The Ethics of Privacy in Charitable Crowdfunding for Oneself Using Semi-Structured Interviews with 24 Participants

by

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Abstract

The practice of donation-based crowdfunding has grown rapidly in recent years, with more than US$30 billion raised, in donations, on GoFundMe alone. Online donation-based crowdfunding campaigns can be created for oneself or on behalf of others to seek donations from friends, family, and the wider public. Crowdfunding campaigners experience significant pressure to share substantial financial, medical, and other personal information as part of their crowdfunding campaigns. Due to this pressure, privacy-related concerns in crowdfunding are widespread. However, to date there has been limited research exploring the privacy-related impacts of crowdfunding. To address this gap, interviews were conducted with 24 crowdfunding campaigners who were crowdfunding for their own health- and housing-related needs. First, these interviews were analyzed to determine the privacy-related concerns of campaigners and the advice they had for others considering crowdfunding. Second, interviews were analyzed to determine how the approach campaigners took to privacy in everyday life functioned in the context of crowdfunding, while campaigners experienced various forms of tension and pressure. Our evidence shows that giving up personal information related to basic living needs can heighten campaigners' vulnerability and elicit questions, judgement, and probing from members of the public. Openly displaying information that is considered intimate and sensitive not only leads to a loss of informational privacy for campaigners, but also compromises the ability of campaigners to make autonomous privacy-related decisions.

Keywords: Crowdfunding; Charitable Crowdfunding; Privacy; Medical Crowdfunding

Dedication

This thesis is dedicated to all those struggling for a better life in Canada.

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Chapter 1.   Introduction

Crowdfunding can be divided into donation-based crowdfunding and rewards-based crowdfunding. Donation-based crowdfunding involves donating to crowdfunding campaigns without expecting any benefits in return (1). Due to the ease with which people can create a crowdfunding campaign and request donations, donation-based crowdfunding has become a popular way of addressing people's needs (2; 3). People can create donation-based crowdfunding campaigns to raise funds for medical services, rent, and other basic living necessities (4). Other benefits of crowdfunding include supporting the ability of campaigners or beneficiaries to form a social network with others experiencing similar challenges (5). Despite the clear benefits of crowdfunding, there are many concerns associated with this practice.

First, researchers have documented deep inequities in the distribution of funds raised through crowdfunding. Crowdfunding success is often dependent on the reasons of campaigners for creating a crowdfunding campaign, the personal attributes of the campaigner or beneficiary, and the ability to craft a compelling campaign description (6-8). People with various privileges, such as a larger social network and media literacy are more likely to have crowdfunding success (6;8). Second, crowdfunding tends to mask the deeper injustices that have led to a need to crowdfund (4;9;10). Many researchers have highlighted how campaigners, crowdfunding for basic living necessities, usually frame their needs as arising due to misfortunate or bad luck, and not due to the shortcomings of the host country's social system. Third, campaigners face significant pressure to disclose highly personal information (1; 4;11). This is encouraged by crowdfunding platforms, such as GoFundMe, to convince potential donors to contribute to campaigns.

Although many justice-related concerns have been associated with the practice of crowdfunding, the privacy-related dimensions of crowdfunding have received less attention. As campaigners face pressure to disclose highly personal information while crowdfunding, it is important to understand the privacy-related consequences of this practice. The limited existing evidence reports that campaigners undergo a privacy-calculus where they weigh the costs of crowdfunding with its perceived benefits (5;12).

However, this existing research does not provide an in-depth analysis of crowdfunding campaigners' privacy-related concerns, tensions and pressures, and their specific privacy-related decisions to navigate these challenges. Further, it is important to understand the extent to which these concerns and decisions vary depending on the demographic characteristics of the campaigner, and their reasons for creating a crowdfunding campaign.

To address this knowledge gap, a larger research project has been funded by the Social Sciences and Humanities Research Council of Canada (SSHRC). The aim of this project is to understand the perspectives of campaigners crowdfunding for themselves and on behalf of others, for housing- and health-related reasons in Canada. My thesis is embedded within this larger project and provides an overview of the perspectives and experiences of crowdfunding campaigners crowdfunding for themselves for housing- and health-related reasons. Further, the findings from this research contribute to addressing the research objectives of the larger project. These objectives are:

1. To explore and contrast the perspectives of crowdfunding campaigners for health- and housing-related needs on how crowdfunding impacts their medical, financial, personal, and familial privacy;

2. Comparatively understand how decision-making around, and consent to disclose, personal information is navigated by charitable crowdfunding campaigners campaigning on behalf of themselves versus those campaigning on behalf of others; and

3. Disseminate our findings to scholars in fields including applied ethics, anthropology, communications, criminology, law, and political science, among others; policymakers including provincial and national information and privacy commissioners; crowdfunding platforms, and the public to inform discussion of the privacy impacts of charitable crowdfunding.

This thesis contributes to these larger objectives by addressing three specific research questions that form the basis of Chapter Three and Chapter Four. Research question one and two are the focus of Chapter Three, while research question three is the focus of Chapter Four. These research questions are:

1. What types of privacy-related concerns do campaigners crowdfunding for themselves for health- and housing-related reasons have?

2. What advice do these campaigners have for others considering crowdfunding to address privacy-related concerns?

3. How do campaigners approach privacy-related decisions in everyday life, and how is this approach affirmed or challenged during the process of crowdfunding?

These research questions have been created with guidance from my supervisors, Jeremy Snyder, and Valorie Crooks. Both chapters have been submitted to peer-reviewed journals, in the form of scholarly articles. Further, the findings have informed the development of specific recommendations provided in the discussion section of Chapter Three and Chapter Four. These policy-related or other changes could allow for campaigners to have a safer crowdfunding experience, and support Canada's goals of creating a just and equitable society (13).

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Chapter 2.   Literature Review

Giving practices can vary depending on an individual's community, cultural background, and religion. In Indigenous communities across Canada, giving is integral to creating and maintaining relationships and is not necessarily related to poverty (1). Giving can be divided into direct giving and indirect giving. Direct giving is the practice of giving to individuals in need (2). Indirect giving involves giving to intermediaries, including religious institutions or charitable organizations, which then decide how to distribute funds (2). Direct giving can create a hierarchical relationship between the donor and beneficiary, as the donor is viewed as being more moral and praiseworthy (3). Although indirect giving is a solution to the hierarchical nature of direct giving, it also raises concerns. One concern related to indirect giving is the potential for wealthy donors to influence the missions of charitable organizations (4). Thus, these different forms of giving involve various social, ethical, and practical implications (4).

With recent technological advancements, online crowdfunding has replaced the more traditional forms of giving (4). Michael Sullivan coined the term *crowdfunding* in 2006 (4). Generally, crowdfunding is divided into equity-based crowdfunding and donation-based crowdfunding (4). Equity or rewards-based crowdfunding involves donors investing in campaigns, usually new ventures or businesses, in exchange for various benefits. Donation-based crowdfunding, which is the focus of this thesis, involves gathering donations from friends, family, and members of the public without providing any benefits to donors. The practice of crowdfunding has been described as democratizing giving by allowing people from all backgrounds to participate as donors and recipients, and by encouraging donations of both large and small amounts (5). The first donation-based crowdfunding platform was CreateAFund, which allowed charities to create an online presence. CreateAFund had little success and was transformed into GoFundMe (6; 7). Through GoFundMe and other crowdfunding platforms, crowdfunding campaigns can be created for oneself, on behalf of others, and for specific organizations working to address a variety of causes (4; 8).

In the English-speaking world, influential crowdfunding platforms include GoFundMe, Kickstarter, and Fundly. These platforms are joined by others worldwide, including Milaap in India, Tencent in China, and Blue Bees in France, among many others (9; 10; 11). In North America, the largest charitable platform is GoFundMe, which on their website mentions that "more people start fundraisers on GoFundMe than any other platform" (12). Worldwide, the practice of crowdfunding has risen exponentially. GoFundMe alone has raised approximately $30 billion in donations (13). The popularity of crowdfunding is related to the fact that it eliminates some of the barriers in traditional forms of giving. These barriers include the relationship asymmetry between beneficiaries and donors and the elitism that can result when giving is exclusive to relatively wealthy people, as described earlier (14; 4).

Given the online nature of crowdfunding, some of its most visible benefits are the ease with which individuals can create a crowdfunding campaign, request donations from around the world, and donate to campaigns that are many miles away (15;16). According to GoFundMe, raising donations through crowdfunding involves three basic steps: 1. create a campaign that tells your story and provide pictures; 2. share the campaign on other social media sites or through text or email; 3. accept donations and withdraw funds (12). As a result, charitable crowdfunding has been a popular way of raising funds for communities or individuals affected by crises or natural disasters. For example, on GoFundMe's website one person described raising $10,000 in 48 hours for their nephew's medical needs (12). During the COVID-19 pandemic, the CEO of GoFundMe described an alarming increase in campaigns (17). These campaigns focused on raising funds for rent, medical reasons, and many other causalities attributed to the COVID-19 pandemic (17).

Although a clear benefit of crowdfunding is its ability to facilitate fundraising for a variety of needs, research has indicated other benefits as well. For example, Gonzales et al. (18) conducted semi-structured interviews with 24 campaigners to understand their experiences while participating in crowdfunding. Their research found that crowdfunding platforms, such as GoFundMe, deemphasized the transactional nature of donating by allowing beneficiaries or campaigners to stay connected to donors and regularly update

them about their situation (18). Some campaigners also noted that the practice of crowdfunding allowed them to be socially connected in times of crisis. This is important because many people feel isolated while going through challenging times, especially those that are experiencing physical or psychological difficulties that impede their ability to easily connect with others (18).

Crowdfunding platforms, such as GoFundMe, have established a reputation of being a safe and legitimate way to help others. For example, GoFundMe assures donors that they should not be worried about fraudulent campaigns, and to protect donors they have created a Giving Guarantee (19). According to this policy, donations can be refunded upon investigation of claims, if abuse or misuse of funds has occurred and claims are made within one year of donating (19). However, crowdfunding campaigners are encouraged to take personal responsibility of convincing potential donors that their needs are valid and deserving of support by creating an in-depth campaign description (8). Moreover, to answer campaigners' questions and provide guidance throughout the process of crowdfunding, GoFundMe has customer service agents that are available 24 hours a day and 7 days a week (20). Thus, crowdfunding can create a very consumer-friendly process that takes advances in online technology to streamline giving. Despite these benefits of crowdfunding, the need to crowdfund is best described as a symptom of structural injustice (4; 21; 22; 16; 23). Having to turn to crowdfunding in challenging times to meet basic living needs illuminates clear gaps in the social safety net of the host country (16;24).

Evidence has shown that crowdfunding is often unsuccessful in meeting the needs of individuals, and especially the needs of those who are most marginalized in society (25; 26). For example, Kenworthy et al. (26) showed that only 9.2% of people reached their crowdfunding campaign goal. Further, there are grave inequities in the distribution of funds, as it is up to the donor to determine which campaigns are more deserving of receiving help (15; 22; 16). Various factors related to the recipient or campaigner, such as gender, age, and ethnicity, can influence crowdfunding success (16, 25-28). One may assume that due to the inequities in society that make marginalized communities more vulnerable to not having their basic needs met, they stand to benefit

more from crowdfunding. However, traditionally marginalized communities are under-represented in crowdfunding, such as gender and ethnic minorities, and they often experience difficulties in raising donations through crowdfunding (26-27). For example, Barcelos & Budge (27) showed that compared to the general population, transgender people raised a lower percentage of their campaign goal (24% vs. 41%). In another study, being black was associated with recipients receiving $22 less per donation (26). Other factors that determine crowdfunding success are the wealth of the campaigner's social network, level of education, socio-economic status, and their ability to craft an emotionally compelling crowdfunding campaign (23; 26; 29; 28). Kenworthy et al. (28) compared two campaign descriptions and found that the more in-depth and descriptive campaign with seemingly compelling language was more successful at raising funds. Further, the number of times a campaign is shared on social media sites is also related to its likelihood of successfully raising funds (26; 27; 31). Thus, crowdfunding is usually most likely to meet the needs of individuals considered privileged in various aspects of their lives.

Media portrayals of specific communities as deserving of help can influence the likelihood of crowdfunding success, potentially disadvantaging stigmatized groups and needs (25; 28). Analyzing the types of needs that are more likely to accumulate financial support through crowdfunding reveals trends that mirror wider cultural norms (4; 15; 28). The effect of cultural norms on people's giving behavior is no surprise. Even in a universal health care system, which needs are considered essential is subject to deeply embedded cultural norms (28). This is rooted in neoliberal and austerity policies which support crowdfunding and reinforce the need to determine which communities or individuals are deserving of support (28). Crucially, the campaigns or needs that draw the most attention from donors may not be those that describe the most devastating situation or greatest needs (22 23; 25). Considering that people's giving behavior is largely based on the campaigner's story-telling abilities, these justice-related issues are often overlooked (23; 22). As Heller (23) writes, "the theatre of change trumps actual systemic reform" in that these campaigns tend to be superficial and personal and do not draw attention to systemic injustices (p. 21) Fulfilling the needs of individuals who are more privileged in terms of educational attainment or social connections through crowdfunding

can create a sense of inattentiveness to the root cause of crises (4; 23). Thus, crowdfunding could perpetuate a cycle of injustice for individuals marginalized in society.

While much of the attention on the ethical dimensions of crowdfunding has focused on concerns of equity and justice, it also has important implications for personal privacy. Privacy is a multidimensional concept that can be defined in varied ways. Roessler (32) uses an onion analogy to explain what is meant by personal privacy. The inside of the onion represents bodily privacy or intimate details of oneself, the second layer represents the family as private vs. public others, and the third layer represents control over interactions with civil organizations vs. interference from the state (p. 19). Further, the three major types of privacy are informational privacy, decisional privacy, and local privacy (33).

A complete definition of privacy usually involves a complex interaction of these various forms and types of privacy; however, some scholars have conceptualized privacy as either a negative right (e.g. the freedom from intrusion into one's personal space) or as a positive right that provides people with the ability to exercise their rights (e.g. facilitate the formation of a sense of self that is distinct from others) (34). Both forms of privacy contribute to individual rights. Privacy as a negative right involves the separation of physical space and information as public vs. private (34). This includes the ability to control access to medical, financial, and familial information (informational privacy), and the ability to control one's interactions with others (local privacy) (33; 34). Hence, in this way, a violation of privacy can occur when people's private space is violated or when sensitive information is made public.

Alternatively, privacy as a positive right describes the importance of privacy in forming and maintaining people's ability to live autonomously. This definition focuses on the importance of privacy in forming a sense of self, including the ability to think independently and make decisions for oneself (decisional privacy) (33; 34). In this way, a violation of privacy is not solely dependent on the violations of people's physical space or the public disclosure of sensitive information. For example, through this perspective

continuous surveillance would interfere with people's ability to act freely and autonomously (34). Privacy as an individual right recognizes the importance of allowing people to exclude others (negative right) and to gain independence (positive right). In this way, maintaining control over personal aspects of oneself allows people to act authentically and decide how to navigate their life (32;34).

However, some scholars explain the social importance of privacy as it allows for people to have multiple roles that are integral to the functioning of communities (34). The individual rights-based definitions of privacy are limited in their ability to explain the social role of privacy, and how privacy can be maintained after disclosing personal aspects of oneself, including information, to others (34;35). Considering technological advancements, including the rise of the internet of things, disclosures are a part of everyday life. Privacy as contextual integrity asserts that privacy varies depending on the context, and that disclosures do not necessarily threaten people's privacy. In this way, privacy can be maintained through following norms of appropriateness and norms of distribution, which vary depending on the context. This could also contribute to people's sense of self and autonomy, as described by the definition of privacy as a positive right (34;35). For example, sharing personal health records would still allow a person to maintain their privacy, whereas sharing this information with an employer can be seen as a violation of privacy. It is also important to consider that the norms of appropriateness and distribution can vary from time to time. Taken together, upholding people's privacy is complex and involves various factors.

Clearly, privacy can be defined in varied ways. Despite the disagreements that may arise when defining privacy, it is generally agreed that a loss of privacy can negatively impact many dimensions of a person's life. Harms related to giving up personal aspects of oneself can be especially worrisome in online environments, where personal disclosures are common practice (34). Ignoring norms of appropriateness or trust, related to dealing with people's personal lives, can lead to severe implications, impacting their integrity, ability to form relationships, and engage in society (34). Further, people often experience difficulties in deciding between protecting or disclosing personal information. According to Li (36) privacy-related concerns particularly arise

when people have an incomplete understanding of how their information will be handled; however, concerns can be minimized when online agents follow social norms, including the need to uphold the consent of consumers.

In practice, the basis of the value of privacy is typically not well articulated; rather, there is an expectation of a shared sense of its meaning and value. Some crowdfunding platforms ostensibly give users the information they need to navigate the impacts of crowdfunding on their privacy. For example, GoFundMe provides a Privacy Notice that outlines the terms and conditions related to participating in crowdfunding and that applies to campaigners, beneficiaries, and potential donors. This Privacy Notice specifically outlines the many ways GoFundMe can collect, store, and share the information individuals have disclosed to GoFundMe while donating or creating a crowdfunding campaign (20). More specifically, information included in campaign descriptions and any direct communications with GoFundMe or public communications, as described under the section titled "The Use of Personal Information Collected", can be used by GoFundMe (20). GoFundMe explains that such information is used for a variety of purposes, including communicating appropriately with service users, complying with local, federal, and statewide laws, and verifying the identity of users (20). Information collected by GoFundMe can be shared with other service providers that are affiliated with them. Entities that partner with GoFundMe but are not directly affiliated can also access information disclosed or posted by beneficiaries, donors, or campaigners (20).

Notably, GoFundMe indicates that all individuals donating, viewing, or creating a campaign, should be respectful. GoFundMe explains that "we reserve the right, but do not have the obligation, to review and monitor posting or any other content on our services, and to remove postings or content that may be viewed as inappropriate or offensive to others" (20, Section 5: Public Communications). As this above quote indicates, it is unclear how protected individuals participating in crowdfunding are from inappropriate behavior, as they clearly indicate that they do not have the obligation to review *all* content that could be considered offensive or inappropriate. Considering crowdfunding platforms are generally private, for-profit, enterprises, this is not surprising (20). These platforms benefit from people's misfortunes and injustices as they have

created the option of giving a voluntary tip to help support their operations (25; 37; 38). Further, various industries, such as pharmaceutical companies, can partner with crowdfunding platforms to influence their strategic direction (25).

Providing information related to how people's personal information is stored and shared may not be enough to protect the privacy of people engaging in crowdfunding. Considering the highly competitive environment of crowdfunding, campaigners experience various pressures and tensions during this practice. One such pressure comes from crowdfunding platforms explicitly noting the importance of creating an emotionally compelling story that will provide in depth coverage of their reasons for creating a campaign and motivate potential donors (4; 39). This pressure to create a compelling story of need exists in a context where people are often crowdfunding for immediate needs, such as medically necessary services. Despite Canada's commitment to supporting the livelihood of its most marginalised communities (40), individuals are forced to give up highly personal information to raise needed financial benefits that should be covered or provided by the social safety. (32; 41; 42). As Snyder (4) described on p. 1 of Chapter 2, creating a crowdfunding campaign "requires telling a story about the recipient's history that can expose their current emotional state, past traumas, family members' stories, and other intimate details."

Considering well-documented and publicized instances of fraud in crowdfunding, campaigners also experience pressure to establish the legitimacy of their campaign (22; 8). Zenone & Snyder (8) write that the three most prevalent forms of fraud within the practice of crowdfunding are: 1. faking one's own illness; 2. faking/exaggerating another's illness, and 3. impersonation. Due to this, people are often required to link their campaign to a social media account for verification purposes. Although verifying one's identity is important to prevent fraud, this could create tension for campaigners as they may not prefer to link their campaign with other public profiles. Interestingly, platforms such as Instagram, Twitter, or Facebook do not require individuals to verify their identity when creating a profile to prevent identity theft (38; 4). Thus, this approach to verifying a campaigner's identity could be inadequate for preventing fraud while still violating the privacy of genuine campaigners.

Notably, crowdfunding platforms, such as GoFundMe, do not encourage campaigners to consider the potential consequences of publicly disclosing personal information or to consider their own beliefs and values while doing so. This is important since the details disclosed in crowdfunding campaign descriptions are publicly accessible through the hosting platform's website. Although the use of any social media site can create negative impacts, the practice of crowdfunding is especially worrisome. This is because people are often creating crowdfunding campaigns while experiencing significant challenges and having limited options to meet their needs. Highlighting these pressures and tensions illuminates the struggle campaigners experience between protecting their personal information and maximizing donations, especially given the importance of privacy.

Researchers have focused on the privacy implications of disclosing highly personal information while participating in charitable crowdfunding. First, campaigners and recipients have described feeling uncomfortable creating a crowdfunding campaign, as it could elicit judgement from others, including family members, friends, and strangers (18; 30;43). Individuals crowdfunding for gender affirming procedures expressed that requesting donations, through sharing crowdfunding campaigns on social media sites, was a humiliating process (43; 44). Young adult cancer survivors in Ghazal et al. (30) described feeling humiliated by the need to crowdfund for basic living needs, before, during, or after cancer treatment. These feelings were more pronounced among cancer survivors who crowdfunded for their own needs. Some participants in Gonzales et al. (18) overcame these feelings of embarrassment by requesting others to crowdfund on behalf of them (18). Despite these privacy related consequences of crowdfunding, limited research has explored the ways campaigners approach privacy related decisions while crowdfunding, and how campaigners navigate the tension between protecting and disclosing personal information.

In a study conducted by Gonzales et al. (18), participants followed a privacy calculus, where they weighed the emotional and financial benefits greater than the risks associated with giving up their privacy. However, some participants were unable to fully consider the privacy-related consequences of crowdfunding due to the urgency to raise

funds (18). Both campaigners crowdfunding for their own needs and on behalf of others recognized the need to sacrifice personal information to solicit donations from the public (18). Notably, creating a crowdfunding campaign on behalf of others leads to distinct tensions and challenges. For example, a few campaigners in Gonzales et al. (18) noted that they created a crowdfunding campaign on behalf of the recipient despite the recipient being hesitant to disclose their private life. It is important to note that 16 out of 21 participants in this study were White or European American. People of color or individuals who belong to marginalized communities could experience heightened tension and pressure while crowdfunding. They could be giving up highly personal information while receiving marginal benefits in return, especially considering the unfair distribution of funds described earlier. This heightened tension can be seen among the participants in Fritz & Gonzales (43), who identified as a part of the transgender community. For these participants, weighing the costs and benefits of sharing personal information was a normal practice within their everyday lives, and a major part of how they navigated the world as transgender people. Many participants in Fritz & Gonzales (43) reported having experienced negativity online related to their gender identity, which influenced their reluctancy to share personal experiences while crowdfunding. Likewise, a few participants with more positive experiences were generally more comfortable with sharing personal information during the process of crowdfunding.

Although the evidence above highlights how campaigners approach privacy-related decisions while crowdfunding, there remains a significant lack of research that documents the various types of privacy-related concerns, tensions and pressures campaigners experience, and how participating in crowdfunding challenges their approach to privacy in everyday life. Currently (July, 2024), the limited privacy-related research that is available has largely been conducted in the United States. Addressing these knowledge gaps is especially important considering that the information disclosed in campaign descriptions is highly personal, and misuse of this information could threaten various aspects of campaigners' privacy, including their individuality, sense of self, and relationships.

These knowledge gaps are addressed through two research studies conducted as part of this thesis and presented in Chapter Three and Chapter Four. Both studies are embedded within a larger project that aims to understand the perspective of Canadian campaigners crowdfunding for themselves and on behalf of others for health- and housing-related needs. While recognizing the distinct experiences and perspectives of campaigners who have crowdfunded for themselves, both studies solely report the experiences and perspectives of campaigners crowdfunding for themselves. As part of the larger project data was collected and analyzed related to the experiences and perspectives of campaigners crowdfunding on behalf of others, though it is not presented in this thesis. In Canada, housing and health needs are recognized nationally as basic human rights, affirmed by the Canada Health Act and the National Housing Strategy Act; for this reason, this research included campaigners raising funds for health- and housing-related reasons (45). Data for both studies was collected after obtaining informed consent (provided in Appendix A) and using semi-structured interviews. The interview guide for these interviews is provided in Appendix B.

Chapter Three entails the privacy-related concerns of crowdfunding campaigners and the advice they had for others considering crowdfunding. Empirical research on the privacy-related concerns of crowdfunding campaigners is especially crucial given the extent to which researchers have speculated about the privacy-related impacts of crowdfunding. This is one of the few studies that explored the privacy-related concerns of charitable crowdfunding campaigners and the advice they had for others considering crowdfunding. Chapter Four delves into the approach campaigners took to crowdfunding, and how this approach was challenged or affirmed by their approach to privacy everyday life. This provides insight into how campaigners experienced and navigated privacy-related concerns and pressures.

Recommendations for crowdfunding platforms and government entities are provided throughout this thesis, along with future research directions. Participating in charitable crowdfunding inherently involves a loss of privacy. Ignoring the privacy-related concerns, tensions, and pressures campaigners experience while crowdfunding,

and how these various factors impact their ability to make autonomous decisions, could leave the negative implications of crowdfunding unaddressed and even heighten them.

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Chapter 3.   "Privacy is a Privilege" – A Thematic Analysis of Canadian Crowdfunding Campaigners' Concerns and Advice

Background

Donation-based crowdfunding uses online platforms to seek donations from friends, family, and the public (1). With charitable crowdfunding, people can raise donations for themselves, on behalf of others, and for specific organizations (1; 2). GoFundMe is the largest donation-based crowdfunding platform operating in North America and Europe (3; 4). The practice of donation-based crowdfunding has grown rapidly in recent years, with more than US$30 billion in donations raised on GoFundMe alone (5; 6). This rise in crowdfunding is attributed to a range of factors, including the increased cost of living, the increased visibility of this practice, and how crowdfunding has simplified giving (1; 3; 5; 7).

Crowdfunding campaigners face pressure to reach out to a wide array of potential donors to increase their chances of crowdfunding success (8; 9; 10; 11). Using a random sample of 637 medical crowdfunding campaigns initiated in the United States (US), researchers determined that only 9.2% reached their fundraising goal (7). The factors driving differences in campaign success includes the public perception of which people and needs are deserving of receiving help and how compelling the campaign narrative is to potential donors (3; 12). Given the competitive nature of crowdfunding, GoFundMe provides campaigners with specific advice, including the need to provide potential donors with an in-depth explanation of their reasons for creating a campaign, the financial constraints that have led to the need to turn to crowdfunding, and how any funding raised will be used (13; 14).

Clearly, crowdfunding campaigners experience significant pressure to share substantial financial, medical, and other personal information as part of crowdfunding campaigns. Due to this pressure, privacy-related concerns in crowdfunding are widespread (2). While privacy can be defined in varied ways, Roessler (15) explains

privacy protection as being layered, where the inner most layer represents control over intimate details of oneself; the second layer represents information one would normally disclose to family and friends; and the outermost layer represents the ability to control interactions with civil organizations. Having the ability to control personal aspects of oneself is important for many reasons, including an individual's sense of self, their ability to make decisions that reflect their authentic selves, and to avoid undue judgement (2; 15; 16). Despite the importance of privacy, crowdfunding platforms like GoFundMe put pressure on crowdfunding campaigners to publicly disclose the most intimate details of their lives (11; 14)

Researchers have argued that crowdfunding campaigners undergo a privacy-calculus where they weigh the perceived risks of crowdfunding against the potential benefits. Following this calculation, they often choose to trade their privacy for greater odds of crowdfunding success (17; 18). The costs of giving up this privacy are relevant to anyone engaging in crowdfunding and especially so for forms of crowdfunding that typically involve intimate and personal information like medical treatment. The campaigner's context can create other privacy-related vulnerabilities as well, especially for people who have identities and needs that are often stigmatized. For example, transgender people seeking gender affirming health care or people seeking addiction and substance use services may face risks of harm from having their normally personal information made public (19;20). Although crowdfunding platforms, such as GoFundMe, often require campaigners to consent to their terms and condition (e.g.21; 22)., whether this consent is fully informed is questionable. Considering these decisions are often made in the face of pain, ill health, and financial distress, the consequences of exposing highly personal information on the internet may not be foreseeable. Complicating this decision-making, online platforms often lack transparency around their privacy policies (23; 11; 18). Thus, the practice of making highly personal information public during charitable crowdfunding poses serious ethical concerns regarding the recipient's autonomy (16; 24; 25).

Despite these clear ethical concerns, to date there has been limited research exploring the privacy dimensions of crowdfunding. Currently (July, 2024), existing

empirical studies have focused largely on the US context, and have assessed the impact of donation-based crowdfunding on campaigners' and recipients' privacy using semi-structured interviews (26; 17; 18). This present study is a part of a larger funded project which seeks to enrich the public understanding of the ethical dimensions of privacy and control over personal information as it is experienced in the unique context of charitable online crowdfunding. This larger project, focused on the Canadian context, involved interviewing crowdfunding campaigners who have crowdfunded for their own needs and on behalf of someone else. For this paper, we analyzed semi-structured interview data on residents of Canada who have used online crowdfunding for their own medical and housing-related needs. This paper aims to highlight campaigners' privacy-related concerns attributed to the practice of crowdfunding and their recommendations for managing these concerns. This research adds much needed evidence that can be integrated into the heavily speculative discussions of the ethical dimensions of medical crowdfunding, which primarily discusses the perspectives of campaigners in the US and is focused narrowly on medical treatments.

Methods

Recruitment

We sought to interview participants who resided within Canada, were 19 years of age, or older, and had used online donation-based crowdfunding to support their own medical- and housing-related needs within a year of the interview. While health and housing needs in crowdfunding campaigns are often intertwined (27), we sought to interview people who had crowdfunded for each of these needs as their associated privacy concerns may differ. Thus, by including a broader subset of crowdfunding types, we were able to better understand the full scope of the privacy implications of donation-based crowdfunding for basic living needs.

Ethics approval was sought and received from the authors' affiliated Research Ethics Board and recruitment began in August 2022. Initially, JS posted a call for participants on Twitter, Craigslist, and Reddit. To supplement this recruitment approach,

potential participants that met the inclusion criteria were identified through a database of scraped campaign data from the GoFundMe crowdfunding platform. AG reviewed campaigns in the medical and housing category, including the campaign title, creation date, URL, campaign text, campaigner location, and campaign beneficiary, to identify potential participants. Upon identifying potential participants, AG used the extracted campaigner data to identify public profiles on other online platforms (e.g., Facebook) to send direct invitations to participate. 426 crowdfunding campaigners identified through the database were contacted through Facebook messaging. Participants who responded to these messages were asked to provide their email address for additional communication, including to provide a consent document (provided in Appendix A). Subsequently, AG scheduled a time to conduct the interview via Zoom or over the phone, depending on participants' preferences.

Data Collection

Interviews and recruitment continued, simultaneously, between August 2022 and September 2023. In total, 24 individuals consented to participate. These semi-structured interviews were led by an interview guide created initially by JS and VAC that probed participants on questions related to demographics; decisions to crowdfund; campaign results; privacy in everyday life; privacy during crowdfunding; privacy when raising money for oneself; and reflections on their crowdfunding experience (provided in Appendix B). The audio from each interview was recorded and ranged from 15-40 minutes. Each audio recording was downloaded and stored on a password protected Google Drive folder. Recordings were transcribed with Otter AI and AG reviewed each transcript to confirm the accuracy of this transcription against the audio recording.

Data Analysis

Following completion of data collection in September 2023, AG reviewed all interview transcripts and JS and VAC reviewed a subset of the interview transcripts. During an initial meeting in September 2023, AG, JS, and VAC identified potential options for analysis through a triangulated discussion of analytical directions. To probe

discussions of privacy more deeply and conduct a preliminary analysis of the data, JS, VAC, and AG came up with five analytical questions: how open/private are you in your daily life?; what is your intended audience?; what privacy issues do you think exist in crowdfunding?; what advice would you give around honesty or openness and giving information?; and does asking for donations from others contribute to feelings of shame? Using NVivo software, AG coded excerpts from each interview transcript according to these five probing questions. Subsequently, all authors agreed to focus the current analysis on participants' privacy concerns related to crowdfunding and their advice for others considering crowdfunding.

Taking all the excerpts coded previously, AG identified themes related to participants' privacy related concerns while crowdfunding and the advice they had for others considering crowdfunding. Braun and Clark's (28) approach to thematic analysis guided the process of identifying themes. AG undertook the coding while JS resolved uncertainties. The process of triangulation and record keeping during the data collection and analysis contributed to establishing rigour.

Findings

In this sample of 24 interview participants, 15 participants were crowdfunding for medical needs, six for housing needs, and three for both. There were 10 participants who identified as men, 12 as women, and two who identified as non-binary. Eight of the interview participants met their crowdfunding goal and 16 did not. All participants utilized GoFundMe. Upon reviewing extracts of the coded data using investigator triangulation, we identified three themes related to privacy concerns and three common pieces of advice provided by our participants to support privacy protection.

First, participants expressed concerns over the public disclosure of highly personal information and the accessibility of their crowdfunding campaign to the wider public. Second, participants expressed feeling vulnerable due to the unwanted probing and messaging elicited in response to creating a crowdfunding campaign. Lastly, participants expressed uncertainty regarding the crowdfunding platform's information

sharing and collection practices, and the potential harms related to how their information is handled by crowdfunding platforms. Based on their experiences of crowdfunding, participants recommended others considering crowdfunding to be both cautious and specific, be informed, and consider the uncertainties related to the practice of crowdfunding.

Public Accessibility of Crowdfunding Campaigns

The participants reported being concerned about the public nature of crowdfunding campaigns, and the how the information posted in their crowdfunding campaign description could be accessed by the wider public, including strangers. Many of the participants wanted to restrict who saw their crowdfunding campaign, and a few expressed being unaware that despite their desire to keep the campaign closed off from strangers, the wider public could still access their crowdfunding campaign through a Google search. The accessibility of the campaign to the public was anxiety provoking for some participants, as one participant who was crowdfunding for gender affirming care stated*:*

> *...I didn't want certain people to see this. So, I was very careful on social media about making it not visible to certain people. But then being asked to do the study. It kind of made me be like, 'Oh, okay, interesting.' Like people I don't even know can find this*

Participants recognized the complexity of limiting the visibility of their crowdfunding campaign, due to the public nature of crowdfunding and seeming permanency of the Internet. One participant also noted that the information provided in the crowdfunding campaign description could be stored by members of the public. Thus, information presented in a crowdfunding campaign could be potentially available to others even after the campaign is deleted.

Considering the public visibility of crowdfunding campaigns and lack of options to restrict campaign visibility, participants described various risks. Participants described these risks as heightened feelings of vulnerability and potential negative perceptions by the wider public. As one participant explained "*there's definitely the risk of one's name*

being permanently attached to the stigma of poverty or need…," which could have negative consequences, including in terms of work opportunities or relationships. The risks of having their campaign publicly accessible varied, including depending on their past experiences and the types of information disclosed in their campaign description (e.g., physical address or location). The intersection of various factors in heightening feelings of vulnerability was highlighted by one participant who did not share their address with specific family members in everyday life: "…*If they come across [the crowdfunding campaign] they now know that I am living in [redacted] there's my name, there's pictures of me and my family...*" This participant was crowdfunding to relocate out of a specific area after their home was flooded and felt sharing their location was necessary. Another participant who was crowdfunding for gender affirming care explained that "…*my family, like, they don't accept my identity as a transgender person. So, I was worried, like, when I did make those details public… what if they were to, like, call that surgeon's office and like, cancel my surgery...*" Thus, the harms related to the public nature of crowdfunding were often not experienced equally across all campaigners, and withholding personal information was often not possible when it was pertinent to communicating the rationale of the campaign to potential donors.

Intrusive Messaging

The ability of potential donors to freely contact crowdfunding campaigners through private or public messages was also described as a privacy-related concern. A few participants reported that these messages were relatively unfocused and harmless; however, other campaigners experienced these messages as highly invasive as they often probed campaigners on their reasons for creating a crowdfunding campaign. Participants generally took the view that people had a right to request more information to determine whether they would like to donate to the campaign or not. For example, one participant explained that "…*a lot of times, people will want to know like a lot more information because…they're donating their money...*" That said, these inquiries could go well beyond what the campaigner saw as reasonable, and often these messages were overly broad or intrusive. As one participant who uses a mobility aid expressed: *"...sometimes it's like*

things they don't necessarily need to know. So, it's like 'well what have you been doing to get around'...[or] ... well, how do you use the bathroom?'..."

Participants expressed how they were made to feel vulnerable because of these questions, as some participants responded to these messages by disclosing more information than they usually would or intended to do so at the start of their campaign. This is illustrated by one participant who was crowdfunding to raise funds for gender affirming surgery: *"...I definitely was influenced to share more than I wanted to, because of other people...asking me more questions in regards to my surgery."* Other participants who described negative interactions with potential donors dismissed these questions. Even in these cases, the experience of receiving messages and questions from members of the wider public was described as unpleasant.

Information Collection & Sharing by Platforms

Another area of concern for participants was the collection of information by crowdfunding platforms. Participants emphasized that GoFundMe, the platforms used by all participants, encouraged people to be transparent when describing their reasons for creating a crowdfunding campaign, and often the information requested, such as the campaigner's full name, was required to create a crowdfunding campaign and not optional. A participant explained:

> *...when you were hosting the campaign, you have to put your full name, as well as the person that's collecting the funds. So, if you want to make it so that it's not directly tied back to your first and last name, so that people can't just Google search you or Facebook search you or whatever, you have to get somebody else to do that on your behalf.*

Clearly, this participant felt this to be unfair, as they may have preferred to not share specific information online for a variety of reasons, including to protect themselves from harm.

Further, sharing this information was concerning for many participants because they were uncertain whether their personal information would be shared to other social media platforms – "…*they turn around and give that information out to their advertisers,*

for instance, or it gets leaked from a hack or something like that." One participant recognized this collection and sharing of information by online platforms to be a normalized practice: *"...it's sort of a thing where like, if you use social media at all, you have like data being collected by websites, and...it kind of feels like what difference does it make if like GoFundMe does it…"*. This information, potentially collected by crowdfunding platforms, may not have been available to the public as part of their campaign but could have created privacy implications depending on how that data was used. Thus, participants emphasized the need to clearly know "…*whether people store information about you, what does the company...do with your information?"* In general, participants did not feel that they had a clear understanding of how their information was handled by crowdfunding platforms.

Advice to Other Campaigners

To address these potential privacy-related concerns described in the previous sub-sections, participants also provided advice to others considering creating a crowdfunding campaign. First, most participants recommended that others engaging in donation-based crowdfunding be both cautious and specific when sharing their information. More precisely, participants emphasized the need to avoid disclosing unnecessary details regarding family or other sensitive topics unrelated to their campaign rationale, especially considering the public accessibility of crowdfunding campaigns. They recommended that campaigners included specific financial details and information about their needs. As one participant put it, *"...be specific to what the situation is... I don't give too much information in terms of family, and you know, things like that."* Thus, participants recommended to strategically disclose specific details that were important to communicating the rationale for creating a crowdfunding campaign.

As the information provided in the campaign description was accessible by the wider public, participants recommended potential crowdfunding campaigners to be informed of the physical and mental costs of crowdfunding. This was because participants found that crowdfunding could result in unwanted messages, contact, or negativity from members of the public or from individuals known to the campaigner.

Participants also expressed the need to be informed about the realities of crowdfunding, including being aware of the limitations related to restricting or withholding information relevant to the campaign. Participants emphasized that protecting personal information while trying to crowdfund for health or housing needs can be an illusion:

> *Be prepared that you need to put your privacy on the line, you need to definitely put it out there. Because you have to be honest, and no one's gonna give you money if they feel like you're not being honest. Yeah. And you need to be prepared to be a little bit embarrassed…*

While this lesson was clear to many participants from their experience crowdfunding, they were less clear as to how others considering crowdfunding could be made aware of these concerns.

Likewise, some participants recommended considering the uncertainties of the consequences of disclosing highly personal information to the public and crowdfunding platforms – *"…you don't have complete control over who sees even if you think you do so…"* For this reason, a few participants recommended to *" only share that you would be comfortable with everybody knowing."* Thus, participants recommended sharing information that they would be comfortable with everyone knowing, which can help cope with unforeseen negative consequences.

Discussion

Our thematic analysis drew on interviews with 24 participants who managed crowdfunding campaigns for their own medical and housing-related needs. These participants identified three areas of privacy-related concerns arising from their experience of creating a crowdfunding campaign for themselves: 1) public disclosure and accessibility of highly personal information; 2) intrusive probing by potential donors; and 3) information collection and sharing by platforms. Creating a crowdfunding campaign can make anyone more vulnerable to harms. However, based on the patterns in our research, there are other factors, such as social stigma surrounding a specific need or family tensions, which could further exacerbate vulnerabilities associated with giving up highly personal information. As Barcelos & Budge (19) and Palad & Snyder (20) have

reported, the privacy-related risks related to crowdfunding are heightened for people with complex personal contexts. Our research confirms these previous findings and demonstrates that privacy-related risks are particularly sensitive to personal contexts. This can be seen in the participants responses within the categories of intrusive messaging and public accessibility of crowdfunding campaigns. Our findings also confirm previous studies reporting that crowdfunding campaigners are often making privacy related decisions while experiencing various forms of pressure to share more, being unaware of the possible negative consequences that could arise, and without a comprehensive understanding of the crowdfunding platform's privacy-related policies and practices (2;11;14;17; 26).

In the face of these challenges, participants described three key pieces of advice: 1) be both cautious and specific; 2) be informed of the potential negative consequences; and 3) consider the uncertainties (See Table 1). This advice was developed through the experiences of these participants while crowdfunding; thus, the applicability of this advice for others considering crowdfunding could depend on various factors, including their approach to privacy in everyday life and their beliefs and values surrounding privacy. There are clear tensions in the advice offered by participants to others considering crowdfunding. The tension between protecting one's privacy and maximizing donations can in part be attributed to the lack of privacy-related protections provided by crowdfunding platforms, and the lack of transparency of existing policies and procedures. For example, crowdfunding campaigners advise others to be aware of potential negative consequences but also expressed being uncertain about the types of negative consequences that could potentially arise. Considering participants' privacy-related concerns and the advice they had for others, we formulated a few key recommended actions for crowdfunding platforms, which are synthesized in Table 1 below.

Table 1:   Advice and Recommended Actions for Campaigners to Address Privacy-Related Concerns

Participants' Advice to Other Campaigners
Be Cautious and Specific   • Have a plan. Set boundaries. Strategize with people you trust.   • Try to keep family, highly personal information vague, generic. Assume everything you post is available to everyone. Do not assume any privacy.   *Be Informed*   • Crowdfunding has costs and can be an invitation to harm you (criticism, intrusive questions, being doxed, etc.). More so for some needs, people.   *Consider Uncertainties*   • Don't assume you know what is going to be done with the information you post. Others may use it in ways you can't predict and so may the crowdfunding platform.
Authors' Recommended Actions
• Crowdfunding platforms should establish specific consequences related to harmful behavior towards campaigners.   • Policy makers should enforce the need for crowdfunding platforms to transparently communicate terms and conditions, and privacy policies.   • Crowdfunding platforms should create options for campaigners to restrict who views their campaign on the platform itself.

While taking a closer look at the terms and conditions of GoFundMe, there are many inconsistencies that could in part help explain the privacy concerns of crowdfunding campaigners. To begin with, although GoFundMe's privacy statement prohibits any harmful behavior towards crowdfunding campaigners, they do not guarantee any action will be taken to protect users (21;22). Currently, crowdfunding platforms encourage donors to probe crowdfunding campaigners about their reason for creating a crowdfunding campaign (22). Addressing this is especially important considering participants in this study who were raising funds for stigmatized needs or practices, such as gender affirming care or disability related expenses, noted receiving

unwanted messages that heightened their vulnerability. Thus, crowdfunding platforms should establish specific consequences related to harmful behavior towards campaigners. Second, the overall lack of guidance for crowdfunding campaigners could be partially addressed by crowdfunding platforms and government entities better explaining to the public how their information is handled while crowdfunding and educating them on the potential privacy-related risks of this practice. This could allow campaigners to make decisions that better reflect their values and beliefs. Currently, GoFundMe's privacy statement and terms and conditions are extremely lengthy and may be difficult for some to read and understand (21;22). Comparatively, the page on GoFundMe's website outlining various tips for establishing a successful campaign is easy to follow and provided in plain language (13).

Lastly, although campaigners may share their campaigns on other social media platforms that allow users to limit who views their campaign, the participants in this study were sometimes unaware that their campaign may be visible to the wider public through the crowdfunding platform. Considering many crowdfunding campaigners preferred to limit the public visibility of their crowdfunding campaign, campaigners should be able to adjust the visibility of their campaign on the hosting crowdfunding platform itself or have access to other tools to better protect sensitive information. This could allow campaigners to protect their privacy even after they have disclosed their personal information to crowdfunding platforms. These actions are guided by the advice of former crowdfunding campaigners and could be implemented by crowdfunding platforms. However, government intervention would likely be needed to encourage and enforce these actions as the current advice given by these platforms is often to sacrifice privacy to demonstrate deservingness for help and to guard against fraud. Taken together, these results indicate that it is essential to create options that are considerate of the fact that the privacy-related harms or concerns related to crowdfunding are not experienced in the same way or to the same degree by all campaigners.

Strengths & Limitations

This is the first research study to explore, in-depth, the privacy-related implications of donation-based crowdfunding for health and housing reasons in Canada and one of the very few empirically informed studies on the ethical dimensions of crowdfunding. As such, it can significantly contribute to identifying future research directions. Like with all research studies, our study had several limitations. First, we recruited people into this study who had a public profile on social media or an online presence where they could see the call for participants on Reddit or Twitter. Thus, our sample of participants favors people who are relatively comfortable with navigating online social media platforms. Finally, this study only included participants who resided in Canada.

Conclusion

The findings of this analysis indicate that crowdfunding campaigners' privacy concerns are complex and intertwined. While considering this complexity is essential, the findings clearly demonstrate the need for interventions to better educate and protect all people engaging in crowdfunding for medical-and housing-related needs. Future research is needed to explore how equity and inclusion can be supported within the practice of crowdfunding given the finding that campaigners are differentially vulnerable to harm through this practice. Researchers should also conduct a thorough evaluation of the privacy related policies of crowdfunding platforms, including whether crowdfunding platforms are complying with existing policies and protections. Lastly, research highlighting the pressure that campaigners experience to disclose highly personal information across different health systems, health needs, and other contexts could also help highlight the urgency to address these privacy-related concerns.

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Chapter 4.　"People I don't even know can see this" – Privacy Approaches by Canadians Crowdfunding for Medical and Housing Needs

Background

The practice of online crowdfunding involves campaigners sourcing money from large groups of people, typically using online platforms (1; 2; 3) There are two main types of crowdfunding: donation-based and reward-based. The latter form of crowdfunding includes specific incentives for donors to contribute to funds, which are typically used for start-up businesses or other commercial enterprises (3). Donation-based crowdfunding (sometimes called charitable crowdfunding) involves people raising funding for themselves, others, or larger organizations, to cover specific costs without providing any benefits in return to donors (2; 3; 4). Donation-based crowdfunding campaigns raising money for medical care, rent, or other basic living expenses have become increasingly common in recent years (1; 3; 5; 6; 7). The GoFundMe crowdfunding platform alone has raised approximately $30 billion in donations since 2010, with 150 million people having either received a donation or having donated to a campaign (8).

Although donation-based crowdfunding has helped millions of people to better afford their basic living needs, this practice raises many ethical concerns. These concerns include the risk of fraudulent campaigns, inequities related to the amount of donations raised, and the fact that crowdfunding for public goods can obscure the failings of public institutions to provide access to these goods (6; 9; 10). More specifically, crowdfunding "undermines the goal of creating just institutions that ensure that everyone's basic needs are met in the future" (3, p. 83). This is especially worrisome since crowdfunding donations are inequitably distributed; people with larger social networks and other privileges are more likely to meet their needs through crowdfunding (1; 4; 5; 7; 10; 11). Likewise, individuals who are well-networked and privileged may also be better positioned to advocate for systemic change, and thus having their needs met through the practice of crowdfunding could lessen their interest in advocating for systemic change (3;

10; 11). While these ethical concerns are receiving increased scholarly attention (1; 4; 5; 7; 10; 11), an under-explored ethical concern is the extent to which crowdfunding challenges the privacy related preferences and values of campaigners (2; 10; 11; 12).

Privacy is a complex concept with multiple dimensions (13; 14; 15; 16; 17). Roessler (13) explains that the three dimensions of privacy are informational, decisional, and local. Informational privacy includes having control over personal information about oneself (13;14). This can include a dimension of expressive privacy, understood as having control over the level of intimacy shared with others including by deciding who has access to the different types of personal information (18). Decisional privacy broadly encompasses the ability to make decisions for oneself without undue interference from others (13;14). Local privacy is the ability to control physical interactions with others (13;14). These varied forms of privacy are often interrelated, and all share a common feature: the ability to control access to personal aspects of oneself (13). Having control over personal aspects of oneself is important for many reasons, including the ability to decide one's life course, avoid negative judgement and harm, and form relationships authentically, all of which are fundamental to an individual's autonomy (13; 15; 16).

Considering the importance of privacy and following the proliferation and increased use of various social network sites, researchers have explored the ways in which people navigate their privacy online (19; 20; 21; 22). Social networking platforms have been publicized as allowing people to easily form new relationships or strengthen existing ones, share updates, and seek support (19; 20; 21). Often, people weigh these benefits of using online platforms against their potential negative consequences. The negative consequences include data collection and sharing by platforms and the potential for critical judgements resulting from publicly disclosed information (19; 20; 21). Social networking sites can be distinguished by the ability to curate a public or private profile (19). Although social media users can control the amount, and types of information, they provide to others online and can use various privacy control settings, there is evidence indicating that people's privacy-related decisions online may not be fully informed or autonomous (17; 20; 21). This can in part be attributed to the tendency of users to passively consent to platforms' terms and conditions and because users are rarely

provided with transparent and easy to read terms and conditions outlining how their information will be handled (22; 19; 20).

Like efforts aimed at enriching the public understanding of how people navigate their privacy on social network sites more broadly, researchers have speculated about the privacy-related implications of charitable crowdfunding (18; 23; 24). However, sharing personal information in the context of charitable crowdfunding is different from other online interactions. This is in part because individuals raising funds via crowdfunding are sometimes trying to overcome extremely difficult circumstances. These crowdfunding campaigners may have basic needs going unmet with few or no other options available to meet them (3; 23). Empirical research on crowdfunding has shown that campaigners undergo a privacy calculus. They weigh the costs of crowdfunding – a loss of privacy while also experiencing the stigma associated with the public disclosure of highly personal information –with the likely benefits of crowdfunding, including financial and emotional support (3; 18; 23; 24). For example, participants in a study by Gonzales et al. (23) expressed the belief that to receive financial support via crowdfunding donations, it was important to provide an honest and transparent story. However, existing research has reported that the need to be transparent while crowdfunding can incur costs, including negativity from co-workers, family members, and friends (18; 23; 24).

Research on the impact of crowdfunding on privacy has also emphasized the experiences of specific communities (18; 24). For example, Fritz and Gonzales (18) interviewed 20 transgender participants to understand how their privacy was impacted by the process of crowdfunding. Many participants described weighing the costs and benefits related to sharing personal information online as a normal practice in their daily lives, especially given the complexity of navigating the world as a transgender person. Most participants reported having had negative experiences with placing private information online related to their gender expression, which influenced their privacy-related decisions during crowdfunding. A few participants who reported positive experiences related to sharing their gender expression with others were more comfortable with sharing their private information during charitable crowdfunding (18). Nevertheless, privacy related decisions can vary considerably depending on the intersection of various

factors. For example, Fritz & Gonzales (18) demonstrated that the privacy related decisions and consequences for participants in their sample varied depending on the intersection of their past experiences of experiencing negative judgements, comfort levels with sharing personal aspects of themselves, and the acceptance of their gender identity by others in their community.

Further, researchers have speculated that crowdfunding campaigners experience various forms of external and internal pressure to disclose substantial and normally private information about themselves (3; 10; 11;18; 23). Crowdfunding platforms regularly remind campaigners that an emotionally compelling campaign description that highlights their reasons for creating a campaign is likely to increase their chances of success (2; 6; 10; 11; 25; 26). Moreover, the need for crowdfunding campaigners to establish the legitimacy of their needs to potential donors is also a source of pressure, especially considering well-publicized instances of crowdfunding fraud that have been reported (6). To mitigate the risk of fraud, GoFundMe encourages potential donors to probe campaigners on their reasons for creating a campaign and how the funds will be used (27; 28). This pressure to abide by the plan set out in the campaign description limits the campaigner's ability to change course and thereby their control over their own needs (10). The limited evidence on crowdfunding indicates that campaigners are often left feeling vulnerable due to having to balance their preferences and values surrounding privacy with their immediate need to raise funds (3; 24).

There is a significant lack of empirical research exploring the ways crowdfunding campaigners approach privacy-related decisions considering these pressures. Currently (July, 2024), the empirical research which does exist focuses largely on the United States (US) context (18; 23). Little is known about how campaigners, including those outside the US, experience various internal and external privacy-related pressures and tensions related to disclosing personal information, whether their specific privacy-related decisions during crowdfunding differ from their privacy-related decisions in everyday life, and how their ability to make autonomous decisions is impacted. Further, existing research on privacy and donation-based crowdfunding seldom provides in-depth analysis of the types of information that crowdfunding campaigners choose not to provide in their

campaign descriptions, or the types of information crowdfunding campaigners feel is sensitive though crucial to include.

This analysis is part of a larger project that has used semi-structured interviews with crowdfunding campaigners living in Canada to explore the privacy related ethical implications of charitable crowdfunding for health- and housing-related needs. These interviews have probed various aspects of the approaches crowdfunding campaigners in Canada have taken to disclosing personal information while crowdfunding for essential needs. Through this research, we have been better able to understand campaigners' privacy-related decisions while crowdfunding as well as the ways the practice of charitable crowdfunding challenged campaigners' sense of self and their ability to make informed decisions. In the current analysis, we highlight the complexity of pressures experienced and privacy-related decisions taken by crowdfunding campaigners, while crowdfunding for themselves, depending on their current circumstances and type of need being addressed. Our research contributes to the advancement of researchers', policymakers', and the public's understanding of the practice of crowdfunding and how the experience of crowdfunding can be improved to better protect the privacy of users.

Methods

Recruitment

We sought to recruit participants who resided in Canada, were 19 years of age, or older, and had used online donation-based crowdfunding to support their own medical- and housing-related needs within a year prior to the interview. While health and housing needs in crowdfunding campaigns are often intertwined (29), we interviewed people who had crowdfunded for each of these needs to better understand the variety of privacy-related tensions and decisions taken during the process of creating a charitable crowdfunding campaign for basic living needs.

Ethics approval for the study was received from the authors' institutional Research Ethics Board and recruitment began in August 2022. Initially, JS posted a call for participants, with our contact information, on Twitter, Craigslist, and Reddit. To

supplement this recruitment approach, potential participants that met the inclusion criteria were identified through a database of scraped campaign data from the GoFundMe crowdfunding platform. AG reviewed this campaign data, including the campaign title, creation date, URL, campaign text, campaigner location, and campaign beneficiary, to identify participants. Upon identifying potential participants, AG used this data to identify public Facebook or other public online profiles to send direct invitations to participate. 426 crowdfunding campaigners identified through the database were contacted through Facebook messaging. Participants who responded to messages were asked to provide their email address for additional communication, including to provide a consent document (provided in Appendix A). Subsequently, AG scheduled a time to conduct the interview via Zoom or over the phone, depending on participants' preferences.

Data Collection

Interviews and recruitment continued, simultaneously, between August 2022 and September 2023. In total, 24 individuals consented to participate in a single semi-structured interview. These interviews were guided by an interview guide created by JS and VAC prior to beginning recruitment that probed participants on questions related to 1. demographics; 2. deciding to crowdfund; 3. results of the campaign; 4. privacy in everyday life; 5. privacy during crowdfunding; 6. privacy when raising money for oneself; and 7. reflecting on their crowdfunding experience (provided in Appendix B). The audio from each interview was recorded and ranged from 15-40 minutes. Each audio recording was downloaded and stored on a password protected Google Drive folder. Recordings were transcribed with Otter AI, and AG reviewed each transcript to confirm the accuracy of this transcription against the audio recording.

Data Analysis

In December 2023, AG, JS and VAC independently reviewed the interview transcripts. At a collaborative meeting to facilitate triangulated confirmation of emergent analytic directions, the authors agreed there was significance in thematically analyzing

how crowdfunding campaigners approached privacy in their everyday lives and how this approach was challenged or affirmed during the process of crowdfunding given the scope and scale of such discussion in the interviews. Following a more detailed review of the transcripts, AG inductively identified three ways that participants approached privacy in everyday life. Specifically, these approaches were: 1. highly guarded and concerned; 2. middle-of-the-road; and 3. mostly-open. JS resolved any uncertainties related to categorizing participants approach to privacy in everyday life. Upon categorizing each participant into one of these types, AG identified patterns related to participants' approaches to privacy in everyday life and their approaches to privacy while creating a crowdfunding campaign.

Findings

Our sample included 15 people in Canada crowdfunding for themselves for health needs, six for housing needs, and three for both health and housing needs. The household income level of participants ranged from $0 to $200,000 (median income range of $25,000 to $49,999), and the age of participants ranged from 18 to 67 years of age (median age range of 30-39). Our analysis identified three types of approaches participants took to privacy in their everyday lives and further highlighted how these approaches were challenged or affirmed by the process of crowdfunding. These approaches were: 1. highly-guarded and concerned; 2. middle-of-the-road; and 3. mostly-open. Participants who were highly-guarded and concerned emphasized being highly restrictive regarding the personal details they were willing to provide to the wider public, including through online platforms. Participants who had a middle-of-the-road approach to privacy were open to providing a broad overview of their personal experiences during everyday life. Lastly, the mostly-open category included participants who were characterized as largely making their personal lives an open book.

Highly-guarded & Concerned

Eight out of the 24 crowdfunding campaigners in our sample were categorized as being highly-guarded and concerned. Crowdfunding campaigners in this category were

characterized as the most guarded with the information they provided to strangers out of the entire sample. A quote by one participant exemplified the level of caution that participants took when deciding to share their personal information: *"...If you don't personally know me, I wouldn't really tell you anything besides my name. Probably."* Personal information that participants typically held back from strangers included their address, phone number, medical history, and employment history. All these participants emphasized their preference for sharing aspects of their personal life with only those whom they personally knew to be trustworthy.

Most participants in this category put extreme limits on their use of social media in everyday life, restricting it for the purpose of viewing content posted by others. In circumstances where participants in this group posted online, they highlighted the use of platforms that allowed them to control and limit who saw their profile. Many highly-guarded campaigners emphasized the need to be cautious when disclosing their physical address or location for fear that disclosing this information publicly could harm them. For example, one participant said: "…*So, you're telling everybody that you're away from home, which means you can tell people, whoever wants to break in, that you don't have anybody there. It's just stupid. You're advertising your house is empty…"* Thus, these participants were often concerned of the negative repercussions of sharing their personal details and activities with others. Participants in this group also highlighted various other potential negative consequences of sharing personal information online, such as the risk of information being misinterpreted by others. Two participants emphasized the importance of respecting their children's privacy, and the need to avoid sharing personal details without their permission. Lastly, being more closed-off to the wider public was also reported by some participants to be a personal preference, and not necessarily related to any foreseen harms of sharing information: *"...I'm just not the kind of person who used to broadcast my life. So, I am used to not doing that at all."* In this way, for some participants, being more cautious regarding sharing information was a form of personal identity.

Most campaigners who were highly restrictive with sharing their personal information in everyday life were also highly restrictive when creating a crowdfunding

campaign. This could be seen, for example, in keeping their crowdfunding description concise and to the point. A quote by one participant shows the level of caution exercised by many participants in this category*: "I kind of just put a very…brief synopsis. And the reason for that is like, I didn't want to give people a lot of details, but just enough that they knew kind of what was going on."* Although most campaigners mentioned variations on wanting to provide the 'bare minimum' needed to allow potential donors to understand their situation, a few also recognized the importance of including a detailed explanation if they wanted to reach their campaign goal. As one participant explained: *"…While I'm perfectly aware that had I have done more to my crowdfunding campaign, I may have gotten more money, but I am also very much aware that too much information and, you know, people around… know too much…"* Thus, campaigners perceived a trade-off between maintaining their privacy and succeeding with their crowdfunding campaigns.

However, not all participants in this category chose to apply a cautious approach to information sharing in the context of crowdfunding. Two highly-guarded participants created a crowdfunding campaign that included a detailed explanation of their needs. These participants explained that this transparency was important to create an appealing campaign and related to the need to urgently raise funds. One of these participants explained: *"I actually felt quite uncomfortable making a GoFundMe, it pushed me out of my comfort zone, because they tell you to put pictures of yourself. And our story was that, like, we were more vulnerable than some because I had just had a baby..."* This quote exemplified how some crowdfunding campaigners' prior beliefs were challenged by the pressures of crowdfunding. While most campaigners in this category maintained their highly-cautious approach, a few felt compelled to be more open to encourage giving by others.

Middle-of-the-road

Thirteen out of the 24 crowdfunding campaigners were categorized as having a middle-of the-road-approach to privacy in their everyday life. These campaigners mentioned being comfortable sharing information with people they knew or perceived to

be trustworthy (e.g. family and friends). Further, participants in this group emphasized the variability and context sensitivity of their decisions related to sharing personal details with strangers or people they knew to a lesser extent. As one participant said, *"…I don't have a written set of rules. But I do have a sense, as well as the situation arises, I have to be the guy that improvises."* These privacy-related decisions were often characterized as being dependent on various factors, including the type and risks associated with sharing the information being requested and their present circumstances. One participant explained: "*…I guess it depends on like, a wider sense that like, sometimes I have, like, publicly vented about, like, frustrations I've had, like health care. But like, I don't tell people like every single like, thing that happened to me since childhood."* Most participants in this group refrained from easily sharing any personal information they characterized as sensitive, which included their phone number, address, and details about intimate relationships, as they felt this could have put them at higher risk of negative consequences, such as identity theft or physical harm.

At the same time, many campaigners in this group were open to broadly sharing their everyday life experiences, such as those related to their health status or gender identity. For example, one participant said: *"…I'm not, I don't, you know, post everything day to day, obviously, but I do share the broad issues, so they do know what's going on. So, people do realize that when I do ask for something, they understand the need."* Multiple participants reported having shared their personal experiences to advocate for marginalized communities. The specific forms of advocacy work mentioned were blogs, radio interviews, or talking to strangers who had reached out through messaging apps or online platforms.

Further, for participants in this group, privacy-related decisions varied depending on the social media platform. For example, a few participants reported the use of platforms with privacy settings to limit and control who saw specific posts. As one participant said: *"Yeah, so Instagram, I'm not going to give as many details as maybe Facebook… I think it's because I get to choose who sees my content on Facebook, but not so much on Instagram."* On the other hand, two participants were more comfortable with sharing information about themselves on Twitter, despite it having been open to the

public. This was because their Facebook included family members with whom they did not feel comfortable sharing details of their personal life. Lastly, many participants expressed having complex personal life histories or present circumstances that made their privacy-related decisions vary from time to time.

All participants in this category provided a broad description of their needs in their crowdfunding campaigns, which was seen as sufficient for potential donors to make an informed decision on whether to contribute to the campaign. The reasons they offered for having kept their campaign descriptions broad varied from wanting to avoid sharing highly personal details to the belief that sharing more information would not necessarily have resulted in more donations. This was illustrated by one participant who stated that:

> *I just told the very basic, honest story, like you know I needed for this and, you know, financially tight position and it was just a plain story. But I guess, you know, if people want to help, they're going to help, but if you don't want to be too dramatic or too sappy or too desperate, right?*

In this way, how they approached crowdfunding was not markedly different than how they approached privacy in everyday life, in that they had sought balance and limits to providing information.

Campaigners in this group were willing to discuss their personal experiences or difficulties with strangers if it did not involve highly sensitive information. Nevertheless, a few campaigners highlighted the difficulty they experienced when they chose to include some details in their campaign description that challenged their approach to privacy in everyday life. One campaigner raising funds for gender affirming surgery explained this tension: *"In my situation, it was like especially hard because like there were like things, for example, that I did want to keep private but like couldn't because of the nature of my crowdfunding."* Participants also explained that the choice over what information to include in their campaigns depended on the perceived privacy controls included in the social media site used to share their campaign. This was consistent with their approach to privacy in everyday life, as privacy controls on specific social networks often influenced what information about themselves, they were willing to share. However, participants expressed confusion over these controls in the context of crowdfunding. For example,

one participant explained "*…I didn't want certain people to see this. So, I was very careful on social media about making it not visible to certain people. But then being asked to do the study. It kind of made me be like, Oh, okay, interesting. Like people I don't even know can see this…*" Thus, some campaigners in this category inadvertently shared more information to the public than they had intended.

Mostly-open

Three crowdfunding campaigners were classified as being mostly open about sharing their personal information with others in their everyday lives. These individuals described themselves as readily willing to talk about their private life with strangers. They did not present themselves to be restrictive of the information they provided to others, including people whom they did not know well. One participant described the characteristic openness in sharing personal information that was seen across all participants in this category*: "I give up my instant messaging information on various platforms like readily just to strangers. I am willing to talk to strangers and I'm not ashamed of like, any of my medical or employment related, like anything, any part of the narrative there."* As this quote described, participant in this category had a relaxed approach to sharing personal information on a broad range of social media platforms. They gave the impression of not being overly concerned of the potential risks related to placing personal information on the internet. For example, one participant said *"um, I don't really have set rules I guess it's just kind of what I feel like sharing…"*, demonstrating a casual and open approach to sharing information.

Nevertheless, there were a few personal details that participants in this group were hesitant to share with others. These details included personal data that these participants mentioned could be dangerous if shared publicly, such as their physical address or highly confidential documents. For example, one participant explained: "*Other than, like, not sharing my physical address, but that's the literal location like the space in which I am staying...*" Another participant emphasized avoiding family members that had negatively judged and disagreed with certain aspects of their personal life in the past, such as their gender identity.

Participants in this category had an approach to crowdfunding that generally followed their open approach to privacy in everyday life. When creating a crowdfunding campaign, these participants explained that they were generally unaware of potential negative consequences related to openly sharing the information provided in their crowdfunding campaign. As one participant said:

> *...Well, I just need the money. And so like, I guess I'm going to agree to these things. I don't even really know what the privacy issues were. There wasn't...like, energy available to really consider these things in the face of what I needed. And I would say that, in general, I don't really have trust that any of the privacy and private data collected on me is like in any way moral. But I also think that I can't do anything about it personally. So why bother? Really?...*

As this quote described, the negative consequences of openly sharing the information provided in their campaign description, including the risk of it being used in a malicious way, was not an immediate concern. Further, participants were often indifferent towards the potential stigma that could follow the creation of a crowdfunding campaign: *"...I don't care how it like tanks my reputation. That I have like a bad credit score or something, or that, you know, I'm on disability, I don't care about any of that."* Thus, these campaigners generally had few concerns with the potential negative consequences of the disclosure of their personal information in everyday life or during the process of crowdfunding. In general, the views of these participants represented the normalization of having personal information accessible in both their everyday lives and while crowdfunding.

Discussion

This analysis used interviews from 24 participants to determine the types of approaches campaigners in Canada take to privacy in their everyday life and, subsequently, to understand how this approach was challenged or affirmed during the process of crowdfunding. The three approaches to privacy were: 1. highly-guarded and concerned; 2. middle-of-the-road; and 3. mostly open. The highly-guarded and concerned category included participants who were the most restricted with sharing their personal information in everyday life. Most participants in this category were also highly restrictive in providing personal information while crowdfunding. However, despite

being highly restrictive in sharing their personal information in everyday life, a subset of participants in this category provided a thorough description of their needs to create a compelling campaign description. The middle-of-the-road category included participants who vary considerably in their decisions related to disclosing personal information. These decisions were shown to be dependent on various factors, including the type of information being requested, the individual requesting the information, and the potential consequences of disclosing specific personal information. The participants in this category were open to providing a broad overview of their personal life to the wider public in everyday life and during the process of crowdfunding. Finally, the last category of mostly-open participants included individuals who were the least restricted in providing personal details to others in their everyday life, and during the process of crowdfunding.

Past research has provided a broad overview of how crowdfunding campaigners navigated protecting their personal information while trying to maximize donations during crowdfunding, and whether campaigners were concerned of any privacy-related negative consequences of crowdfunding (18; 23; 24). Our research contributes to this existing knowledge by providing a more comprehensive overview of the privacy-related decisions and precautions campaigners took during crowdfunding, whether these decisions affirmed or challenged their approach to privacy in everyday life, and the consequences of these decisions, if any. Like Fritz and Gonzales (18) and Gonzales et al. (23), our findings showed that for some campaigners, their approach to privacy when crowdfunding affirmed their approach to privacy in everyday life. However, the current analysis documents that some campaigners will create a crowdfunding campaign filled with personal details to reach their fundraising goal, even if doing so challenges their approach to privacy in everyday life. Thus, for some campaigners, their privacy-related decisions taken during crowdfunding do not represent their day-to-day values and beliefs around privacy protection. This is noteworthy because, irrespective of the potential negative consequences that may arise due to the public disclosure of sensitive information, making decisions that truly reflect oneself is a central feature of autonomy. This includes the development and maintenance of a sense of self and the ability to control one's life course, both of which may be undermined by crowdfunding (15;21).

While some crowdfunding campaigners in our sample used specific strategies from their everyday lives to mitigate the risk of giving up personal information, these strategies were often inadequate in the context of crowdfunding. This could be attributed to the campaigners incomplete understanding of crowdfunding, resulting in campaigners making privacy-related decisions that do not reflect their intentions, which could have severe negative consequences, including harming their sense of self (15; 21). For example, even though crowdfunding campaigns are accessible by the public through a simple Google search, some participants mistakenly believed that they could restrict who viewed their crowdfunding campaign through the privacy control settings of social media sites used to share their campaign. This was observed among some participants in the middle-of-the-road category, as they mentioned their ability to mitigate harms related to disclosing highly personal information while crowdfunding by using privacy control settings. Due to this incomplete understanding, campaigners did not always realize the ways in which crowdfunding challenged their approach to privacy in everyday life. This limited understanding of the privacy implications of crowdfunding was seen among participants in the mostly-open category as well. These participants expressed their openness to providing information to others as in part stemming from their unawareness of the risks related to disclosing highly personal information during crowdfunding. Moreover, some of these participants mentioned not having the time to understand the privacy implications of crowdfunding amidst the challenges that led them to creating a crowdfunding campaign.

Our findings affirm existing research highlighting how online social network users are not adequately informed about privacy risks and the limits to privacy control settings on social network platforms (19;20;22). Although this unawareness of the accessibility of information posted online exists for social network users generally (19;20;22), it could lead to severe negative consequences during charitable crowdfunding depending on the campaigner's reasons for creating a crowdfunding campaign. The vulnerability of campaigners could be heightened during the process of crowdfunding since our findings show that there are often major differences between the types of information shared during the process of creating a campaign as compared to sharing information online in everyday life.

Together, our findings provide evidence of compromised informed consent related to the disclosure of private information through crowdfunding. Considering campaigners' general urgency to raise funds, the time constraints in doing so, and the desire of most participants in our sample to protect certain aspects of their privacy, it is important that crowdfunding platforms are held responsible to relieve these pressures on privacy experienced while crowdfunding and implement changes that could better protect campaigners' privacy after they have created a crowdfunding campaign. First, platforms could develop easy to follow and transparent terms and conditions. This is especially important since a recurrent theme in our findings is that campaigners are not fully informed of the risks of giving up highly personal information when crowdfunding. Second, crowdfunding platforms could also create privacy-related options for campaigners. Like Gonzales et al. (23) & Fritz and Gonzales (18), our findings highlight that campaigners often prefer to protect aspects of their personal information. For example, crowdfunding platforms could create an option that allows crowdfunding campaigners to create a private campaign that can only be shared with known supporters and protected with a password or other privacy measures. Considering that the privacy-related costs of crowdfunding are generally not distributed evenly among campaigners, the lack of privacy-related options can have severe consequences for certain campaigners. With these changes, crowdfunding campaigners may be better able to engage safely in the practice of crowdfunding, make decisions that reflect their values and beliefs, and protect the personal information they have disclosed to crowdfunding platforms. Lastly, crowdfunding platforms should also emphasize the importance of creating a crowdfunding campaign that aligns with the campaigner and recipient's privacy-related beliefs to avoid unforeseen consequences and potential regrets. These recommendations have been formulated based on the experiences of the campaigners in our sample. These recommendations are unique and have not been documented in previous empirical research on charitable crowdfunding.

Limitations

Our study has several limitations. First, we recruited individuals into our study who had a public profile on social media or an online presence where they could see the

call for participants on Reddit or Twitter. Thus, our sample of participants may favour people who are relatively comfortable with navigating online social media platforms. Another limitation is that the sample used for analysis includes only those who had created a crowdfunding campaign for themselves. Creating crowdfunding campaigns on behalf of others could involve different approaches to sharing information, such as disclosing private information without consent or permission. It is important to note that this study did not aim to create a representative sample of crowdfunding campaigners but, rather, to provide a range of perspectives on approaches to privacy in everyday life and when crowdfunding.

Conclusion

Our study provides sufficient evidence to indicate that for many people, the practice of crowdfunding infringes on many aspects of their privacy and neglects to recognize the need to better protect their highly personal information disclosed while creating a crowdfunding campaign. This in turn leads to many consequences, including harming their sense of self. Considering the severity of potential negative consequences of giving up personal aspects of oneself, it is important that government entities and crowdfunding platforms consider making policy changes that better protect charitable crowdfunding campaigners' privacy and their ability to freely and autonomously engage in the practice of crowdfunding. As many crowdfunding campaigners experience varied forms of pressure and tension during the process of crowdfunding, it is important for future research to analyze the short-term and long-term consequences of these privacy-related decisions. It would also be beneficial to explore the approach crowdfunding campaigners take to creating a campaign when raising funds for others, as making privacy-related decisions on behalf of another person in vulnerable situations could lead to distinct negative consequences and ethical issues.

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Chapter 5.   Conclusion

Chapter Three and Chapter Four contributed to the literature on charitable crowdfunding in many important ways by addressing the research goals of the larger project related to understanding the ethics of privacy in charitable crowdfunding. For this research, privacy is defined as being multifaceted and interrelated. A central feature of privacy is having control over personal aspects of oneself including informational privacy (control over medical, financial, familial, and personal information) and decisional privacy (the ability to make decisions for oneself). **First, both chapters addressed the research goal of exploring the perspectives of crowdfunding campaigners on how crowdfunding impacts their medical, financial, personal, and familial privacy.** Chapter Three assessed the privacy-related concerns of charitable crowdfunding campaigners using semi-structured interviews with individuals who crowdfunded for themselves for health- and housing-related needs. These privacy-related concerns helped highlight the various ways crowdfunding impacted the privacy of campaigners.

The results from Chapter Three determined that the public accessibility of crowdfunding campaigns was concerning to many campaigners. Many campaigners initially wanted to restrict who saw their campaign though later realized that their campaign could be accessed through the crowdfunding platform's website. As a result of this misunderstanding, some campaigners unintentionally gave up personal information to members of the wider public, including strangers. Depending on the campaigner's reasons for creating a crowdfunding campaign, this public accessibility of campaigns infringed on their medical, financial, and familial privacy. Even for campaigners who were aware of the public accessibility of crowdfunding campaigns, having highly personal and intimate information, related to their health- and housing-related needs, disclosed in readily accessible crowdfunding campaign descriptions was worrisome. Campaigners also expressed concerns over the ability of potential donors or members of the public to freely contact campaigners. This ability to freely contact campaigners led to them being probed on their reasons for creating a crowdfunding campaign. Through this probing, campaigners often became compelled to share information that they originally

refrained from sharing while creating their campaign description. Lastly, the information collection and sharing practices of crowdfunding platforms also infringed on campaigners' privacy, as some campaigners expressed being unsure why specific details were needed, such as their legal name. Campaigners also felt unsure about how this information will be used and shared with other platforms.

Chapter Four described how campaigners approached privacy in everyday life and how this approach functioned in the context of crowdfunding. These findings further shed light on the degree to which crowdfunding impacted campaigners' privacy. The three different types of approaches participants took to privacy in everyday life were: 1. highly-cautious and concerned; 2. middle-of-the-road; and 3. mostly-open. Many campaigners described experiencing various forms of tension and pressure to be more open about their lives and needs while crowdfunding. These tensions not only impacted their ability to make decisions, but also inadvertently led them to sharing information they did not intend to share. For example, some campaigners in the highly-cautious and concerned category explained that they provided the bare minimum needed to create a campaign. Despite being highly restrictive, they described sharing details in their campaign description that they normally would not have in their everyday life. Some participants in the middle-of-the-road-category used the privacy control settings of the social media platforms used to share their campaign to restrict access to their campaign. However, in some cases these campaigners were unaware that crowdfunding campaigns are generally easily accessible on the hosting platform's website. These participants emphasized their preference for using the privacy control settings of various social media platforms to be in control of who sees their campaign description. Similarly, participants in the mostly open category emphasized their openness stemming in part from not being fully informed of the privacy-related risks of charitable crowdfunding and not having the time to consider these risks while going through the challenges that led them to crowdfunding. These misconceptions and tensions related to the practice of crowdfunding impacted campaigners' privacy as it led them to making privacy-related decisions that were not fully informed or autonomous. Such decisions could have negative future ramifications for crowdfunding campaigners. As described earlier, privacy is a multifaceted concept, which in part means that the full scope of impacts of crowdfunding on campaigners'

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privacy could be better described with a long follow-up period. This research was likely to report the immediate impacts of crowdfunding on campaigners' privacy and not the long-term impacts of crowdfunding on privacy.

The second research goal for this project was to understand how decision-making around and consent to disclose personal information is navigated by charitable crowdfunding campaigners campaigning for themselves. The first chapter demonstrated how privacy-concerns impacted campaigners' ability to make privacy-related decisions. For example, Chapter Three highlighted how campaigners lacked awareness of platforms' terms and conditions. More specifically, campaigners were unsure of the accessibility of crowdfunding campaigns, how privacy control settings function in this context, and the crowdfunding platform's information collection and sharing practices. Thus, their consent to disclose personal information could not be considered fully informed. Similarly, Chapter Three also provided evidence that highlighted the intrusive messaging by potential donors or other members of the public as creating pressure for campaigners to disclose more information than they originally intended. This pressure conflicted with crowdfunding campaigners' ability to make decisions that are reflective of their values and beliefs.

As described earlier, Chapter Four compared campaigners' privacy-related decisions in everyday life with their decisions during crowdfunding. This comparison provided more in-depth coverage of the tensions campaigners experienced while making crowdfunding campaigns, and how the decisions campaigners made while crowdfunding often challenged their approach to privacy in everyday life. It highlighted the significance and seriousness of the privacy-related concerns described in the findings of Chapter Three. For example, Chapter Three described how the public accessibility of campaigns was worrisome for some campaigners, and Chapter Four highlighted *how* this public accessibility challenged campaigners' approach to privacy in everyday life. Further, the findings from Chapter Four provided insight into the specific reasons campaigners preferred to avoid publicly disclosing information considered sensitive. The results from Chapter Four showed that campaigners' privacy-related decisions were complex and context dependent in everyday life and while crowdfunding. Although campaigners

deployed various strategies to protect their personal information, their decisions and strategies were often proven to be inadequate in the context of crowdfunding. Campaigners also expressed that due to the severity of their needs, time constraints, and lack of awareness of privacy concerns they were often unable to make well-thought-out privacy decisions. Making decisions that reflect oneself and that are autonomous is extremely important for the campaigner's sense of self or integrity and their ability to decide their future or life-course. Highlighting these points is especially important in this context, where campaigners were crowdfunding for housing- and health- related needs. This type of information can be considered highly intimate and could have negative ramifications if disclosed without being fully informed.

Recommendations

Considering these findings, a few key recommendations are provided in the following section for crowdfunding platforms to consider. These recommendations are: 1. to clearly communicate terms and conditions; 2. to effectively convey the potential privacy-related risks of crowdfunding; and 3. to create consequences for all harmful behavior directed towards campaigners, including inappropriate messages, and bullying. These changes are informed and justified by the findings of this thesis research. These recommendations are important because campaigners expressed uncertainty regarding the ways crowdfunding platforms operate, and the potential privacy risks related to crowdfunding. Further, establishing specific consequences for harmful behavior directed towards campaigners can help alleviate potential harm resulting from the public disclosure of personal information.

Crowdfunding platforms are generally for-profit entities in competition with one another (1). For this reason, they will be most likely to enact change in response to pressure from the public and legislation requiring crowdfunding platforms to provide campaigners with a safer experience. The government has introduced a new Online Harms Act (Bill C-63), which requires social media platforms to recognize and curtail harmful behavior, such as bullying, exploitation, and inappropriate communication (2). Although it is unclear whether this act would apply to charitable crowdfunding platforms,

legislation in this vein could be beneficial for charitable crowdfunding campaigners. Campaigners will also benefit from legislation that requires crowdfunding platforms to clearly communicate the terms and conditions related to engaging in the practice of crowdfunding, including the accessibility of private information disclosed in campaign descriptions, and how their information is stored, collected, and shared. This legislation could include the 10 Fair Information Principles that form the basis of the Personal Information Protection and Electronic Documents Act (PIPEDA): 1. accountability; 2. identifying purposes; 3. consent; 4. limiting collection; 5. limiting use, disclosure, and retention; 6. accuracy; 7. safeguards; 8. openness; 9. individual access; 10. challenging compliance (3). PIPEDA "sets ground rules for how private sector organizations collect, use, and disclose personal information in the course of for-profit, commercial activities across Canada", and currently does not apply to charity groups or the act of fundraising (3, para 1). Since campaigners are often crowdfunding for basic living needs and experiencing time constraints in reaching their fundraising goals, it is of utmost importance to create better protections for them.

Transforming the policies and procedures surrounding charitable crowdfunding is important to allow for people to have a safer crowdfunding experience. First and foremost, it is arguably unjust that some individuals are having to crowdfund for needs that should be addressed by Canada's social safety net (1;4). Through the process of crowdfunding, these individuals are often made to feel even more vulnerable. Past research indicates that people who are more privileged, for example in terms of social capital or education, are more likely to have their needs met (1; 5-8). Thus, crowdfunding seems unlikely to meet the urgent and basic needs of the most marginalized. In this way, the current practice of crowdfunding conflicts with the values of Canada. Further, crowdfunding for health reasons is antithetical to the goal of Canada's universal health care system as it aims to provide care based on need rather than privilege. Our findings show that people are having to turn to crowdfunding to raise funds for various procedures that are often considered essential to the campaigner, such as hip replacement surgery or gender affirming surgery. Thus, our current healthcare system is proving to be inadequate, as some people are having to risk their privacy to raise funds. It is unjust that some individuals must turn to crowdfunding to meet their basic needs. Despite sacrificing

their privacy and personal information and opening themselves up to the possibility of experiencing various harms, many crowdfunding campaigners are unsuccessful at meeting their fundraising goals or raising any funds at all (1;4; 9-10).

Future Research Direction

This thesis suggests several areas for continued research. First, future research should explore closely whether crowdfunding platforms are operating in a manner that aligns with their own terms and conditions or privacy statements. Further, this research should explore how existing policies can be changed to better protect the privacy of campaigners and beneficiaries. For example, GoFundMe has a privacy notice that outlines the privacy-related terms and conditions that campaigners are subject to and protected by while participating in crowdfunding (11). However, this privacy statement is lengthy, and it is not clear how they handle privacy violations. This study indicates that current protections are inadequate, as campaigners in our sample have experienced negative comments and messages. Second, it may be beneficial to understand how privacy-related decisions led to short *and* long-term impacts. This can be done with campaigners who have created crowdfunding campaigns in the past 5-10 years and will likely provide crucial insight into the impacts of charitable crowdfunding. Considering this study included participants who created a crowdfunding campaign within the last year, it revealed various *immediate* privacy concerns and consequences; campaigners touched on some potential privacy impacts that could only be determined with a longer follow-up time.

The findings from both chapters indicate that research should determine how the principles of equity and inclusion can be supported by crowdfunding platforms. This is especially important since Chapter Three and Chapter Four showed that people's privacy related concerns and decisions vary depending on their personal circumstances and are complex. This complexity often stems from personal histories and identities that are traditionally marginalized. For these reasons, it is important that crowdfunding platforms uphold the principles of equity and inclusion. By implementing various changes that

support the principles of equity and inclusion, the practice of crowdfunding could be made more accessible to diverse groups of people

Lastly, our findings are based of the experiences of people who crowdfunded for themselves for health and housing reasons. Crowdfunding for others' needs will pose different challenges while making privacy-related decisions and create different privacy-related concerns. Thus, it is important that future research aims to understand and analyze the privacy related concerns and decisions of charitable crowdfunding campaigners crowdfunding on behalf of others and compare them to the findings from this thesis. Subsequently, these research efforts have the potential to comprehensively inform the development and implementation of policies and legislations requiring crowdfunding platforms to create a safer experience for campaigners and beneficiaries.

Our evidence indicates that the impacts of giving up highly personal information during the process of crowdfunding has complex consequences. Privacy is a multifaceted concept; openly displaying information that is considered intimate and sensitive not only leads to a loss of informational privacy for campaigners, but also in part compromises their ability to make decisions that are truly reflective of their beliefs and values. Giving up personal information related to basic living needs can elicit questions, judgement, and probing from members of the public. While the need for crowdfunding is likely to remain, it is crucial that the practice of crowdfunding is made safer and equitable for campaigners.

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Appendix A.   Participant Information and Consent Form

**Campaign Organizer and Recipient Perspectives
on the Ethics of Privacy in Charitable Crowdfunding**

Principal Investigator: Jeremy Snyder, PhD

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Research Assistant: Ashmita Grewal

                                  Faculty of Health Sciences

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Sponsors: Social Sciences and Humanities Research Council

You are being invited to take part in this research study because you have organized a crowdfunding campaign for your own medical or housing related needs.

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences. If you wish to participate in this study, you will be asked to sign this form. Please take time to read the following information carefully.

Background

Charitable crowdfunding is the practice of using online platforms to raise money online for a range of activities, including schooling, medical care, and disaster relief. Crowdfunding has many benefits, but some academics have raised ethical concerns with charitable crowdfunding, including over how normally private details are shared in these campaigns in order to encourage donations.

What is the purpose of the study?

In this project, our goal is to understanding how crowdfunding campaigners navigate their privacy while crowdfunding for their medical or housing-related needs.

Who can participate in this study?

Any residents of Canada aged 19 or older who has initiated a crowdfunding campaign for your own medical or housing-related needs within the last year.

What does the study involve?

You will participate in an interview by phone, Zoom, or Skype (whatever your preference). We will ask you some questions about your background, questions about your experience with your crowdfunding campaign, and ask about how you navigated personal information and the campaign recipient's privacy while running the campaign. These interviews are expected to be 45 minutes long and the audio will be digitally recorded. All participants will receive a $25 e-gift card from the retailor of their choice in appreciation of their time.

What are the possible harms and discomforts?

Risks from participation in this study are minimal.

What are the potential benefits of participating?

We hope that the information learned from this study can be used to better understand how charitable crowdfunding impacts privacy.

What happens if I decide to withdraw my consent to participate?

If you choose to withdraw your consent to participate, any data from your interview will be destroyed.

How will my taking part in this study be kept confidential?

Your confidentiality will be respected. After your interview is transcribed, your name and any personally identifying information will removed from the transcript and the original recording will be destroyed. Prior to destruction, digital copies of the interviews will be kept on a password-protected folder on the principal investigator's computer. If you choose to receive any publications resulting from this study, we will need to retain your email address to do so. This information will be kept for two years in a locked cabinet in the principal investigator's locked office. Transcripts will be destroyed after 8 years. Any publications using information from your interview will not include your name or any other personally identifiable information.

Who do I contact if I have questions about the study during my participation?

If you have any questions or desire further information about this study before or during participation, or if you experience any adverse effects, you can contact Jeremy Snyder by phone or email.

How do I withdraw from the study?

If you wish to withdraw from the study at any time, you may contact the principal investigator, Jeremy Snyder, by phone or email.

After the study is finished

If you would like to receive a copy of any publications stemming from this study, you may indicate so during the interview.

Who can you contact if you have complaints or concerns about the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, you may contact the SFU Office of Research Ethics by phone or by email.

Appendix B.   Campaign Recipients Interview Guide

Participant verbal consent

Hi, my name is [NAME] and I am a [describe background as student]. I'm helping conduct research on how people who have used crowdfunding think about issues related to privacy under the supervision of Drs. Jeremy Snyder and Valorie Crooks at Simon Fraser University.

Have you gotten a chance to review the consent document we sent you? [If no, give them time to do so now. If yes, proceed to the questions below].

Before I start the interview, I have a few questions to see if you are willing to take part in the study:

- Have you read and understood the information in this consent form?

- Have you had enough time to think about the information provided?

- Have you been able to ask for advice if needed?

- Have you been able to ask questions and have had satisfactory responses to your questions?

- Do you agree to have the audio from this interview digitally recorded?

- Do you understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes?

- Do you understand that your participation in this study is voluntary?

- Do you understand that you are completely free at any time to refuse to participate or to withdraw from this study?

- Do you understand that there is no guarantee that this study will provide any benefits to you?

- Are you willing to participate in the study as described here and in the consent form?

- Would you like to receive a copy of any publications developed through this interview?

- **About You**

    - In what province do you live?

    - What gender to you identify as?

    - What is your age range?

        - 18-29

        - 30-39

        - 40-49

        - 50-59

        - 60-69

        - 70 or older

    - What is your family income range?

        - 0-$24,999

        - $25,000-$49,999

        - $50,000-$74,999

        - $75,000-$99,999

        - $100,000-$124,999

        - $125,000-$149,000

        - $150,000-$200,000

        - $200,000-$249,000

        - $250,000+

    - What is your educational background?

        - Some secondary

        - Completed secondary

        - Some post-secondary

        - Completed post-secondary

        - Some graduate

        - Completed graduate

- **Deciding to Crowdfund**

    - What were you trying to raise money for?

    - Why did you choose crowdfunding as a way to raise this money?

- Did you try any other means of raising this money, either before or after the crowdfunding campaign?

- How did you become aware of crowdfunding as an option?

- Had you ever donated to a crowdfunding campaign before starting your own?

- Did you try to share your campaign as widely as possible or keep it within friends and family? Why?

- Did you regularly update your campaign with additional information? Why or why not?

- How did you determine the financial goal of the campaign?

- **Results of the Campaign**

  - Did you meet your crowdfunding goal?

  - What factors do you think contributed to getting people to donate? What factors do you think held people back from donating?

  - Did your campaign receive any wider attention, such as media coverage?

  - Is there anything you would do differently in terms of running your crowdfunding campaign?

I'd like to ask you some questions about how you manage your private information in your life generally and how you did so in your crowdfunding campaign. Private information can be many different things, like your age, photos of yourself, past experiences, and information about your family members. Many people have very different approaches to privacy and care more or less about what is private and what is public. What we have in mind is the difference between aspects of yourself and your loved ones that you are comfortable having open to the public compared to those aspects you want to have control over who knows or sees.

- **Privacy in Everyday Life**

  - In general, how open are you about sharing details about your private life with friends and family?

  - Do you use social media? If so, do you share personal details? Images? Videos?

    - Do your decisions to share personal details vary between social media types (e.g., Instagram vs. Facebook), and why?

- What personal information are you more reluctant to share with others and what are you more open about normally?
    - Your location (e.g., tracked via phone)?
    - Your address?
    - Your phone number?
    - Your birth date, including year?
    - Your credit scores?
    - Your income?
    - What internet sites you visit?
    - Your purchasing history?
    - Your email correspondence?
    - Your medical history?
    - Your employment history?
- How do you decide what personal information to share with others? Do you have specific rules like no pictures of your kids online? No birthdates? Nothing without permission? Anything goes?

- **Privacy in Crowdfunding**

    - Given what we've already talked about in relation to privacy, in general what kinds of privacy issues do you think exist in relation to crowdfunding?
        - Were you concerned about any of these issues in relation to your campaign?
            - If so, did these concerns change throughout your experience of campaigning?
    - How did you determine what personal details you would post in the campaign description?
        - Do you remember actively deciding not to include details in the campaign because you were concerned that they were too revealing? Please tell me about this.
    - How did you decide what photos and videos you would post in the campaign?
        - Do you remember actively deciding not to include images or videos in the campaign because you were concerned that they were too revealing? Please tell me about this.

- o Were there particular topics that felt more sensitive or private than others? Medical? Family? Financial?

  - o Did you feel like you had complete control over what personal details were disclosed in your campaign?

    - ▪ Was there any pressure to share as much detail as possible in order to meet your goals? If so, how did that make you feel? How did you respond to this pressure?

- **Privacy when Raising Money for Oneself**

  - o Have there been any difficulties in presenting yourself as a person in need of help to your friends and family? E.g., embarrassment, pride, shyness?

  - o Do you feel like your privacy was compromised at all through this process? Did ever feel uncomfortable or withhold information?

- **Reflecting Back**

  - o Is there anything you would do differently about crowdfunding in general and sharing personal information in your campaign specifically?

  - o What advice around privacy would you give to another person considering crowdfunding?

  - o Who do you think has a responsibility to make any changes or give any advice around privacy in crowdfunding?

    - ▪ Government?

    - ▪ Crowdfunding platforms?

    - ▪ Campaigners?

Thank you for your time. Is there anything that we didn't cover that you think I should know about your experience with crowdfunding, especially as it relates to privacy?

End recording. Ask if they would like a gift card for Tim Hortons or Starbucks (unless they have previously requested a different company). Ask if they would prefer an e-card (if possible) or physical card. Ask the email address and/or mailing address to which the card should be sent.