

Ethical Issues in Use of Crowdfunding to Finance Healthcare

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People are increasingly turning to crowdfunding to cover their medical expenses. Data from the most popular medical crowdfunding site, GoFundMe, indicate that there are over 250,000 campaigns launched per year to fund healthcare related costs and the annual dollars raised exceed \$650 million. The ethical issues associated with medical crowdfunding are numerous and have been well described, but much of the literature provides an index of the ethical concerns citing the need for a closer examination of the problems. This paper provides an in-depth discussion of three areas of particular concern, namely: justice issues related to crowdfunding for healthcare; the impact of medical crowdfunding on patient/provider relationships and the informed consent process; and the effect of crowdfunding beyond the clinical context including issues of privacy, crowdfunding for pediatric patients, and patient overall well-being. This paper concludes that the problems that crowdfunding presents in the context of healthcare are neither unique nor entirely the result of crowdfunding. However, further empirical research is needed that will serve as the foundation for a more extensive ethical analysis of crowdfunding for healthcare and prompt efforts to develop mitigation measures, guidance for those using crowdfunding, regulatory measures governing crowdfunding platforms, or policy regarding healthcare institutions' involvement in crowdfunding.

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Preface

I dedicate this project to my children, Cavan, Declan, and Nora.

1.0 Introduction

1.1 The Concept and Origins of Crowdfunding

Crowdfunding is a way for an entrepreneur to access capital to fund a business venture without employing traditional sources which typically pay some return to the funder (e.g., bank loans or stock offerings), by instead “financing projects or businesses with small contributions from large numbers” of contributors (Collins & Pierrakis, 2012). Currently it is described as “the practice of funding a project or venture by raising small amounts of money from a large number of people, typically via the Internet” (Calic, 2018). It utilizes the “easy accessibility of vast networks of people through social media and crowdfunding websites to bring investors and entrepreneurs together,” and expands “entrepreneurship by expanding the pool of investors beyond the traditional circle of owners, relatives, and venture capitalists” (Smith, 2021).

This “online crowdfunding,” or the use of internet sites to support the practice, began in the late 1990’s, but versions have existed for centuries. “Offline crowdfunding,” the collection of money from individuals through direct interaction, has roots dating back to the seventeenth century (Gras, 2017). Some of the earliest known crowdfunding requests were in music and the arts. Beethoven and Mozart raised money through subscription services to fund performances. France used a version of crowdfunding to pay for the Statue of Liberty: it raised money for the statue project through entertainment, sales of miniature figurines, auctions, and informational meetings and rallies (Neiss, 2013). In more recent times, the practice has been used predominantly in the commercial sector (Freedman & Nutting, 2015), though in the 20th century, noncommercial

“offline” crowdfunding remained common in the form of bake sales, basket raffles, or spaghetti dinners to raise money within a community for a needy person or cause.

The first recorded instance of online crowdfunding occurred in 1997, when a British rock band financed a reunion tour through online donations from fans (*The History of Crowdfunding*, n.d.). The first dedicated crowdfunding platform was created in 2000 (*The History of Crowdfunding*, n.d.). In the two decades since then, online campaigns have diversified, yet still reflect a range of requests for support of music, arts, and entrepreneurial ventures, as well as requests that tap funders’ altruism or charity for a good cause. Campaigns exist for a mind-boggling array of requests: to launch new flavors of ice cream, pay for a wedding, rebuild after a home fire, and access healthcare.

The global crowdfunding market is growing, with North America and Asia being the largest markets in 2021 (Statista Research Department, 2021). As of 2020, the crowdfunding volume in the United States and Canada was 62.05 billion dollars (Statista Research Department, 2021). As of 2019, there were 2,729 crowdfunding platforms worldwide, with 1,606 operating in the United States (Volna, 2019). There is evidence that an economic recession fuels the use of crowdfunding as businesses and individuals seek to circumvent banks for loans. As of 2020, worldwide, the average amount raised by a successful crowdfunding campaign was roughly \$30,000 (Shepard, 2020). Year over year, the amount of money raised per crowdfunding campaign increases with growth expected to continue at a 25% annual rate (Simon, 2016; Snyder, 2016; Snyder et al., 2016).

1.2 Crowdfunding for Healthcare

Crowdfunding is increasingly used in the domain of medicine, medical research, and healthcare (Moran, 2017), where it is “donation based,” meaning there is no tangible return to the donor, whereas commercial crowdfunding typically returns a good or money to the donor (Belleflamme, 2010). Donation-based crowdfunding is completely charitable with only intangible returns to the donor in the form of a sense of altruism and regular updates on the health status or progress of the patient. Appeals may be from individuals seeking funding (for themselves or on behalf of the patient), or from a group or cause such as collaborating scientists, research organizations, or advocacy groups seeking support for investigative projects. This paper will focus primarily on appeals from individuals for funds to support access to healthcare.

Crowdfunding is a well-established and growing practice used by an increasing number of people in the United States and around the world to finance their healthcare needs (McClanahan, 2018). Given rapidly rising costs of healthcare in the United States and the large portion of its GNP that is expended on healthcare (Elflein, [2020](#)), it is not surprising that Americans would turn to crowdfunding to finance their healthcare needs.

About 500,000 Americans declare bankruptcy each year due to medical bills, as well as lost income due to illness (Sanger-Katz, 2019). In fact, medical expenses are the leading cause of bankruptcy in the United States, according to a study indicating that roughly 62% of personal bankruptcies in 2007 were reportedly due to medical bills, even though most of those people had insurance. This was an increase from about 46% in 2001 (Sisler, 2012). According to the World Health Organization, health expenditure per capita increased in the United States by 146% between 2004-2014 (Bassani, 2018). Current estimates indicate that 30-40 percent of crowdfunding campaigns on major platforms are medical in nature (although on average only 11 percent meet

their funding goals) (Helhoski, 2015; Martinez, 2019). The top seven crowdfunding platforms are Kickstarter, Indiegogo, Causes, patreon, GoFundMe, CircleUp and LendingClub (Nguyen, 2021), while the most popular platforms for soliciting funds specifically for medical expenses are GiveForward, GoFundMe, Healthline, FundRazr and StartACure (Fuscaldò, 2016).

In countries with publicly funded healthcare systems, crowdfunding campaigns generally aim to finance treatments outside of or beyond the national healthcare benefits. For example, a cancer patient may have her chemotherapy covered by a healthcare plan but will seek funds to cover the ancillary costs of the illness such as travel expenses, a wig purchase, or replacing lost income from time off work. However, in the United States, where healthcare coverage is not guaranteed for everyone, crowdfunding is used to cover some of the most basic healthcare needs. One report shows evidence of a “substitution effect” in the use of crowdfunding whereby crowdfunding campaigns are a direct substitute for healthcare insurance. The most successful crowdfunding campaigns exist in countries like the United States where healthcare expenditure is high, and public or state sponsored healthcare is low (Bassani, 2018).

1.3 Ethical Issues in Using Crowdfunding for Healthcare: Outline of the Argument

This paper will address three areas of ethical concern associated with crowdfunding for healthcare interventions. The first section will address considerations of fairness. It will discuss both the ways in which crowdfunding may be said to “level the playing field” in healthcare, and the several ways in which crowdfunding may be unfair. Crowdfunding will be shown both to redress, in part, pre-existing social inequities that are evident in healthcare and to create or exacerbate other injustices.

Then the paper will turn to the ways in which crowdfunding has implications in the context of clinical care. It may affect the informed consent process, especially the voluntariness of patients' consent, as well as the voluntariness of their continuation in treatment. It may also affect patients' ability to appreciate the risks disclosed to them by their healthcare providers. Crowdfunding also has effects on the patient-provider relationship more generally, and discussion of these effects will form the final portion of the paper's third section.

In the fourth section, the paper will address effects of crowdfunding beyond the clinical context. It will focus on patient privacy and aspects of patient well-being. It will include attention to issues regarding crowdfunding for children's healthcare, as well as effects on extended family. It also acknowledges that there are potential benefits to those who crowdfund, beyond the financial benefit, as well as perceived benefits enjoyed by donors. Also considered, however, is the potential for crowdfunding to be an unwelcome opportunity that may lead some campaigners to sacrifice things important to them, even beyond their privacy, such as dignity and their personal values.

This paper concludes that while the problems created or exacerbated by crowdfunding are not unique, they are worthy of examination so that they can be mitigated when possible and so that participants are at least aware of them prior to engaging in crowdfunding.

2.0 The Justice and Fairness of Crowdfunding for Healthcare

2.1 Introduction

Crowdfunding is often hailed as a great equalizer, a universally available platform that allows all people the opportunity to appeal for and access funding for their needs (DeLuca, 2019; Vishwanathan, 2018), be it for healthcare or other essential needs. Crowdfunding is championed for providing an opportunity for donors to demonstrate their goodwill and altruism, while enabling those seeking funding to get what they need and cannot otherwise obtain (DeLuca, 2019).

Crowdfunding may indeed be a relatively quick, convenient, and transparent way to seek financial assistance to pay for unforeseen and pressing medical expenses. It also affords a way to build a virtual community of support to accompany patients as they go through a health-related struggle. However, even the most seemingly straightforward appeals to fund a standard healthcare intervention raise several questions about the justice of crowdfunding for healthcare.

One set of issues focuses on justice considerations regarding choosing to use—or having to resort to using—crowdfunding. These issues engage with the macro-level questions of whether societies have an obligation to provide at least basic healthcare to their members, to ask whether it is ethically appropriate as a matter of social or distributive justice that people must turn to crowdfunding to have even their most basic healthcare needs met. In turn, there are concerns about the impact crowdfunding may have on support for meaningful, comprehensive healthcare reform.

A second set of issues center on the process of crowdfunding for healthcare and the fairness of advantages some people and their appeals may have in the crowdfunding domain. The related

concern here is how differential success in crowdfunding perpetuates existing social injustices and possibly exacerbates already existing healthcare inequities.

2.2 A Social Obligation to Provide Healthcare Necessary for Fair Equality of Opportunity

In societies with universal healthcare, crowdfunding is primarily used to fund ancillary healthcare costs, such as travel to clinics or supplementing lost wages due to illness, because essential medical interventions are provided by the healthcare system. However, in countries without universal or publicly funded healthcare coverage, and particularly in the US, crowdfunding appeals are increasingly used by those who lack health insurance—including those who “fall through the cracks” by virtue of not qualifying for Medicaid and yet not being able to afford health insurance (and/or not working for employers that provide health insurance) and those who choose not to purchase insurance as well as those for whom Medicaid or their health insurance plan provides inadequate coverage to meet their healthcare needs. Indeed, “the number of successfully funded health projects is higher” on crowdfunding platforms based in countries where “financial resources allocated to health are high, but at the same time where the public health coverage is lower” (Bassani, 2018).

The use of crowdfunding for healthcare is thus related to the structure and adequacy of funding for healthcare in societies, which in turn are based on how societies address three “focal questions” posed by Norman Daniels:

(1) Is health, and therefore health care and other factors that affect health, of special moral importance? To answer this question, we need to see how meeting health needs is connected with other goals of justice. ...

(2) When are health inequalities unjust? To answer this question, we have to understand the factors and social policies that contribute to population health and health inequalities. ...

(3) How can we meet health needs fairly under resource constraints? Since health is not the only important good we pursue ... [we must address] disagreements about priority setting (Daniels, 2008, p. 11)

He considers these questions to more appropriately focus discussion of justice in healthcare than the question he attempted to address decades earlier: is there a right to healthcare?

Addressing these questions is not within the scope of this paper; however, this paper will assume that these questions are answered in a way consonant with the theory of justice embraced by Norman Daniels, who posed them as fundamental. It will assume that meeting health needs promotes health, and that health protects opportunity, and that therefore meeting health needs protects opportunity. It will assume with John Rawls's theory of justice as fairness, as well as other approaches to distributive justice, that justice requires protecting opportunity, and that therefore meeting health needs is morally required or at least has special moral importance (Daniels, 2008, p. 30). The analysis of this paper will assume, based on arguments by Daniels, that it is possible to distinguish health needs from mere preferences (including those that are mere preferences related to matters of health), and that it may be possible to give priority to some health needs over others based on the degree to which meeting or failing to meet them impinges on opportunity.

The sense of 'opportunity' at issue here is what Daniels defines as a normal opportunity range, the range or array of life plans that reasonable people are likely to develop in a particular society with its particular degree of wealth and technological development at a particular time period (Daniels, 2008, p. 43). Considerations of justice enter by asking whether society *should* be

arranged so as to provide its members with *fair* opportunity or a fair share of the society's normal opportunity range. Rawls, for example, argues that to be a fair, just society, its basic structure must be open to all of its members and work to the advantage of all. Daniels argues that healthcare should be included among the basic structures of society because of its effect on meeting health needs and, in turn, their effect on opportunity.

Rawls argues that if a society is justly structured, then the distribution of goods and life prospects resulting from its operation will be fair (i.e., the outcome of a fair process). Two fundamental principles elucidate what it means for the basic social structure to be open to all and work to the advantage of all. The first, the principle of fair equality of opportunity, seeks to correct for the moral arbitrariness of social and natural contingencies and their impact on people's life prospects (their access to a fair share of the society's normal opportunity range). Seeking to provide fair equality of opportunity requires that a society redress disadvantages or inequalities of opportunity that are the result of injustices or misfortune. The details—for example, whether only unjust disadvantage, or also underserved disadvantage, should be redressed—remain matters of ethical debate. For the purpose of this paper, however, it may be assumed that a just society must (at least to some degree) redress disadvantages that substantially impair individuals' fair equality of opportunity or their access to a fair share of the normal opportunity range. It is clear that healthcare serves this purpose.

The second principle of justice, the difference principle, will receive less attention here. It demands that the distribution of goods that result from individuals' exercise of their talents redound to the benefit of all, with priority given to those who are least well-off. Together these principles have a strong "tendency to[ward] equality" (Rawls, 1999, p. 86-93), in particular equality of opportunity, not equality of material outcome. Healthcare can only strive, within

scientific and technological constraints, to ensure fair equality of opportunity, not equality of outcome.

2.3 The Use of Crowdfunding in the Absence of a Just Healthcare System

If the arguments sketched here are accepted—i.e., if health needs and healthcare are morally important, and society has an obligation to provide healthcare to help ensure fair equality of opportunity—then in the absence of a healthcare system that provides for those needs, it would seem that crowdfunding is a potentially justifiable attempt to obtain healthcare, restoration of health, and thus opportunity. When a society does not provide a structure of healthcare or health insurance that adequately meets the population’s health needs, crowdfunding might be viewed as an alternate means of meeting health needs. Absent an adequate, universal healthcare structure, crowdfunding may be thought to help level the playing field for healthcare seekers by providing a free, widely available platform to solicit funds. The platforms couple or coordinate individual initiative and charitable giving; charity is often relied upon to provide in the US what is provided by the state in other economically developed societies. On one hand crowdfunding appeals highlight the fundamental problem of inadequate access to basic healthcare. On the other hand, the success of crowdfunding appeals may have a negative impact on meaningful healthcare reform in two critical and related ways. First, it may dampen the urgency to push for such reform by acting as a “band-aid” to the system. Second, those in the best position to advocate for such reform (e.g., the educated, tech savvy, socially well-connected) are precisely those who are most successful in crowdfunding campaigns, which diminishes the incentive for them to become involved in advocating for fundamental healthcare reform.

The existence of a thriving healthcare crowdfunding industry serves to let policymakers “off the hook” and allows them and society to avoid responsibility for reforming healthcare and associated structures so that it is accessible to all. Policymakers and health economists may use the rate and magnitude of personal bankruptcies due to healthcare bills as a measure of the impact of healthcare costs on the economic health of a society. They may be misled regarding the magnitude of the problem because of the effect crowdfunding has on household finances. Crowdfunding initiatives have been found to reduce personal bankruptcy by nearly 4 percent as a result of the funds raised through crowdfunding sites; for example, it is estimated that for every \$1,207 raised on just one crowdfunding platform, GiveForward, approximately 1 bankruptcy is avoided (Burtch & Chan, 2019).

Avoiding financial ruin due to medical expenses is a good thing both for individuals and the economy; however, masking the truth about the economic impact and financial burden of health expenses on people and society in general may mitigate the perceived urgency of healthcare reform.

It is also interesting to consider whether healthcare institutions would suffer financially if crowdfunding were not employed by patients in need of medical care. Would this somehow dramatically affect their bottom line and prompt them to speak in support of healthcare reform? Or might the strain on systems such as Medicaid be even greater and force a course correction sooner rather than later? Similarly, it could be hypothesized that if the millions of people who currently utilize medical crowdfunding could not, there would be a noticeable increase in morbidity and mortality, which might also increase calls for healthcare reform. Admittedly, other persistent rates of (or increases in) morbidity and mortality—e.g., rates of maternal mortality among Black women, Black infant mortality, or reductions in estimated lifespan for White males—

have not led to increased support for the Affordable Care Act, which has simultaneously witnessed increased legal challenges and erosion of public support among some White voters in the US. Nevertheless, it might be reasonable to speculate that as very expensive and much desired interventions emerge (e.g., treatment for Alzheimer disease that costs \$56,000 per year, gene therapy for Sickle Cell disease, or CAR T cell immunotherapy for cancer), crowdfunding may be increasingly utilized by a wider range of US patients. Given the resistance to expanding Medicaid under the Affordable Care Act—e.g., the 2018 refusal by South Carolina that left nearly half a million residents without healthcare (Hiltzik, 2018)—it may take an increase in the number of insured, middle class people who are unable to afford medical care to increase support for a more adequate healthcare system in the US. If crowdfunding were not an option for them, debate about coverage for such expensive interventions—and even broader debate about more fundamental issues of healthcare reform and pricing of therapies—might ensue.

Indeed, those who are currently most successful at medical crowdfunding—namely, the affluent, educated, attractive, tech savvy and socially well connected—may also be best suited to advocate for real and meaningful healthcare reform that would benefit society overall. But their success may remove them from the pool of those advocating to their government representatives for healthcare reform. Affluent constituents are substantially better represented by the legislators in the US Senate than poorer constituents (Bartels, 2016; Carnes, 2014; The Economist, 2019). If members of a higher socioeconomic class both benefit from more robust health insurance plans and are more successful at crowdfunding than those in lower socioeconomic circles, healthcare reform may be a less pressing issue for them. If their beliefs and desires are mirrored by policymakers, then that healthcare reform may not be policymakers' most pressing issue either. In a survey asking people why they donate to crowdfunding campaigns, respondents rarely or never

sited the failings, shortcomings, or lack of a better healthcare system (Snyder et al., 2017a; Snyder et al., 2017b) which may suggest a lack of understanding or awareness of the systemic problem of meeting health needs.

Crowdfunding continues to address symptoms of systemic failure, putting out small fires here and there while never fully extinguishing the inferno. It cannot replace more comprehensive healthcare reform. Whether (or the degree to which) it hinders reform is perhaps largely a matter of speculation. That this advantages some patients over others in unfair ways, working to the benefit of those already privileged, is more clear and the focus of the next section.

2.4 The Fairness of Healthcare Crowdfunding

A well-documented concern with crowdfunding for healthcare is that due to a range of biases and existing inequities, the platform benefits some healthcare seekers more than others (Snyder, 2017b; Burtch & Chan, 2014). Biases on the part of potential donors gives some types of patients advantages over others. In addition, differences between patients may make them more or less successful in accessing crowdfunding platforms. Many of these differences parallel those that make it more difficult for patients to access healthcare outside of crowdfunding. These include economic, educational, linguistic, and even psychological differences (Petersen, 2017; Snyder, 2017b).

Launching a medical crowdfunding campaign requires skills and assets associated with being educated and affluent. In order to create a campaign for oneself or on behalf of another, one must be socially and technologically savvy. The campaigner must first have a level of understanding to know that crowdfunding exists as an option, and then have access to a computer

and internet service, both of which require resources, either to have access at home, or to have the time, funding for transportation, and adequate health to utilize publicly provided computer and internet services. Creating a campaign, however basic, requires a level of education and training to draft a persuasive message, navigate the sites, open an account on the platform, and manage the financial aspects of incoming donations.

Successful campaigns require an even greater skill set typically held by affluent people: marketing skills. These skills are valuable in writing the patient's narrative. A well-crafted narrative has a superior chance of attracting attention and donations. The ability to tell an engrossing story raises more money (Mesko, 2018; Mollick, 2014; Snyder, 2017b). Financially successful campaigns are also associated with frequent and detailed health and funding status updates including photos and information (Mollick, 2014). Opening, managing, and updating an account takes time, energy, and focus. In other words, all of the skills and assets required for and associated with successful crowdfunding campaigns and are also skills and assets associated with the socioeconomically advantaged (Burtch & Chan, 2019). One way to phrase it, if you are good at crowdfunding, to some extent, you are "already winning at life."

The fact that some people will have the educational and economic resources to mount a successful campaign while others lack the resources suggests that crowdfunding for healthcare may mirror rather than help to redress the economic disparities that lead many patients to need financial assistance and seek crowdfunding in the first place. In short, it could be argued that the demands of successful crowdfunding campaigns exacerbate, rather than remedy disparities in healthcare.

Indeed, some crowdfunding platforms acknowledge the systemic barriers that exist to launching a successful campaign. Some make an effort to assist fund seekers with improving their

campaigns. GoFundMe, for example, has a “happiness team” which is a corps of customer service representatives who occasionally contact users with ways to improve their stories (Heller, 2019). Moreover, healthcare institutions sometimes suggest crowdfunding to patients who need a procedure but cannot afford it (Vega, 2019), which itself presents some ethical concerns discussed in section 3.5.2.

In addition to their differences in being able to utilize crowdfunding technologies, patients differ in how appealing they are to the potential funders whom they want to reach. Not only economic capital and all of its concomitant advantages, but also the components of having social capital matter for successful crowdfunding for healthcare. The fact that those with greater social connections will fare better in appeals for financial assistance than those with fewer is not new. Even with traditional fundraising efforts (such as a bake sale to raise money for a school trip), the wider the social circle of the funding seeker, the better the chances of success. In some cases, the social capital of a funding seeker benefits others. Families with many social connections may be able to sell more baked goods, raise more money, and contribute more to the school bus that takes the entire class to the museum.

The internet and crowdfunding amplify the advantage of particular types of social capital. Patients or their surrogates who already have a social media presence can announce their crowdfunding campaign to hundreds or even thousands with the click of a button. The bigger the social circle and the louder the “megaphone,” the more successful a campaign will be. Those with powerful connections, wide networks, and friends with money will raise more funds than those without. All of this is by design. The goal of a crowdfunding platform is to reach as big an audience as possible, to extend beyond your own personal set of friends and family, and to actively engage strangers.

Further, as a social media platform, crowdfunding is a visual platform. Looks matter. Physically attractive seekers garner more attention and tend to be more successful. Young patients, cute patients, and White patients have the most successful campaigns and raise more money than unattractive, Black, or older patients (Bassani, 2018; Dressler, 2018; Snyder, 2016). Again, factors that advantage a person in real life also advantage them in crowdfunding for their healthcare. To the extent that these advantages reflect, for example, racism, sexism, antisemitism, anti-Muslim or anti-immigrant prejudices, crowdfunding is one more domain affected by social biases. To the extent that it is unfair for access to healthcare to be affected by these biases, it would seem that crowdfunding for healthcare “bakes in” and amplifies this unfairness.

The type of illness for which treatment is sought also plays a role in the success of a campaign. Donors are more likely to support patients with illnesses which are viewed as “faultless,” as opposed to those patients deemed “blameworthy” for their condition. Substance use disorder, conditions resulting from alcoholism or obesity, and other stigmatized illnesses are conditions for which it is more difficult to achieve fundraising goals (Zenone & Snyder, 2020). The bias reflected here relates to the second focal question that Daniels presents: when are health inequalities unjust? The bias against some health conditions on the part of prospective donors suggests that they fail “to understand the factors and social policies that contribute to population health and health inequalities” (Daniels, 2008, p. 11). Even conditions that seem to be mediated by lifestyle choice are at least partly the result of an “arbitrary natural lottery for talents and skills, including motivational traits such as determination and diligence” (Daniels, 2008, p. 53). “This natural lottery shapes our prospects in life *even assuming fair equality of opportunity*. We may deserve some credit for the way in which we develop and exercise our talents and skills, but do

not deserve (and are not responsible for) the results of the combined social and natural lotteries that contribute so much to our capabilities” (Daniels, 2008, p. 54-55, emphasis added).

Patients who are “born with” their condition—with a heritable, genetic condition—may be more sympathetic as they clearly cannot be responsible for their ill health; nevertheless, with increased use of prenatal testing and concern that patients’ parents may be blamed for choosing to have children with genetic conditions (Carlson, 2002; Holm, 2008), there may be an erosion of sympathy and support for these types of appeals. Moreover, as discussed in section 4.2, crowdfunding to access care for heritable conditions presents additional ethical concerns.

All of these factors serve as filters for the success of crowdfunding campaigns and serve to widen already existing disparities in healthcare. Those who come to crowdfunding to seek funds for healthcare because they lack resources (employment, insurance, or wealth) to afford what they need are again disadvantaged in competing for attention and crowdfunding dollars. This way of meeting basic health needs is not constrained by considerations of fairness and the requirement that only relevant factors be taken into account in distributing the means to access healthcare.

Finally, it must be considered whether crowdfunding platforms are better viewed as a space in which people can give gifts and be altruistic, and whether as a means of coordinating gift-giving, crowdfunding should not be susceptible to criticism for evidencing and exacerbating biases. It might be argued that criticizing healthcare crowdfunding platforms for technology-related barriers, social biases, and unfairness is tantamount to criticizing a family for throwing a big birthday party for their child and inviting a whole lot of people to bring gifts, but throwing the party at a difficult-to-access venue and promising minimal, if any, refreshments and entertainment. This line of reasoning would further claim that there is nothing wrong with (or unfair in) ignoring the invitation if one doesn’t find the child or family particularly appealing. While it may be ethically criticizable

to be racist, sexist, or otherwise “prejudiced”—consciously or subconsciously—in accepting or declining invitations to give, matters of social affiliation and gift-giving are generally not considered to be subject to demands of justice.

One could argue that crowdfunding is nothing more than a way for people to connect via a charity-based platform. Seekers can share their stories to the extent they are comfortable. Donors are free to give money as they see fit. This model may be acceptable when the stakes are purely commercial; however, the model becomes less appropriate when the stakes are health. The apparently benign charity model becomes less plausible when what is given is, in effect, fair equality of opportunity. When a donor’s choice of whether to support a crowdfunding campaign is both a matter of personal preference and part of a broader system of meeting health needs, then considerations of fairness would seem to apply. If healthcare crowdfunding is viewed as just another social media platform subject to “likes” and donations the way other sites operate, then considerations of justice and fairness may not apply. Donors choose who and what they want to fund based on their own preferences. But if healthcare crowdfunding is viewed as a meaningful resource that patients use to access healthcare in the absence of a fair and adequate healthcare system, then concern about the unjust inequalities it perpetuates is warranted.

3.0 Concerns about Crowdfunding's Effects in the Clinical Context

3.1 Introduction

A different set of ethical concerns is evident as the analysis moves to the clinical context from the broader social context, where crowdfunding reveals pre-existing concerns regarding justice and fairness. In the clinical sphere, crowdfunding may actually cause ethical concerns with respect to informed consent, patient privacy, and the patient-provider relationship. This section examines those concerns.

3.2 Informed Consent and the Patient-Provider Relationship

Informed consent in the clinical setting is the granting of permission by a patient to receive a treatment or participate in a clinical trial with knowledge of the associated risks and potential benefits. The process of informed consent is crucial for protecting patients and respecting and maintaining their autonomy, or right to self-govern, and make health-related decisions they believe are in their best interest. Obtaining informed consent before a medical procedure or before enrollment in a trial is an ethical and legal requirement.

Informed consent seeks to uphold patient autonomy. According to Ruth Faden and Tom Beauchamp, there are three conditions necessary for an action to be considered autonomous: “X acts autonomously only if X acts (1) intentionally, (2) with understanding and (3) without controlling influences” (Faden & Beauchamp, 1986, p. 238). They acknowledge that there are

limitations to human knowledge and therefore a consentor (or patient) does not have to fully satisfy 1, 2, and 3 to successfully give consent, but should do so within reason.

Using the requirements for an autonomous action, Faden and Beauchamp develop a concept of informed consent as autonomous authorization (Faden & Beauchamp, 1986, p. 277). They define informed consent in two senses. In sense1 “informed consent is given if a patient or subject with (1) substantial understanding and (2) in substantial absence of control by others (3) intentionally (4) authorizes a professional to do (I intervention)” (Faden & Beauchamp, 1986, p. 278). With this definition, they differentiate between an autonomous action, which satisfies conditions 1-3, and informed consent, which necessarily includes action 4. In contrast to informed consent they define informed refusal, whereby a person makes a decision satisfying conditions 1-3 but then elects to decline the treatment.

Faden and Beauchamp also describe a second type of informed consent, sense2, that considers the entire network “of cultural and policy rules and requirements of consent that collectively form the social practice of informed consent in institutional contexts where groups of patients and subjects must be treated in accordance with rules, policies, and standard practices” (Faden & Beauchamp, 1986, p. 277). Informed consent in this sense is not necessarily an autonomous act or an authorization, but rather the norm-governed practice that fulfills the legal or regulatory obligation of gaining informed consent. Elements of informed consent sense2, for example, may include requiring a witness to the process, the age requirement for consent, or mandatory waiting periods.

Informed consent is foundational to the ethical delivery of medical care. Therefore, it is important to consider whether and how crowdfunding to finance a treatment affects the informed consent process. As the next sections demonstrate, the fact that a patient has crowdfunded for her

treatment has a meaningful (and at times negative) impact on the elements of informed consent, namely 1) physician disclosure of risks and benefits and patient appreciation of risks and benefits and 2) the patient's voluntariness of decision making. The integrity of informed consent may be compromised in certain circumstances when a patient uses crowdfunding.

The backdrop of the informed consent process is the patient-provider relationship. It is the context in which informed consent for clinical care is obtained and is considered a fiduciary relationship. As discussed below, healthcare providers have a fiduciary duty to their patients to promote their health-related interests. The patient-provider relationship relies on trust and openness in order for patients to meet their goals for their health and to allow providers to fulfill their professional duties. Privacy of the relationship and of the patient's health-related information is a prerequisite for creating the trust and facilitating openness within the relationship. Crowdfunding disrupts this privacy, may introduce conflicting interests, and may generally disrupt the patient-provider relationship. It may also influence the informed consent process.

3.3 Crowdfunding's Effects on Informed Consent: Disclosure and Appreciation of Risks and Potential Benefits

The informed consent process consists of three behavioral steps: reception, comprehension, and utilization (Faden & Beauchamp, 1980). Reception consists of the patient actually obtaining the relevant information, comprehension implies the patient understands the information, and utilization involves the patient relying on that information to either give consent or withhold consent (Faden & Beauchamp, 1980).

Disclosure of the likely outcomes of a medical intervention satisfies the requirements for informed consent in sense2, as a norm-governed social practice. The patient must be informed orally or provided literature detailing the possible outcomes. In sense2, disclosure is the process or act of the information being delivered to the patient and the patient receiving it. This fulfills the legal and regulatory requirements for the institution and individual providing the care. Disclosure may be almost irrelevant to informed consent in sense1 (which focuses on the patient *understanding* the pertinent information) but it is a critical component, or first step, in moving towards gaining informed consent in sense2. The pertinent details regarding a treatment or procedure and the possible outcomes, including possible adverse events, as well as information about alternatives, must be made available to the patient and the patient's questions answered. Regardless of the medical intervention sought but especially for procedures that are new, particularly risky, or have meaningful or substantial risks, a thorough disclosure of information is crucial. A physician is legally and ethically obligated to provide this information. Failure to provide adequate disclosure disadvantages patients by robbing them of their ability to make an informed decision consonant with their values, preferences, and priorities, thereby impairing their ability to act autonomously.

Although crowdfunding may have a significant impact on disclosure only in rare circumstances (discussed below), it may more routinely affect the second of the behavioral steps in the informed consent process, namely understanding and appreciation of the risks and potential benefits of a procedure. First, while the symptoms of a health condition and the general psychological impact of being ill may diminish any patient's ability to comprehend or assimilate medical information, patients who are financially precarious may face additional distractions that impair their understanding and appreciation of information disclosed. Patients engage in

crowdfunding because they face financial pressures. Prolonged financial duress alongside an illness may compound the patients' problems, weakening their physical, mental, and emotional state and causing heightened anxiety. Sudden access to funds (or a pathway to receiving adequate funding) may come with a sense of relief and desire to move ahead regardless of the information presented during the disclosure process. In such cases, it isn't solely the crowdfunding that hinders a patient's ability to appreciate and weigh risks against potential benefits. Nevertheless, patients who have crowdfunded may be compromised in ways that the non-crowdfunding patient is not, making them more susceptible to overlooking possible negative outcomes.

Granted, provider disclosure is no longer the sole source of information about a procedure, if it ever was, for any patient. Information about health conditions and treatments is available from family, friends, and various media, particularly websites. Patients who obtain information to initiate a crowdfunding campaign, however, not only will have obtained information, but will have committed to it, perhaps to a greater degree than patients who simply do their own research on their conditions. Indeed, crowdfunding patients *publicly* commit to an account of their condition and its treatment. If that information is inaccurate, it may be especially difficult for a physician to correct their misunderstanding. The disclosure may create cognitive dissonance between what the patient has come to believe and what the provider is presenting. Further, whereas the understanding component requires the patient have an intellectual understanding of the facts surrounding the proposed intervention, appreciation requires the patient to recognize that those facts apply to her. When crowdfunding, the patient may have publicly presented (and personally come to believe) the most favorable version of the risks and potential benefits of the interventions being funded. Thus, pursuing crowdfunding may influence the patient's ability to appreciate that an intervention's risks and potential benefits really do apply to her circumstances.

Moreover, crowdfunding may have a direct impact on the disclosure component of informed consent in relatively rare cases. Consider, for example, Stem Cell Therapy (SCT). SCT is very lucrative for institutions to provide (Szabo, 2019), but it remains largely unproven (Vox, 2018). SCT carries with it credible risk (Marks, 2017; Rettner, 2017). Because it is expensive and not covered by insurance, crowdfunding is often used to access it (Vox, 2018). SCT is also a trendy therapy that claims, through direct marketing to patient-consumers, to work where traditional interventions have failed, and many patients come to their providers armed with assumptions about the treatment bolstered by the direct marketing campaigns that have sprung up to promote the practice (Turner, 2018). If a physician is financially incentivized to administer SCT because it improves the hospital's bottom line or reputation as an institution providing cutting edge therapies, it is conceivable that providers might downplay risks and overplay the potential benefits of SCT.

Further, in the case of SCT or other unproven or experimental treatments for which patients use crowdfunding, if patients arrive with both their minds largely "already made up" and the ability to pay, they may not ask questions or assimilate as adequately the information that is provided. Studies have shown that subjects seeking to participate in clinical research have trouble appreciating the implications for their care and that most patients fail to fully grasp all of the possible risks associated with participating in a clinical trial for an unproven treatment (Lidz, 2004). Failure to appreciate the unproven status and potential consequences of receiving an intervention may seriously undermine the informed consent process. Insofar as crowdfunding aids a patient in accessing an experimental intervention (by providing funds where insurance will not), it further exposes patients to circumstances in which appreciating information disclosed is the most difficult. In the same way that crowdfunding exacerbates existing inequities in healthcare, crowdfunding seems to exacerbate the challenge of ensuring that physically, emotionally, and

financially precarious people have an understanding and appreciation of the risks and benefits of a particular treatment.

3.4 Crowdfunding's Effects on Informed Consent: Voluntariness of the Decision

The third and final step of the informed consent process is *utilization* which involves patients relying on their understanding of the information provided to either give consent or withhold consent (Faden & Beauchamp, 1980). A goal of informed consent is to promote autonomous decision making by a patient. In order to meet the standards of informed consent, patients must make their decisions absent undue internal or external pressure or outside influences. They must also feel they have the right and ability to change their minds based on gaining new information or changing circumstances, or to honor their own wishes and values. The use of crowdfunding to access healthcare may result in undue pressures affecting this perception, as well as their original informed consent.

Crowdfunding effectively brings a third party into the typically dyadic patient-provider (or patient-healthcare team) relationship; the third party is the scores of friends and strangers who contribute to the campaign (Renwick, 2017). A relationship, certainly perceived and to some extent real, forms between the campaigner and those who donate. The relationship is developed through comments, suggestions, or feedback from visitors to the site. Crowdfunding for commercial ventures creates a sense of connection between seeker and funder that fosters “openness and accountability” on the part of the seeker (Perlstein, 2013), while funders may become emotionally invested in the success of both the campaign and the venture itself. In medical crowdfunding, similar effects present serious ethical concerns.

A crowdfunding campaign is a public event. A particularly heart-wrenching campaign may even make the evening news. Donors are interested in what happens. They are waiting and watching. A patient may feel substantial pressure to not back out or change her mind out of a desire to not disappoint the donor pool. A patient may come to feel accountable to donors or even a broader public, and this sense of accountability may lead them to discount or override their own wishes and values when the time to give informed consent arrives.

Involvement in the crowdfunding campaign may impair a person's ability to develop more authentic treatment-related preferences in light of her own values because donors have contributed in support of a particular treatment plan. Though authenticity is not a requirement of an acceptable informed consent decision (Faden & Beauchamp, 1986, p. 237-239), pursuing a treatment plan for the sake of others' preferences is ethically problematic unless one's own interests include the interests of those others (as when a patient undergoes treatment because his spouse wants him to). Donors and the patient may have a *shared* interest—the patient's health—but the donors' interests or well-being are not *even partly constitutive of* the patient's well-being.

While a patient may feel pressure to proceed as planned to avoid *feeling* like a fraud, a patient may also have justified concerns about committing fraud or appearing to do so. Because donated funds typically cannot be returned, patients who opt out of the planned treatment are stuck with money obtained under what turns out to be “false pretenses,” even though they were not sought under false pretenses (Zenone, 2019). They may be accused of fraud, if not officially, legally accused, at least called out for making fraudulent appeals (Zenone, 2019). On top of the loss of privacy and any damage to reputation the patient incurred by initially disclosing her illness, the patient now risks publicly jeopardizing her reputation for integrity. These are all ways that the

existence of donors can, quite unintentionally, exert undue influence on a patient's medical decision (Moore, 2018).

Furthermore, the initiator of a crowdfunding campaign may not be the patient but rather an agent—typically a family member or friend—acting on behalf of (and even occasionally without the consent of) the patient. Of course, it is not unusual for family to play an important role in decision making for a patient. Trusted relatives can support a very ill patient and help to maintain or communicate a patient's identity and wishes. Families may also pressure a patient to undergo a therapy against her wishes, and patients may accede to these pressures quite justifiably so long as they consider furthering the interests and well-being of the pressuring family members to be among their own interests. A family member's initiating crowdfunding, however, introduces an additional reason that patients may experience familial pressure to pursue treatment. Moreover, this may be *internalized* pressure, not actual pressure by family members.

A patient may not feel she has the ability to change her mind about a treatment for fear of disappointing the family member or friend. By investing time and effort into launching the campaign, the campaign initiator creates her own personal stake in the campaign. The initiator also develops an interest in providing informative updates and photos to keep the donations coming in. A patient's changing her mind would derail the narrative. The family's or agent's vested interest in the patient's health, and thus medical decision making, constitutes an additional source of pressure that may undermine patient autonomy, either because the initiator actually exerts pressure, or because the patient feels internal pressure to make good on the initiator's investment of time, effort, and emotion.

In addition, a healthcare crowdfunding campaign may introduce competing interests into the family dynamics that typically surround patient decision making. The cost of their care may

lead patients to agree to participate in crowdfunding to reduce the financial strain their illness places on others. They may subsequently feel they must continue on the path to planned treatment due to the monetary and nonmonetary “sunk costs” of both early stages of healthcare and the crowdfunding campaign itself. On the other hand, forgoing treatment for which crowdfunded funds were raised presents a slightly different set of issues for patient and family. The funds raised would still benefit a family financially: the funds would be available to be used in a different way. While using the funds for other purposes may present a risk to both the patient’s and family’s reputation, the possibility of leaving one’s family with a nest egg may conceivably prompt a patient to forgo treatment she would otherwise want to have.

In addition, a family member may initiate the crowdfunding campaign without the patient’s consent or contrary to the patient’s wishes as a way of mitigating the expense of the patient’s healthcare *for the sake of the family’s* financial well-being. While typically the patient’s and the family’s financial well-being (and indeed overall well-being) will be interconnected, in at least some cases, those interests may diverge. In such cases, the family or family member that initiates the crowdfunding campaign may be using the patient, her condition, and her narrative to benefit financially (or at least mitigate financial losses). It is also conceivable that some family members may initiate a campaign primarily to reap psychosocial benefits from doing so. What effect these conflicting interests may have on the patient’s decision making is not clear.

Families’ interests coupled with crowdfunding may thus influence patients’ decisions in either direction: to consent to or refuse—or continue with or discontinue—a treatment plan. Familial pressures and financial pressures on patient decision making are not new; their coupling through the medium of crowdfunding, however, seems to intensify their potentially negative impact on patients’ decisions. Crowdfunding can literally create a larger pot of financial resources

that are at stake (i.e., that could be repurposed if the patient forgoes treatment). The public nature of crowdfunding spreads the reputational risks of wanting to change course beyond the patient to the family, which may lead to actual or internalized familial pressure to stay the course out of concern for reputation, not the patient's health.

Finally, crowdfunding platforms themselves have some indirect influence on patients' decision making. Crowdfunding platforms are for-profit enterprises. The relationship of the platform to the patient is purely transactional. The platform financially benefits from a successful campaign by taking a percentage of each transaction and collecting fees per donation and processing fees (Agrawal, 2014). The better the appeal, the more money made by the platform. Therefore, it is in a site's interest to host and promote a popular campaign. "Happiness teams" are provided by the platforms to assist campaigners in improving their crusade under the guise of an altruistic customer service. In fact, the goal is to increase traffic and donations. A platform may facilitate a campaign's going viral by making its own donation and increasing visibility. This can drive attention and funds to a patient's cause, increasing the site's profit shares while potentially increasing a patient's feeling of obligation to proceed with the treatment as publicly stated, even if she experiences a change of mind.

The decision to proceed with or decline medical care is normally made by the patient taking into account the advice of the healthcare provider and often in concert with other trusted individuals. Ideally, the patient feels free to act according to her wishes without undue pressure or the need to provide explanations to others beyond those whom the patient chooses to include in the decision making process. Crowdfunding necessarily injects other parties and influences into this process making it difficult for the patient to act based solely on her own values and preferences. The public statement of one's plans, the agent who launched the campaign, donors, the platform

itself, the desire to save face, the need to protect one's reputation and integrity all may erode the patient's self-determination in decision making. Although clinicians are trained to assess the patients' decisional capacity and the voluntariness of their consent to help ensure their decisions are free of manipulation or undue influence, they may be ill-equipped to ensure a patient who has crowdfunded is not being unduly influenced by internalized pressures resulting from the crowdfunding process or manipulated by the initiator of a campaign (Kubheka, 2020).

3.5 Crowdfunding's Effects on the Fiduciary Nature of the Patient-Provider Relationship

Beyond its effects on components of the informed consent process and patients' decisions to pursue and continue treatment, crowdfunding may have negative effects on the patient-provider relationship. It may impose unwelcome burdens on clinicians, undermine trust between patients and clinicians, and imperil the fiduciary nature of the patient-provider relationship. Crowdfunding can also spark interpersonal conflict within the relationship that can erupt into the public sphere.

3.5.1 Crowdfunding's Imposition of Burden, Risk, and Potential Conflict

Successful crowdfunding campaigns require posting frequent status updates on a patient's condition. A crowdfunding patient's clinician may be faced with burdensome requests to participate in the effort by providing regular clinical updates to be posted online (Young, 2017). Such requests may be burdensome in several ways. First, providing frequent clinical updates (presumably in layperson's language appropriate for posting) can be time consuming, which in turn may raise questions regarding the fair and equal treatment of patients. Particularly if the

demands on clinicians of providing information for crowdfunding are greater than the demands made by insurers to process claims, crowdfunding may unfairly divert clinicians' time and attention from other patients' care. It may be ethically problematic for one patient to demand a greater share of the physician's time or staff resources to update a webpage and serve the patient's financial interests. Crowdfunding patients who are unable to obtain all the information and updates they want from their clinicians to promote their campaigns may experience mounting dissatisfaction that erodes their patient-provider relationship. Similarly, crowdfunding has been shown to cause strain in the patient-provider relationship particularly if the appeal is for a treatment that is not considered medically necessary or appropriate (Moore, 2018).

Second, in order to create the most compelling, attractive, and creative crowdfunding request, patients may want to name their treating doctor and use photos on their pages. A crowdfunding campaign gives a level of publicity to a patient, to the treatment sought, and potentially to the providing physician, which may introduce conflicting interests if the physician is concerned about her professional reputation, particularly if a disagreement arises between the parties. A physician (or healthcare institution) may also be concerned about negative publicity if a patient's condition worsens, or a patient dies.

While patients need not seek consent from a provider or healthcare institution to launch a campaign, seeking consent from their provider before subjecting the provider to unwelcome publicity might be ethically appropriate and practically advisable to avoid causing a rift between patient and provider. The public sharing of patient information is contrary to the ethos of privacy of the patient-provider relationship, and being asked to participate directly in a crowdfunding patient's appeal may place them at odds with institutional policies. Though there is no breach of privacy on a clinician's part when the patient permits or requests that the clinician share

information, clinicians may nevertheless find it uncomfortable to do so. They may justifiably worry that their being seen to share one patient's information may lead other patients to worry about the privacy of their information.

On the other hand, a clinician or healthcare institution may be placed at an ethical and legal disadvantage if a conflict arises between them and a crowdfunding patient, and the patient does not grant permission to discuss her case. The well-known and extensively analyzed case of a young patient in the United Kingdom named Charlie Gard illustrates this concern (Cave, 2018; Dressler, 2018; Kubheka, 2020). The family of Charlie Gard raised \$1.2 million dollars to fund an experimental treatment for his rare mitochondrial DNA condition. When Gard's physician in the UK deemed the experimental treatment inappropriate for his patient, because it was unlikely to be effective, he was placed in the position of defending his determination publicly, while not being at liberty to discuss details of his patient's condition due to the constraints of confidentiality and the patient-provider relationship.

Third, a clinician may be pressed to "manufacture" news for the sake of the campaign during periods when there is no change in a patient's status worth reporting to maintain donor interest. Or patients may be less than truthful in describing their condition and clinical care, thereby placing their clinicians in a difficult position if the campaigns receive media attention and clinicians are publicly pressed for comment. Moreover, clinicians have an interest in medicoscientific truth and in avoiding being used in a campaign involving a false narrative aimed at deceiving donors. If a clinician realizes a patient is using false or misleading medical information in a crowdfunding appeal, the clinician may then face a conflict between maintaining a therapeutic alliance and a "perceived obligation to society to prevent dishonest crowdfunding efforts" (Young, 2017). Crowdfunding may interject a conflict between the obligation of the physician to her

particular patient and the obligation to maintain the trustworthiness of the medical profession for the good of society and other patients (Young, 2017).

3.5.2 Crowdfunding's Effect on the Fiduciary Nature of the Patient-Provider Relationship

The relationship between healthcare providers and their patients is a quintessential fiduciary relationship. As the American Medical Association states:

“The practice of medicine, and its embodiment in the clinical encounter between a patient and a physician, is fundamentally a moral activity that arises from the imperative to care for patients and to alleviate suffering. The relationship between a patient and a physician is based on trust, which gives rise to physicians’ ethical responsibility to place patients’ welfare above the physician’s own self-interest or obligations to others, to use sound medical judgment on patients’ behalf, and to advocate for their patients’ welfare. A patient-physician relationship exists when a physician serves a patient’s medical needs. Generally, the relationship is entered into by mutual consent between physician and patient (or surrogate)” (American Medical Association, n.d.).

The healthcare professional has a duty, a fiduciary duty, to use her professional judgment on behalf of the patient or in service of the patient’s health-related interests, and not to sacrifice or trade-off that primary interest in the patient’s well-being for the sake of secondary interests such as profit, reputation, or the benefit of third parties. To receive the benefit of the professional’s judgment, the patient must place her trust in the professional.

The patient-provider relationship has practical, material benefits for the patient. The relationship is foundational to the success of the care provided. Trust is an essential component.

Patients with high trust in their healthcare providers have been found to adhere better to treatment protocols (Brion, 2014) and to have improved outcomes (Murray, 2014). Fostering the connection between a patient and physician helps to ensure that the physician discharges her professional duty with respect to patient needs and desires, promotes patient autonomy and well-being by facilitating patients' sharing of their values and preferences, and provides an atmosphere conducive to realizing informed consent. Tension or discord between patient and physician may jeopardize the relationship, and place patient care at risk. As just discussed, when patients initiate crowdfunding, this can impose burdens on clinicians and increase the risk of conflict within the patient-provider relationship. Crowdfunding can also introduce conflicting interests that threaten the fiduciary relationship between provider and patient. This can occur when the public nature of the campaign intensifies the clinician's concern for her reputation (or the reputation of the institution).

Conflicting interests are also introduced when crowdfunding is suggested to patients or their families by the treating healthcare professional or institution providing care (Pol, 2019). This phenomenon is most commonly seen in hospitals performing transplant surgery (Johnson, 2018; Keshner, 2018; Pol, 2019). Transplant surgery is normally covered by health insurance or Medicaid, but still carries substantial costs for anti-rejection medications and ancillary expenses (like travel to transplant centers for evaluation and follow-up care). Among the numerous criteria that must be satisfied to qualify for transplantation is proof of the patient's ability to pay for the ongoing cost of the medications which will support the new organ. Crowdfunding may be pursued to support those costs, and some institutions suggest its use and even provide marketing infrastructure or personnel (often a social worker) to assist patients and families in their campaigns (Pol, 2019).

On one hand, taking steps to help a patient fund a medical procedure may be materially beneficial to the patient and an ethically welcome step toward a more holistic view of patient well-being. Because the patient-provider relationship relies on trust, the suggestion of crowdfunding to fund transplant surgery may be seen by the patient as an act of caring and trustworthiness and may strengthen the relationship. Patients who were not previously aware of the option of crowdfunding may gain a sense of hope or feel they have a path to alleviating the financial burden of treatment. Indeed, it is likely that the institutions which offer crowdfunding assistance see it as a service to their patients. Most importantly, crowdfunding may benefit a patient by enabling access to needed healthcare; suggesting it may be in the patient's interest.

On the other hand, initiating and supporting crowdfunding efforts may introduce into the relationship the institution's and provider's conflicting interests. Being a high-volume transplantation center is good for an institution's reputation and bottom line. Increased volume of transplantation is in the interest of both centers and their surgeons. Recognizing what the institution and provider stand to gain from having the patient undergo transplant surgery may justifiably lead patients and their families to question whether the transplant team and institution always have the patients' best interests adequately in mind. Moreover, resources expended in support of patient crowdfunding campaigns—for example, to support marketing services—may be drawn from other cost center activities (e.g., nursing or social work), which demonstrates how crowdfunding is both conducive to and yet undermining of patient interests.

It is reasonable to speculate that patients may worry that rebuffing an institution's or provider's offer to partner in crowdfunding could be viewed as a lack of commitment to being a transplant candidate, which would be detrimental to their evaluation as candidates. They might worry that preference may be given to patients who agree to crowdfund. Transplantation is a

healthcare context in which patients specifically compete for a scarce resource to a far greater degree than other contexts in which patients compete, for example, for physicians' and nurses' time and attention, coveted appointment times, or even a limited pool of "charity care" resources. Moreover, those patients who do collaborate with the institution in crowdfunding for their care undoubtedly develop some points of relationship that those who don't crowdfund do not. The transplant team may become more invested in the patient's success both in crowdfunding and in surgical recovery and rehabilitation.

Another therapy that is popular for crowdfunding is Stem Cell Therapy (SCT), whose efficacy is not yet established (Vox, 2018), yet it is available at reputable institutions and promoted as a treatment for a wide variety of conditions. The Mayo Clinic website, for example, states: "People who might benefit from stem cell therapies include those with spinal cord injuries, type 1 diabetes, Parkinson's disease, amyotrophic lateral sclerosis, Alzheimer's disease, heart disease, stroke, burns, cancer and osteoarthritis" (Mayo Clinic Staff, n.d.). Some uses of SCT are marketed directly to potential consumers (Turner, 2018). Because SCT is not an FDA approved treatment, it is not covered by health insurance. Patients must pay for SCT out of pocket with price tags averaging \$5,000-\$8,000. Crowdfunding campaigns for SCT have sought and raised millions of dollars (Vox, 2018).

SCT thus presents the characteristics of classic conflict of interest. The therapy itself is unproven so its indications and guidelines for use are unclear. Without needing to negotiate with insurers to set the level of reimbursement for SCT, institutions can set its cost where the market (patients) will bear it. Crowdfunding enables patients to afford a higher cost than they would otherwise be able to. Offering a cutting-edge therapy is beneficial to the institution's reputation, and providing SCT as a high-volume service (not through a limited-volume, research protocol)

could be highly remunerative. It is reasonable to consider an institution offering SCT to face a conflict of interest and to be risking the patient's well-being for the sake of its profit and reputation. The physician offering SCT may face a conflict of interest—whether to act in the patient's health-related interest or to act in the institution's financial interest (and her own interest in preserving favorable terms of employment) (Loewenstein, 2011). Though crowdfunding does not create these conflicts of interest, it facilitates the possibility of patients actually becoming a source of financial gain in the context of an especially uncertain health benefit and makes the possible conflict of interest real (Loewenstein, 2012). Recognizing the conflict of interest may erode patients' trust of their physicians and the information they disclose, though in reality, patients tend to continue to trust their own physicians even when made aware of the physicians' conflicting interests (Loewenstein, 2011). Recognition of conflicts of interest does erode the public's trust in the medical profession and healthcare institutions.

Because crowdfunding enables patients to access an unproven therapy that they might not normally be able to obtain, it may fuel disagreements within the patient-provider relationship if a physician does not want to recommend an unproven therapy like SCT. Patient-provider disagreements are not unique to crowdfunded treatments, but crowdfunding may not only make some points of disagreement practically possible (i.e., without crowdfunding, the patient might not be able to seek SCT at all) but may also place the physician in additional difficult positions. Because SCT is not established as effective but also not prohibited, when a patient involves a physician in crowdfunding for SCT, the professional must balance publicly acknowledging the availability of the therapy—and potentially lending credibility to its claimed benefit—while appropriately counseling the patient about its risks and protecting her own professional reputation. Especially if the patient is forgoing a treatment deemed effective in order to try SCT, the physician

and the patient-provider relationship may experience particular conflicts. If a healthcare professional recommends against using SCT, the patient may feel abandoned by their provider. If the provider declines to offer or facilitate the treatment, the therapeutic relationship may be ended. Again, these conflicts and sequelae are not unique to or created by crowdfunding, but crowdfunding may enable them to arise where they would not in its absence.

Which party initiates crowdfunding—whether it is the patient (or patient’s family) or instead the provider or institution—affects the specific impact of crowdfunding on the patient-provider relationship. When it is introduced by the institution or provider, patients may feel their care (both the literal delivery of the healthcare and the caring attention of the doctor) is attached to their agreement to crowdfund. Patients do not always welcome the suggestion of crowdfunding. Moreover, the conflict of interest on the part of the institution that stands to benefit from a successful campaign, and the underscoring of how the provider’s loyalties may be divided between her employer and the patient, may be disruptive to the relationship.

How patients (and families) feel about the loss of privacy, the burdens of the process, and the risk of failure of the campaign is likely different when the campaign is undertaken by patients (and families) as a result of their own initiative, even in the face of financial pressures, rather than at the suggestion of those who also hold over them the substantial gate-keeping powers regarding access to healthcare, particularly access to a place on a transplant list and donor organ. In addition, the suggestion to crowdfund presented by the healthcare provider or institution complicates the relationship by introducing, or at least explicitly emphasizing, the fact that “you’ll get what you can pay for” as opposed to “you will get what you need.”

4.0 Crowdfunding's Immediate and Longer-term Effects Beyond the Clinical Context

4.1 Crowdfunding's Impact on Patient Privacy

Like the theory and doctrine of informed consent, protection of the privacy of patients is a cornerstone of bioethics. Just as the right to give informed consent or refusal respects patients' autonomy and enables them to promote their well-being by controlling access to their bodies, the right to privacy enables them to control access to their personal information and thereby protect their autonomy and well-being. The right to privacy allows people to promote their own well-being, and both reflects and respects their autonomy. Privacy allows people to develop their individuality and aspects of their life plans free from public censure.

Privacy is critical to the patient-provider relationship and to informed consent. The right to privacy and related duty of confidentiality allows patients to share information—e.g., about symptoms, behaviors, and values—and to gain the benefit of the provider's expertise in relation to the information without incurring the risk of the information becoming more generally known. Just as privacy is crucial for individuals to be able to develop their individuality and pursue some aspects of their life plans free from censure, privacy is critical to the flourishing of the patient-provider relationship, which is itself frequently critical to successful healthcare. Healthcare professionals' duties to maintain confidentiality allow patients to disclose the details of their health concerns and seek help while mitigating risks to their reputation, relationships, and economic interests. Maintenance of the privacy of health-related information is essential for the overall well-being of the patient.

By design, however, crowdfunding requires at least some loss of privacy. The more detail a campaign provides, the more successful it will be in reaching its funding goal (Renwick, 2017). Appeals benefit from divulging as much as possible including the nature of the illness, financial circumstances, and other details about family, work, and life in general. Though patients typically accept the loss of privacy, it nevertheless, stands in stark contrast to the long-held practice of keeping such detail private between patient and provider, and perhaps the patient's close well-wishers who include the patient's well-being as among their own interests (and not in a largely voyeuristic way).

Moreover, in several ways, crowdfunding differs from the use of other social media platforms to share news of an illness for oneself, a child, or another family member or friend. First, when people use a social media platform like Facebook or Instagram, they may enable settings that control who can see their account and the information posted. "Privacy" settings on both Facebook and Instagram limit the audience to those to whom access is granted. By contrast, the objective of a crowdfunding campaign is to reach as wide an audience as possible. Crowdfunding platforms encourage campaigners to spread the word publicly, and platforms can themselves take steps to enhance the attention given to a campaign. So, while all social media postings entail a loss of privacy to some extent, a crowdfunding campaign involves a greater loss of control of the flow of personal information than other forms of social media.

Additionally, social media postings and crowdfunding campaigns serve different purposes. Non-crowdfunding social media announcements about illness are typically just that: an announcement, a sharing, possibly including details of a treatment plan to inform friends, family, well-wishers, or simply to share with others who are known to varying degrees. Typically, the goal is primarily to build a community of support and sharing. Participating in an online disease support

group involves posting information about one's health condition to gain psychosocial support and practical advice about managing one's condition. Others on the support group platform incur a similar loss of privacy for a similar potential benefit.

A crowdfunding campaign, on the other hand, is designed to raise funds with the intention of using the money for an intervention or related expenses, or to pay off expenses incurred. The development of a community of psychosocial support is secondary to the economic support. Crowdfunding is explicitly transactional in a way that most other social media posting is not. In this way, the patient crowdfunding for healthcare is more like a social media influencer whose sole product is to sell herself as worthy of financial support. A seeker of funds is requesting a donation, and to that end, may feel the need to share as much information as possible and to package it in the most interesting and attractive way. Moreover, the need to move others emotionally to induce them to donate can lead campaigners to embellish their life stories or accounts of their health condition. While this impulse to embellish is not unique to this form of social media, that one receives money for doing so raises the ethical stakes and may be considered fraudulent.

There are some alternative crowdfunding models that seek to protect privacy and that have the concomitant effect of reducing the incentive or opportunity for the beneficiary of donations to embellish the account of their illness. These alternative models seem to be focused on supporting patients with needs that are stigmatizing. Some groups fundraise on behalf of individuals, thereby eliminating the need for individual patients to divulge their particular circumstances. One example is the Loveland Therapy Fund (<https://thelovelandfoundation.org>) that campaigns for black women and girls seeking mental healthcare. There are also foundations that erase patient medical debt that allow individuals to avoid crowdfunding entirely. RIP Medical Debt (<https://ripmedicaldebt.org/>), for example, buys medical debt and pays it off using donations from

the public. Their website states that this non-profit has relieved over \$4.5 billion in debt. The beneficiaries are households whose incomes are less than two times the federal poverty level guideline. Recipients of the debt relief do not have to petition, make a case, or create an appeal. RIP Medical Debt does not use any patient specific information at all. Instead, precise analytics are used to calculate where debt relief will have the most impact, the bill is paid, and a letter is sent to the patient home, all without the patient even knowing the process is unfolding. The RIP Medical Debt website touts the non-profit's role in helping patients themselves avoid the need to crowdfund (RIP Medical Debt, n.d.).

The standard model of crowdfunding to pay healthcare expenses, however, requires patients to create a *permanent* public digital footprint out of their illness, personal suffering, and financial situation (Parvin, 2019). To some extent, a crowdfunding patient creates a privacy-violating digital presence for those who surround the patient as well. Particularly in the face of health needs and financial pressures, patients may not recognize all the ways their decision to forfeit privacy can negatively impact their lives for years to come. A patient who crowdfunded to defray the expenses of receiving a new liver may, for example, be observed drinking in a bar years later and be subjected to subtle or not-so-subtle scrutiny and even censure. Although pregnant women are often subjected to the public gaze and intrusive comments and questions (Church, 2016) this problem may be intensified for women who fund their fertility treatment through a campaign. "A woman's body isn't public, and pregnancy isn't a public event unless she chooses to make it one" (Norwich, 2012), but women who choose to crowdfund to support their pregnancy-related healthcare in any way necessarily choose to make themselves and their condition public. When they share the news of the birth of their babies on their pages, they may be subjected to more intense scrutiny of their mothering and childcare behaviors.

Much of the literature about the loss of privacy in crowdfunding focuses on the ways privacy is forfeited during and immediately following the crowdfunding campaign and medical treatment. Less attention has been paid to the long-term unforeseen consequences and ethical concerns associated with patients publicizing their medical problems. Crowdfunding platforms generally do not warn campaigners about short- or long-term risks, and not all patients will appreciate them when choosing to undertake a campaign. This raises the question of whether patients are acting with the material understanding necessary to autonomously undertake a campaign and the release of the information necessary for its success. Of course, the requirements of informed consent do not apply to placing personal information onto the Internet. Nevertheless, the value of keeping much of one's health-related information private applies just as much, if not more, when the scope of the exposure is so great in terms of both the number of people and entities that have access to the information and the duration of exposure. Patients' interests would be well-served by considering these broader and longer-term consequences of crowdfunding before undertaking it. To the extent that healthcare institutions and providers participate in or encourage crowdfunding, they should discuss these implications with their patients.

In addition, the privacy of people surrounding the patient may be affected by the patient's decision to crowdfund. Moreover, the patients for whose care crowdfunding is pursued do not always initiate or consent to the crowdfunding. The extended family of crowdfunding patients and children for whom crowdfunding campaigns are established are not able to consent to their immediate or long-term loss of privacy.

4.2 Ethical Implications for Extended Family of Crowdfunding Patients

Crowdfunding campaigns compromise the privacy of people related to the patient. Members of the immediate household will have their financial situation made public in the course of making the patient's financial need public. Some details revealed to make the patient's need more vivid or poignant may be embarrassing or compromise the well-being of family members. If one reason that crowdfunding is necessary involves a family member's job loss and current unemployment, revelation of that fact may be embarrassing. Moreover, revelation of the patient's health condition and situation might make obtaining new employment more difficult if prospective employers become aware of the crowdfunding campaign and the possibility of the prospective employee facing "distractions at home."

Campaigns to fund treatment for a genetic condition disclose information not only about the patient's health, but also about genetically related family members often without their consent (Kubheka, 2020). Indeed, because members of the public may not know who is *genetically* related to the patient, even non-genetic, socially-related relatives may suffer what has been termed "group harm" due to the publicity of genetic risks or genetic conditions faced by a relative (Weijer, 1999). Family members may be faced with unwanted questions about their own health or risk of developing the disease. Such inquiries could affect opportunities and relationships ranging from their ability to obtain life, disability, and long-term care insurance to their friendships, dating relationships, and marriage prospects. Granted, members of genetic conditions groups may generally benefit from the increased publicity and attention paid to their condition. Nevertheless, the risks of stigma and discrimination for related third parties seem greater and more immediate than these potential benefits. Moreover, any such benefits might be achieved more directly through appeals to attract attention to the need for research on the genetic condition.

4.3 Ethical Concerns about Crowdfunding for Pediatric Care

Particular ethical concerns arise when parents pursue crowdfunding to meet their children's health needs, because children lack decisional capacity to appreciate and weigh the risks and potential benefits of launching a crowdfunding campaign. Even adolescents who are approaching the maturity necessary to make decisions about many things are likely to lack the range of experience to appreciate the long-term implications of a crowdfunding campaign that makes their health condition (and other features of their life) public. It is because of their children's lack of decisional capacity that parents are charged with giving permission for their medical treatment. They are considered to be in the best position to safeguard their children's interests in light of the values that the parents are anticipated to be sharing with and inculcating in their children (Salter, 2012). Barring evidence to the contrary, parents are assumed to act and to make medical decisions in ways that promote their children's health-related interests.

Parents are generally granted substantial latitude in raising their children and even in making health-related decisions regarding them. Short of the parents' engaging in neglect or abuse, the state does not intervene (Diekema, 2004; Salter, 2012). Even from the perspective of ethical evaluation, parents are given wide latitude in raising their children according to their own values and preferences (Groll, 2014; Ross, 1998; Salter 2012). Parents are generally (putatively) assumed to have their children's interests at heart *because* they are assumed to have the right and obligation to implement a conception of the good—a set of values—that informs their decision making on behalf of the family (Salter, 2012). Questions only arise when it seems that the parents are clearly and importantly acting contrary to the objectively ascribable welfare interests of their children, or when there are obviously conflicting interests between parents and child, or between siblings with parents seeming to trade-off one child's interest for another child's benefit.

So, given the longer-term negative implications of making a person's health condition and other features of their family life public, the question arises: does parental use of crowdfunding to fund their children's healthcare suggest that they are not appropriately safeguarding their children's interests, specifically their privacy interests? Evaluation of crowdfunding for pediatric healthcare requires evaluation and balancing of several factors including the child's health condition, the necessity and appropriateness of the proposed medical treatment for it, the financial need for crowdfunding, and alternatives to crowdfunding. Also of relevance may be the child's short- and longer-term situation with and without crowdfunding, the interests of other family members—and especially other children—and how those would be affected by crowdfunding, and which of those interests the parents have an ethical, parental responsibility to protect. There is no concise formula for evaluating these factors to determine whether a particular case of crowdfunding for pediatric healthcare is ethically appropriate, suspect, or clearly problematic. It may be instructive, however, to describe three scenarios to illustrate how these factors might be taken into account.

In the most ethically defensible case, parents would have exhausted other reasonable alternatives to fund their child's care. The proposed care plan would be uncontroversial, i.e., it would be a matter of providing standard care for a condition that has the prospect of benefitting their child. The parents would undertake a crowdfunding campaign with understanding of the associated potential benefits, burdens, and longer-term privacy-related risks. They would recognize that the risks may apply not only to their child who is in need, but also to any other children they may have who would also suffer risks to their privacy. The parents take what steps they can to minimize the risks while pursuing a successful campaign within ethical bounds (e.g., not misleading prospective donors, and not unduly sacrificing their other children's privacy for the

sake of the one child, for example, by having the siblings record appeals or pose with the patient). The parents consider the family's well-being to be intimately related to the well-being of each of its members, and are conducting themselves and raising their children to embrace the values of interrelatedness and mutual care (Groll, 2014; Ross, 1998; Salter, 2012). They justify some sacrifice of the family's privacy, including the privacy of their children who cannot consent to the sacrifice, for the sake of promoting the health-related well-being of their ill child (Groll, 2014; Ross, 1998). They consider the suffering, debilitation, or risk of death of the ill child clearly to be a greater harm to the family and their other children, than the effects of crowdfunding, which they deem necessary to be able to provide healthcare for their ill child. They seek to avoid harm (or the greater harms) to all of their children (Salter, 2012).

In contrast, one can imagine a scenario in which parental crowdfunding for their child's healthcare is not ethically justified, or at least the parents' reasoning and some of their actions are ethically problematic. Perhaps the parents turn to crowdfunding, not out of financial necessity, but to avoid depleting discretionary financial reserves. When campaigning, they may even be untruthful about their degree of financial need. They may consider their own family's well-being—both health-related and financial—to be paramount and more important than values of truthfulness or the well-being of others who may be competing for donors' dollars. They may press their other children into participating in the crowdfunding effort without concern for their privacy interests (or their emotional interests that may be harmed by being asked to bear some responsibility for the outcome of the campaign and thus their sibling's healthcare). These may be parents who “play favorites” among their children—or who are blind to the emotional needs and privacy concerns of their children who are well—and pour their energies into crowdfunding for the ill child and require

the siblings to participate in the effort. Also problematic would be their crowdfunding for a treatment that was not considered medically necessary or appropriate.

Perhaps more difficult to evaluate would be a family in which the parents are unwilling, due to their ethical, political, or religious commitments, to receive government aid even for their ill child. They would rather turn to private sector crowdfunding, even though doing so sacrifices their child's privacy (and that of his siblings). Whether they have the right to impose their values or conception of the good on their children to the detriment of their children's privacy interests may be an open question (Salter, 2012). If their values seriously risked their children's lives or physical well-being, the parents would not be ethically justified in implementing their values. But the children's privacy interests may not carry such weight (Salter, 2012). It may be ethically suspect for the parents to crowdfund rather than accept government aid, but they may be able to justify their values-based choice. (A parallel may be drawn with analysis of the decisions of members of a religious group, like the Amish, who eschew health insurance, but rely on the mutual aid of their community to fund needed healthcare).

Also somewhat difficult to analyze would be parents who turn to crowdfunding for one child's healthcare to avoid depleting that child's or their other children's college funds, although those monies would be adequate to provide the necessary healthcare and the legal restrictions on the funds would permit the use of the monies for necessary healthcare. It may seem obvious that it is in the best interest of the parents, ill child, and siblings to have the care provided without dipping into the family's coffers or jeopardizing any of the children's future educations and livelihoods (Groll, 2014). But crowdfunding sacrifices the children's privacy, and they cannot evaluate the trade-off themselves or consent to the potential sacrifices (of either college funding or privacy). If instead of the children's college fund, the alternative to crowdfunding was dipping

into the parents' own retirement funds, the ethical evaluation remains challenging. It may seem obvious that it is better for parents to sacrifice their child's or children's privacy interests for the sake of the children's own future material interests than for the sake of the parents' own material well-being; however, in families that consider the well-being of other members to be constitutive of each members' interests, it could be justifiable for the parents to take their own material well-being into account (Groll, 2014). As a practical matter, if they decimated their retirement funds, they might become a "financial burden" on their children in the future.

What seems clearly problematic in parents' crowdfunding for their children's healthcare would be their treating their children unfairly (playing favorites and sacrificing important interests of some for the sake of one), selfishness (sacrificing children's interests for the parents' individual interests alone), deception of donors, undue pressure on their children, or crowdfunding for frivolous or inappropriate interventions. This sketch of how to analyze parents' crowdfunding for their child's care attempts to take seriously that members of families typically have interrelated interests, that sometimes family members' interests conflict, and that parents—the members who wield decisional authority, financial power, and ethical and financial responsibility—have a responsibility to adjudicate those conflicting interests fairly.

4.4 Additional Effects of Crowdfunding

Crowdfunding for healthcare has some clear benefits. Most obviously, many patients' health needs are met through crowdfunding while enabling them to avoid financial strain or ruin. Donors report positive feelings of altruism or enjoy what is known as "motivational crowdwork" (Gerber, 2012). Providers—both individuals and institutions—are paid for the healthcare they

provide. Instead of providing charity care funded through “charity care funds,” sometimes established in institutions through fundraising, institutions provide care that is funded through charity given to individual patients who solicit it. Crowdfunding reduces the amount of unreimbursed healthcare that could increase healthcare costs throughout the institution or system.

Crowdfunding also has some potential negative effects beyond those discussed in previous sections of this paper. For some patients, crowdfunding may be an unwelcome opportunity much like the unwelcome offers that Faden and Beauchamp discuss in the context of elaborating their account of autonomy (Faden & Beauchamp, 1986, p. 340-341). While they argue that neither circumstances nor an offer can be coercive (Faden & Beauchamp, 1986, p. 344-346), an offer or opportunity can be one that a person wishes she did not receive or face. Particularly if the offer or opportunity affords something that the person desperately needs, but at a cost of something important that the person does not want to sacrifice, it may be profoundly unwelcome even if the person avails herself of it. The classic example is of someone who is given the opportunity to trade sex for goods she desperately needs. The opportunity to engage in crowdfunding may not constitute so dramatic an example; however, a patient in need of funding for healthcare may intensely wish that crowdfunding platforms did not exist so that she did not have to consider sacrificing privacy, or risk being tempted to embellish the truth to create a more sympathetic and successful appeal (Parvin, 2019).

Commodifying suffering and packaging one’s illness for financial gain is an extraordinary burden for an ill individual to assume, one that risks dehumanizing them by reducing them to the problems they face (Parvin, 2019). For some people, the requirements of crowdfunding necessitate the sacrifice of their personal values (e.g., privacy, modesty, self-sufficiency) or self-concept (e.g., as someone who does not seek charity or does not appeal to emotion), or the interests of others

(e.g., family members' privacy). For some, crowdfunding is a matter of undignified begging, not coordinated altruism. It may require dozens of anguished choices and distressing revelations. A campaign forces a patient to choose between withholding information to maintain some level of privacy and being very open in order to make more money; between marketing themselves and maintaining dignity; between appeasing family or adhering to their own values; between sticking to the truth or embellishing for the sake of a successful campaign. Patients report anguish over the need to crowdfund for themselves; parents report anguish over the need to crowdfund for their children (Heller, 2019). To some, the need to crowdfund entails a public admission of failure to be able to provide for their family. For the sake of obtaining healthcare, some people may feel that their self-image suffers death by a thousand cuts. Yet they may pursue it.

Moreover, some may sacrifice their privacy, dignity, and personal values, yet be unsuccessful in raising sufficient money. They may risk asking whether they are good enough, sick enough, attractive enough to deserve others' help, and the campaign may return that answer of 'no.'

A positive mental state is known to improve patient outcomes (Fanaroff et al., 2019; Harvard Medical School, 2008). There is evidence that a successful campaign can bolster a patient. Social support through the internet has been shown to reinforce feelings of emotional encouragement and at times create an identity shift from powerlessness to empowered (Gonzales & Hancock, 2008). The demands of crowdfunding or an unsuccessful crowdfunding campaign may contribute to diminished feelings of self-worth, and in turn contribute to a patient's illness, not health.

5.0 Conclusion

While it purports to empower patients and help “level the playing field” in response to the “original sin” of a lack of basic healthcare coverage for all within the American healthcare system, crowdfunding for healthcare actually presents a range of potential ethical concerns. Empirical research is needed to determine the reality and magnitude of the concerns discussed in this paper. The paper sought to establish that crowdfunding has potential long-term negative implications for patients and their family members because of the sacrifice of privacy that it requires. It may also have negative psychological effects for those who launch campaigns. These effects may be disproportionately borne by those who lack skills and social connections beneficial to successful crowdfunding, as well as by those who are already disadvantaged because of existing social biases against people of color and people who are poor, less educated, less conventionally attractive, or considered to be responsible for their ill health. Thus crowdfunding may reinforce or exacerbate existing social inequalities. Therefore, as a mode of addressing lack of access to healthcare, it may be particularly unfair. If it reduces pressure to develop more just means of providing healthcare, and in turn more fair equality of opportunity, crowdfunding would fail to redress—and may, in fact, reinforce—injustice in healthcare and society.

Within healthcare institutions and the clinical context, crowdfunding may fuel conflicting interests and undermine trustworthiness, trust, and the fiduciary nature of the patient-provider relationship. In at least some cases, it increases clinicians’ workload and may lead to conflict within the patient-provider relationship. It may present challenges to the voluntariness and understanding requirements of informed consent, first, by making it more difficult for patients to “hear” what is disclosed to them and to appreciate the risks of proposed interventions to which

they have publicly committed in their crowdfunding campaigns. Second, such public commitment to a course of clinical care may make it more difficult for patients to change their minds and give an informed refusal of what is proposed or withdraw from a therapy once it has been consented to.

The problems that crowdfunding presents in the context of healthcare are neither unique nor entirely the result of crowdfunding. Some of the concerns are associated with any use of social media to share information about one's health and healthcare. Many of the concerns expressed in this paper are speculative in nature and highlight the need for further empirical research that will serve as the foundation for a more extensive ethical analysis of crowdfunding for healthcare and prompt efforts to develop mitigation measures, guidance for those using crowdfunding, regulatory measures governing crowdfunding platforms, or policy regarding healthcare institutions' involvement in crowdfunding.

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