

**Safety.net? Care, Charity, and Medical Crowdfunding in  
Canada**

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## **Abstract**

In a country that prides itself on a universal public health insurance system, why are a growing number of people turning to GoFundMe and similar crowdfunding platforms for health-related expenses in Canada, as beneficiaries and contributors?

This dissertation argues that while assisting loved ones monetarily in times of need is not a new phenomenon, the increasing use and visibility of personal crowdfunding as a response to illness and injury signals a shift in the ways we think about, and engage in, giving and care relations. This research project offers a critical look at personal medical crowdfunding in Canada through a lens of feminist political economy complemented by multiple approaches to critical discourse analysis. It reveals personal medical crowdfunding as a space and practice that reflects and further cultivates neo-liberal ideals of privatization, individualism, and entrepreneurialism in relation to health-related financial struggles. Discourses and behaviours within the confines of crowdfunding platforms are found to be shaped – and at times, constrained – by the unique dynamics of personal medical crowdfunding as a practice, including “unspoken rules” around personal fundraising etiquette. This dissertation begins by situating the practice of personal medical crowdfunding within a context of neo-liberal re-structuring of Canadian health and social welfare policies which increasingly downloads responsibility for citizen well-being onto individual households and registered charities. Drawing on three sources of data – GoFundMe’s promotional materials, GoFundMe medical campaigns, and in-depth interviews with people who have participated in personal medical crowdfunding as a campaign creator, beneficiary, or contributor – I examine the ways in which crowdfunding discourses produce, reproduce, or challenge

“common-sense” ideas about deservingness, responsibility for individual well-being, and health. Despite conflicted feelings amongst interview participants, GoFundMe decisively frames medical crowdfunding as a form of charity. An analysis of medical crowdfunding campaigns further illustrates that campaigns contain discourses of deservingness that characterize the beneficiary as hardworking, generous, and typically, as someone who would “never ask for help” for themselves. By touting self-reliance as an honourable trait, crowdfunding discourses reinforce the stigma that many beneficiaries experience when seeking financial assistance for oft dire medical reasons.

**Keywords:** medical crowdfunding; welfare state; philanthropy; neo-liberalism; discourse analysis

## **Dedication**

For my mom who was not allowed to finish elementary school because in the context of their family situation, educating boys was the priority. Thanks to her, I now have more than enough degrees to share.

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## Table of Contents

Abstract .....	ii
Dedication .....	iv
Acknowledgements .....	v
Table of Contents .....	vi
List of Tables .....	ix
List of Acronyms .....	x
<b>Chapter 1. Introduction.....</b>	<b>1</b>
Exploring Medical Crowdfunding .....	3
Towards a Critical Theory of Medical Crowdfunding .....	9
Data Sources .....	11
Discourse Analysis .....	13
Overview of Chapters .....	14
Conclusion .....	18
<b>Chapter 2. Taking Care: Crowdfunding, Social Reproduction, and Neo-liberalism.</b>	<b>20</b>
GoFundMe: Cashing in on Compassion .....	21
GoFundMe Medical Crowdfunding in Canada .....	27
Understanding Medical Crowdfunding through a Feminist Political Economy Framework .....	30
Reproducing Capitalism .....	32
Medical Crowdfunding and Social Reproduction.....	37
Crowdfunding and the Commodification of Care Relations .....	40
Canada’s Social “Safety Net” .....	41
Social and Occupational Welfare Programs in Canada .....	41
Medicare .....	42
Employment Insurance (EI) – Sickness and Caregiving Benefits.....	43
Disability Supports .....	46
The Privatization of Social Welfare in Canada .....	49
Neo-liberalism and Privatization .....	50
Conclusion .....	55
<b>Chapter 3. Methodology .....</b>	<b>57</b>
Discourse, “Common Sense,” and Neo-liberalization.....	59
“Struggle Over Needs:” Fraser’s Critical Theory of Discourse.....	60
Critical Discourse Analysis (CDA) .....	61
Reconciling Two Approaches to Discourse.....	62
Addressing a Meta-Critique of Critical Theories of Discourse .....	64
Research Methods.....	67

Qualitative Interviews with Participants .....	67
Research Ethics .....	67
Interview Participant Categories .....	68
Interview Participant Recruitment Methods .....	69
Critical Reflexivity .....	71
Interview Structure .....	73
Post-Interview Reflections .....	75
GoFundMe Articles .....	76
GoFundMe Campaigns (Publicly Accessible).....	77
Sampling Methods .....	77
Transcription and Coding .....	81
Conclusion .....	82
<b>Chapter 4. Charity Not Solidarity? Understanding the Ethos of GoFundMe Medical Crowdfunding.....</b>	<b>84</b>
The Social Embeddedness of Material and Non-material Economies.....	85
The Embedded Logic of Redistributive Traditions .....	87
Money Pools: An African Tradition .....	88
Family “Begging Letters:” A European Tradition.....	93
Formal Philanthropy: A Western Tradition .....	96
The Meanings of “Charity” .....	97
Formal Philanthropy and the Canadian State.....	103
Examining the Logic of GoFundMe Medical Crowdfunding.....	109
Training Entrepreneurs: Promotional Communication and Instrumentalization..	110
Technical Optimization: Neo-liberal Management of Everyday Life .....	115
Preserving a Charitable Ethos.....	119
Conclusion .....	124
<b>Chapter 5. “(Never) Asking for Help:” Discourses of Needs and Deservingness in GoFundMe Medical Crowdfunding .....</b>	<b>127</b>
Understanding Social Discourses on Needs and Care .....	129
Crowdfunding Discourses as Needs Talk .....	129
“Good/Bad Dependencies” in Crowdfunding Discourses .....	134
Discourses of Needs: The Struggle to Define Needs.....	137
Unknown Needs.....	137
The Expansiveness of Needs .....	142
Untold Needs, Unfunded Needs .....	149
Discourses of Deservingness: The Struggle to Justify Needs.....	153
“Bad” Dependencies .....	154
“Good” Dependencies.....	159
Conclusion .....	172

<b>Chapter 6. Safety Nets Fail: Responsibility and Resistance in Medical Crowdfunding Discourses.....</b>	<b>174</b>
Discourses of Responsibility: The Struggle to Fulfill Needs.....	176
Crowdfunding – A First Resort or Last? .....	176
Responsible but Not Accountable: Crowdfunders’ Distrust in Governments .....	180
Resistance <i>through</i> Crowdfunding, Resistance <i>to</i> Crowdfunding.....	187
Resisting the Norms and Logic of Crowdfunding .....	188
The Limitations on Resistance .....	193
Resisting the Narrow Definition of “Health” .....	197
Conclusion .....	204
<b>Chapter 7. Conclusion: Rethinking Personal Medical Crowdfunding .....</b>	<b>208</b>
Towards a Critical Theory of Medical Crowdfunding .....	210
Operational Critique: System Failures.....	210
Moral Critique: Making False Promises and Celebrating Inequality .....	212
Ethical Critique: “Us” versus “Them” .....	214
Towards Emancipatory Alternatives.....	218
Rejecting the Myth of Exceptionalism .....	219
Stemming the Tide(s) of Privatization.....	221
Conclusion .....	223
Rigging the “Game:” How GoFundMe Adds Insult To (Literal) Injury .....	224
<b>References.....</b>	<b>228</b>
<b>Appendices.....</b>	<b>265</b>
Appendix A. Informed Consent Form .....	265
Appendix B. Sample Interview Questions.....	268
Questions for Campaigners.....	268
Questions for Contributors.....	271
Appendix C. GoFundMe Articles.....	274
Appendix D. Summary of GoFundMe Campaigns Analyzed .....	276
Campaigns retrieved by using GoFundMe’s “browse medical [campaigns]” function .....	276
Campaigns retrieved by searching “Canada” and filtering for “Medical” campaigns on GoFundMe .....	278

## **List of Tables**

Table 1	Employment Insurance (EI) Sickness and Caregiving Benefits
Table 2	Canada Pension Plan – Disability Benefits
Table 3	Moments of Struggle in Nancy Fraser’s Needs Talk Model
Table 4	Nancy Fraser and Linda Gordon’s Genealogy of “Dependency”

## List of Acronyms

BIPOC	Black, Indigenous, or people of colour
CAP	Canada Assistance Plan
CERB	Canada Emergency Response Benefit
CHST	Canada Health and Social Transfer program
CDA	Critical Discourse Analysis
CPP	Canada Pension Plan
CPP-D	Canada Pension Plan – Disability
CUSMA	Canada-United States-Mexico Agreement
EI	Employment Insurance
FTA	Free Trade Agreement
ICU	Intensive care unit
MCI or MFI	Micro-credit institutions or micro-finance institutions
NAFTA	North American Free Trade Agreement
NPIC	Non-profit industrial complex
ODSP	Ontario Disability Support Program

OHIP	Ontario Health Insurance Program
PSW	Personal support worker
ROSCA	Rotating savings and credit associations

## Chapter 1. Introduction

*I don't expect much from this[,] as I'm definitely not going to share it on my Facebook, my small amount of pride is all I have left and I'd rather hold on to it for a little while[. C]onsidering everything I've sacrificed, asking anonymous strangers on the internet is something I can handle which honestly I'm not sure [which] is sadder? (Sanger-Greenway, 2020) GoFundMe medical campaign for an amputee in Calgary, Alberta.*

I have spent nearly a decade working in the marketing department of various Canadian registered charities, and in almost all cases, the marketing strategy has been the same: tell the story of the individuals who benefit from the charitable service. Put a name and a face to the cause. Have pictures and a video? Even better. But of course, the funds raised were never allocated solely to any one individual. Donors understand that their donations to registered charities support people like – and sometimes including – little Johnny who needs a specialized wheelchair or Zahar who could use a hot Thanksgiving meal. Today, however, with the popularity of personal crowdfunding sites such as GoFundMe, it is increasingly common to directly contribute money to a single individual who needs financial assistance. On the flip side, more people are having to tell their own personal story of struggle, to advocate for themselves or their loved ones, and to share it widely on the internet. Have pictures and a video? Even better.

Helping out friends and family monetarily in times of need is not a new phenomenon, but the advent of online personal crowdfunding – and the growth in its use and visibility as a response to illness and injury – signals a shift in the ways we think about, and engage in, giving and receiving care. Raising concerns about the inequities wrought by profit-driven intermediaries such as GoFundMe, this dissertation is dedicated

to providing a deeper, critical look at the use of personal medical crowdfunding in Canada.

Indeed, the health, social, and economic crises triggered by COVID-19 has challenged and renewed questions of how Canadians care for, and ought to care for, one another in times of medical need. COVID-related crowdfunding caused a spike in the total number of fundraising campaigns on GoFundMe's website (Saleh et al., 2021), and according to the platform, accounted for over \$625 million USD in contributions between March and August in 2020 (GoFundMe, n.d.-a). But even before the COVID-19 pandemic, people around the world had increasingly been turning to crowdfunding platforms like GoFundMe, Fundrazr, Give.Asia, and Ketto to pay for individual needs such as health care, housing, and emergency relief, representing a growing trend towards the (re-)privatization of welfare provisioning. Without denying the generosity, the goodwill, and the genuine needs that have motivated the upswing in personal crowdfunding, there is a need to question who stands to benefit the most and the least from this emerging phenomenon.

So often, we are exposed to the success stories of crowdfunding – the campaigns that “go viral” and far exceed their fundraising goals – but studies consistently show that those are the exception, rather than the rule. Researchers find that Canadian and U.S. medical crowdfunding campaigns are unlikely to reach their stated fundraising goal (Barcelos, 2019; Berliner & Kenworthy, 2017; Kenworthy & Igra, 2022; Pol et al., 2019; Saleh et al., 2020), and instead, they often raise little to no money (Igra et al., 2021; Kenworthy, 2018; Kenworthy & Igra, 2022; Zenone & Snyder, 2020). Nevertheless, North American mainstream news media, especially in Canada, tend to portray medical

crowdfunding in a positive or neutral light (Murdoch et al., 2019). The struggles – and more importantly, the inequities – of raising money through crowdfunding are therefore infrequently documented and poorly understood by the general public. This study addresses that gap by sharing and analyzing some of the untold experiences and challenges of people in Canada who have participated in medical crowdfunding, including personal stories and insights that go beyond what is publicly shared in the crowdfunding campaigns.

## **Exploring Medical Crowdfunding**

Two overarching sets of questions guide this research; first, in a country that prides itself on a universal public health insurance system, why are a growing number of people turning to personal fundraising for health-related expenses in Canada, as beneficiaries and contributors? What do their stories tell us about the current state and evolution of not only our healthcare system but also of other social welfare programs that are meant to be a “safety net” when sickness affects the income and finances of an individual and often those of their caregivers? Second, what are the implications of normalizing personal medical crowdfunding as a “solution” to unmet needs? How does this practice reflect or reproduce discourses about who deserves to be helped and by whom, who does not? More broadly, what does the popularity of personal crowdfunding tell us about the way that we assign responsibility for, and participate in, care for one another?

For years, the bulk of academic research on the topic of online crowdfunding has focused on business fundraising since early adopters of the technology mostly sought financing for artistic and other entrepreneurial projects. Meanwhile, relatively little

attention was paid to what is sometimes today referred to as “social crowdfunding”– a term which few have explicitly defined but which has come to loosely signify fundraising for pro-social interests, including for social enterprises (for-profit and non-profit), non-profit organizations, registered charities, as well as community and individual needs<sup>1</sup>. I define “social crowdfunding” as the generation of typically small monetary contributions through the use of web-based platforms from a large number of contributors for social causes and personal welfare. Unlike other forms of crowdfunding, contributors to social crowdfunding campaigns are neither entitled to equity (that is, an economic share of the company or project) nor material rewards. Social crowdfunding can be further divided into philanthropic and personal crowdfunding. With philanthropic crowdfunding, funds are channeled through a registered charity or non-profit organization, whereas funds raised through personal crowdfunding campaigns are disbursed to a named individual, family, or specified group. My research focuses on personal crowdfunding but includes some hybrid cases in which the campaigners raise funds for a specified individual(s) with the intention of forwarding any excess funds to a charitable or non-profit organization.

The designation of this type of crowdfunding as “social” (as opposed to business or civic crowdfunding, for example) carries multiple layers of meaning. First, this research seeks to understand the ways in which personal crowdfunding campaigns are often perceived, constructed, and used as a replacement for state social provisions, which may be lacking or inadequate. In the US, Berliner and Kenworthy (2017), for instance,

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<sup>1</sup> The lack of definition(s) for “social crowdfunding,” in part, mirrors the looseness of the term “social enterprise” in Canada. The Government of Canada (n.d.-a), for example, states that “[a] social enterprise is a revenue-generating organization whose objective is to have a social impact. Definitions of ‘social enterprise’ vary, but there is no unified definition in Canada.... A social enterprise does not have a specific corporate form” (paras. 1-2).

found a higher number of medical crowdfunding campaigns in states that rejected expanded Medicaid than states that approved it. In Canada, where the publicly funded single-payer health insurance scheme covers most care that is deemed “medically-necessary” and performed in hospital or by an eligible physician, the popularity of medical crowdfunding points to gaps in the system for direct but ineligible costs (Snyder et al., 2017), as well as to an inadequate social safety net that would otherwise enable people to cover indirect costs (e.g., travel, loss of income during and after treatment, etc.). Rising uptake of personal fundraising for health reasons is a symptom of privatization in its varied forms, which, as H. Armstrong et al. (1997) explain, range from the highly visible (e.g., contracting out services to for-profit providers) to the less recognizable – namely, that of normalizing personal responsibility for social welfare. Second, GoFundMe markets itself as a “social fundraising” platform, which speaks to a particular way in which it is positioning its role in neo-liberal society. Third, I explore the ways in which the social crowdfunding environment might serve as what Fraser (1989a, 1992) designates as “the social” – a term that she borrows from Arendt (1998) to describe a discursive space in which the legitimacy of specific needs as public issues is articulated, contested, and negotiated. Fourth, the “social” of “social crowdfunding” also highlights its fundamental reliance on social media for dissemination. As will be discussed, this structural dependence shapes the logic, biases, and outcomes of the technology.

Scholars have started to address the gap in research on non-business personal crowdfunding, primarily through quantitative approaches. Thanks to early research, we

know that the vast majority of medical<sup>2</sup> crowdfunding campaigns fall short of their fundraising goal in Canada (Pol et al., 2019; Saleh et al., 2020), the US (Berliner & Kenworthy, 2017; Igra et al., 2021; Kenworthy et al., 2020; Kenworthy & Igra, 2022; Saleh et al., 2020) and the UK (Saleh, et al., 2020). A 2020 study of over 1,000 Canadian GoFundMe campaigns found that the median amount raised amounted to 67% of the amount requested (Saleh et al., 2020). A smaller study of 423 health-related campaigns in British Columbia found that the campaigns collectively raised only 39.9% of the combined total requested (Snyder et al., 2020a). Berliner and Kenworthy (2017), moreover, suggest that beneficiaries with more complex health issues might feel compelled to under-state their financial needs in a crowdfunding campaign in order to mitigate the appearance of “having needs that exceed what a campaign can [reasonably] address” (p. 240).

A small but growing number of studies incorporating qualitative methods have also helped illuminate how needs are articulated, contextualized, and justified in medical crowdfunding campaigns originating in the US (e.g., Barcelos, 2019, 2020; Berliner & Kenworthy, 2017; Kenworthy, 2021; Paulus & Roberts, 2017), New Zealand (e.g., Wardell, 2021, 2024), and Canada (e.g., Lukk et al., 2018; Snyder et al., 2017). Through various techniques of textual analysis, these studies explore constructions and negotiations of illness narratives (Barcelos, 2019, 2020; Berliner & Kenworthy, 2017; Schneiderhan & Lukk, 2023; Wardell, 2021), subjectivities (Gonzales et al., 2018; Wardell, 2021), and personal worthiness (Berliner & Kenworthy, 2017; Paulus &

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<sup>2</sup> Campaign creators self-select their campaign category on GoFundMe’s site. Other categories include memorial, emergency, nonprofit, financial emergency, faith, sports, volunteer, and travel.

Roberts, 2017; Snyder et. al, 2017; see also Snyder, 2023; Wardell, 2024). For example, in separate studies of crowdfunding for trans care (Barcelos, 2019) and for intentional weight loss (Wardell et al., 2023), researchers have found that campaigns for stigmatized bodies and medical interventions often draw upon and reproduce normative assessments of morally-worthy body types. The authors suggest that these self-representations arise out of campaigners' desire to elicit sympathy and possibly financial support from readers. In recent years, scholars have supplemented campaign-based analyses with qualitative interviews and focus groups with crowdfunding users (e.g., Schneiderhan & Lukk, 2023; Kenworthy, 2024), highlighting the voices of people with first-hand experience of personal medical crowdfunding.

In the course of this research, scholars have raised ethical concerns around medical crowdfunding in relation to privacy, profit extraction, and uneven outcomes. In a bid to justify the need for money and with the active encouragement of crowdfunding platforms, users regularly include deeply personal and graphic descriptions and images in their publicly-viewable campaign, portraying beneficiaries, their medical procedures, and their emotional and financial struggles in great detail (Gonzales, 2018; Snyder et al., 2017). As the preceding statistics show, however, foregoing one's privacy carries no guarantee of meeting one's fundraising goal; instead, medical crowdfunding outcomes tend to reflect – and in doing so, exacerbate – socio-economic inequalities along intersecting axes of oppression, including race (Igra, 2021; Kenworthy et al., 2020; Saleh et al., 2020), gender (Kenworthy et al., 2020; Saleh et al., 2020), and age (Lukk et al., 2018; Saleh et al., 2020). These ground-breaking studies have helped paint a picture of the troubling inequities of medical crowdfunding.

Research and theorizing in the areas of care work, social reproduction, and privatization further illuminate the broader context in which personal medical crowdfunding has entered into the popular imaginary as a “solution” to unmet health-related financial needs. Understood against a backdrop of neo-liberal restructuring, the growing use of medical crowdfunding is symptomatic of what Peck and Tickell (2002) famously describe as a “roll-back” of the welfare state and a “roll-out” of privatization and individualization, both materially and ideologically. Fraser (2016) locates this crisis of care as an inherent contradiction of capitalism: by artificially separating production from reproduction, the capitalist system undermines and threatens the very activities – daily and intergenerational – that reproduce and sustain the bodies and minds of present and future workers. Overwhelmingly, neo-liberalism’s response to the glaring gaps in care is to push responsibility on to individuals via the market: privatized care and so-called “self-care.”

This dissertation builds upon existing literature on care and crowdfunding through a Canada-focused, qualitative analysis of discourses and practices surrounding personal medical crowdfunding, supplementing the quantitative picture that other scholars have begun to illuminate. Due to the absence of universal healthcare in the United States, the use of GoFundMe in that country far exceeds that which is seen in Canada and has resulted in a higher proportion of scholarly studies that draw from strictly U.S. data. Meanwhile, the provision of universal public health insurance in Canada complicates the explanation for crowdfunding’s growing presence in this country, prompting important questions around perceptions of where responsibilities lie for social provisioning related to medical needs.

## **Towards a Critical Theory of Medical Crowdfunding**

The aim of this research is to build a critical theory of medical crowdfunding as part of the more expansive, collective project of a renewed critique of capitalism. Fraser (Fraser & Jaeggi, 2018) insists that critical theory must capture the inherent flaws and crises wrought by capitalism in its various stages and forms. Following Fraser's lead (Fraser & Jaeggi, 2018), my focused critique of medical crowdfunding contains three entwined strands: functionalist/operational<sup>3</sup>, moral, and ethical. An operational critique of personal medical crowdfunding as a practice raises questions about its effectiveness in meeting beneficiaries' health-related needs. Specifically, to what extent does medical crowdfunding help people communicate and meet needs? An operational critique also takes into consideration how the experience of crowdfunding participants measured up to their expectations. This line of inquiry also relates to Fraser's (Fraser & Jaeggi, 2018) larger critique of capitalism's inherent dysfunctionality, exploring the link between personal medical crowdfunding and capitalism's structural reliance on privately-funded stopgaps to address its crisis tendencies (see also Fraser, 2016). A moral critique of crowdfunding addresses the vastly uneven outcomes of medical crowdfunding as a matter of injustice. How are these inequalities connected to the profit motive of GoFundMe as a platform? What do GoFundMe users think about the unequal results of medical crowdfunding campaigns? Finally, an ethical critique of medical crowdfunding examines the ways in which this practice enables or compromises our ability to live a fulfilling,

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<sup>3</sup> Fraser (Fraser & Jaeggi, 2018) employs the term "functionalist" to describe critiques of capitalism that target its inherent, ongoing tendency towards crisis. To avoid confusion with other meanings of the word "functionalist" (for example, to describe the inter-relationships between various components of a larger system – a definition that I apply to a different topic in this dissertation), I henceforth use the term "operational critique" when referring to Fraser's framework.

meaningful life (Fraser & Jaeggi, 2018). In cases where campaigners are met with relative fundraising success, who are they and what are the non-monetary “costs” of achieving that outcome? As the opening epigraph suggests, for example, many beneficiaries experience a deep sense of shame about having to ask for financial help.

In outlining the scope of my research study, it is equally important to specify what this project is not and does not address. First, this project focuses only on personal medical campaigns, thereby excluding campaigns by non-profit or registered charitable organizations. I also limit my analysis to medical campaigns for which the beneficiary is not deceased<sup>4</sup> because in-memoriam contributions have a different rationale. Second, this project, while focused on medical crowdfunding campaigns, is not a study of our health care system – at least not exclusively; instead, it takes a more comprehensive view of the multiple services and resources – public and private – that a person might have to navigate in order to fund the care they need. Examples include employment insurance, disability benefits, and registered charities. Third, this study does not teach readers how to use crowdfunding nor improve their odds of fundraising success. While the goal is to provide insight into the underlying logic of medical crowdfunding, such knowledge cannot be applied to increase contributions. On the contrary, one of the aims of this study is to help people realize that, in spite of GoFundMe’s tips and guides on how to improve performance (see Kenworthy et al., 2020), a better predictor of fundraising results is one’s postal or zip code (van Duynhoven et al., 2019; Igra, 2020; Kenworthy & Igra, 2022), which strongly correlates with one’s level of income, wealth, and educational

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<sup>4</sup> Sadly, many campaign beneficiaries pass away over the course of fundraising, after which the campaign sometimes carries on as an in-memoriam fund for the deceased person’s dependents. I did not include such campaigns in my data.

attainment (see, for example, van Duynhoven et al., 2019). Fourth and most important to me is that this study is a critique of medical crowdfunding – and more broadly, of capitalism – but it is not a criticism of the people who have used it in the past nor of people who will use it in the future. In my work, I do not judge or question the legitimacy of any beneficiary’s requests, nor do I approach any contributor’s actions as anything but a genuine, admirable desire to support others.

### *Data Sources*

In order to probe and capture the “common-sense” ideas – what Gramsci (1971) describes as the taken-for-granted “truths” circulating in societies (see also Crehan, 2016) – that surround personal medical crowdfunding, this study draws on three sources of data, each reflecting motivations, opportunities, and constraints that are unique to each source: publicly-accessible GoFundMe medical crowdfunding campaigns for beneficiaries who are seeking/receiving medical care in Canada; promotional information (text and images) created and published by GoFundMe on its website; and 19 in-depth interviews with personal medical crowdfunding campaigners<sup>5</sup>, beneficiaries, and contributors in Canada. I examine GoFundMe’s promotional material to unearth the desired discursive framing of a profit-seeking company. Written medical crowdfunding campaigns, in turn, offer a rich source of data for exploring how campaigners understand, articulate, and justify their need for monetary support. However, we must also be mindful of the ways in which both what is and is not written in a crowdfunding campaign are shaped by the context of its creation. For instance, campaign descriptions are often written urgently and in moments

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<sup>5</sup> It is common for crowdfunding campaigns to be created and managed by a friend or family member of the beneficiary, hence the separate categories of crowdfunding “campaigner” and “beneficiary”. Beneficiaries who set up and manage their own campaigns are referred to as “campaigner-beneficiaries” throughout this study. See Appendix A for definitions of each participant category.

of uncertainty and acute distress, campaigns are meant to shared widely raising privacy concerns, and the primary goal of crowdfunding campaigns is to secure money.

Meanwhile, qualitative interviews with GoFundMe users offer critical perspectives and insights surrounding crowdfunding, particularly as they give interview participants the opportunity to reflect on their experiences, past and present. To date, few studies feature interviews with GoFundMe users, as most principally analyze text found in crowdfunding campaigns.

Because GoFundMe's platform environment projects a strong association between personal crowdfunding and charity, I hypothesized that participants' perspectives and feelings about crowdfunding might differ significantly depending on the specific role they played – for example, a beneficiary of a campaign might feel pitied while a contributor might feel honoured to be able to support a friend in need. I therefore invited volunteers who represent different roles in the crowdfunding experience for the purpose of data source triangulation. The interview data collected reflects the perspectives of individuals in Canada who have contributed to personal medical crowdfunding campaigns, created a medical crowdfunding campaign for themselves or a loved one, and/or benefited from a medical crowdfunding campaign (see Chapter Three for descriptions of each participant category). Gathering information from multiple sources can be a means of testing the validity of certain claims, or – as in my case – of trying to offer a more expansive and well-rounded account of a complex phenomenon (Patton, 1999). That is, my goal was not to necessarily reconcile the diverse perspectives held by participants but, rather, to acknowledge that crowdfunding can elicit a variety of emotions and meanings for user groups – all of which are illuminating.

## *Discourse Analysis*

With an eye to exploring the language and logic that sustains medical crowdfunding, this study takes discourse – by which I mean the systems of meanings and ideas that are communicated through language (written, spoken, gestural, or visual), including what can and cannot be said or thought (Bischoping & Gazso, 2016) – as its object of analysis, with an understanding that a) neo-liberal capitalism was born out of, and is legitimized through a specific ideological vision (Fairclough, 2010; Jones, 2013), especially in the minority world (Brown, 2015; see Connell & Dados, 2014 for rise of neo-liberalism in majority world contexts), and b) discourse is central to ideology (Fairclough, 2010; van Dijk, 2013). In other words, discourse forms a key “battleground” in upholding the dominance of neo-liberalism as an organizing principle of society (Fairclough, 2010). Exploring how discourse is produced, negotiated, and circulated therefore offers insight into how neo-liberal logic has become “common sense” (Hall & O’Shea, 2010).

In this work, I therefore draw upon multiple approaches to discourse analysis, incorporating Critical Discourse Analysis [capitalized to denote the critical approach to discourse studies (Fairclough, 1989, 1992, 2010; Wodak and Meyer 2015; van Dijk, 2013, henceforth referred to as CDA] as well as Fraser’s feminist discourse analysis framework outlined in her essay “Struggle Over Needs” (1989b, see also Fraser, 1989a). For the purposes of this dissertation, I refer to her framework, which appears otherwise unnamed, as needs talk.”<sup>6</sup>

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<sup>6</sup> I recognize that Fraser’s concept of “needs talk,” which refers to social discourses on people’s needs, forms only a part of her broader approach aimed at theorizing “the politics of need interpretation” (Fraser 1989b, p.10) in late-capitalist societies. Curiously, Fraser (1989b) does not consistently refer to her theory

Fraser (1989a, 1992) proposes that the production and circulation of discourses about needs (of various segments of society) or needs talk has become a prominent feature of Western welfare states as stakeholders attempt to claim or deny public responsibility for meeting social needs. For example, the COVID-19 pandemic re-kindled the long-standing debate around the need for mandatory job-protected, short-term sick leave provisions in Canada, ultimately leading to temporary and permanent reforms to sick leave entitlements for workers varying across provinces/territories and jurisdictions (Dunne, 2023; Tucker & Vosko, 2021). Applying the framework of needs talk to medical crowdfunding discourses facilitates an examination of how needs and needs satisfaction are interpreted, legitimized – and ultimately, privatized – in crowdfunding spaces. In my analysis of discourses produced by GoFundMe (Chapter Four), I draw on methods and observations that have been used in CDA to highlight how the company – as a stakeholder in the needs talk process – attempts to shape popular discourses around health care funding.

## **Overview of Chapters**

In Chapter Two, “Taking Care: Crowdfunding, and Social Reproduction and Neoliberalism,” I explore why, and in what contexts, crowdfunding exists, and consider approaches to its study. The chapter begins by offering a review of the early literature on medical crowdfunding, providing primarily quantitative insight into whom the beneficiaries are, their reasons for soliciting funds, and the relative performance of their campaigns. Next, I offer an overview of GoFundMe’s revenues and business model to

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by any name, preferring instead to characterize it in general terms as “an approach,” (p.162), “a model of social discourse,” (p.162), “a socialist-feminist critical theory” (p.10).

paint a better picture of its motivations and logic. Through a survey of three Canadian welfare programs – Medicare, Employment Insurance, and disability benefits – the chapter puts crowdfunding within its socio-political context of neo-liberalization. I then turn to explain how a lens of feminist political economy can help us understand the functions of medical crowdfunding under late-capitalism. Drawing primarily on conceptions of social reproduction developed by feminist political economists such as Secombe (1974), Wallerstein (1983), and Fraser (2016; Fraser & Jaeggi, 2018), I explore how personal medical crowdfunding contributes to the material and ideological reproduction of capitalism, even as it reveals some of the system’s inherent contradictions with regards to social relations of care.

In Chapter Three, “Methodology,” I establish the relevance and utility of employing critical discourse analysis to study personal medical crowdfunding by discussing the relationships between discourse, “common sense,” and neo-liberalization. I reflect on the theoretical foundations of the two main discourse frameworks that I utilize – namely, CDA and Fraser’s notion of “need-talk” – and illustrate their compatibility. I then describe the methods I used to collect and analyze data from multiple sources.

Chapter Four, “Charity Not Solidarity? Understanding the Ethos of GoFundMe Medical Crowdfunding,” explores how other practices of resource redistribution have been used across time and different cultures to address unmet health-related needs. What values do these practices reflect and how do they shape our understanding of care-giving and -receiving? I examine four redistributive mechanisms in particular – collective money pools or rotating savings and credit associations (ROSCAs) used widely in the global majority countries; 19th century family “begging” letters; formal Western

philanthropy, and personal medical crowdfunding. In surveying these seemingly disparate redistributive modalities, this chapter invites readers to consider the deeper logic and values that guide each of these practices. The second portion of the chapter homes in on the underlying logic of medical crowdfunding through GoFundMe by analyzing promotional text produced and published by the platform. Following a discussion of how neo-liberalism has become embedded into everyday discourses (Brown, 2015; Fairclough, 1992, 2010) and in our collective “common sense” (Hall & O’Shea, 2010), I use CDA to examine GoFundMe’s extensive catalogue of user guides (e.g., “how to” articles) to gain a better sense of the values and beliefs that structure medical crowdfunding as a redistributive practice. I argue that GoFundMe projects a strong ethos of charity onto crowdfunding as a practice that encourages campaigners to think of personal fundraising as an entrepreneurial endeavour.

Chapters Five and Six draw upon the same data set, comprising 41 medical crowdfunding campaigns originating in Canada and 19 participant interviews. In both chapters, I approach the discursive analysis through Fraser’s needs talk framework, which proposes that the interpretation, legitimization, and fulfillment of needs (of a particular social group) represent three analytically-distinct moments of struggle for power. In Chapter Five, ““(Never) Asking for Help’: Discourses of Needs, Deservingness, and Care in GoFundMe Medical Crowdfunding,” I explore how needs are articulated and negotiated in crowdfunding campaigns. In what ways do campaign creators attempt to position the beneficiary as someone who is worthy of monetary contributions? What do these discourses tell us about the ideas and beliefs that inform our participation in care relations? Chapter Five brings Fraser’s needs talk framework together with Fraser and

Gordon's (1994) theory of "good" versus "bad" dependencies to show how medical crowdfunding discourses reflect and reproduce stigmatizing narratives of adult dependency. Indeed, as needs talk, the text in crowdfunding campaigns often attempt to justify the beneficiary's worthiness by painting a picture of them as exceptionally hard-working, reliable, and typically financially independent.

Chapter Six, "Safety Nets Fail: Responsibility and Resistance in Medical Crowdfunding Discourses," unfolds in two parts, which address the following questions respectively: what discourses of responsibility for funding and providing care can be found within medical crowdfunding spaces? In what ways does the medical crowdfunding landscape enable and/or constrain acts of resistance against dominant or "common-sense" ideas and logic? I begin the chapter by examining to whom crowdfunding participants assign responsibility for meeting beneficiaries' needs, shedding light on crowdfunding users' views on the roles of governments, individuals, businesses, and charitable organizations in supporting the health of people in Canada. Next, I examine acts or moments of resistance in the practice of medical crowdfunding in order to explore interview participants' views on the question of whether or not crowdfunding can foster a collective desire for systemic change. In comparing medical crowdfunding campaign text to interview participants' responses, I suggest that personal fundraising spaces such as GoFundMe and specifically, the urgent need for funds, can hamper expressions of resistance and calls for transformative change significantly.

The dissertation concludes in Chapter Seven, "Rethinking Personal Medical Crowdfunding," with reflections and recommendations for how to better support care relations in Canada based on the insights and knowledge of interview participants.

## Conclusion

In *Undoing the Demos: Neo-liberalism's Stealth Revolution*, Brown (2015) asks: "What, precisely, is neo-liberalism as a worldview – what does it want, aspire to, dream? What are its transformations of state, economy, citizen, and value?... What are its rapid self-transformations and adaptations?" (p. 48). Brown's questions invite us to explore the many dimensions of this contemporary iteration of capitalism, ranging from its ideological underpinnings to its actually-existing (Brenner & Theodore, 2002) forms. I propose that a critical analysis of personal medical crowdfunding as a social practice and as a space of discursive struggle is one way of providing answers to her questions.

Despite the growing visibility of personal crowdfunding via GoFundMe and similar platforms, the percentage of people in Canada who have created a personal medical crowdfunding campaign likely remains low relative to usage rates in the neighbouring USA where public universal healthcare is notoriously lacking<sup>7</sup>. For this reason, it would be all too easy to dismiss the significance of medical crowdfunding in Canada. Indeed, it is tempting to think of GoFundMe as simply a web-based, more conspicuous version of asking friends and family for financial support. However, arguably social crowdfunding is much more than a technology-enabled acceleration of an existing practice; it signals a deepening neo-liberalization of care, which in turn, reconfigures social roles and identities, ushering in greater privatization and individualism. Studying medical crowdfunding helps us better understand not only the

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<sup>7</sup> In the US, an estimated 8% of the population has created a personal. medical crowdfunding campaign for themselves or a someone else, and an estimated 20% of the population has contributed money to a personal medical crowdfunding campaign (NORC at the University of Chicago, 2020). I have not found comparable statistics for the Canadian population. However, I provide a brief account in Chapter Two of research studies that have collected data on medical crowdfunding campaigns in Canada.

complex material realities and inequities faced by people confronting extraordinary medical expenses in Canada, but it also provides a window into the beliefs and values that emanate from and sustain the practice of personal medical crowdfunding. The aim of this dissertation is to bring to light what is or might be lost when we uncritically welcome for-profit platform intermediaries such as GoFundMe into our care relations.

## **Chapter 2. Taking Care: Crowdfunding, Social Reproduction, and Neo-liberalism**

In a country that prides itself on a public universal healthcare system, why is it that a growing number of people are privately funding expenses through medical crowdfunding<sup>8</sup>? This chapter briefly describes the context in which medical crowdfunding through the for-profit platform GoFundMe has risen in popularity in Canada and presents the theoretical framework for this study. It begins with an exploration of GoFundMe's revenue streams followed by an overview of how and to what extent people in Canada are using GoFundMe for health-related expenses. I then draw on social reproduction theory to highlight how medical crowdfunding can serve as a form of caregiving, a substitute for caregiving, as well as a means of privately funding caregivers. Borrowing insights from feminist political economy, I propose that GoFundMe medical crowdfunding be understood as a distinctly capitalist phenomenon, even as it seemingly replicates non-market practices of caregiving and receiving – specifically, the gifting or lending of money to family or friends in times of need. The small but growing use of medical crowdfunding in Canada signals a failure of both the market and the state in sustaining the welfare of individuals and families. As Fraser (2016) explains, the inherent conflict between care and capital accumulation is that profit maximization requires wages to be so low that it compromises the ability of individuals and families to reproduce – daily and intergenerationally – the labour capacity and

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<sup>8</sup> GoFundMe has not publicly disclosed how many people in Canada have contributed to medical crowdfunding campaigns. However, it reported that people in Canada made two million monetary contributions to GoFundMe campaigns across all categories in 2023 (Arsenych, 2023).

relations necessary to the survival of capitalism. As a response to this crisis, medical crowdfunding via GoFundMe not only introduces a profit-hungry intermediary into care relations, but in doing so, also re-privatizes welfare and reproduces social inequalities. It is therefore not simply a temporal coincidence that GoFundMe was created and exploded in popularity in many parts of the world in an era of neo-liberalism. Instead, I suggest that the practice of circulating money within personal networks in times of need has taken on new forms and meanings in this stage of financialized capitalism, shaped by technology and neo-liberal ideals of individualization, competition, and privatization.

### **GoFundMe: Cashing in on Compassion**

GoFundMe, a for-profit company, was founded in 2010 in the United States under the name “CreateaFund” as an online platform that enables individuals to create fundraising campaigns for personal reasons, ranging from weddings, vacations, to funerals and emergencies. Today, users can also create campaigns to benefit groups, private businesses, and non-profit organizations located in 19 countries in North America and Europe. Financial contributions can be made from any country. The premise – or rarely-fulfilled promise – of crowdfunding is that a large number of people contribute small amounts of money, thereby invoking the idea that small, individual choices can add up to effect great change.

Because GoFundMe is privately-owned, there is little transparency about its revenue model and earnings. However, GoFundMe often promotes itself by reporting the cumulative total of funds raised through its platform, which can give us a sense of its sizeable market share and rapid growth. GoFundMe (2015) processed the equivalent of \$1 billion USD in contributions during its first five years across all categories (i.e. not

limited to medical campaigns). In 2016, the founders sold a controlling stake of the company to a group of venture capital firms, at which time the *San Diego Union-Tribune* (van Grove, 2016) reported an estimated valuation of \$600 million USD for the startup. According to GoFundMe's yearly reports, cumulative contributions increased by about \$4 billion USD every two years from 2015 to 2019 (GoFundMe, 2015; 2017; 2019a). The COVID-19 pandemic accelerated activity on the platform, jumping by \$6 billion USD over two years to reach a cumulative total of \$15 billion USD in 2021 (GoFundMe, n.d.-a). After acquiring the fundraising platform for non-profits Classy in 2022, the company reported in its year end review that it had processed \$25 billion USD in contributions since its founding in 2010 (GoFundMe, 2022a), and by 2024, that total had reached \$30 billion USD (GoFundMe, 2024a).

These staggering figures speak not only to individual generosity but also to the high profit-generating potential for the platform. Until 2017, GoFundMe deducted a platform fee of 5% plus a payment processing fee per contribution. Based on figures published by GoFundMe in its 2016 year-end report (GoFundMe, 2016), the company would have grossed up to \$150 million USD in revenue from 2010 to 2016 solely from the platform fee. However, Forbes (Adams, 2016) reported that the company projected much higher revenues – \$100 million USD for 2016 alone with an operating profit margin of 20%. The platform fee was eventually eliminated in Canada and the US in favour of a model where contributors can leave an optional “tip” for the company. GoFundMe's CEO disclosed in interviews that the tipping model was profitable in 2018 (Salinas & Fortt, 2018) and again in 2019 (Lunden, 2019). As of 2024, the company

continues to deduct a payment processing fee of 30 cents per transaction plus 2.9% for campaigns benefitting individuals and businesses or 2.2% for charitable organizations.

Even without access to GoFundMe's financial statements we can gain insight into GoFundMe's business model by looking at the specific social and economic contexts in which the platform emerged and currently thrives. For Lapavitsas (2011), one of the defining characteristics of the shift towards financialization in the US and other countries is that the stagnation of real wages since the 1970s, coupled with the retrenchment of public provisions (discussed later in this chapter), has pushed individuals to become more entangled in the volatile world of finance, leading to a greater burden of risk at the household level. As individuals struggle to keep up with the cost of living, they are engaging more in personal borrowing and investments – the result of which, as Lapavitsas (2011) argues, is that “[b]anks and other financial institutions have been able to extract profit directly out of wages and salaries” (p. 620) through commissions and fees. Fraser (2017) adds that because capital accumulation through finance relies less on industrial labour, financialization has chipped away at the power of labour movements and unions, leaving fewer social protections for workers. It is against the backdrop of these social and economic forces – financialization at the individual or household level, roll-back of public welfare provisions, and privatization – that GoFundMe has emerged as a profitable intermediary for the sending and receiving of monetary gifts between individuals as they privately bear the risk and costs of health-related crises.

Beyond transaction fees and optional “tips” from contributors, we must also situate GoFundMe within the context of a boom in technology companies like Google and Meta that accumulate capital by mining and monetizing user data. As Kenworthy

(2019) explains, medical crowdfunding platforms around the world generate revenue from multiple streams, including “the collection and sale of user data, advertising, and cross-platform marketing strategies” (p. 6). Zuboff (2019) has coined the term “surveillance capitalism” to describe this current phase of financialization, in which demographic and behavioural data is collected and sometimes sold to third parties to not only surveil and predict user behaviour, but also to shape it in ways that fit commercial interests. In this way, the ability to collect users’ demographic and behavioural data is transformed into power (Zuboff, 2019) as well as profit. Even though GoFundMe provides some detail of how user-provided and “passively collect[ed]” (GoFundMe, 2024) user data may be used by the company, the language is broad enough to encompass a wide range of profit-making activities. In its Privacy Notice, GoFundMe (2024b) states:

“We...use [de-identified] data for various lawful purposes, including but not limited to our research on our customer demographics, interests and behavior. We also disclose this information with our affiliates, agents, business partners, research facilities or other third parties” (section H. Aggregated Data)

This practice leaves open the highly-lucrative option of selling user data. In fact, this type of vague language sits at the heart of what Zuboff (2019) describes as an age of “unprecedented asymmetry in knowledge and power” (p. 118) between users and technology companies. Moreover, the asymmetry in power and the profit-driven extraction of user data can easily be obscured by the oft-made claims about participatory media platforms as fundamentally democratic by virtue of facilitating greater participation in content creation and of linking that content to

social and cultural action (Langlois, 2011). As these corporate giants and their products reach deeper into the most intimate moments of everyday life – from dinnertime conversations transcribed by smart speakers (e.g., Google Home, Amazon Echo) to personal medical details shared in crowdfunding campaigns – most users, including GoFundMe contributors, campaigners, and beneficiaries, likely cannot even imagine how their data is or might be used to serve profit interests, particularly because new technologies are designed to capture interactions that were previously unobservable to outsiders (Zuboff, 2019; see also Langlois, 2011).

Over the years, GoFundMe has also actively pursued profit from the non-profit and charitable sector. In 2019, GoFundMe launched GoFundMe Charity as a separate website for charitable organizations to raise funds, signalling the company's desire to further develop its revenue stream as a paid service to charitable organizations. The shift meant that registered charities could no longer create campaigns on the main GoFundMe.com website (although they could still be named as a beneficiary in campaigns started by individuals). To create a fundraiser on GoFundMe Charity, organizations could choose between two fee structures: 1) pay no platform fee and give donors the option to provide a voluntary tip to the company; or 2) forfeit 3% of funds raised. The project was short-lived and charity-initiated campaigns were reintegrated into the original platform in 2021. However, GoFundMe's acquisition of the charity fundraising platform Classy in 2022 suggests that GoFundMe is still strategically expanding its share in the charity market.

In fact, GoFundMe now dominates the personal and non-profit crowdfunding industry in North America and Europe – a market position it has achieved in part by buying out its competitors. Describing itself as “the world’s largest social crowdfunding platform,” GoFundMe owns its former competitors Youcaring (which had previously acquired Generosity.com and Giveforward), Crowdrise, and Classy. This follows a global trend in the online crowdfunding industry of larger for-profit platforms squeezing out or acquiring smaller and non-profit ones (Kenworthy, 2019).

In the face of public criticism over GoFundMe as a predatory intermediary, successive GoFundMe CEOs have framed the situation as unintended, largely unforeseen, and even regrettable. In 2021, GoFundMe’s CEO Tim Cadogan wrote a widely-published open letter to U.S Congress in support of a federal aid package in response to the COVID-19 pandemic. In it, he claims that:

We are proud of the role that GoFundMe plays in connecting those in need with those who are ready to help. But our platform was never meant to be a source of support for basic needs, and it can never be a replacement for robust federal COVID-19 relief that is generous and targeted to help the millions of Americans who are struggling (Cadogan, 2021).

This messaging is consistent with GoFundMe’s past public statements that it “does not aim to be a substitute social safety net” (Belmonte, 2018), but claimed intentions aside, this statement does not erase the reality that this venture capitalist-backed company exists to extract profit from, on the one hand, tragedies, systemic failures, injustices, and even global pandemics, and on the other hand, the generosity of individuals, (mostly small) businesses, and communities.

### ***GoFundMe Medical Crowdfunding in Canada***

According to GoFundMe's past CEO Rob Soloman in a 2019 interview, about one third of all donations made through the platform are allocated to (self-identified) medical campaigns (Cerullo, 2019). This statistic is perhaps not surprising given the lack of a universal health insurance program in the United States; however, a substantial number of GoFundMe medical campaigns originate in Canada (see for example, Snyder et al., 2020a; Saleh et al., 2020) as well as in the UK, where healthcare is publicly insured. Much to the frustration of researchers, verifiable statistics about medical crowdfunding in Canada through GoFundMe are limited and further constrained by GoFundMe's basic search engine and proprietary algorithms. Notably, GoFundMe's algorithms control which campaigns are shown, and in what order, to its website visitors (see discussion in Chapter Three). It is also unclear whether the list of crowdfunding campaigns that researchers can retrieve using GoFundMe's search engine represents an exhaustive inventory of publicly-viewable medical campaigns on the site, and moreover, GoFundMe campaigners can opt to exclude their campaign from GoFundMe's search engine altogether. Even without access to hidden campaigns, however, based on a dataset of over 2.6 million unique crowdfunding campaigns across all categories retrieved between 2018 to 2021, Schneiderhan and Lukk (2023) found that about 4% or 90,000 campaigns in their sample originated in Canada. They calculated a per capita rate of 204 campaigns per 100,000 people in Canada, placing our country as the third highest campaign count per capita. Although these figures do not reflect only medical crowdfunding campaigns, they give us a sense of overall GoFundMe campaign creation rates in Canada.

A survey of recent studies also helps paint a picture of how people in Canada are using GoFundMe for direct and indirect health care costs. In 2018, Pol et al. (2019) conducted searches for campaigns related to liver or kidney transplants in Canada on GoFundMe's website, recording as many campaigns as GoFundMe's search engine would generate over the course of two days. They found 429 unique campaigns that met their study criteria. Another study identified 107 Canadian GoFundMe campaigns that were launched between June 2018 and 2019 exclusively for complementary and alternative cancer treatments (Snyder et al., 2020b). In a third study, researchers (Saleh et al., 2020) extracted all medical campaigns on GoFundMe's "Discover" page, which they found to generate a maximum of 1,000 campaigns<sup>9</sup> at a time based on the undisclosed criteria of GoFundMe's algorithms, on two separate days in February and March 2019. After removing duplicates, they had a sample of 1,091 unique personal medical campaigns originating in Canada for a variety of medical needs. Additionally, in an analysis of 423 GoFundMe medical campaigns that were launched in 2018 in two densely populated regions in British Columbia, Snyder et al. (2020a) found that over half of the campaigners cited lost wages due to illness or treatment as a reason for crowdfunding. Other commonly mentioned reasons include out-of-pocket costs for medical equipment and supplies, travel to access treatment, and complementary, alternative, or unproven treatments (Snyder et al., 2020b).

At the same time, these numbers only tell us about GoFundMe usage on the demand side without revealing to what degree, if any, those requests for financial

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<sup>9</sup> Without access to a web scraping tool, I am not able to confirm if the 1000-campaign limit is still in effect on GoFundMe's "Discover" page. I have tried to manually generate the maximum number of campaigns on the page by clicking the "Show more" button, but a loading error eventually occurred with each of my attempts. Each click of the "Show more" button generates an additional 12 campaigns.

assistance are met. Although research on medical crowdfunding – particularly in Canada – is in its infancy, a study of 429 Canadian GoFundMe campaigns for organ transplant patients found that the total amount raised only accounted for 21% (\$2.3 million) of the total value requested across all campaigns (\$11.2 million) (Pol et al., 2019). Importantly, the researchers also found that the funds were unevenly distributed – campaigns for liver transplants, for example, raised 49.1% of the total amount requested in that category while campaigns for kidney transplants raised only 11.5% of the total amount requested. Other studies show that crowdfunding tends to reproduce and even exacerbate existing socio-economic inequalities along lines of race, gender, and age. Specifically, medical crowdfunding outcomes tend to be worse for beneficiaries who are or appear to be Black, Indigenous, or people of colour (BIPOC) (Igra, 2021; Kenworthy et al., 2020; Lukk et al., 2018; Saleh et al., 2020), women (Kenworthy et al., 2020; Lukk et al., 2018), and adults, especially seniors (Lukk et al., 2018). Moreover, Igra’s (2021) study on U.S. medical crowdfunding campaigns demonstrates that even in the absence of interpersonal racial discrimination (for example, either contributing only to white beneficiaries or contributing larger amounts than to BIPOC beneficiaries), the financial capacity of an individual’s personal network reflects entrenched wealth inequalities based on race, ethnicity, and geographic location. A racialized beneficiary is therefore likely to receive fewer and smaller contributions than someone who is white. A Canadian study found that people living in postal codes associated with relatively high socio-economic status are more likely to use crowdfunding for health-related costs – a finding that supports concerns that crowdfunding fundamentally privileges wealthier people with strong media

connections, tech-savviness, and educational attainments (van Duynhoven et al., 2019; see also Snyder, 2016).

Admittedly, participation in medical crowdfunding is still likely quite low across the country, despite the disproportionate attention that has been paid to it in the media. A basic search using Factiva, a tool that aggregates content from news media outlets and publications, shows that between June 2019 and June 2024, the word “GoFundMe” appears in approximately 3,000 to 6,000 unique pieces of content originating in Canada *each year*, thereby contributing to name recognition for the company. The small but growing use of crowdfunding as a privatized means of funding medical expenses in Canada thus invites a deeper analysis of the changing material conditions, social relations, and cultural logic that drive such a change.

### **Understanding Medical Crowdfunding through a Feminist Political Economy Framework**

This study is grounded in a tradition of critical theory, which aims to emancipate individuals by rendering visible the institutions and power structures that uphold capitalism as the dominant organizing principle of society. Central to this line of critique is that medical crowdfunding delivers, and even thrives on, unequal outcomes – a defining tenet of neo-liberalism and market fundamentalism (Davies, 2017). Through the lens of feminist political economy, this study explores ways in which medical crowdfunding exacerbates existing inequities along lines of race, gender, ability, and socio-economic status. In particular, I draw on the work of Fraser (Fraser & Jaeggi, 2018) who emphasizes that critical theory must be able to locate intrinsic features of capitalism as being at the source of a given social problem, rather than incidental to it.

Even though GoFundMe labels people who contribute to personal crowdfunding campaigns as “donors,” which implies a relationship of charity between giver and receiver, I pursue an understanding of medical crowdfunding through the concept of social reproduction rather than charity. There are several advantages to this conceptualization. First and foremost is that my interview participants had mixed feelings about whether medical crowdfunding is synonymous with charity – a concept which carries stigma because of the inherent imbalance of power between giver and receiver (see discussion in Chapter Four). As such, I use the language of “contribution/contributor” instead of “donation/donor” in the context of personal crowdfunding. Second, care is a more expansive category than charity; it encompasses state welfare provisioning, paid and unpaid care labour, community supports, as well as formal charity. Third, although I have chosen medical crowdfunding campaigns as my focus, this project is not strictly about the healthcare system. As Buckland and Spotton Visano (2022) point out in their study on financial vulnerability in Canada, although Medicare relieves some of the financial concerns related to treatments deemed “medically necessary” in one’s province/territory, the cost of basic needs, utilities, recreation, and education pose a significant burden for many. By focusing on care rather than healthcare narrowly defined, this study points out not only the gaps within Canada’s Medicare system, but also those at its edges – that is, in supportive social and occupational welfare programs, such as employment insurance, provincial and federal disability programs, and supplemental employer-sponsored programs, upon which people rely when they become ill. This approach better reflects the patchwork and often contingent nature of an individual’s safety net in Canada.

In adopting a framework of care, I follow in the footsteps of feminist scholars and activists of The Care Collective in putting forth a “radical vision of a caring world” (The Care Collective, 2020, p. 21). This vision is centred on a conceptualization of care as complex, as essential, and as a relation of mutual interdependence (The Care Collective, 2020). It also emphasizes that while the level of caregiving and receiving required during one’s lifetime will fluctuate, there is no period in which care is unnecessary – care is a constant and therefore requires structures and policies that reflect this reality.

### ***Reproducing Capitalism***

Social reproduction generally refers to the daily and intergenerational activities that produce and sustain a viable labour force, including but not limited to biological reproduction, caregiving, education, and socialization. Bakker (2007) proposes that most definitions of “social reproduction” include one or more of the following foci:

(a) biological reproduction of the species, and the conditions and social constructions of motherhood; (b) the reproduction of the labour force which involves subsistence, education and training; and (c) the reproduction and provisioning of caring needs that may be wholly privatised within families and kinship networks or socialised to some degree through state supports (p. 541).

While it is common to describe social reproduction in terms of activities – such as cooking, cleaning, or child-rearing – and in turn, to equate social reproduction with definable tasks, this study, instead, puts an emphasis on analyzing reproduction as a series of social relations that occur at and between different levels and spaces in society. Thus, for example, the task of educating children in and outside of the home is

understood as a social process through which children learn the basic skills, knowledge, and comportment to become future workers and members of society. Viewed as a social relation, social reproduction involves a web of actors that, as Vosko (2002a) notes, may share an interest in reproducing the next generation of workers such as the state, businesses, and trade unions. A relational approach can also bring to light the motivations and differential power of the actors involved, as well as the historical conditions that shape reproductive practices. Crucially, and following in the tradition of socialist feminism, conceptualizing medical crowdfunding as care or reproductive labour puts an emphasis on its relationship to waged work in the formal economy. As Luxton (2006a) warns, the concept of “social reproduction” loses its analytical value when it is used to describe daily tasks that produce and sustain life *tout court*; instead, critical insight lies in understanding how these activities are necessary to sustain a labour force (as well as a “relative surplus population” [Marx, 1906]), thereby allowing continued profit extraction (see also, Picchio, 1992; Vosko, 2002a; Vosko, 2002b). In other words, social reproduction theory helps illuminate a set of social relations that sustain capitalism as the organizing principle of life (Luxton, 2006a). Fraser (see also Fraser & Jaeggi, 2018) adds that critical theory must identify the structural properties of capitalist systems that make certain social configurations necessary. In the context of this study, a critical theory of medical crowdfunding sheds light on a crisis of care that is inherent to capitalism (Fraser, 2016; The Care Collective, 2020) and explains how this crisis has created a space for medical crowdfunding – through a for-profit platform no less – to flourish.

Secombe (1974) argues that capitalism – like any social order – must continuously reproduce itself in order to remain dominant. In particular, he theorizes

three “departments” or areas of reproduction that are necessary to capitalism’s renewal and expansion: the means of production, the forces of production (labour-power), and the relations of production (Seccombe, 1974). Although the daily and intergenerational maintenance of the latter two areas are primarily accomplished through domestic caregiving activities (Seccombe, 1974), capitalist societies generally assign little to no market value to such labour. Drawing on Marx, Bhattacharya (2017) argues that this is one of the ways in which capitalism creates the façade of production and reproduction as separate spheres – in deeming social reproduction as a spatial realm of the “non-economic,” capitalism’s influence over, and presence in, reproductive activities and reproductive spaces such as public schools is less visible.

Rather than simply being overlooked, reproductive labour is invisibilized and its contributions are minimized in capitalist societies because of the conflict inherent to the wage relation. Drawing on Wallerstein’s theorization of the function of the “semi-proletarianized household” in capitalist societies, Fraser (Fraser & Jaeggi, 2018) explains that capitalism’s drive to maximize profits for owners means that workers must be paid at or below subsistence levels. Any shortfall must then be covered by non-market means, primarily through unwaged, feminized reproductive labour, state provisioning, charity, and communal sharing. Thus, Wallerstein (1983) argues that under capitalism, it is not desirable that all households be fully-proletarianized (i.e., that all household members are made into wage workers) since it would threaten profit levels. Instead, semi-proletarianization has historically been carried out alongside its complementary process of “housewifization” (Dunaway, 2012; see also Abramovitz, 1996; Mies, 1986; Seccombe, 1974) which renders invisible the contributions of feminized reproductive

labour to economic production. This labour is performed primarily behind the closed doors of private households by middle-class women “homemakers” as well as by the un-waged (i.e. enslaved) or under-waged racialized women working in their homes (Abramovitz, 1996; see also Glenn, 1992). And even as more women have become proletarianized in recent decades, the legacy of housewifization is that a) women continue to carry a disproportionate burden of the physical and emotional labour of filling the gap between wages and subsistence costs; and b) paid care labour is assumed to require little skill and training, and therefore is poorly remunerated (The Care Economy, n.d). The de-valuing of reproductive labour has also contributed to a racial division of labour (Glenn, 1992). Thus, while we often think of employment income as funding day-to-day life, social reproduction theory demonstrates that unpaid and under-paid reproductive labour also subsidize and shape the organization of the wage-labour system. Through analyses of different forms of social reproduction, feminist political economists have made significant contributions to social theory, bringing attention to how care-giving activities are a) central to the functioning of capitalism, and relatedly, b) primary sites of exploitation and oppression (but also of resistance) of women and girls, especially along intersecting lines of race, ability, and migration status.

Meanwhile, reproductive labour not only sustains capitalism economically but also ideologically (Secombe, 1974). In addition to the biological and cultural aspects of reproducing life itself, social reproduction entails the socialization of present and future populations into willing participants in the capitalist order. Notably, this includes perpetuating the myth of the artificial separation between production and reproduction (Fraser, 2016; Fraser & Jaeggi, 2018). The continued accumulation and concentration of

capital requires that people believe that reproductive activities rightfully sit outside the domain and thus responsibility of the market, and increasingly, of the state. Particularly during the formative childhood years, young people are exposed to and, to different degrees, learn and absorb cultural norms, roles and identities, and even language that enable capital's dominance. Put another way, social reproduction helps build shared logic or "common-sense" – an evolving, uncritical, and often contradictory, set of beliefs and meanings that are taken-for-granted as universally true (Hall and O'Shea, 2013). The idea that women are natural caregivers is one example of a common-sense idea that shapes reproductive practices. Socialization that aligns with capitalism is necessary not only for current and future waged workers, but also for those who perform unwaged reproductive labour, as this is what reproduces and solidifies, as Secombe (1974) argues, the relations of production. He adds that reproductive activities contribute to the psychological aspects of reproducing labour-power by teaching and upholding, for example, hegemonic sexual relations, cordial social interactions, and by generally managing everyday tensions (Secombe, 1974). This type of "ideological work" (Fairclough, 2010) is thus essential to maintaining the coherence of the capitalist totality.

This is not to say, however, that all tasks related to reproducing life are undertaken to strictly build waged labour capacity. Social reproductive activities are not capitalist inventions; but the designation of those activities as outside of the realm of production is unique to capitalism (Bhattacharya, 2017; Fraser, 2016; Fraser & Jaeggi, 2018; Wallerstein, 1983). The production/reproduction divide, in other words, arises out of structural necessity:

these non-waged labor forms are the product of constraints specific to the capitalist world-economy....[T]hese informally organized relations are not some survival from a precapitalist past nor are they just a method of subordinating women.... Non-waged labor is, in terms of the modern world-system, no less ‘capitalist’ than the labor in the most advanced robotized plant (Smith & Sudler, 2009, p. 263; emphasis mine).

The irony – or perhaps the genius – of the mythical production/reproduction divide is that it is precisely the exclusion of (most) reproductive labour from the wage system that embeds it so firmly into the capitalist order. And once incorporated into the broader system of capitalist production, reproductive activities are shaped in particular ways – gendered, undervalued, racialized – and imbued with certain values – familialism, self-sufficiency, and individual responsibility.

## **Medical Crowdfunding and Social Reproduction**

Applying a lens of social reproduction to medical crowdfunding reveals multiple and overlapping ways in which this type of personal fundraising is connected to both the reproduction of life and of the capitalist socio-economic order. First and foremost, medical crowdfunding speaks to the inadequacy of market wages and of state provisioning, and in turn, to the unsustainable extent to which the capitalist economy depends on unwaged/under-waged reproductive labour to reproduce life and renew labour power for the waged economy. A medical emergency or illness heightens this crisis as individuals/families often face extraordinary subsistence costs (e.g., food, travel and accommodations near treatment facilities, prescription drugs etc.) as well as a loss of wages for the person experiencing illness or their caregiver which puts even greater

pressure on informal (i.e. non-professional) caregivers to fill the gaps. This burden of caregiving falls disproportionately on women because, as Luxton (2006) explains, “women’s work in the home acts as a residual subsistence labour, expanding or contracting as much as possible to offset the impact of market forces, state practices, or changing family circumstances” (p. 38).

Second, with the advent of personal crowdfunding, the necessary expansion of caregiving duties is increasingly taking the form of creating, managing, and promoting a medical crowdfunding campaign. This labour is commonly undertaken by the beneficiary, their primary caregiver (e.g., a parent), or by a friend or family member. The technical and emotional labour of asking for financial assistance through a crowdfunding campaign is therefore itself a form of social reproduction as it is a non-market means of sustaining daily life. Consistent with other forms of reproductive labour, a recent study of over 600 medical crowdfunding campaigns in the US shows that crowdfunding labour is disproportionately performed by women, even as men and women were equally represented as the campaign beneficiaries in the sample (Kenworthy et al., 2020).

Third, on the side of the crowdfunding contributors, sending a monetary gift through a crowdfunding platform may be, in many cases, an expression of care – financial as well as emotional support in the form of well wishes that often accompany monetary contributions – and in other cases, may represent a substitute for care when the contributor is, for instance, physically distant from the beneficiary or limited in their own capacity to provide hands-on support. Across many societies, the gifting of money and other material items is a well-established means of fostering and maintaining community ties through solidarity, obligation, and reciprocity (Mauss, 2000). A crowdfunding

campaign may also inspire friends and family to assist in daily reproduction in other ways, such as preparing meals, providing childcare, or visiting the beneficiary.

Fourth, as medical crowdfunding becomes normalized as a solution to crises of care in Canada and beyond, the discourses produced in and around crowdfunding spaces (e.g., in news stories, on campaign pages) form part of the Western cultural imaginary. For instance, predominantly positive news coverage about medical crowdfunding (Murdoch et al., 2019) may encourage audiences to think of GoFundMe as a viable and desirable response to an unexpected medical event or condition, thereby putting the responsibility on individuals rather than on the state or an employer (if applicable). The widespread dominance of such logic was made apparent during the COVID-19 pandemic when GoFundMe benefitted from a higher volume of crowdfunding campaigns and donations through its platform than ever before: between March 1 and August 1 of 2020, COVID-19-related campaigns alone generated over \$625 million USD in contributions through over nine million separate transactions (recall that each transaction represents an opportunity for GoFundMe to earn a monetary “tip”) (GoFundMe, n.d.-a). As discussed earlier, socialization both in and outside the home is a necessary component of the ideological reproduction of the capitalist order (Secombe, 1974).

Meanwhile, medical crowdfunding can also represent a counter-discourse(s) to the invisibilization of reproductive labour under capitalism. By articulating the heavy burden of caregiving and increased expenses that come with illness and injury, crowdfunding campaign creators/beneficiaries make visible the tremendous gaps left by the market and the state that unpaid caregivers are (impossibly) meant to fill. In that sense, the generosity of crowdfunding contributors, although unevenly distributed

amongst beneficiaries, signals a common understanding or experience of the struggles to sustain day-to-day life. In Chapters Five and Six, I explore medical crowdfunding as a space for cultivating discourses on needs, which forms part of the broader struggle to legitimize, interpret, and define solutions for needs as collective rather than individual issues (Fraser, 1989a, 1989b).

### ***Crowdfunding and the Commodification of Care Relations***

As medical crowdfunding continues to grow in popularity, it adds to the repertoire of commodified relations that make up daily life. The introduction of the capitalist wage relation not only commodified labour power but also ushered in the incursion of the commodity form in households (Seccombe, 1974; see also Bhattacharya, 2017). As Seccombe (1974) explains, under capitalism, reproductive activities are heavily mediated by market commodities since it is through processes such as cooking and cleaning that purchased goods are transformed into renewed labour capacity. Social reproduction is thus doubly beneficial to capitalism because it reproduces the forces and relations of capitalist production without wages while also generating profits for commodity producers. The widespread use of GoFundMe as a crowdfunding intermediary adds yet another point of profit extraction into the reproduction of life and labour capacity.

Recognizing that friends and family have always circulated money and other resources as a non-market form of care (other examples of private redistributive practices are explored in Chapter Four), the purpose of this research is to analyze how, and to what ends, such behaviour has been adapted and has taken on new meaning as a technology-mediated practice under neo-liberal capitalism, such that it becomes a system-sustaining activity. For many of the crowdfunding contributors with whom I have spoken, the act

itself is fairly mundane – sending \$10 or \$20 online to a friend with a few clicks of a button – and yet, when understood as a social relation within capitalism, it takes on a different meaning and function. Through the framework of social reproduction, we come to understand medical crowdfunding as a social relation that reproduces capitalism by privatizing responsibility for individual health and well-being and privileging a competitive and entrepreneurial ethos.

In the next section, I briefly explore the Canadian government’s role in supporting social reproduction in Canada with attention to the complex nature of the social welfare landscape that results from jurisdictional boundaries between the provincial/territorial and federal governments.

## **Canada’s Social “Safety Net”**

### ***Social and Occupational Welfare Programs in Canada***

Rather than focus solely on the Canadian healthcare system, this study approaches welfare programs in Canada from the perspective of a person who is unexpectedly dealing with a serious medical situation – that is, I take a more comprehensive view of the (often dizzying) array of welfare programs that one might encounter. For example, a person who needs to have a limb amputated might find themselves navigating separate applications for employment insurance (sickness benefits), provincial disability benefits, federal disability benefits, the federal disability tax credit, and housing assistance. In fact, most of my research participants (who were either patients or their primary caregivers) needed to access multiple government programs. In Canada, charitable organizations also play a substantial role in direct social service delivery, financed through a combination of government funds and private donations (as explored in Chapter Four; see also Luxton,

2006b; Valverde, 1995). Here I provide a brief description of three Canadian welfare programs that were commonly mentioned by research participants in this study:

Medicare, Employment Insurance – specifically, sickness and caregiving benefits – and disability benefits.

The design of Canada’s welfare programs reflects a hierarchical treatment of workers, giving uneven access and benefits to different groups. Cameron (1995) argues this labour segmentation was further cemented in the late 1980s and 1990s when Canadian policymakers further paved the way for a capitalism-friendly, bifurcated labour environment comprising an upper-tier of workers with stable employment, relatively high wages, and some level of state protections and benefits, alongside a lower-tier of workers employed in “non-standard” jobs (e.g., part-time, casual, contract work, etc.) that have little to no job security, relatively low wages, and few state protections and benefits. Upper-tier workers can access what Cameron (1995) calls the “occupational welfare system” (e.g., Employment Insurance and the Canada Pension Plan) while lower-tier workers must generally rely on social assistance programs (e.g., low-income assistance, federal and provincial/territorial disability programs) aimed at the poor.

### *Medicare*

Medicare, more commonly referred to as “universal healthcare” in Canada, was introduced in Saskatchewan by Premier Tommy Douglas in the 1960s and eventually adopted across all 10 provinces and three territories. Medicare is a non-means-tested public insurance scheme whereby the governments pay for necessary medical costs for all citizens but do not directly deliver those services (P. Armstrong et al., 1998). In Canada, each province/territory administers its own healthcare system but agrees to conform to a

set of national standards in exchange for federal funding for public insurance. The Canadian Medicare system is built on five main principles outlined in the Canada Health Act: 1) the programs must be administered by a non-profit public authority; 2) coverage must include all medically necessary services (as defined by each provincial/territorial authority) provided by hospitals, physicians, and dentists when performed in a hospital; 3) coverage must be available for all residents<sup>10</sup>; 4) residents must be covered when travelling in Canada and, to a limited extent, when travelling outside of the country; and 5) access to medically necessary services must be available for all residents regardless of their ability to pay.

Practically speaking, most patients who qualify for Medicare are never presented with a bill for treatment that takes place in a hospital. However, since its inception, the Medicare program has privileged certain types of health care professionals and modalities (namely, those provided by medical doctors) at the exclusion of others (P. Armstrong et al., 1998) such as dentistry, physiotherapy, psychotherapy, optometry etc., leaving significant gaps in coverage for individuals to fill. An estimated two-thirds of Canadians have private health insurance, obtained primarily through their employer(s) (Allin et al., 2020).

#### *Employment Insurance (EI) – Sickness and Caregiving Benefits*

Canada's Employment Insurance program provides temporary taxable income to eligible workers who are unemployed "through no fault of their own" (referred to as

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<sup>10</sup>The Canada Health Act defines "resident" as: "a person lawfully entitled to be or to remain in Canada who makes his home and is ordinarily present in the province, but does not include a tourist, a transient or a visitor to the province." The Act further stipulates that each province/territory determines its own minimum residence requirements to qualify for its health insurance plan (Government of Canada, n.d.-b).

“regular benefits”) or who require unpaid time off due to illness (“sickness benefits”), pregnancy (“maternity leave”), and limited caregiving responsibilities (“parental benefits” for a newborn or newly adopted child, “family caregiver benefits” for a critically ill or injured child or adult, and “compassionate care benefits” for end-of-life care). In all cases, the applicant must have lost over 40% of their insurable earnings for at least one week to qualify, amongst other criteria.

EI regular benefits were first introduced in the 1940s, but it took another 30 years for the federal government to roll out sickness and caregiving benefits (Tucker et al., 2020). The first wave of new benefits – for maternity and sickness – were created in the early 1970s with parental benefits introduced almost two decades later. The second wave began with compassionate care benefits in 2003 followed by caregiving benefits to care for a critically ill child (2012), a person with a serious medical condition (2014), and critically ill adult (2017).

Despite these advances, there are several barriers and deficiencies to EI benefits programs. As Tucker et al. (2020) point out, EI caregiving benefits apply to only the gravest of circumstances and therefore barely “[touch] the surface” (p. 21) of addressing the everyday and lifetime care needs of individuals. Moreover, EI is a contributory program whereby workers must pay regular premiums towards EI when employed. One of the program’s main eligibility requirements – and thus a barrier to access – is that individuals must have worked a minimum number of insurable hours during a prescribed time period to qualify for assistance. The erosion of the standard employment relationship (i.e. full-time permanent employment with a single employer) in recent decades (Vosko,

2000a) has meant that an increasingly large number of people are excluded from EI benefits altogether.

Because EI is designed to only cover a portion of an individual’s income, even individuals who qualify for assistance suffer a significant loss of income compared to regular earnings. EI is generally calculated as 55% of the person’s average insurable weekly earnings up to a maximum amount that is adjusted annually (in 2023, the maximum amount was \$650 a week). Each type of EI benefit is subject to specific eligibility criteria and maximum number of payable weeks after a one-week waiting period, as summarized in Table 1.

Table 1

Employment Insurance (EI) Sickness and Caregiving Benefits

<b>Benefit name</b>	<b>Reason</b>	<b>Number of weeks Payable (maximum)</b>
Sickness	Unable to work due to medical reasons	Up to 15 weeks
Family Caregiver Benefit for Children	Providing care to a critically ill or injured person under 18 years of age	Up to 35 weeks
Family Caregiver Benefit for Adults	Providing care to a critically ill or injured person 18 years of age or older	Up to 15 weeks
Compassionate Care Benefit	Providing care to a person of any age who requires end-of-life care	Up to 26 weeks

*Note.* The federal government defines “caregiver” as a family member or family-like member of the person requiring care. Data for the EI sickness benefit are from *EI sickness benefits: What these benefits offer* by Government of Canada, 2023 (<https://www.canada.ca/en/services/benefits/ei/ei-sickness/benefit-amount.html>). Copyright 2023 by Government of Canada. Data for EI caregiving benefits are from *The 3 types of caregiving benefits* by Government of Canada, 2023 (<https://www.canada.ca/en/services/benefits/ei/caregiving.html>).

## *Disability Supports*

Unlike other Canadian social welfare programs that are intended to act as a temporary, last resort for individuals, Prince (2015) stresses that disability assistance programs are often the first and only resort for individuals whose capacity to earn employment income is reduced due to physical, mental, intellectual or sensory impairments. Difficulty in finding employment, in accessing disability supports, as well as inadequate levels of those state benefits have meant that people with disabilities in Canada are more likely to live in poverty than people without disabilities (Statistics Canada, 2018). Moreover, even amongst people with disabilities who live above the official poverty line, 24% reported having an unmet need for a required aid, device, or prescription medication due to high cost (Statistics Canada, 2018). Financial support for people with disabilities was initiated at the federal level in the 1930s and 1940s through the Old Age Pension program. In 1966, the federal government instituted the Canada Assistance Plan (CAP), a cost-sharing agreement between the federal and provincial/territorial governments that funded eligible welfare programs, including but not limited to disability assistance and benefits. Even with the uniform conditions placed on provinces/territories through CAP, however, there has always been significant variation in social assistance programs across the country. In 1996, CAP was replaced with the Canada Health and Social Transfer program (CHST) which meant both cuts to, and restructuring of, funding. This shift only further cemented the autonomy of provinces/territories in designing and delivering their own social assistance programs (including those for people with disabilities), resulting generally in more restrictive and punitive programs (Boychuk, 2015). Thus, Boychuk (2015) stresses that whether pre- or

post-CAP, Canadian disability programs are “best understood” (p. 38) at the provincial/territorial level. Nonetheless, I provide a brief summary of both federal and provincial/territorial disability programs below to highlight the complexity and limitations that applicants must navigate.

Because of the variations in costs of living in each province/territory, rather than summarize disability payment levels, it is more instructive to compare the average incomes of people with and without disabilities in the same jurisdiction. The Conference Board of Canada (n.d.) found that based on 2012 Statistics Canada data for the provinces only<sup>11</sup>, Manitoba, Nova Scotia, Ontario, and PEI fared the best in minimizing the average income gap between those living with and without disabilities. On one end of the spectrum, Manitobans with disabilities earn about 24% less than those who are not living with disabilities. On the opposite end of the spectrum is Alberta, where people with disabilities earn 33% less on average than people without disabilities (Conference Board of Canada, n.d.). Across the country, the average income of people with disabilities is 72.7 percent that of people without disabilities (Conference Board of Canada, n.d.).

In addition to monthly income support, provincial/territorial disability programs often comprise monetary supplements for specific circumstances as well as non-monetary services. Monetary supplements often include additional allowances for transportation, service animals, and assistive devices. Non-monetary supports are generally targeted at increasing employment for people with disabilities through education and training.

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<sup>11</sup> Territories were excluded in the analysis performed by The Conference Board of Canada because of missing data for key indicators (see Conference Board of Canada, n.d.).

At the federal level, the government offers a series of benefits for people with disabilities under the age of 65 including monthly financial support through the Canada Pension Program – Disability (CPP-D), retirement savings plans with the potential for matching bonds and grants from the government, and income tax credits and deductions. Like the EI program, CPP-D is a contributory scheme that requires individuals to have paid premiums into the program while they were employed. Unlike EI, however, a person’s CPP contribution history directly affects how much assistance they will receive through the program.

Despite the theoretical availability of financial disability support at two levels of governments as well as other public and private benefits (mainly EI, provincial/territorial worker’s compensation, and private insurance), a study conducted by the OECD (2010) found that three-quarters of the respondents with disabilities received only one benefit. Moreover, around one-fifth of the respondents were receiving neither employment income nor any financial assistance (OECD, 2010). The authors (OECD, 2010) of the report attribute this paucity of uptake in part to what they describe as the “patchwork” (p. 51) nature of Canada’s disability assistance programs, each with their own objectives, eligibility criteria, and benefit levels. Notably, provincial/territorial disability payments are often clawed back from individuals receiving CPP-D, such that CPP-D is considered – and in some jurisdictions required to be – the “first payer” of disability benefits for individuals (OECD, 2010). Benefits from EI, worker’s compensation, and long-term disability plans through private insurance also affect provincial/territorial disability payment levels (Prince, 2015). The following table summarizes the 2023 CPP-D payment types and levels:

**Table 2**

**Canada Pension Plan – Disability Benefits**

<b>Benefit Amounts</b>		
<b>Benefit Type</b>	<b>Average Amount (Monthly)</b>	<b>Maximum Amount (Monthly)</b>
CPP Disability Benefit	\$1053.20	\$1464.83
CPP Children’s Benefit	\$264.53	\$264.53

*Note.* From Government of Canada, 2023

(<https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit/benefit-amount.html>). Copyright 2023 by Government of Canada.

Across Canada, income gaps for people with disabilities are further exacerbated by the severity of disability (Conference Board, 2017; Statistics Canada, 2018) as well as gender and household status (Statistics Canada, 2018). Specifically, the likelihood of living below the poverty line is heightened for people with more severe disabilities, women, lone parents, and individuals who live alone (Statistics Canada, 2018).

***The Privatization of Social Welfare in Canada***

The three programs briefly outlined above represent some of the main components of Canada’s occupational and social welfare provisioning and help paint a picture of the state’s current role in supporting the reproduction of society as well as its labour force. The degree to which states take responsibility for social reproduction is constantly negotiated since the artificial boundary between production and reproduction is never static – indeed, both realms have undergone marked transformations through different regimes of capitalism (e.g., industrial capitalism, Fordism, neo-liberalism) and in response to changing political and social currents (Fraser & Jaeggi, 2018). All three

programs described above, for example, are part of the legacy of the post-war welfare state. While Canadian governments have a strong history of funding or delivering social supports even before the world wars (Valverde, 1995), the circumstances during and after World War II helped push governments to further develop a “safety net” for Canadians. Of particular interest to this study is the transition from the height of the Keynesian welfare state to neo-liberalism. In the next section, I explore some of the defining characteristics of neo-liberalism as well as some of its effects on welfare policies in Canada.

### *Neo-liberalism and Privatization*

The question of how to define neo-liberalism has invited a host of theories and interpretations, each perspective highlighting that neo-liberalism takes different forms in different places and times. As such, this “roughly coherent paradigm” (Davies, 2017, p. 2) produces varied and uneven effects (Brenner & Theodore, 2002; Peck, 2012), largely dependent on one’s geographic location, socio-economic position, migration status, race, and gender (see, for example, Braedley & Luxton, 2010; Connell & Dados, 2014; Ong, 2006). More so than simply an “anti-statist” doctrine, neo-liberalization is better understood as a process of re-structuring social roles and relationships with an emphasis on pro-market strategies, regulations, and behaviours (Peck, 2012; Peck & Tickell, 2002). Historically, in Canada and other Western welfare states, (re-)privatization – or, the shifting of the boundary between public and private ownership and responsibility – has been a hallmark of the transition away from the Keynesian welfare state. In practice, this has translated to actions such as selling government assets, contracting out government functions, cutting welfare spending, modelling government behaviour after for-profit businesses, and re-casting social welfare as individual responsibility (Canadian Centre for

Policy Alternatives, 2000; Fudge & Cossman, 2002). In Canada, where political leanings vary across provinces/territories, neo-liberal restructuring has taken and continues to take different forms, carried out at different paces, as exemplified in the regional variations of social assistance programs discussed earlier in this chapter.

In *The Care Manifesto*, the authors explain that neo-liberalism has exacerbated a long tradition of devaluing and undermining care “while twisting, reshaping and deepening inequality” (The Care Collective, 2020, p. 4). But rather than understanding neo-liberal capitalism as fundamentally incapable of care (The Care Collective, 2020), I suggest that neo-liberalization has transformed the meaning of care, infusing it with an individualizing thrust. In the same way that neo-liberalism does not translate to “small government” so much as to a state that actively governs in favour of big corporations (Foucault, 2008), neo-liberalism does not (and functionally, cannot) erase care entirely, for production remains structurally dependent on social reproduction. Instead, neo-liberalism privileges particular versions and configurations of care that align with capital’s interests. For example, forms of care that are un-/under-waged, that lead to consumer purchases (e.g., “self-help/care” products), and that are privatized rather than socialized are all compatible with, and even fruitful for, profit maximization (see Glenn, 1992). Moreover, it is helpful to remember that wealthy people remain well cared for – that is, care is still a central component of daily life, but it is increasingly unevenly distributed for a number of reasons.

At the macro level, the pressures of globalization have crept into Canada’s healthcare and welfare systems. Participation in trade agreements such as the Canada-United States-Mexico Agreement (CUSMA) and its predecessors (North American Free

Trade Agreement (NAFTA) and Free Trade Agreement (FTA), for instance, introduce constraints and risks to the government's authority over domestic policy decisions (P. Armstrong et al., 2001; Williams et al., 2001). Williams et al. (2001) explain that trade agreements "generally restrict the capacity of governments to give preferential treatment to local providers, restrict governments' ability to make domestic policy, and make public governments accountable to private corporations [e.g., private entities can claim damages against governments for loss of market share]" (p. 16), all in the name of so-called "fair competition." More generally, neo-liberalism's love affair with corporate monopolism disguised as "pure competition" has helped cement a general acceptance of growing inequities as a natural outcome of "playing the game" (Davies, 2017; see also Coburn, 2001).

Social policy at the provincial/territorial level is similarly guided by a business-oriented mentality that emphasizes cost-cutting ("accountability"), outsourcing ("efficiency"), and for-profit providers ("competition"). In the area of health care reform, the case of Ontario's provincial government led by Mike Harris is often used to illustrate and warn against the shift towards privatization in health care in this country. Between 1995 and 2003, over 11,400 hospital beds were cut in the province (Ontario Health Coalition, 2018), and the long-term care system was overhauled to allow more for-profit providers to compete in a space previously dominated by non-profits (Canadian Centre for Policy Alternatives, 2000; Williams et al., 2001). The disastrous and life-compromising effects of these privatization reforms on the levels of capacity and quality of care were acutely felt during the COVID-19 pandemic (Ontario Health Coalition, 2020; Marrocco et al., 2021; see also P. Armstrong, 2023).

Across the country, health authorities are also restructuring to reduce hospital care in favour of more community- and home-based health services. Although moving to out-patient services can be positive in many respects, it can also open up gaps in public medical insurance coverage since home care is not covered under the Canada Health Act, and there are “tremendous variations” in provincial/territorial coverage (Health Canada, 2004, p. 2). Even when such services are paid for by the public purse, the gendered burden of informal care is inevitably – and problematically – heightened (Health Canada, 2004; Commission on the Future of Health Care in Canada, 2002; see also Gilmour, 2002; Luxton, 2006a, 2006b). While the federal and some provincial governments have introduced and expanded caregiving leaves since the early 2000s (as outlined in the previous section), they tend to be limited and restricted to critical or end-of-life scenarios (Tucker et al., 2020). In a study of caregiving/receiving between non-family members in emergency medical situations, Luxton (2006b) explains that while such relationships are essential in a lot of communities, many public and employer-provided policies do not adequately support individuals who provide care to next-of-kin.

Healthcare spending has been a primary target for austerity measures since it represents the largest welfare budget line item; but social assistance programs have been similarly attacked under neo-liberal governments. CAP, which ran from 1966 to 1995, instituted and extended a 50-50 conditional cost-sharing agreement between the federal and provincial/territorial governments for various welfare programs that were already in place in the provinces and territories. By 1996, however, the Government of Canada replaced CAP with the Canada Health and Social Transfer (CHST) and subsequently, separated the funding streams into the Canada Health Transfer and the Canada Social

Transfer. In the course of these changes, the federal government reduced its share of funding while also lifting some of the conditions attached, thereby increasing the autonomy of provincial and territorial governments – and their politics – to shape social assistance programs (Boychuk, 2015; Jenson, 2013). As Boychuk (2015) explains, the governments of Alberta under Ralph Klein and Ontario under Mike Harris had already initiated programs of severe retrenchment in their social assistance programs prior to the dismantling of CAP, which suggests that federal cost-sharing would have done little to protect against anti-welfare politics. Despite variations in social assistance benefit levels across the provinces and territories since the 1990s, the level of decommodification for individuals who receive social assistance remains low by design (Béland & Daigneault, 2015). In fact, in Ontario, an employable single person was entitled to less in social assistance in 2013 than in 1993 in absolute dollar terms (Graefe, 2015). For people with disabilities, who account for the largest category of social assistance recipients in Canada, the real value of the yearly maximum amount of social assistance fell over 13% between 1994 and 2006 (Prince, 2015).

In the context of these and other macro-level trends towards privatization and re-privatization, care relations at the individual and community levels have been reconfigured. For the non-wealthy, neo-liberal markets have reduced our capacity to both give and receive care (The Care Collective, 2020). Indeed, the popularity of medical crowdfunding is one manifestation of this double assault on care. Beneficiaries turn to crowdfunding because they are not receiving adequate care from the state nor from the market; meanwhile, contributors give generally small amounts of money because they, too, cannot provide more hands-on care for a variety of reasons (e.g., physical distance

from beneficiary, lack of time/resources to take on more caregiving responsibilities). As federal and provincial/territorial governments rewrite social policies to reflect neo-liberal ideals of market citizenship and “self-care,” individuals, communities, and organizations have had to adapt both to changing material conditions as well as ideological currents.

## **Conclusion**

Building on Marxist traditions, feminist political economy recognizes that people make decisions about their lives but not always in conditions of their choosing. In the case of medical crowdfunding, participants exercise agency and sometimes even resistance to dominant logics as they respond to challenging situations that are shaped by macro-level policies (e.g., the downloading of responsibility for social welfare onto individuals and communities), meso-level group dynamics (e.g., interpersonal behaviours that reflect cultural understandings of who is “deserving” or not), as well as micro-level interactions (e.g., the specific response that a campaigner got from their campaign). This study explores the articulations between these levels as they manifest in the medical crowdfunding space.

The goal of this research is not only to gain a better grasp of medical crowdfunding – to systematically analyze its logic and dynamics, its ethos, the language that makes it tick – but also to explain its role in the functioning of capitalism. As such, this work should not be read as a critique of the benevolent impulse to help a friend or stranger in need so much as it is a critique of neo-liberal capitalism’s need for “band-aid” solutions like GoFundMe to temper its crisis tendencies. Rather, my aim in developing a critical theory of medical crowdfunding through a feminist political economy lens is to bring awareness to the embedded inequities of medical crowdfunding that are borne out

of its place within capitalist systems. Indeed, it is precisely through critical theory that we stem the tide of individualizing blame and instead, focus on how the broader structures and logic of neo-liberalism encourage and even propel individuals to use GoFundMe.

Just as reproductive labour has taken on new meaning and functions with the introduction of the wage labour relation, so too has the practice of sharing financial resources between friends and family – and occasionally, strangers – in times of need (see Chapter Four). Indeed, we have now reached a time when privately subsidizing social reproduction directly generates profit for crowdfunding platforms, even beyond the profit generated through the renewal of labour power.

## Chapter 3. Methodology

Against a backdrop of privatization, in its multiple and overlapping forms (H. Armstrong et al., 1997), and of rising labour market precarity (Vosko, 2010; Standing, 2011), it is perhaps not surprising that talk about socio-economic needs proliferates. Indeed, as Fraser (1989a, 1989b) argues, social discourses about needs have come to occupy a key space in political culture in welfare state societies. As a platform, GoFundMe is a venue for needs talk – one in which campaign creators solicit private funding by specifying the needs of a named beneficiary. Although many GoFundMe medical campaigns can be viewed publicly, the needs talk occurring on this platform is highly privatized – GoFundMe is a vehicle for securing private gifts rather than state provisions. Nevertheless, needs claims that are cast as private matters on this platform still form part of the larger whole of social discourses about needs that circulate, and in doing so, may affirm and/or challenge dominant ideas about the giving and receiving of care in Canada. Following Fraser’s lead in examining needs talk through a prism of discourse, I approach the needs claims that are made in medical crowdfunding campaigns and the responses they yield as forms of discursive struggle. In this chapter, I advocate for a multi-method approach to studying medical crowdfunding discourses that employs principles and techniques of needs talk and CDA.

Taking a discourse-oriented approach to examining medical crowdfunding as a practice entails specific theories and understandings of what constitutes discourse and how it functions in society. “Discourse” is defined in this study as “a web of meanings, ideas, interactions and practices that are expressed or represented in texts (spoken and written language, gesture, and visual imagery), within institutional and everyday settings”

(Bischoping & Gazso, 2016, p. 129). Fairclough (2010) and Wodak and Meyer (2015) also encourage analysts to think about discourse not only in terms of what it is, but also what it does – that is, for example, to examine the ways in which discourses mediate relations especially with regards to sustaining the power of some parties or institutions over others. Discourse both reflects and shapes social relations (Fairclough, 2010). As expressions of values and ideas as well as means of making sense of the world, discourses contain insights into the complex dynamics of personal medical crowdfunding as a component of care relations. The medical crowdfunding landscape is a site rich in discourses, representing the diverse interests and viewpoints of various actors, including campaign creators, beneficiaries, contributors, and the owners of the crowdfunding platform. To study these, I draw on three sources of data: 1) semi-structured interviews with people who have created, contributed to, or received funds from a Canadian personal medical crowdfunding campaign; 2) publicly-viewable GoFundMe personal medical campaigns in Canada; and 3) articles published by GoFundMe aimed at campaign creators or potential campaign creators.

In offering an overview of my methodological approach and methods, I begin this chapter by examining the relationship between discourse, “common sense,” and neo-liberalization, as a means of underscoring the significance of critical approaches to discourse analysis. I then discuss and reflect on the two principal frameworks that guide my analysis, namely, CDA and Fraser’s theory of needs talk, highlighting each framework’s respective strengths for analyzing data. This chapter concludes with a description of the methods I used to collect, code, and analyze the data for this study.

## **Discourse, “Common Sense,” and Neo-liberalization**

“Common sense” is understood here as a form of everyday thinking comprising popular knowledge and taken-for-granted “truths” deployed intuitively and with little critical reflection (Hall & O’Shea, 2010; see also Gramsci, 1971). Such “truths” form a central part of the repertoire of ideas and beliefs that are reflected and/or explicitly contained in discourses (see, for example, Hall & O’Shea, 2010 for common-sense ideas in political discourses). Citing Gramsci (1971), whose theorizations of common sense illuminate its connection to hegemonic power, Hall and O’Shea (2010) explain that:

common sense ‘is not critical and coherent’.... However, it does have a ‘logic’ and a history. It is always, Gramsci argues, ‘a response to certain problems posed by reality which are quite specific and ‘original’ in their relevance.’ It draws on past ideas and traditions; but it also keeps evolving to give meaning to new developments, solve new problems, unravel new dilemmas (p. 9).

In this study, I posit that personal medical crowdfunding has increasingly become a common-sense – and therefore, rarely critically-questioned – response to illness, injury, and more broadly, social reproductive needs in Canada. Crowdfunding builds on existing practices of resource redistribution within familial and community networks, some of which I explore in Chapter Four, while also introducing new ways of thinking about the giving and receiving of care. For Hall and O’Shea (2010), the incorporation of neo-liberal ideals into what passes as common sense has meant that “the broadly egalitarian and collectivist attitudes that underpinned the welfare state era are giving way to a more competitive, individualistic market-driven, entrepreneurial, profit-oriented outlook” (p.

11). The question of why people are turning to a for-profit platform to privately raise/give funds for health-related expenses in an established welfare state thus invites an examination of discourses that exist across the medical crowdfunding landscape to try to better understand the common sense that structures the practice of personal medical crowdfunding.

Heeding van Dijk's (2013) call to tailor one's methodology and methods to the specific context of the given research project, which entails considering "one's aims, expertise, time and goals, and the kind of data that can or must be generated" (para. 2), I bring together two analytical frameworks to examine medical crowdfunding discourses. Fraser's (1989a) critical discourse theory, elaborated in the essay "Struggle Over Needs," informs my overall approach to crowdfunding discourses as a form of needs talk. In Chapters Five and Six, I apply tenets of her theoretical approach to analyzing crowdfunding campaign texts and interview responses from participants. In examining texts authored by the company GoFundMe in Chapter Four, I draw on insights and strategies used by CDA practitioners.

### **"Struggle Over Needs:" Fraser's Critical Theory of Discourse**

While Fraser borrows from a number of discourse theories, including those of Foucault, Rorty, and Habermas, in her extensive body of work (see Fraser, 1989b), critical engagement with such paradigms ultimately led her to develop what she described at the time of writing to be her "most ambitious effort to date to develop a socialist-feminist critical theory" (Fraser, 1989b, p. 10), more specifically, "a model of social discourse designed to bring into relief the contested character of needs talk in welfare state societies" (Fraser, 1989b, p. 200). In "Struggle Over Needs," (Fraser, 1989b) – and

a variation of the essay entitled “Talking about Needs” (Fraser, 1989a) – Fraser proposes that because social discourses about needs figure prominently in the West, it is necessary to understand how needs are discursively constructed, framed, and negotiated as well as the power dynamics that inevitably shape those actions. Thus, the needs talk framework tends to place analytic focus on the processes of communicating and/or contesting needs with lesser attention paid to the content of the messages (Fraser, 1989a, 1989b; see also Langlois, 2011).

Specifically, Fraser (1989a, 1989b) describes three overlapping stages or “moments of struggle” that often appear in needs talk: interpretation, legitimation, and satisfaction of needs. In each of these stages, different actors – for example, citizens, politicians, institutions – represent their respective interests in the debate, and in the process, often appeal to common-sense arguments about what is best for society<sup>12</sup>. By breaking down political debates about social issues into multiple, overlapping struggles, her theory aims to capture the complexity of discursive exchanges about social needs, while also highlighting how discourses are shaped by from the “bottom up” by actors with lesser power, such as marginalized populations, and from the “top down” by actors with greater power, such as politicians and topical “experts” (Fraser, 1989a, 1989b).

### **Critical Discourse Analysis (CDA)**

Complementing Fraser’s “Struggle Over Needs” approach, CDA is a methodology that recognizes the central role of language in how social phenomena are

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<sup>12</sup>Specifically, Fraser (1989b) argues that reprivatization discourses – that is those that emerge in response to oppositional voices attempting to politicize a set of needs – often express “entrenched needs interpretations that could previously go without saying” (p. 171). Meanwhile, Hall and O’Shea (2010) emphasize that discourses from actors on all sides of a political debate reflect common-sense arguments, demonstrating the dynamic and often contradictory nature of “common sense.”

framed, negotiated, and conceived (Fairclough, 1992, 2010; Wodak & Meyer, 2015). CDA understands discourse as “a mode of action, one form in which people may act upon the world and especially upon each other, as well as a mode of representation” (Fairclough, 1992, p. 63). Accordingly, discourse has a dialectic relationship with reality: discourses simultaneously construct or constitute reality while reflecting and being constrained by it (Fairclough, 1992, 2010; Wodak & Meyer, 2015). Hegemonic or dominant discourses can therefore shape what is “possible to think, say, or do” (Padamsee, 2009, drawing on Foucault).

CDA is a trans-disciplinary methodology that deliberately allows room for the use of different analytic strategies (Bischoping & Gazso, 2016; Fairclough, 2010; van Dijk, 2013; Wodak & Meyer, 2015). Fairclough (2010) prescribes analyzing texts at three levels – as text (micro), as discourse practice (meso) and, and as social practice (macro) – each of which require separate methods of analysis. For example, at the micro level, one might look at how a text is constructed as a sentence; at the meso level, one might explore what power an actor possesses to circulate a text; and at the macro level, one might ask how the content of a text challenges dominant ideologies.

## **Reconciling Two Approaches to Discourse**

Although I could reasonably draw on just one of either Fraser’s or Fairclough’s frameworks to analyze all of my data, each approach exhibits unique strengths for analyzing different categories of crowdfunding discourse. Specifically, Fairclough’s (1992) insights on the heavily promotional character of contemporary discourse elicits compelling observations about GoFundMe’s marketing materials. Meanwhile, because needs talk was designed to explain the multi-layered struggle of communicating needs, it

is an instructive model for analyzing the personal fundraising requests made in medical crowdfunding as well as responses to them from contributors.

However, bringing together multiple theories or methodologies necessarily requires critical reflection on their compatibility with each other as well as with the goals set out for this project. Power is a central and explicit concern in CDA and in needs talk, making their agendas well-aligned with that of feminist political economy. Specifically, both approaches to discourse are grounded in a tradition of critical theory (Fairclough, 2010; Fraser, 1989a) and are therefore driven by emancipatory goals. Feminist political economy makes explicit the “politics of everyday life” (Luxton, 2020), and in positing that power can be asserted, legitimated, and constituted discursively, CDA and needs talk can help identify imbalances of power in the production, reproduction, and circulation of crowdfunding discourses that serve to sustain the capitalist totality (Fairclough, 1992, 2010; Wodak & Meyer, 2015; Fraser, 1989a). The compatibility of Fraser’s and Fairclough’s approaches in this regard can be attributed to the shared influence of Gramsci, who theorized how power and domination can be exercised and maintained through cultural hegemony rather than purely through threat of force (Gramsci, 1971). Functionally, both Fairclough and Fraser developed their approaches to address the significance of discourse in shaping social relations in the contemporary moment. While Fraser (1989a, 1989b) is interested in how social discourses on needs constitute a major category of political debate in welfare state societies, Fairclough (2010) explains that CDA has “made quite a substantial contribution to critical research on neo-liberal capitalism” (p. 12) precisely because both the emergence and maintenance of the neo-liberal project have relied heavily on the circulation of specific intellectual, political, and

everyday discourses (see also, Hall & O'Shea, 2010). Describing neo-liberalism as fundamentally "discourse-driven," (Fairclough, 2010, p. 13), Fairclough points to the intellectual origins of neo-liberal ideology, explaining that "there was manifestly an 'imaginary' for neo-liberalism, a discourse of neo-liberalism, before strategies to operationalize and implement this imaginary and discourse in practice started to be effective" (p. 13; see also Jones, 2013). Brown (2010) further qualifies this idea by acknowledging that neo-liberal restructuring was carried out in a dramatically different manner in the majority world than in the minority world (see also Connell & Dados, 2014). Neo-liberalism in the minority world was, and continues to be, implemented through "soft, rather than hard power" and therefore "has taken deeper root in subjects and in language, in ordinary practices and in consciousness" (Brown, 2010, p. 47). Fairclough (2010) adds that "this imaginary, discourse and ideology of neo-liberalism has continued to be crucial in justifying and legitimising neo-liberalism in its moments of crisis" (p. 13). Importantly, the emancipatory goals of CDA and Fraser's model of discourse rest on the premise that, while certain ideas and values can become dominant or hegemonic in a given historical moment and within a certain population (Gramsci, 1971), discourses of resistance and opposition are not only possible, but may also form part of everyday exchanges (Fairclough, 2010; Fraser, 1989a, 1989b).

### **Addressing a Meta-Critique of Critical Theories of Discourse**

Since the analysis of social discourses is itself an instance of discourse that constitutes a discursive practice and a social practice, those who engage in various critical discourse theories often encounter the question of how practitioners can make claims and normative assessments about, for example, which discourses reinforce the dominance of

the status quo, and which do not. In many cases, this dilemma is animated by Foucault's apparent stance that discourse analysis precludes the possibility of asserting that any piece of knowledge is more truthful than any other piece of knowledge, past or present (see Bischooping & Gazso, 2016 for discussion). Put differently, since a critical discourse analyst is a person who is similarly shaped by social discourses around them, one must ask how they can claim to operate from an all-knowing standpoint.

Both Fairclough and Fraser, in fact, have grappled with this line of questioning. Fairclough (2010) maintains that particular discourses can be said to be superior to others if the former offers greater explanatory power than the latter. Wodak (1999) adds, moreover, that the conclusions drawn by Critical Discourse Analysts should be treated as interpretations that, as Bischooping and Gazso (2016) write, "are more or less accurate and plausible, rather than as definitive truths (p. 147). In the quest to demonstrate how discourses perform "ideological work" (Fairclough, 2010, p. 75), CDA practitioners must demonstrate that the discourse in question is not only inadequate for explaining a given social phenomenon but also that the discourse is "necessary to establish and keep in place particular relations of power" (Fairclough, 2010, p. 9). As I argue in upcoming chapters, for example, the reproduction and circulation of certain common-sense "truths" such as the belief that people who work hard at crowdfunding will be rewarded for their efforts – despite ample evidence to the contrary (e.g., Berliner & Kenworthy, 2017; Igra et al., 2021, Kenworthy & Igra, 2022; Pol et al., 2020; Saleh et al., 2020) – is essential to GoFundMe's continued accumulation of profit.

As Fairclough explains (2010), the emancipatory potential of CDA in part lies in the dialectical nature of discourse itself. It is precisely in the understanding of discourse

as dialectically related to other elements of social life (e.g., people, institutions, power, experiences) that critical discourses have the capacity to potentially act upon or change aspects of society.

Meanwhile, Fraser (1985) challenges Foucault's supposedly neutral standpoint by pointing out the inconsistencies and unresolved ambiguities in his work. Importantly, she argues that Foucault's apparent refusal to take a normative position is squarely contradicted by the "sorts of normative political judgments he makes all the time – for example, 'discipline' is a bad thing" (p. 172). Responding to Habermas' charge that Foucault rejects the "very commitments to truth, rationality, and freedom that alone make critique possible" (Fraser, 1985, p. 166), Fraser (1985), instead, proposes that Foucault's work might plausibly be interpreted as objections to a particular "system of practice and discourse" (p. 166) found in modernity on exclusively strategic/philosophical/normative grounds – each of which yields different readings of Foucault's stance on emancipatory projects. Since Foucault never clarified his position, Fraser puts forth the possibility of more nuanced readings of Foucault that make his theories of discourse adaptable and compatible to feminist social theorizing. Thus, feminist scholars including Fraser continue to critically engage with, modify, and incorporate elements of Foucault's insights on discourse in their own theories and analytical frameworks (A. Armstrong, n.d.; Bischooping & Gazso, 2016; Fairclough, 2010).

Having outlined how practitioners of CDA, together with Fraser's needs talk framework, might respond to a common meta-critique of critical discourse theories, I turn now to discussions about the methods I employed to recruit interview participants, select text samples, and code data.

## Research Methods

This study is informed by three non-overlapping sources of data, consisting of a) one-to-one interviews with people who have used GoFundMe in various capacities for health-related expenses in Canada; b) online articles produced and published by GoFundMe; and c) publicly-viewable personal medical campaigns on GoFundMe for beneficiaries in Canada.

### *Qualitative Interviews with Participants*

From 2021 to 2023, I interviewed 20 participants in Canada, primarily via Zoom due to location differences and COVID-19 restrictions. Three interviews took place in-person after COVID-19 restrictions had been lifted in my region. Data for one interview was omitted due to suspected dishonesty for the purpose of receiving an honorarium<sup>13</sup>, resulting in data from 19 interviews. Participants received \$25 by e-transfer post-interview as a small gift to acknowledge their contribution of time and knowledge. In 2021, I received approval from York University's Academic Excellence Fund to cover eligible research costs, including the participant gifts.

### *Research Ethics*

York University's Research Ethics Board (REB) granted approval of my research protocols in 2021 (Certificate # STU 2021-090) and subsequently renewed the certificate

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<sup>13</sup> After the interview, I reflected on several peculiarities about the encounter that, *taken together*, led me to suspect that the participant lied about his identity, his experience with crowdfunding, and his geographic location. The participant chose not to turn his camera on for the Zoom interview but waived anonymity for the study; the full name he provided felt generic, stereotypically White, and unusual for someone who spoke with a strong African accent; a Google search of his email address did not yield any search results; and all of his interview responses were short, vague, and importantly, did not seem to fit the Canadian context. For example, the fundraising goal he set for his friend's crowdfunding campaign was curiously low given the cost of living in that particular city and for the circumstances described. The participant also seemed evasive when I tried to engage in friendly chatter about what it is like to live in that city. I honoured the agreement to send the participant the \$25 after the interview; however, after discussing my concerns about the interview experience with my supervisor, I omitted the data from this interview.

in 2022. Given the cost of living in Canada, the time required to participate in an in-depth interview and taking into consideration that I stand to gain professionally and financially from the interviewees' participation in my study, I offered each participant a gift of \$25, sent via e-transfer.

### *Interview Participant Categories*

Participation in a medical crowdfunding campaign includes different roles. The 19 interview participants in this study consist of:

- 9 contributors – individuals who primarily contributed to one or more medical campaigns
- 3 beneficiaries – individuals who received money from a crowdfunding campaign that they did not create nor manage on a day-to-day basis. Beneficiaries include any member of the named beneficiary's household who also benefits from the funds raised. For example, if a campaign is created to support a child with an illness, the child's parents are also considered beneficiaries
- 5 campaigner-beneficiaries – individuals who created and managed a campaign for themselves or their household
- 2 campaigners – individuals who created a campaign for someone other than themselves

In many cases, interviewees have played multiple roles in crowdfunding. For example, several beneficiaries have also contributed to other crowdfunding campaigns in the past. The categorizations above therefore reflect the primary crowdfunding role to which they spoke in interviews.

### *Interview Participant Recruitment Methods*

Because crowdfunding relies heavily on Facebook and email as tools of dissemination, I primarily utilized these channels for recruitment. Below, I describe and reflect on the recruitment methods I employed. Since my research draws on interview responses of a purposive sample of the population, the findings are not meant to be generalizable to the broader population. Rather, my goal in choosing to interview participants in-depth is to highlight the voice, experience, and perspectives of individual crowdfunding participants while at the same time identifying unifying threads.

Targeted outreach: To recruit crowdfunding campaigners and campaigners/beneficiaries, I searched for inactive Canadian medical crowdfunding campaigns on GoFundme, then used GoFundMe's embedded webform to contact each campaigner. To my surprise, this did not yield any responses.

Targeted social media outreach: To recruit volunteers across all crowdfunding roles, I reached out to Facebook groups focused on peer support (e.g., "Canadian Cancer Support Group"), community-building (e.g., neighbourhood groups), and resource sharing (e.g., "COVID-19 Coming Together," mutual aid groups). I searched Facebook group names across a range of health conditions, including limb loss/amputeeism, cancer (in general and specific types), organ transplant (in general and specific types), pediatric care, parents of sick children, and type 1 diabetes. Private Facebook groups generally require approval from an administrator to join. Rather than requesting to join the group – which I felt would increase the probability of rejection since I am an outsider, and my presence might be perceived as an invasion of privacy – I sent messages to administrators explaining my research and asking them to share my call for participants on my behalf in

the group. Seven administrators agreed, 12 did not respond, and two declined. I recruited six interview participants via this method.

Online networking, word-of-mouth, and paid advertising: I posted my call for participants in my email signature and to my Facebook, Twitter, and Instagram accounts, and I asked people in my network to share it to theirs. Five participants were recruited through online networking or word-of-mouth, including one person who saw my study featured in a national competition for Canadian researchers. *New Sociology*, a York University-based student-run academic journal, also shared my post to their Instagram account @newsoc\_journal, and I worked with the account administrator to increase the exposure of the post through Instagram's paid advertising option. The total advertising cost amounted to \$40 and was paid to Instagram; *New Sociology* and its administrators did not receive any compensation. The advertising cost was covered by the Academic Excellence Fund as a direct research expense. The paid Instagram post yielded seven interviews, one of which was discarded as described above (see footnote 13).

Postering: I utilized printed posters to recruit participants, posting them on bulletin boards at local libraries, cafes, and community centres. Printing costs were covered by the Academic Excellence Fund as a direct research expense. None of the interview participants mentioned seeing my poster.

Snowball sampling: After each interview, I invited participants to share information about my study and my contact information with people who had been involved in the same crowdfunding campaign as well as to anyone in their network whom they felt might be interested in participating in the study. This type of peer-based recruitment, known as snowball sampling, is often used in qualitative studies to access

populations that are challenging to reach or who might be disinclined to participate without the trust of a peer's referral (Kirchherr & Charles, 2019). Because targeted outreach, as described above, was less successful than I had expected, I put more emphasis on snowball sampling once interviews were underway. Snowball sampling also presented the opportunity to gain multiple perspectives of the same campaign. Two participants were separately referred to the study because they were involved in the same crowdfunding campaign as two other interviewees.

### *Critical Reflexivity*

As discussed earlier in this chapter, a commitment to critical reflexivity in CDA as well as other critical discourse frameworks lends strength to these approaches. With regards to interview data, Bischooping and Gazso (2016) explain that because discourse analysts view both the interviewer and the interviewee as “carrier[s] of discourse” (p. 169), which is understood to be socially constructed and to extend beyond the immediate talk that is generated in an interview<sup>14</sup>, there is often less emphasis put on “introspective reflexivity on the interviewer/ researcher’s part” (p. 169). Instead, reflexivity in discourse analysis tends to focus on drawing a connection between instances of discourse and macro-level phenomena, including power dynamics (Bischooping and Gazso. 2016).

In both CDA (see Bischooping & Gazso, 2016 for discussion), people are often understood to draw upon, and contribute to, different discourses depending on the context and their positioning relative to a given scenario. Based on my own background as a marketing professional for registered charities, I was particularly interested when

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<sup>14</sup> Meanwhile, in narrative analysis, greater emphasis is put on the interviewer’s positionality because they are viewed as joint producers of the content of an interview alongside the interview participants (Bischooping & Gazso, 2016).

designing this study in exploring if and how people might speak about medical crowdfunding differently in the context of active fundraising versus outside of it. That is, I recognized that my previous jobs required me to draw on particular discourses suitable to the fundraising environment as well as to the specific social cause for which I was working, and by extension, that crowdfunding contributors, campaigners, and beneficiaries might similarly adjust their vocabulary, tone, voice, etc. as they move through different stages of crowdfunding or depending on the role they play in a particular campaign. For instance, someone who wrote a heartfelt comment on their friend's crowdfunding campaign page might also, in a conversation without that friend, acknowledge that they feel inundated by similar fundraising requests. Or a crowdfunding beneficiary-campaigner might assume a more hopeful, positive tone in their written campaign than they might in-person.

Accordingly, I approached the interview itself as a space that might elicit discourses about personal crowdfunding, care relations, and social welfare that differ than what is found in, for example, a crowdfunding campaign of which the main goal is to raise funds. I explicitly probed interview participants with questions around the responsibility of governments, registered charities, individuals, and corporations in supporting people who experience health-related financial struggles in Canada (see Appendix D for Sample Interview Guide) – topics that may or may not be addressed in the text of the crowdfunding campaign in which they are involved. Additionally, I exclusively interviewed participants who were involved in a crowdfunding campaign that was no longer actively raising funds. For campaigners and beneficiaries, this inclusion criteria – along with the option for anonymous participation – was designed to create a

space for them to speak without the pressures and constraints that come with fundraising (see Chapters Five and Six). For campaigners, beneficiaries, and contributors, sharing their experience of participating in a campaign that has subsequently closed allows the benefit of hindsight as well as a chance to speak to the final fundraising outcome which may or may not have met their expectations.

Because the academic privilege of the research interviewer – embodied in different forms of symbolic capital that are cultivated and gate-kept through elite institutions such as universities (Briggs, 2002, drawing on Bourdieu) – may imbue the interviewer with greater authority than the interviewee, I aimed to counteract the power imbalance by establishing a personable tone from the start, often incorporating humour (Kaaristo, 2022) and casual language. I began each interview by briefly explaining my interest in the topic and by reminding them that they could skip or return to questions, and/or withdraw their responses or participation by contacting me at a later date up until the point when data analysis is complete. In most cases, I framed this in a light-hearted way by assuring them that my goal is not to “catch” them saying something controversial or dramatic. Doing so seemed to put participants at ease and set a friendly tone for our conversation.

### *Interview Structure*

Interviews were semi-structured (sample question guide is found in Appendix D) and participants were given the option to view the questions in advance. Only one participant accepted the offer. Interviews lasted 30 minutes to three hours, according to how much information and time interviewees wished to share. All participants read and signed an informed consent form (Appendix C) prior to the interview, which also gave them the options of consenting to an audio recording (for transcription purposes) and to

waive anonymity. It became apparent to me after completing a number of interviews that some participants seemed to waive anonymity for my benefit, incorrectly assuming that anonymity would pose an inconvenience to the study. From that point forward, I made a point to explain to participants that there is no pressure to waive anonymity. Moreover, there are multiple instances in which participants waived anonymity but I subsequently pseudonymized their data because they were connected to another interview participant who had requested anonymity. For example, if I used the real name of a campaign contributor with their consent, it would be possible to guess the otherwise anonymous identity of the beneficiary of the same campaign.

I organized the interview questions into two to three themes, adjusted according to the interviewee's experience of crowdfunding. The first set of questions surround details of the crowdfunding campaign in question, including the reason for the campaign, the participants' involvement, and whether the fundraising goal was met (if known). Opening the interview with these relatively straightforward questions also helped establish a rapport with the interview participant, easing them into questions that might require deeper introspection and reflection. By framing these questions in an open-ended way – for example, “can you tell me more about the campaign you started?” – I hoped to lend authority to their voice and experience. The second set of questions pertained to alternative supports for addressing beneficiaries' needs and specifically solicited interview participants' opinions on the ideal role of government, registered charities, businesses, and individuals in supporting people facing health-related financial struggles. For interview participants who are beneficiaries of a campaign, I followed with a third set of questions surrounding their feelings around the results of their crowdfunding efforts

and how they compared to their initial expectations. For all participants, I ended the interview by asking them to explain in their own words what they consider to be the best way to support people with health-related financial struggles in Canada.

### *Post-Interview Reflections*

Most of the people that I interviewed participated in a medical crowdfunding campaign that reached or exceeded the fundraising goal – an outcome which has been found to be statistically unlikely in Canada (Pol et al., 2019; Saleh et al., 2020). It is unclear why the respondents to my call for research participants skewed towards campaigns that achieved relatively successful outcomes; however, it is possible that campaigners and beneficiaries who had overall positive experiences of crowdfunding felt more inclined to share their story. The skewing of the participant pool towards those who were relatively successful in their fundraising was amplified in cases where an interviewee referred someone else to the research study who had been involved in the same crowdfunding campaign. For example, if a beneficiary's friend created a crowdfunding campaign on their behalf, I invited the beneficiary to share information about my study with the campaign creator. However, the use of snowball sampling does not explain why contributors who volunteered for the study without any referral happened to give to campaigns that were met with relative success.

Given that the bulk of the interview participants were statistical outliers in terms of reaching or even exceeding their stated fundraising goals, one might reasonably expect that they conveyed a more positive outlook on medical crowdfunding than users involved in campaigns with poorer fundraising outcomes. However, the semi-structured, in-depth interview process allowed me to adapt interview questions to the participants' responses in order to probe deeper reflections as well as possible silences and omissions. By

establishing a friendly, confidential, and conversational tone in interviews, I did my best to create a comfortable space for interview participants to think through and acknowledge the range of emotions that they may have felt during and after the campaign.

### ***GoFundMe Articles***

Between February and August 2023, I collected 19 articles published by GoFundMe on its website, which it files under the category “Resources.” Upon visiting the website, I selected my language (English) and country (Canada) from the respective drop-down menus in order to prompt content that is customized to Canadian users. One of the articles, for example, entitled “What is Crowdfunding? The Clear and Simple Answer” (GoFundMe, n.d.-d) prominently features an image of the Canadian flag as well as links to news articles and reports citing health care-related statistics for this country.

GoFundMe does not publish a comprehensive list of its resources, so it is not clear how many articles of this type exist – moreover, GoFundMe often makes minor edits to this content, updating the publication date shown at the top of each article each time. Instead, GoFundMe lists about a dozen of its articles in a drop-down menu on its home page, then makes extensive use of hyperlinks in each article to guide readers to additional resources that might be of interest.

Following that logic, I began my search by reading the article “How to write your GoFundMe Fundraiser Story – 12 helpful hints” (GoFundMe, 2022b) then followed embedded hyperlinks to locate additional articles that I felt could be relevant to personal medical crowdfunding. Appendix C contains a list of all the articles used in my analysis. After coding 19 articles (see Transcription and Coding section in this chapter), I felt that

the data had reached a point of saturation as I found the information and links in the articles to be repetitive.

### ***GoFundMe Campaigns (Publicly Accessible)***

#### *Sampling Methods*

Since GoFundMe is not publicly-traded, access to its campaign data is limited by what the company is willing to share. While some researchers, especially those employing quantitative methods, have created web scraping applications<sup>15</sup> to retrieve large numbers of campaigns for analysis (see, for example, Igra, 2021; Kenworthy & Igra, 2020), the inner workings of GoFundMe's algorithms remain a company secret<sup>16</sup>. As such, researchers, including myself, can only make educated guesses as to how GoFundMe's algorithms select the campaigns it displays, and the order in which they will appear to website visitors, both of which may affect a campaign's fundraising outcome<sup>17</sup>. Furthermore, GoFundMe appears to frequently update its website structure and algorithms. Over the course of this research study, for example, changes have been made to GoFundMe's navigational menus and the level of information that is displayed to visitors.

I manually retrieved 41 publicly-viewable medical campaigns located in Canada using GoFundMe's search engine on April 19, 2023 for analysis (see Appendix D for a

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<sup>15</sup> Web scraping entails the use of bots to automatically extract data from websites (University of Wisconsin-Madison, 2019). Once the data have been collected, bots can further be used to pull information from the data set.

<sup>16</sup> GoFundMe's guarding of their data aligns with the status quo across many business industries. While some progress has been made towards convincing private companies to share data with researchers, policy makers, and other institutions to address social issues, open data policies amongst for-profit companies remains a rarity (Hansen & Pang, 2023).

<sup>17</sup> The effect of GoFundMe's algorithmic ranking of campaigns on fundraising outcome of any given campaign is unknown. Personal crowdfunding, however, relies primarily on contributions from the beneficiary/campaigner's personal networks rather than from strangers who might use GoFundMe's search engine to identify potential beneficiaries.

list and summary of all campaigns analyzed). I pulled the data using two search methods (detailed below), using the following criteria: 1) must be health-related; 2) treatment/care must take place in Canada; and 3) campaign descriptions were written in English, including campaigns that were written in languages in addition to English. Each results page showed 12 campaigns, and users have the option to generate the next 12 campaigns by clicking a button that reads “show more.” The total number of campaigns resulting from that search is unknown and only discoverable by continuing to click the “show more” button or possibly by using a web crawler (see footnote 9).

I set a target of 20 campaigns from each search method with the intention of retrieving additional campaigns after an initial round of coding if I felt saturation had not been reached. After the first round of coding, I felt comfortable that consistent thematic patterns were identifiable in the campaigns and that the discourses were becoming repetitive. To confirm my assessment, I coded an additional campaign (drawn from search Method 1) and found that no new codes were generated from it. Moreover, the campaigns represented a certain level of diversity across different factors. The final data set includes campaigns that reflect a variety of different ages of beneficiaries, household makeup, citizenship statuses, employment statuses, and reasons for fundraising. The health-related needs mentioned in the campaigns selected include but are not limited to short- and long-term conditions, disability, dental work, and pre- and post-treatment campaigns.

In each of the searches, I used systematic sampling, selecting every fourth campaign in the results list until I reached my target of 20 campaigns per search method. Systematic sampling is a technique normally used in quantitative research to obtain a

sample in which every unit of a given dataset has an equal chance of being selected for analysis, thereby making research findings generalizable to the full data set (Scharrer & Ramasubramanian, 2021). Cresswell (2005), however, explains that in qualitative research, “the intent is not to generalise to a population, but to develop an in-depth exploration of a central phenomenon” (p. 203). I selected campaigns at a chosen interval in order to generate a sample that precludes “cherry-picking” and that, to some degree, might counteract the ranking bias resulting from GoFundMe’s algorithms<sup>18</sup> by drawing samples that are farther down on the results list. Any fourth campaign that did not meet the three criteria above was discarded, and I selected the campaign that fell on the next multiple of four<sup>19</sup>. Because additional campaigns in the results list are generated on the spot (by clicking “show more”) – and would therefore likely change if I re-started my manual search – I generated more campaigns than I assumed I would need to collect my desired sample, then took a screenshot of all of the results before sampling every fourth campaign. To protect the confidentiality of interview participants, I did not analyze any written campaigns in which interview participants were involved.

In the first search method, I opted to browse campaigns by category, selecting “medical” fundraisers from GoFundMe’s menu. The resulting campaigns all originate in Canada, suggesting that the platform recognizes my geographic location (further corroborated by the “Canada – English” symbol that appears at the bottom of my screen, indicating the language shown on the website) and is therefore showing campaign results for my country. Choosing every fourth eligible campaign, I identified 20 campaigns for

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<sup>18</sup> See Kenworthy & Igra, 2020 for discussion on researchers’ struggles with, and strategies for, overcoming GoFundMe’s ranking bias.

<sup>19</sup> For example, if the fourth campaign was ineligible for analysis, I selected the eighth campaign instead.

analysis out of a list of 129 campaigns or 11 pages of results (I generated and took a screenshot of 156 campaigns or 13 pages of results in case I needed more campaigns.) The disadvantage of this search method is that the algorithm also appears to prioritize campaigns with recent contribution activity, as indicated by the “Last donation  $x$  hours/days ago” line which appears in the preview of each campaign on the results page. Out of the 156 campaigns that I generated through the search, the campaign with the least recent “donation” was received five days before I pulled the data, and the campaign with the most recent “donation” was received only a minute before my search. It is not surprising that GoFundMe’s for-profit business model favours campaigns that have proven fundraising momentum; however, it does not paint an accurate picture of active campaigns, since it suppresses campaigns that do not have hyper-recent contribution activity, thereby obscuring older and less popular campaigns in manual searches. Although I was not able to manually determine the total number of campaigns generated by my search terms (as discussed earlier), my search results hint at the large volume of medical campaigns that exist on GoFundMe’s platform at any specific time, given that even campaigns that received their most recent “donation” a week earlier did not qualify to be featured within the first 13 pages of search results. Moreover, out of 156 campaigns, there was only one campaign for which five days had elapsed since its most recent “donation.”

To compensate for the bias of the first search method, I conducted a second manual search, in which I typed the word “Canada” in the search bar and selected “medical” using GoFundMe’s filter options. This search method has the disadvantage of only retrieving campaigns in which the author has written the word “Canada” in the

campaign text itself; however, an advantage is that campaigns are included even if they do not appear to have had a hyper-recent “donation.” This time, I generated a larger number of total campaigns before selecting my final sample because I noticed a pattern emerging: campaigns that were relatively less successful were appearing farther down in the results list, albeit not strictly in descending order of money raised. Out of 528 total campaigns collected using this method (44 results pages), the last 133 campaigns to appear on the results list had raised \$0, demonstrating that GoFundMe’s algorithms suppress campaigns with lower fundraising performance. Using the same sampling technique as the first search method I employed, I selected every fourth eligible campaign for analysis until I reached 20 campaigns.

### ***Transcription and Coding***

Audio recordings of the interviews were initially transcribed using Microsoft Word’s built-in automation tool and then manually edited to correct errors and indicate linguistic elements that are not readily captured by a machine such as emotions and pauses. Even though the manual editing proved time-consuming, I found that having to carefully comb through – and often listen multiple times to sections of the interview recording – helped to familiarize me with a significant volume of interview data.

I manually coded all three sources of data using NVivo. For participants who requested anonymity, I pseudonymized their transcript prior to uploading it to NVivo. I used inductive coding to identify thematic patterns across all data. Inductive coding is a grounded theory approach to analyzing data that involves making observations about the data as they emerge instead of checking data against *a priori* assumptions or hypotheses (Scharrer & Ramasubramanian, 2021). Generating codes through the data in this way is

an iterative process and required that I revisit the codes and data periodically to combine, divide, and reorganize codes (Elo & Kyngäs, 2008; see also, Kirchherr & Charles, 2018). In the early stages of coding, I used codes that were more general – for example, coding a topic such as “Governments.” As I gathered more data, I created sub-categories of codes that indicated, for example, how the participant felt about governments (e.g., governments as incompetent/mal-intentioned/greedy). Prior to uploading data, I colour-coded interview data according to the participant’s role (i.e. campaigner, beneficiary etc.) so that it would be easier to compare and contrast perspectives on the same topic, according to different roles.

## **Conclusion**

In *Unruly Practices*, Fraser (1989b) posits the need for a “genre of critical theorizing that blends normative argument and empirical sociocultural analysis in a ‘diagnosis of the times’” (p. 6). In this study, I bring the overlapping normative goals of feminist political economy and critical discourse theories together with the analytic tools that CDA and needs talk offer in order to examine medical crowdfunding as a neo-liberal practice. Discourse analysis is but one avenue for exploring the connections between – and in the case of capitalism, the artificial separations of – the political, economic, and social aspects of everyday life, but importantly, it is one that can take into account the agency of social actors (Fraser, 1989) as well as the common-sense or hegemonic ideas that shape social norms and behaviours. In this chapter, I have explored the core tenets as well as critiques of CDA and needs talk. I have situated critical approaches to discourse analysis as particularly relevant for understanding neo-liberalism, which is said to be driven largely by discourse (Fairclough, 2010). By utilizing two frameworks – each for

different sources of data – my aim in this work is to offer deeper insight into the varied discourses about crowdfunding that emanate from different actors. I also described, and reflected on the rationale for, the methods I used for data collection and analysis.

In the next chapter, I examine the underlying ethos of different practices of material redistribution across space and time, including that of GoFundMe medical crowdfunding. Through techniques of CDA, I offer a closer look at the way in which GoFundMe frames personal crowdfunding to campaigners.

## **Chapter 4. Charity Not Solidarity? Understanding the Ethos of GoFundMe Medical Crowdfunding**

Personal medical crowdfunding via GoFundMe and similar online platforms is a relatively new response to unmet welfare needs, but societies have devised and established a variety of ways across space and time to (re-)distribute money to address and mitigate gaps in social reproduction. Polanyi (1965) theorizes the propensity for material redistribution and reciprocation within communities as a form of social protection, aimed at social bonding (see also Mauss, 2000) and collective survival. Tax-funded welfare programs, community fundraisers, “care-mongering,” formal philanthropy, etc. are all means of supporting the fluctuating needs of people around us. Ranging from the informal to the formal, and from the voluntary to the obligatory, these redistributive practices reflect and reinforce underlying values, beliefs, and social norms. In this chapter, I examine four redistributive forms – informal money pools (Hossein & P. J., 2022), family “begging letters” (N. Christie, 2004), formal Western philanthropy, and GoFundMe medical crowdfunding – to demonstrate how such practices are shaped profoundly by, and indeed, reinforce, hegemonic – and sometimes even counter-hegemonic – values. Through this investigation, I aim to create a better understanding of the logic and principles that structure GoFundMe as a social practice so that we can explore the implications of personal medical crowdfunding.

The ensuing exploration unfolds in three sections, beginning with a discussion about the relationship between society and material and non-material economies. I then turn to canvass existing research on three redistributive traditions to explore how underlying values and logic or “common sense” can produce vastly different solutions to

the same perennial problem – namely, the struggle to meet social reproductive needs financially. Turning to my central case study, in section three I analyze online texts authored and published by the company GoFundMe as a means to make visible the logic of medical crowdfunding. Overall, this chapter asks: what are some ways that societies have tried to address financial struggles related to health, and how do they reflect, strengthen, or challenge prevailing norms and ideas? What are some of the taken-for-granted values, beliefs, and meanings that structure GoFundMe’s medical crowdfunding space?

### **The Social Embeddedness of Material and Non-material Economies**

Anthropologists, economists, and sociologists, amongst others, have long debated the relation between society and economic behaviour (see Granovetter, 1985), especially as it relates to the introduction and evolution of capitalism. Polanyi (1965) argues in *The Great Transformation* that economic liberalism has caused the economy to be disembedded from society, such that economic goals supersede and may even destroy pro-social aims. He explains that whereas the social protection afforded by community and solidarity once made self-interest secondary to collective needs, the twin developments of the nation state and so-called “self-regulating” markets have paved the way towards a more atomized society (Polanyi, 1965). And even though Polanyi posits that pro-social counter forces have prevented “market society” from fully materializing, his treatise has prompted a number of important critiques. After surveying arguments about the nature of economic behaviour – ranging from utilitarian theories of *homo oeconomicus* to conceptions of humans as fundamentally social beings – Granovetter (1985) takes a more nuanced position and contends that Polanyi exaggerates both the

social embeddedness of the pre-capitalist economies and the extent to which capitalism has detached economic interactions from social norms. Similarly, Fraser (2017) argues that Polanyi romanticizes the concept of society, at the cost of ignoring the plight of historically marginalized populations who have been systematically and strategically excluded from so-called “social protections.”

Moreover, in examining the values and logic of redistributive traditions and economic behaviours, it is helpful to consider that material redistribution is entangled with other systems of exchange and distribution that are centred around material and non-material resources, including gift economies (N. Christie, 2004; Mauss, 2000) and socio-emotional economies (Clark, 1999; see also Hochschild, 1979). As will be discussed in this chapter, for example, the 19<sup>th</sup> century tradition of women writing “begging” letters to ask for financial support from distant kin involved not only the circulation of money but also cultural capital (Bourdieu, 1986) in the form of one’s honour and reputation (N. Christie, 2004). Moreover, Clark (1999) points out that feelings of obligation, respect, gratitude, and sympathy circulate in, and help regulate, everyday interactions and relationships. Similar to gifts of material items, exchanges of sympathy can create bonds of intimacy, obligation, and reciprocity:

sympathy often connects people asymmetrically. In the first place, the sympathizee is “one-down” in relation to the sympathizer by the mere fact of having a problem serious enough to warrant sympathy. Furthermore, the sympathizee is one-down because gifts of sympathy have strings, because they obligate. The person who ‘owes’ repayment is ‘much

obliged' to the sympathizer until an opportunity arises for repayment – and equalization” (Clark, 1999, pp. 20-21).

Zelizer (2011) also points out that gifts of money, in particular, can invoke obligations beyond repayment. She explains that contrary to assertions that all money is the same, there are different kinds of money because money serves a symbolic function in societies (Zelizer, 2011). Money received through a crowdfunding campaign, for instance, carries different meanings than money received through a paycheque or through illegal means. The way in which money is obtained may dictate how it should be spent, who can spend it, and what is expected of the recipient in terms of reciprocation, accountability, or expressions of gratitude (Zelizer, 2011). The examination of redistributive practices to follow thus involves what Zelizer (2011) refers to as “special monies” or non-wage money, which are shaped by social and cultural norms. By exploring the underlying values, meanings, and expectations attached to redistributive practices, we can therefore gain insight into the politics of social reproduction.

### **The Embedded Logic of Redistributive Traditions**

When exploring different practices of resource redistribution, there are any number of traditions and their regional variations from which to choose. I have selected a small sampling of practices that reflect different cultures and geographic regions, time periods, and degrees of formalization or institutionalization to demonstrate how the “common-sense” values of a given community at a specific point in time can shape the way in which participants devise solutions to address crises of care under capitalism (Fraser, 2016). In particular, money pools represent a primarily participant-led system that is common in majority-world countries, thereby offering a non-Western perspective

of resource redistribution. Meanwhile, family “begging” letters from the 19th century provide a window into a historical predecessor of Western philanthropy. Finally, charitable giving through formal institutions, to which I devote considerable attention, is a dominant and widely celebrated system in Canada and other Western nations.

Ultimately, I argue that medical crowdfunding reproduces many of the same foundational values and discourses as formal Western philanthropy. The intention of my overview of different practices is neither to draw surface-level comparisons between them nor to assert the superiority of one method over another. However, recognizing how these approaches differ, as well as where they overlap, invites us to think more deeply about the underlying logic of the emerging phenomenon of medical crowdfunding and its implications for the way that we give and receive care in Canada.

### ***Money Pools: An African Tradition***

Money pools or money cooperatives, often referred to in scholarly contexts as rotating savings and credit associations (ROSCAs) but known by localized names such as *susu* in Ghana and Liberia; *partner* in Jamaica; *tontine* in Cambodia, Malaysia, and Singapore and parts of Africa; and *kamethi* in India etc., are informal collectives of people who own and manage a shared pot of money. Each collective sets its own rules, but generally, participants contribute a set amount to the common fund on a schedule, and the full value of the pot is distributed to a single participant on a rotating basis. For example, a group of 10 people might agree to contribute \$100 every month for 12 months, and each month, one member will receive \$1,000. In this way, each member benefits from having access to a larger sum of cash than they might have been able to save on their own without the accountability and discipline afforded by the group

structure. There are no restrictions on where or how the pot of money is spent once it is handed over to a member. That is, as a “special money” (Zelizer, 2011), the money circulated in a money pool embodies an explicit rejection of limitations on its use. Commonly cited uses include investing in one’s small business, paying tuition, making a large purchase such as a car, celebrating milestones etc. (see, for example, Hossein & Bonsu, 2023).

The origin of this cooperative savings-and-lending model dates back to at least the 1600s in Africa and was an important resource for enslaved Africans (Hossein, 2013). Money pools continue to be widely used around the world, particularly by poor women in majority-world countries<sup>20</sup> who have been or continue to be excluded from commercial banking institutions (Hossein & P. J., 2022). Money pool collectives are generally headed by a single organizer – usually a woman – who administers the common pot of money and screens potential members. While money pools are mostly used for, and described as, a tool for small business owners operating in informal economies, a closer examination of this mutual aid practice reveals the inseparability of its economic and social dimensions (Bonsu, 2022; Bouman, 1995; Hossein 2013, 2022). In fact, money pooling is not always a stand-alone activity, but rather, a secondary function of a wider set of communal practices, which may include collective dancing or praying, and pooling labour and non-monetary goods (Bouman, 1995). Even in the groups that focus primarily on saving and lending, members come together on a regular basis to share not only the collective pot of money, but also knowledge and support for business, family, social and spiritual matters

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<sup>20</sup> Many diasporic populations also continue their money pooling traditions in minority-world countries (Hossein, 2013).

(see volume by Hossein & PJ, 2022). In their study of Ghanaian *susu* collectives, Hossein and Bonsu (2023) found that interviewees “pushed back if we focused on the financial aspect [of *susu*], and they wanted us to record the personal connection and social interactions they experienced in their *susu*” (p. 125). Notably, money cooperatives are important sites for feminist struggles, providing a self-managed structure for women – especially racialized women who experience discrimination and/or exclusion from commercial banks – to access and develop both economic and social capital to support their daily and intergenerational needs (Hossein, 2022; Kinyanjui, 2014; Njie, 2022).

Guided by the African philosophy of *ubuntu* – famously translated by Kenyan philosopher Mbiti (1969) into English from Zulu and Xhosa<sup>21</sup> as “I am because we are and since we are, I am” – money cooperatives embody an epistemological understanding of humans as interdependent. This “common-sense” view of humanity shapes the practice of money pooling implicitly but also explicitly. Scholars who have studied this cooperative model – many of whom also have first-hand experience participating in money pools (see volume by Hossein & P. J., 2022) – emphasize that participation in money pools is a conscious act of solidarity and communitarianism: “[a]ll the women individually mentioned to me that their rationale for joining the group was to help others in need.... They identified themselves as willing to forgo the interest on their money (sharing the benefits), because they care about their friends who need help” (Bonsu, 2022, sec. 5.6.2., para. 2).

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<sup>21</sup> The concept of *ubuntu* exists under various names in different Bantu languages (Zulu and Xhosa belong to the Nguni Bantu family of languages.)

The emphasis on social bonds also manifests when a member requires emergency funds. Although members usually agree upon the order of disbursement in which each person will receive the pot in advance, the schedules are sometimes adjusted to prioritize a member who has unexpected expenses such as an illness in the family (see, for example, Bonsu, 2022). As Hossein & Kinyanjui (2022) explain, “ROSCAs are a form of social protection and insurance. The members insure themselves against expenses arising from death, old age, sickness, marriage, and birth” (sec. 12.5, para. 6) as well as disability or unemployment (Bouman, 1995).

Membership in a money pool can thus prove to be life-saving in the case of an emergency; but it is important to recognize that money cooperatives are primarily a proactive rather than reactive tradition. While individual collectives often disband after a set period – ranging from weeks to years but typically 12 months – the act of forming or joining money pools with friends, family, co-workers, and neighbours is often a continuous practice over one’s lifetime (Hossein & P. J., 2022). It forms part of a way of life, driven not only by the material conditions of poverty and racial and gender marginalization, but also by a desire to live out and cultivate social values and beliefs (Hossein & Kinyanjui, 2022). Thus, money cooperatives should not be seen simply as a coping mechanism (Hossein & Kinyanjui, 2022) but a cooperative practice that forms part of the “ordinary behaviours” (Vélez-Ibáñez, 2010) of life-making for millions of women around the world (Hossein, 2013).

In recent decades, growing positive interest in money cooperatives has led to their adaptation and appropriation, altering the ethos of ROSCAs and the meanings attached to the money circulated within them. On the non-profit end of the spectrum, Bangladeshi

economist Mohammed Yunus was awarded the Nobel Peace Prize for developing Grameen Bank, which provides loans in small sums to groups of borrowers – mostly women – who would not typically qualify for a loan at a commercial institution. Building on the model of self-managed money pool collectives that already existed informally in Bangladesh, Grameen Bank relies heavily on the accountability and trust afforded by the group structure of borrowers – in addition to exceptionally high interest rates – to guard against defaults on loans. However, Grameen Bank, and other similar non-profit micro-finance initiatives (MFIs or MCIs for micro-credit institutions), have been criticized for putting borrowers (often women) and their families in unmanageable debt, contributing to increased violence against women (Rhaman, 1999 in Sengupta, 2013) and suicide rates (Taylor, 2011).

Predictably, the excitement around micro-credit – culminating in the United Nations declaring 2005 as the International Year of Microcredit – and the neo-liberal agenda quickly ushered in profit-making interests. As Bateman et al. (2018) explain, while the goal of helping the world’s poor become entrepreneurs through the extension of credit fit nicely with neo-liberal doctrine, subsidizing those loans from government coffers and charitable donations contravenes the drive for profit. To rectify this,

[w]ith the World Bank and USAID [United States Agency for International Development] taking the lead...[f]rom the mid-1990s onwards start-up financial support, technical assistance and many other forms of support would simply not be forthcoming unless an MCI was structured to operate as a commercial undertaking, while all existing MCIs were instructed to commercialize their lending practices as soon as

possible. Governments in the Global South were expected to further support the move by comprehensively de-regulating their local financial systems in order to create the best possible ‘enabling environment’ for for-profit microcredit to flourish (Bateman et al., 2018, p. 5).

The micro-credit industry has since become a boon to for-profit financial institutions, with little to no evidence that formal micro-loan systems improve the lives of women borrowers (see studies in volume by Bateman et al., 2018). It is apparent to many researchers of, and participants in, informal money pools that the logic of neo-liberal financialization – with its emphasis on risk, profit, individualism, and entrepreneurialism – is fundamentally incompatible with a social and economic model that is built around interdependence, cooperation, and *ubuntu*. The global discourse built up around MFIs/MCIs, whether for-profit or non-profit, individualizes poverty by proposing that a lack of credit is all that holds poor women back from realizing their innate entrepreneurial potential (Kabeer, 2015). Meanwhile, the guiding principle of informal money pools is an explicit commitment to collectivizing both the risks and benefits of daily life.

### ***Family “Begging Letters:” A European Tradition***

Family “begging” letters,” most often written by women (N. Christie, 2004), were a common means of soliciting private financial support from extended family in Western Europe and North America in the 19th century. They formed part of a larger tradition of “begging letters” – as they are called by historians – that were written to wealthy individuals, with senders ranging from strangers to kin (Andrew, 2014; Crocker, 1999) as

well as voluntary associations (Crocker, 1999)<sup>22</sup>. In the United States, government efforts to reduce and police street begging at the turn of the 19th century helped fuel the popularity of written solicitations to the wealthy (Crocker, 1999). Meanwhile, in Canada, correspondence requesting financial assistance from family members – however distant their relation – was one of the most common forms of letter-writing in the 1800s (N. Christie, 2004).

The reasons for financial need outlined in family “begging letters” varied but were deeply inflected by female dependency (N. Christie, 2004). Women often sought financial assistance from extended family when the men in their immediate family were unable or unwilling to provide for them (see, for example, letters in N. Christie, 2004). Unlike medical crowdfunding, authors of family “begging” letters usually sought long-term income (i.e. an annual remittance or pension) from potential benefactors rather than a one-time gift. Because the sums were often small, it was not unusual to seek support from multiple benefactors nor to make repeat appeals to the same family member over time (Andrew, 2014; N. Christie, 2004). Letters provided an opportunity for the sender to a) establish, or sometimes remind the recipient of, the familial connection – and therefore obligation – between them, and b) to explain or justify their circumstances (N. Christie, 2004).

In her analysis of 19th century “begging letters” from Upper Canada (present-day Ontario), historian N. Christie argues that rather than being imposed upon and internalized by individuals, notions of the “deserving” versus the “undeserving poor”

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<sup>22</sup> Soliciting wealthy members of society partly reflects the unprecedented levels of concentrated wealth that came out of industrialization – in the US, for example, the number of millionaires increased forty-fold between 1880 and 1916 (Howe, 2010).

were “formed *first and foremost within the family structure*, and it is this language of familial norms, expressed in these ubiquitous female begging letters, which defined the practice of institutional charity” (p. 72; emphasis mine). That is, she asserts that “common-sense” ideas around deservingness and what constitutes respectable behaviour in contexts of private donations primarily flowed outward from the family to charitable institutions. Meanwhile, my research project adheres more closely to CDA methodology in its understanding of “common sense” as a culmination of knowledge and beliefs that are cultivated, negotiated, and circulated through multiple social actors, none of which exercise complete autonomy nor absolute authority to originate ideas (Bischoping & Gazso, 2016; Fairclough, 1992; Wodak & Meyer, 2015).

The practice of seeking familial beneficence through letter-writing existed alongside formal charity services as well as, in certain areas of Canada, localized systems of poor relief (see Carmichael & Elson, 2022). However, poor relief programs were not only designed to provide meagre assistance but accessing them was also heavily stigmatized (Carmichael & Elson, 2022; N. Christie, 2004). Because this was common knowledge in this era, letter writers often hinted that the family name would become stained should the letter’s recipient refuse the request for financial support (N. Christie, 2004). This type of familial fundraising was therefore a means of avoiding formal systems of poor relief, motivated largely by public reputation, gendered norms, and negative connotations around receiving public assistance. As N. Christie (2004) explains:

[t]he vast build of these letters were penned by impecunious widows and impoverished spinsters or dependent female orphans, the penumbra of patriarchy, who either because of an inability or a lack of desire to see

work or out of their desire to preserve their social status, can be defined as the ‘shame-faced poor,’ whose lives remain largely hidden outside the structures of work and systems of poor relief (p. 71).

Moreover, “begging” letters reveal a complex relationship between familial assistance and the connotations of charity. On the one hand, authors of family “begging” letters sometimes described the potential monetary assistance as a form of private “charity” – a means of invoking the duties of a “good Christian” (N. Christie, 2004; see also Andrew, 2014). On the other hand, N. Christie (2004) argues that the requests largely operated under the veil of familial affection and Christian benevolence; however, the money exchanged between family members mostly rested on an economy of “calculative reciprocity” (p. 74), in which debts were carefully tracked and repaid across generations. As such, requests made through “begging” letters are better understood as a means of making claims on unpaid debts and obligations within familial networks (N. Christie, 2004) rather than so-called “begging” for “unearned” charity.

As one of the components that made up the “life strategies of poor women” (N. Christie, 2004, p. 70) in Canada in and around the 1800s, family “begging” letters drew upon and strengthened prevailing attitudes towards familial obligation, respectability, and reciprocity. The carefully crafted discourses of deservingness and needs found in these letters (Andrew, 2014) reveal how a strong “economy of obligation” played out within families, shaped by patriarchal norms (N. Christie, 2004, p. 76).

### ***Formal Philanthropy: A Western Tradition***

Largely born out of a legacy of Christian almsgiving, voluntary gifting through legally-recognized charitable or philanthropic organizations is a well-established and

generally respected practice in many Western societies. Today, Canada boasts the second-largest non-profit and charitable sector in the world based on the number of workers and volunteers (Imagine Canada, 2005). It is home to 170,000 non-profit and charitable organizations which together, employ roughly 2.5 million people and account for 8.7% of the national GDP (Statistics Canada, 2009). The size and degree of professionalization of the sector speak to the extent to which voluntary giving through registered charities has become a revered and firmly institutionalized practice in Canada (along with the US and many other welfare states).

### *The Meanings of “Charity”*

The stark contrast between 19th century familial and non-familial “begging” letters and, for example, contemporary mega-institutions like the Red Cross – both of which were/are often understood or rhetorically referred to as “charity” – demonstrates the complexity and dynamism of the notion of “charity.” This points to a need to further define what is meant by the term and to distinguish between its many different and evolving forms. As will become evident in Chapters Five and Six, people who participate in medical crowdfunding do not agree on whether medical crowdfunding constitutes a form of charity. The significance of this discrepancy becomes more evident when we consider the meanings of the word “charity” in Western societies. In “A Genealogy of ‘Dependency: Tracing a Keyword of the US Welfare State,’” Fraser and Gordon (1994) deconstruct and trace the evolution of the term “dependency” in the U.S. political lexicon, making note of the word’s multiple registers or levels of meaning. Following their framework, I examine the concept of “charity” (which I use interchangeably with “philanthropy”) in Canada in order to better understand its ideological underpinnings in various environments.

I draw attention to three overlapping registers at which “charity” operates in Western societies in the 21st century. First is the economic register, where “charity” refers to a voluntary transfer of a non-reciprocal gift – most often monetary but may also take the form of a physical item or service – between two parties, one of which does not otherwise have access to the gifted resource. The mediation of a legally-recognized charitable organization distinguishes formal charity from informal practices of gifting (see, for example, definitions in Statistics Canada, 2000) that may or may not be subjectively understood as “charitable” by the giver and receiver (as will be explored in Chapter Five in the context of medical crowdfunding). In all circumstances, the charitable relationship is premised on a systemically uneven distribution of resources between the giver and receiver. As Ross explains, “philanthropy has always been the reflection of a class society because it has depended on a division between rich givers and poor recipients” (as cited in Arnove, 2010, pp. 1-2). Charity is generally thought to flow unidirectionally not only because direct reciprocity would transform a gift into an exchange, but also because charity is motivated by the idea that the “haves” should help the “have-nots” in situations where sympathy for the “have-nots” is culturally warranted (Clark, 1999). This conception stands in contrast to, for instance, cooperative money pools which are built on the premise of shared sacrifice (i.e. loss of interest income) and benefit for all participants.

However, even as charity implies a recognition of inequality – and to some extent, the injustice of it – the aim of charitable giving tends to be a temporary, modest to moderate reduction of pain and suffering rather than to alter the hierarchical relationship between giver and receiver, or more broadly, between the rich and the poor. Formal

philanthropy perpetuates the myth that vast economic inequality and impoverishment are natural (Eikenberry & Nickel, 2006; see also Livingstone, 2013) and inevitable, rather than a product of capitalist relations. Particularly in the case of elite Western philanthropy, which involves billionaire benefactors such as Bill Gates, Melinda French, George Soros, and Warren Buffet, the mainstream celebration of charitable giving obscures the source of philanthropists' vast wealth: a system of surplus extraction that is subsidized by un-/under-waged reproductive labour (Gilmore, 2007). Thus, the practice of charity preserves the prevailing social order rather than upending or even challenging it.

A second level of meaning of “charity” refers to a legal status in Canada that is conferred to organizations that fit specific criteria set out in the Income Tax Act. Canada has two classifications for organizations that do not operate for profit: both registered charities and non-profit organizations enjoy income tax exemptions, but only charities can issue donation tax receipts for eligible gifts. Registered charities in Canada may take the form of a charitable organization, a public foundation, or a private foundation. In addition to not operating for profit, two of the primary criteria to receive registered charity status are: a) to be “constituted and operated exclusively for charitable purposes”; and b) that the organization’s “purposes and activities provide a tangible benefit to the public as a whole or a significant section of it” (known as the “public benefit test”) (Government of Canada, 2006).

Legal charitable status lends authority and legitimacy to eligible organizations and their causes, to the exclusion of others, and also secures significant economic benefits afforded by governments – benefits that are regressive (Valverde, 1995) and ultimately

subsidized by taxpayers (Reich, 2018; Valverde, 1995). Since the early 2000s, the number of private foundations has grown rapidly in Canada (Canada Revenue Agency, 2022) and the US (Reich, 2018). In 2020, private foundations in Canada held \$81.3 billion which is almost double the \$41.6 billion held by their public counterparts. However, private foundations granted less than 4% (\$3.2 billion) of that wealth whereas public foundations granted over 12% (\$5.1 billion) of their assets (Imagine Canada, 2022 as cited in Philanthropic Foundations Canada, n.d.). It is worth noting that the initial idea of a private philanthropic foundation – an invention undertaken by U.S. industrialist John D. Rockefeller – was met with great political opposition and suspicion when it was first proposed in 1910 (Arnove, 2010; Reich, 2018). This reflected a political climate in which people were fiercely critical of the unprecedented amount of wealth concentrated in the hands of the new industrial millionaires and, by extension, of the intentions and implications of their charitable initiatives (Arnove, 2010). In recent years, the growing amount of tax-sheltered wealth in Canada and the US that is held in private foundations without evidence of substantial disbursements has renewed the voices of critics such as Gilmore (2007), who posits that private philanthropic foundations are “repositories of twice stolen wealth” (p. 46): untaxed profits gained through the exploitation of workers.

The prevalence and prominence of charities, and by extension, of charitable activity in Canada contributes to various meanings of “charity” at the social/moral register. The common designation of non-profit and charitable organizations as the “third sector” establishes charity as a fundamental pillar of Western society. Relative to the private and public sectors, the charitable sector is also generally propped up to be a source of moral good. Accordingly, voluntarism and formal charitable giving are

celebrated activities in this country. Children and youth are socialized at a young age to participate in formal charity, often through school, religious institutions, community organizations, and government programs. The now-defunct Canada Student Services Grant program, for example, was a federally-funded government initiative that would have given eligible youth up to \$5,000 for completing 500 volunteer hours in a specified period. Even without the incentivized program, an estimated 12.7 million volunteers contribute up to 1.32 billion hours of unpaid work each year in 2018 through the Canadian non-profit and charitable sector (Statistics Canada, 2018b).

At the same time, the social/moral meanings of “charity” reinforce a false binary between those who are on the giving versus receiving ends of formal/informal charity. Because donations of time and money are voluntary, donors and volunteers are generally praised for being virtuous, benevolent, and generous. This is particularly pronounced in today’s era of ultra-rich and/or celebrity philanthropists (see, for example, McGoey, 2015; Littler, 2015). This admiration is rooted in the common understanding of charity as counterposed to capitalism: giving away one’s money, particularly to a stranger, appears antithetical to individual wealth accumulation. However, conceptualizing charity in this way reflects and upholds a core tenet of capitalism itself – that of private property. It is only because private ownership is so deeply engrained as common sense that charitable giving is so widely viewed as a commendable personal sacrifice. When represented and understood as individual benevolence, philanthropy obscures the fact that capitalist accumulation and its attendant dispossession (Harvey, 2005) are at the heart of gross discrepancies in wealth as well as the insufficiency of wages in covering the costs of social reproduction (see Chapter Two). It is also through respect for private property that

donors are granted the power to decide which causes and/or charitable organizations are most deserving of their gift(s).

Meanwhile, this contemporary conception of charity in relation to private property only developed in the 19th century. As Andrew (2014) explains,

[t]he traditional notion of beneficence was that charity was a basic obligation entailed by the ownership of property, that as God was the sole Proprietor, and men only his stewards, charity to the poor, to God's poor, was not mercy, but justice (p. 277).

Giving money to the poor was a prescribed religious duty attached to one's status as property owner. Over time, however, and at the lead of English clergy, this view began to shift: given that God holds ultimate authority over how and to whom property is distributed, parting with one's God-given wealth became understood as an individual and voluntary choice, not an obligation (Andrew, 2004). And insofar as the poor could make claims to some of those possessions, that merely translated to a "[r]ight to ask for it, that is to *beg the Charity* of all well-disposed Christians" (Sherlock, 1754 as cited in Andrew, 2014, p. 277; emphasis mine).

Re-positioning the poor as rightful "beggars" rather than rightful claimants added to the increasing stigma around being a recipient of charity. This legacy has been carried forward to today, further shaped by a negative connotation of "dependency" that developed, as Fraser and Gordon (1994) explain, starting in late 1800s in the United States when industrialization cemented the image of the white, male, waged worker as the universal subject and a symbol of freedom. Defined in opposition to the cultural tropes of

the “pauper,” the racialized colonial “native” and the slave, as well as the “housewife,” the white waged worker was characterized as economically independent, and therefore, honourable (Fraser & Gordon, 1994). That honour is further multiplied when one’s capacity to earn wages is so high that they have excess to give away voluntarily. In this way, charitable donations are a type of “special money” (Zelizer, 2011) that confers different values to its giver and recipient. The donor, who is respected for earning “wage money,” gains even more respect when it is converted into “charity money.” Meanwhile, “charity money” taints its recipient because adult dependency became associated in this period with personality weaknesses and was even pathologized (Fraser & Gordon, 1994; see also Russells, 1980). To this day, the stigma of adult dependency is so strong that it is extended even to those who receive government entitlements rather than formal charity (Fraser & Gordon, 1992). The common thread between recipients of formal charity and of government benefits is that even if a group may be deemed somewhat deserving depending on their situation, the money that its members receive is deemed unearned because it was not secured through waged work (see Zelizer, 2011). As will be explored in Chapters Five and Six, the stigma of adult dependency carries through to medical crowdfunding practices.

#### *Formal Philanthropy and the Canadian State*

Although the third sector is often held up as an autonomous pillar of society – and therefore one that provides necessary balance to the other sectors – the boundaries between state, private business, and the voluntary sector have historically proven to be less clear-cut (in Canada, see Valverde, 1995). In pre-Confederation Canada, private charities played a significant role in social welfare provisioning, even in regions where the imported English Poor Law obligated municipalities and parishes to provide poor

relief (Carmichael & Elson, 2022; see also Morton, 2014). The divisions of responsibility between state and charity reflected not only fiscal considerations, but also echoed and reinforced underlying Victorian morality: drawing from Garland's research on the British welfare system, Valverde (1995) speculates that in Ontario, care for people who were poor, sick, elderly, disabled, or considered morally but not criminally "deviant" was left to private charities because of the prevailing view that the state should not engage in the reform of so-called "personal vices." Nonetheless, the Ontario government quietly funded charities that provided such services dating back to as early as 1820s (Valverde, 1995), leading Valverde to conclude that "similar to (and perhaps influenced by) developments in the US...the ideology of a self-sufficient civil society has been upheld at the level of rhetoric and to a large extent at the level of service delivery, but not financially" (p. 39). The invisibility of government involvement in private social service delivery in this era was not only politically expedient but also crucially upheld the ideological divide between public and private responsibility that structures the capitalist state. Put another way, charities provided a vehicle for maintaining the belief that the daily and generational reproduction of large sections of the population was first and foremost a private matter, while allowing some flexibility for governments to fill gaps as necessary or when it suited their agendas.

The exigencies of the First World War pushed the Canadian federal government to enact legislation to incentivize private donations to designated war charities, thereby initiating the Canadian government's official role as a charity registrar and regulator (Watson, 1985; as cited in Carmichael & Elson, 2022). In the post-war period lasting until the 1980s, the charitable sector grew rapidly thanks to state welfare spending (e.g.,

direct funding, tax-exemptions for registered charities) (Carmichael & Elson, 2022), and, to a lesser extent, private fundraising (see Tillotson, 2008). Carmichael and Elson (2022) explain that “the type and growth of registered charities [in this period]...reflected direct federal and provincial government funding priorities as well as the priorities inherent in the social welfare transfers by the federal government to the provinces and territories” (para. 11). In certain areas of social service delivery, this has led to the development of a quasi-governmental class of registered charities such as hospitals and public universities, which are primarily funded through government transfers (see discussion in Senate of Canada, 2018).

The trajectory of Canada’s voluntary sector is also consistent with what Wolch (1990) identifies as the “shadow state” phenomenon – a pattern that appeared in Western nations in the 1970s-1990s, whereby welfare states leaned heavily on non-profit and charitable organizations to relieve fiscal and political pressures. Former Prime Minister Brian Mulroney was perhaps the most explicit about his plans to save money by relying on charities and volunteers to deliver social programs<sup>23</sup>, but whether under the leadership of the political Left or Right, Canada’s charitable sector faced considerable neo-liberal retrenchment after the 1980s (Carmichael & Elson, 2022; Wolch, 1990). Cuts in federal funding along with a shift towards shorter-term grants left registered charities scrambling to keep up with the increased demand for their services wrought by government welfare roll-backs (Carmichael & Elson, 2022).

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23 In 1983, then Prime Minister Mulroney explained to members of the Progressive Conservative Party:

One of the major priorities of my government will be the complete revision of social programs in order to save as much money as possible. One way of meeting that objective is to encourage the voluntary sector to participate more in the implementation of social programs. Volunteer work is the most efficient method of work in Canada (as cited in Valverde, 1995, p. 35.)

Defined as a “para-state apparatus,” the shadow state comprises non-profit and charitable organizations that increasingly deliver social services, all while having a diminished capacity – and in some cases, desire – to advocate for systemic change (Wolch, 1990; see also Gilmore, 2007). While contracting services out to the voluntary sector can be beneficial because registered charities often have more localized knowledge and deeper connections to the communities that they serve, Rodriguez (2007) warns against the development of the non-profit industrial complex (NPIC), whereby even leftist social movements and the non-profit organizations that support them (see McCarthy & Zald, 1977) become institutionalized proxies for racist state control and repression. Indeed, Western shadow states often tend towards greater professionalization, bureaucratization, and alignment with state functions and goals (INCITE! Women of Color Against Violence, 2007; Wolch, 1990; see also Livingstone, 2013). In addition to providing some level of peace and stability, established voluntary sectors therefore tame the revolutionary zeal of protest, making public dissent “safe for capitalism” (Smith, 2007, p. 3; see also Livingstone, 2013).

Particularly as government austerity has pushed the voluntary sector to seek more donations from individuals, businesses, and grant-making foundations, formal philanthropy helps normalize the belief that unmet social reproductive needs are a private responsibility. According to Imagine Canada (2018), Canadian registered charities received approximately \$18.5 billion in donations during the 2014 tax year, with businesses contributing at least \$2.3 billion and individuals accounting for between \$9.6 to \$16.2 billion of that total. Based on available data between 2004 and 2013, the social causes that have consistently received the greatest number of donations also fulfill

primarily reproductive functions: health (48-57%), social services (39-43%), religion (31-38%) and hospitals (17-18%) (Imagine Canada, 2018).

The neo-liberal era has further transformed the notion and practice of charity by welcoming the incursion of market supremacist principles into traditionally non-profit models and spaces. Philanthrocapitalism (Bishop & Green, 2009), or the belief that humanitarian endeavours are best served by business acumen and even profit-seeking mechanisms, has been gaining traction in public discourse and social policy. In the for-profit arena, this has translated to businesses seeking profit by entering traditionally non-profit spaces or pursuing what is normally considered to be a social cause. Examples include the dominance of for-profit providers in both the micro-finance/micro-credit (Bateman et al., 2018) and medical crowdfunding industries (Kenworthy, 2019).

Meanwhile, many leaders in the Canadian charitable sector also show signs of buying into a philanthrocapitalist mindset as they lobby governments for greater latitude to earn income through business activities and to pursue a wider variety of causes that are currently not recognized as charitable under common law (Special Senate Committee on the Charitable Sector, 2019). At its heart, philanthrocapitalism, like privatization, is a promotion of market supremacy. The peak form of philanthrocapitalism is not that charities adopt business strategies to help people, but that businesses – like GoFundMe – unapologetically extract profit from social causes.

In summary, as an economic relation, a legal form, a moral concept, and social institution, “charity” is imbued with layers of meaning that are both patterned by and inform common-sense understandings of responsibility, equity, and the existing social order. Across all three registers of meaning, formal charity affirms values that are

congruent with capitalism, even as it is often celebrated as being capitalism's antithesis. As Livingstone (2013) argues, modern charity is better understood as a form of capitalism, rather than a social form that exists within capitalist societies. The close relationship between the third sector and the capitalist state, particularly in Canada (see Valverde, 1995), reflects a mutual dependency: the growth and development of Canadian charities is attributable to increased government welfare spending (Carmichael & Elson, 2022; Reckart, 2014), while social services delivered by voluntary organizations help cut costs for governments and temper widespread discontent (Eikenberry & Nickel, 2006; INCITE! Women of Color Against Violence, 2007; Livingstone, 2013; Roelofs, 1987).

At the heart of the charity relationship is a systemic imbalance of wealth and power, which is tacitly justified, normalized, and preserved through formal charitable activities: private donors are celebrated for their generosity while beneficiaries are socialized to feel as if they have personally failed or are defective. Through formal charity, resources and services that people require for daily and intergenerational reproduction are understood as privatized goods rather than citizen entitlements (even if they are partially or substantially funded by governments). Needs, in other words, are met through voluntary – and therefore, unreliable – gifts. The framing of those gifts as acts of benevolence makes it challenging for recipients to make claims to those resources; they can only express gratitude for what they are given (see Clarke, 1999; Zelizer, 2011). Thus, even as formal charity exhibits some aspects of collectivism – channeling the resources of multiple people to benefit a larger segment of the population – the practice is nevertheless a vehicle of privatization.

As demonstrated by this survey of three redistributive traditions – namely, money pools, family “begging” letters, and Western philanthropy – each exhibits a unique ethos, reflecting different understandings of inter-dependence, obligation, and reciprocity in society. An examination of these practices suggests that in as much as they are forms of material redistribution, they are also animated by symbolic exchanges of power, honour, and sympathy (Clark, 1999; Mauss, 2000; Zelizer, 2011; see also N. Christie, 2004) . In the next section, I turn to exploring the logic of GoFundMe by analyzing articles published by the company.

### **Examining the Logic of GoFundMe Medical Crowdfunding**

*“Now what I would like to show you is precisely that neo-liberalism is really something else. Whether it is of great significance or not, I don’t know, but assuredly it is something, and I would like to try to grasp it in its singularity.” – Foucault, 2008, p. 130.*

Precisely because we have a long history and wide range of redistributive traditions and systems that people turn to in times of financial need, it is easy to think of GoFundMe as simply a digitized incarnation of past or existing practices. However, I contend that social crowdfunding is not merely a web-based extension of asking for financial assistance from friends and family; it is – to borrow Foucault’s words quoted in the epigraph above – “something else,” with its own dynamics, logic, and ideas that are drawn from other practices and institutions. In this section, I examine texts published by GoFundMe on their website as a means to understand how promotional materials produced by the for-profit platform both reflect and strengthen specific underlying values. I analyze 19 samples of text drawn from GoFundMe’s extensive collection of resources aimed at (potential) crowdfunding campaign creators including, “how-to” guides and blog articles about crowdfunding (see Appendix C for full list). The texts

examined fall into three categories: 1) articles that define crowdfunding; 2) general crowdfunding tips and strategies that are applicable to medical crowdfunding; and 3) information and fundraising tips related to a specific health-related expense (e.g., “IVF Funding: Guide to Costs, Fundraising, and Treatments” [GoFundMe. 2021d].) Following Fairclough (2010), I analyze the texts across three dimensions. His approach considers discourse as:

- a discourse practice, involving the production, circulation, and interpretation of text
- a spoken or written piece of text, involving grammar, tone, sentence and paragraph structure, vocabulary, and voice
- a social practice, involving dynamics of power, hegemony

I propose that the discourse produced and circulated by GoFundMe helps us better understand the ethos that drives the platform, and by extension, the activity that takes place through it. While GoFundMe users also shape the practice (which is explored in Chapters Five and Six), this chapter focuses on what discourse produced by GoFundMe can reveal about its underlying ethos.

### ***Training Entrepreneurs: Promotional Communication and Instrumentalization***

*Sympathy has become big business – Clark, 1999, p. 125*

In *Misery and Company: Sympathy in Everyday Life*, Clark (1999) explores the ways in which sympathy – defined as “a cognitive, emotional, or physical reaching out to others (p. 8) – shapes social interactions, particularly in times of trouble. Clark (1999) introduces the concept of “sympathy entrepreneurs” which refers to individuals and

organizations that help define the social contours of sympathy, including when it is appropriate or due, how it should be displayed, and to whom it should be directed. Sympathy entrepreneurs span the non-profit to for-profit spectrum and may include registered charities, greeting card companies, florists, artists (Clark, 1999), and – as I propose – personal crowdfunding platforms including GoFundMe. In fact, I argue that GoFundMe plays a dual role in the enterprise of eliciting sympathy. As a business, one way that GoFundMe generates profit is through the translation of sympathy into monetary contributions made via its website. GoFundMe’s infrastructure directs potential contributors towards certain actions, primarily, sending a financial gift via the platform, sharing a campaign, or leaving a supportive comment for the beneficiary. The company also helps shape ideas of what occasions or circumstances warrant a crowdfunding campaign by offering users pre-defined fundraiser categories of fundraisers, including medical, memorial, animal, travel, and faith, amongst others. In addition to “brokering sympathy” (Clark, 1999) as a platform that hosts crowdfunding campaigns, GoFundMe also trains campaigners to be their own sympathy entrepreneurs. At the level of discourse practice, GoFundMe’s texts emulate the genre of educational materials (e.g., textbooks, manuals) that are directed at professional fundraisers for registered charities.

GoFundMe’s resources are often referred to as “guides” and offer strategies to attract potential “donors” to one’s crowdfunding campaign, including how to choose a “catchy” campaign title (GoFundMe, n.d.-e), unique hashtag (GoFundme, 2021g), and even how to write and circulate a press release to attract news media coverage (GoFundMe, n.d.-g).

The resources read like a digital textbook, complete with explanations of techniques,

references to research studies, and hyperlinked examples of GoFundMe crowdfunding campaigns that demonstrate the use of a given strategy.

The instructional tone of the texts gives readers the sense that they can indeed learn and apply this knowledge – which is normally reserved for professional fundraisers, marketers, and publicists – to meet their own social reproductive needs. An article entitled “Medical Fundraising Tips: Financial Support When You Need It” (GoFundMe, n.d.-b), for example, teaches readers how to choose a more compelling campaign title, explaining that “GoFundMe titles for medical fundraisers should be specific. For example, ‘Help Martha Fight Cancer’ is more engaging than ‘Martha’s fundraiser’” (GoFundMe, n.d.-b, Make your title count section, para. 1). The same article also guides readers away from common blunders: “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” (GoFundMe, n.d.-b, Use your fundraiser to tell your story section, para. 1).

In other articles, GoFundMe teaches readers to re-orient their interpersonal communications and interactions with peers – which, GoFundMe emphasizes must always be truthful and genuine to be effective – to nevertheless be aimed at extracting value. For instance, GoFundMe advises readers to not only add as many “friends” on Facebook as possible by searching for friends of one’s spouse, friends of one’s children and their parents, current and former classmates and colleagues etc. to increase visibility for their campaign (GoFundMe, n.d.-f, Getting Started on Facebook section); but the company also instructs readers to “[e]ngage with their posts as much as you do your own. ‘Like’ their photos and respond to their posts in a friendly and social way” (GoFundMe,

n.d.-f, Not Engaging with Others section) in order to encourage reciprocation. Overall, GoFundMe's "how to" articles encourage users to adopt a promotional and entrepreneurial mindset in thinking about care, so that they become marketers for their own daily and intergenerational needs (see also Clark, 1999).

As a social practice, these prescribed actions are consistent with what Fairclough (2010, drawing on Wernick, 1991) describes as "the colonisation of discourse by promotion," whereby everyday acts of communication are increasingly instrumentalized. Fairclough (2010) locates this discursive shift within the broader context of the neo-liberal era in which inter-personal relationships (and their attendant obligations) are no longer strongly bound by traditions of kinship, community membership, feudal arrangements, etc. As such, there is a heightened demand for dialogic negotiation of these relationships, and by extension, a need for more training in communication skills (Fairclough, 2010). In the context of medical crowdfunding, GoFundMe provides precisely this communicative training to people who are creating crowdfunding campaigns on its website.

One discursive technique that Fairclough identifies in instrumentalized communications is synthetic personalization (Fairclough, 1989a) – an attempt to simulate informal, often friendly, person-to-person conversation in communications directed at mass audiences. Through the use of techniques such as employing second-person singular pronouns (e.g., you, your) throughout the texts as well as informal vocabulary, GoFundMe mixes educational instruction with a conversational style of writing that reads as if the company is offering advice directly to the reader as an individual. GoFundMe pushes synthetic personalization even further in adopting the voice of a knowledgeable

peer who is helping readers navigate complicated health challenges. In a growing number of articles on its website that are dedicated to specific health conditions such as visual impairment or infertility, GoFundMe offers information and advice about treatment and funding options that are not limited to medical crowdfunding. In articles such as “IVF Funding: Guide to Costs, Fundraising, and Treatments” (GoFundMe, 2021d), “How Fundraising for Transplant Surgery Can Help Cut Costs” (GoFundMe, 2021e), and “How to Get a Service Dog: Unleash Your Independence” (GoFundMe, 2021f), GoFundMe explains, for example, different types of service dogs, fertility treatments, as well as public and private sources of assistance that might be available to readers. Projecting the persona of a friendly expert in this way helps draw attention away from GoFundMe’s primary role as a profit-driven intermediary.

The colonization of discourse by promotion can be said, in fact, to take place at two levels in these examples. At the first and more explicit level, GoFundMe provides step-by-step instructions to readers on how to best market their needs to others. From content creation strategies (e.g., include photos and videos, tell a compelling story) to outreach techniques (e.g., thank donors to increase retention, send personalized emails), GoFundMe orients readers towards adopting a promotional ethos in personal communications. Promotional culture is embedded into “common sense” at a second level when GoFundMe models this very behaviour in its communication to potential crowdfunding campaigners. GoFundMe’s staff writers may, in fact, genuinely want to help readers locate useful and accurate information about their medical treatment options; however, the purpose of each article is always to offer medical crowdfunding as a possible financing solution. In the same way that GoFundMe instructs readers to

regularly interact with Facebook “friends” posts “to show...you care about them” (GoFundMe, n.d.-b, Not Engaging with Others section), GoFundMe spends time and money providing readers with non-crowdfunding resources to demonstrate how instrumentalized communication can nevertheless feel personable and sincere. The penetration of promotional culture into discursive practices is thus doubly reinforced: GoFundMe uses promotional and synthetically personalized discourse to teach readers how to produce and circulate their own discourse of the same nature.

***Technical Optimization: Neo-liberal Management of Everyday Life***

A central feature of neo-liberalism is the constant drive for optimization – particularly, of the self – through various technologies and techniques (Ong, 2006; Foucault, 2008). Neo-liberal ideology understands an individual’s financial circumstance as a function of personal behaviour, and therefore asserts that it is within a person’s power to improve their economic standing (Buckland & Spotton Visano, 2022). Accordingly, throughout GoFundMe’s resources, there is a consistent and heavy emphasis on strategies and tactics that campaigners can use to increase their chances of fundraising success. For example, the article “The Beginner’s Guide to Viral Fundraising” (GoFundMe, 2021b) lists the optimal days and times to post on specific social media channels. The instructional nature of GoFundMe’s resources helps position as a subject matter expert, particularly when it cites behavioural data collected from its own platform, such as: “Fundraiser descriptions of 400 words or more receive more donations” (GoFundMe, n.d.-c, Tell a Unique Story That’s Easy to Skim section) or “Fundraisers with five or more photos raise more than those with fewer” (GoFundMe, n.d.-c, Upload High-Quality Photos and Videos section). The generous use of

probabilities and statistics – for instance, “every time you share your fundraiser, you’ll bring in an average of \$43 in donations” (GoFundMe, n.d.-d., Share and Update section) – in these guides not only reconfigures communicative acts towards extractive ends, but also turns them into mechanisms of optimization. As Ong (2006) explains, “neo-liberal logic recasts politics as a problematization of life, away from social issues to technical management of social life. This calculation transforms and gives meaning to life (p. 178).” The discourse produced and circulated by GoFundMe through its website is not designed to bring attention to the injustices of health care systems nor of economic inequality; its purpose is to generate profit for the company by encouraging readers to take steps that can increase “donations.” In so doing, readers are also being trained to take individualized actions – and therefore responsibility – to meet care needs.

Persuading readers to adopt the prescribed steps to optimize GoFundMe’s earning potential requires that users feel like these techniques are effective and easy to learn and execute. To that end, GoFundMe structures many of its articles – such as “Top 6 Fundraiser Title Tips that Inspire Donations” (GoFundMe, n.d.-e) and “How to Write Your GoFundMe Fundraiser Story – 12 Helpful Tips” (GoFundMe, 2022b) in the trendy “listicle” format which breaks information down into easily digestible blocks of content. Used in conjunction with instructional content, this format conveys the (false) sense that the prescribed techniques are achievable by non-professionals and will produce positive results. At times, GoFundMe also suggests that it is sharing insider knowledge with its readers, for example, by revealing “the 4 secrets to a winning fundraiser title” (GoFundMe, n.d.-e, para. 2).

As compelling as these strategies seem, however, GoFundMe’s tips paint an unrealistic picture of the crowdfunding landscape. In a study of 1,091 Canadian GoFundMe medical campaigns launched between February 2018 and March 2019, only 38% reached their fundraising target, and outcomes were less favourable when the beneficiary appeared in photos to be a woman (raised 10.9% less per campaign than men) or Black (raised 15.8% less per campaign than non-Black beneficiaries) (Saleh et al., 2020). A 2018 study found that only 10% of US-based medical campaigns studied reached their goal (Kenworthy, 2018), while a smaller study in the US suggests that campaigns to fund trans surgeries fare worse than other medical crowdfunding campaigns (Barcelos, 2019). In a similar vein, a Canadian study of GoFundMe campaigns for organ transplant patients found that campaigns for liver transplants were more likely to reach their fundraising goal and received a greater number of donations than those for kidney transplants (Pol et al., 2019). Although the researchers noted that kidney transplant campaigns had higher fundraiser goals on average, the discrepancy in performance is otherwise unexplained and more importantly, raises ethical concerns about uneven outcomes (Pol et al., 2019). Meanwhile, for all of the emphasis that GoFundMe puts on statistics related to strategies, there is a conspicuous absence of data related to overall crowdfunding outcomes published by the company – information that the GoFundMe undoubtedly monitors and uses to optimize its own performance and profits.

In so far as creating and managing medical crowdfunding campaigns requires a certain level of technical literacy and promotional skills (Berliner & Kenworthy, 2017), Kenworthy et al. (2020) find that “outcomes are only minimally associated with campaign characteristics under users’ control, such as photos, videos and updates” (p. 1).

Nevertheless, GoFundMe gives guidance to the contrary, insisting that, for example, “[o]ne of the key ways you can raise more funds is by giving your fundraiser a compelling title” (GoFundMe, n.d.-e; para. 1). GoFundMe’s guides regularly hint at the possibility that amateur campaigners might achieve social media virality with articles such as “The Beginner’s Guide to Viral Fundraising” (GoFundMe, 2021b) which concludes, at the end of what GoFundMe estimates to be a mere six-minute read, “now that you’re equipped to design a viral fundraiser, start your fundraiser today” (GoFundMe, 2021b, Take Advantage of Viral Fundraising section” even when those prescribed outcomes are not based in evidence. Instead, researchers consistently find that crowdfunding outcomes are overdetermined by other factors, including the beneficiary’s (perceived) race (Igra, 2021; Kenworthy et al., 2020), gender (Kenworthy et al., 2020; Saleh et al., 2020), and neighbourhood of residence (van Duynhoven et al., 2019).

Although GoFundMe’s profit-earning potential is clearly tied to the fundraising performance of its users, it would also be a mistake to conclude that GoFundMe includes optimization strategies solely with profit in mind. Rather, in keeping with CDA’s recognition of a dialectical relationship between discourse and the social world, the emphasis that GoFundMe puts on technical optimization reflects and fortifies the broader neo-liberal worldview. Under neo-liberalism, technical optimization is not only a means; it is also an end. That is, the neo-liberal subject not only believes that there are techniques to optimize all aspects of life but they also have a continuous desire for self-improvement. In that sense, the circulation of strategies of improvement is only one component of the neo-liberal mindset; the incorporation of technical optimization into

common sense also requires training. In this case, GoFundMe’s resources contribute to both of these functions.

### *Preserving a Charitable Ethos*

While the advent of GoFundMe has helped reduce some of the stigma around asking for financial support, the company has always framed crowdfunding as a form of charity, regardless of whether a campaign’s beneficiary is a registered charitable organization, an individual, or a private business. For example, monetary contributions through the website are labelled as “donations” and those who contribute money are referred to as “donors” in all of GoFundMe’s literature. This choice of vocabulary partly reflects the need to differentiate between types of online crowdfunding – some of which reward contributors or “backers” with equity or consumer products (and are therefore not considered to be donation-based) – but we should also consider how this discursive framing might import some of the meanings and beliefs associated with “charity” (as discussed in the previous section) to the domain of personal medical crowdfunding.

As described earlier, many of the techniques, knowledge, and strategies found in GoFundMe’s resources are derived from the field of professional charity fundraising, covering topics such as “research[ing] the local media landscape” (GoFundMe, n.d.-g, heading two) to build a contact list, identifying the ‘likes,’ ‘dislikes,’ and values of a target ‘audience’ to tailor one’s message, and knowing the optimal days and times to post on each major social media channel (GoFundMe, 2021a). GoFundMe even suggests to amateur campaigners – who presumably do not have a marketing budget in the same way that a fundraising professional does – to nevertheless invest in paid services and activities such as running a direct mail campaign (GoFundMe, n.d.-i); using a press release service

(GoFundMe, n.d.-c), which is said to give campaigners “an excellent chance of being picked up by both local and national press” (GoFundMe, n.d.-c, Get press coverage section); creating “swag” such as custom-printed t-shirts or homemade jewelry, or installing engraved bricks or plaques to honour contributors publicly (GoFundMe, 2021b). In addition to learning industry techniques, GoFundMe also instructs readers to practice and hone these skills – as professionals would – by soliciting feedback from friends and family on, for example, a proposed fundraiser title or by testing out “your in-person pitch or presentation with friends and family first. Repeat it until you feel comfortable and your ‘audience’ is convinced that others will make donations” (GoFundMe, 2021i, section 1). In casting readers in the role of charity fundraiser/marketer/publicist, GoFundMe’s discourse locate medical crowdfunding firmly in the realm of Western charity.

While recognizing that personal connection and social bonds lie at the heart of contributor-beneficiary relationship, GoFundMe’s discourse explicitly presents that relation as an object that can be managed or manipulated through measurable techniques. Articles such as “Use Psychology to Boost Your Fundraiser” (GoFundMe, 2020) extract findings from academic research studies on charitable donor behaviour and encourage readers to utilize this knowledge to elicit desired behaviours from their “audience.” GoFundMe even redefines “social media” – normally considered by consumers to be a tool of self-expression and of social connection – as being “all about engaging with others and building a connection that *encourages people to take action*” (GoFundMe, n.d.-f, section 3; emphasis mine). GoFundMe’s guides stress the importance of thanking donors and showing gratitude but further mobilize it for instrumental ends: “Thanking

your donors is key to keeping your crowdfunding community engaged and dedicated to your cause. Sometimes it can even inspire repeat donations” (GoFundMe, 2021b, para. 1). In these examples, GoFundMe invites readers to adopt an instrumental view of social media technology as well as of their social relations. This logic of technical optimization is at the basis of an informational society which extracts economic value from behavioural data (see, for example, Zuboff, 2019).

In examining GoFundMe’s discourse as a social practice, it is worth considering how GoFundMe and the development of personal crowdfunding in general have shifted the meaning of what constitutes charitable activity. In GoFundMe’s discourse, not only can amateurs empower themselves to perform the work normally reserved for charity professionals, but campaigners are also encouraged to apply these techniques to meet the needs of a named individual rather than, in the case of formal charity fundraising, for a larger, often disadvantaged segment of the population. While visitors to GoFundMe’s website can browse through different categories of fundraisers – including “medical,” “travel,” “emergencies” and “memorial” – many of the categories comprise campaigns that benefit individuals, businesses, non-profits, community groups, and registered charities alike. By depicting these different types of campaigns side-by-side, GoFundMe’s algorithms draw an equivalence between for-profit, non-profit, personal, and community requests, blurring the line between public and private benefit. Interestingly, this understanding of “charity” is closer to that which was prevalent in the age of non-familial “begging” letters than in today’s highly professionalized landscape of registered charities.

More significantly, universally applying the language and logic of charity to all campaigns hosted by GoFundMe in this way erases a long-standing and defining characteristic of philanthropy (formal or informal) – a concern for systemically marginalized populations. This is not to suggest that GoFundMe campaigns for an individual is illegitimate nor unworthy – in today’s climate of economic austerity, rising labour precarity (on Ontario, Canada, the UK, Australia and the US, see Vosko & the Closing the Gap Research Group, 2020), unaffordable housing (see Doran et al., 2022 for intersection of health and housing crises in Canada), and retrenchment of welfare programs, it is not surprising that many low- and middle-income earners in Canada need financial support when dealing with health-related expenses. However, pre-GoFundMe, it would have been unusual to refer to the act of giving money to a family member experiencing illness as “making a donation.” Thus, equating individuated financial requests with fundraising dedicated to supporting disadvantaged segments of the population represents an important shift in the meaning of “charity” as a practice.

In framing medical crowdfunding as a form of charity, GoFundMe contributes to a discourse that also imports and preserves some of the common-sense principles that guide formal charity. Importantly, it is clear in GoFundMe’s guides that the company is teaching readers how to *ask* for help, not how to make claims nor demands. In turn, there is an implicit understanding that beneficiaries should be grateful towards their “donors.” Valverde (1995) makes a similar observation in her analysis of Canada’s public/private social provisioning in the 1800s: “[b]ecause [poor] relief usually came through philanthropic organizations, even if some or (in the cases of Houses of Industry) most of the funds were public, the poor were put in the position of having to be grateful for aid

received, at least outwardly” (p. 41). While GoFundMe campaign beneficiaries tend to be genuinely thankful (as discussed in Chapters Five and Six) and have a strong desire to show their gratitude, it is important to recognize that these behaviours and expectations are largely shaped by the conventions of Western philanthropy. Moreover, when GoFundMe addresses potential contributors (“donors”), emphasis is placed on the “donor’s” freedom to choose. In an article that introduces the concept of crowdfunding, GoFundMe explains to readers, “With crowdfunding, you can help a friend or help an entire community. You can...fulfill a student’s dream of attending college – and so much more” (GoFundMe, n.d.-d, para 1) which puts the power in the hands of the contributor in a way that reinforces the hierarchical nature of the “donor”/beneficiary relationship that the basis of “charity.”

As a fairly new technology and practice (founded in 2010), GoFundMe medical crowdfunding has nevertheless established a distinct ethos and discourse around care. Discourse analysis of GoFundMe-produced texts can only tell us one side of the story – recall that CDA takes into account negotiated and oppositional interpretations and receptions of discourse (see Chapters Five and Six). Moreover, not all campaign creators choose or know to access these resources. Nevertheless, this type of analysis can reveal the intended ethos of GoFundMe as the architect and owner of the technological platform – principles that further inform its structure, including its proprietary algorithms that determine the visibility (or lack thereof) of each campaign, the functions that are available to users, and the types of campaigns that are pitched to media via their press team. In drawing an equivalence between individual crowdfunding and charity (customarily understood to benefit a larger, marginalized segment of the population),

GoFundMe medical crowdfunding preserves many of the underlying values of formal Western philanthropy, including privatization, individualism, and the stigmatization of adult dependency.

## **Conclusion**

While in the Introduction to this dissertation, I posed Brown's (2005) question of "What does neo-liberalism dream of?", this chapter has sought to answer this question by looking more closely at different actions and practices that humans have developed in response to an all-too-common nightmare – extraordinary costs associated with illness, injury, and medical emergencies. Although far from being an exhaustive or even representative sample of responses to this problem across space or time, the preceding analysis of informal money pools, familial "begging" letters, Western philanthropy, and personal medical crowdfunding nevertheless demonstrates that social practices reflect and shape beliefs and values – whether spoken, unspoken, or purposely disguised (see section on "begging letters"). Each practice, in other words, is guided by and embodies a distinct ethos.

A survey of the scholarly literature on these four redistributive models reveals that each one contains common-sense ideas and attitudes about (in)dependency, public and private responsibility, and justice. The central focus of this chapter has been personal medical crowdfunding, which I argue borrows and reproduces many of the core tenets of formal Western philanthropy. Through a Critical Discourse Analysis of some of GoFundMe's extensive collection of resources and "how to" articles, I demonstrate the ways in which GoFundMe encourages potential campaigners to adopt an entrepreneurial and

promotional mentality towards addressing gaps in social reproduction – one that emphasizes individualism and optimization techniques.

GoFundMe’s representation of the perennial problem (unmet social reproductive needs) and its prescribed solution (personal medical crowdfunding) is consistent with neo-liberal logic. As Brown (2005) explains, under neo-liberalism,

“[n]ot only is the human being configured exhaustively as *homo oeconomicus*, but all dimensions of human life are cast in terms of a market rationality.... [It results in] the production of all human and institutional action as rational entrepreneurial action, conducted according to a calculus of utility, benefit, or satisfaction against a microeconomic grid of scarcity, supply and demand, and moral value-neutrality. Neo-liberalism does not simply assume that all aspects of social, cultural, and political life can be reduced to such a calculus; rather, it develops institutional practices and rewards for enacting this vision” (p. 40).

Without denying the generosity and goodwill that is fostered through GoFundMe medical crowdfunding, it is nevertheless a technology that cultivates and purportedly rewards an entrepreneurial ethic. The infusion of a market rationality in the giving and receiving of care is largely obscured by the crowd-sourced and voluntary structure of medical crowdfunding – indeed, there is a strong sense of communitarianism when a large number of people voluntarily contribute funds towards the care of another person. However, when juxtaposed against a practice such as informal money pools – which is a conscious and explicit act of solidarity and resistance against unjust institutions – the

often unconsciously capitalistic nature of personal medical crowdfunding comes into clearer view.

Both medical crowdfunding and philanthropy are vehicles of privatization. They are presented (and often lauded) as technological fixes to gaps in care, which – to borrow Eikenberry and Nickel’s (2006) words – “disguises social problems as administrative rather than systemic” (p.17), as if the problem stems from poor management or execution. But what figures like "10,000 campaigns are started every day [on GoFundMe]" (GoFundMe, n.d.-h) and that only 30 to 38% of 3,396 GoFundMe medical campaigns met their fundraising goal across Canada, the UK, and US (Saleh et al., 2020) actually reveal is that the problem was never the lack of technological solution but that we live in a system that robs workers of adequate wages to sustain social reproduction.

## Chapter 5. “(Never) Asking for Help:” Discourses of Needs and Deservingness in GoFundMe Medical Crowdfunding

*Care, I mean...the fact that it takes one whole person to care for a whole other person – sometimes it takes more – it’s pretty remarkable. – Alicia, beneficiary*

As a first-time parent, Alicia thinks back to the time when her partner was unexpectedly hospitalized for two-and-a-half months with an infection:

I can’t even imagine if we had had kids at the time. You know, who’s providing the other care work that needs to be done? That’s not covered by the government so that’s why you end up needing extra money. Getting sick is expensive. Disability is expensive.

This reality is what drives thousands of Canadians to start medical crowdfunding campaigns for themselves or others. In trying to raise funds to cover financial and service gaps in care, GoFundMe campaign creators contribute to a social discourse of needs that circulates amongst friends, family, and occasionally news media audiences. Discourses, as Bischooping and Gazso (2016) explain, “concurrently constrain or enable individual subjectivities; they can be deeply immersed in knowledge production and infused with relations of power” (p. 587). This chapter aims to add to feminist political economy scholarship by exploring GoFundMe’s crowdfunding environment as a space of needs talk related to health.

As a form of needs talk, medical crowdfunding discourses reveal not only the gaps in and between Canada’s occupational and social welfare programs (Cameron, 1995) but also offer a window into common-sense ideas about who/what is responsible for filling the gaps. In their genealogical inquiry into the meaning of the term

“dependency” in relation to the U.S welfare state, Fraser and Gordon (1994) argue that new understandings of what it means to be “dependent” have developed and circulated with industrialization as well as late capitalism. Specifically, they trace the emergence of a cultural narrative of “good dependencies” versus “bad dependencies” – a dichotomy which is then mapped on to assessments of who is deserving of state-funded assistance and/or private charity, and who is not (Fraser & Gordon, 1994; see also Fraser & Gordon, 1992). Similarly, since crowdfunding is premised on voluntary gifts of money, narratives of deservingness figure prominently in crowdfunding campaigns (see, for example, Berliner & Kenworthy, 2017; Kenworthy, 2024; Lukk et al., 2018; Snyder et al., 2017). By examining medical crowdfunding discourses found in publicly-viewable campaigns and through interviews with participants, I argue that the industrial and post-industrial conceptions of “good/bad dependencies” (Fraser & Gordon, 1994) are strongly reflected and inflected in crowdfunding needs talk. This study thus brings together Fraser’s (1989a, 1989b) needs talk and Fraser & Gordon’s (1994) “good/bad dependencies” to analyze how medical crowdfunding discourses produce and reproduce gendered ideas about individual deservingness, responsibility, and care.

This chapter unfolds in three sections. First, I outline Fraser’s (1989a, 1989b) needs talk and Fraser and Gordon’s (1994) “good/bad dependencies” theories, providing a brief contextualization of medical crowdfunding as a site of analysis using this dual framework. Second, drawing from 19 in-depth participant interviews and 41 publicly-accessible GoFundMe medical campaigns in Canada (see Chapter Three), I explore how needs are articulated in medical crowdfunding discourses, discussing both what is included and left out of personal fundraising appeals on GoFundMe. Finally, the third

section shifts attention to how needs claims are justified – and more specifically, how the campaign beneficiary’s worthiness is discursively established – in crowdfunding spaces.

## **5.1. Understanding Social Discourses on Needs and Care**

### ***Crowdfunding Discourses as Needs Talk***

Because needs talk is so prominent in political culture in welfare states, Fraser (1989a, 1989b) proposes that it is necessary to understand how needs are constructed, framed, and negotiated and the power dynamics that inevitably shape those moments (see also Langlois, 2011). Fraser’s framework does not deny the importance of the content of needs discourses (i.e. the needs and their fulfillment); instead, it recognizes and brings attention to the politics and complexity of needs talk as a series of overlapping communicative processes (Fraser, 1989a, 1989b). Meanwhile, my analysis of crowdfunding discourses that follows highlights both the form of the needs talk and the needs themselves, in part because – as research participants attest – the health-related financial needs of Canadians are poorly understood by people who have never faced them. Accordingly, the purpose of this chapter is two-fold: to give voice to people who have first-hand experience of where personal and social safety nets fall short in times of health-related need and to improve understandings of how discourses of need are constructed within the crowdfunding environment.

Specifically, Fraser (1989a, 1989b) describes three stages or “moments of struggle” that often appear in needs talk. One stage is to establish the legitimacy of a need as an “official-political”<sup>24</sup> matter rather than strictly an individual or market concern –

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<sup>24</sup> Fraser uses the term “official-political” to designate scenarios in which government institutions are directly involved in processes (such as debates, service delivery, funding etc.) Meanwhile, she uses

and by extension, responsibility for fulfilling those needs (Fraser, 1989a, 1989b). Needs that are relegated to personal (household) or market domains, and therefore effectively marginalized from public debate, are described as being “enclaved” or contained to only a small segment of the population (Fraser, 1989a, 1989b). We therefore might consider GoFundMe’s medical crowdfunding space to be a site of enclaved needs discourses – personal medical crowdfunding campaigns are individuated appeals for private funding directed at friends, family, and community networks, not governments. Even though concerns raised in personal GoFundMe medical campaigns may occasionally spill into public discourse via news media or advocacy efforts and may (rarely) result in policy changes, by design, the majority of crowdfunding needs talk – and most importantly, the expectation of funding – remains firmly contained within personal networks.

As is the case with other social needs that are deemed to be personal or private, crowdfunding needs talk demonstrates that it is not only top-down pressure (e.g., from governments) that keeps needs discourses contained to the private sphere but also the needs talk participants who proliferate and normalize discourses that locate needs fulfillment as primarily a private responsibility. In fact, Fraser (1989a, 1989b) argues that it is the economic and domestic/personal institutions in society that depoliticize social needs in the sense that they make reprivatization discourses possible. In the case of medical crowdfunding, GoFundMe is the primary economic institution with a profit-driven interest in privatizing needs discourses. Mainstream news media institutions in Canada and the US, which have been shown to represent personal crowdfunding

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“political/politicized/discursive-political” in the more general sense of something that is contested across different social groups. See Fraser (1989a, 1989b) for her more detailed explanations.

campaigns in a predominantly positive or neutral light (Murdoch et al., 2019)<sup>25</sup>, may also inadvertently contribute to the depoliticization of needs talk by sharing links to GoFundMe campaigns in human interest stories, effectively offering up personal fundraising as an unproblematic “solution” to the individual’s plight.

A second moment of struggle in the needs talk process surrounds the interpretation of what those needs are, who needs them, and what is necessary to satisfy them (Fraser, 1989a, 1989b). The popularity of GoFundMe, as well as of similar personal fundraising platforms, as a vehicle to address health-related financial shortfalls demonstrates that there is a mismatch between the interpretation of needs by policymakers and by crowdfunding beneficiaries. For example, and as discussed in further detail in Chapter Six, many research participants expressed frustration at the narrow definition of “healthcare” in the Canadian system. This is not surprising given that contestations over needs, and especially what is required to satisfy those needs, is “precisely the point [of] need claims” (Fraser, 1989a, p. 293) as groups, including governments, struggle for the power to define and re-define needs according to their own interests.

When it comes to interpreting and defining needs, Fraser (1989a, 1989b) observes that needs claims are commonly structured as “A needs X in order to Y.” statements or justifications. For example, in one of the GoFundMe campaigns I observed entitled

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<sup>25</sup> In a study of Canadian English-language mainstream newspapers in Canada and the US, Murdoch et al. (2019) found that in stories referencing illness-related crowdfunding, 93.75% of the articles portrayed medical crowdfunding in general in a positive light and that 83% of the articles indicated to readers where they could donate to a specific medical crowdfunding campaign to support the person(s) at the centre of the article. Without making claims about the causal effect of such portrayals, the researchers suggest that the news articles nevertheless lend legitimacy to crowdfunding as a source of (private) funding for illness-related care (Murdoch et al., 2019).



preferred form of support. In contrast, government provisioning may take the form of money given directly to the beneficiary (e.g., social assistance, disability benefits) or paid to providers (e.g., for hospital bills, childcare fee subsidies), or services (e.g., shelters, public schools). Registered charities today mostly provide services and goods because in the early 19th century US, cutbacks to outdoor poverty relief under the Poor Laws and the attendant rise in private charity translated to a decline in the availability of cash assistance for the people who needed it most (Abramovitz, 1996). But in fact, there is no regulation that prohibits charitable organizations from giving money directly to beneficiaries in Canada. However, it is not widely practiced in this country even though cash-based support allows greater flexibility and aligns with the recipient’s interpretation of what they require in that moment. The current tendency in the charitable sector to avoid distributing cash to beneficiaries thus might partly reflect, and in turn, affirm, the social meanings and rules that are attached to “charity money” as a “special money” (Zelizer, 2011).

**Table 3**

**Moments of Struggle<sup>26</sup> in Nancy Fraser’s “Needs Talk” Model**

<b>Moment</b>	<b>Struggle</b>
Legitimacy	to establish specific need(s) as a matter of concern/interest to governments
Interpretation	for the authority to define the need(s) of a specific social group and what is required to fulfill the need(s)
Provision	to secure access/fulfillment of defined need(s) from government institutions

<sup>26</sup> As Fraser (1989a; 1989b) emphasizes, it is analytically useful to delineate the moments of struggle but in actual practice, the processes generally overlap.

### *“Good/Bad Dependencies” in Crowdfunding Discourses*

Fraser and Gordon (1994) identify the term “dependency” as a central talking point of the U.S. welfare state – a keyword that reverberates through policy decisions, political debates, and public opinion around social assistance programs. By tracing the evolution of the denotations and connotations of “dependency” across multiple registers of meaning (socio-legal, economic, moral), the authors argue that “dependency” undergoes major semantic shifts that correspond to the transitions between pre-industrial, industrial, and post-industrial stages of capitalism (Fraser & Gordon, 1994; see discussion in Chapter Four).

With feudalism as the dominant social order in pre-industrial Western Europe, formal subordination and their attendant dependencies were at the foundation of everyday life (Fraser & Gordon, 1994). Peasants, for instance, laboured for their lord, and the lord provided land and physical protection to the peasants and their family. Industrialization and the struggle for civil rights (for white men) brought about a change in what it meant to be “in/dependent” (Fraser & Gordon, 1994). In fact, industrial/post-industrial “independence” denotes the opposite of what it once did – as Fraser and Gordon (1994) explain, “independence” in the 18th century was attributed to land-owning classes who did not have to work for others to sustain themselves, whereas today, selling one’s labour as a commodity is what makes an individual “independent” of others. This re-invented notion of “independence” gives rise to a dichotomy of “good” versus “bad” dependencies, in which earning wages to provide for one’s family is honourable while needing financial help from others, especially as an adult, is associated with moral failure or deviancy (see also Abramovitz, 1996; Gordon, 1994; Piven & Cloward, 1972;

Valverde, 1995), inherent “weakness” (e.g., addiction; being a woman, child, or person of colour) (see also N. Christie, 2004; Gordon, 1994 for women’s dependence) or “defects” (e.g., disabilities, mental illness) (Fraser & Gordon, 1994).

In Western nations, adherence to the moral barometer of “good/bad dependencies” is readily observable in many historical and contemporary discourses around welfare recipients (see, for example, Gordon, 1994; Gazso et al., 2020; Little, 1998), as well as in the design of the social programs themselves which are often structured to discourage “welfare dependency” (i.e. “a bad dependency”) through features such as residual assistance levels, strict eligibility criteria, and “workfare” requirements (see, for example, Gordon, 1994 for US “mother’s aid” programs; Piven & Cloward, 1972 for US poor relief programs; Valverde, 1995 for historical Canadian welfare approaches; Vosko, 2000 for welfare-to-work programs in Ontario). Thus, as Sapiro (1990) points out, welfare programs have always strongly implicated and encouraged private provisioning (for Canada, see Valverde, 1995), such as through family (see, for example, N. Christie, 2004), community, and charities, as a first resort. In that sense, and as discussed in Chapter Four, online personal crowdfunding should be understood as a practice that sits along a historical continuum of systems that attempt to redistribute resources, often as an alternative to welfare state provisioning.

Table 4

Nancy Fraser’s and Linda Gordon’s Genealogy of “Dependency” Model

Stage	Dominant Meanings of “Dependency”	“Good/Bad Dependencies”
Pre-industrial	A commonplace relation of subordination formalized in social hierarchies – e.g., feudalism	Because most people were economically and legally dependent on others, dependency did not carry a negative connotation, especially not for individuals.
Industrial	Selling one’s labour for wages becomes equated with (economic) independence, and is a prized, character trait. The idealization of the white wage-earning man cements the devaluing of social reproductive labour – and by extension, the women who predominantly perform it.	<p><b>“Good”:</b> Racial and gender subordination are preserved through certain dependencies that are deemed “natural” – e.g., women and children’s dependency on male breadwinner; Black enslavement, colonization.</p> <p><b>“Bad”:</b> receiving private charity and/or government social assistance, as caricatured in the figures of the “pauper,” the colonized “native,” and the “slave.” The policing, exploitation, and subordination of these figures is justified by framing their forced dependency as a sign of their innate inferiority.</p>
Post-industrial	Adult dependency is understood as an individual condition – one that is universally “avoidable” through hard work.	All adult dependencies are stigmatized as individual failures.

In the next section, I explore the responses of interview participants as well as text found in medical GoFundMe campaigns as discourses about needs that reflect Fraser’s (1989a; 1989b) three overlapping moments of struggles and Fraser and Gordon’s (1994) “good/bad dependencies” theory. Since the needs talk framework aims to understand how needs claims are made (and contested) primarily in the official-political arena, Fraser’s (1989a, 1989b) theory does not apply as neatly to analyzing crowdfunding discourses

since personal fundraising is fundamentally a vehicle of privatization. However, if we understand crowdfunding to be a site of discourses of depoliticization/privatization, then it is useful to analyze how crowdfunding discourses might function as a precursor or barrier to needs talk that elevates claims to the official-political sphere. By focusing our attention on how struggles for the legitimacy, interpretation, and provision of needs claims also play out in privatization discourses, we gain a deeper perspective of the broader discursive activity that takes place around health-related needs in Canada.

## **Discourses of Needs: The Struggle to Define Needs**

### *Unknown Needs*

*Interviewer: What would you say to someone who says, “Well, Canada has universal healthcare. Why would you even need to start a GoFundMe?”*

*Kaleen (beneficiary): “I would say that they need to lose a limb and tell me that our healthcare is universal. Because it is far from universal.”*

Even though crowdfunding beneficiary Kaleen, who had to have both legs amputated after an accident, conflates universal coverage with comprehensive coverage<sup>27</sup> in her response quoted above, her point is well-taken: a common refrain when I spoke to campaign beneficiaries is that most people are unaware of the gaps in health and welfare provisioning unless and until they, or someone close to them, has experienced the same

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<sup>27</sup> Universality and comprehensiveness are two of the five principles that govern Canada’s Medicare system. Under the Canada Health Act, “universality” means that “the provincial and territorial plans must cover all residents (Government of Canada, n.d.-c, Universality section), and “comprehensiveness” means that:

The provincial and territorial plans must insure all medically necessary services provided by: hospitals; physicians; and dentists, when the service must be performed in a hospital.

Medically necessary services are not defined in the Canada Health Act. The provincial and territorial health care insurance plans consult with their respective physician colleges or groups. Together, they decide which services are medically necessary for health care insurance purposes.

If a service is considered medically necessary, the full cost must be covered by the public health care insurance plan (Government of Canada, n.d.-c. Universality section).

struggle. Particularly in a country which is often praised and admired for its universal public healthcare system Medicare, one of the major functions of medical crowdfunding discourses is to establish and bring awareness to the beneficiary's financial needs that are not covered through state provisioning.

Many campaign beneficiaries themselves felt frustrated by not only the insufficiency of material support from governments but also by the lack of informational support. Beneficiaries often did not know what to expect in terms of their upcoming financial needs nor where to seek public or charity assistance. While it is common for crowdfunding beneficiaries to rely on a combination of public and private sources of funding/services to cover care gaps, many find that navigating the various programs is itself a source of emotional and mental strain. Beneficiary Shirley explains to me that in the early days of her son's hospitalization, she was too stressed to search for registered charities that might offer her family some financial relief: "Your brain is so frazzled, you just don't know where to start so I didn't do anything like that." It was only after her son was diagnosed that she was able to seek out charitable services for families with sick kids. Meanwhile, even after almost a decade of living with a cognitive disability caused by a hit-and-run collision, beneficiary Stephanie still is not certain if there are free services for people in her situation: "If you know [of any], tell me 'cause I'd like to know." The frustration is shared by beneficiary Christine, a single mother of four children who lost three limbs after being bitten by her dog:

There are little programs here and there, but you need to dig, right? And when you're in the middle of a trauma, nobody is sitting there going, 'Look, this is what we can do for you.' Nobody is sitting there offering

you any assistance, not even your social worker in the ICU [intensive care unit]....And they don't even tell you, in my case, of what to expect in recovery. So you're actually leaving ICU thinking, 'Well, you know this might not be so bad,' not realizing that it could get worse in the next two years, you know?

In Shirley's and Christine's quotations above, it is worth noting their use of the second-person pronoun "you" which Bischooping and Gazso (2016) explain can be a means of asserting that "any reasonable listener would perceive things in the same way or feel the same way" (p. 35) about a situation. In so doing, narrators may also invite empathy by encouraging readers to imagine themselves in the same challenging circumstances.

At the same time, the rising uptake of personal medical crowdfunding suggests that although many campaigners and contributors may not know exactly what challenges the beneficiary will face, they understand intuitively that the financial need will be substantial. This sense of impending economic struggle is partly what prompted Nelly and two friends to start a crowdfunding campaign on IndieGogo for their friend Stephanie (whose situation is described above), who was in a medically-induced coma after a hit-and-run and therefore could not communicate her day-to-day financial needs (e.g., rent, bills). Co-campaigner Nelly explains that,

at that moment it was "we don't know if this money is going to go to her medical expenses. We don't know if she's alive. If she is, and she gets to go home, is it long-term care? Does she even go home? Oh wait, she has a home – is this going to rent? Is this going towards her family having to sell

her place? Worst case scenario if [Stephanie] passes away, is it covering her funeral costs?"

With so much uncertainty, Nelly and her co-campaigners could only guess at the amount of money their friend might need based on other campaigns they saw: "we set [the crowdfunding goal] for I think [\$]25,000 because that was the number we always saw in campaigns back in the day [laughs]. It was just like everyone asked for 25 [thousand, so we thought,] 'Yeah, maybe 25 [thousand] is enough.'" Similarly, campaigner-beneficiary Rayna considered not only how much she and her family would be spending to stay near her son's hospital but also looked at other campaigns to determine if their \$5000 goal seemed reasonable. Upon reflection, Nelly adds that,

it was a blind ask and I think the majority of [campaigners] have to do that because you just don't know 'cause you can't wait to do the campaign. We did it right away...and I'm so glad we did because the second [Stephanie's story was covered on news media], we already had the campaign up and people were telling everyone, so within the first two days I think – I don't remember the timeline – we had already surpassed our goal.

Christine felt a similar sense of urgency – from her hospital bed, she instructed her adult daughter to start a crowdfunding campaign. On the advice of the psychiatrist at the hospital, they set the campaign goal at \$100,000 – an amount that the doctor suggested is typically what patients need in their first-year post-amputation. Christine's campaign raised just shy of that amount and true to her physician's estimate, the money was depleted within a year. "[My doctor] was going on an average [cost], but I'm a triple amputee. I'm going to say with every limb [that is amputated] comes a little bit more cost

– like my wheelchair has a lift in it so I can reach stuff up high because I can't climb on a counter,” she explained to me.

While GoFundMe (n.d.-c) instructs campaigners to “[l]aunch your fundraiser with an achievable fundraising goal, create momentum, then aim for more. Don’t worry—you can always raise it later” (Begin with a Realistic Goal section, para 1), many interviewees disagreed with this advice in principle and in practice. Beneficiary Alicia found that increasing the fundraising goal for her partner’s campaign had little impact once the campaign naturally lost momentum around the two-week mark. She was relieved that her partner had regained consciousness by that time, but there was still uncertainty around the length of his hospital stay, whether he’d live with long-term impairments or disabilities, and therefore, their future expenses. Susanna, who has created GoFundMe campaigns for a friend and for a community initiative, also feels that the platform’s environment is ill-suited for repeat asks and moving goal posts, even if those options are technologically possible. When Susanna was raising funds for a food security project, she eventually switched the campaign over to a different platform because “it...got weird to keep moving the goal back....even the way [GoFundMe is] designed ‘cause there’s a goal, so it’s not supposed to be sustainable, it’s supposed to be an event, a crisis.” Susanna’s intuition is corroborated by research studies that suggest that GoFundMe’s infrastructure and ethos privilege campaigns for acute health emergencies over those for chronic conditions (Gutske, 2015 as cited in Snyder, 2016a; Snyder, 2016b, Kenworthy, 2018). She adds, “so you're allowed to ask for money in this special scenario [i.e. an emergency crisis], but otherwise, you can't make it feel like you made a GoFundMe being like ‘I'm starving,’ [because] people will think, ‘don't beg me for money!’” Contributor Melissa, who lives

with a debilitating autoimmune disease, agrees, reflecting that “the experience of being sick and *chronically* ill – no one feels sorry for you. You don’t get a GoFundMe. You take out a loan” (emphasis mine).

Beneficiary Kaleen’s experience is an exception to the patterns observed by participants above. She knew the approximate amount she needed to pay out-of-pocket (after government subsidies) for her prosthetic legs, and her friend successfully raised funds for her a second time via GoFundMe when she needed an additional amputation. It is worth noting, however, that the campaigns for Kaleen were only targeted at a portion of the costs related to her health care and were designated for tangible purchases (i.e. prosthetic limbs). Researchers have observed that the logic of GoFundMe’s environment tends to favour campaigns for acute, seemingly “solvable” situations over chronic, overlapping conditions or stigmatized illnesses (Kenworthy, 2018) and procedures (Barcelos, 2019, 2020; Zenone & Snyder, 2020). GoFundMe, in other words, privileges some needs and categories of needs talk over others. The campaigns for Kaleen did not address, for example, the partial loss of income that resulted from her accident since EI replaces only 55% of eligible income. Meanwhile, income replacement is the most commonly-cited reason for the crowdfunding cases that were analyzed in this study (see Appendix D).

### ***The Expansiveness of Needs***

In spite of GoFundMe’s advice to campaigners to provide “a detailed cost breakdown” (GoFundMe, n.d.-c, Begin with a Realistic Goal section) in their campaign as a form of transparency, this strategy was not widely adopted in the campaigns observed or by research participants, except for cases in which the beneficiary is a visitor

to Canada and was therefore ineligible for Medicare coverage. This pattern, along with the interviewees' responses above, suggest that it is rare for campaigners and beneficiaries to know exactly what their health care-related needs and costs will be at the time of the campaign's creation, which is often while the beneficiary is still in hospital where costs are covered under Medicare. Beneficiary Stephanie tells me, "I literally thought health care was free [in Canada before being hit by a car], but when they say healthcare is free, they're talking about the hospitals...the minute you step out of the hospital – it's not free." While Medicare covers some non-hospital services, such as visits to family physicians, Stephanie was caught off-guard by the many services that were excluded from public insurance.

She and other interview participants have pointed out that many people who are generally healthy are unaware of the physical, financial, and mental tolls that come with severe illness or injury. Contributor Danielle, who also lives with a disability, notes that the COVID-19 pandemic was probably particularly jarring for people who are generally in good health and have grown to take it for granted: "An interesting thing about COVID was all of a sudden, healthy people realized they couldn't live on 2000 [dollars] a month [as provided by the Canada Emergency Response Benefit.] And then it's like, well, people [receiving] disability [benefits] got less than [\$]1,000 a month [even before the pandemic]."

Meanwhile, as needs talk, medical crowdfunding campaigns have helped cultivate discourses that emphasize the expansiveness of health care-related expenses and their consequences for the beneficiary's caregivers and/or dependents. Recall that Chapter Two explored how capitalism is dependent on un-/under-waged social reproductive

labour to create surplus value for owners – a structure that is established and normalized through ideology, institutions, and social practices. In many cases, crowdfunding campaigners contribute to a counter-discourse by bringing attention to the *generalized* financial need that accompanies illness/injury in the short- and long-term.

Since most care provided in public hospitals is covered for Canadian residents (see footnote 10), one of the most common reasons for medical crowdfunding is to partially replace lost wages for the beneficiary and/or their caregiver(s). While people are understandably concerned about having enough money to pay for everyday bills, the needs talk surrounding this topic also reveals dominant-hegemonic (Hall, 2012) views of reproductive labour, which are heteronormative and masculinist. Specifically, when it comes to the topic of caring for someone who is ill, crowdfunding discourses often simultaneously bring attention to the work that caregivers do, while also reinforcing the idea that this labour – especially when provided by family members – should be performed for free.

On the one hand, many of the campaigners that I studied described how a caregiver had to take time away from paid employment – or sometimes had to quit their job entirely – to care for the beneficiary. Doing so makes visible the high level of dedicated care that beneficiaries often require – which, as Alicia reminds us at the beginning of this chapter, can require the time and efforts of a “whole person.” That is the case for beneficiary Rayna, who has exhausted EI maternity, parental, and sickness benefits and has not been able to return to paid employment since giving birth to her son who has a congenital heart defect and other medical needs. As she explains, “as much as I want to go back to work, it’s like, he kind of is my job.” Meanwhile, when beneficiary

Shirley's adolescent son needed to be airlifted to an out-of-town hospital, she was devastated that she would not be able to go with him: "at the time, my husband wasn't working so I was bringing in the income....I had already used up all my paid sick days, all that kind of stuff when my son first got sick, so I had nothing left, right? And if I didn't work, I don't get paid." Shirley's dilemma speaks to the scarcity and insufficiency of paid, job-protected sick and caregiving leaves available to workers in Canada, especially for those who do not have permanent, full-time positions or who otherwise do not meet the high barrier of eligibility requirements (Tucker et al., 2020; Tucker & Vosko, 2021). At the time, Shirley worked part-time at a hospital – a job she eventually left for another position that offered vacation and health insurance benefits for her family. In their study of the history of sick leave in Canada, Tucker et al. (2020) conclude that provincial/territorial and federal governments have generally been slow and sparing in their implementation of paid/unpaid family caregiver leave, which is limited to documented cases of serious, and often life-threatening conditions and personal sick leave. The dearth of government-mandated protected sick leave in Canada – the harmful effects of which were amplified by the COVID-19 pandemic – meant that Shirley had to privately raise funds through GoFundMe to be able to travel with her teenaged son to the hospital and take four months away from paid employment to care for him.

On the other hand, crowdfunding campaigns almost always frame the fundraising request as a means to pay for basic necessities like housing and food, and almost never to compensate the caregiver for their labour, even if their "pay" would ultimately be put towards the same basic goods. That is, social reproduction is understood as separate from, and different in economic value than, commodity production, even as caregiving

reproduces labour power (P. Armstrong & H. Armstrong, 1983; Seccombe, 1974; see Chapter Two). One rare exception is the campaign that Myla (they/them) created to help pay for care before and after their gender-affirmation surgery. In the campaign write-up, Myla explained that part of the funds would be used to compensate their friends who would provide accommodations and hands-on care for them post-surgery. In doing so, Myla acknowledges the value of caregiving labour, which is normally presumed to be free. (Myla also noted that their friends had volunteered to help, without any expectation of compensation).

In speaking to participants about their experience of navigating through various public and private programs and institutions – notably our healthcare system but also private insurance providers, banks, etc. – it was evident that many of these systems operate on the assumption that every adult has access to an unpaid caregiver, whether that be a spouse, a family member, or a friend, etc. Beneficiary Christine, who is a lone parent, likens the assumption to a form of ableism that prevents individuals like herself from accessing the services that they need. Many of the interview participants likewise encountered significant struggles because they normally live alone. Beneficiary Stephanie, for instance, had to ask a roster of friends to take turns sleeping on her couch for several weeks to comply with her occupational therapist's orders. In some cases, beneficiaries rely on out-of-town loved ones to temporarily provide care for them. Contributors Wali and Mohammed both gifted money to separate crowdfunding campaigns that helped pay for flights to bring a family member(s) from overseas to care for the beneficiary.

Needs talk that reflects the assumption that reproductive labour should be provided for free is often informed by and perpetuates the belief that caregiving is unskilled or low-skill work – an idea deeply institutionalized in the “traditional” family structure, the formal economy, and the spaces and relations between them (P. Armstrong & H. Armstrong, 1983; 2004; Abramovitz, 1996; *The Care Economy*, n.d.; for labour market, Vosko, 2000). Built on gendered conceptions of social reproduction as primarily “natural” or “instinctual,” tasks involved in the daily and intergenerational reproduction of life such as cooking, cleaning, and tending to the sick are thought to be activities that require no formal training and little effort. P. Armstrong and H. Armstrong (1983) further explain that,

because capitalism is premised on the separation of most aspects of workers' reproduction from the commodity production process, and because women have the babies, women will at times be limited in their access to the production process. Such limitations permit the elaboration of the sexual division of labour (p. 45).

By extension, gendered divisions of labour have historically assigned caregiving tasks to women and girls as unwaged labour in order to enable accumulation, while also contributing to the “tendency to confine them to jobs in the labour market that are associated with domestic labour such as domestic work and service industries” (Vosko, 2000a, p. 40). The advent of online crowdfunding has only added to the repertoire of informal labour that makes up un-/under-waged reproductive activities, introducing an additional level of specialized skills (Berliner & Kenworthy, 2017) to caregiving that is similarly portrayed as accessible to amateurs (see Chapter Four). It is also worth noting

that while many unwaged reproductive activities – such as socializing children, tending to the elderly etc. – help enable the wage-labour system through (seemingly) indirect means, the work of creating and promoting a crowdfunding campaign, when successful, *directly* subsidizes wages in the form of cash.

Meanwhile, it was mostly in private conversations – not in the campaign description itself that is aimed towards soliciting funds – that several crowdfunding participants described the challenges of caregiving, including the management of crowdfunding campaigns which was often performed on top of regular paid employment duties. For example, crowdfunding campaigner Tue points out that:

There's also very big pressures on the person who started [the] crowdfunding [campaign], because usually they're the ones who also is the caretaker. I think people are mad that...the money they raise is not used towards the person that's ill but also the person who crowdfund [sic]. Say, for me, I was under a lot of stress so I needed the money to...take one or two days off [from paid employment] just to help me de-stress.

For another interviewee (the primary caregiver), the trauma of watching their loved one (the beneficiary) become ill and suffer through multiple health complications triggered episodes of psychosis that required the caregiver's hospitalization. Campaigner Nelly also recalls the stress of dealing with impromptu media calls and interview requests during her workday, but recognizing the tremendous amount of work that was required to raise funds for her friend, she is happy to have reduced that burden for the beneficiary's family members.

Although every caregiver that I spoke to volunteered to take on the primary care-taking role and often said that they were happy to have done so, it is clear that – contrary to assumptions about the unskilled nature of care work – the high demands of caregiving sometimes left them feeling pushed beyond their capacity and capabilities. Notably, beneficiary Rayna expressed some hesitation about becoming a de-facto nurse to her toddler son who requires 24/7 care. She explains:

I pretty much became his own personal nurse because he needs suctioning [of his tracheostomy tube] frequently [and] his feeds run continuously except for three hours a day....so pretty much I'm not qualified [to be] a nurse, but I'm qualified to be *his* nurse.

Recognizing their son's need for around-the-clock care, their provincial government covers the cost of a homecare nurse to help with their son's needs overnight. Rayna uses those precious eight hours to take care of their other child and to catch up on whatever sleep she can. The gendered burden of care on women like Rayna is likely to grow as provincial health authorities download more care responsibilities to individuals through neo-liberal restructuring (see Chapter Two). "So that's pretty much what it's come down to – I'm his nurse during the day," explains Rayna.

### ***Untold Needs, Unfunded Needs***

Given that crowdfunding campaign goals are often determined hastily and without the benefit of knowing the beneficiary's short- and long-term needs, what do beneficiaries do when they have used up the campaign funds and exhausted any public assistance? Rather than risk the stigma attached to asking for financial help again through crowdfunding, almost all of my interview participants turned to other coping

mechanisms, including taking on personal debt, moving in with others to save money, or living without necessities or basic activities they once enjoyed. Mark, for example, took out a personal loan to pay for surgery. Knowing that their friends and family are not wealthy, Mark is very grateful to have raised almost \$800 of the \$5,000 requested on GoFundMe but feels disappointed that the procedure was not fully covered by Medicare. Rayna appreciates the \$5,000 she raised through crowdfunding but now years later, her family continues to pay hundreds of dollars out-of-pocket each month for medical supplies for their son, who requires a trach(eostomy) tube and a feeding tube. In order to save money, Rayna has had to learn from other parents in similar situations how to clean the equipment to the best of her non-professional ability to extend the use beyond the manufacturer's guidance. One of their respiratory therapists has also acknowledged that it would be too costly for the family to replace the trach tubes every five uses as recommended by the manufacturer. Rayna adds that it can be hard to keep track of, and to decide when to dispose of the equipment: "you kind of look at [the trach tubes] and see if they're cracked, chipped, if they're de-colouring [sic] and stuff like that. Then you'll be like 'OK, I need to toss it now.'"

Beneficiaries Kaleen and Christine have had to give up on many activities because they cannot access the appropriate types of prosthetic limbs and equipment to ensure safety. Living in a small town with limited accessible infrastructure, Kaleen struggles walking on the mostly unpaved roads because she was initially only able to afford the co-pay for "the cheapest of the cheapest of the cheapest" set of prosthetic legs – ones that have feet which cannot move to accommodate uneven surfaces such as gravel roads. Her husband carried her into their house for three years before they were able to

install a wheelchair-accessible ramp subsidized by the Ontario Renovates program. Meanwhile, it took over a year and a half for Christine to find funding (from a charity) for a hydraulic chair that would allow her to safely use the bath. She explains that unlike the hydraulic chair,

the one that ODSP [Ontario Disability Support Program] and the Ontario government will help pay for is completely unsafe for somebody with more than one amputation. My [Personal Support Worker] and I used it once.... It was terrifying for me and for her and she does not want to be responsible for me falling in the tub....That I [did not] have the tools to make her job safe for her is not acceptable on so many levels.

Christine has also had to give up swimming and running because each sport requires a different set of prosthetic legs. “Of course, in many of our cases, being active directly affects our life expectancy after [amputation],” she tells me. “But nobody offers you anything to be active.”

Like Christine, Kaleen used to be a runner, proudly telling me about how she held school records for long-distance running and track-and-field. Because Ontario’s Assistive Devices Program (and by extension, her private insurance) will not cover any portion of running blades, Kaleen diligently applies to registered charities in Canada and the US in hopes of being chosen one day. “I keep applying for running legs, but I haven’t got them yet, but I can understand why because I’m not just one leg, I’m two legs [sic] so I’m taking two grants away from them to be able to give to two people.” She adds jokingly, “Well, give me one this year and give me one next year!”

Importantly, the details of these struggles and sacrifices are usually left out of published crowdfunding campaigns, mostly because beneficiaries could not anticipate the long-term costs of their illness or condition, and partly because many do not dare to ask for help a second or third time through crowdfunding. Thus, while medical crowdfunding platforms have provided a space for campaigners/beneficiaries to potentially define their needs, often their ability to interpret their own needs is still constrained by a number of factors. First, there is uncertainty surrounding their health condition, and therefore, their future health needs. Although much of this uncertainty cannot be mitigated, beneficiaries felt that more informational resources could have been made available at the hospital to help them navigate various public and private programs and services. Second, the unique environment of online medical crowdfunding appears to give rise to some “unspoken rules” that govern the practice, including setting up a campaign shortly after the illness/incident to increase fundraising success and not asking repeatedly for financial assistance from friends and family.

Whether campaigners choose crowdfunding because they think of the beneficiary’s health-related financial needs as a private matter or because they don’t trust that governments will be helpful (discussed in Chapter Six), crowdfunding needs talk exemplifies the struggle over the authority to interpret needs. In the course of soliciting private funds, GoFundMe campaigners and beneficiaries reveal gaps in and between Canada’s healthcare system and other welfare programs (see Chapter Two), attesting to a misalignment in the interpretation of needs by the government and by beneficiaries. GoFundMe’s platform thus provides a space – albeit one that obscures needs talk from the official-political realm – for campaigners to express their understanding and

experience of what the beneficiary needs are and how best to address them. Meanwhile, asking for private funding through crowdfunding both serves as a critique of the government's inability and unwillingness to provide for its citizens while ironically, also relieving the government of that responsibility. Being afforded some latitude to define a beneficiary's needs, however, does not equate to total authorial freedom. As interview participants expressed above, many of their needs are left untold and/or unfunded, in part constrained by crowdfunding norms. In the next section, I continue to explore constraints on crowdfunding discourses by focusing on an added layer of struggle – that of fundraising.

### **Discourses of Deservingness: The Struggle to Justify Needs**

In privatizing health-related financial needs, the practice of personal crowdfunding infuses discourses with a fundraising imperative – that is, because crowdfunding contributions are voluntary, one of the main struggles of the campaigner or beneficiary is to convince potential contributors to voluntarily part with their money. The classic claim structure of *A* needs *x* in order to *y* (Fraser, 1989a, 1989b) thus becomes overlaid with – and I argue, overtaken by – a discourse of deservingness. In other words, in addition to providing space for campaigners to establish the *A* needs *x* in order to *y* chain-of-needs (Fraser, 1989a, 1989b), GoFundme's crowdfunding environment compels campaigners/beneficiaries to explain why *A* **deserves** *x* in order to *y*. Even though this inherently contains an explanation or claim to what *A*'s needs are, the structure of the discourse is fundamentally altered. In this section, I explore how *A* needs *x* in order to *y* plays out in crowdfunding discourses and specifically how it reproduces and/or challenges discourses of dependency (Fraser & Gordon, 1994). Specifically, I argue that

even though the popularity and visibility of crowdfunding have opened up a space to discuss individual economic struggles and to ask for financial help from friends and family, my analysis of crowdfunding campaigns and interviewee responses shows that “good/bad” dependencies remain dominant themes in medical crowdfunding discourses.

### ***“Bad” Dependencies***

Importantly, personal medical crowdfunding via GoFundMe and similar platforms has brought awareness to the consistent cracks and fissures in welfare states and has helped normalize talking about personal financial struggles, especially in middle- and upper-income households. Researchers have found, for example, that over 65% of Canadian GoFundMe campaigns for cancer-related expenses came from forward sortation areas, which represent the first 3 alphanumeric characters of Canadian postal codes, within the three highest income-earning quintiles (van Duynhoven et al., 2019). As Chapter Four shows, various practices of asking for and receiving monetary assistance precede the invention of GoFundMe, but the proliferation of privatizing needs talk via personal crowdfunding also pushes against the aforementioned idealized image of the independent waged worker. Put simply, GoFundMe has opened up an enclave for talking about financial struggles. Despite the breakthrough of normalizing financial needs talk, however, most crowdfunding beneficiaries still express embarrassment and even shame about their position, reflecting common-sense ideas about “good” versus “bad” dependencies.

Beneficiary Shirley, for instance, recalls being upset when she learned that her sister had started a campaign on her family’s behalf: “I was kind of mad at her. I was like, ‘That’s embarrassing! What are you doing?!’” Beneficiary Kaleen had the opposite

experience of a family member who disapproved of the crowdfunding campaign made in Kaleen's name: "My mother-in-law was not happy with it whatsoever because she thought we were asking the town, like we were being charity cases." And even though Kaleen didn't agree with her mother-in-law's view of the situation, Kaleen herself also internalized a sense of shame about asking for help. When her mother-in-law told Kaleen to stop sharing the campaign on social media, Kaleen clarified that she had never done so. She explained to me, "I would never do that. I never shared it, not once with anybody, because I was too embarrassed to."

As Kaleen's use of the phrase "charity cases" suggests, the notion of "bad dependencies" is closely associated with the stigma that surrounds receiving "charity." In Chapter Four, I explored the various meanings of "charity" at the economic, legal, and social/moral registers. The negative connotations of being on the receiving end of charity primarily emanate from the economic and the social/moral levels of meaning because they cement a false, hierarchical dichotomy between giver and receiver. Contrary to the reality that people invariably will be both givers and receivers of care in their lifetime (see The Care Collective, 2020; Tucker et al., 2020) – some of which may be perceived as "charity" – the neo-liberal conception of "charity," as well as the role that formal and informal philanthropy play within capitalist systems, paints the giver-receiver relationship as uni-directional and irreversible (see Chapter Four). Beneficiary Myla's conflicted feelings about crowdfunding for their gender affirmation surgery reflects this contradiction:

I am very active and involved in my community. I think the way my parents raised me is like I tend to be generous with everything that I have,

even though I don't have much but I'm always willing to give for others, and so when it's for me to ask for help in return like that, even that to me is...it's so hard for me to do.

Christine's daughter was likewise reluctant to create a crowdfunding campaign for her mother. Christine explains: "My daughter was horrified that I was asking for 'charity.' In her eyes, it was begging for charity." Looking back, Christine also characterizes her situation as 'asking for charity' but she consciously set aside negative feelings about being in that position to focus on practical concerns, including her responsibility as a parent of four children. "I had just come off life support.... So [the money raised] was lifesaving to me. So at that point, and because I was so sick, I really didn't give a fuck."

Given the widespread internalization of beliefs around "bad dependencies," it is not surprising that often it is a friend or family member who creates a campaign on the beneficiary's behalf. When Helen initially created the first of two campaigns to help fund Kaleen's prosthetic legs, she did so without telling Kaleen but arranged with Kaleen's husband to have the money sent directly from GoFundMe to their bank account. While loved ones might naturally feel compelled to take the burden of managing a crowdfunding campaign off of the hands of the beneficiary as a form of caregiving, it is also telling that several interviewees confirmed that if someone else hadn't started a campaign on their behalf, they would have been too ashamed to do it on their own. Like Kaleen, beneficiary Myla also had two crowdfunding campaigns in their name at different times – the second started by a friend who saw Myla struggling to keep up with rent and tuition, all while trying to prepare for their second gender-affirmation surgery.

Myla admits that they rarely shared the second campaign through their own social media accounts and that they have a hard time even acknowledging the campaign's existence. "I just feel like I have already asked way too much from the...first time...and I think I just didn't feel like I deserve the help at this point, I don't know." Myla's discomfort speaks to the generally unspoken rule that people should only ever ask for financial help from friends and family once because anything else is "bad" dependency.

The stigmatization of extended or long-term financial need as a sign of personal failure surrounds not only acts that are commonly deemed or perceived as charity, but also extends to certain types of state social services. Fraser and Gordon (1992) explain that because some welfare programs in the US have a contributory component (e.g., a percentage of workers' paycheques are deducted for Social Security), accessing those services is more likely to feel like a contractual – and therefore honourable – entitlement. By contrast, receiving payments from programs that are funded through general taxation, such as Aid to Families with Dependent Children (AFDC), appears as an unearned benefit (i.e. charity) and an undesirable dependence on the state (Fraser & Gordon, 1992). As discussed in Chapter Two, since the late 1980s, Canada's social policies have shifted welfare programming towards a similarly dichotomous framework, in which people with higher-paid, stable employment enjoy differential treatment and access to social services than people in un-/under-paid, precarious jobs (Cameron, 1995). Crowdfunding contributor Danielle and beneficiary Stephanie, for example, recounted to me the multiple barriers they faced trying to apply for government and workplace disability benefits, worsened by the mostly invisible nature of their respective disabilities. Stephanie applied to her provincial disability benefits program three times, each time having to deliver and

pick up a hard-copy application for each of her physicians to fill out successively. She tells me, “My doctor – he said, ‘You know, [Stephanie], people who are in the position where you apply for [disability benefits] don’t look like you, right? They’re on the streets, you know, shooting up some drugs – like that’s when they apply.” Stephanie describes the experience as one that involved “a lot of shame, a lot of energy.”

While Stephanie, Danielle, and other interview participants pushed back against gatekeepers and naysayers, the contract versus charity myth (Fraser & Gordon, 1992) is pervasive even among those who could benefit from welfare services. For instance, as Shirley’s son nears the age cut-off for their provincial medical coverage (the Ontario Health Insurance Plan or OHIP covers prescription medication costs for children and youth aged 24 and under), she is encouraging him to think carefully about how his career and employment choices will affect his ability to pay for his life-long medication needs (which cost thousands of dollars per month.) She explained to me that:

There are a couple of moms that I met and their kids are like my son’s age – he is 18 now – and they’ve applied for ODSP [Ontario Disability Support Program]. But I don’t want to go that route because [when you receive] ODSP – then you’re judged, right? So I don’t want my son to rely on ODSP. My son is like a really good kid – like he actually just got a job here, so I want him to work, you know what I mean? I want him to think he can still go out there and live life and do stuff, like I don’t want him to think, ‘I’m sick’ and I guess take advantage of that. Or you know, think ‘I can’t do this, I can’t do that,’ right? So I just tell him, ‘Bud, you gotta get a good job where you have benefits. And all that stuff is covered.’

Shirley worries not only that her son will be judged by others for receiving disability benefits but that it will diminish his work ethic and confidence in his own abilities. Notably, she does not have the same qualms about him receiving coverage under OHIP because adult dependency is mitigated by the age cap, or through private insurance because it is attached to employment.

### ***“Good” Dependencies***

Discourses of “bad” dependencies often operate alongside discourses of “good” dependencies. In the case of crowdfunding campaigns, demonstrating that a beneficiary is typically financially independent forms an important part of the justification of why the beneficiary deserves the help of friends and family. In the GoFundMe campaigns observed, the beneficiary's independence was commonly established in four ways, by mentioning that: 1) they had been working in paid employment before the illness/accident; 2) they intend to return to paid employment; 3) they have dependents (e.g., children, a spouse, an elderly parent); and 4) perhaps most importantly, that the beneficiary would normally “never ask for help.”

Since income replacement is often the impetus behind medical crowdfunding campaigns, it is not surprising that most campaigns explain that the beneficiary was gainfully employed prior to their illness/injury. The needs talk, however, goes beyond simply naming the need (e.g., A needs their income replaced in order to pay for everyday expenses) because campaigners feel compelled to justify their request in order to secure voluntary monetary contributions. Thus, potential contributors are often reminded in crowdfunding campaigns of the beneficiary’s hard-working character, their accomplishments, and their service to others. For example, in a campaign for her sister

who was injured while training to become a firefighter, creator Miriam emphasizes her sister's discipline and long-term devotion to what is often considered to be a heroic career: "She has been working towards becoming a firefighter for the last 2 years, training every day, sacrificing her job to put more time into training and volunteering" (Sabbah, 2023). Beneficiary David, who "would like to avoid...being a financial burden on [his] family" (Gregory, 2023) while he undergoes cancer treatment, also makes note of his long-term service in the military – a career that was cut short by circumstances beyond his control: "I am not usually one to ask for financial help. It would be so much easier if I were still a medic in the Canadian military. Unfortunately for me, I was injured (not due to combat) and after 8.5 years of service, I was forced to release for medical reasons (Gregory, 2023).

In several campaign descriptions, campaigners describe how the beneficiary's selflessness continues to shine through in the face of personal adversity. For example, in a campaign for a 30-year-old who is undergoing treatment for acute leukemia, his fundraising team writes:

As a testament to John always putting others first...he completed a marathon by walking around the hematology unit, 453 laps totaling 42.2 km to raise awareness of the national shortage of blood and marrow donations (Minto, 2023)

Many campaigns also emphasize the temporary nature of the financial need by explaining that the beneficiary and/or their primary caregiver will and is eager to return to paid employment – and therefore, self-sufficiency – as soon as they are able. Campaigns commonly make note of the various efforts taken by the beneficiary or their family

members outside of crowdfunding to make ends meet. Campaigner Sue, for example, admits that she and her husband Jim have fallen “dangerously behind on things like [paying] property taxes and even monthly utilities” (S. Miller, 2023) due to Jim’s inability to work while being treated for cancer. She writes: “My income is nowhere near enough to carry us, and at the moment I’m waiting on a start date for a new job” (S. Miller, 2023), demonstrating her desire to support her household to the best of her own ability by seeking out new or additional employment. Another campaign explains that the beneficiary Cathy, a former professional golfer, has been “forced to sell assets to ‘Keep The Wolves Away’” (B. Christie, 2023) after suffering complications from a kidney transplant.

In addition to describing the personal sacrifices of the beneficiary and/or their family members, campaigns often make note of their resourcefulness in navigating bureaucratic institutions and processes. A campaign to support “Kayden’s Cancer Journey,” for example, describes how the mother of the 11-year-old Kayden “is doing the best that she can to line everything up, and has requested compassionate care leave from her job with Ei [sic]” (Lincoln, 2023). Despite her determination, however, “she has already hit the first hurdle of a min 28day [sic] wait period” for EI payments (Lincoln, 2023). Similarly, a campaign to fund a wheelchair accessible vehicle for a family explains that “Heather [the mom] *managed* to get government funding for a motorized wheelchair that Henry can use to get around with the limited motion of his right hand” (Cho & Crawley, 2023; emphasis mine), but still needs additional financial support for the van.

In these examples of crowdfunding campaigns, potential funders are thus assured that the beneficiary and their caregivers are not sitting around idly while relying financially on friends and family members. Instead, they are conforming to ideal of the neo-liberal subject, actively pursuing a range of other options for self-sufficiency, including finding new employment, selling personal belongings, and diligently applying for social services.

Discourses of deservingness in crowdfunding campaigns are often built around not only the beneficiary's self-sufficiency but also their ability to provide for others. In the campaigns analyzed, the chains-of-dependence – most often familial – are often explicitly spelled out in the written campaign description and also implied through images of the beneficiary with their family members. Some campaigners, for example, directly reference the beneficiary's dependents in the campaign title, including “*La famille d'Adélie*<sup>28</sup>” (Hervé & Lauwerier, 2023); “Helping Mark, Meghan, and Lucas; Medical Costs for a Young Family” (Waxer, 2023); “Let's Show Marta and Her Beautiful Family Some Love” (da Silva, 2023); and “Help Julia, mom of 7, recover crucial dental costs!” (George, 2023). Framing a fundraising request around the needs of an entire family like this has the logical benefit of communicating that the well-being of multiple people is at stake; but it also serves to bolster the worthiness of the beneficiary by attaching a “good dependency” to their name. Recall that under capitalism, financial dependence of children, women, and the elderly on a male<sup>29</sup> breadwinner is still often

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<sup>28</sup> The title of the campaign is in French, but the campaign text is written in both French and English. Only the English text was used in this study.

<sup>29</sup> Respect may likewise be shown to female breadwinners for supporting others although it tends to be entangled with expectations of motherhood.

considered to be natural and desirable, such that the ability of a man provide for others is a testament to his admirable character (Fraser & Gordon, 1994). The honour that is bestowed upon individuals who financially support familial dependents mirrors that which is afforded to charitable donors (see discussion in Chapter Four).

On top of emphasizing the dependability of the beneficiary as a sign of their worthiness, campaigners often make note of the pride that beneficiaries take in providing and caring for others. In this self-created campaign for a 40-year-old worker, the campaigner-beneficiary expresses that he is eager to return to his parenting responsibilities:

My daughter had to move back to Nova Scotia as I was no longer able to care for her during my numerous surgeries, hospital visits, recovery, etc. I look forward to the day we are reunited! (Hanlon, 2023).

Conversely, some campaigns convey the lament that beneficiaries feel when they cannot fulfill those duties:

When you have two young children, 6 and 3 and a husband living around you, all you want to do is get up and join them. Sadly, this part of life is on pause, and you contemplate if you'll ever get that time back (da Silva, 2023).

Campaigners also often describe beneficiaries' general propensity to help the people around them, as in this description of a father with terminal cancer as someone who is "so so kind and has always been the first to jump in to help others" (Waxer, 2023). In the same vein, a campaign to support a woman who developed a disability after a kidney transplant describes the beneficiary's long

history of volunteerism and explains that “[s]he desperately wants to return to a life where she can contribute in some way” (B. Christie, 2023).

Finally, campaigners frequently characterize the beneficiary as someone who would “never ask for help” or expect something in return for their past service to others, at once asserting their dependability but also personal independence. In a campaign for her husband who was diagnosed with colon cancer, campaigner Christiane describes him as “[o]ne that gives, one that's always there to help, always there to offer a helping hand to all that needed it. And never asking for anything in return” (Jechoux, 2023). Similar testimonies of the beneficiary’s history of aiding others emphasize that their generosity extends beyond friends and family to “complete strangers” (Gregory, 2023). In an effort to support their brother Dave while he undergoes treatment for cancer, siblings Robert and Lori write:

People who know Dave well also know that he would give the shirt off his back to anyone who needed it. He put his own life on hold to help our mother when she was terminally ill, then our stepfather, he's given money to his family and friends, he helps with their home renovations, he has even rescued complete strangers on the side of the road. And, you also know that Dave would never ask for anything for himself, which is why Rob and I are asking on his behalf (Gregory, 2023).

In the case of a crowdfunding campaign for beneficiary Tina who had to be airlifted to Vancouver to be treated for an unknown condition, her willingness to suffer

silently serves as testament to her “stubborn independen[ce]” (Hunter & Dagasso, 2023).

The campaigners write that,

[t]hrough the course of her life Tina has endured a stroke, multiple blood transfusions, four eye surgeries, all alongside struggling with diabetes since childhood. In turn, this has compromised her health many times while at no point did she ever want to put anyone out and ask for help (Hunter & Dagasso, 2023).

In all of these attributions, the emphasis that is put on the beneficiary’s track record of self-sufficiency suggests to readers that the beneficiary likewise shares a distaste for adult dependency and implies a safeguard against additional fundraising requests in the future. The beneficiary’s history of self-reliance therefore helps justify their worthiness: *A* deserves your financial support in order to *y* because *A* is normally independent. This pattern aligns well with GoFundMe’s structural bias towards campaigns that are for acute rather than chronic illnesses (Kenworthy, 2018) that might require repeat or long-term funding.

Regardless of the accuracy of the characterizations of the beneficiaries as people who “never ask for help,” the frequency with which this attribution appears in crowdfunding campaigns – to the point of being a cliché – as well as in my interviews with participants suggests that, in fact, most people are deeply embarrassed about asking for monetary assistance as adults. Doing so implies adult dependency which is heavily stigmatized in late capitalist societies. When I asked contributor Danielle, who lives with a disability, about why she thinks people feel so ashamed to ask for help, she explained,

“Oh, it's a whole cultural thing. It's capitalist, it's Calvinism, it's Protestant work ethic...and this whole idea that ‘we are our productive capacity.’” Particularly under the neo-liberal era of capitalism, one’s identity and self-worth are so strongly tied to their ability to produce as a worker that not being able to produce and provide for oneself – whether temporarily or in the long-term – can be seen by oneself and others as a personal failure. It is ironic then that even as crowdfunding attempts to secure financial support for beneficiaries, medical crowdfunding discourses tend to reproduce the idealization of economic independence by asserting that person *A* is worthy of assistance because they “never ask for help.”

The false sense of exceptionalism was also apparent in my research interviews when participants would bring up the idea of so-called “scammers” or other people whom they felt were similarly undeserving of crowdfunded support. Notably, all references to “the undeserving” were initiated by the interviewees without my prompting. That is, in trying to establish that person *A* deserves monetary support, the vast majority of interview participants – representing crowdfunding campaigners, beneficiaries, and contributors alike – pointed to a person(s) *B* whom they believe does not deserve the funds they raised/were trying to raise. Beneficiary Kaleen, for example, feels that the GoFundMe landscape has changed dramatically since the time of her campaigns: “[I]t was before everybody decided to do all of it fraudulently, like they do now. It's just crazy, like you can't – I do not donate to GoFundMes unless I specifically know the person because you just can't trust [laughs] nowadays.” Interestingly, Kaleen recalls different rumours that circulated around her own crowdfunding campaigns, including an accusation that she lied about her double amputations. Given her own experience of being wrongfully cast as a

liar, Kaleen’s distrust of strangers’ crowdfunding campaigns may therefore seem surprising; however, I suggest that it speaks to the strength and endurance of the “scammer” character in crowdfunding discourses.

GoFundMe (n.d.-i), meanwhile, claims that less than a tenth of a percent (or 0.001) of campaigns on its website have been found to be fraudulent – which the company defines as involving illegal activity, false impersonation, and/or misleading statements written in the campaign story. Nonetheless, the fear of crowdfunding “scammers” appears to be so widespread and threatening to GoFundMe’s bottom-line that the company offers a one-year money-back guarantee to contributors if a campaign is deemed fraudulent by the company.

In addition to sharing stories about people lying about their health to scam contributors out of money, many interviewees make a sharp distinction between the “deserving” and “undeserving” based on the perceived legitimacy of their reason for fundraising. Beneficiary Christine explains: “I mean, you see there's a line. You'll see there's a line. The people that need it, and the people who think that they should have it to pay off their credit card. [The latter people think,] ‘Well, this worked for me last time. I'm just going to do it again.’” Beneficiary Kaleen has similar views on the matter: “I don't know, it's embarrassing when people have to help you financially, I guess. I mean, some people are OK with it 'cause they do it all the time; but the real ones are not OK with it.” Although neither beneficiary makes accusations of outright fraud in those cases, Christine and Kaleen draw a comparison between beneficiaries who have a “true” financial need versus those who are accustomed to regularly relying on others. Both Sari (contributor) and Shirley (beneficiary) explicitly link this type of perceived “bad

dependency” with the practice of “begging” – “GoFundMe – it's not begging, but it feels like a glorified begging at times too. Unless it's a real major need, you know?” (Sari, contributor) – or asking for “charity:”

I don't feel as though a GoFundMe is like asking for charity. I think it is [charity in] an instance for where, like say people are raising money because, you know, ‘I want a new car and I can't afford it,’ right? To me, that's like you're asking for charity, but to me, doing it from a medical perspective, you just genuinely need the help (Shirley, beneficiary).

In the separate interviews with beneficiaries Christine, Kaleen, Shirley and contributor Sari, the test of legitimacy appears to comprise two elements: 1) “real” needs versus extraneous ones; and 2) one-time versus repeated requests. By drawing an equivalency between repeated requests to pay for non-essentials with asking for “charity” or “begging,” such discourses reproduce the widespread – though sometimes unspoken – belief that charity is a “bad dependency.” Put differently, gifts given as “charity” constitute a type of special money (Zelizer, 2011) that carries a negative connotation. In this way, crowdfunding participants ironically fuel the stigmatization of needing help from others, while also trying to reconcile feelings of shame around their own need for monetary assistance.

Meanwhile, for beneficiary Rayna, the relative success of other people's crowdfunding campaigns for non-medical expenses leaves her mostly feeling dejected rather than indignant. Whether it is seeing other medical or non-medical campaigns “go viral,” she appears to internalize the blame, wondering where she went “wrong” in her own campaign:

We had so many people trying and it just didn't – it didn't work out so I don't know how these people are able to...raise so much money.... I wish I had the answer [laughs nervously] 'cause [I think] it would work, and this way, I could help get more awareness out and try and pay it forward a little bit but I don't know how to do it.

Rayna ultimately reached her \$5,000 fundraising goal thanks to a friend who contributed a disproportionately large sum. While she is thankful for her friend's exceptional generosity, she had hoped that her campaign would gain more visibility in order to raise awareness and additional funds for congenital heart disease, lung disease, and the local children's hospital – a scenario that is often represented in news media. However, as discussed in Chapter Four, GoFundMe's "how-to" resources and upbeat marketing belie the harsh reality that most Canadian medical crowdfunding campaigns fall short of their fundraising goal (Pol et al., 2019; Saleh et al., 2020) and that inequitable crowdfunding outcomes largely reflect existing social inequalities (Igra, 2021; Igra et al., 2021; Saleh et al., 2020; see also van Duynhoven et al., 2019).

Whether in assigning blame to oneself or to the "undeserving," medical crowdfunding discourses often affirm common-sense beliefs about "good" versus "bad" dependencies. Perhaps in an attempt to reconcile the discomfort of needing financial support from friends and family, crowdfunding beneficiaries often set themselves apart from other beneficiaries whom they deem to have illegitimate needs or malicious intentions. Ironically, this "Othering" tendency inadvertently contributes to the stigmatization of needing financial assistance as a form of asking "charity" or "begging," both understood pejoratively.

Unlike discourses that try to establish the legitimacy of a given need as a public responsibility (see Fraser 1989a, 1989b; Fraser & Gordon, 1994), the moment of struggle over legitimacy in crowdfunding discourses centres around the fundraising imperative. Instead of assigning responsibility, crowdfunding involves convincing potential contributors to give money. Instead of trying to establish the legitimacy of a need, crowdfunding discourses tend to focus on establishing the legitimacy of the beneficiary. As discussed above, this is most often accomplished through a demonstration of the beneficiary's financial independence, their hard-working nature, and their generous personality. This approach undermines a core tenet of the Canadian Medicare system: universality, or the principle that "all residents of a province or territory be entitled, on uniform terms and conditions, to the publicly funded health services covered by provincial/territorial plans" (Senate of Canada, 2003, Section 17.1, para. 1) regardless of their ability to pay, their employment status (past, present, or future), and – as is relevant in this discussion – their personality. Because the fundraising imperative shifts the legitimacy of the need towards the legitimacy of the beneficiary, the result is that not only is the traditional claim structure of *A needs x in order to y* transformed to *A deserves x in order y* but more precisely, that *A deserves to y*. For instance, at the heart of the campaign for "Dominique's Extended Battle with Advanced Cancer" (Dzikowski et al., 2023) and so many others like it, is the argument that Dominique deserves money in order to avoid cancer-related debt but also, more straightforwardly, that Dominique deserves to avoid cancer-related debt. Similarly, the aforementioned campaign "Fundraising a Wheelchair Accessible Van for Henry" (Cho & Crawley, 2023) which advocates that Henry deserves an accessible van in order to get around with his family is also trying to convince readers

that Henry deserves to get around with his family. In personal crowdfunding spaces, claims for the legitimacy, provision, and interpretation of needs for a specified group (e.g., women need accessible childcare in order to participate in paid employment) are morphed into discursive claims about the worthiness of a specified individual, which is measured by their personality, and more specifically, their history of displaying financial independence. When I asked beneficiary Kaleen how she feels about having to crowdfund multiple times and apply regularly to charities for prosthetic legs, she explains, “I don’t think it’s very fair when all I’m trying to do is walk.”

The purpose of this analysis is not to cast doubt on whether or not the beneficiaries are as generous, self-sufficient, and humble as they are described, but instead, to point out that within the personal crowdfunding environment, descriptions of these positive character traits become part of the argument for, or the proof of, the beneficiary’s personal worthiness. That is, because the financial needs related to health care are cast as a private matter in the crowdfunding environment rather than as a social issue for which governments are responsible, it becomes necessary to remind readers that the beneficiary is what broader society would consider to be “a good person” so as to justify the voluntary monetary support. Importantly, the idealized image of the “good person” is one who always helps others but “never asks for anything” nor depends on others. The genuine shame and embarrassment felt by beneficiaries about needing financial help therefore turns out to be a rather integral component of the crowdfunding process.

## Conclusion

Viewed through the dual frameworks of needs talk (Fraser, 1989a, 1989b) and “good/bad dependencies” (Fraser & Gordon, 1994), discourses cultivated in and around crowdfunding spaces offer an important window into how health-related financial needs are framed, negotiated, and depoliticized in Canada. As needs talk, personal crowdfunding campaigns reveal a misalignment in the interpretation of needs by the governments and by beneficiaries. The crowdfunding environment offers campaigners/beneficiaries greater control to interpret the beneficiary’s needs while also significantly shaping what can and cannot be written because potential contributors must be convinced that the beneficiary is worthy of their money. When it comes to defining needs, crowdfunding platforms such as GoFundMe, IndieGogo, and Fundrazr theoretically provide a space for campaigners/beneficiaries to interpret and communicate their needs. Crowdfunding platforms thus afford beneficiaries and campaigners some authorial control over how their needs are defined, even if those discourses largely frame needs as private matters. However, the ability to interpret needs is constrained by a number of factors. First, the lack of certainty around one’s state of health (e.g., healing time, future complications, long-term impairments) makes it challenging for campaigners/beneficiaries to specify what their needs will be and how much money they need. While much of that uncertainty cannot be mitigated, participants remarked that they would have benefited greatly from professional guidance on public and private programs that might be available to them. Second, the unique dynamics of the personal fundraising environment shape the timing and content of crowdfunding discourses. Because GoFundMe is primarily designed for emergency requests for acute needs, it is often

intuitively understood by campaigners, beneficiaries, and contributors that campaigns need to be set up as soon as possible to capitalize on the urgency of the situation, and that making future requests for help would be frowned upon and therefore unsuccessful. What this mostly translates to is fundraising goals that are set hastily and with little basis in the specific needs of the beneficiary – in more than one instance, campaigners determined their fundraising target by following perceived trends. Taken together, the two factors create a considerable risk that campaigners will underestimate or understate (see Kenworthy, 2018) their financial needs, thereby compromising their ability to authoritatively define their needs. The result is that many needs are left untold and therefore unaddressed, leaving many beneficiaries – and often their caretakers – to bear significant sacrifices to their health and quality of life.

Moreover, since personal crowdfunding is fundamentally a vehicle of privatization, there is no longer a struggle to establish the legitimacy of the need or the benefitting population as a public concern; instead, the question revolves around the legitimacy of the individual beneficiary. Berliner and Kenworthy (2017) aptly describe medical crowdfunding as a practice that “reinfor[ces] deservingness as a moral criteria [sic] for resource allocations in a hyper-individualized economy” (p. 235). As I have shown, crowdfunding discourses regularly tout individual financial independence as an honourable trait and more importantly, as a justification for why the beneficiary deserves monetary assistance from friends and family. In reinforcing the stigmatizing dichotomy of “good” versus “bad” dependencies in this way, crowdfunding beneficiaries inadvertently reproduce and give strength to the very shame that many of them experience.

## **Chapter 6. Safety Nets Fail: Responsibility and Resistance in Medical Crowdfunding Discourses**

Shortly after hearing that a semi-truck had collided with a bus carrying members of a junior Canadian hockey team in her hometown, Sylvie Kellington set up a GoFundMe page called “Funds to Support the Humboldt Broncos.” What began as a local effort to cover incidental expenses like hospital parking and coffee – with an initial goal of \$5,000 – quickly ballooned into a global campaign that not only raised \$15.2 million but prompted a series of regulatory changes, including a mandatory minimum training standard for all semi-truck drivers nation-wide and a prohibition in Saskatchewan of all non-residents from driving semis on out-of-country Class 1 licenses<sup>30</sup>. Even though the GoFundMe campaign itself did not call for regulatory reform, it nevertheless helped garner the worldwide attention needed to legitimize and elevate the surrounding needs talk to political spheres provincially and nationally. In the eight months that it took for courts to decide how to equitably disburse the GoFundMe money, stakeholders debated over questions of responsibility – for not only the crash itself, but also for improving highway safety and alleviating the financial needs of injured and deceased passengers and their caregivers. In this chapter, I explore medical crowdfunding as a space where participants may: a) assign responsibility for needs fulfilment (Fraser, 1989a, 1989b); and b) express resistance to unjust situations, policies, and institutions. The guiding questions of this chapter surround the interview participants’ perception of the transformative

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30 Compliance with the mandatory driver training, however, has been an issue for most provinces/territories (Bandera, 2021). In 2024, the Saskatchewan government relaxed the restriction on non-resident drivers, making exceptions for foreign agricultural workers from 40 countries (Dudha, 2024).

potential of medical crowdfunding as a space of needs talk. Do crowdfunding campaigners, beneficiaries, and contributors consider crowdfunding as a practice that can harness a collective desire for change? To what extent do crowdfunding participants view or use crowdfunding as a site of resistance?

I continue to draw on Fraser's (1989a, 1989b) needs talk framework throughout this chapter, exploring how medical crowdfunding campaigners, contributors, and beneficiaries define needs, legitimize them, and assign responsibility for their fulfillment. Each of these phases are understood as moments of struggle that are theoretically distinct (for analytic purposes) but functionally overlapping and blurry (Fraser, 1989a, 1989b). This chapter unfolds in two sections. First, I turn to discourses of responsibility or needs satisfaction. By analyzing text found in medical crowdfunding campaigns and prompting interview participants with questions (see Appendix B) about the ideal roles of governments, charitable organizations, and private businesses in supporting people in Canada with health-related expenses, I offer a deeper look into how and to whom/what crowdfunding participants assign responsibility for the care of people with medical needs. Second, I examine moments and acts of resistance against dominant discourses of deservingness (see Chapter Five) and health, revealed predominantly in interviews with participants as they reflected on their experiences with medical crowdfunding. In many cases, participants spoke to multiple roles they have played in crowdfunding – for example, a beneficiary who has also contributed to other crowdfunding campaigns – as well as to their own experiences of disability and illness.

In comparing discourses found in the written text of medical crowdfunding campaigns versus in participant interviews, I contend that expressions of resistance to the

status quo are less pronounced in crowdfunding campaigns than in interview responses, constrained by the strong ethos of charity that permeates GoFundMe's platform environment. To the extent that criticisms and critiques of Canada's "safety net" provisions can be found in crowdfunding campaigns, they are tempered by the dynamics of personal fundraising and channelled towards individualistic "solutions."

## **Discourses of Responsibility: The Struggle to Fulfill Needs**

### ***Crowdfunding – A First Resort or Last?***

Crowdfunding campaigners and beneficiaries often characterize personal medical crowdfunding as "a last resort" – a sentiment that surely reflects the shame attached to asking for help (see Chapter Five) – and yet GoFundMe campaigns are often created within days of an accident or illness, making it ironically a first resort. The aforementioned campaign for the Humboldt Broncos, for example, was created on the same day of the collision in anticipation of expenses to come. Looking back, beneficiary Christine is glad that she had the foresight to ask her daughter to set up a campaign from her hospital bedside because she quickly ran into financial roadblocks. "All the [safety] nets that you put in place to help you and your family [in case of emergency] – [they] take six months to a year to access," she explains. The lone mother of four children was shocked to learn that her mortgage insurance – an extra cost she had borne for years – was not accessible to her when she was hospitalized following a triple amputation.

The failure of so-called "safety nets" was a recurring theme in interviewee responses. Beneficiary Kaleen is thrilled that she now has a private insurance plan that covers the majority of the costs for her two prosthetic limbs (she did not have extended

health benefits at the time of her accident), but she's keenly aware of how many amputees have been failed by their private health insurance providers:

People who have [private health] insurance – their insurance maxes out....And just so you know, you need new [prosthetic] legs every five years. You don't just get your prosthetics and you're good to go for the rest of your life. No, no, no, it does not work like that.

When contributor Melissa's dad became ill with cancer, they held the in-person fundraiser barbecue for him precisely because his private benefits provider stopped paying: "his insurance ran out...all that stuff ran out."

It is likely because of these first-hand experiences of being let down by various "safety nets" – or the fear of hypothetical failures – that people regularly create GoFundMe campaigns or are willing to contribute to them before the beneficiary has likely had time to confirm which "safety net" options are (or are not) available to them. As discussed in Chapter Five, the dynamics of personal medical crowdfunding are such that campaigners often feel compelled to set up a campaign as soon as possible to capitalize on the urgency of the diagnosis or situation. Moreover, in several of the crowdfunding cases in this study, the campaign was set up before the beneficiary's scheduled treatment as a pre-emptive measure against impending income loss. In Canada, while some workers may qualify for EI sickness benefits, the strict eligibility requirements create barriers to access, and the low income replacement rate of 55% is, as Tucker and Vosko (2021) describe, especially "punitive for part-time and temporary employees and those working in low-wage industries" (p. 5). For example, workers must be able to show, among other criteria, that their regularly weekly employment income has

decreased by more than 40% for at least one week due to medical reasons. Additionally, workers must have paid EI premiums for a minimum of 600 insurable hours of work in the 52 weeks before the start of the claim or since the start of their most recent claim (whichever is shorter). Importantly, eligibility for employment insurance, which falls under federal jurisdiction, does not provide job protection for sick leaves, the latter of which is predominantly legislated at the provincial/territorial level<sup>31</sup>. Currently, eight out of 14 jurisdictions across Canada mandate five protected days or fewer for workers<sup>32</sup>, which puts people at significant risk of not only losing income but their jobs altogether due to sickness or caregiving responsibilities. All of these detailed conditions and calculations can understandably lead to confusion, added stress, and uncertainty, especially when the beneficiary's health may be at stake.

Like many, campaigner-beneficiary Rayna, whose son was hospitalized for almost a year and half after his birth, struggled to navigate the EI application process. As she recounted to me:

I went through that for most of 2020, fighting with EI. I was literally on the phone [for] hours on end, sitting at my son's bedside freaking out because I wasn't getting my money and then the calls would drop or stuff like that.... [W]hen you're sitting in a hospital with a child [and] you don't know [if] he's going to make it the next day, you don't want to be on your phone.

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<sup>31</sup> Employees of the federal government fall into a separate federal jurisdiction regardless of their province/territory of residence. There are therefore 14 jurisdictions that regulate sick days for workers – one for each of the 10 provinces, three territories, and the federal government.

<sup>32</sup> See Tucker & Vosko, 2021 for variations across jurisdictions.

For Rayna, it therefore made sense to put out a request to friends and family first with a promise to donate any surplus funds to a charitable organization – a practice that has become fairly common in medical crowdfunding campaigns. Although, as raised in Chapter Five, personal medical crowdfunding goals are often set in haste and likely under-report financial need (Kenworthy, 2018), in moments of mental and emotional distress, crowdfunding contributions – however small – may offer beneficiaries and their caregivers some relief against the uncertainty or inadequacy of supposed “safety nets” like employment insurance, job protection legislation, and private insurance.

The incongruence of labelling GoFundMe as a “last resort” even as campaigners generally create fundraisers within days of, or sometimes before, health-related financial struggles manifest might therefore reflect a widespread sense of cynicism that governments (as well as private insurers) will fulfill their role as “safety nets” – a perspective that both reflects and dovetails nicely with the “small government” rhetoric of neo-liberalism. That is, personal crowdfunding is seen by many as a safeguard against the porosity – real or presumed – of public and private sector “safety nets.” Still, it is worth repeating that as a supposed safety net against safety nets, personal medical crowdfunding campaigns, on the whole, perform poorly (in Canada: Zenone & Snyder, 2020; Saleh et al., 2020; in US: Barcelos, 2019; Berliner & Kenworthy, 2017; Igra et al., 2021; Kenworthy, 2018), and that the odds are predictably stacked against historically marginalized populations (Barcelos, 2019, 2020; Saleh et al.; 2020; van Duynhoven et al., 2019). In spite of this grim reality, people continue to turn to GoFundMe as medical crowdfunding is further cemented in the popular imaginary as a means of needs fulfillment. In so doing, crowdfunding participants – somewhat inadvertently – privatize

care in Canada by passing the burden of health care funding to individuals in their network which exacerbates existing inequalities (Igra, 2021; Igra et al., 2021; Saleh et al., 2020).

***Responsible but Not Accountable: Crowdfunders' Distrust in Governments***

At the same time, launching personal fundraisers does not mean that crowdfunding participants believe individuals are solely responsible for funding health-related needs of people in Canada. On the contrary, when asked about the responsibility of different pillars of society – the state, private businesses, and charities – in supporting people with extraordinary health-related expenses, interview participants overwhelmingly – and often without skipping a beat – responded that governments should be covering the cost. Many participants, however, questioned the integrity of governments in Canada: “I’ll be honest – I don’t really care for the government. I think they just screw people over,” explains beneficiary Shirley, whose adolescent son lives with an autoimmune disease.

Text found in crowdfunding campaigns similarly reflects a sense of distrust and/or disappointment in government programs but are worded in a notably milder manner. While many of the campaign descriptions contain criticisms of public provisioning – commonly with regards to inaccessibility, wait times, and insufficiency – few of them are pointed complaints, but rather, passing commentary that convey an overall sense of passive dejectedness rather than mobilizing anger. For example, campaigners often reference the residual nature of government benefits without sharing their or the beneficiary’s feelings about the lack of support or its serious consequences. A campaign for a 29-year-old cancer patient explains that “[t]hough he lives with supportive

roommates and is receiving disability payments, the government support is not enough...he has been unable to keep up with the cost of living and he has fallen into debt” (Dzikowski et al., 2023). Campaigners generally provide little to no elaboration of their passing criticisms of governments – in the form of, for instance, stories like Rayna’s (above) that recount frustrating interactions with government social service providers. Instead, in a campaign for a 70-year-old man who experienced life-threatening sepsis, the campaigners seem to trust that the meagerness of government benefits is such a well-established fact that there is no need to explain why multiple sources of government support do not add up to a sufficient income in cases of serious illness, even in a country with Medicare: “for the time being, [the beneficiary’s] only income comes from some US Social Security, Canadian Old Age Security and Canada Pension which leaves a significant gap” (Lief & Williamson, 2023). The campaigners then go on to frame the financial gap left by the state as an “opportunity for Kermit’s [the beneficiary’s] many friends...to show their care and support for his health and successful recovery!” (Lief & Williamson, 2023).

Crowdfunding campaigns for financial needs resulting from exclusions from government welfare programs follow a similar pattern. In one campaign, the creator Miriam offers a simple causal explanation of why her sister cannot access certain occupational welfare benefits while she recovers from a bad fall: “My sister is a tattoo artist, therefore she is not eligible for government help (i.e. welfare, disability, employment insurance) as she is self-employed” (Sabbah, 2023). Her sister is self-employed, *therefore*, she is ineligible for those benefits. In the campaign “Let’s Give Ariana Her Legs” benefitting a child with a rare disease, campaigner Vanessa states

matter-of-factly that “Trexo [robotic] legs cost \$50,000 and are not available for funding assistance” (Asmus, 2023). Neither of the campaigns convey a sense of outrage, for example, that the voluntary nature of Canada’s EI self-employed program leaves many unsuspecting workers with insufficient resources in case of sickness or injury nor that the government will not pay for a mobility device for an otherwise wheelchair-bound seven-year-old. The criticisms are instead mildly worded and give the impression that: a) there is no hope of changing government programs to better serve Canadians; and b) government incompetence is such a widely held belief amongst readers that further explanation or “proof” is unnecessary.

This discursive pattern is largely consistent with findings of a 2016 study of 80 Canadian medical crowdfunding campaigns that sought to understand how campaigners justify their requests. In it, researchers Snyder et al. (2017) note a curious and problematic absence in campaign descriptions:

...the fact that Canadian feel that they must appeal to families, friends and strangers for resources related to their medical care might reasonably be seen as an injustice – and yet, these campaigners almost exclusively chose not to frame their appeals for funding around the perceived injustice of their situation” (pp. 366-367).

The authors conclude that the popular uptake of medical crowdfunding thus risks “masking systemic injustices in the provision of healthcare” (p. 367) because the needs claims of a wider population are effectively depoliticized in crowdfunding spaces in favour of individual requests for private funding.

In contrast, interview participants readily shared detailed accounts of negative experiences with government services. However, in the case of the interviewees who were beneficiaries of a GoFundMe campaign, their stories of being failed by their governments rarely figured prominently, if at all, in their respective written medical campaigns. One reason for the discrepancy in content between public, written campaigns and private conversations is likely that in the context of a personal fundraising request, soliciting financial contributions takes priority over making demands or strong criticisms of governments (see also Chapter Five). Meanwhile, when given the opportunity to discuss how governments could better support people who need financial support for health-related reasons, interview participants had a variety of ideas to share, ranging from the familiar to the innovative, and from the micro- to macro-levels.

Interestingly, it was often interviewees with the more modest and least controversial demands for governments – for example, paying for prescription medications, offering a small stipend to beneficiaries for incidental expenses – who spoke with the least force, as if they were asking for a favour rather than an entitlement. Beneficiary Shirley, for example, who at one point was paying \$400 a month out-of-pocket for vitamin K for her son, after it had been prescribed and fully covered by Medicare during his hospital stay, said: “I mean, I wish the government would, you know, step up to the plate – for example, like even [to pay for] meds, right?...[Prescription m]eds are expensive so *it would be nice* if the government had different programs [to fund that]” (emphasis mine). Shirley, moreover, limited her “wish” for public funding to only children and seniors – age groups that generally have reduced or no capacity for earning income. Currently, some provinces/territories offer monetary

support for prescription medications outside of hospitals for certain populations, often based on their age, household income, disability status, income assistance status, and medical condition(s). “We’re lucky [to have] OHIP here,” Shirley tells me. Most of her son’s prescribed drugs – which she estimates to cost \$2,000 a month – are covered through OHIP based on his age, but her family still struggled to pay for the \$400 per month vitamin.

Like Shirley, campaigner-beneficiary Mark was humble and unassuming when explaining how the government could have provided better support pre- and post-surgery:

Other than [supporting medical patients] financially...I mean, yes, I would have liked someone [i.e. a medical professional] to stay at home to help me but I’m not sure that the government can really do that? If they can, yeah, I would have appreciated that.

In addition to taking out a personal loan to pay for surgery, Mark needed hands-on care during the recovery period. “I told my parents to come back for the time being because I needed the support. They lived with me for that period.” Certain provinces and territories do, in fact, provide homecare in specific medical scenarios. It is unclear whether Mark’s circumstances would have qualified for government-funded homecare but as contributor Wali explained to me based on his recent experience of being injured, the wait times to access such services can sometimes render them ineffectual. Personal crowdfunding might therefore seem like a reasonable pre-emptive measure to fill the gaps left by governments by, for example, hiring a private caregiver. However, based on my research, it appears far more likely that people rely on the unpaid labour of loved ones when available, as Mark did, or carry on with their needs unmet (see Chapter Five).

Meanwhile, interviewees who spoke about the need to reduce the red tape and barriers of accessing government support programs tended to express a sense of indignation and often anger. Speaking to her work experience supporting people with mental health struggles, contributor Melissa explains that she has encountered too many young people who have been excluded from welfare programs in Canada. Her terminally-ill friend, for example, who is the beneficiary of a GoFundMe campaign to which Melissa contributed, does not have enough insured employment hours to qualify for EI sickness benefits (see Chapter Two for EI eligibility requirements). Melissa explained that the beneficiary had only recently completed her education and was working part-time while trying to establish herself as an artist: “Why can't she get the EI? Why? Why can't she get a basic income support for this time? She's dying. [The government is] not going to have to take care of her that long.” Raising the question of government responsibility to Melissa fueled a rush of emotions, prompting a slew of examples of deficiencies in care in Canada:

Why is it so hard for [the beneficiary] to get treatment without driving hours for it? Why? Why isn't there better care available for her? For my friend whose mom and dad are in their 90s, and she's working, trying to support them, and she's lucky to get a PSW [government-funded Personal Support Worker] in [their home] for 10 minutes to do their job. She's going broke trying to live in Toronto, and trying to support her aging parents, all on her own because she's an only child. Um, what else? I just...I have so many thoughts I can't even like sort them all out at once.

Beneficiary Christine, a triple amputee, is an outspoken critic of the current state of social welfare programs in Canada, particularly of the restructuring of social welfare and health care funding in Canada that took place in and after the late 1990s (see Chapter Two). She believes that part of the problem of governments not being held accountable for their failures is not citizen apathy but a lack of transparency and awareness. Christine was told that when the CBC was preparing a segment on her story for the show *The Current*, a “fight broke out in the newsroom” because several journalists were mistakenly adamant that prosthetic limbs are fully funded through Medicare. “My story [on CBC] and even [my crowdfunding] fundraiser opened a lot of Canadians’ eyes...that they didn't have all these [safety] nets they thought they did.” During our conversation, Christine also shared numerous stories – her own and that of other people she knows – of having to “fight” with governments to access and maintain disability benefits in Canada. Despite her cynicism about public welfare programs, she remains steadfast in holding that the responsibility for the health and well-being of Canadians lies with governments.

Like Christine, other interviewees see the issue of unmet health and social needs in Canada within their broader contexts. Beneficiary Stephanie feels that health and other welfare systems are often poorly designed – inaccessible, insufficient, and hard to navigate – because decision-makers and administrators lack first-hand experience of having to use these services. She has since worked for government agencies, finding ways to centre the patient/beneficiary experience. For contributor Sam, one of the root causes of the growth of personal medical crowdfunding in Canada is insufficient wages. In addition to raising minimum wages, which vary by province/territory, to keep up with

inflation, he suggests that a universal basic income scheme would significantly alleviate the need for personal fundraising.

Overall, my conversations with GoFundMe users coupled with an analysis of written GoFundMe medical campaigns offer a window into how discourses of responsibility take form both in and adjacent to medical crowdfunding campaigns spaces. While the belief that governments should be financially supporting crowdfunding beneficiaries in Canada can be detected in many of the written crowdfunding campaigns examined, it is often expressed with little force and even less elaboration. Rather, the needs talk found in campaigns is primarily dedicated to soliciting private contributions by focusing on personal characteristics that make the beneficiary worthy of support (see Chapter Five). Meanwhile, research participants, when given the opportunity to discuss in interviews the state of Canada's safety net provisions, were more likely to express disappointment, anger, and frustration with government policies and institutions. Thus, although the impulse and need to privately raise funds for medical expenses are understandable, discourses in crowdfunding campaigns also tend to overshadow and therefore undermine discourses about citizen welfare entitlements and government responsibility.

### **Resistance *through* Crowdfunding, Resistance *to* Crowdfunding**

Fraser's (1989a, 1989b) needs talk framework understands the process of making and negotiating needs claims as comprising multiple overlapping "moments of struggle," which implies opposing discourses and dynamics of power. In their survey of various definitions of "resistance," Hollander and Einwohner (2004) find that despite differing opinions on whether visibility, recognition, and intent are fundamental components of

“resistance,” the presence of an oppositional force(s)/action(s) is common to most conceptualizations of the term. In my study, resistance is understood as actions and behaviours that intentionally challenge or reject existing relations of power (Faith, 1993) – that is, the status quo – and the material and ideological structures that uphold them (Rubin, 1996). Thus, even as personal crowdfunding sites like GoFundMe depoliticize needs talk by framing unmet health-related social needs as private fundraisers for individual beneficiaries, it is worth exploring if and how resistance is communicated, negotiated, and enacted in medical crowdfunding spaces.

Because personal medical crowdfunding campaign descriptions and updates are usually written by the beneficiary or their loved one(s), medical crowdfunding needs talk often contains a thread of resistance simply by virtue of allowing people to define their own needs and how they should be fulfilled. Most often, needs claims made in crowdfunding campaigns run counter to what is prescribed by social welfare policies and private insurance providers. Barcelos et al. (2019) explain, for instance, that individuals in Canada and beyond often turn to medical crowdfunding to access trans care that is otherwise not fully covered by public or private insurance schemes<sup>33</sup>. As discussed in the previous section, many written GoFundMe medical crowdfunding campaigns also contain passing criticisms of government provisioning.

### ***Resisting the Norms and Logic of Crowdfunding***

While medical crowdfunding is largely premised on individuals making a one-time monetary gift to a beneficiary, the co-creators of a campaign called “Sheri! A tall

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<sup>33</sup> However, in their study of 410 trans crowdfunding campaigns on GoFundMe created between March 2012 and May 2016, Barcelos et al. (2019) found that the campaigns raised only 24% of their goal on average.

drink of water we can't live without” suggest either a single or monthly contribution – the latter of which is an exceedingly unusual request for a personal campaign on GoFundMe. Granted, as part of its series of “how-to” articles for crowdfunding campaigners, GoFundMe (2021h) insists that many contributors “are probably willing to give again – they simply need a reminder” (section 6). Nevertheless, even the company’s strategies focus mainly on soliciting a “second donation” rather than a regularly recurring gift. GoFundMe notably does not have a pre-programmed option to make ongoing contributions at scheduled intervals on its for-profit platform even though its non-profit counterpart GoFundMe.org – which utilizes the same technology (GoFundMe.org, n.d.) – accepts monthly donations. Arguably, to accept recurring contributions for personal crowdfunding campaigns might imply adult dependency (see Chapter Five) and shatter the illusion perpetuated by GoFundMe that most illnesses and injuries are easily and quickly solvable (see Kenworthy, 2018). The creators of Sheri’s campaign put little emphasis on the idea of monthly contributions, neither explaining its heightened impact on the beneficiary nor expressing a preference for monthly contributions over one-off gifts. Still, mentioning a monthly option can serve as a passing but important reminder that health conditions – even acute ones – often translate to prolonged periods of income loss and out-of-pocket expenses (see Chapter Five).

Understanding that people with longer-term needs are often ill-served by GoFundMe’s model, campaigner Susanna has taken a more subversive approach to securing funding through the platform. Even though her friend Myla was able to raise a lump sum of money to help with their first gender affirmation surgery, Susanna felt it would be better to have someone else raise funds for Myla’s second procedure. She

explains that “it’s quite hard to ask for money for yourself because you’re seen as a beggar. I knew that people would be more likely to give to [Myla] if I made the campaign than if they made it. It’s a charity mindset.” Susanna adds that she similarly would not create a campaign for her own needs, not due to shame, but because she believes it would yield better results if someone asked on her behalf.

Moreover, since it was Myla’s second campaign, Susanna opted to frame their needs from a different angle:

Something that I remember when I did [their] second campaign – I noticed that medical ones don't do particularly well, so I framed it in a relation to helping them get through their degree 'cause people will pay for degrees. And I think it's interesting 'cause working- and middle-class people both know that post-secondary degrees cost a lot of money, regardless of race and privilege. And so I think they're more likely to donate to something like that.

In the second campaign, which was launched after Myla’s procedure had been completed, rather than soliciting monetary contributions to help with the loss of income during Myla’s recovery period, Susanna explained the need in relation to Myla’s education. That is, instead of:

[Myla] needs [financial assistance] in order to [avoid health-related debt.]

*A*   **needs**                    *x*                    **in order to**                    *y*.

Susanna opted for:

[Myla] needs [financial assistance] in order to [complete their degree.]

*A* **needs** *x* **in order to** *y*.

And, in fact, the costs of finishing their degree – both direct (e.g., tuition) and indirect (e.g., limited income-earning opportunities while studying) were major components of Myla’s financial struggles, which were further exacerbated by the loss of income during their recovery. In other words, Susanna’s campaign description was truthful, but she opted to shift focus of the needs-claim to something that she believes would have wider appeal. This type of strategic framing of an issue, and often of its solution, is a common practice in the production and circulation of needs talk, especially in increasingly saturated spaces such as crowdfunding websites. As the popularity of crowdfunding platforms like GoFundMe grows – according to the company, the website hosts upwards of 10,000 new campaigns per day (GoFundMe, n.d.-h) and has processed \$25 billion USD in contributions to individuals and non-profits since its inception (GoFundMe, 2022a) – campaigners/beneficiaries may feel growing pressures to combat the compassion fatigue that is known to circulate in charity fundraising (Moeller, 1999) and now crowdfunding environments. This example thus demonstrates that on the one hand, crowdfunding can allow campaign creators to exercise some control over how needs are interpreted and communicated, while on the other hand, those interpretations may be strongly shaped by the dynamics of the crowdfunding space itself.

Contributor Danielle agrees that despite her misgivings surrounding medical crowdfunding, she would not want to take the option away from people entirely because

the need for health-related financial support is so extensive across the country. In fact, she often finds herself having to push back against the widespread talk of “scammers” that permeates conversations around personal fundraisers, explaining that:

to actually get help, you have to persistently and doggedly ask for it, which is hard in and of itself. And if you’re not at peace with yourself, it’s excruciating....For people to say ‘I can’t afford to eat this week’ – OK, I’m going to take that seriously.... [People will ask me,] ‘What if they’re scamming you?’ and I’m like, ‘I’m only giving 10 bucks. If they’re scamming me – whatever.’ But the consequences of them actually not having food? The fallout of that is way worse.

For contributor Susanna, the immediacy of the financial need in many crowdfunding campaigns is both a point of convergence and divergence between GoFundMe and mutual aid practices. Spade (2020) describes mutual aid as a process which brings together the work of ensuring each other’s survival and bringing about social change. Understanding that the ethos of GoFundMe – particularly as cultivated by the industry giant itself as a form of charity (see Chapter Four) – is often at odds with the central tenets of mutual aid practices, Susanna nevertheless sees the value of GoFundMe as a tool for community building efforts:

I think GoFundMe is interesting 'cause I would say it does constitute solidarity or mutual aid because it's a community-grounded resource to try to...redistribute resources [from] people who have it in the community to those who don't, and who are in need of it. And that’s kind of the crux of what mutual aid and solidarity is. *But* GoFundMe is divorced from the

community efforts and the histories and legacies that have created mutual aid, which...in Toronto, Tkaronto specifically, it's like sex work activism, specifically black sex worker, black trans activism, Indigenous organizing, queer and trans organizing... these very grassroots community spaces that are very anti-police, anti-oppression, who have been doing this work and using mutual aid and solidarity not just because the government is not providing resources, but in resistance to the government to create a new pathway forward that's outside of the white settler state. And so GoFundMe operates in that same practice, but not the same ethos. It's kind of divorced from it. And so interesting things happen. And I've done this myself too in utilizing GoFundMe as a campaigner – you have to...you are doing mutual aid and solidarity, but you have to appeal to, and perform charity a bit.

### *The Limitations on Resistance*

As Susanna sees it, giving and receiving money through GoFundMe mostly constitutes survival work without the commitment to transformative change. To borrow from Fraser's (1989a, 1989b) vocabulary, crowdfunding is a primarily space for needs talk that is firmly enclaved, rarely "running away" into the official-political arena. This raises the question of whether GoFundMe can be understood as a step or component of mutual aid or communal redistributive traditions that are built on principles of solidarity and resistance (see Chapter Four) – one that harnesses the potential to initiate GoFundMe users into broader community-building practices. Susanna, who engages regularly in solidarity work in her local community, asserts that "When I made [the beneficiary's GoFundMe] page, it wasn't about resistance 'cause that wasn't the place to take up my

cause. It was the place to get [the beneficiary] money.” Thus, she feels that the charity-based ethos of the platform is simply too dominant for her to see GoFundMe as a space that is conducive to collective organizing.

On top of the strong pull of the charitable ethos of GoFundMe, contributor Anahi believes that it can be challenging for many people to recognize – let alone strongly criticize – the weaknesses of Canada’s social welfare programs because of comparisons drawn with the neighbouring United States. In the same vein, Nelly recognizes that even though she and her co-campaigners raised nearly \$50,000 for their friend, that amount would have been woefully insufficient had the beneficiary been hospitalized in the United States. Indeed, in a different GoFundMe campaign called “My Canada Visa for Healthcare” (DeLeon, 2023) the beneficiary explains that he is not requesting funds for direct medical expenses, but, instead, needs funds to renew his Canadian work visa so that he can continue to have access to Medicare. He writes: “[f]or the first time, I am getting the [medical] treatment I have been begging for in the USA my entire life” (DeLeon, 2023). Similarly, a campaign simply titled “Medical expenses” details how a Latvian woman unexpectedly gave birth to her son while visiting family in Canada:

Due to...complications and the seriousness of [the mother’s] condition, Jonathan was born via C-section at 33 weeks. The baby still had a long stay in the NICU, but thankfully this was covered by insurance as her husband is a Canadian citizen! However Anzelika [the mother] is not a Canadian citizen [so] no [public] insurance is covering her doctor & specialists appointments [sic], emergency room visits and the hospital stays overnight where she had to be monitored due to her complications! If

anyone has the heart to help this young family with unexpected financial burden it would be greatly appreciated! (Wall, 2023).

The campaign description above underlines both the strictness of Canadian Medicare eligibility as well as the complex emotions that accompany such a harsh duality. On the one hand, the family is grateful that the baby's care is fully covered by public insurance on account of his father's Canadian citizenship. On the other hand, the emergency care that enabled the mother to safely give birth to that same child must be paid out-of-pocket. Expressions of discontent with Canada's social welfare programs is therefore tempered in many cases by gratitude for having *some* access to such programs, however imperfect or limited.

But for contributor Melissa, it is precisely because she lives in Canada that she has higher expectations of her governments. Explaining that her friend (the beneficiary of a GoFundMe campaign) is struggling to access welfare programs as she deals with a terminal illness, Melissa says,

I don't understand why in Canada this happens. That is me getting on my Canadian high horse. You know, we're very judgy about our neighbours to the south...[but] look at homelessness in Toronto. There's a reason why people are homeless and it's not because they didn't try.

Many of the crowdfunding campaigns in this study also evoke values that are associated with Canada being a respected welfare state, including the idea that, as one campaigner wrote, "[n]o family should have to go through such a tough time and worry that their son may not be able to get the medical help he needs due to the financial side of it!" (Lincoln, 2023). While most people in the world would likely agree with this needs

claim, I suggest that there is a heightened commitment to this idea in Canada, which is broadly admired for its public universal health care program (P. Armstrong et al., 2001). That is, invoking the idea that everyone, regardless of their financial situation, should have access to medical care subtly frames the gaps in government welfare programs as a matter of injustice – one that feels “un-Canadian.”

Within the context of a crowdfunding campaign, however, the subtle appeal to injustice is made primarily in service of personal fundraising, thereby prescribing private funding as the “solution” that will fulfill the beneficiary’s needs. In doing so, a systemic injustice is reduced to an individualized problem and solution – one that is conceptualized largely as voluntary benevolence. Contributor Anahi worries that within the GoFundMe environment, the sense of gratitude that beneficiaries have towards their supporters might overpower and shift focus away from “making demands” to improve government services for everyone.

Meanwhile, a small number of interviewees acknowledged the conflict of participating in individualized crowdfunding to address a problem that is faced by many others across Canada. Contributor Isabella, for instance, explains that as happy as she was to support a fellow mom in her community through GoFundMe, “it feels unjust that somebody is spending time organizing something like this when it should already be covered [by taxpayer-funded programs.]” Susanna explains that a similar tension runs through other forms of mutual aid:

That’s the thing about mutual aid...it’s this weird site where it is doing the government’s job for free, so it’s almost complicit in [excusing

government responsibility], but at the same time, I have no interest in letting people die....

But as much as these interviewees try to reconcile the contradictions of personal crowdfunding – holding space to both contribute privately to the needs of loved ones while also recognizing the systemic injustices at play – many of them explain, as Susanna does above, that the moral imperative to immediate help someone in need takes priority. Several of them, in fact, argue that addressing the urgent financial needs of an individual is in and of itself a type of resistance against a system that thrives on the marginalization of specific populations. Contributor Danielle remains adamant, however, that in so far as personal crowdfunding can be life-saving to an individual beneficiary, it would be a mistake to rely on it as a system of care: “It’s this duct tape measure we have...that’s what crowdsourcing is. Is it effective? Yes, because duct tape is great. However, maybe you do need a [metal] screw or something!” she explains while laughing. Bischooping and Gazso (2016) explain that metaphors, such as the one used by Danielle, “work by taking mental associations about a source domain, one that is usually concrete and readily accessible, and mapping them onto a target domain that is usually more abstract or unfamiliar” (p. 38). In invoking a metaphor that likens Canada’s social welfare programs to a structure that needs to be repaired, Danielle underlines the systemic nature of the issue at hand and points to individual crowdfunding as an inadequate “fix” in the long term.

### ***Resisting the Narrow Definition of “Health”***

In addition to small acts of resistance against crowdfunding culture, a prominent thread running through participant interviews and the observed crowdfunding campaigns is a disagreement over what constitutes “health” and by extension, where responsibility

lies for supporting the health and well-being of Canadians. Analyzing crowdfunding discourses therefore provides a window into the misalignments in interpretations of what the *X* variable is in “A needs *X* in order to be healthy.”

Determination of what constitutes *X* largely falls under provincial/territorial jurisdiction. The Canada Health Act (1985), which governs the country’s public health insurance regime, has as its objective "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers" (section 3). Notably, the passing of the Act in 1984 opened up the public insurance scheme to fund preventative as well as curative treatments (P. Armstrong & H. Armstrong, 1998), although individual provinces/territories ultimately decide what is considered medically necessary in their respective jurisdictions. Still, expanding the focus of the Act from illness to health meant expanded coverage, in some regions, that included a wider range of practitioners (e.g., midwives) and modalities (e.g., physiotherapy) (P. Armstrong & H. Armstrong, 1998). At the same time, the growing use of online personal crowdfunding for health-related needs in Canada points to systemic gaps in needs satisfaction, which in part, result from differing interpretations of needs.

One such discrepancy arose between my interpretation of the phrase “medical expenses” and that of an interview participant. In the call for participants for my research study, I specified that I was seeking interviewees who had used GoFundMe as a campaigner, beneficiary, and/or contributor for medical expenses in Canada. Danielle volunteered to share her experience of contributing to multiple friends’ campaigns in the past, and when asked to describe the specific circumstances, she explained that in one

campaign, her friend [they/them] needed to replace a broken vacuum so that they could work part-time as a cleaner. “They couldn’t afford things to allow them to make money because they don’t have money because they have a disability. So it was not actually a medical thing, but it’s a result of a medical thing, you know?” Here, Danielle applies an expanded interpretation of “medical expenses,” challenging the narrowness of conventional understandings – including my own – of medical need. She adds that “studies show that literally just having a disability means that you pay 30% more to be alive than a healthy person.” Indeed, based on data from 2015 to 2018, researchers found that people aged 18 to 69 who live with disabilities in the United States require an additional 28% income on average – on top of what is already provided by governments – to achieve an identical standard of living as someone who does not live with a disability (Morris et al., 2020). A comparable statistic for Canada could not be found, but a growing body of literature shows that living with a disability carries significant additional direct and indirect costs around the world (McColl & Schaub, 2014). A 2017 survey found that 17% of persons (or 1.5 million people) aged 15 and over in Canada with one or more disabilities had an unmet need for an aid or device due to cost (Statistics Canada, 2018). In some disability communities, the hidden costs of disability are colloquially known as the “crip tax”<sup>34</sup>. Alicia and her partner (the campaign beneficiary), for example, used part of the money raised from the campaign to cover rent for a wheelchair-accessible apartment that would normally have been outside of their budget. In that sense, medical crowdfunding can in some circumstances help to lighten the burden of the “crip tax,” if

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<sup>34</sup> “Crip” is a reclamation by people living with disabilities of the otherwise pejorative term “cripple.” (Loeppky, 2021)

only on a temporary and inequitably-distributed basis. Notably, one of the contributing factors to Danielle's friend's (the beneficiary's) financial struggles is that they live with a debilitating disability but does not qualify for disability benefits based on their provincial/territorial government's criteria. Thus, the beneficiary's campaign served as a site where they could explain and circulate talk about their condition and their needs, countering the government's interpretation of what constitutes "disability."

More generally, multiple interviewees expressed the idea that the absence of illness is not the equivalent of being healthy. For contributor Anahi, the bias towards a biological understanding of "health" in the Canadian healthcare system is evident:

I think the current system focuses a lot on patches, like 'Oh, now you're sick, so now we do something.' But I think that we need to see health as a social aspect and not only as a biological one...if we expand [the interpretation] that way, then we can think about all these other aspects that support health and that play a very important factor that are not necessarily pills.

Anahi went on to explain that well-being can include the act of taking care of others, including, for example, not only cooking for others, but cooking *with* others as a practice of communal care. In her Latin American culture, people employ the concept of *red* (Spanish for "net" or "web") in relation to care networks. She further explains that she has heard people describe themselves as, metaphorically-speaking, a single stitch in a larger woven net that supports a community.

Similarly, contributor Melissa laments not being able to help others financially as she once did before she became chronically ill (and before GoFundMe was popular.) "I

lost my housing. I lost my car – everything,” she tells me. Now many years later, Melissa’s financial situation has improved, and she has resumed employment while managing her autoimmune condition, but the fear of “losing everything” again due to illness has made Melissa more cautious with her money. Still, she tells me that in an ideal world, she would be able to not only support her own needs but also “comfortably help my neighbours too. We’re supposed to help people if we can, you know?”

Anahi and Melissa’s reflections emphasize care-taking/receiving as a social activity, one that is rooted in interpersonal connection as much as it is about fulfilling physical needs. For Melissa, this manifests as a sense she has that,

GoFundMes are a little lonely. I don’t know. I don’t have a better word for it. You just send the money, you don’t get to give anybody a hug. Like when my dad had cancer, we had a barbecue for him, and everybody came and there were games and people bought [fundraising] tickets.... And it was an event, and everybody got to see my dad.

Certainly, raising money through GoFundMe does not preclude in-person interactions or gatherings; in fact, the sharing of a GoFundMe campaign may very well prompt friends and family to visit the beneficiary to bring food and other gifts. At the same time, what Melissa’s observation points to is the individualistic, distanced, and often transactional nature of online crowdfunding. GoFundMe’s platform is notably designed to facilitate asynchronous actions and communications. The convenience of sending money with the click of a few buttons, on one’s own schedule, can make for an easy replacement for a more intimate interaction such as a phone call or visit. And in an era in which digital communication is increasingly the norm, contributors may actually

prefer the distance afforded by virtual communication, perceiving live or in-person interactions as somewhat intrusive. Isabella, for example, felt more comfortable quietly contributing money to a GoFundMe campaign for a fellow community member than sending a meal because the latter would have required “bothering” them with questions about dietary restrictions and preferences. She also noted that for contributors, the ease and instantaneity of sending money electronically can offer a sense of emotional relief:

It feels like an immediate return for the feeling of distress....It’s a very tangible, quick thing where you're like, ‘I don't have to go to the store or anything’ ....You don’t even have to type in your credit card [necessarily] – you just click on the thing and if your Chrome [internet browser] is set up [with your payment information], it automatically does it for you. And so suddenly...it might not take the pain away so quickly, but it makes you feel like you've done something, anything.

Indeed, when asked why they think GoFundMe has become such a popular means of addressing social needs, most interviewees attributed GoFundMe’s industry dominance to its user-friendliness and efficiency. But while the reach, simplicity, and instant gratification offered by GoFundMe may translate to more monetary contributions than one might receive through in-person solicitation, the transactional experience of giving money through GoFundMe also runs the risk of not nurturing social bonds as effectively (see, for example, Mauss, 2000), and in the worst-case scenario, may even be prone to being forgettable. For instance, when asked about her giving history, campaigner Nelly had only a vague memory of some of the beneficiaries she has supported: “Yeah, I don't remember exactly which one, but I believe it was like a friend of a friend’s or

something. It was one of those [campaigns] you just come across and you know them, and [so you think] ‘Yeah, sure, here. Here’s a bit [of money],’ but then that was it, right? It was like a blip in my day.” In this scenario, Nelly’s initial connection with the beneficiary was strong enough that she contributed to their campaign, but the experience neither moved their relationship beyond the level of acquaintances nor even cemented a clear-cut memory in Nelly’s mind. And while her monetary gift may have been gratefully received by the beneficiary, the casual, spontaneous nature of Nelly’s contribution also suggests that – similar to impulse donations to registered charities – gifts given through GoFundMe can often be highly transactional, unpredictable, and contingent.

Meanwhile, in Anahi’s home country, people use the verb “to activate” to describe how they respond when someone in their community is struggling from an illness or other non-medical emergency. Friends, family, and neighbours “activate” or mobilize to offer hands-on care as well as to solicit and gift non-monetary resources. She explains,

So for example, with the [COVID-19] pandemic, people had a lot of hardship. Like they were having problems to eat, to find food and things like that. It was really, really bad and what they did is create these networks among friends or among neighbors.

Rather than giving money directly to the beneficiary, Anahi tells me that it is more common for people within the network to procure items for the beneficiary, such as food, medication, or clothing<sup>35</sup>. Community “activations” of this variety are similar to the

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<sup>35</sup> The reasons for purchasing and gifting items to the recipient rather than giving money in this non-Canadian context are beyond the scope of my study but nevertheless point to the social meaning(s) of money that are specific to a culture or region (Zelizer, 2011; see Chapter Four).

practice of participating in a money pool cooperative (or ROSCA, as detailed in Chapter Four) in the sense that while money is a fundamental component of the process, participants also place heavy emphasis on the social aspect of each practice, or as Anahi phrased it, “It's not about fundraising....It's about...networks.” And while it is true that the success of GoFundMe campaigns also hinges on personal networks – more specifically, the financial capacity of one’s network which is inflected by intersectional inequities (Igra, 2021, van Duynhoven et al., 2019) – it is fundraising that necessarily takes centre stage because GoFundMe derives its profits from money that flows through its website. That is, as a platform that thrives on fundraising transactions, GoFundMe’s environment prioritizes network extraction over network-building. Even though drawing upon a community as a financial resource and strengthening community bonds are not necessarily mutually exclusive, contributor Susanna sees GoFundMe as a platform that “adapts” or appropriates mutual aid and solidarity practices to turn a profit, making it a space of individual survival rather than of collective resistance.

Nevertheless, all interviewees – including those who strongly critique and resist certain aspects of GoFundMe and its culture – agree that the platform has opened up a space for needs to be articulated, disseminated and, in some cases, met. Contributor Danielle feels that the sheer volume of GoFundMe medical campaigns in Canada makes evident that needs are not being adequately met for people living in this country.

## **Conclusion**

As many GoFundMe contributors and campaigners attest, part of the continued allure of GoFundMe is that it gives users the feeling that they are “making a difference.” This chapter has explored questions around the transformative potential of personal

online medical crowdfunding, seeking to understand how and to what extent campaigners and beneficiaries assign responsibility through crowdfunding needs talk, and if and how acts of resistance are carried out in crowdfunding spaces.

In comparing publicly-accessible GoFundMe medical campaigns with the responses of interview participants, I noted an important discrepancy in discourses of responsibility. In written campaigns, critiques of “safety nets,” when present, are more likely to appear as accepted matters-of-fact rather than passionate calls-to-action or lamentations of injustice (see also Snyder et al., 2016). Meanwhile, when given the opportunity to freely share their views on government responsibility for the health and well-being of Canadians, interviewees were significantly more vocal about the systemic failures of Canada’s welfare programs. I attribute the discrepancy to the overpowering nature of the fundraising imperative and the individualizing thrust of GoFundMe. That is, the need to convince readers to make a voluntary contribution along with the charitable ethos embedded into the platform feeds a tendency to focus on the worthiness of the beneficiary (see Chapter Five) rather than to explain how their individual circumstances reflect broader collective issues. Even seasoned community organizers like Susanna intuitively know, for example, that GoFundMe is “not the place” to rally against governments or build social movements, but instead, it is a place to solicit money. Despite a widespread distrust in Canadian governments, the belief that governments should be responsible for the health-related financial needs of Canadian patients remains apparent in crowdfunding needs talk.

Medical crowdfunding spaces like those created by GoFundMe thus embody a deep tension between a patriotic commitment to universal healthcare as an entitlement in

Canada and the urgency of reducing the financial struggle and emotional turmoil of individuals, who are most often close friends and family members. In some cases, GoFundMe users will exercise their resistance to particular aspects of personal crowdfunding even as they participate in supporting beneficiaries in need. Earlier, for example, I situated Susanna's decision to frame her friend's crowdfunding campaign around their degree completion instead of their medical needs as an act of pushing back against the dynamics of personal crowdfunding. While it is impossible to know if her strategy raised more or less funds than if she had put greater emphasis on medical need, my point is to highlight how GoFundMe participants may try to subvert or resist certain aspects of crowdfunding culture while still using the technology. The acts of resistance – however micro – are worth examining because it shows both the possibilities and constraints of medical crowdfunding.

Exploring the themes of responsibility and resistance in crowdfunding spaces reveals that the privatized, individualistic, and charity-based ethos of GoFundMe personal medical crowdfunding limits space for both the language and actions of collective resistance against injustices, while simultaneously perpetuating the inequitable redistribution of financial resources through the mechanisms of the platform itself. The irony of the situation is not unique to medical crowdfunding but forms part of a larger self-perpetuating social problem wrought by neo-liberalization. Mazelis (2017) observes that, “[a]s the public safety net has eroded, society places increasing pressure on individuals and private safety nets. This is [sic] turn encourages the language and perspective of individualism, in a vicious cycle” (p. 5). Moments of resistance can and do exist in medical crowdfunding spaces, and yet the possibility of using GoFundMe to

pursuing collective social transformation to break free of the vicious cycle is slim given that the platform thrives on unmet needs and private safety nets. Sustained inequality and unmet needs, in other words, are conditions of possibility for the medical crowdfunding industry.

## **Chapter 7. Conclusion: Rethinking Personal Medical**

### **Crowdfunding**

Approximately one year before I embarked on this research project, I explained to one of my professors that I wished to study how medical crowdfunding unfairly puts people in a “popularity contest.” Her response was to ask, “OK, but what *don't* we know about crowdfunding?”

Her simple – yet poignant – question has helped guide this exploration of medical crowdfunding in Canada. With an eye to understanding why personal medical crowdfunding has gained visibility and popularity, in the sense of becoming a ‘commonsense’ response to health crises, in a country that prides itself on its public health insurance system, this dissertation has shared first-hand accounts from people who have, in various capacities, participated in personal crowdfunding for health-related expenses in Canada. Their stories not only reveal significant gaps and shortcomings in Canada’s welfare “safety net,” but also shed light on the ways in which people think about, seek, and provide care in Canada in the age of neo-liberalism.

This dissertation began by locating the practice of personal medical crowdfunding – specifically through the platform GoFundMe – within its broader political, social, and economic contexts in Chapter Two. Applying the lens of social reproduction, drawn from feminist political economy, offers insight into personal crowdfunding as a social relation that sustains capitalism materially (by privately funding the reproduction of present and future workers) and ideologically (by maintaining the idea that care activities are private matters that fall outside of the responsibility of the market). Chapter Three outlined the critical discourse theories and methods I used to collect data. Chapter Four explored how

different redistributive traditions across space and time, including medical crowdfunding, reflect an underlying ethos that drives each practice. An analysis of GoFundMe's promotional materials (mostly "how to" articles targeted at campaigners) revealed how the company frames personal crowdfunding as charity and accordingly, encourages campaigners to apply techniques of optimization that are typically reserved for professional fundraisers.

In Chapters Five and Six, I explored personal medical crowdfunding as a space of enclaved needs talk – wherein stakeholders struggle for the power to interpret, legitimate, and secure private funding for their health-related needs (Fraser, 1989a, 1989b). In Chapter Five, I examined both the opportunities and limitations afforded by medical crowdfunding for campaigners to define the beneficiary's needs. Although crowdfunding platforms like GoFundMe give campaigners and beneficiaries some authorial control, my interview participants also disclosed that many of their needs are left untold and unmet through crowdfunding, in part due to the unique dynamics and "unspoken rules" of personal fundraising. It is worth emphasizing that since these unmet needs are arising from campaigns that already fared unusually well in their fundraising, it is reasonable to think the needs would be even greater for beneficiaries of less successful campaigns. The chapter also exposed how deservingness is discursively constructed in medical crowdfunding campaigns, demonstrating that a beneficiary's worthiness is often tied to their personal character. My data showed that deservingness is frequently established by painting a picture of the beneficiary as someone who is reliable, hard-working, and generous with others, but importantly, would (normally) "never ask for help." I illustrated that the tendency to appeal to these personality traits as justification of the beneficiary's

worthiness reflects and reinforces the capitalist dichotomy of “good” and “bad” dependencies (Fraser & Gordon, 1994).

Chapter Six explored the themes of responsibility and resistance in crowdfunding discourses and finds that despite a deep cynicism about governments’ intentions and competencies, interview participants maintain that their governments should be responsible for ensuring the basic welfare of people in Canada. Even as individuals use GoFundMe to give and receive financial support, they commonly push back against or try to subvert some of the discourses about, and customs of, personal crowdfunding spaces, such as the intractable fear of “scammers” or the way in which “health” is narrowly defined. At the same time, resistance against the language, norms, and logic of crowdfunding and broader calls for collective justice are often stifled by the urgent need to raise funds (and its attendant conventions and expectations).

## **Towards a Critical Theory of Medical Crowdfunding**

From the outset, my main objective in this study has been to develop a critical understanding of medical crowdfunding in Canada. Following Fraser’s (Fraser & Jaeggi, 2018) framework for developing a critical theory of capitalism – and in my case, of a narrower phenomenon emblematic of capitalism – my critique of personal medical crowdfunding is threefold: operational (see footnote 3), moral, and ethical.

### ***Operational Critique: System Failures***

The basis of an operational critique of capitalism, according to Fraser (Fraser & Jaeggi, 2018) is not merely an evaluation of its performance according to its logic (i.e., prescribed functions); the critique also necessarily entails a normative assessment of how well or poorly a capitalist mode of organization in a given realm serves society’s needs

and desires. Applying this line of inquiry to medical crowdfunding necessitates taking into account the intended and unintended effects of its capitalist organizing principles.

To that end, an operational critique of medical crowdfunding calls attention to its poor performance (in dollar terms) as a personal medical fundraising tool. While some might question the value of pointing out GoFundMe's ineffectiveness as a product (i.e., an outcome), when we consider the gravity of the situations at hand – people who may be at risk of missing rent/mortgage payments, accumulating medical debt (Chapter Five), rationing medications (Gupta et al., 2019; Holbrook et al., 2021), re-using equipment against professional guidance (Chapter Five), or foregoing activities such as bathing safely (Chapter Five) – the critique bears emphasis: GoFundMe fails to deliver the necessary funds to a majority of its medical crowdfunding consumers, with many campaigners raising little to nothing (Igra et al., 2021; Kenworthy, 2018; Saleh et al., 2021; Zenone & Snyder, 2020). Moreover, as I demonstrate in Chapters Five and Six, GoFundMe campaigners' ability to interpret and communicate their needs via crowdfunding – often in resistance to interpretations of beneficiaries' needs dominant among policymakers and public institutions – is hampered by the ethos of charity that surrounds medical crowdfunding, thanks in no small part to GoFundMe's marketing efforts (Chapter Four).

An additional concern about GoFundMe medical crowdfunding relates to its role in upholding the dominance of capitalism as an organizing principle. I have situated personal medical crowdfunding within its neo-liberal context as an example of what Fraser (Fraser & Jaeggi, 2018) characterizes as a “release valve” for capitalism. That is, privately-funded, temporary stopgap measures, including personal crowdfunding and

charitable donations, often help contain poverty and its effects to populations that hold the least political power, and in doing so, stave off widespread social unrest and political upheaval (INCITE! Women of Color Against Violence, 2007; Livingstone, 2013; Roelofs, 1987). As with charitable donations, making contributions to personal crowdfunding campaigns is framed as voluntary benevolence, but when we consider that taxpayers are privately filling gaps left by governments and capitalist markets which depends on un-/under-waged reproductive labour, then we can see with greater clarity the functionalist role that personal medical crowdfunding plays in sustaining a deeply dysfunctional capitalist social order.

***Moral Critique: Making False Promises and Celebrating Inequality***

Building on the operational critique of GoFundMe's poor performance, the moral critique takes issue with GoFundMe's false promises of fundraising success and social media virality (Chapter Four) which are rarely questioned or challenged by mainstream news media (Murdoch et al., 2018). While GoFundMe touts that thousands of campaigns are created per day on its platform, the company conveniently omits from its advertising how little money campaigners typically raise relative to their crowdfunding goal. People who browse through GoFundMe campaigns by category or as suggested by the platform's algorithms also tend to obscure this reality by prioritizing campaigns with fundraising momentum (Chapter Three). Research studies on personal medical campaigns in particular – which according to GoFundMe accounts for a third of all money raised through its platform (Cerullo, 2019) – paint a grim picture of crowdfunding outcomes, especially for already marginalized populations (Igra, 2021; Igra et al., 2021; Lukk et al., 2018; Kenworthy et al., 2020; Saleh et al., 2020).

The fallout of giving false hope to people in need goes beyond a shortfall in funds – the effects of which should not be taken lightly. It takes a toll on beneficiaries’ mental health. The overly-optimistic tips and tricks that GoFundMe offers to campaigners only heightens many campaigners’/beneficiaries’ sense of personal failure when they do not reach their crowdfunding goal, which is the statistically likely outcome. For example, even though campaigner-beneficiary Rayna ultimately reached her \$5,000 goal thanks to a friend who gave an exceptionally large sum to top up the campaign, she is still left wondering why her son’s serious heart condition was not enough to garner the sympathy and support of “random people” (i.e. strangers) as she had been led to believe by popular representations of medical crowdfunding campaigns. She is also disappointed that she was not able to raise awareness for congenital heart disease nor raise excess funds to donate to related charities.

An overlapping moral critique of crowdfunding calls attention to the perverse winner-takes-all mentality that pervades crowdfunding and GoFundMe’s business model. GoFundMe serves as a pseudo-competitive marketplace of unmet social needs. In this environment, vastly uneven fundraising results across personal medical campaigns are not only widely observable but normalized and celebrated. Medical crowdfunding is by no means a zero-sum game – a monetary contribution to campaign A is unlikely to translate to a loss of a contribution to campaign B as they are generally independent events – but there is still something unsettling about a platform where total contributions are exceptionally concentrated in a small number of “viral” campaigns by design. In one study of over 100,000 COVID-19-related U.S. personal crowdfunding campaigns, for instance, researchers found that after “limiting the analysis to campaigns that received at

least 1 donation, the top 1% of campaigns received 23.1% of all donations and 23.6% of all money raised” (Igra et al., 2021, p. 4). Moreover, some of the success of the campaigns in the top 1% was attributable to money contributed by GoFundMe’s charitable division as either seed or matching funds (Igra, et al., 2021). Instead of trying to mitigate or hide the deep inequities of personal medical crowdfunding, GoFundMe’s policies and actions often favour relatively high-performing campaigns. Notably, there are no monetary limits on campaigns, GoFundMe’s algorithms give additional exposure to already-popular campaigns on its website, and the company often directs its resources – including financial contributions and public relations efforts – towards a select number of campaigns that are newsworthy at the given moment in time. The industry giant thus cultivates an environment that mimics neo-liberal free markets: an acceptance of vast disparity, unfettered concentration of wealth directed towards a miniscule elite, and a “governing” body (i.e. GoFundMe) which intervenes in favour of relatively high-performing campaigns.

### ***Ethical Critique: “Us” versus “Them”***

The ethical critique of crowdfunding concerns the way it affects users’ ability to live a dignified, meaningful life (Fraser & Jaeggi, 2018), of which a significant component is our relationships with others (Fairclough, 2010; Fraser & Jaeggi, 2018). As Fairclough (2010) explains, critical social research necessarily contains this ethical strand, which seeks to understand “why contemporary capitalism prevents or limits, as well as in certain respects facilitat[es], human well-being and flourishing” (p. 2). Thus, the ethical critique stems from a view of capitalism as a social and economic regime that impoverishes and alienates its workers, waged and unwaged (Fraser & Jaeggi, 2018).

On the one hand, GoFundMe has become a highly visible display of not only great need, but also of relations of care. Medical crowdfunding has been shown to inspire acts of caring, which may solidify or renew interpersonal relationships. All of the beneficiaries whom I interviewed expressed deep gratitude for the generosity of their contributors, and a few interviewees were pleasantly surprised to find strangers supporting their campaign. On the other hand, GoFundMe also predominantly fuels caring actions in a way that favours an in-group, individualistic mindset. Personal crowdfunding is predicated on existing interpersonal relationships – that is, a contributor gives money to a named individual who is most often a friend or a friend of a friend of the contributor. Implicit in this network model is the idea that it is safer to contribute to a beneficiary whom one knows personally or through a friend than to an unnamed stranger, such as someone on the street or on the receiving end of a registered charity’s services. As Granovetter (1983) explains, person A is more likely to trust person C if there is an intermediary contact, Person B, who can provide assurances to Person A or intervene on Person A’s behalf if an issue arises. The heavy reliance on personal connections as an implied vetting mechanism has also been shown to exacerbate socio-economic inequities (Igra, 2021; Igra et al., 2021; see also van Duynhoven et al., 2019). By contrast, public, universal provisioning programs like Medicare are not only designed to be redistributive across populations groups – crucially negating the reliance on the wealth of one’s personal contacts – but also remove the stigma of receiving “charity” (see Chapter Four for analysis of the word “charity” across different registers of meaning) since all Canadian residents contribute to, and directly benefit from, the public health insurance scheme.

To be sure, there are other private resource distribution practices that similarly rely on familial and community networks to support a single beneficiary, but as illustrated in Chapter Four, many of those practices also prioritize community-building through fostering longer-term commitments to one another that are not primarily based on a one-time monetary gift. Meanwhile, my analysis illustrates that there is a strong “us” versus “them” mentality that runs through crowdfunding discourses, whereby participants not only tend to draw a line between legitimate and illegitimate reasons for crowdfunding, but also extend the judgement to the beneficiaries as “deserving” or “undeserving” people. In Chapter Six, for example, I detailed how a central focus in many campaigns is to establish the worthiness of the beneficiary by attesting to their prior record of self-sufficiency, dependability, and hard work. In interviews, it was surprisingly common for participants across all categories (beneficiary, campaigner, and contributor) to voluntarily bring up the topic of crowdfunding “scammers,” even though only one interviewee had first-hand experience with a dishonest campaigner.

More broadly, due largely to GoFundMe’s cultural impact, words like “fundraiser” and “cause,” which were once primarily associated with helping marginalized groups (e.g., lone mothers) or addressing a public issue (e.g., climate change), are now readily used to describe efforts to aid an individual. This is not to deny the legitimacy of the beneficiary’s needs, but to point out, instead, that the rapid growth of GoFundMe has blurred the line between private and public benefit – which, in Canada, is one of the main criteria that qualifies an organization as charitable. The personal and social are thus presented as equivalent. A phrase such as “raising funds for a good cause” can interchangeably refer to a personal medical campaign for a family member

undergoing cancer treatment or a charitable fundraiser for cancer research. Both personal crowdfunding and formal philanthropy represent voluntary, private funding and are therefore ill-suited to addressing social issues such as climate change and pandemic relief. However, blurring the line between individual and marginalized populations as beneficiaries of voluntary contributions only deepens the tendency to mistake collective struggles as individual ones. And as promotional language, framing, and dissemination techniques are increasingly integrated into both personal crowdfunding and charity marketing, contributing money to a personal medical campaign can begin to feel like just another “donation” – a consumer choice amongst many, a yes/no transaction. On the side of the campaigner or beneficiary, GoFundMe also encourages campaigners to take a highly instrumental view of friends and family, leveraging their social networks to increase campaign visibility and contributions. Thus, the adoption of personal medical crowdfunding has also affected the way that we view and engage in relations of care.

Moreover, while personal medical crowdfunding has given people greater control over how their story of health-related financial struggle is told, my research suggests that crowdfunding discourses predominantly reproduce rather than challenge the stigma attached to asking for money. Feelings of embarrassment and shame were readily expressed in the responses of interview participants and in crowdfunding campaign descriptions. I have attributed these sentiments to a capitalist conceptualization of adult dependency as a deficiency in an individual’s personal character (Fraser & Gordon, 1994) – a belief that GoFundMe perpetuates by its persistent framing of crowdfunding as a form of charity (see Chapter Four).

Meanwhile, it is worth acknowledging that GoFundMe has helped normalize acknowledgments of personal financial struggle, even if there is still deep stigma attached to it. Personal medical crowdfunding has brought greater attention to the financial vulnerability of even middle- to upper-income people in Canada (see van Duynhoven et al., 2019) in the face of major health issues. At the same time, GoFundMe’s business model has become so heavily associated with, and promoted as, a response to short-term, emergency situations that campaigns for longer-term or episodic needs – such as for people with chronic illnesses – tend to fare significantly worse on the platform (Kenworthy, 2018). In interviews, several participants recognized that repeated requests for money via crowdfunding may not be well received by friends and family (see Chapter Five). As such, GoFundMe has helped normalize asking for financial help only in moments of acute, temporary need, thereby reinforcing capitalist tropes of what constitutes “good” versus “bad” dependencies (Fraser & Gordon, 1994).

## **Towards Emancipatory Alternatives**

One might be tempted to conclude from the foregoing critique that the answer is to abandon the practice of personal medical crowdfunding altogether. Such a response, however, is not realistic in the short term, although it is one my findings support in the long term. Nor does the strategy of simple abandonment address the core problem: namely, that people in Canada are struggling financially to meet their health-related needs. Instead, my hope is that the findings of this study can help us understand that the small but rising popularity of GoFundMe personal medical crowdfunding is a symptom of, as opposed to a cure for, two converging developments – a false conception of illness (and related caregiving responsibilities) as exceptional, and a creeping re-privatization

which, taken together, further entangle the survival and well-being of those facing personal medical crises, currently and in the future, in the insidious logic and dynamics of neo-liberal capitalism. Moving away from personal medical crowdfunding and similar vehicles of privatization necessitates collective resistance against individualization and responsabilization in favour of collectivism and universality.

### *Rejecting the Myth of Exceptionalism*

As several interview participants observed, an aura of exceptionalism often surrounds healthy people's mindset around illness, chronic conditions, and disabilities. Even as we are regularly reminded by medical professionals and charities that two out of five Canadians will be diagnosed with the disease in their lifetime (The Public Health Agency of Canada, 2021), individuals are often caught off-guard by illnesses and conditions that cause temporary or long-term interruptions to their employment (or that of a loved one who must provide hands-on care). The framing of sickness and caregiving responsibilities as exception can also be observed in social policy, notably within the "special benefits" component of Canada's Employment Insurance (EI) program. As Tucker et al. (2020) demonstrate, existing sick and caregiving leaves and benefits administered by various levels of government in Canada's liberal welfare have improved over the years but are still "[out] of necessity, premised on exceptionalism – cast falsely as accommodations – as though responsibilities for care are aberrations rather than ongoing in workers' everyday lives across the lifecycle" (p. 45, emphasis mine). The COVID-19 pandemic challenged such misconceptions radically – albeit fleetingly – revealing the fault lines in social policies and associated social safety nets and in healthy people's everyday conceptions of care needs. Meanwhile, GoFundMe both feeds and

feeds on the mentality of exceptionalism, accumulating profits by cultivating an environment that privileges knee-jerk responses over sustained support, monetary extraction over relationship-building, and acute illnesses and injuries over chronic or recurring conditions (Kenworthy, 2018).

This false sense of exceptionalism hinders our collective ability to see the proverbial forest for the trees and therefore to seek sustainable, collective solutions rather than contingent stopgap measures aimed at individuals. Fluctuations in caregiving/receiving needs are not the exception, they are the rule – that is, a normal and inevitable part of the life course. The struggle to meet financial needs when one’s capacity to earn an income is diminished for health reasons, whether temporarily or permanently, is not a personal failure but a systemic one – a sign of an inadequate social safety net that universally supports people in their times of need.

Correcting this collective myopia does not necessarily require that we ignore the crowdfunding requests of loved ones but, instead, can entail a variety of actions that treat care needs as wholly unexceptional and therefore, a collective responsibility. For example, building on lessons (to be) learned from the COVID-19 crisis, Tucker et al. (2020) call for reforms to EI sickness and caregiving benefits aimed at improving accessibility, sufficiency, and worker-centered protections and flexibility. In tandem with advocating for expanding social assistance programs provincially and healthcare programs (broadly conceived), efforts to build and maintain non-state collective systems of social support at the community-level – such as money pools (Chapter Four) and other mutual aid initiatives – remain important for populations who are or have been historically marginalized by, and therefore (rightfully) distrustful of, governments. More

broadly, following The Care Economy Initiative (n.d.), Canadian governments and voters must re-orient public policies and public spending to treat “care, paid and unpaid, as a fundamental component of [the nation’s] basic infrastructure...[that is] key to the functioning of all the other parts of the economy” (para. 7, point number 1).

### *Stemming the Tide(s) of Privatization*

From the start, I have approached personal medical crowdfunding spaces as a form of enclaved needs talk (Fraser, 1989a, 1989b) or discourses that re-privatize responsibility for welfare needs. True to H. Armstrong et al.'s (1997; see also Canadian Centre for Policy Alternatives, 2000) assertion that privatization takes many, often overlapping, forms, medical crowdfunding exemplifies multiple manifestations of privatization. The most obvious form of privatization in crowdfunding is that individuals are being asked to pay for medical equipment/services, lost wages, travel and accommodations to access treatment, etc. The less visible but related component of that shift is the added work and mental burden that is downloaded onto individuals. Amateur campaigners are taking on the stress and workload of soliciting funds and, in some cases, news media coverage. Beneficiaries often feel the stigma of asking for help from others. Beneficiaries’ friends and family members, many of whom are themselves confronting the pressures of rising precarity and inflation, are encountering a growing number of GoFundMe requests on their social media feeds. Perhaps the most insidious facet of privatization via crowdfunding, however, is the welcoming in of a profit-hungry intermediary – GoFundMe and similar for-profit platforms – and with it, the market-driven tactics that favour monopoly over justice.

Resisting privatization compels greater investment in public infrastructure and social provisioning. One example is to devote more resources to hospital social workers to ensure that all in-patients have support in navigating what is often a piece-meal safety net of public (governmental) and private (charitable) programs. Although several beneficiaries told me that they were assigned an in-hospital social worker, most of the interviewees felt that the service fell short, often because the social workers were overstretched with patients or were neither well-versed in public nor charitable resources. Meanwhile, beneficiary Christine received superior care and support from someone whom she describes as “sent by angels” – an employee of a health charity (unrelated to Christine’s medical condition) that operated out of the hospital who, *by chance*, noticed Christine’s deteriorating mental health. This person went above and beyond – and likely unpaid – to assist Christine even after she was discharged. The emotional and material support that Christine received through this person – securing funding for a stairlift and a specialized prosthetic arm for exercise, applying for a driver’s license etc. – ought to be standard care for all hospital patients who need it rather than a result of “divine” happenstance.

The COVID-19 virus not only revealed the inadequacies and insufficiencies of pre-pandemic welfare policies and programs – especially with regards to employment insurance, including sickness and caregiving benefits – but also showed us that governments are, in fact, capable of expanding and changing policies to better serve the needs of Canadians. What is lacking therefore is a willingness to acknowledge that even without a deadly epidemic, the status quo still constitutes a crisis in care (The Care Collective, 2020; Tucker et al., 2020; see also Fraser, 2016). Emancipatory pathways and

possibilities, therefore, lie in the inherent contradictions of the capitalist system. Capitalism's crisis of care is made abundantly clear in the growing number of medical crowdfunding campaigns in Canada. Taken together, these campaigns capture in words, photographs, videos, and even hashtags the financial struggles and uncertainty faced by individuals and their caregivers in this country. They document the gaps and inadequacies of Canada's safety net. But if we continue on with the "whack-a-mole" approach of dealing with medical crowdfunding campaigns as isolated struggles – some of which we will contribute to, most of which we will not – then we are unlikely to engage in the kind of collective needs talk that is necessary to demand better welfare policies and infrastructure.

## **Conclusion**

*Critique is grounded in values, in particular views of the 'good society' and of human well-being and flourishing, on the basis of which it evaluates existing societies and possible ways of changing them (Fairclough, 2010, p. 7).*

Returning to the original question posed by my professor when I began to undertake the research for this dissertation, while it is impossible to know everything about personal medical crowdfunding, I have sought greater clarity on the motivations, limitations, and complex and evolving consequences of this increasingly normalized social practice. Personal medical crowdfunding both stirs a collective sensibility and individualizes struggles; it elicits both deep generosity and deep(er) shame; and is both life-affirming and life-denying in ways that exacerbate inequities along intersecting axes of oppression.

In most cases, GoFundMe makes visible some of the best facets of our shared humanity – the desire to lend emotional and material support to people who are

struggling – and channels it towards a profit-extracting, individualistic, and pseudo-competitive practice. GoFundMe is not the cause of poverty nor of insufficient public provisioning in the form of social welfare, healthcare and the like; but it by no means solves these profound social problems either. Instead, it ushers us further into short-term, short-sighted thinking and actions that are modeled on free market logic and its all-too-familiar expressions of private responsibility, commodification (promotional culture), and individualism.

***Rigging the “Game:” How GoFundMe Adds Insult To (Literal) Injury***

GoFundMe creates a pseudo-competitive environment for medical fundraisers, encouraging campaigners to adopt strategies to optimize campaign shares and contributions (see Chapter Four). On its own, this is problematic given the gravity of the situations that prompt the fundraisers. Whereas GoFundMe was originally founded to enable people to collect small contributions towards big occasions such as weddings and vacations, today it has become a de facto safety net for food, housing, and medical expenses. Meeting survival needs has thus become intertwined with promotional techniques and considerations – hashtags, optimal word counts, and justifications of personal worthiness, amongst others.

But the more insidious problem is that the “competition” is rigged. If true competition, as Davies (2017) explains, implies some baseline standard of equality at the outset – for example, rules against discrimination; matching players based on ability, size, experience etc. – then platforms like GoFundMe that use algorithms and a PR team to boost exposure of campaigns that show the greatest promise of raising funds (and therefore the company’s profits) can only be described as anti-competitive and worse yet,

biased against the campaigns that are struggling the most. Nevertheless, few people question GoFundMe's money-hungry tactics because, as Davies (2017) points out, neo-liberal capitalism teaches us to accept gross inequality of outcomes as inevitable and normal. Worse yet, the quiet assumption that lurks beneath the practice of personal medical crowdfunding is that beneficiaries who deserve financial support from friends and family will receive it, or conversely – although less likely to be spoken aloud – that those who struggle to raise funds through crowdfunding must not deserve the help.

In reality, personal crowdfunding outcomes (dollars raised and the number of times the campaign is shared) have been shown to correlate with the beneficiary's perceived race (Igra, 2021), age (Lukk et al., 2018), gender (Saleh et al., 2020); medical need (Pol et al., 2019), and postal code (van Duynhoven et al., 2019). In the case of racism, a recent US study concludes that even discounting overt discrimination against beneficiaries who appear non-white, the diminished economic power of BIPOC communities wrought by centuries of systemic racism translate to poorer fundraising outcomes for non-white beneficiaries (Igra, 2021). What is therefore at issue is not the participants of the "game" – the campaigners, the beneficiaries, and contributors who are doing their best to care for themselves and each other – but the flawed, exploitative arena in which they are supposedly playing.

Voluntary, private contributions to medical crowdfunding campaigns help release some of the political pressure that might otherwise build up and erupt if poverty and unmet needs were more widespread (Fraser in Fraser & Jaeggi, 2018). Knowing all of this, we might very well continue to choose to give money to community members and loved ones in the name of our shared humanity, but the neo-liberal twist introduced by

medical crowdfunding is that when beneficiaries are not able to raise adequate funds – which is statistically likely – we are conditioned to think, however quietly, that the beneficiary is responsible for that outcome. This tendency is cultivated by the logic of neo-liberalism, which, as Kotsko (2017) explains, demonizes individuals – allowing them just enough freedom to be held personally liable for their life situation. In the context of crowdfunding, this translates to the availability of technology like GoFundMe, which enables individuals with internet access and some level of computer literacy to set up a campaign with no upfront cost. Users can choose the level of detail they wish to share about their situation, they can set and adjust the fundraising target, and they can stop accepting donations or remove the campaign altogether at will. Contributors can choose whether to give money and/or to share the campaign. But for all of these “choices” that beneficiaries, campaigners, and contributors are empowered to make, what they cannot control is the overall fundraising results (which are likely to be poor), their access to government welfare provisioning, nor the unabashed winners-take-all logic that structures GoFundMe’s algorithms and business decisions. In spite of all of these uncontrollable factors, individual crowdfunding outcomes are largely presented and internalized as a measure of the beneficiary’s efforts and worth – that is, a campaign that exceeds its fundraising goal appears to speak to the character of the beneficiary or the legitimacy of the need, while a campaign that raises only a small fraction of its intended goal is often met with questions and self-reflection related to what the campaigner “could have done better.” Even when contributors are sympathetic towards those who do not raise the level of funds they need, they largely accept the inequity as a natural outcome of a game with winners and losers.

It is only in pushing against the grain of neo-liberal rationality that we can understand that the beneficiary who only raised \$100 is not at fault for falling short of their goal, and equally important, that the person who raised \$1,000,000 is likewise not to blame for the other person's outcome. To believe otherwise is to fall into neo-liberalism's trap – one that narrows our analysis to the behaviours of individuals rather than examine the material and ideological conditions in which they live and the structures which contribute to deeply inequitable fundraising outcomes.

The disparate medical crowdfunding outcomes on platforms like GoFundMe and the problematic discourses produced and reproduced in personal crowdfunding spaces point to the need for more expansive public welfare supports – ones that treat fluctuating needs for caregiving/receiving as an unexceptional component of life. As long as there are disparities in wealth, some people will always have more access to financial supports than others for health issues. GoFundMe medical crowdfunding exacerbates this reality and encourages us to believe that grossly unfair outcomes are not only natural but wholly justified. Instead, we need to resist GoFundMe's logic, recognizing that both the beneficiary who raised \$100 and \$1 million are teammates rather than competitors in a common struggle against an inadequate welfare state and exploitative markets. Meanwhile, in a world where we encourage and celebrate personal medical crowdfunding, it is GoFundMe that wins, and the rest of us who lose.

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# Appendices

## Appendix A. Informed Consent Form

**Date:**

**Study Name:** Crowdfunding for our lives: GoFundMe, welfare, and a neo-liberal ethos of care

**Researcher name:** Vincci Li, PhD student, Social and Political Thought Program, York University, [vincil@yorku.ca](mailto:vincil@yorku.ca)

Supervisor: Dr. Leah F. Vosko, [lvosko@yorku.ca](mailto:lvosko@yorku.ca) and/or 416-736-2100 Ext: 33157

**Purpose of the Research:**

The purpose of this project is to better understand your experience as:

- a) a crowdfunding campaigner/beneficiary – someone who has created a medical crowdfunding campaign (through GoFundMe, FundRazr or similar website) in Canada for a specific individual, family, or group; or someone who is the designated recipient of such a campaign; OR
- b) a contributor – someone who has given money to a medical crowdfunding campaign through GoFundMe, FundRazr or similar website in Canada AND donated to a charitable organization in the past

This study is NOT about crowdfunding strategies or how to improve fundraising success. Instead, I am interested in your reasons for using crowdfunding as well as your perspectives on other sources of financial support, including government social programs (e.g. income assistance, healthcare, etc.) and charity services. In general, I want to learn what you think is the best way to help people who are facing a medical challenge in Canada.

This research involves a confidential interview to talk about your experience and perspectives. The study results will be published as a PhD dissertation, and may be shared as conference presentations, in academic or news publications, and books. To ensure your privacy, your identity will not be revealed in any of the above (unless you request it).

**What You Will Be Asked to Do in the Research:** As a research participant, you will be asked to spend 60-90 minutes telling me about your experience with medical crowdfunding campaigns in Canada. You will also be asked to share your thoughts about government social assistance programs, charity, and the best way to help people in times of need. The interview will be conducted by phone or Zoom video chat, according to your preference.

**Risks and Discomforts:** For campaigners/beneficiaries: Speaking about your experience with raising funds through online crowdfunding may bring up some uncomfortable memories and emotions about a challenging time. For that reason, you will be asked to share only what you wish to discuss.

To minimize risk of your friends, family, or campaign contributors reacting negatively to your responses, you will be assigned a pseudonym (fake name) in the study. *General* information about your crowdfunding campaign may be included in the final study – for example, “John (fake name) created a cancer fundraiser for his friend” – but not specific details that would allow someone to easily identify you or your campaign. However, you may request to have your identity shared if that is important to you. Doing so may increase the risk of negative reactions from your peers.

You will be given an opportunity to review your responses after the interview and make any clarifications or corrections up until analysis of the data is complete. You may also choose to withdraw your participation and responses as outlined in the “Voluntary Participation and Withdrawal” section below.

For contributors: I do not foresee any risk of discomfort or harm in participating in this research. Nevertheless, you will be assigned a pseudonym (fake name) in the study, unless you request to have your identity shared. Participants who elect to be named in the study may face the risk of negative

reactions from peers. You will be given an opportunity to review your responses after the interview and make any clarifications or corrections up until analysis of the data is complete. You may also choose to withdraw your participation and responses as outlined in the “Voluntary Participation and Withdrawal” section below.

**Benefits of the Research and Benefits to You:** The goal of this research is to tell the story of people who use online crowdfunding to ask for/give help related to medical challenges, and to connect these experiences with the bigger issues that people are facing in Canada.

Importantly, by participating in this study, you will have a chance to share what you think is the best way to help people in times of need – whether through crowdfunding or other alternatives. The wisdom and knowledge that you have gained through your experience of using crowdfunding may be helpful to people who are facing similar struggles.

You will NOT receive compensation for your time; however, the Principal Investigator would like to offer a \$25 electronic gift card/e-transfer as a small token of gratitude for sharing your experience and knowledge.

For campaigners/beneficiaries, participation in this study is an opportunity to reflect on your crowdfunding experience – which for many, is a very emotional one – and to speak openly about it without the constraints of having your identity known to readers. Recalling the memory of your crowdfunding journey may bring about positive feelings towards people who supported your campaign. The final study results will be shared with you so that you can see how you’ve contributed to this research. You may also find comfort in knowing that other research participants experienced a similar journey as you.

For contributors, this is an opportunity for you to reflect on your giving choices and therefore to give in a way that is meaningful to you in the future. Importantly, by participating in this study, you will have a chance to share what you think is the best way to help people in times of need – whether through crowdfunding or other alternatives.

**Voluntary Participation and Withdrawal:** Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer, to stop participating, or to refuse to answer particular questions will not influence the nature of the ongoing relationship you may have with the researchers or study staff, or the nature of your relationship with York University either now, or in the future. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible. Should you wish to withdraw after the study, you will have the option to also withdraw your data up until the analysis is complete.

**Confidentiality:** All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Instead, a pseudonym (fake name) will be assigned to you.

If you prefer to conduct the interview over Zoom instead of by phone, please note that Zoom is an externally hosted cloud-based service. When information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). Further, while York University researchers will not collect or use IP addresses or other information which could link your participation to your computer or electronic devices without informing you, there is a small risk with any platform such as this of data that is collected on external servers falling outside the control of the research team. If you are concerned about this, I am happy to conduct the interview via telephone.

Your interview, whether via Zoom or phone, will be recorded using a digital voice recorder (no video) so that your responses can be transcribed into written form. I may also take hand-written notes during your interview. I will be using software called NVivo to organize and analyze interview data (your identity will

be removed prior to uploading the data into the software). Please note that it is the expectation that participants agree not to make any unauthorized recordings of the content of a meeting / data collection session.

Audio recordings will be saved in a password protected file to research team members' local computer, not Zoom's cloud-based service. All other electronic data will be securely stored on a laptop and in a password-protected online storage account provided by York University. Hard copy data, including this consent form, will be stored in a locked cabinet. If a transcriber is hired for this project, they will sign a letter of confidentiality before accessing your information. Otherwise, Dr. Leah Vosko (my supervisor) and I are the only people who will have access to your data. Your data will be stored until December 31, 2027, at which time it will be destroyed. Paper copies will be shredded and disposed, and electronic data will be erased. Confidentiality will be provided to the fullest extent possible by law.

**Questions About the Research?** If you have questions about the research in general or about your role in the study, please feel free to contact me at [vincil@yorku.ca](mailto:vincil@yorku.ca) or my supervisor, Dr. Leah Vosko, at [lvosko@yorku.ca](mailto:lvosko@yorku.ca) and/or 416-736-2100 Ext: 33157. You may also contact the Graduate Program in Social and Political Thought at [spt\\_gpd@yorku.ca](mailto:spt_gpd@yorku.ca) and/or (416) 736-5320.

This research has received ethics review and approval by the Delegated Ethics Review Committee, which is delegated authority to review research ethics protocols by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5<sup>th</sup> Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail [ore@yorku.ca](mailto:ore@yorku.ca)).

**Legal Rights and Signatures:**

I, \_\_\_\_\_ [insert full name], consent to participate in "Crowdfunding for our lives: GoFundMe, welfare, and a neo-liberal ethos of care" conducted by Vincci Li. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

**Signature** \_\_\_\_\_  
Participant

**Date** \_\_\_\_\_

**Signature** \_\_\_\_\_  
Principal Investigator

**Date** \_\_\_\_\_

**Additional consent (where applicable)**

- Audio recording:** I consent to the audio-recording of my interview(s).

**Signature:**

**Date:**

\_\_\_\_\_  
Participant: (name)

\_\_\_\_\_

- Consent to waive anonymity:** I, \_\_\_\_\_ [insert full name], consent to the use of my name in the publications arising from this research.

**Signature:**

**Date:**

\_\_\_\_\_  
Participant: (name)

\_\_\_\_\_

## **Appendix B. Sample Interview Questions**

### *Questions for Campaigners*

*Preamble:*

*I am interested in understanding the perspectives of GoFundMe users who have created a medical crowdfunding campaign. I want to learn why people turn to GoFundMe to raise money for health care expenses and their opinions on the ideal roles of governments, charities, individuals, and corporations in ensuring our health and well-being.*

*Please remember that you can skip questions, return to questions later, or retract statements during or after the interview, until the analysis is complete. You can also end the interview without penalty at any time. Everything you say to me will be kept strictly confidential. All information that you provide will be protected, stored, and presented in ways which protect your identity. The interview should take about 60–90 minutes. Please feel free to ask any questions as we go along. Do you have any questions before we start?*

#### *I. Background and Campaign Details*

1. Can you tell me about the GoFundMe crowdfunding campaign that you started?
2. Where did you get the idea to use GoFundMe?
3. Can you describe the process of creating the GoFundMe campaign?
4. Can you describe the expenses that you were raising money for? How did you feel about raising money this way for those expenses?
5. I'm curious about how people think about crowdfunding in relation to fairness or perhaps unfairness. Do you feel like there was anything unfair about your

crowdfunding experience or maybe the situation leading up to the decision to start a campaign?

6. We often hear about people on the news who have very successful GoFundMe campaigns, but the vast majority of people do not reach their goal on GoFundMe. How does that make you feel?

## *II. Alternative Support*

*Preamble: In this portion of the interview, I'm going to ask you to think about our right to health and well-being and where responsibility lies for supporting that.*

7. Many of us feel we have a right to adequate and affordable health care when living in Canada. Can you tell me your thoughts about this right, now that you have gone through this experience?
8. Did you look into or use other sources of support to help you with this medical challenge? This can include financial and non-financial support such as services.  
OR If you started the campaign for someone else, do you know if they looked into or used other sources of support? This can include financial and non-financial support such as services.
9. Are you aware of any government supports that were available to you/the beneficiary?
10. Are you aware of any supports from charitable organizations that were available to you/the beneficiary?
11. What do you think role of individuals, including oneself, should be in supporting people who are facing a medical challenge? (Clarify if necessary: one example

- would be giving to a GoFundMe campaign). What forms of support should they provide?
12. What do you think role of corporations should be in supporting people who are facing a medical challenge? What forms of support should they provide? “Corporations” can include, for example, your/the beneficiary’s employer, or other private businesses.
13. What are other sources of support that I have missed?
14. Besides money, did you ask for other forms of support in your GoFundMe campaign? What were they?

### *III. Giving/Receiving Support*

15. Were there any strangers who contributed to your campaign?
16. For the contributors whom you know personally, why do you think they gave to your crowdfunding campaign?
17. [If applicable] You expressed in the campaign that you felt a bit embarrassed/hesitant/uncomfortable about asking for help. Can you tell me more about that?
18. GoFundMe describes contributions through their website as “donations” and the people who give them as “donors.” This is wording that is usually associated with charitable organizations.
19. Do you think you are likely to start another GoFundMe campaign either for yourself or a friend if an unforeseen medical issue came about?
20. Has this experience changed the way that you support others who are facing a medical challenge?

21. COVID-19 has taken a financial toll on a lot of people. Many people have had to apply for government social assistance (CERB, EI), and there has been an increased demand on charities as well as a spike in activity in GoFundMe. After having gone through the experience of raising money through GoFundMe, what do you think is the best way to support people who are facing a medical challenge?

### ***Questions for Contributors***

*Preamble:*

*I am interested in understanding the perspectives of people who have given money to a Canadian GoFundMe medical campaign and to charitable organizations. I want to learn why people give to GoFundMe and to charities and their opinions on the ideal roles of governments, charities, individuals, and corporations in ensuring our health and well-being.*

*Please remember that you can skip questions, return to questions later, or retract statements during or after the interview, until the analysis is complete. You can also end the interview without penalty at any time. All information that you provide will be protected, stored, and presented in ways which protect your identity. The interview should take about 60–90 minutes. Please feel free to ask any questions as we go along. Do you have any questions before we start?*

#### **I. Giving History**

1. Have you given to more than one GoFundMe campaign specifically for medical expenses in Canada?
2. Can you tell me more about the GoFundMe medical campaign(s) that you gave to?

3. Have you donated to a charitable organization in the past? If yes, which organizations did you give to?
4. When people give to GoFundMe campaigns, it is often for people whom they know personally, such as friends, family, or coworkers. Does that make it different than donating to a charitable organization?
5. We often hear about people on the news who have very successful GoFundMe campaigns, but the majority of people do not reach their goal on GoFundMe. How does that make you feel?
6. Do you think charities help address unfair situations in society? If so, how?
7. Do you think medical crowdfunding helps address unfair situations in society? If so, how?

## *II. Alternative Support*

*Preamble: In this portion of the interview, I'm going to ask you to think about our right to health and well-being and where responsibility lies for supporting that.*

8. What do you think the government's responsibility should be in supporting people who are facing a medical challenge?
9. What do you think the role of charitable organizations should be in supporting people who are facing a medical challenge?
10. What do you think the role of corporations (e.g., employers and other businesses) should be in supporting people who are facing a medical challenge?
  - a. Do you think corporations do a good job of that?

11. Earlier I asked if you felt an obligation to give to certain charities and to [x] crowdfunding campaign. What do you think the role of individuals should be in supporting people who are facing a medical challenge?
12. What are some other sources of support that I have missed?
13. Why do you think GoFundMe has become so popular?
14. COVID -19 has had a huge financial toll on a lot of people. Many people have had to apply for government social assistance (CERB), and there has been an increased demand on charities as well as a spike in activity in GoFundMe. What do you think is the best way to get people the help they need when facing a medical challenge?

## **Appendix C. GoFundMe Articles**

### Titles of Articles Analyzed

1. What is Crowdfunding? The Clear and Simple Answer (GoFundMe, n.d.-d)
2. 10 Ways to Achieve Online Fundraising without Social Media (GoFundMe, 2021i)
3. 6 Ways You Can Find Help with Medical Bills (GoFundMe, 2022c)
4. How to Ask for Donations (GoFundMe, 2019b)
5. How to Create a Fundraiser Hashtag That Inspires Donations (GoFundMe, 2021g)
6. How to Get Local Media to Cover Your Fundraiser (GoFundMe, n.d.-g)
7. How to Write Your GoFundMe Fundraiser Story – 12 Helpful Hints (GoFundMe, 2022b)
8. Medical Fundraising Tips – Financial Support When You Need It (GoFundMe, n.d.-b)
9. Raise More Money with This Medical Crowdfunding Guide (GoFundMe, 2019c)
10. The Beginner’s Guide to Viral Fundraising (GoFundMe, 2021b)
11. Top 6 Fundraising Title Tips That Inspired Donations (GoFundMe, n.d.-e)
12. Top Fundraising Tips (GoFundMe, n.d.-c)
13. Top Social Media Fundraising Tips to Help Raise More Money (GoFundMe, n.d.-f)
14. 20 Affordable Ways to Say Thank You to Donors (GoFundMe, 2021c)
15. Use Psychology to Boost Your Fundraiser (GoFundMe, 2020)
16. How Fundraising for Transplant Surgery Can Help Cut Costs (GoFundMe, 2021e)
17. How to Get A Service Dog: Unlock Your Independence (GoFundMe, 2021f)
18. IVF Funding: Guide to Costs, Fundraising and Treatments (GoFundMe, 2021d)

19. Donor Retention Strategies: Six Tips to Encourage Recurring Giving (GoFundMe, 2021h)

## Appendix D. Summary of GoFundMe Campaigns Analyzed

### Campaigns retrieved by using GoFundMe’s “browse medical [campaigns]” function

Campaign Title	Campaigner	Campaigner's Relation to Beneficiary	Medical Condition	Reason for Need	Creation Date	Amount Requested	Amount Raised as of 4/19/2023	Donations as of 4/19/2023	Amount Raised as of 5/19/2024	Location
Help Tennille Beat Ovarian cancer!	Allison Nelson	unspecified	cancer - ovarian	general	4/15/2023	\$6,500	\$3,365	38	unknown	Outlook, SK
Landin's Fight with Leukaemia	Chantelle Wrubleski	unspecified	cancer - leukaemia	extra costs, income loss	4/18/2023	\$20,000	\$3,650	52	\$10,900	Naicam, SK
Helping Mark, Meghan, and Lucas	Hannah Waxer	sister-in-law	cancer - colon	palliative care not fully covered by Medicare	4/15/2023	\$40,000	\$21,530	167	\$27,346	Summerside PEI
La famille d'Adélie	Hervé and Vincent Lauwerier	uncle	cancer - leukaemia	loss of income, extra costs	4/16/2023	\$15,000	\$9,278	68	\$15,548	Val-Morin, QC
Laura's chance to live... again.	Holly Miller	unspecified	unspecified	loss of income	4/15/2023	\$1,000	\$7,140	53	unknown	St. John's, NL
Chris Mansell	Jason McAllister	unspecified	brain hemorrhage	loss of income, extra costs	4/16/2023	\$10,000	\$6,861	65	\$10,251	Prince George, BC
Un llamado de emergencia por Josué 19 años	Johphery Contreras and Vanessa Rivery	unspecified	infection, pending amputations	loss of income	4/5/2023	\$30,000	\$5,332	143	unknown	York, ON
Please help Sarah on her road to recovery	Miriam Sabbah	sister-in-law	broken limbs	loss of income	4/17/2023	\$5,000	\$2,035	26	unknown	Lasalle, QC
For medical help	Rohit Vohra	self	liver failure	loss of income, extra costs	4/13/2023	\$20,000	\$7,131	97	\$8,696	Collingwood, ON

Campaign Title	Campaigner	Campaigner's Relation to Beneficiary	Medical Condition	Reason for Need	Creation Date	Amount Requested	Amount Raised as of 4/19/2023	Donations as of 4/19/2023	Amount Raised as of 5/19/2024	Location
Jim's cancer Treatment	Sue Miller	wife	cancer - skin	loss of income	4/15/2023	\$10,000	\$8,135	71	\$9,820	Amaranth, ON
Please donate to help Sajjad Khan's family	Calgary Pakhtun Association (CPA)	ethnic association	cardiac arrest	loss of income	1/26/2023	\$75,000	\$47,405	468	unknown	Calgary, AB
Dominique's extended battle with advanced cancer	Multiple family members	family	cancer - Hodgkin's lymphoma	loss of income, extra costs	7/3/2023	\$1	\$11,810	116	unknown	Surrey, BC. Beneficiary is in Calgary, AB.
Fundraising a Wheelchair Accessible Van for Henry	Carol Cho and Heather Crawley	friend, family member	disability	not covered by Medicare	3/19/2023	\$50,000	\$43,840	284	unknown	Unknown
Help Holly conquer cancer	Holly's Support Squad	friends	cancer - non-Hodgkin's lymphoma	loss of income	4/16/2023	\$10,000	\$3,915	28	\$14,120	Victoria, BC
Help Kermit Stick recover from a serious illness	Chuck Lief and Robert Williamson	friends	sepsis	loss of income, extra costs	8/2/2023	\$125,000	\$79,795	274	\$114,313	Dartmouth, NS
Help For Bradi	Erin Sproule	friend	injuries from violent attack	general expenses, loss of income implied	12/3/2023	\$200,000	\$125,123	1.4k	\$141,718	Milton, ON
Nico's Gender Affirming Surgery	Emily Rutledge	friend	gender affirmation	not fully covered by Medicare	4/14/2023	\$4,000	\$3,480	37	\$5,000	Guelph, ON
Patti Kusturok - Medical Assistance Fund	Joey McKenzie and Calvin Vollrath	unspecified	cancer	loss of income, extra costs	1/27/2023	\$45,000	\$52,875	613	\$56,815	Winnipeg, MB

*Campaigns retrieved by searching “Canada” and filtering for “Medical” campaigns on GoFundMe*

Campaign Title	Campaigner	Campaigner's Relation to Beneficiary	Medical Condition	Reason for Need	Creation Date	Amount Requested	Amount Raised as of 4/19/2023	Donations as of 4/19/2023	Amount Raised as of 5/19/2024	Location
Daphne Browne Hip Surgery Fundraiser	Sean David	family	hip surgery	visitor to Canada	4/15/2023	\$20,000	\$8,300	51	\$8,820	Etobicoke, ON
Janna Kowalski	Brett Judson	friend	cancer - brain tumour	general expense	3/31/2023	\$10,000	\$50,900	411	unknown	Stratford, EI
Sheri! A tall drink of water we can't live without	Teresa Bradley and Larissa Diakiw	unspecified	cancer	loss of income, extra costs	4/13/2023	\$15,000	\$3,675	29	\$17,278	Edmonton, AB. Beneficiary is in BC.
Help Adam on his recovery journey postamputation	Adam Hanlon	self	amputation	loss of income, no benefits	2/15/2023	\$50,000	\$4,405	37	\$4,525	Leduc, AB
Please help my aunt Nga	Chloe Do	family	liver transplant	visitor to Canada, no insurance	3/16/2023	\$200,000	\$40,599	425	unknown	Calgary, AB
Be a Hero for John: Donate to His cancer Treatment	Christiane Jechoux	wife	cancer - colon	extra costs	9/2/2023	\$30,000	\$860	8	unknown	Mont-Tremblant, QC
Help Hephzibah get her confidence back	Dale Thompson	friend	dental work	not covered by Medicare	1/20/2023	\$6,000	\$1,000	14	unknown	Toronto, ON

Campaign Title	Campaigner	Campaigner's Relation to Beneficiary	Medical Condition	Reason for Need	Creation Date	Amount Requested	Amount Raised as of 4/19/2023	Donations as of 4/19/2023	Amount Raised as of 5/19/2024	Location
Medical Emergency BRAIN TUMOR SURGERY	Erica Bogle-MacFarlane	sister-in-law	cancer	visitor to Canada, no insurance	4/17/2023	45000USD	\$975 USD	16	3058 USD	Trenton, NJ
My Canada Visa for Healthcare	Felix DeLeon	self	general	lack of universal healthcare in US	10/2/2023	895 USD	\$735 USD	10	\$735 USD	Brooklyn, NY. Beneficiary is in Toronto, ON.
Help Johnathan Siery beat Acute Leukemia	Jeremy Minto, Amanda Minto, Julie Siery, Caitlin Teixeira, Kevin Siery	friends, family	cancer - leukaemia	loss of income	3/13/2023	\$20,000	\$20,464	121	\$21,189	Deep River, ON
Had a Massive Heart Attack, Need Help with Bills	Michael Cress	self	cardiac arrest	loss of income, unable to get EI	2/24/2023	\$3,200	\$1,160	16	unknown	Bridgetown, NS
Milo's Top Surgery	Milo McAlister	self	gender affirmation	not fully covered by Medicare	2/15/2023	\$3,000	\$3,172	55	unknown	Thunder Bay, ON
Let's Give Ariana Her Legs	Vanessa Asmus	unspecified	rare disease, unable to walk	not covered by Medicare	2/26/2023	\$50,000	\$20,235	137	\$20,455	Airdrie, AB
Medical expenses	Christina Wall	friend	pregnancy complications	visitor to Canada	4/15/2023	\$35,000	\$3,090	15	\$5,250	Prince George, BC
Help Cathy Burton enjoy a better future.	Bob Christie	unspecified	disability	loss of income	2/8/2023	\$5,000	\$7,300	53	\$7,525	Binscarth, MB
Kayden's cancer Journey	Shawna Lincoln	unspecified	cancer - brain tumour	loss of income, EI waiting period, travel	1/31/2023	\$10,000	\$2,881	28	\$2,881	New Brunswick

Campaign Title	Campaigner	Campaigner's Relation to Beneficiary	Medical Condition	Reason for Need	Creation Date	Amount Requested	Amount Raised as of 4/19/2023	Donations as of 4/19/2023	Amount Raised as of 5/19/2024	Location
Tina Erikson medical support funding	Cheyenne Gunter and Crystal Dagasso	unspecified	chronic conditions leading to hospitalization	loss of income, extra costs, travel	1/24/2023	\$10,000	\$7,000	37	unknown	Coombs, BC. Beneficiary is in Dawson's Creek, BC
Donate to support Melissa Boyle	Adam Pacchiana	unspecified	cancer - breast	loss of income	2/18/2023	\$13,500	\$17,875	80	\$17,875	Saint John, NB
With costs while David goes thru cancer treatment	Robert Gregory	brother	cancer - throat	loss of income	3/31/2023	\$6,500	\$6,860	33	\$6,860	Almonte, ON
Let's show Marta & her beautiful family some love	Sara da Silva	unspecified	cancer - colon	loss of income and "sense of security"	3/10/2023	\$20,000	\$22,129	241	\$27,544	Whitby, ON
Help Murray from the Dayglos KICK CANCER'S ASS!	Marcus Pollard	unspecified	cancer - colon	alternative therapies not covered by Medicare	4/6/2023	\$15,000	\$10,625	163	\$13,549	Victoria, BC
Help Julia, mom of 7, cover crucial dental costs!	Wilhelm George	unspecified	dental work	not covered by Medicare	2/19/2023	\$25,000	\$1,860	15	\$1,860	West Kelowna, BC
Patricia Facey	Sandra Oake	co-worker	stroke	loss of income	2/15/2023	\$10,000	\$3,000	33	\$3,000	Mississauga, ON