Medical crowdfunding and the communication of health-related financial needs in digital environments

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Abstract

Thousands of Canadians have turned to medical crowdfunding to ask for financial support from others for health-related needs. The popularity and high visibility of medical crowdfunding does not come without criticism that has drawn attention to ethical and equity issues inherent to this practice. In this thesis I present two qualitative analyses that explore how health-related financial needs are communicated in these new digital and online environments. First, a thematic analysis of the campaign narratives written by Canadians seeking funds to diagnose, treat, or manage Lyme disease reveals what is written about their health and financial needs to encourage others to donate. Second, interviews with 14 Canadian print news journalists explores three types of responsibilities they hold when writing stories based on medical crowdfunding campaigns. Both analyses contribute to the growing literature on crowd studies and how digital environments are evolving as dynamic spaces for communicating about health.

Keywords: medical crowdfunding; qualitative analysis; illness narratives; ethics; digital environments

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Chapter 1.   Introduction

Fundraising methods have evolved in recent years and now frequently take place via crowdfunding. Crowdfunding refers to the process of creating an online campaign to raise a target sum of money from contributions gathered from a large number of people via the internet (Berliner & Kenworthy, 2017). Similar to the sharing economy, crowdfunding is derived from the idea that goods, information, services, and money can be transferred and exchanged online via a shared or collaborative platform (Miller, 2019). Crowdfunding has grown to become a global phenomenon, which analysts valued at US$10.2 billion in 2018, and it is expected to continue growing at 16% annually to reach US$28.8 billion by the end of 2025 (Valuates Reports, 2019). One form of crowdfunding matches funding donors with recipients who have created campaigns for health-related financial needs, known as medical crowdfunding. This thesis is focused on the practice of medical crowdfunding. I conceptualize medical crowdfunding as an emerging phenomenon that is transforming the ways in which individuals communicate health-related financial needs and experiences in digital environments. My thesis contributes to the growing literature on medical crowdfunding, deepening the overall qualitative understanding of this practice by its users and other stakeholders.

Crowdfunding websites are for-profit platforms that serve as sites for resource exchange (McAlpine, 2014). These platforms are now used to connect a range of entrepreneurial, creative, philanthropic, and other initiators with those who decide to provide monetary support (Massoultion, 2015; McAlpine, 2014). There are several different types of crowdfunding platforms and four different crowdfunding models: equity, debt, rewards, and donation-based models (Breedlove, 2018). Medical crowdfunding falls under the donation-based crowdfunding model, which facilitates people donating to public and private campaigns without receiving any compensation for their contribution (Breedlove, 2018).

This thesis uses qualitative research methods to explore the uses and implications of medical crowdfunding amongst different Canadian stakeholder groups. This chapter begins by outlining the frameworks that situate my research. This includes concepts in health geography and digital sociology. Following this, I provide a literature review of major topics in medical crowdfunding literature to establish the themes discussed in current scholarship and to contextualize my research. Next, I outline the thesis and articulate the significance of this

research as it relates to concepts in health geography and digital sociology broadly. I conclude by offering a statement of positionality, reflecting on my experience conducting this research.

1.1. Situating This Research

This thesis uses two frameworks to conceptualize the practice of medical crowdfunding among Canadians: health geography and digital sociology. In this section, I frame my use of these two concepts, followed by a brief overview of each framework in the subsequent sections.

First, I situate my research in the field of health geography, which is a sub discipline of human geography that involves studying the relationships existing between people and places. To expand on this, health geography seeks to "explore the social, cultural and political contexts for health within a framework of spatial organization" (Dummer, 2008, p. 1177). Some fundamental geographic research themes include health inequalities and polarization, scale, globalization, and urbanization (Dummer, 2008).

Second, I position medical crowdfunding relative to the emerging research methods presented in digital sociology as it works to unpack how 'new' digital data transforms and produces new ways of knowing (Marres, 2017). Arguably, medical crowdfunding campaigns serve as personal accounts describing experiences in health and illness, which present publicly accessible data for potential analysis on social and crowd behavior.

1.1.1. Health Geography

Health geography emerged out of medical geography as a subdiscipline of human geography. In 1946, the World Health Organization defined health as "a state of complete mental and social well-being and not merely the absence of disease." Health geography is informed by this definition. Health geographers acknowledge that health is realized through a holistic perspective that embraces society, space, and the role of spatial constructs in the playing out of health, wellbeing, and disease (Dummer, 2008). Health geography is a significant shift from its origins in medical geography, which was rooted in positivism and predominantly focused on the study of spatial epidemiology (Kearns & Moon, 2002). The former medical geography was grounded in

applied work using concepts such as central place theory or distance decay, which used spatial analytic techniques (Kearns & Gesler, 1998). The separation between the two disciplines came after academic calls to separate from medical geography and link health geography with social theory, highlighting the social nature of medicine and health (Kearns, 1994; Elliot, 2018). Today, health geography is contributing to health research in substantial ways, using both quantitative and qualitative methods (Dummer, 2008). New technologies such as geographical-positioning systems (GPS), accelerometers, and portable heart monitors enable quantitative researchers to collect data on reasonably small samples for new forms of health geographic analysis (Rosenberg, 2017). Qualitative health geographers have developed alternative epistemological methods to explore the connections between health and place, including considering individuals' lived experiences as ways of knowing about how health is lived out in place (Elliot, 2018).

Common research topics within health geography include examinations of therapeutic landscapes, the built environment, migration and mobilities, urban/rural comparisons with their implications on health and wellbeing, health risks, access to health services, and vulnerability (Rosenberg, 2016). These explorations often result in new learnings about the socio-spatial inequities and inequalities in health that particularly affect marginalized populations. Given the understanding of health as a social construct, health geographers also often use the social determinants of health model to examine health-related situations that apply to individuals, communities and populations. The Public Health Agency of Canada (CBPP, 2016) provides frameworks for how to approach and address the social determinants of health whereby they describe the concept as follows:

> *The social determinants of health influence the health of populations. They include income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; gender; and culture.*

Health geographers explore the social determinants of health from spatial and place-based perspectives using a range of methods and interdisciplinary collaborations.

When considering the pursuit of equitable health care provision, access to health services is often studied by health geographers in relation to supply-side barriers, gaps, or pitfalls that can affect the health care system or demand-side barriers inhibiting patients' access to health services (Canadian Medical Association, 2013). Health geographers explore both supply and demand factors as they relate to the spatial dimensions of formal and informal care provision. Supply-side barriers include lack of management of chronic disease, long wait times, lack of family

physicians, services not being locally available in areas of need, and rigid payment models that do not accommodate patients' preferred methods (Canadian Medical Association, 2013). Common demand-side barriers can include patients' health literacy, time off of work, potential cognitive issues, immobility, transportation options, payment for medications, language, or cultural beliefs and norms (Canadian Medical Association, 2013). These barriers are relevant to the topics pursued in my thesis as both supply- and demand-side barriers are some of the factors that push Canadians to consider (or opt for) pursuing financial support via medical crowdfunding. My research also offers new insight into the ways that crowdfunding is being used by Canadians across the country as a means to communicate health-related financial needs to a public audience.

1.1.2. Digital Sociology

Digital sociology developed from the belief that digital data have the potential to transform ways of knowing society (Marres, 2017; Halstead, 2017). Many digital sociologists are engaged with studies about identity, personality, and expression in online environments (Marres, 2017; Halstead, 2017). Digital sociologists work from the perspective that digital data can be used for more than computational purposes and that they can inform how we investigate and understand social life (Marres, 2017; Halstead, 2017). In my opinion, digital sociology offers methods that are highly compatible with the social and theoretical approaches of health geography and the emerging research approaches being used in medical crowdfunding studies.

This digital sociology framework accounts for the technical as well as the social aspects of online social media use. For example, research by digital sociologists has introduced and underscore the notion that the computational algorithms used by social media platforms disadvantage particular socioeconomic groups (Halstead, 2017). Some scholars interested in online research methods have studied how online communities form and share information (Lai & Chen, 2014) as well as the ways in which digital landscapes can suit personalities and promote user wellbeing (Hamburger, 2004). A new direction in digital sociology involves exploring the public-private distinction, including as it relates to social media sites being used to harvest private information for marketing and other research purposes (Hewson, 2016). Digital sociologists suggest this public-private blurring includes ethical concerns about information-harvesting that blurs real and pseudonym identities (Hewson, 2016). My thesis draws from digital sociology through recognition that there are important ethical dimensions about how publicly-available online correspondence or data is used and shared by others, especially in the medical crowdfunding context.

1.2. Spatial Geographies of Medical Crowdfunding

Fundraising for an individual's medical care is not a new phenomenon. In the Canadian context, such efforts were often undertaken by community and church group fundraising events, coin donation buckets placed at cash registers, or similar activities. Crowdfunding has brought these efforts into the digital domain. Medical crowdfunding is popular in the North American context. For example, over 75% of web traffic on GoFundMe is contributed by North Americans - 70% from within the United States of America and 7% from Canadians (Similarweb, 2019; Smith, 2019). My thesis research contributes to our nascent knowledge on the spatial geographies of medical crowdfunding in the Canadian context.

Media accounts of medical crowdfunding in the United States often reference cases of individuals or families filing for medical-related bankruptcy or several mortgages being taken out for medical care (Burtch & Chan, 2014; Crist, 2019; Sainato, 2019). The American health care system operates as a multi-payer system that places citizens with great personal financial responsibility for their health, particularly relative to that of Canadians under a single-payer universal health care system (Knowledge@Wharton, 2017; National Bureau of Economic Research, 2019). While wait times are cited by over half of Canadians as a significant barrier to accessing health care, in the United States cost is the most significant barrier to care cited by over half of Americans (National Bureau of Economic Research, 2019). These contextual variables assist with understanding why people crowdfund for medical care in certain locations, and they also point to the fact that the motivations for doing so may be very place-based. In this thesis I articulate several important place-based contextual elements that shape the aspects of medical crowdfunding that I explore in the Canadian context. This includes factors such as the availability of diagnostic testing and treatment for a specific contested chronic illness in Canada, and the code of ethics that shape journalistic practice in Canada.

1.3. Research Objectives

I work from the perspective that medical crowdfunding platforms are digital environments where some Canadians choose to engage with peers and unknown others alike to communicate health-related financial needs. I use qualitative approaches to examine perceptions

and experiences as they relate to sharing health information via medical crowdfunding campaigns or preparing news media stories of such campaigns. My two research objectives are:

1. to explore Canadians' crowdfunding campaign narratives to unpack the ways in which health and need are communicated online by people managing a contested chronic illness when there is financial incentive to do so; and
2. to explore the considerations that shape Canadian print journalists' coverage of medical crowdfunding campaigns.

1.4. Thesis Outline

This thesis is organized into two empirical chapters (Chapters 2 and 3), both of which are structured as scholarly journal articles. Chapter 2 has been submitted for publication in *Health: An Interdisciplinary Journal for the Social Study of Health of Health, Illness and Medicine* and is currently undergoing revision. Chapter 3 is in preparation for submission to *The Journal of Mass Communication.* Drawing from two datasets, crowdfunding campaign descriptions and qualitative interviews with professional print journalists in Canadian media, this research is exploratory. By that I mean that analysis of each dataset offers new perspectives on medical crowdfunding from stakeholder groups that are yet to be explored from a research perspective.

Chapter 2 applies a qualitative analysis to crowdfunding campaign narratives written by Canadians who are crowdfunding for Lyme disease-related medical expenses. I specifically explore if and how these narratives are constructed in similar ways across campaigners. Chapter 3 uses semi-structured interviews to unpack and perspectives of medical crowdfunding held by Canadian media print journalists. In this analysis I explore the responsibilities these media professionals hold towards preparing news stories based on crowdfunding campaigns. Chapter 4 unites the emerging themes, relating back to the concepts established in health geography and digital sociology.

1.5. Importance

This thesis uses qualitative datasets that highlight new perspectives of two stakeholder groups in the practice of medical tourism: Canadian crowdfunding campaigners and Canadian print media journalists. Each stakeholder group has been included for unique reasons. First,

exploring the perspectives of crowdfunding campaigners through qualitative analysis of their own campaign narratives is not only important for advancing our understanding of the phenomenon, but also for discerning the role of medical crowdfunding platforms in the communication of health in digital environments. The information gained from this analysis will be important to health professionals and clinicians as they look to provide additional insight into patient-oriented healthcare communication, such as patient guides that address the use of medical crowdfunding to support care needs. The perspectives of Canadian print media journalists are also significant as they represent a group of professional stakeholders who work closely with crowdfunding campaigns and campaigners yet maintain emotional distance from the stories they work with. This analysis has the potential to inform the development of professional guidelines regarding covering crowdfunding for journalists and other media professionals.

1.6. Positionality

The proximity between the researcher and their subject is a vital (Moore, 2012). I identify distinctly outside of the study groups I encountered within this research as I do not have Lyme disease and I am not a journalist. I have never been involved in the organization of a medical crowdfunding campaign, nor do I have any peers who have done so. Therefore, I position myself as an outsider on the topics I explore in this thesis. Having come across crowdfunding campaigns in my personal life, however, I was familiar with the ways that campaigns are shared and elements that contribute to an increase in campaign momentum online.

During the research process interacting with media professionals (Chapter 3), the participants were much more senior than myself. Many interviewees had several years of professional experience in the Canadian print media industry. In some cases, I felt unsure as to how to frame questions about their profession given the difference in knowledge and firsthand experience.

1.7. Summary

This thesis uses qualitative methods to advance our empirical-based understanding of medical crowdfunding practices within Canada. I use the narratives and perspectives of two important stakeholder groups involved in this phenomenon. Engaging with literatures from health geography and digital sociology and the emerging literatures of medical crowdfunding, I position medical crowdfunding as a spatial phenomenon in two ways: as a way to locate health care gaps

in local contexts and as an intangible environment where individuals communicate health and illness directly to the public.

Chapter 2.
What was lost, missing, sought, and hoped for: Qualitatively exploring medical crowdfunding campaign narratives for Lyme disease

2.1. Abstract

Purpose: Lyme disease remains a contested illness in Canada, thereby making the diagnostic and treatment journeys difficult for some people. One outcome of this is that increasing numbers of people are turning to medical crowdfunding to support access to alternative therapies, non-local health care providers, and assist with managing the costs of everyday life.

Methods: In this analysis, we qualitatively explore the narratives shared in Canadians' crowdfunding campaigns to support Lyme disease treatment or diagnosis to identify whether or not any common elements shared in these narratives exist, and if so, what they are. We identified 238 campaigns for inclusion from three prominent crowdfunding platforms.

Results: Thematic analysis of the campaign narratives shows four consistent themes shared in these campaigns: what is lost (e.g., bodily ability), what is missing (e.g., local care options), what is sought (e.g., funds to cover treatment abroad), and what is hoped for (e.g., return to wellbeing).

Conclusion: These themes demonstrate the highly personal and emotional nature of medical crowdfunding, particularly in the context of a contested illness that may lead some to question the legitimacy of one's financial need. This analysis contributes valuable new insights to the nascent scholarship on medical crowdfunding, and particularly to our understanding of how people communicate about their health and bodily needs on this public platform. It also identifies important directions for future research, including the potential for crowdfunding narratives to be used for advocacy.

Keywords: Medical crowdfunding, Contested illness, Lyme disease, Illness narrative

2.2. Introduction

Crowdfunding via social media enables users to create campaigns on platform websites, such as GoFundMe and FundRazr, to reach out for assistance with raising monetary donations for a particular cause (Barclay, 2012). Crowdfunding emerged with the rise of the "sharing" and "crowd" economies and has been facilitated by the introduction of Web 2.0, which has enabled people around the world to send monetary donations easily, quickly and safely (Berliner & Kenworthy, 2017; Darwish & Lakhtaria, 2011). Crowdfunding websites assist people with seeking funding for a range of causes such as creative pursuits, business start-up costs, and even medical care (Burtch & Chan, 2014). Specifically, people register with these sites to run funding campaigns that typically include features such as posted narratives that relay their 'pitch' to potential donors that often include background contextual details, photos and/or videos, a chronicle of donations, and comments from readers or donors.

Medical crowdfunding campaigns are based on a donation-based model of giving, where people financially contribute to causes motivated by altruism and typically do not expect anything in return (Mollick, 2014; Omand, 2015; Snyder, Crooks, Mathers & Chow-White, 2017). Many crowdfunding websites have a separate medical category, demonstrating the rise in popularity of this particular type of crowdfunding. Technavio (2018) found that the crowdfunding sector in the Americas is sizeable, valued at approximately US$26.64 billion. In 2016 alone, the crowdfunding platform GoFundMe supported Canadian campaigners in raising over US$66 million from 88,000 campaigns across all categories, including medical (GoFundMe, 2016). The continual growth and social acceptance of the crowdfunding model signals a move away from conventional forms of fundraising for medical and health-related needs, such as donation buckets placed at store cash registers and community events, towards one that favours disparate networks of people making individual donations to compelling campaigns (Gonzales, Kwon, Lynch, & Fritz, 2018; Omand, 2015).

Research has shown that people campaign for a variety of costs related to medical care via crowdfunding sites, including surgical costs, medical care abroad, experimental therapies, diagnostic tests, pharmaceuticals, diagnostic testing, and expenses associated with getting to-and-from medical facilities (Gonzales et al., 2018; Vox, McBride Folkers, Turi & Caplan, 2018). The health conditions people seek to treat via the funds raised by these campaigns are similarly diverse, crossing the spectrum of chronic and acute conditions as well as medical emergencies (Snyder et al., 2017). While medical crowdfunding may have benefits for patients, such as

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providing financial access to life-saving care, many critics suggest that the considerable turn to crowdfunding for medical needs signals larger systematic and equity concerns (Moore, 2019; Snyder et al., 2017). One such concern is the growing recognition that certain groups may be less likely to reach their medical fundraising goals than others, including people with limited social networks and those diagnosed with stigmatized illnesses such as lung cancer, mental illness, contested illnesses, and HIV/AIDS (Dressler & Kelly, 2018). There are also strong ethical concerns with regard to medical crowdfunding, including that funding platforms actively encourage people to disclose highly personal details of their health status and illness journeys in their narratives that they may not otherwise share with others (Gonzales et al., 2018; Moore, 2019). Scholarly research regarding medical crowdfunding, including explorations of its causes and consequences, is nascent and thus many things remain currently unknown about how and why people opt to participate in this phenomenon as a campaigner or donor. Here we explore a heretofore unexplored question: what do campaigners who are managing contested chronic illnesses share in their crowdfunding campaign narratives so as to persuade others to (potentially) donate?

2.2.1. The Contested Nature of Lyme Disease

Contested chronic illnesses are conditions that lack standard diagnostic testing, rely heavily on subjective measures to determine their presence, are typically based on diagnoses of exclusion, have no standard treatment protocols, are not recognized as legitimate by some health care professionals or medical organizations, and have disputed understandings and definitions (Scales, 2018; Swoboda, 2008). Examples of contested chronic illnesses include fibromyalgia, chronic fatigue syndrome, gulf war syndrome, and Lyme disease (especially chronic Lyme disease). The contested nature of these illnesses often results in diagnostic and treatment uncertainties as well as skepticism in medical, legal, and even public circles; as a result, those diagnosed or in the process of being diagnosed with such conditions may feel abandoned by their health systems or public/private health insurers (Stone, 2013, 2014). Patients may be inclined to seek other care options, including experimental therapies or treatment abroad, both for diagnosis and/or treatment (Scales, 2018). The chronic nature of these conditions means that treatment is likely to be lengthy, if not life-long, and will need to be responsive to fluctuations in symptoms and ability levels, which can generate significant personal costs (e.g., travel to-and-from providers, time off of paid work, nutrition regimens and over-the-counter medications and

supplements) (Crooks, 2015). This reality, coupled with the choice some people make to pursue non-conventional treatment/therapeutic/diagnostic protocols for contested chronic illnesses that require out-of-pocket payment, is likely a significant driving factor in the decision to appeal to others for financial support via medical crowdfunding (Snyder, Turner, & Crooks, 2018; Vox et al., 2018).

Here we focus on Canadians' crowdfunding narratives in the context of a particular contested chronic illness: Lyme disease. Lyme disease is a vector-borne illness transmitted through a species of ticks carrying the pathogen B. *burgdorferi* (Habegger, 2014; O Johnson et al., 2018). Within 24-48 hours of an infected tick bite, people begin to develop flu-like symptoms (Bouchard et al., 2018; Habegger, 2014). Unless successfully treated at an early stage by antibiotics, Lyme disease typically increases in severity to include symptoms such as headaches, arthritis, Lyme carditis, mental haziness, and rashes that can last for many years after the initial tick bite (Habegger, 2014). Symptoms will manifest differently in each person, and there is no standard protocol for how treatment should be administered once they become chronic (CDC, 2018). Early diagnosis is sometimes made through observing the presence of a tell-tale rash around the tick bite, which some argue is far too subjective (CDC, 2018; Petrow, 2018). Several weeks after infection, various laboratory tests can be used to support or rule-out diagnosis through testing for the presence of specific antibodies (Government of Canada, 2018). Some of these laboratory tests are well known for generating high rates of false negatives, while others are not readily available within public health care systems and require private purchase (Caruso, 2017; Kling, Galanis, Morshed & Patrick, 2015). Both of these factors contribute to the contested nature of Lyme disease.

For many years it was believed that the geographic scope of Lyme disease within North America was primarily limited to certain regions of the United States, and thus it was of little concern to the Canadian medical community (Habegger, 2014; Scales, 2017). In recent years, two important things have happened: (1) environmental change has made areas of Canada more habitable to Lyme-carrying ticks; and (2) the public health and advocacy communities have raised significant awareness of tick-borne disease and the likely underreporting of Lyme disease (Habegger, 2014; Eogden, 2009). An outcome of these changes is that rates of Lyme disease diagnosis and suspected cases have been on the rise in the country (Bouchard, 2015). However, Health Canada has been slow to prioritize Lyme disease research efforts or systems to track diagnosis rates and geographic spread (Pelley, 2017; Scales, 2017). This reality, coupled with the diagnostic uncertainty that surrounds Lyme disease as a contested chronic illness, has resulted in

many private health insurance companies in Canada being unwilling to cover the costs of diagnosis or treatment, many aspects of which fall outside the scope of the national publicly-funded health care system (Smith 2017). Additionally, some physicians and administrators lack the information, training, and/or tools needed to adequately support such patients (Smith, 2017). As a result, some Canadians cite a prolonged and exhausting diagnostic journey, navigating the public health care system to find providers who are "Lyme literate" or seeking private care elsewhere (Scales, 2017; Smith, 2017).

In the remainder of this article, we present the findings of a thematic analysis of the campaign narratives from 238 medical crowdfunding campaigns for Canadians seeking funding to support Lyme disease-related care, treatment, or diagnosis. In doing so, we build on the deeply established scholarly tradition of using health narratives to generate vital insights into people's lived experiences of health and illness that can inform health policy and medical practice and assist in understanding emergent health-related phenomena (Aktinson & Rubinelli, 2012; Chandler, 2014; Rian & Hammer, 2013; Shapiro, 2011). In the case of the current analysis, we turn to the highly personal narratives shared on medical crowdfunding campaign sites to explore what people relay in their public-facing stories, living with Lyme disease or pursuing diagnosis in the hopes of encouraging donations. More specifically, we set out to identify whether or not any common elements are shared in these narratives, and if so, what they are. Doing so contributes valuable new insights to the nascent scholarship on medical crowdfunding, and particularly to our understanding of how people communicate about their health and bodily needs on this public platform. By conducting this analysis, we also respond to calls for social science researchers to contribute critical perspectives that assist with illustrating what medical crowdfunding can tell us about the complex relationships that exist between patients and the health systems from which they receive care (Snyder et al., 2016).

2.3. Methods

Narratives written by campaigners are the core content of medical crowdfunding campaigns. These personal stories provide the information that readers can use to evaluate the potential for making a donation. As the very popular crowdfunding platform GoFundMe (2019) explains to campaigners:

Your fundraiser story is the place to let readers know what you or your beneficiary is going through. You may be tempted to keep your story as short as possible, but people will be more willing to support your cause if they have a full understanding of the financial, physical, and emotional trouble you're experiencing. Your fundraiser description length can also influence donations.

It is thus not surprising that campaign narratives are often lengthy and rich in detail. Such narratives form the basis of the current analysis, which is specifically focused on Canadians' Lyme disease campaigns.

2.3.1. Data collection

After reviewing the online platforms available for crowdfunding along with media and industry coverage of these platforms, we determined that FundRazr, YouCaring, and GoFundMe are those that are most commonly used for medical campaigns, including by Canadians. Since the commencement of this analysis, YouCaring has been purchased by GoFundMe and has been subsumed into this larger platform. Our goal was to gather a sample of up to 250 campaign narratives across these three sites. We started by first conducting a keyword search for "Lyme" in the search engines on each platform. The results were gathered over a two-month period at the end of 2017, after which the campaigns were hand searched to eliminate any that were not focused on humans, were fundraising for organizations rather than individuals, or were not focused primarily on Lyme disease. We gathered 12 campaigns from FundRazr and 13 from YouCaring, which in both cases was the full sample of Lyme disease campaigns posted by Canadians. GoFundMe yielded 4841 campaigns that matched the keyword search. To manage this large return, we hand searched for Canadian campaigns that met our inclusion criteria until we filled our overall target of 250 campaigns. We ultimately included 213 from GoFundMe for a total sample of 238 campaign narratives after removing 12 campaigns initially selected that the full team felt did not meet our inclusion criteria upon triangulated review. Satisfied with the size of the overall dataset, we did not seek to add to the GoFundMe sample after removing these 12 campaigns.

2.3.2. Data Analysis

In addition to extracting the 238 medical crowdfunding campaign narratives into a Word document, we created a spreadsheet to store specific campaign details: title, number of donations, number of social media shares, campaign creation date, location, funding received, and funding requested. The information in the spreadsheet was collected so we could contextualize the sample, while the narratives formed the basis of a thematic analysis. Thematic analysis is used in qualitative research to identify patterns in datasets and to assist with determining what underlies these themes (Braun & Clarke, 2006; Maguire & Delahunt, 2017).

Our first step for the thematic analysis was to extract a random sample of 30 campaigns to be reviewed independently by team members. Following independent review, a meeting was held to discuss emergent themes central to the question: what do campaigners who are managing contested chronic illnesses, in this case Lyme Disease, share in their crowdfunding campaign narratives so as to persuade others to (potentially) donate? In other words, we were seeking to explore whether thematic patterns in the narratives emerged through analysis. An outcome of the team meeting was agreement on four overarching themes that formed the basis of the reviewed narratives: what was lost, what was missing, what was sought, and what was hoped for (these are described in detail in the next section). Next, a team member hand-coded the narrative dataset in Word, identifying segments of narratives that fit within the scope of each theme while seeking input from the team as needed. Quotes for each theme were extracted and reviewed by the team to confirm interpretation of each theme. In the section that follows, we present the findings of this thematic analysis.

2.4. Findings

The majority of the 238 campaigns included in this thematic analysis were created by users based in Ontario (41%), Alberta (21%) and British Columbia (16%), all of which are heavily populated Canadian provinces. The remainder were created by users in New Brunswick (5%), Saskatchewan (4%), Manitoba (4%), Quebec (4%), Nova Scotia (3%), and Newfoundland and Labrador (1%). On average, campaigns had 253 Facebook shares and 40 donors. Campaigners requested an average amount of CAD$27,064 from donors, ranging from $500 to $200,000. Campaigners were pledged an average amount of CAD$5,374 in donations or 19.9%

of the average requested amount. The highest amount raised in one campaign was CAD$60,090, which had set a fundraising goal of $60,000. Campaigners were fundraising for a variety of treatments associated with Lyme disease, including: holistic treatments, experimental stem cell therapies, and antibiotic treatments. Some campaigns named specialized clinics that campaigners sought treatment from, which were typically abroad. In addition to core medical expenses, campaigns commonly requested funding to assist with costs of everyday life (e.g., to supplement income that had been lost) and of accessing medical care (e.g., parking passes, vehicle-related costs).

Despite differences in campaigners' geographic locations within Canada, campaign funding requests, social media networks, and the specific activities they sought to have funded, we identified four common thematic aspects of the narratives shared in their Lyme disease-related crowdfunding campaigns. Narratives commonly spoke to *what was lost*, whereby campaigners referred to aspects of their lives that had been negatively affected by Lyme disease and the symptoms they experienced. A second common element in campaign narratives referenced *what was missing* in regard to the structural resources, such as health services or expanded insurance, they would like to have had in place in order to assist them with coping with Lyme disease. The (perceived) lack of resources typically led to a description of *what was sought*, as campaigners commonly stated what the money raised through crowdfunding was needed for and how it would be spent. Once the logistical details had been established in the narratives, many campaigners also expressed *what was hoped for*, which focused on anticipated future improvements in symptoms, wellbeing, and even awareness of and understanding for Lyme disease more broadly. In the remainder of this section, we discuss these four themes in detail. Though we consider each separately, we acknowledge that there is a strong interrelationship between these four aspects of campaigners' crowdfunding narratives. We explore some of these interrelationships in the discussion section that follows.

2.4.1. What was lost

Campaign narratives identified many aspects of wellbeing and everyday life that had been negatively impacted by Lyme disease or the search for diagnosis. Campaigners described things such as employment, physical ability, and overall health and wellbeing as having been lost or diminished as a result of managing this contested chronic illness. Many times, campaigners

included in-depth descriptions of the loss of bodily abilities, such as where: "*greatly affected by his illnesses, Paul is no longer able to walk, or talk and has limited use of his arms. He gets around by using a motorized wheelchair. With the help of head tracking technology Paul is able to speak through a machine.*" As shown in this narrative excerpt, statements describing what was lost were occasionally coupled with remarks about coping strategies – in this case, the use of mobility aids and assistive technologies.

Narratives made it clear that the loss of bodily ability also reduced the capacity for those with Lyme disease to perform some routine tasks and responsibilities. As was explained by a campaigner: "*I suffer from fatigue, difficulty concentrating, food intolerances, and many more symptoms. I am unable to attend school, and I need to spend a lot of time resting each day.*" Not surprisingly, there was significant focus on changes to employment status. One campaigner noted how no longer working created an economic strain on their family: "*it's incredibly hard to focus on getting better when you take care of others. I've even applied for jobs because I feel like it would be easier on me [to provide for the family] and help pay for treatment.*" Lyme disease symptoms were quite debilitating for some and impacted the ability to engage in recreational activities such as dining out, playing sports, and travelling. In a clear statement of what was lost, one campaigner wrote: "*life as I lived it was exciting - full of activity and adventure. I was a decorated athlete, physical educator, and avid outdoor enthusiast.*" It was not uncommon for campaigners to use past tense in some segments of their narratives so as to emphasize a sense of loss.

An important sense of loss pertained to the time spent seeking diagnosis and/or treatment for Lyme disease. Many campaigners wrote extensively of their diagnostic journeys, or misadventures, in their campaign narratives. In many ways, diagnostic journeys were associated with the time that was lost to treatment. For example, one campaigner explained that "*the photo is of me in better days. I have had rheumatoid arthritis since I was 14. Most likely misdiagnosed Lyme as I have some of the nasty co-infections that come from Lyme.*" The prolonged diagnostic journey transformed the lives of individuals managing Lyme disease. Discussing the diagnostic journey, one campaigner explained that "*I hate that this disease continues to rob me of a 'normal' life.*" The tone of this narrative excerpt conveys the emotion many campaigners shared when discussing the loss of time, ability, and sense of self to Lyme disease, its symptoms, and the diagnostic journey. In fact, many campaigners explicitly referred to these losses as "*emotionally exhausting.*"

2.4.2. What was missing

Despite the presence of a publicly-funded universal health care system in Canada to support medically necessary care (Government of Canada, 2018), many campaigners expressed discontent with this system and identified health care supports that were missing. As one explained, *"through this experience [of diagnosis] I have come to understand that Health Canada is an utter failure in terms of the diagnosis and treatment of tick-borne diseases.*" Another campaigner expressed that *"not having the right medical support makes this illness very scary. I feel very alone."* Some campaigners felt that reliable Lyme disease testing and treatment protocols were particularly missing, with sentiments such as "*Canadian labs do junk tests that are unreliable and unnecessarily cause suffering"* being common elements of narratives.

Many campaigners relayed a sense of frustration over identifying health care providers who were willing to treat Lyme disease or validate their diagnoses. They reported finding that 'Lyme literate' providers were missing from their local health care resources. One campaigner explained that *"I awaited 18 months for another appointment with a top neurologist that specialized in chronic headaches. Over this period of time I brought up Lyme Disease to all the doctors and was flatly told 'not possible, this can't be Lyme Disease,' 'we don't have Lyme in Canada.'"* It was not uncommon for descriptions of missing health care resources to be used as an opportunity to call attention to the gaps in Canadian health coverage. One campaigner elaborating on this issue recounted, *"I have just started additional therapy with a Lyme Literate Naturopathic Doctor (LLND) which is not covered by Canadian Health Care nor are the treatments."*

Local access to desired health care resources were missing for some. Narratives showed many instances in which campaigners had turned to private clinics in the United States to assist with their diagnostic journeys or treatment. As one campaigner explained, *"the Canadian blood test is very simple, generic and not in depth. There are many co-infections that can be involved with Lyme, and the Canadian test doesn't look for any of them. So, like almost everyone else who ends up actually having Lyme, I tested negative on the Canadian test. In order to get a complete Lyme test, I would need to get my blood drawn here and send it off to a lab in California."* However, narratives also documented how testing accessed in the United States may not be recognized by physicians at home, with someone stating that their "*test results sent to the United*

States showed a positive result for LYME but wouldn't be considered in Canada." Reflecting the lack of local care options experienced by some campaigners, there were instances of people seeking or having already obtained treatment in the United States, with one campaigner asking "*so what choice [do I have] but to get treated at a medical clinic that specializes in the treatment of LYME...elsewhere*."

2.4.3. What was sought

The goal of crowdfunding is to seek financial donations from others, and so it is not surprising that the reviewed narratives touched heavily on the care and support campaigners sought. Funding to support diagnostic testing, local treatment, or treatment abroad were the most common statements of what was sought within the narratives. As one campaigner explained, they were *"just wanting to share info on what you're [donors] helping to pay for!"* Many narratives included clear statements about financial need and existing resources: "*I would need to get my blood drawn here and send it off to a lab in California called Igenex. These tests cost money. Money our family doesn't have.*" Sometimes descriptions of what was sought were brief, while others were extensive and significantly detailed. In many instances the most detailed descriptions of what was sought included URLs that directed people to other websites for more information or segments of text, including billing estimates, copied from clinic websites.

The out of pocket expenses associated with Lyme disease treatment made day to day expenses financially arduous, as this campaigner described: *"I've been living month to month, rent to rent, JUST enough food to survive, but not to fully overcome this part that requires tools and my finances to be set… HEALING, is a full time job."* As the symptoms of Lyme disease became increasingly debilitating, many campaigners described themselves, in their narratives, as being increasingly reliant on immediate friends and family for financial support. As one campaigner explained, Lyme disease had *"placed an ongoing financial burden on those closest to me."* Managing Lyme disease treatment urged many campaigners to seek funds through crowdfunding to regain their financial equilibrium, as this campaigner explained how their illness created financial instability saying, *"I have since fallen behind on all of my bills. My credit score has also fallen from 798 to 346 due to my inability to pay any of my bills."*

2.4.4. What was hoped for

Campaign narratives often communicated some degree of hope for change, for access to care, for enhanced wellbeing, and/or improved health. As one campaigner explained: "*I dream of being able to walk properly, talk, read, write, dance, laugh, play sports and earn an income again. In other words, I dream of resuming my life of 10 years ago.*" The return to an ideal state of health was often combined with campaigners' references to forward-looking goals to describe what was hoped for. Many times, this narrative described how hope for improved health was for the sake of family and loved ones, as this mother wrote: "*it is hard to look back at pictures of myself and see how vibrant and healthy I was before this. I wish they could have that mommy back.*" What was hoped for also captured testimonials that spoke to the character of the campaigner such as this campaign that said: *"our goal is that Carolyn will get well and be able to go to university and pursue the amazing dreams she has to make a difference in the world."* Youth was often used to appeal to donors through sympathy. Narratives stated that campaigners wished or hoped for a more optimistic future without Lyme disease: *"[we] have one wish which is for Mikayla to live out the rest of her teenage years and into adulthood without the debilitating, chronic pain that has filled the majority of her young life.*"

Some narratives expressed significant hope for increased awareness of Lyme disease. In some cases, campaigners asked for their crowdfunding campaigns to be shared among others and through their social networks to increase the number of people who view their campaigns and learn about Lyme disease. "*Please if anything just share my story. Help us get recognized and believed.*" In effect, these narratives were viewed as a form of advocacy, using the platform of crowdfunding to amplify the impact of their stories and raise overall awareness. Another campaigner said that they were seeking funds to improve their health so that their adverse experience with Lyme disease could be used to benefit others *"so that one day I will be strong enough to help raise awareness of Lyme disease, so that other people do not have to experience what I have been through.*" Some campaigners focused on particular types of advocacy, such as hopes for raising Lyme literacy among Canada's medical community, while others were quite broad with regard to their hopes for how their campaigns or their future activities could be used to have a positive impact on the lives of people managing Lyme disease.

2.5. Discussion

Through analyzing 238 medical crowdfunding campaigns posted by Canadians with Lyme disease (or who are seeking diagnosis), we were able to identify four common narrative themes: what was lost, what was missing, what was sought, and what was hoped for. The commonality of these themes across the 238 reviewed campaigns was striking, given that the guidance provided to those writing campaigns does not explicitly encourage people to touch upon each of these aspects in their narratives. Although in the previous section we explored these themes separately, there are indeed important intersections and overlaps between them. There were particularly strong connections between narrative references to what was missing and what was sought, as well as to what was lost and what was hoped for. For example in some cases, narratives referred to desired local treatments for Lyme disease as something that was missing, while funding to obtain those treatments abroad or elsewhere formed the basis of what was sought from donors in the crowdfunding campaign. With regard to the connections between what was lost and what was hoped for, both themes within the reviewed narratives touched profoundly on aspects of health, wellbeing, and physical/mental ability. While narratives typically did not express the potential for what was sought to enable *all* of what was lost to be regained, that which was hoped for typically held deep parallels to some of what was emphasized as having been lost.

There are some significant connections between the findings of this analysis and the existing medical crowdfunding research. For example, Barcelos and Budge's (2019) study focused on the use of crowdfunding for gender-affirming surgery found that these campaign narratives also placed heavy emphasis on what was missing from the health care system, in terms of both the practical and emotional care needed by transgender people, and how these missing elements served as significant barriers to surgery. In the context of the current study focused on Lyme disease, campaigners often recounted what was missing relating to health and social care, and connected these elements to lack of access to diagnosis and treatment. In both studies, narratives detailed encounters with health care providers who invalidated campaigners' bodily experiences. In the context of Lyme disease, such invalidating encounters are heavily shaped by the contested nature of this chronic illness (Scales, 2017, 2018; Smith, 2017). With regard to crowdfunding campaign narratives providing space for articulating lack of access to care and treatment, this has also been documented in research exploring the use of medical crowdfunding to fund unapproved, experimental therapies for brain injury and cancer (Vox et al., 2018). Once again, in these cases, campaigners felt pushed to explore care options that were not available

locally to them, articulating this as what was sought. The use of medical crowdfunding to seek experimental therapies, including those offered abroad, which was also documented in the current analysis, draws valuable reference to emerging ethical debates about the role of crowdfunding in normalizing and validating such unproven therapies (see, for example: Moore 2019; Snyder et al., 2018; Vox et al., 2018).

When taken together, the themes identified in this analysis reveal the highly personal and emotional dimensions of campaign narratives and the practice of medical crowdfunding in general. They also support contentions made elsewhere that people will forego privacy and share deeply personal details about their health and wellbeing in the hopes of receiving enough donations to fund their requests (Gonzales et al., 2018; Snyder, 2016). The narratives reveal that campaigns for Lyme disease support are much more than a simple appeal for funding – otherwise. In the case of the 238 campaigns reviewed for this analysis, narratives offered a space to chronicle changes over time, articulate hopes and fears, and also advocate for better awareness of and treatment for Lyme disease. Moore (2019) argues that some people feel emotionally invested in the medical crowdfunding campaigns to which they donate. The findings of this thematic analysis show how this potential for emotional investment is established by campaigners through the content of their narratives. The richness of campaign narratives and the ways in which they compellingly document campaigners' journeys managing Lyme disease may also assist with offsetting potential donors' concerns regarding fraud through establishing legitimacy (Zenone & Snyder, 2018). Although transparently articulating a request for funding is an important element of crowdfunding campaigns (Gonzales et al., 2018), the analytic findings shared here demonstrate significant awareness among campaigners of the value of sharing experiential insights in the narratives that can both assist with justifying and explaining the monetary request. Similarly, emotional references to what was lost, missing, sought, and hoped for may assist with constructing people managing a contested chronic illness such as Lyme disease as individuals who are *worthy* of receiving help and support from others (Berliner & Kenworthy, 2017; Lukk, Schneiderhan & Soares, 2018).

Crowdfunding platforms are increasingly becoming a social space for sharing stories, and this analysis illustrates the ways in which these stories are shared through campaign narratives. While the findings have provided significant new insight into the components of Lyme disease campaigners' narratives, they also offer important direction for future research. For example, little is known about how campaigners decide which experiential details to share nor how this differs in cases where people campaign on behalf of others. Which details are too personal to

share? How important is it to establish credibility as a chronically ill individual in the narrative? What is the process by which people go about writing their campaign narratives, and is input from others ever sought? Questions such as these can and should be explored through in-depth interviews with campaigners. Though perhaps not completely unexpected given the contested nature of Lyme disease, the current analysis has shown that campaign narratives are being used to articulate goals around Lyme disease advocacy and are a form of advocacy in and of themselves. While the practice of crowdfunding easily lends itself to being used for advocacy in that people can campaign on behalf of marginalized individuals or to raise money to address injustice (Aitamurto, 2011; Doan & Toledano, 2018), in the case of raising funds for a contested illness, producing the narrative and having it read and supported by others may be thought of as a form of advocacy. Indeed, some narratives reviewed for this analysis mentioned awareness-raising as a goal of participating in crowdfunding. There is great potential for future research to explore the ways in which advocacy can be nurtured by the practice of crowdfunding outside of the actual act of donating or receiving funds.

2.6. Conclusion

We set out to identify whether or not any common elements are shared in Canadians' medical crowdfunding narratives for Lyme disease, and if so, what they are, by asking: what do campaigners who are managing contested chronic illnesses share in their crowdfunding campaign narratives so as to persuade others to (potentially) donate?. Through thematic analysis of 236 campaigns, we identified four common narrative themes: what was lost, what was missing, what was sought, and what was hoped for. Some combination of each of these themes was present in each of the narratives we reviewed, while most contained content relevant to all four. Campaigners clearly reached beyond simply asking for funding in their campaign narratives, providing additional experiential information and detail in order to encourage donations and build legitimacy. This may have been particularly important to do in the context of Lyme disease, where debate and uncertainty remain in the medical community and wider public about the accuracy of testing, legitimacy of diagnosis, and value of particular treatments in Canada and beyond (Scales, 2017; Smith, 2017).

Individuals use crowdfunding platforms to communicate illness experiences when raising money for medical care by building an emotional connection with potential donors (Moore,

2019). Traditional fundraising methods were formerly limited to ones' immediate social network; however, by linking to social media, crowdfunding has expanded the reach of contemporary campaigns. The depth and emotionally compelling nature of the information shared in campaign narratives regarding what was lost, missing, sought, and hoped for, may in part be a response to the fact that those who are socially and geographically distant from the campaigner may read campaign narratives that are shared through social media. Regardless of the reasons for which they are written, medical crowdfunding has become a powerful platform for sharing narratives that hold potential for providing new insight into how people communicate about their health and bodily needs, including in the context of contested chronic illnesses such as Lyme disease.

Chapter 3.

Responsibility to the story, campaign(er) and profession: exploring important considerations shaping Canadian print journalists' coverage of medical crowdfunding campaigns

3.1. Abstract

Medical crowdfunding is growing in popularity in a number of countries, including Canada. While in the crowdfunding context people write and share their own stories, this practice intersects with conventional media practices when journalists prepare stories about such campaigns. What are print journalists' responsibilities towards covering human interest stories based on medical crowdfunding campaigns? In this qualitative analysis we explore this question through reporting on interviews conducted with 14 Canadian media professionals. Thematic analysis of the interviews identified three key domains of responsibility for journalists, which are: to the story, to the campaign and campaigner, and to their profession.

Key Words

medical crowdfunding; journalists; responsibilities; professional ethics; qualitative; Canada

3.2. Introduction

Online social fundraising platforms such as GoFundMe and CrowdRise enable people to create campaigns to reach out to a large number of viewers to request financial assistance for a cause or project. The ease and efficiency of crowdfunding, facilitated by the expansion and availability of web services and technology, has encouraged users to engage in this practice for financial needs ranging from business start-up funds and college tuition to vacation funds and medical care. Regarding the latter, the crowdfunding platform GoFundMe has hosted over 250,000 campaigns set up to assist with costs related to health care or medical need alone, raising US$650 million in their medical crowdfunding category to date (Martinez, 2019). Crowdfunding sites offer campaigners platforms to share details of their health histories and needs, photos, and often compelling appeals for donations from others (Berliner & Kenworthy, 2017; Gonzales et al., 2018; Paulus & Roberts, 2017). While some have argued that acquiring funds for medical care through crowdfunding has resulted in people accessing vital care that would otherwise be unaffordable, critics have pointed out that the practice masks the inequities and health system limitations that result in people being unable to cover their own medical expenses and can introduce ethical concerns regarding privacy and misrepresentation (Berliner & Kenworthy, 2017; Young & Scheinberg, 2017; Zenone & Snyder, 2019). Despite such ethical and equity concerns, numerous reports suggest that the popularity of medical crowdfunding is on the rise (Durand et al., 2018; Lukk, Schneiderhan and Soares, 2018).

In the context of medical crowdfunding, campaigners (who may, or may not, be the fund recipient) can share their stories and pleas for support directly with those in their social networks and more widely with other members of the public through social networking platforms. Traditionally, to get wide coverage of a fundraising appeal for an individual recipient in the North American context, forums such as newspaper articles, television news stories, community newsletters and the like were primarily relied upon (Gonzales et al., 2018; Sisler, 2012). The more contemporary social media-based practice of medical crowdfunding does, however, intersect with conventional media coverage in instances when journalists prepare human interest stories based on medical crowdfunding campaigns that raise awareness, and thus the fundraising potential, of campaigns. There is some concern that such media coverage unfairly advantages campaigners with high profiles, wide social networks, sensational stories, and/or who are particularly adept at self-promotion (Paulus & Roberts, 2017; Moore, 2018). There is also recognition that media coverage of medical crowdfunding campaigns can increase the likelihood

of reaching campaign fundraising goals, thereby making it highly desirable to campaigners (Barclay, 2012; Murdoch et al., 2019; Van Duynhoven et al., 2019). It is thus not surprising that many sites and agencies that give advice to medical crowdfunders about how to enhance campaign success, such as Fundly, recommend sending out press releases to news agencies or directly contacting journalists via e-mail or social media to pitch their stories.

Although media coverage can play a role in the fundraising success of a medical crowdfunding campaign, there has been little scholarly consideration or scrutiny of such media coverage or media professionals' involvement in preparing and sharing these human interest stories. One exception is a recent content analysis by Murdoch et al. (2019) that explores media coverage of campaigns in Canadian and American newspapers. After reviewing 336 articles published over a two-year period, they found that most coverage portrayed the actual practice of medical crowdfunding in a neutral fashion while being supportive in tone of the campaign(er). The most critical or cautionary inclusion in the reviewed articles occurred in instances where stories covered people who were crowdfunding for unapproved or experimental therapies. In some of these instances, journalists included a comment referencing the lack of a scientific basis for the treatment focused upon in the campaign. Murdoch et al's (2019) study is the only scholarly contribution to date that explicitly explores the connection between the Canadian news media and medical crowdfunding. As such, there are many pressing knowledge gaps and heretofore unexplored questions that remain unanswered.

In this article we qualitatively explore print news journalists' responsibilities when preparing and sharing human interest stories that are centred on medical crowdfunding campaigns, campaigners, and/or fund recipients from the perspectives of Canadian media professionals. By responsibilities, we are referring to professional aspects of such coverage that news journalists have control over or can oversee that can have practical, legal, dutiful, ethical, or other dimensions. Based on the thematic findings of interviews with 14 Canadian journalists who have published human interest stories centred on medical crowdfunding campaigns, we identify three broad types of responsibilities that they and likely their wider media colleagues hold toward such coverage. These are their responsibilities to the news story, to the campaign and campaigner, and to their profession. After expanding on these responsibilities in the findings section, we explore their ethical facets in the discussion section and draw out some of the professional and practical implications.

3.3. Methods

Data collection for this exploratory study was conducted over a five-month period, from October of 2018 to February of 2019. Our goal was to examine print media professionals' roles as amplifiers, critics, and/or promoters of medical crowdfunding in the Canadian context. They are a professional group who crowdfunding campaigners turn to so that their stories can be shared for wider public consumption (Kneese, 2018; Murdoch et al.,2019; Van Duynhoven et al., 2019). Thus, Canadian print journalists were selected as key informants based on their professional proximity to, and their relatively high number of encounters with, medical crowdfunding campaigns. While some research suggests that traditional media platforms such as print journalism are being threatened by the rise of social media (Allgaier et al., 2013; Chafe et al., 2011; Wahl-Jorgensen et al., 2016), here we offer a different perspective by considering how print journalists engage with new media platforms as sources of stories and potentially play a role in the success or failure of medical crowdfunding campaigns.

3.3.1. Recruitment

We sought to recruit print media journalists whose crowdfunding-related stories were carried in Canadian newspapers to participate in semi-structured phone interviews. Ethics approval for this study was obtained from Simon Fraser University prior to the commencement of interviews. To identify potential participants, we searched media databases to identify journalists who had written at least one human interest story based on a medical crowdfunding campaign that included a direct link to the campaign that was published within two years of the interview. To do this, Boolean operators were used to search for keywords such as "crowdfunding AND medical" or "GoFundMe AND medical" in Canadian news media databases. Two hundred ninety-seven media professionals were identified as eligible, 244 of whom had publicly-available contact information. Potential participants were sent an invitation to participate via email or Twitter. In most cases, a follow-up e-mail or direct message was also sent. We sought to interview as many as possible prior to the end of our data collection period. Thus, we were guided by a temporal cut-off for data collection.

In an initial email, overviews of the study goals and procedures, confidentiality and privacy, and the nature of the interview were shared with potential participants. Those who expressed an interest in participating were sent a document containing more details about the

study objectives and data collection procedures. They were told that they would receive a CDN$20 electronic gift card to a coffee shop of their choosing to acknowledge their important contribution to knowledge. Participants were also informed that they were not expected to have in-depth knowledge of the crowdfunding sector, as our study aimed to explore the subjective experiences of professionals encountering medical crowdfunding campaigns in their work.

3.3.2. Data collection

All interviews were conducted by the first author by phone or Skype, based on participant preference, and were digitally recorded. Interviews varied in length, ranging between approximately 30 minutes to an hour. To begin each interview, the interviewer restated the study goals and gave participants the opportunity to ask any clarifying questions. Next, verbal consent was obtained and recorded. Participants were then asked to provide their professional backgrounds and explain their current work to provide better context to support their answers before proceeding onto the interview questions.

A semi-structured interview guide was created collaboratively by all authors using insights gleaned from reviewing medical crowdfunding campaigns, reading coverage of such campaigns in media sources, and our own previous research on medical crowdfunding (e.g., Snyder et al., 2017, 2018; Van Duynhoven et al., 2019). The guide included open-ended questions to stimulate discussion of medical crowdfunding and potential links to broader social, political, and economic issues of access to health care in Canada. For example, participants were asked: is there anything distinctive, unique, or different you look for when you use medical crowdfunding campaigns as sources for news coverage? By keeping the interviews semi-structured, participants could add any relevant details beyond the specific questions being asked.

3.3.3. Analysis

The interviews were transcribed verbatim. Due to the digital nature of the data collection, the participants' tone, pauses in speech, and other factors describing the interview context were recorded as field notes to be used to supplement the analysis. Each transcript was given an identifying number, and once reviewed by all authors, phone recordings were destroyed.

Data analysis was conducted thematically. Thematic analysis involves interpreting the main themes within qualitative data to distinguish overarching patterns and contrast them against

existing knowledge and the study questions, goals, and/or objectives (Clarke & Braun, 2013; Maguire & Delahunt, 2017; Nowell, Norris, White & Moules, 2017). The first step in our analytic process was to independently review interview transcripts to identify main themes and outliers. A team meeting was held to compare and contrast these themes across investigators and to reach confirmation on the scope and scale of emergent themes. It was at this point that journalists' responsibilities emerged as a significant focus or meta-theme of analysis. Three themes supported this meta-theme, which are introduced and explored in the findings section. Consistent with thematic analysis, these themes were contrasted against the existing literature and our research goals to aid in interpreting their significance. We believe that our use of investigator triangulation throughout data collection and analysis to facilitate dependability and establishment of an audit trail by recording key decisions in our field notes to support reliability, among other factors, contribute to the rigour of this analysis (Nowell et al., 2017; Tobin & Begley, 2004).

3.4. Findings

In total, 14 media professionals participated in the study. They had published stories based on medical crowdfunding campaigns in newspapers in three Canadian provinces: British Columbia, Ontario, and Quebec. One reporter from a television news station, one freelance writer, and twelve reporters and/or editors employed at local newspapers participated. Their experience as media professionals ranged from three to twenty-two years in journalism. Despite their differences in depth of experience, geographic location, and occupation, the interviews revealed three common areas to which all participants believed they and their media colleagues held responsibility when publishing human interest stories about medical crowdfunding campaigns. Specifically, they had responsibilities to the news story, to the campaign and campaigner, and to their profession. In the remainder of this section we explore these responsibilities in-depth, drawing on verbatim quotations from participants to support our consideration of each theme.

3.4.1. Responsibility to the news story

Participants reflected heavily on the importance of the responsibility they held to ensure the that news stories they were preparing based on medical crowdfunding campaigns were suitable for the publication venue. Given that news coverage of this nature tended to be categorized as human

interest, participants explained that they were most drawn to campaigns that were remarkable or outstanding. One participant described a crowdfunding campaign that they had published: "*all three of the family members had a life-threatening life occurrence, so it kind of makes a good story. But if it had just have been one of them, it might not have been as newsworthy.*" Often, they felt a responsibility to cover medical crowdfunding cases that were unique or extreme: "*if it's something that happens a lot or something that is extremely rare, I think that might be a story worth telling.*" Finally, many of the participants recognized that most medical crowdfunding campaigns that were sent to them as potential stories, or that they found on their own, were emotionally compelling and that they felt a responsibility to carry that emotion forward into their piece. As one explained "*the more emotional the [crowdfunding] story is, that's the magic that it works,*" and another commented that "*those pull-at-your-heartstring type stories usually sort of, draw some interest.*"

Many participants worked in community newsrooms and felt a responsibility to cover medical crowdfunding campaigns that had local relevance. One participant described their position by saying explaining that "*one of the roles that the media performs in society is that we tell stories of community.*" It was explained that a campaign need not be raising funds for a local person, but the issue at hand needed to have local relevance or interest. This said, participants indicated that campaigns featuring prominent or well-known community members were particularly compelling to write about:

> *…the thing that was particularly interesting about her story was firstly the rarity of the medical condition, and number two she was well known in the community… There was a lot of concern for her because she is both well known, and a very pleasing person… And there was a lot of concern about her family's ability to move forward given that they had small children, and they were dealing with a very serious - to be quite honest potentially fatal - medical condition. So that's why I wrote that particular story.*

As demonstrated by this quote, the coupling of exceptionality or uniqueness with compelling local interest may almost necessitate covering a medical crowdfunding story in local media outlets.

3.4.2. Responsibility to the campaign and campaigner

Participants commonly indicated a strong sense of responsibility to help the individual at the centre of the medical crowdfunding campaign as driving their decisions to cover such stories. This desire to help those in medical need assisted participants with determining which campaigns they opted to cover, sometimes even shifting into feeling a sense of obligation. One participant explained that:

> *...well I feel an obligation, so I want to make sure that the people are deserving. I know often times we want to help them. We're seeing people at their very worst, so we want to be able to, through the power of media [help them]. Not just do a story but because of the story, they then have money to not have to worry about replacing the things they lost, to focus on getting healthy or save their life... It is rewarding to know that oh, we're not just covering something, were helping a person make whatever they're going through a little bit better.*

Another participant went so far as to inform a family about the opportunity to crowdfund upon learning of their story, *"I actually suggested, I'm like 'have you thought about starting a GoFundMe page?' because they had lost everything, and she was caring for a sick husband, it was just a sad situation."* This quote demonstrates not only the power of crowdfunding, but the unique position media professionals are in to be able to help. Related to this, however, was a responsibility to acknowledge what their roles were in providing help and the limits of their own and their published story's ability to assist campaign recipients. For example, no participants discussed becoming donors to the campaigns they covered nor assisting with fundraising efforts beyond writing news pieces that included embedded crowdfunding campaign links.

Participants cautioned that another aspect of journalists' responsibilities to the crowdfunding campaigns they covered is the need to be sensitive to issues of privacy for the campaign recipient and close family members. Although medical crowdfunding campaigns already exist in the public domain, participants acknowledged that their coverage in media outlets can substantially grow the number of public views and potentially also donations. Several explained that in their experience of covering such stories, the personal privacy of the campaign recipient (who may, in fact, not be the campaigner) becomes lessened once campaigns get shared through media coverage. *"The only downside we see is you lose a bit of your privacy when people know what's going on. People [campaign recipients] are very private and they're not always*

keen to do that.'' One participant recalled a situation in which an ex-husband was offended to hear about a story in the news that involved his daughter being the focus of fundraising efforts for a wheelchair ramp:

> *[H]e thought it made him look cheap. Like he didn't care for his daughter, wasn't providing for her. And so, there was an angry phone call from the dad saying, "how could you write this?" And so, it was kind of this balance between this outpouring of help, money... And then the mom calls him back and she's in tears. "My ex-husband's so angry at me, and I don't know what to do." I'm like "I don't know what to do, either!"*

Alternatively, news coverage may allow a recipient to have a more public voice because "*in some ways, people kind of consider opening up to the media to be their way of thanking the community for the help that they've already received.*" Participants explained that in some cases journalists may feel a responsibility to give campaign recipients a public voice, particularly when stories are compelling and locally relevant.

3.4.3. Responsibility to the profession

Participants reflected on the potential personal and professional implications of covering medical crowdfunding campaigns, explaining that they had professional responsibilities associated with writing such stories. For example, they commonly considered their own roles as journalists, reporters, or editors and the ways in which their coverage of these campaigns may imply an endorsement of the procedure, treatment, or therapy sought. As one participant explained:

> *I'm very cognisant of the fact that, while we aren't medical experts, anything that appears in the newspaper or on our website does give it a stamp of 'we're standing behind this.' So, I'm always very careful to point out to the team that we have to do as much due diligence on this before we say [for example] 'green tea will cure cancer'... I encourage strongly, the team to be careful of what we're giving an implicit stamp to in terms of treatments [referenced in medical crowdfunding campaigns].*

In order to protect their own reputations and those of the newsrooms they are affiliated with, many participants mentioned also confirming the legitimacy of the story behind a campaign to be an important professional responsibility. Interestingly, one participant explained an instance where they decided not to mention a crowdfunding campaign in a story out of concern around

fraud or misrepresentation: *"we did a story on her, where she talked about escaping the fire and almost dying in the fire. We didn't mention her fundraising page because we were worried that not everything was legitimate."* Participants talked about undertaking efforts such as speaking directly with the campaigner or campaign recipient, looking through their social media coverage, and/or obtaining substantiating information from others prior to making the decision to carry a story based on a medical crowdfunding campaign or embedding a campaign link in the published piece.

Some participants reflected on their unique position to be able to raise issues regarding health system concerns or limitations through their strategic coverage of medical crowdfunding campaigns. Thus, participants talked about how they were able to select campaigns that highlighted inequities or systemic challenges that they could bring forward in a professional capacity through their journalistic coverage. As one participant explained, *"yes, [structural limitations] definitely is something that we consider… [we ask] is there a bigger picture or why the funding is needed?"* Another participant talked about sometimes speaking with medical professionals directly to identify limitations and inequities brought forward by campaigns and including excerpts from such interviews in their published stories.

> *I'll get them [medical professionals] to talk about why that's [specific procedure] not funded and, you know, what are the odds of that working or what type of treatment is that, type of thing. If it is something where there is some quackery concerns, we'll try really hard to say that, to have a medical professional talking about their concerns.*

Overall, several participants believed they had a professional responsibility or duty to select medical crowdfunding campaigns for coverage in news stories that supported highlighting health system shortcomings or even advocating for change.

3.5. Concluding Discussion

In the previous section we established that the fourteen Canadian print media professionals we interviewed identified three specific types of responsibilities they, and likely others in their profession, hold towards writing and publishing stories based on medical crowdfunding campaigns. With regard to their responsibilities to the story itself, participants

indicated that they considered their specific local audience and aimed to ensure that the stories they wrote were worth knowing and relevant to readers' interests. Their responsibilities to the medical crowdfunding campaign being covered reflected a deep consideration given to the intended campaign recipient, including this person's privacy, and the participants' desires to help via their professional capacities. Finally, participants explained that they and other media professionals covering medical crowdfunding campaigns had professional responsibilities they needed to undertake. This included a responsibility to uphold professional standards, such as ensuring that the medical crowdfunding campaigns they covered were legitimate, and recognize that campaign coverage can be undertaken strategically to raise awareness of health system limitations or other inequities. In the remainder of this section we contrast the findings of this thematic analysis against the existing literature to identify ways in which they support existing knowledge and establish new insights.

The existing medical crowdfunding research has raised a number of ethical and equity concerns that are echoed or affirmed by the findings of the current analysis. For example, a number of studies have expressed concern over the fact that sensational campaigns or those for well-known recipients are most likely to get significant amounts of attention (e.g., likes and shares, donations, and/or coverage on other platforms such as news outlets) relative to other ongoing medical crowdfunding campaigns (Berliner & Kenworthy, 2017; Kneese, 2018; Paulus & Roberts, 2017). Our interviews with Canadian print media professionals confirm this is indeed the case, at least when it comes to covering campaigns in print news stories. Those we spoke with affirmed some of the speculation in the existing research that not all campaigns have an equal or fair chance of gaining media coverage, which is thought to be one factor that can contribute to having a campaign reach its financial goal (Murdoch et al., 2019). As Murdoch et al. (2019) note, by cherry-picking sensational or exceptional campaigns, journalists are also facilitating uptake of their own journalistic coverage and thus they have a deeply vested interest in deciding which campaigns are worthy of coverage. Participants' comments regarding their responsibility to ensuring the legitimacy of the story behind a crowdfunding campaign and being sensitive to issues of privacy echoes concerns raised by ethical and legal scholars about the potential downfalls of medical crowdfunding. For example, it is widely acknowledged that the practice of medical crowdfunding opens up opportunities for fraud (Moore, 2018; Siering, Koch, & Deokar, 2016; Zenone & Snyder, 2019). It is thus not surprising that participants reported taking efforts to ensure the campaigns they opted to cover were not fraudulent and also to ensure the accuracy of some of the health-related claims being made. Although participants acknowledged privacy

concerns along the lines of those identified in the existing research, such as that campaigns can be made on behalf of unknowing recipients (Gonzales et al., 2018; Snyder, Mathers & Crooks, 2016), they offered little insight into how they and other media professionals may act to ensure privacy concerns are thoroughly identified and addressed.

Participants expressed awareness that media coverage of specific medical crowdfunding campaigns in news stories could be interpreted by readers as an endorsement of the treatment being sought, in addition to adding legitimacy to the campaign itself. This raises particular ethical concerns in the context of untested and unproven treatments or even in relation to covering stories focused on contested diagnoses such as chronic Lyme disease. One such ethical concern is that news coverage of campaigns may spread misinformation about the efficacy of an unproven or untested treatment (Moore, 2018; Murdoch et al., 2019; Vox et al., 2018). Another ethical concern is that coverage related to a contested diagnosis that implies (dis)agreement may threaten journalists' abilities to present their work in an impartial way, which is necessary for journalistic objectivity (Boudana, 2011). Participants' careful navigation of such ethical tensions, which included sometimes reaching out to medical professionals for confirmation or input, serves as an interesting contrast to their belief that selective coverage of medical crowdfunding campaigns can be done to highlight health system gaps or limitations. There is a longstanding tradition of using journalism to highlight inequities and injustices, including in relation to health care access and use (Hinnant et al., 2019; Wallington et al., 2010; Walsh-Childers & Braddock, 2018). In the Canadian context this often translates into critical coverage of access gaps and wait times in the public health care system along with pushes to increase health care privatization (Armstrong, 2001; Barua et al., 2018; Hurley & Guindon, 2008). There has also been fairly extensive recent critical media coverage regarding the financial burden of paid parking at hospitals and a push for the elimination of such fees (e.g., Little, 2019; Robinson, 2019; Parmar, 2019), which is an issue that has featured prominently in many Canadian medical crowdfunding appeals (Dressler, 2018; Snyder et al., 2017). While some of the participants we spoke with felt a sense of professional responsibility to strategically cover medical crowdfunding campaigns that highlight health system gaps and limitations, this same sense of responsibility drove them to want to avoid the murky territory of reporting on campaigns that may be based on health misinformation or seeking funds for dubious 'medical' practices. Although such coverage may potentially highlight gaps around access to untested procedures or funding for experimental therapies abroad, participants felt that the potential for their stories being viewed as an endorsement to be too risky.

The Canadian Association for Journalists has developed a series of ethical guidelines for journalism practice that are anchored around the principles of accuracy, fairness, privacy, independence, conflict of interest, transparency, promises to sources, diversity, and accountability (CAJ, 2019). All of the responsibilities participants shared with us are covered by the considerations in these ethical guidelines. For example, journalists are encouraged to verify their sources. In the current study we learned this is often done by reaching out to speak directly with medical crowdfunding campaigners. Journalists are also encouraged to consider the needs of readers when gathering and sharing the news. In relation to covering medical crowdfunding campaigns, interview participants discussed doing this through evaluating the local relevance of the story (even if the campaigner/campaign recipient is not local) and seeking to cover campaigns of well-known local individuals. Although the responsibilities participants talked about are not unique to covering medical crowdfunding campaigns relative to other types of stories, there are important contextual elements around this practice that introduce particular ethical considerations that inform how these responsibilities play out. For example, medical crowdfunding is an inequitable practice. It is widely acknowledged that people with deep social networks and/or who are adept at writing in a gripping or compelling fashion are more likely to reach their fundraising goals (Monroe, 2019; Kneese, 2018). A recent study has shown that Canadians who crowdfund for cancer care live in areas with high educational attainment, high income, and high levels of home ownership and suggests that those who are campaigning may not be those with experiencing the greatest barriers to accessing care (Van Duynhoven et al., 2019). Media coverage of medical crowdfunding campaigns is likely to reinforce such inequities by sometimes giving relatively privileged people additional public attention. Although participants expressed a desire to strategically cover campaigns that highlight particular health system gaps as a way of promoting change, they did not reflect on the potential for their coverage of select campaigns to reinforce inequities around whose medical needs become most visible to the public or whose campaigns are most likely to be successful. In our opinion, this is an ethical issue that warrants further consideration.

A number of important directions for future research emerge from this thematic analysis, and here we share three. First, this analysis has raised important issues regarding several facets of Canadian media professionals' responsibilities in writing stories about medical crowdfunding campaigns. Given the constant and rapid evolution of social media (Young & Scheinberg, 2017), mobile technologies (World Economic Forum, 2019), and internet-based communication (Gernsbacher, 2014), it would be useful for future research on this topic to identify ways in which

these responsibilities shift in response to such change. Second, this analysis positions media professionals as important stakeholders in the practice of medical crowdfunding. Not only can they write stories about such campaigns, but their coverage may inform the success of a campaign in terms of the ability to reach a fundraising goal. There are certainly other stakeholder groups whose perspectives should be researched using a responsibility lens, including campaigners, campaign recipients, donors, social media influencers, lawyers, physicians and other health care professionals, and those who have personally or professionally benefitted from the expenditure of funds gathered through such campaigns. Finally, the current study was undertaken in the Canadian context. Canada is a country in which residents have public access to medically necessary health care and preventative care as legislated by the Canada Health Act (Government of Canada, 2018). Although the findings of this analysis are likely to have some degree of transferability to other contexts, undertaking similar studies in jurisdictions where contextual factors around professional standards in journalism, the popularity of medical crowdfunding campaigning, and/or the availability and affordability of health care are different would be highly meaningful. Such studies would allow researchers to identify if and how the same or similar responsibilities emerge in different jurisdictions and also which ones may be unique to particular contexts. Insight along these lines has the potential to inform the development of professional standards regarding journalistic coverage of medical crowdfunding, should this ever be needed.

Chapter 4.   Conclusion

4.1. Overview

Contributing to the limited empirical research that exists on medical crowdfunding, and specifically that which considers medical crowdfunding in a Canadian context, this thesis used two qualitative analyses to unpack the narrative patterns in medical crowdfunding campaigns and the perceptions of this practice through the point of view of media stakeholders. The first analysis collected crowdfunding campaign texts to explore the narratives present within Canadian crowdfunding campaigns from the viewpoint that they are illness narratives. The second analysis engaged with Canadian print media journalists through semi-structured interviews to explore their perceptions of this practice as key informants and identify the responsibilities that they, and their colleagues, hold towards generating news content based on campaigns.

4.2. Revisiting Objectives

My thesis research offers new insight into the nature of medical crowdfunding from multiple stakeholders and establishes new pathways for future research to unpack this practice. The rest of this chapter will revisit my research objectives stated in Chapter 1, while reflecting on the findings of both analyses. By comparing these objectives with the findings, I highlight the ways in which this research contributes to the disciplines that underpin the foundation of my thesis. Although my thesis research objectives are distinct, I will reflect on the underlying themes that connect these objectives. I then conclude with a summary of the importance of this work.

(1) To explore Canadians' crowdfunding campaign narratives to unpack the ways in which health and need are communicated online by people managing a contested chronic illness when there is financial incentive to do so

This research objective reflects my interest in qualitatively exploring the nature of medical crowdfunding from the perspective of campaigners. Using the view that crowdfunding campaigns are forms of unsolicited illness narratives, I used this analysis to dissect some of the emotive and expressive elements of medical crowdfunding by examining how people discuss their illness experiences in their campaigns. As a health geographer, I chose to focus on a case that has a place-based element. Specifically, I focused on narratives written by those campaigning

for funds for Lyme disease-related care. Canada offers important place-based context for the journeys of people managing this contested chronic illness due to uncertainty among members of the medical community regarding the diagnosis (and especially of chronic Lyme), limited diagnostic and treatment options available through the public health care system, increasing spread of the geographic territory of ticks that transmit Lyme disease within the country, and the stalled public health responses to growing rates of Lyme disease diagnosis. I discussed these issues in greater detail in Chapter 2.

Prior to addressing this objective, I informally reviewed the content of many medical crowdfunding campaigns and found Lyme disease to be a contested chronic illness that accounted for many campaigns on crowdfunding platforms such as GoFundMe, YouCaring and FundRazr. Through the analysis presented in Chapter 2, my co-authors and I identified four common elements of campaign narratives across over 200 campaigns, which were: what was lost, what was missing, what was sought, and what was hoped for. When combined, these elements form highly detailed accounts of the health journey for each individual, and offer a sound justification as to why readers should donate. When referring to what was lost, many campaigners discussed their personal ideas of health and how it had deteriorated due to the onset of (chronic) Lyme disease. What was missing identified the structural gaps in health care provision. This narrative was often quite charged, with harsh language used to describe feelings of abandonment and disappointment in the domestic health care system. What was sought was written directly for the audience, providing highly specific accounts of how and where the money raised would be spent in order to support the campaigner's health. What was hoped for described the optimism and anticipation of a full return to health given a successful campaign. This narrative was written to establish confidence in the reader, to convince them to donate. All four narrative elements were written with a specific tone, based on the objective of each.

The narratives outlined by campaigners provide insight into the challenges to accessing health care in the form of diagnosis or treatment for Lyme disease. These insights can offer an indication of the locations, either geographic ones or related to health system navigation, where such health barriers exist in relation to a given illness. These findings are valuable and would be of great use for provincial and federal health authorities concerned with equitable access to health services.

I believe qualitative thematic analysis was a valuable method to investigate the personal and emotional connotations within these medical crowdfunding campaigns. Qualitative analysis

is known for enabling researchers to explore complex emotional geographies and other elements of lived experience (Baxter & Fenton,2016; Morag, 2001; Poynter, 2010). Crowdfunding platforms are a place for individuals to share chronicles of their health experiences, simultaneously justifying their requests for donations. Medical crowdfunding literature discusses this dynamic as performances of illness depicting themselves, or loved ones, as worthy of donations (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018). My analysis in Chapter 2 revealed elements of this performativity in terms of exploring how campaigners explain their illness journey to others in order to gain donations.

This research reflected concepts in health geography, such as contextualizing the place-based elements of care and health, as well as using digital sociology, such as through understanding society through technological intermediaries. With handheld devices and seamless internet connection that spans vast regions and geographic space, it is easier now than ever to for people to connect with their social networks and participate in practices such as medical crowdfunding (Manyika et al., 2016). Information posted online is becoming widely accepted as data to inform about society and social behavior in digital environments (Halstead, 2017), and in this case crowdfunding may be further normalizing the practice of asking for financial support for health-related costs.

(2) To explore the considerations that shape Canadian print journalists' coverage of medical crowdfunding campaigns

This research objective demonstrates my interest in how people perceive crowdfunding in particular environments. By engaging with Canadian print media journalists, I was able to seek stakeholders who have familiarity of this practice yet are emotionally and financially removed from the actual campaign. Journalists are impartial to the success of the campaigns they encountered, yet those I interviewed had valuable insights to offer on the practice of medical crowdfunding. Though I was initially interested in the ways that these campaigns were selected for coverage and the components of these campaigns that were prioritized when they were featured as news stories, I produced an analysis that focused on journalists' responsibilities in covering campaigns.

Analysis of these interview transcripts raised many ethical and equity concerns, consistent with the concerns raised in medical crowdfunding literature. First, it is important to acknowledge that not all crowdfunding campaigns will be selected for media coverage. This raises questions about the equity of crowdfunding and the reinforcement of structural and socio-economic disadvantages. In these digital environments, campaigns with the most views, shares, and overall momentum will be prioritized by algorithms by being listed higher on platforms or social media sites (Halstead, 2017). Many participants in the study confirmed that selecting stories that were trending was a consistent method of finding stories for coverage which they knew would be good stories to feature for their public audience. Privacy, again, was another concern consistent with the literature ((Gonzales et al., 2018; Snyder, 2016)). While increased views after being featured in the news contributes to campaign momentum, this also exposes the personal health details of the campaigner to a much larger network. Once personal details have been shared online, it is virtually impossible to erase from internet archives, potentially harming a person's online identity indefinitely (Couts, 2011). Finally, it was noted to be important that these participants reflected on the potential harms of spreading misinformation. Sometimes Canadian crowdfunding campaigns were written seeking experimental or unproven treatments, which the participants in this study were wary of. As professionals, they recognized their impact in the minds of readers and had to be cautious of what they were reporting to avoid contributing to spreading false and potentially dangerous medical information. A final point also worth noting was the observation that each of the ethical concerns and forms of responsibility were reflected by the existing Canadian Association for Journalists ethics guidelines for journalism practice (CAJ, 2019). This reveals that medical crowdfunding stories challenge journalists' professional duties of ethical reporting, which may be something that future scholars want to consider exploring further.

4.3. Future research directions

The research from this thesis has used two distinct qualitative methods for exploring medical crowdfunding, drawing also from frameworks in health geography and in digital sociology. Future research should continue to consider the perspectives of stakeholders engaged in this practice, from campaigners, peers, health providers, to journalists in other jurisdictions. and more through qualitative methods. For example, a comparison with the crowdfunding narratives shared by people with Lyme disease in the United States would be valuable to draw insight about the differences in accessibility challenges. As more qualitative research methods are

developed and tried, the potential for knowledge gain from medical crowdfunding is substantial, and this new knowledge may be a source for meaningfully improving access to healthcare and policy adaptation.

It has been acknowledged that medical crowdfunding is an inequitable practice, yet it is often presented as a viable option for anyone who is in need of financial or emotional support (Snyder, Mathers & Crooks, 2016). Those with relatively large and affluent social networks who have the ability to write compelling stories, and maybe also have media connections, will have a greater advantage in online environments than those who lack these characteristics (Paulus & Roberts, 2018). Consequently, this perpetuates socio-economic disadvantages and barriers to health mentioned in Chapter 1 (Canadian Medical Association, 2013). People with limited resources are already face with barriers to health care based on the outcomes of how they have lived out various health determinants (Canadian Medical Association, 2013). It is quite problematic that although crowdfunding is promoted as an equal opportunity for individuals to raise money for any range of services, people who are crowdfunding for stigmatized reasons or have more demand side barriers to health will likely experience compounded barriers when crowdfunding online. This is an area worthy of more research attention.

4.4. Bridging the two analyses

Although separate methods were applied to each analysis in this thesis (Chapters 2 and 3), certain themes cross-cutting were evident that connect the findings and offering insight into unique aspects of researching medical crowdfunding. In Chapter 2, patients offered campaign illness narratives that were highly descriptive, yet personal. The campaigners in this analysis provided sensitive health information in exchange for online views that could lead to shares and donations. Individuals can decide how much information they divulge online, but in competitive digital crowdfunding environments there is an overarching recognition that personal information shared with viewers can create a sense of trust and community. As campaigners grow their online community by sharing their illness experiences, they are effectively engaging their social network, although this may be undermining the privacy and autonomy of the individual. The media professionals interviewed in Chapter 3 were talking about their roles in sharing such private information through newspaper articles and the responsibilities they hold towards doing so. One of these responsibilities related to privacy, which is something that may be given up by campaigners in the hopes of fulfilling their financial goals.

Privacy emerged as an important topic in Chapter 3, yet it was managed differently by the journalists interviewed for this analysis when contrasted against the highly public campaigns reviewed for Chapter 2. Media professionals perceived privacy as a potential concern within the thematic finding of their responsibilities to the campaign(er). These participants recognized that the power of the media can be beneficial by increasing views and exposure of a campaign exponentially, but in their professional work they had to manage this with a level of care and sensitivity. Within this theme, journalists recognized that sharing personal information to their readership will be irreversible, and can adversely affect the campaigner, or their families.

The attempt to manage and protect privacy, highlights the nature of communications in digital environments. Information has the potential to spread significantly faster and to a broader audience than traditional methods of sharing information via word of mouth or solely via traditional media platforms. This quality also makes medical crowdfunding campaigns unique to other most other types of fundraising stories carried in the media where personal patient information may not be as readily accessible to journalists. The journalist has an especially particular role in framing stories about medical crowdfunding to appeal to a public audience yet balancing this against ethical guidelines of overexposure and privacy for the patient. Another important element surrounding privacy and medical crowdfunding relates to the spatial geographies of this practice. Specifically, campaigner and recipient need not be proximal, which is actually the basis of much conventional fundraising. The geographic range of sharing narratives in digital environments is no longer limited by spatial constraints therefore raising new types of implications for journalistic coverage as well as how researchers such as health geographers engage with the topic.

These findings allow for a deeper understanding of the components of a crowdfunding campaign that make it successful. Not only do campaigns with compelling narratives, pictures and videos attract potential donors (Paulus & Roberts, 2017), but in this analysis it was revealed that certain campaigns catch the eye of journalists in ways that can have increase the exposure and therefore success of a campaign. The analysis in Chapter 2 identifies how campaigners relay these compelling elements to potential donors. By highlighting the components of a campaign that are prioritized by journalists, Chapter 3 also offered a glimpse into the qualitative elements of a campaign that stand out in the digital world. These qualities likely relate to the socio-economic status of a successful campaigner, which may continue to reinforce systemic inequities identified in the crowdfunding literature (Barcelos & Budge, 2019; Snyder, 2016).

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