Short communication

Fund my treatment!: A call for ethics-focused social science research into the use of crowdfunding for medical care

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A B S T R A C T

Crowdfunding involves raising money from large groups of individuals, often through the use of websites dedicated to this purpose. Crowdfunding campaigns aimed at raising money to pay for expenses related to receiving medical treatment are receiving increased media attention and there is evidence that medical crowdfunding websites are heavily used. Nonetheless, virtually no scholarly attention has been paid to these medical crowdfunding campaigns and there is no systematic evidence about how widely they are used and for what reasons, and what effects they have on the provision of medical care and individuals' relationships to their health systems. Ethical concerns have been raised in relation to these campaigns, focusing on issues for campaigners and donors such as exposure to fraudulent campaigns, loss of privacy, and fairness in how medical crowdfunding funds are distributed. Medical crowdfunding websites themselves have not been systematically studied, despite their significant influence on how these campaigns are developed and promoted. In this paper, we identify three very broad and pressing ethical questions regarding medical crowdfunding for social scientists to address and offer some preliminary insights into key issues informing future answers to each: Who benefits the most from medical crowdfunding and how does medical crowdfunding affect access to medical care; How does medical crowdfunding affect our understanding of the causes of inadequate access to medical care; and How are campaigner and donor privacy affected by website design? Our observations indicate the need for increased scholarly attention to the ethical and practical effects of medical crowdfunding for campaigners, recipients, donors, and the health system as a whole.

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1. Introduction

Crowdfunding involves raising money from groups of individuals, often through the use of websites dedicated to this purpose. Crowdfunding campaigns aimed at raising money to pay for expenses related to medical treatment are receiving considerable attention in the media in many countries (Bourque, 2015; Romm, 2015; Delaney; Almanac, 2945; British Woman Paralysed i, 2016). Reasons people use crowdfunding to cover their medical expenses vary, but can include lack of insurance coverage for medically essential or non-essential care, meeting needs related to actually obtaining medical care such as travel costs and time off work, and obtaining funding for unproven interventions at home or abroad (Sisler, 2012; Snyder, 2016). Many different forms of medical-related needs can be crowdfunded, but campaigns for funds for exceptional and acute needs are thought to be more common and more likely to be funded than chronic needs (Gustke, 2015).

Dedicated crowdfunding websites are heavily used for the purpose of medical crowdfunding. For example, in April 2016 the crowdfunding website YouCaring had 15,880 active medical campaigns, joined by FundRazr with 5326. Another crowdfunding website, GoFundMe, reports that medical crowdfunding campaigns on that site increased from 8000 raising $1.6 million in 2011 to over 600,000 raising nearly US$150 million in 2014, making this their largest category of crowdfunding for personal use (Chandler, 2015). Similarly, the website GiveForward reports that medical-related needs are its most popular form of crowdfunding campaign (Gustke, 2015). Growth among these websites is expected to continue at a 25% annual rate (Simon, 2016). Nonetheless, virtually no social science research attention has been paid to these medical crowdfunding campaigns and little is known about how widely

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they are used, for what reasons, and what effects they have on the provision of medical care and individuals' relationships to their health systems.

Medical crowdfunding has the potential to increase access to medical treatment and, in some cases, prevent or reduce extreme financial hardship associated with accessing medical care such as recourse to 'medical bankruptcy' (Burtch and Chan, 2014). However, ethical concerns have been raised in relation to these campaigns, focusing on issues for both campaigners and donors such as exposure to fraudulent campaigns, loss of privacy, and fairness in how funds are distributed (Snyder, 2016). Meanwhile, systematic attempts to understand the scope and scale of these ethical concerns through research are lacking. For example, a search of Google Scholar using "medical" and "crowdfunding" returned only 3 results focusing specifically on crowdfunding for medical expenses rather than research. We think that social scientists are well positioned to generate new knowledge about the ethical dimensions of medical crowdfunding given their interest in the social dimensions of health and the range of methods used by their affiliated disciplines. For example, health geographers can shed light into the spatial dimensions of these campaigns, helping us to understand the geographic extent of the typical donor network from an ethics of care approach. Health economists and health policy experts can provide valuable insights into regulatory dimensions of medical crowdsourcing and the sometimes competing interests of the different parties involved. As a final example, medical sociologists can assist us in understanding how factors such as hope and compassion drive people to donate to campaigns of people they have never met. Here we identify three very broad and pressing ethical questions regarding medical crowdfunding for social scientists to address and offer some preliminary insights into key issues informing future answers to each: Who benefits the most from medical crowdfunding and how does medical crowdfunding affect access to medical care; How does medical crowdfunding affect our understanding of the causes of inadequate access to medical care; and How are campaigner and donor privacy affected by website design? We conclude by further articulating our call for social scientists to meaningfully participate in this new research area.

2. Who benefits the most from medical crowdfunding and how does medical crowdfunding affect access to medical care?

Medical crowdfunding is ostensibly for the benefit of the campaign's recipient, who can be the individual running the campaign or, as is more common, a third party such as a friend or relative of the campaigner. These websites typically advertise low barriers to setting up a campaign, noting that "signing up is free" www.gofundme.com (accesse) or that "Anyone can start a FundRazr campaign and tell their story in minutes for FREE" (www.fundrazr.com (accesse). However, successful campaigns will forfeit significant portions of the funds raised to the hosting website and other parties. A 5% fee per donation and additional 2.9% processing fee and $.30 charge per donation is typical across these websites (e.g. CrowdRise, FundRazr, Generosity, GoFundMe, YouCaring). In some cases, additional credit card and money wire charges are applied as well, a fact that may not be apparent to users when initially setting up their campaigns. While many of these websites allow recipients to receive whatever donations are pledged to the campaign, in some cases funds are awarded only when a target goal is reached (Sisler, 2012). While it is not unreasonable that these for-profit companies should charge fees for the service they provide, the language used on these websites often masks how large these fees are.

Medical crowdfunding companies face problems with the fraudulent use of their websites. Past cases have included campaigners misusing donated funds by lying about their own illnesses, creating fake campaigns for genuinely ill friends or relatives, and using funds for other than the purpose promoted in their campaigns (Bourque, 2015; Snyder, 2016). While medical fraud exists outside of crowdfunding, its ability to appeal to persons without whom one may have a personal connection creates new opportunities for fraud and publicity around fraud may discourage future giving (Sisler, 2012). Many victims of these fraudulent campaigns have found the medical crowdfunding websites on which they were hosted of limited help in preventing or ending fraud, including one case where the website GoFundMe did not intervene against a campaign set up to aid the family of an auto accident victim where the family had no connection to or contact with the campaigner (Simon, 2016). While these websites often request or require that campaigners link a Facebook or other social media account to their campaign in order to verify their identify, these social media sites similarly do not verify the identity of their users, allowing for easy misrepresentation of the identity of the person organizing the campaign.

Crowdfunding websites typically place restrictions on the purposes for which funds raised through campaigns can be used. Generally, these restrictions take the form of blanket prohibitions against violations of "all applicable federal, state, provincial, territorial and local laws and regulations" (www.crowdrise.com/about/t). While these legal restrictions may not seem ethically problematic, they may be used to restrict campaigns for medical services that are illegal in the recipient or donor's home jurisdiction but legal elsewhere, such as for reproductive services or gender reassignment treatments. Some websites have additional restrictions, such as GoFundMe's prohibition against campaigns for "offensive, graphic, perverse or sensitive content" and, specifically funding to pay for an abortion (www.funds.gofundme.com/in). YouCaring similarly restricts "divisive" campaigns, giving the example of funding for abortion (Romm, 2015). These restrictions are only listed in the terms and conditions statements, meaning users will likely be unaware of them when organizing fundraising campaigns. Moreover, crowdfunding websites actively promote and partner with social networking sites like Facebook and Twitter, each with their own limits on the use of their services. Similarly, banking and credit card companies that process donations can impose their own limitations, shifting control over what medical treatments may be funded away from campaigners.

3. How does medical crowdfunding affect our understanding of the causes of inadequate access to medical care?

The language used on Crowdfunding websites emphasizes that donors are more likely to give to campaigns for recipients with whom potential donors sympathize. Rather than focusing on the gravity of the recipient's need, focus is shifted to the emotional pull of the recipient's situation. For example, CrowdRise provides a template for creating "compelling" campaigns for raising funds for persons with cancer described in terms of helping "victims pay the bills" (www.crowdrise.com/medical). This website focuses on other sympathetic classes of recipients as well, giving examples of helping veterans ("how can you support our troops?") and the families of injured persons (www.crowdrise.com/medical). The landing pages of these websites' medical crowdfunding areas regularly feature emotionally compelling images and videos of campaigns for sick children.

Medical crowdfunding websites tend to use language that portrays the need for donations as resulting from an emergency or unforeseeable event rather than due to systemic problems leading to inadequate medical care for campaigners. This language echoes