

“Not by Money Alone”: Social Support Opportunities in Medical Crowdfunding Campaigns

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ABSTRACT

Medical crowdfunding helps patients receive financial support from their distributed social networks online. However, little is known about *who* the patient’s supporters are, *what support* they provide, and *why*. To address this, we interviewed fifteen people involved in medical crowdfunding, including both beneficiaries and supporters. We found that support networks were larger than beneficiaries expected, with strangers offering support. Supporters offered not only monetary but also volunteering contributions including campaign creation, promotion, and external support. However, the emphasis medical crowdfunding interfaces place on monetary contributions led to social issues. Beneficiaries’ close friends felt pressured to donate money they could not afford to give. And anyone promoting the campaign worried they would be judged for requesting money. To mitigate these concerns, we suggest making the variety of volunteering contributions more visible and discuss the design challenges of including such signals in existing systems.

Author Keywords

Social Support; Online Financial Support; Medical Crowdfunding

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; See <http://acm.org/about/class/1998> for the full list of ACM classifiers. This section is required.

INTRODUCTION

When Amy—a mother, a wife, and a soccer coach—was diagnosed with a brain tumor, she could no longer work. Because of an injury, her husband could not work either. To lessen the family’s financial hardship, Amy’s sister created a crowdfunding campaign on GoFundMe on Amy’s behalf (see Figure 1). Immediately, a large number of people started sharing the campaign URL via social media sites. In

only two days, the campaign’s URL was shared 409 times, bringing in \$26,064 from 258 donors. This example shows the important role medical crowdfunding supporters¹ play in assisting the patient by reaching out to a wider audience of potential donors [7,28]. With the help of supporters, medical crowdfunding campaigns have reduced all medical-related bankruptcies by 3.9% in the United States in the period between 2006 and 2011 [28].

Despite the impact of medical crowdfunding campaigns, publicly soliciting and presenting donations can cause a number of concerns. First, as the beneficiaries² of medical crowdfunding campaigns, patients may feel ashamed about requesting money for their personal medical and financial situations. This is unique challenge for medical crowdfunding; other crowdfunding beneficiaries, such as entrepreneurs in Kickstarter, do not solicit donations for personal *medical* situations [18,19]. Although patients often share their medical problems online [26,36,37], they seldom solicit *monetary* contributions for these problems. Second, the public presentation of donation activity can cause tension among donors. Publicly visible donor names and donation amounts often signal strong relationships between the donors and beneficiaries [21,30]. However, some people then feel obligated to contribute money to avoid social stigma [8,22,30].

In this paper, we uncover benefits and concerns that medical crowdfunding beneficiaries and supporters perceive while participating in these campaigns. We interviewed fifteen participants: three beneficiaries and twelve supporters. We found that the beneficiaries’ greatest concern about asking for donations for themselves was how their audience might judge them. Family and friends helped the beneficiaries overcome this concern by creating a campaign and asking for donations on their behalf. Despite this, beneficiaries and supporters still struggle with perceived public judgment when soliciting and contributing monetary support through medical crowdfunding

¹ We define *supporters* as those people who directly or indirectly contribute to medical crowdfunding campaigns.

² We define *beneficiaries* as the patients and/or their immediate family members who benefit from donations of medical crowdfunding campaigns. Immediate family members can be the beneficiaries if a campaign solicits donations for funeral costs.

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campaigns. To mitigate these concerns, we suggest highlighting the variety of contributions rather than focusing primarily on monetary donations. Supporters already provide diverse volunteering contributions focused around medical crowdfunding campaigns by creating and promoting campaigns as well as offering external support (e.g., serving meals or organizing offline fundraising). We discuss potential design enhancements to a campaign's interface that could capture these volunteering contributions while addressing the challenges associated with such changes.

The contributions of this paper include:

- 1) Uncovering the variety of support activities that occur around medical crowdfunding campaigns.
- 2) Identifying various benefits and concerns that arise for supporters and beneficiaries in the course of medical crowdfunding campaigns.
- 3) Discussing the challenges of designing campaign interfaces to recognize the breadth of work occurring around these campaigns.

RELATED WORK

Medical crowdfunding refers to the practice of soliciting monetary donations from distributed individuals to cover a patient's medical related expenses [20,28]. Not only do online medical crowdfunding sites facilitate monetary donations, but they also allow patients to receive other types of support from their social network. Thus, we want to understand the extended types of support that occur through medical crowdfunding sites. First, we introduce a theoretical framework that provides a lens for understanding social support in the context of health. We then discuss how social support for health takes place online and the key differences between online health communities (OHCs) and medical crowdfunding sites. Finally, we suggest unique support opportunities in medical crowdfunding by highlighting the differences between medical and other types of crowdfunding campaigns.

Social Support for Health

Patients seek and receive social support from their social networks to cope with their health difficulties [9,11,12]. Social support is often characterized as a multidimensional concept consisting of structural (e.g., social network resources and affiliations), functional (e.g., instrumental, emotional, and informational forms of support), and perceptual (e.g., satisfaction) dimensions [10]. A supportive social network provides various types of support by investing both tangible and intangible resources. Although medical crowdfunding sites are specifically designed to facilitate tangible support, such as monetary donations, we are interested in exploring social support beyond monetary donations in medical crowdfunding sites. To understand how and why extended social support occurs, we first examine a framework that defines social support as outcomes of social capital [9]. According to Carpianno's framework, the amount of social support that individuals

Amy's fight

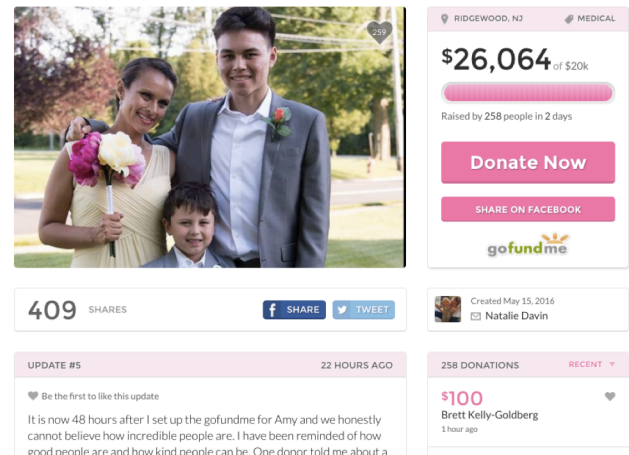


Figure 1 An example of medical crowdfunding campaign: Fundraisers describe the needs for raising funds and donations are displayed on the lower right side of a campaign webpage, © GoFundMe.

can access depends on (1) social cohesion: patterns of social interaction and values (e.g., networks, norms, and social trust) and (2) social capital: actual and potential resources that are possessed within one's social networks (e.g., time, money, and knowledge) [5]. We seek to understand how people utilize social cohesion and social capital in the context of medical crowdfunding. We also examine limitations of existing medical crowdfunding sites that affect the support-seeking and support-giving behaviors.

Online Health Support

OHCs facilitate the exchange of emotional and informational support through members of social networks who possess relevant knowledge and experience [2,16,17,29,37]. For example, OHCs connect patients with people who have had similar medical experiences [16,17,37]. From peer-patients, patients receive more sympathetic emotional support and/or unique informational support about managing the everyday experience of illness that even clinicians often cannot provide [36,37]. On the other hand, the patient's close networks that possess in-depth knowledge of and experience with the patient's personality or daily life, provide more intimate emotional support that peer-patients cannot offer [12,29]. Thus, personal health blogs such as Caring Bridge [40] and Lotsa Helping Hands [41] allow patients to only invite people whom they can trust [2,29]. Patients then share their health journey to a selective audience and receive emotional support [2].

OHCs vs. Medical Crowdfunding Campaigns

Many sites for medical crowdfunding campaigns allow distributed individuals to support someone in need financially. In contrast to OHCs where patients typically share their health concerns directly with a closed group, medical crowdfunding requires promotion to reach out to potential donors outside of the medical crowdfunding sites.

In this process, unique social support opportunities can arise. For example, patients' supporters who have many social media friends can support the patients by sharing their campaigns. In our research we investigate the types of support that supporters provide while participating in medical crowdfunding campaigns and how and why this support occurs.

The Role of Community in Crowdfunding Campaigns

Crowdfunding is an internet-based open call for donations from a distributed network to support specific purposes [15]. A large body of research in crowdfunding focuses on entrepreneurial crowdfunding which requests funds in exchange for a business venture's art, products, or services [14]. The infrastructure underlying entrepreneurial and medical crowdfunding campaigns share many similarities; both campaign creators describe reasons for raising funds and allow anyone to share a campaign URL on social media sites to solicit donations from a wider set of audiences. Despite their similarities, differences in their crowdfunding models, campaign legitimacy work, and the involvement of the beneficiaries in crowdfunding campaigns suggest unique support opportunities in medical crowdfunding campaigns.

Crowdfunding Models

Kickstarter, the largest entrepreneur crowdfunding platform, uses an *all-or-nothing* model where campaign creators can only receive collected funds if a campaign goal is reached within a certain fundraising period [38]. This can prevent fundraisers initiating a campaign, because the effort put into a campaign could become useless [14,15]. Thus, much of entrepreneurial crowdfunding research investigates various success factors such as funding goal amount [25], frequent updates [39], and importance of early donations [31]. Past work has also found that signals of the fundraiser's social capital, such as social network size, and the number of Facebook "likes" for a project page, are correlated with crowdfunding success [25].

On the other hand, medical crowdfunding sites such as GoFundMe, YouCaring, and GiveForward use a *direct donation* model where fundraisers keep all donations even if the total does not reach the goal amount. Thus, medical crowdfunding donors may have less motivation to contribute money through a crowdfunding website, as they could directly donate to the beneficiary to avoid the service fees. However, the publicly displayed donor names and donation amounts on medical crowdfunding campaigns may motivate the beneficiaries' close friends to contribute money to the campaigns [23]. The donation amount often signals a strong connection between the beneficiary and their supporters [21,30].

Campaign Legitimacy Work

Both entrepreneurial and medical crowdfunding fundraisers put significant effort into conveying the legitimacy of their crowdfunding campaigns to potential donors [33]. Previous entrepreneur crowdfunding research [15,24,25,39]

highlights the importance of specifying reward structures in campaign description and updates to increase the likelihood of crowdfunding success. In addition, the quality of materials of the campaign (e.g., videos and grammar accuracy) was associated with the likelihood of success in fundraising [25]. Thus, entrepreneurial fundraisers put extensive effort in preparing and examining campaign materials before launching a campaign [19]. Fundraisers often ask for advice from other fundraisers who have succeeded before, study advice blogs, or hire professionals to prepare high quality campaign materials [19]. However, Kim et al. found that potential donors did not expect high quality work on campaign materials in the context of medical crowdfunding [20]. Instead, campaigns that signal the legitimacy and worthiness of the beneficiary as well as his or her own contributions are helpful in attracting donors [1,20,33].

Beneficiaries Involvement throughout Fundraising

Entrepreneurial crowdfunding creators are often the beneficiaries of the collected funds [33]. Because the beneficiaries are in charge of creating products or services that they raise funds for, they spend a significant amount of time attracting supporters both online and offline [14]. However, medical crowdfunding beneficiaries, often the patients and their family, are not be able to create and run a campaign as they are often going through difficult medical situations (e.g. surgery, cancer treatment, or staying in an intensive care unit). The beneficiaries may need more help from their supporters to promote and even create a campaign on their behalf. Despite the important role of the supporters in medical crowdfunding campaigns, researchers have not yet explored how supporters help beneficiaries to solicit and receive financial support.

RESEARCH QUESTIONS

To better understand supporters, beneficiaries, and their experiences with medical crowdfunding campaigns, we developed the following research questions:

RQ1: *Who* provides *what types* of support in the course of medical crowdfunding campaigns and *how* and *why*?

RQ2: What are the *benefits* the beneficiaries and supporters perceive when participating in crowdfunding campaigns?

RQ3: What are the *challenges* the beneficiaries and supporters perceive when participating in crowdfunding campaigns?

METHODOLOGY

To answer our research questions, we conducted semi-structured interviews with fifteen participants including three beneficiaries and twelve supporters of medical crowdfunding campaigns.

Participants

To recruit fundraisers and supporters, we first posted flyers in public places and sent emails to local communities. Our inclusion criteria were 1) people who have organized medical fundraising campaigns or have been benefited from

campaigns via online crowdfunding platforms or 2) people who have donated to or promoted campaigns to their social networks. To ensure participants participated in online medical fundraising campaigns, we asked them to submit URLs for one or more medical crowdfunding campaigns that they had organized, benefited from, donated to, or promoted via a variety of communication channels. We excluded people who only participated in personal fundraising campaigns using PayPal accounts, charitable crowdfunding created by organizations, and medical crowdfunding campaigns created for raising funds for pets.

Only two beneficiaries responded to the initial recruitment call. We therefore ran a second round of recruitment. In our second round, we sent a direct message to all fundraisers with an on-going campaigns on the three largest medical crowdfunding sites: GoFundMe, YouCaring, and GiveForward. We further asked our participants to promote the study on their social media sites or by directly contacting any acquaintances who have participated in medical crowdfunding campaigns as a beneficiary or supporter. In total, we recruited three beneficiaries and twelve supporters who had participated in medical crowdfunding campaigns. The campaigns were held on a variety of sites including GoFundMe, GiveForward, YouCaring, and Fundrazr.

Of our fifteen participants, one was male and fourteen were female; with an average age of 32. All three of the beneficiaries created their own campaign as a fundraiser. All twelve supporters had a personal relationship with the beneficiaries of the medical crowdfunding campaigns as shown in Table 1; six supporters identified themselves as a close connection. We explain the relationships between the beneficiaries and supporters in more detail in the results section.

Supporters participated in medical crowdfunding campaigns in various ways. They provided support either 1) to help beneficiaries directly to raise money through medical crowdfunding or 2) to address the beneficiaries' needs that could be fulfilled through various communication channels outside of medical crowdfunding. We refer to the supporters who provided medical crowdfunding related support as campaign creation assistants, campaign promoters, and monetary donors. We use the term external supporter to define supporters who provided support outside of the medical crowdfunding. Each support activity is explained in detail in the results section.

Interview Procedure

We invited thirteen local participants to our lab and conducted phone interviews with two participants (B2 and S7) who could not reach the lab. The interviews with three beneficiaries lasted approximately average of one hour and fifteen minutes; Supporters interviews took approximately average of 45 minutes. We compensated each beneficiary and supporter with a \$20 or a \$10 Amazon gift card,

	Campaign Type		
B01	Funeral costs		
B02	A service dog costs for Type 1 diabetic		
B03	Medical costs for joint hypermobility syndrome		
	Supporter's role	Relationship with a beneficiary	Campaign Type
S01	Monetary donor External supporter	Close friend	Funeral costs
S02	Monetary donor	Distant friend	Skin cancer
S03	Monetary donor	Distant friend	Skin cancer
S04	Monetary donor Campaign promoter External supporter	Close friend	Stomach cancer
S05	Monetary donor External supporter	Close friend	Colon cancer
S06	Monetary donor	Distant friend	Car accident
S07	Monetary donor Campaign promoter External supporter	Close friend	A service dog costs for Type 1 diabetic
S08	Monetary donor	Distant friend	Skin cancer
S09	Monetary donor	Distant friend	Skin cancer
S10	Monetary donor Campaign promoter External supporter	Close friend	Brain tumor
S11	Monetary donor	Distant Friend	Jaw cancer
S12	External supporter	Close friend	Colon cancer

Table 1. Summary of the study participants and medical crowdfunding campaign information that participants have involved in.

respectively. The beneficiaries received more than the supporters because the interviews took longer. Also, we valued the difficulty of revealing sensitive medical and financial information.

The semi-structured interview consisted of questions identifying types of participation and contribution to the crowdfunding campaigns. We also asked more specific questions of the two groups, as we described below.

Beneficiaries: Beneficiaries were asked why they created medical crowdfunding campaigns and for any concerns and any benefits they had anticipated or experienced during the campaigns. They were also asked to specify who had helped them through the campaign, what types of support they received, and how each type of support impacted them.

Supporters: We first asked supporters to identify their relationship with the beneficiaries of the campaign they participated in. We also asked how they discovered the campaign, why they participated, and how they tried to contribute to the campaign. They were finally asked to summarize the overall experience of medical crowdfunding as a supporter.

During the interviews, we showed participants the webpage of the medical crowdfunding campaign they had initially submitted to elicit feedback about their activities. We asked them to feel free to refer to and point to the webpage while answering questions.

Data Analysis

All interviews were recorded and transcribed. Two researchers coded transcribed data using inductive coding [34] using Nvivo [42]. One researcher first highlighted all statements in the interview transcripts that provided explanations for the support activities beneficiaries had received and/or supporters had provided. Another researcher reviewed the highlighted sentences and the two researchers coded them using an inductive process. They iteratively generated and refined themes until they began to see broader patterns in the data. They discussed the codes between each iteration and converged on a set of themes that we discuss next.

RESULTS

We found that supporters largely engaged in four types of support activities using a variety of online communication channels such as crowdfunding campaign webpages, social media sites, as well as offline interactions. These support activities are composed of *monetary* contributions and *volunteering* contributions. The volunteering contributions include assisting in the creation and sharing of campaigns as well as offering external support such as serving meals or organizing local fundraising events. We organize the results around three themes highlighted in our research questions: the types of support activities, the benefits, and the challenges that beneficiaries and supporters perceived.

We define people who gave monetary or volunteering contributions to medical crowdfunding campaigns as *supporters*. We identified three types of relationships between supporters and beneficiaries in our study: *Close supporters* include immediate family members, best friends, and girlfriends etc.; *distant supporters* include friends of the beneficiaries' close connections and acquaintances (e.g., those known from school, work, hobby groups or other organizations); *strangers* include people who do not know the beneficiaries and are not connected through social media or any other channels. Of our twelve supporter participants six were close supporters and six were distant supporters. In this paper, we use the term "supporter participants" to refer our twelve participants who supported campaigns and "beneficiary participants" to refer to the three participants who benefited from campaigns.

Support Activities & Reasons for Support (RQ1)

Although medical crowdfunding campaigns were originally created for financial support, supporter participants offered a variety of volunteering contributions in addition to monetary donations. These include creating a campaign, promoting the campaign, and offering external support. For each support type, we explain *who* the supporters are, *how* they provide each support and *why*.

Assisting in the Creation of Campaigns

The first support type we discovered was creating these campaigns. Medical crowdfunding sites enabled people to easily create a sharable campaign webpage describing their reasons for raising funds and goal amount.

Eight out of twelve supporter participants contributed to a campaign created by the beneficiaries' family member, friend, or student (not the beneficiary him- or herself). Seven supporter participants explained that the beneficiaries' family or friends created the campaigns for one of the two following reasons: 1) In three cases, the beneficiaries could not initiate and manage a campaign because of their personal medical situations; and 2) In four cases, the beneficiaries hesitated to create a campaign because they feared the judgment of their potential supporters.

Although none of our supporter participants were directly involved in assisting in the creation of campaigns, three participants described in detail how others helped create campaigns on behalf of beneficiaries. B1 who had seen other people creating medical crowdfunding campaigns on behalf of beneficiaries explained that, "*the people choosing to set up a campaign are people who already know the person well enough to 'vouch' for them.*" In another case, S10 had offered to create a crowdfunding campaign when the beneficiary mentioned her dire financial predicament and concerns about creating a campaign. In another example, S4 explained that students who were aware of their teacher's (the beneficiary) difficult medical conditions, voluntarily created a campaign to help the beneficiary "save face" from asking for money for himself: "*They [the beneficiaries] themselves cannot be the ones who ask for money because they want to maintain some sort of integrity. So, the support that they require wasn't just making money with this. It [creating a crowdfunding campaign] was also to help them save face*" (S4).

When creating a campaign, the beneficiary participants explained that writing a fundraising pitch was the most challenging task. They struggled in deciding the appropriate amount of information to reveal and how to frame their needs in a persuasive way. Thus, the beneficiary's family and close friends often helped them by revising the fundraising description. The fundraising description included the beneficiary's medical status (e.g., medical condition, surgery status), reasons for raising money (e.g., uncovered chemotherapy costs by insurance, airplane ticket costs for the beneficiary's family to visit the beneficiary),

and their life difficulties (e.g., childcare for the beneficiary's child during surgery, depression brought on by medical conditions).

Promoting Campaigns

The second support type was promoting campaigns. Four supporter participants promoted campaigns on Facebook or via email. Three were close supporters and one was a distant supporter. One beneficiary participant explained that their supporters asking for monetary donations on their behalf signaled that *"they care and they want to help. That really means a lot."* Campaign promoters publicized campaigns via face-to-face conversations, phone calls, and online communication channels (e.g., instant messaging services, social media sites, and online communities) to better expose the campaigns to a wider audience. When promoters shared the campaign URL on social media sites, they sometimes encouraged their friends to spread the word. Moreover, online communities were often chosen to publicize campaigns to people who share similar medical conditions, hobbies, or organizations with the beneficiaries. Finally, some promoters posted flyers on various public places and wrote hand-written letters to their family and friends who did not have social media accounts.

All of our participants were surprised to see how quickly the number of shares (and donations) increased, only a few days after the social media promotion: *"Almost everyone I know posted about this. So, I think he's probably a really great person and people really care about him and going out of their ways to help him raise funds"* (S3).

Donating Money to Campaigns

The third support type was monetary donations. Eleven supporter participants contributed monetary donations to the campaigns. All but one of our supporter participants found campaigns on Facebook shared from other supporters (one saw a campaign mentioned in a local newspaper). Before donating money, all of them read the donation page to see who contributed money and their donation amounts. Five participants explained that seeing others' monetary contribution records motivated them to donate money. The record of donation also helped them gauge an appropriate contribution amount.

Our participants had a variety of intrinsic or extrinsic motivations for donating money. Five out of six distant supporters donated money after seeing a campaign promoted by their close friends. They described feeling socially responsible when many of their friends had already shared and/or donated to the campaign: *"[I donated because] he's my age and some of my good friends are good friends with him and they said all these really good things about him"* (S8).

All supporter participants except one who donated money wrote their name when donating to a campaign. They wanted beneficiaries, their friends, and potential viewers to recognize their contribution to the campaign. In some cases,

people felt they were representing a group or organization and described wanting the group to be recognized. As S11 said, *"[I wrote my real name because] I wanted to show my friend that some people in her fraternity supported her."* By donating money, she was also reminding her friend of the larger social group supporting her. Supporters also wanted their monetary donations motivate others to contribute money. Two monetary donors hid their donation amount because they thought it was a small contribution and did not want friends to be disappointed.

Offering External Support

The fourth support type was offering external support. External support refers to support that is not directly mediated through a campaign interface, but addresses the beneficiary's needs that can be fulfilled outside of medical crowdfunding sites. External support includes 1) offering practical assistance (e.g., helping chores, social visits) and 2) organizing external fundraising events (e.g., venue reservation and snack preparation for the event) to complement the unmet medical crowdfunding funding goal.

Practical assistance: All six supporters who provided external practical assistance were close ties of the beneficiaries. They had offered pet or babysitting, food, an alternative therapy, or hospital visits. The beneficiary participants also had received gifts such as flowers for a memorial and help with chores. External practical support often occurred when the fundraising descriptions and updates signaled concrete ways to assist. Although medical crowdfunding campaign interfaces do not directly mediate this external practical assistance, the fundraising description provided detailed information about the medical, life, and financial situations of the beneficiary. This description led close supporters to contact the beneficiary privately, via Facebook messages or phone calls, and offer support. For example, one close supporter supplied food to the beneficiary because her fundraising pitch described that she would use the collected funds to buy basic necessities, including food.

Sometimes updates on the campaign site, such as a successful surgery or discharge from the hospital, enabled supporters to plan visits. Even close supporters who already knew about the beneficiary's medical updates found the campaign description and updates helpful to better understand the beneficiary's needs, emotions, and thoughts: *"I guess I knew his issue a little better because obviously when I am with him, I don't want to steer the conversation towards his medical ailment. [...] I guess having the campaign laid out and having everything written out in his words, you know what isn't [an] okay topic to talk about"* (S5).

In general, supporters provided external practical support instead of monetary donations for two reasons. Some lacked the financial resources to donate money. Others believed this external practical assistance had equal, or more value than monetary donations. For example, S12 said

she chose to offer free professional pet sitting to the beneficiary instead of a monetary donation because she had been paid to take care of the beneficiary's pet before. She explained that offering free pet sitting was more valuable than a monetary donation because finding a professional pet-sitter like her would be difficult. Five of the close supporter participants offered external practical support in addition to a monetary donation. Their motivation was to help beneficiaries as much as possible. However, they also noted that the visibility of a monetary donation on the campaign interface made them feel obligated and pressured to donate money even though they had already provided external support, which is invisible on the campaign interface.

Supporters who did not provide any external practical support ascribed this to not knowing the beneficiary's needs and/or to their distant relationships with the beneficiary. Even supporters who did provide external practical support explained that they were especially cautious about deciding the kind of support to offer. They wanted to offer the support that beneficiaries really needed and were willing to accept. This is why they initially contacted beneficiaries to ask them about their additional needs: *"I just wouldn't want to over step my boundaries if it wasn't something they [the beneficiaries] weren't comfortable with"* (S4).

All of our supporter participants' external support was accepted by the beneficiaries. Beneficiary participants also appreciated receiving external practical support from their close supporters as it reduced external expenses. However, B1 described that, at one point, she had to turn away offered food because she already had enough.

Organizing and participating in external fundraising events: Five participants organized or participated in external fundraising events to raise more money to complete the medical crowdfunding goal amount. Close supporters held external fundraising events because they believed donating their time, effort, and talents to organize external fundraising events could result in the collection of a larger amount of money than what they could donate individually. The fundraising events took place at local coffee shops, bars, or restaurants. Close supporters invited potential supporters by distributing posters to nearby businesses as well as creating a Facebook event page. In this manner, distant supporters and strangers made monetary donations through external fundraising.

Benefits (RQ2)

We uncovered benefits that both the beneficiary and supporter participants perceived while participating in support activities.

Benefits for Beneficiaries & Supporters: Perceived Credibility

All of our supporter participants trusted the campaigns they donated to because the campaigns were for beneficiaries they knew or were shared by their close friends. Further,

publicly visible donor names and donation amounts on a crowdfunding page made them perceive the campaigns as more credible than fundraising through private methods such as using a PayPal account. Although most donors had concerns about the fees³ that crowdfunding sites take from their donations, they used crowdfunding sites because of their convenience and because their public donations would signal their support.

Benefits for Beneficiaries: Unexpected Support from Distant Supporters and Strangers

All of the three beneficiary and five supporter participants were surprised to see financial and emotional support from distant supporters and strangers. B2 described the pleasure she felt when reading the many encouraging messages left on her Facebook Timeline by people who have similar medical conditions or who have family with similar medical conditions. She even formed a new friendship with some of the strangers while answering their questions about buying a service dog: *"I got to hear so many stories from, like I said, strangers that I had never met. Talking about their nephew who is diabetic and having the same struggles, and how inspiring I am. [...] I got to know these people on like a more personal level through this campaign"* (B2).

Medical crowdfunding campaigns also resurfaced the beneficiary's more distant and dormant connections, increasing their social capital. The campaigns enabled our beneficiary participants to re-connect with their distant friends and/or close friends who they had not contacted in a while. For example, one supporter described that she grew closer to her friend again because she contacted the beneficiary via a phone call for the first time in a long time after discovering her medical crowdfunding campaign on Facebook. Since then, they have maintained regular contact. B3 also noted that receiving monetary donations and encouraging messages from her distant friends was one of the greatest benefits that she experienced from medical crowdfunding: *"Maybe one of my Facebook friends shared and then someone else donated that I just knew in high school but I wasn't Facebook friends with. Then I've gotten back in contact with them. It's kind of nice"* (B3).

The unexpected amount of donations also surprised our three beneficiary participants. B2, a participant with Type 1 diabetes noted that she was surprised to receive a donation from a stranger, a couple who donated \$5000, half of the cost of the diabetes alert dog she needed. She later learned that the donor's son had died of the same medical condition. The donor invited B2 to a golf outing that the donor's family organized in their son's memory. The donor's family had previously donated all the proceeds to a charitable organization funding Type 1 diabetes research. However, when they discovered B2's medical crowdfunding campaign via a friend, they decided to donate

³ GiveForward, GoFundMe, and YouCaring take 8%, 7%, and 4% respectively.

the proceeds to B2's campaign. The donor noted that contributing to B2's campaign made them feel more satisfied because their donation made a more personal and immediate impact on Type 1 diabetes. They wanted to see B2 succeed and continue her life: *"It was an incredibly overwhelming experience, like it's hard to describe. [...] I would probably say like 20% maybe came from people I didn't know"* (B2).

Benefits for Beneficiaries & Supporters: Triggering External Support

Some supporter participants who could not afford to donate devised alternative ways to assist beneficiaries. One beneficiary appreciated the supporters' offerings in place of monetary donations: *"There was a couple people who said, 'I can't give money but I'll make cupcakes for the memorial or if you need a babysitter.' [...] It seemed like people would still continue to offer things if they couldn't donate money because a lot of people can't donate money"* (B1).

Our supporter participants also valued organizing and participating in offline fundraising events. Supporter participants who organized offline fundraising events enjoyed seeing other supporters around the beneficiaries: *"The fundraiser they had at the coffee shop, the food and drinks to sell and the artists come in and selling their art and crafts things like that to help him raise money. I've never would have been that creative and it was so cool to just see all of that. And, it was really an amazing reflection of his friends"* (S6).

Challenges (RQ3)

In this section, we address various challenges that beneficiaries and their supporters faced while participating in medical crowdfunding campaigns.

Challenges for Beneficiaries: Perceived Social Stigma

All of the beneficiary and four supporter participants described the beneficiary's concern about the possible social stigma of revealing one's personal medical and financial situation. For example, B1 raised funds for her stepbrother's funeral costs. Because he died of a drug overdose, her brother's biological family did not like the campaign, preferring to keep the reason for his death private. While she dealt with the emotional difficulties of losing her brother, she also had to reconcile these conflicting opinions within her family.

All three beneficiaries in our study were concerned that people who saw their campaign might perceive their medical problems as unimportant or as something that the beneficiaries could afford themselves. For example, B2 who has Type 1 diabetes started a campaign to buy a diabetic alert dog that could notify her of changes in her blood sugar levels. The dog cost approximately \$10,000, so although she needed it, she was afraid that others might think the dog was unnecessary. The other two beneficiaries were afraid that people might start to judge the source of their money whenever they traveled, bought clothes, or went to a restaurant: *"It seems like people are scared to ask*

for help. They're scared of the judgment of why are you asking for money; or say you post on Facebook that you went to dinner with a friend, they're worried that somebody's going to be like, 'How could you afford dinner but you're asking for help'" (B1).

Challenges for Both Beneficiaries & Supporters: Uncertainty about the Potential Impact of Sharing

Beneficiaries faced challenges in estimating their audience's size and interest on Facebook. They did not know which of their Facebook friends would see their status updates when publishing the campaign. And beneficiaries were concerned whether their supporters would care enough to click the link and read their campaign: *"I'd put a lot of time into writing out why I thought this was important and why I thought people should donate, but then you share it on Facebook and how many people actually read your statuses, I don't know"* (B2).

For some family members who kept their family member's medical condition private, sharing a campaign for the first time on their social network required courage. They were concerned with how their social network would respond to their shared campaign. However, once they shared the campaign on Facebook, they were surprised to see their friends' willingness to support them. One of our participants explained that he was impressed with his friend who donated money to a campaign even though she was not in a good financial situation: *"He was kind of embarrassed by the whole thing [medical crowdfunding campaign]. He was against the whole sharing and like, 'What is it really going to do? People are only going to donate because they feel bad,' but obviously people are very encouraging"* (S5).

Five of six distant supporter participants did not share the campaign on their social media sites, assuming that most of their friends would not be interested in donating to this campaign because they would not know the patient. Alternatively, some perceived sharing the campaign as excessive because many of their social media friends had already publicized it. However, our findings indicate that even distant supporters often donate to a campaign when it is shared many times in their social network.

Challenges for Beneficiaries: Social Cost

Our participants also mentioned the perceived social cost they felt when directly asking for donations or when sharing a campaign multiple times. Perceived social cost is defined as the favor-asker's perceived value of their friend's time and effort expending to respond to their favor [27]. For example, although participants wanted to share a campaign several times on Facebook, they were worried about bothering their social network. Instead of directly asking for money, B2 shared updates about her journey to purchase a service dog and mentioned her crowdfunding campaign. B1 explained on social media that she understood that some could not donate and asked them to share her campaign on social media instead. Four out of twelve supporter participants who promoted campaigns

signaled their support with endorsements, such as messages expressing how much the patient meant to them. In addition, they explained why the campaign was worthwhile: *"My twin sister posted the link and said like, 'Oh I'm really proud of Jane for following her dreams. Help her.' That was nice. It was nice having other people advocate for me because it's just a little awkward writing down my own campaign"*(B3).

Challenges for Close Supporters: Social Pressure from Expectations

Close supporters struggled with the fact that donations on a crowdfunding page were publicly visible. They stated that this increased social pressure for them to donate money. Close supporters who could not afford to donate felt pressured since they saw their mutual friends' donations on the campaign page. They mentioned that not only the beneficiaries but also other mutual friends would expect a monetary contribution and wonder why they did not donate. Although the patient's close supporters provided external support to the patient (e.g., visiting their hospital), the publicly visible donations made them still feel guilty for not donating money or even for donating less than their mutual friends: *"Seeing everybody donating, you felt kind of pressured into it. [...] It's not only about his brother [the patient] seeing you donate but also other people seeing you"*(S5).

DISCUSSION

While medical crowdfunding campaigns explicitly requested monetary donations, supporters provided that and more. They contributed by volunteering, such as assisting in the creation of campaigns, promoting campaigns, and supporting externally. The broad range of volunteering contributions occurred because medical crowdfunding beneficiaries felt a sense of social stigma when soliciting monetary donations for themselves from a wider audience. Thus, supporters often created and promoted campaigns on behalf of beneficiaries to maintain their integrity. Supporters also actively participated in promoting campaigns in both online and offline communicative channels in order to reach out to as many potential donors as possible. Such promotional practices enabled supporters to leverage resources (e.g., time, money, and knowledge) to further fulfill the beneficiaries' peripheral needs, which included holding external fundraising events.

Some of our findings resonate with Carpiano's framework describing how social capital and social cohesion influence social support for health [5,9]. Our results showed that the amount of support beneficiaries can access depends on their social capital (i.e., resources within their social network) and social cohesion (i.e., trust within their social network). Our participants described those who gave the beneficiaries campaign creation, promotion, and external support as a very supportive family and/or as small-town neighbors willing to participate in each other's lives. Moreover, the close supporters' interactions with potential donors

impacted the beneficiaries' social capital by expanding supportive social networks. For example, close supporters who promoted the campaign by saying "good things" about the beneficiary encouraged their friends to contribute money even though their friends were strangers to or distant friends of the beneficiary. In other cases, our beneficiary participants received monetary donations from some acquaintances and strangers, and they even formed friendships with some of them.

Medical crowdfunding campaigns increase beneficiaries' social capital, but could be designed to promote more social capital. For example, social capital increases with reciprocal interaction between individuals [6]. However, interactions between medical crowdfunding beneficiaries and supporters are often asymmetrical on crowdfunding interfaces. While supporters publicly signal individual monetary contributions on the site, some beneficiaries respond primarily with public updates, while others send individual messages. Researching how this asymmetry in communication between beneficiaries and supporters impacts interaction is an area for future work. Designing interfaces to support more reciprocity could help beneficiaries build more social capital.

Some of the support activities identified in our study closely related to entrepreneurial crowdfunding support activities [19]. The two support activities in our finding—creating campaigns and promoting campaigns—correspond to the three support activities in entrepreneurial crowdfunding work—"prepare", "test", and "publicize" campaigns [19]. According to Hui et al., entrepreneurial fundraisers obtain professional support from their social network to create a more appealing campaign and publicize the campaign to a wider audience [19]. We found that supporters in medical crowdfunding campaigns helped beneficiaries in a similar way with the goal of maintaining the integrity of the beneficiary. Beyond what Hui et al. identified, our study uncovered that medical crowdfunding supporters voluntarily provided more personal levels of external support such as visiting a beneficiary in the hospital.

Similar to past work in philanthropic crowdfunding [33], our study also showed that voluntary contributions from many supporters highlighted the size and commitment of the beneficiary's social network and signaled the worthiness of their cause [33]. For example, supporter participants sensed that a beneficiary is a *"really great person"* (S3) worthy of their support when many friends shared a campaign. Such collective evidence of a beneficiary's worthiness of support has been referred to as a collective endorsement [18]. Tanaka and Volda have further shown the importance of "legitimacy work," that is, the work needed to establish the legitimacy of a philanthropic campaign [20]. However, this legitimacy work has not been emphasized on current crowdfunding platform interfaces. Tanaka and Volda explained lack of support for non-

monetary forms of donations in crowdfunding interfaces could decrease the legitimacy of the crowdfunding platform [20]. Beyond decreasing legitimacy, our study also showed that the lack of external support in the medical crowdfunding interface made some of the close supporters feel pressure to give monetary donations even when they had already provided external support. In the next section, we discuss ways to better recognize volunteering contributions in medical crowdfunding interfaces.

Design Opportunities & Challenges

Despite the variety of volunteering work that supporters could contribute, current medical crowdfunding platform interfaces emphasize only momentary contributions. As a result of this design, two major social issues emerged: (1) the beneficiaries' close supporters expressed social pressure to give monetary contributions and (2) the beneficiary and supporter participants struggled to understand the potential impact of promoting campaigns. To mitigate these challenges, we suggest ways to better recognize external support and campaign promotions on campaign interfaces. However, there are also challenges in deciding what volunteering contribution signals should be made visible [24]. Thus, we also discuss the anticipated challenges and possible future research.

Mediating and Recognizing External Support

Our study showed that medical crowdfunding campaigns' descriptions signaling the needs of beneficiaries led some supporters to give the beneficiaries external support (e.g., serving food, looking after a pet, or planning a local fundraising event). However, one of the beneficiary participants described having to turn away offered food because it had already been taken care of. This finding suggests two possibilities to improve the current medical crowdfunding interface design: 1) scaffolding fundraisers to more explicitly specify the beneficiary's needs that can be supported outside of medical crowdfunding (e.g., offline) and 2) allowing supporters to sign up for the external support opportunities. This interface may serve two benefits for both beneficiaries and supporters. First, because supporters who signed up for external support are visible on the campaign interface, it may mitigate the close supporters' social pressure to donate money via medical crowdfunding if they have already provided external support. Further, supporters can better arrange the external support while avoiding overlapping contributions.

Other types of online health communities such as *Lotsa Helping Hands* [41] and *Caring Bridge* [40] function as shared calendars and health journals that allows patients and their family to coordinate help, send health updates and to receive encouraging messages. Previous research has also examined how the families collaboratively cared for patients by listing their needs on a Facebook page [29] or by sharing a paper-based or digital calendar [3]. Similar to these online care calendars and message boards, medical crowdfunding campaigns could integrate external support

activities to better acknowledge the supporter's external contributions.

However, the decision of what features to make visible and invisible is fraught with design challenges [32]. A fundamental concern deals with the funding models of existing medical crowdfunding systems. As previously discussed, these sites are funded from fees for all donations. Thus, while crowdfunding sites are interested in encouraging a large number of visitors and encouraging trust, they may not want to host long-term users, as such users add resource costs without making further monetary donations. We propose medical crowdfunding fundraisers incorporate links to volunteering-focused sites while making this other external support more visible.

Despite this possible issue, GiveForward, one of the biggest medical crowdfunding sites, recently started integrating external support with their "Give a Meal" and "Wishlist" features. Future studies should investigate how supporters use such integrated features and how they impact both monetary donations and volunteering contributions in crowdfunding campaigns.

Highlighting the Impact of Campaign Promotion

We suggest design opportunities to help patients better understand their audience and the benefits of promoting their campaigns.

Visualizing campaign promotion networks: In line with the previous research about the invisible audience [4], our participants had difficulty understanding their audience. Our beneficiary participants discussed how they wish they knew their audience size and interest, to better target the writing on their medical crowdfunding campaign page. For fundraisers who have a significant number of campaign promotions, showing them a network of who had shared their campaign and to whom they shared it, might help them understand this. It may also help fundraisers target the right social media channels for promotion. A visualization analogous to Google+'s Ripple highlighting information flow [35] could be adapted to visualize these *sharing networks*.

There are a number of risks associated with such a visualization, however. If few people share the medical crowdfunding campaign, beneficiaries and their close supporters might be discouraged. As beneficiaries receive collected funds regardless of whether they reach their fundraising goal, it might be preferable to provide users with a plausible deniability where they are uncertain who has seen or shared a campaign. And as potential supporters might not see all shared campaigns (particularly on filtered feeds like Facebook [13]), beneficiaries might be offended by incorrectly believing someone had seen their campaign but chosen not to support or contact them. Considering the possible issues, future research should investigate ways to visualize the networks of campaign promoters to help beneficiaries better understand their audience.

Emphasizing the value of campaign promotions: Another finding of our work was that supporters typically undervalue sharing activities, feeling that only donations are valued (as they are the focus of current interfaces) and expressing guilt if they could not donate or felt they had donated too little. Thus, supporters might also benefit from better visualizations of the value of sharing. For example, prompts for sharing could include the average value of a share (e.g. “Your share is worth \$5 on average!”) or even more personalized information; a logged-in supporter might be shown the total amount all the friends they shared with have donated to the campaign or the number of times those friends have shared it.

However, while this might motivate supporters to share more, that is not necessarily preferable. For example, many beneficiary participants expressed concerns about their medical information being shared with others. Gamifying the donation sites or encouraging indiscriminate sharing might therefore have negative repercussions for beneficiaries. While medical crowdfunding websites wish to gather more donations, this goal must be balanced against the privacy needs of the beneficiaries. Thus, decisions of what signals of campaign promotions should be made visible must be thoroughly considered.

LIMITATIONS

One of the limitations of our study is the small number of beneficiary interviews. Despite a broad recruitment call on University public lists, reddit, Facebook, Craigslist, messages on crowdfunding sites, and referrals from our participants, we recruited only three crowdfunding campaign beneficiaries. The challenges beneficiaries face with their medical situations may be one reason for this low response rate. We attempted to overcome this limitation through in-depth interviews with our beneficiary participants that lasted approximately 75 minutes on average and with six supporter participants who were close friends with the beneficiaries.

Furthermore, our participants may not be representative of the demographic of medical crowdfunding users. All but one of our participants was female. Also, all of our participants perceived the campaigns that they participated in as successful. Thus, the perceived benefits and challenges that our participants had experienced in medical crowdfunding could be different from those who perceived their campaigns to be unsuccessful. Moreover, our results showed that beneficiaries with a large support network are likely to receive more monetary donations via medical crowdfunding. However, those who have a smaller support network may actually need more support. Future research should investigate ways to help those populations through medical crowdfunding.

CONCLUSION

In this study, we uncovered *who* a beneficiary’s supporters are, *what support* they provide, and *why*. Although patients and their families expressed concerns about sharing medical

information publicly and being judged for soliciting money, we found supporters provided both monetary and volunteering contributions that helped beneficiaries and their families overcome their concerns. The emphasis that medical crowdfunding platforms place on monetary contributions made some close friends feel pressured to donate money they could not afford. Thus, we suggest making supporters’ volunteering contributions more visible. We further discuss that deciding what signals to make visible or leave invisible is fraught with challenges and will require further research.

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