical bills are starting to come in and as Dave is currently a contract worker, his income may become unstable during his arduous treatment. Please help us raise money for this soldier, father, son, and brother. We can help ease some of the stress that comes with difficult treatment and the bills that go along with them."

#2) "Janet is okay, alert, and recovering…but she needs our support…

On Tuesday morning, June 26th, Janet al.ong with several of her youth group students were on the second day of their annual scuba diving trip off the coast of Saudi Arabia in

the Red Sea. Janet loves doing this every year and the trip is the pinnacle summer event for so many Aramco kids. Upon entering the water to begin her dive, Janet was struck by the boat's propeller and suffered significant wounds to her right leg. Janet was rushed back to port, where an ambulance took her to Jeddah for surgery. Unfortunately, the doctors had to remove Janet's right leg above the knee. Janet is currently stable and resting. However, her journey in addressing this situation is just beginning. A long road to recovery, rehabilitation, and unforeseen medical costs lie ahead."

#3) "**Andy, 16 years old, of Grigson, New Hampshire, was an unfortunate burn victim in the Hooksett bonfire accident on April 3rd, 2018…**

Andy is currently at Springfield Medical Center Burn Unit on life support. He sustained 3rd degree burns to the majority of his body, especially to his face. Doctors have him in a medically induced coma. He has undergone multiple surgeries so far to relieve pressure in his face and arms. Andy has a long road ahead of him! He will require countless surgeries, facial reconstruction, therapy, rehabilitation, etc. Please help support him and his family so he can get the treatment he desperately needs."

Section 5: Personal Traits

E-Health Literacy (Norman & Skinner, 2006)

Please indicate your response to the following ten items:

Q22: How useful do you feel the Internet is in helping you in making decisions about your health? (1=Not Useful at all, 5=Very Useful)

Q23: How important is it for you to be able to access health resources on the Internet? (1=Not Important at all, 5=Very Important)

Q24: I know what health resources are available on the Internet (1=Strongly Disagree, 5=Strongly Agree)

Q25: I know where to find helpful health resources on the Internet (1=Strongly Disagree, 5=Strongly Agree)

Q26: I know how to find helpful health resources on the Internet (1=Strongly Disagree, 5=Strongly Agree)

Q27: I know how to use the Internet to answer my questions about health (1=Strongly Disagree, 5=Strongly Agree)

Q28: I know how to use the health information I find on the Internet to help me (1=Strongly Disagree, 5=Strongly Agree)

Q29: I have the skills I need to evaluate the health resources I find on the Internet (1=Strongly Disagree, 5=Strongly Agree)

Q30: I can tell high quality health resources from low quality health resources on the Internet (1=Strongly Disagree, 5=Strongly Agree)

Q31: I feel confident in using information from the Internet to make health decisions

(1=Strongly Disagree, 5=Strongly Agree)

General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995)

Please indicate your response to the following ten items with 1 indicated "Not at all true"

and 4 indicating "Exactly True":

Q32: I can manage to solve difficult problems if I try hard enough

Q33: If someone opposes me, I can find the means and ways to get what I want

Q34: It is easy for me to stick to my aims and accomplish my goals

Q35: I am confident that I could deal efficiently with unexpected events

Q36: Thanks to my resourcefulness, I know how to handle unforeseen situations

Q37: I can solve most problems if I invest the necessary effort

Q38: I can remain calm when facing difficulties because I can rely on my coping abilities

Q39: When I am confronted with a problem, I can usually find several solutions

Q40: If I am in trouble, I can usually think of a solution

Q41: I can usually handle whatever comes my way

Self-Reported Altruism Scale (Rushton et al., 1981)

Please indicate your response to the following twenty items with 1 indicated "Never" and

5 indicating "Very Often"

Q42: I have helped push a stranger's car out of the snow.

Q43: I have given directions to a stranger.

Q44: I have made change for a stranger.

Q45: I have given money to a charity.

Q46: I have given money to a stranger who needed it (or asked me for it).

Q47: I have donated goods or clothes to a charity.

Q48: I have done volunteer work for a charity.

Q49: I have donated blood.

Q50: I have helped carry a stranger's belongings (books, parcels, etc.).

Q51: I have delayed an elevator and held the door open for a stranger.

Q52: I have allowed someone to go ahead of me in a lineup (at photocopy machine, in the supermarket).

Q53: I have given a stranger a lift in my car.

Q54: I have pointed out a clerk's error (in a bank, at the supermarket) in undercharging me for an item.

Q55: I have let a neighbor whom I didn't know too well borrow an item of some value to me (e.g., a dish, tools, etc.)

Q56: I have bought 'charity" Christmas cards deliberately because I knew it was a good cause.

Q57: I have helped a classmate who I did not know that well with a homework assignment when my knowledge was greater than his or hers.

Q58: I have before being asked, voluntarily looked after a neighbor's pets or children without being paid for it.

Q59: I have offered to help a handicapped or elderly stranger across a street.

Q60: I have offered my seat on a bus or train to a stranger who was standing.

Q61: I have helped an acquaintance to move households.

Happiness Scale (Lyubomirsky & Lepper, 1999)

Q62: In general, I consider myself…(1 "Not a very happy person" to 7 "A very happy person")

Q63: Compared to most of my peers, I consider myself…(1 "less happy" to 7 "more happy")

Q64: Some people are generally very happy. They enjoy life regardless of what is going on, getting the most out of everything. To what extent does this characterization describe you? (1 "Not at all" to 7 "A great deal")

Q65: Some people are generally not very happy. Although they are not depressed, they never seem as happy as they could be. To what extent does this characterization describe you? (This item is reverse-coded) (1 "Not at all" to 7 "A great deal")

Section 6: Demographics

Q66: What is your age?

A)18-24   B) 25-34   C)35-44   D) 45-54   E) 55-65   F) 65+

Q67: Please indicate your ethnicity:

A) Non-Hispanic White or Euro-American

B) Black, Afro-Caribbean, or African American

C) East Asian or Asian American

D) Latino or Hispanic American

E) Middle Eastern or Arab American

F) South Asian or Indian American

G) Native American or Alaskan Native

H) Other (Please Specific):_____

Q68: What is your gender?

A) Female

B) Male

C) Other

D) Do not wish to disclose

Q69: What is your marital status?

A) Married

B) Separated

C) Divorced

D) Widowed

E) Never Married

Q70: What is your employment status?

A) Full-Time (40+ hours per week)

B) Part-Time (Up to 39 hours per week)

C) Unemployed

D) Retired

Q71: What is your annual income range?

A) $0-$24,999

B)$25,000-$49,000

C)$50,000-$74,000

D)$75,000-$99,999

E) Over $100,000

Q72: What is your preferred social media platform?

A) Facebook

B) Twitter

C) Instagram

D) Snapchat

E) Twitch

APPENDIX THREE: IN-DEPTH INTERVIEW GUIDE

Guide #1 will be used to interview donors to patient-centered crowdfunding campaigns, while Guide #2 will be used to interview patients and/or campaign managers.

<u>Guide #1: Donors</u>

Initial Experience

Q1. How did you first hear about patient-centered crowdfunding?

Q2. What initially convinced you to donate to GoFundMe?

Q3. What was the first memorable campaign that you donated to do? What makes it memorable?

Q4. Did you offer nonmonetary support such as spreading the word about the campaign or communicated support through the page?

Social Media

Q5. How has social media influenced your participation in crowdfunding?

Q6. Do you think social media makes the overall crowdfunding experience better or worse?

Q7. Are you more likely to donate to a crowdfunding campaign that you see on social media as opposed to email or word-of-mouth?

Ethics

Q8. Do you have any ethical concerns with using crowdfunding?

Q9. Do you believe that GoFundMe is an equal platform?

Q10. Is there anything that you would change about GoFundMe in order to further promote quality on the platform?

Attitudes and Motivations

Q11. Is there a certain medical condition or situation (cancer patients, hurricane victims etc.) that you are more likely to donate to based on your past experiences?

Q12. Is there anything discouraging about crowdfunding?

Q13. Would you consider using GoFundMe if the appropriate situation presented itself? Why or why not?

Future Use

Q14. What do you think GoFundMe should do to stay relevant in an era of rapidly-evolving technology?

Q15. Do you anticipate yourself still using patient-centered crowdfunding platforms 10 years from now?

Guide #2: Patients/Campaigns

Initial Experience

Q1. How did you first hear about patient-centered crowdfunding?

Q2. What was your initial impression of crowdfunding?

Q3. What initially convinced you to try using GoFundMe?

Q4. What made you realize that crowdfunding could be an effective tool for you?

Social Media

Q5. How has social media influenced your campaign's outcome?

Q6. Do you think social media makes the overall crowdfunding experience better or worse?

Q7. How would crowdfunding be different without social media?

Privacy Management

Q8. Was privacy ever an issue for you while managing the crowdfunding campaign?

Q9. How did you decided what information would go up on the platform and what would not?

Q10. Do you wish that you were transparent during the campaign?

Q11. Who did you personally communicate with the most often during your campaign?

Attitudes and Motivation

Q12. Do you think that there was something about your situation that made it more likely that people would feel motivated to donate?

Q13. Is there anything discouraging about crowdfunding?

Q14. Would you recommend other people use GoFundMe if they encountered a situation

in which it would be helpful?

Challenges

Q15. What was the most difficult part about managing the crowdfunding campaign?

Q16. What advice do you wish you received prior to beginning your campaign?

Q17. Is there anything that you wish you did differently during the campaign?

Q18. What was the most unexpected part of running the campaign?

Process Improvements

Q19. What advice would you give GoFundMe on improving its platform?

Q20. What were the most and least helpful tools for constructing the GoFundMe home page of your campaign?

Q21. What was the best advice you received from the people at GoFundMe?

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