Getting the crowd to care: An examination of health-related crowdfunding in Aotearoa New Zealand

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Abstract

Crowdfunding campaigns are increasingly initiated as a means of taking care of friends and family who are facing health-related challenges. Where particular treatments and medications are unfunded or unavailable domestically, money raised through crowdfunding platforms may be used in lieu of state-funded care. As a nascent phenomenon, health-related crowdfunding has begun to receive scholarly attention in recent years; yet, further research is needed into the practices and experiences of users in order to understand the implications – both at an individual and structural level – of this increasingly popular means of financing care. Providing an empirical contribution to the limited literature on health-related crowdfunding, within which few studies have engaged face-to-face with users of crowdfunding platforms, this thesis presents a reflexive thematic analysis of semi-structured interviews with, and the online campaigns of, 15 Givealittle campaigners. As the first study of its kind in the Aotearoa New Zealand context, this research also extends existing crowdfunding literature theoretically by engaging with a care ethics framework, arguing for its value in conceptualising and articulating the process of care, in particular through its ability to connect practices and experiences of care across different scales. Engaging with recent theorising on the politics of deservingness and the commodification of care, I argue that the crowdfunding process can be both cathartic and fraught for funding recipients and their loved ones. Campaigners may not feel they have a choice in turning to crowdfunding in the context of shortfalls in public cover. Further, the process may pose difficulties, for instance in burdening their time and energy; however, despite such challenges, many participants also emphasised strong feelings of emotional support through their campaigns. Nonetheless, in a commodified context, the ability of funding recipients to access the care they need is contingent on raising the money required, and their ability to do so is shaped by how 'deserving' they are deemed by donors. As such, in order to be *taken care of* through health-related crowdfunding, hopeful recipients must embody and enact the deserving subject, a reality that is likely to exacerbate inequalities in access to healthcare in Aotearoa New Zealand.

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Chapter One: Introduction

1.1 Prologue

"Tough guy faces hardest battle yet" reads the title of Levi Holley's campaign, described on his Givealittle page as a "coach, sports massage therapist, actor, voiceover artist and even a competitive armwrestler" (Givealittle, 2019g). Tragically, following a shock diagnosis with inoperable brain cancer in mid-2019, he has become a "man [whose] sole purpose is to survive". As a "normally healthy, fitness and sports minded 44 year old", Levi has always "given his time and skills away freely" by being "a regular at charity events, fundraising for a number of organizations and more recently sponsoring amateur athletes". In light of his commitment to the community, Hannah, Levi's best friend, caregiver and now, campaign manager, appeals: "it's time for us to come together and help this amazing man out."

Hannah's online crowdfunding efforts emerged because of Levi's need to access specialised radiosurgery procedures otherwise unavailable in Aotearoa New Zealand (NZ). As she explains on his page, "New Zealand's medical profession is highly regarded but lacks in advanced treatment" (Givealittle, 2019g). She asks people to "give generously" to fund Gamma Knife treatment in Australia or, alternatively, treatments that are available in the United States, Canada and Europe. Seeking to keep options open for the use of funds raised in the face of changing caring needs (Hoppania & Vaittinen, 2015), she states, "No procedure is off the table." Levi has taken significant measures to self-fund this overseas treatment. Appealing to ideals of personal responsibility (Lawson, 2007; McDowell, 2004), Hannah highlights that he has sold "his car, possessions, and even his prized Batman costume to fund his treatment" (Givealittle, 2019g). Regardless, however, the page explains that without the support of others, he will fall short of the funds required to seek overseas treatment. Reiterating the importance of the campaign to his survival – indeed, emphasising that the stakes of fundraising are "the life or death of another human" (Paulus & Roberts, 2018, pp. 69) – Hannah pleads, "We don't want a lack of funds to result in Levi's death."

Levi's campaign is one drop in an ocean of appeals for health-related costs through crowdfunding platforms. As a burgeoning trend internationally, personal health-related fundraising[1] makes up the largest and fastest growing subset of donation-based crowdfunding (Young & Scheinberg, 2017; Zenone & Snyder, 2018). On Givealittle alone, a popular NZ-based platform, applying the filter 'Health' on any given day typically returns over 1000 live campaigns, reflecting the scale of the phenomenon even in a relatively small country with a history of strong social service provision (Gauld, 2013; Goodyear-Smith & Ashton, 2019). Levi's campaign gained significant traction – raising $29,410 in its first 19 days (Givealittle, 2019g) – however, not all campaigners experience such success. Campaigns vary significantly in their ability to capture the hearts, and ultimately, wallets, of loved ones, acquaintances and strangers. While Levi's circumstances are undeniably challenging, the funds of the 'crowd' are not necessarily distributed according to degree of medical need, highlighting some of the challenges associated with the use of this phenomenon to fill gaps in publicly-funded care (Berliner & Kenworthy, 2017; Dressler & Kelly, 2018). Such concerns necessitate closer examination of how crowdfunding is used for health-related costs, a call to which scholars are increasingly responding (e.g. Berliner & Kenworthy, 2017; Paulus & Roberts, 2018; Renwick & Mossialos, 2017; Snyder et al., 2017; Young & Scheinberg, 2017).

1.2 The rise and nature of crowdfunding

Crowdfunding has risen significantly in popularity in recent decades. Frequently framed as an innovative and alternative means of raising money, online crowdfunding platforms are used to fund initiatives across various sectors, ranging from health to the arts, business ventures, and civic projects (Agrawal et al., 2015; Borst et al., 2018; Langley & Leyson, 2017). The roots of crowdfunding lie in 'crowdsourcing', which refers to open calls for labour, ideas or solutions among digital communities (Berliner & Kenworthy, 2017; Gomez-Diago, 2016; Langley, 2016; Stiver et al., 2015). In a similar vein, crowdfunding campaigns reflect an open call for funding from the online

[1] Some scholars use the term 'medical' crowdfunding, while others use 'health-related' crowdfunding. In the context of this thesis, I opt for the latter in order to incorporate those fundraising to compensate for their living costs while receiving healthcare treatment, as well as those fundraising for treatments and/or medications directly.

'crowd' in order to pool the resources necessary for the initiatives of individuals or organisations (Doan & Toledano, 2018; Gonzales et al., 2018; Gray & Zhang, 2017).

While the medium of online crowdfunding is novel, the principles of crowdfunding are not altogether new. Some scholars have looked to Joseph Pulitzer's 1885 fundraising drive to finance the pedestal of the Statue of Liberty as a precursor to modern-day crowdfunding (Doan & Toledano, 2018; Gomez-Diago, 2016; Paulus & Roberts, 2018; Stiver et al., 2015). Analogous to crowdfunding, Pulitzer raised $100,000 through a campaign in a New York daily newspaper, wherein he published the names of donors, as well as updates on the project and reports towards the fundraising goal. In a similar vein, crowdfunding users set a monetary goal, and are encouraged to post regular updates on their sites, on which donors are able to monitor the campaigner's progress in reaching their fundraising target.

Modern crowdfunding practices have spatially expanded and temporally accelerated since Pulitzer's 19th century campaign. This expansion can be attributed to the development of the interactive world wide web, or Web 2.0, which has made dynamic, real-time interaction with spatially dispersed individuals both convenient and economically viable (Kneese, 2018; Renwick & Mossialos, 2017; Stiver et al., 2015). In contrast to Web 1.0, which is associated with more passive consumption of predetermined content, the development and expansion of Web 2.0 websites has enabled the dissemination of user-generated content (Fritz & Gonzales, 2018; Gomez-Diago, 2016; Gray & Zhang, 2017). Due to its participatory nature, Web 2.0 has been conventionally framed as destablising geographies of content creation and information sharing through its accessibility and affordability as a medium (Davidson & Poor, 2015; Kneese, 2018). In a similar vein, crowdfunding has thus often been understood by mainstream pundits as 'democratising' and 'transforming' existing geographies of finance, a contention that has been widely critiqued (see Chapter Two).

The exponential increase in popularity of crowdfunding over the last two decades has been commonly attributed to the 2008 global financial crisis. The financial crisis led to the widespread roll-out of austerity policies and structural changes in the global economy (Berliner & Kenworthy, 2017; Gray & Zhang, 2017; Langley & Leyson, 2017). The privatisation and de-funding of social services, as well as declining trust in the

banking industry and stricter financing regulations, have forced the hands of individuals to seek alternative sources of funding (Gonzales Cacheda, 2018; Langley, 2016; Renwick & Mossalios, 2017). For those seeking to fund business ventures, crowdfunding has presented an innovative way to cut out the 'middleman' between investor and investee (Gray & Zhang, 2017), while for individuals seeking funds to cover healthcare-related costs, crowdfunding has come to be seen as a viable means of accessing care in an increasingly commodified landscape (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018). This trend is evident in increasing numbers of active crowdfunding platforms globally; growing from roughly 100 in 2007, a US-based research firm estimates that there were 1250 crowdfunding platforms in 2014 (Langley & Leyshon, 2017; Renwick & Mossialos, 2017).

The umbrella term 'crowdfunding' subsumes different types of activities with disparate market sizes. For this reason, it is common to distinguish three different models, namely investment-, rewards- and donation-based crowdfunding (Galuszka & Brzozowska, 2015; Gray & Zhang, 2017; Kromidha & Robson, 2016; Langley, 2016). The former two models provide returns for donors, with investment-based crowdfunding generating financial returns, and rewards-based generating tangible non-financial returns (Gonzales Cacheda, 2018; Langley & Leyshon, 2017). Investment-based crowdfunding is particularly common among those seeking to fund business ventures, while rewards-based crowdfunding is commonly used among the artistic community, where donors may gain access to creative works that otherwise may not have been realised (Galuszka & Brzozowska, 2015; Renwick & Mossalios, 2017).

Donation-based crowdfunding involves the provision of funds with no tangible returns. Such campaigns are typically initiated by charities or individuals seeking support for purported 'good causes', ranging from funding community projects to financing household expenses (Kromidha & Robson, 2016; Stiver et al., 2015). Among some, donating to a crowdfunding campaign may be more appealing than traditional forms of charitable giving, as it disintermediates charitable organisations by connecting donors directly with beneficiaries (Zhao et al., 2019). Despite being less than one percent of the volume of crowdfunding globally, donation-based crowdfunding is

perhaps the most widely known and engaged with model among the general public (Gray & Zhang, 2017; Zenone & Snyder, 2018).

Across all models of crowdfunding, campaigns are constructed on platforms, which are dedicated websites, or 'intermediaries' (Bouncken et al., 2015), that connect potential donors with campaign initiators. Some platforms operate on a for-profit basis, such as GoFundMe, while others are not-for-profit social enterprises (Snyder & Caulfield, 2019). Despite these variances, and while the establishment of campaigns is generally free, most platforms deduct a portion of all donations for administrative purposes (Langley, 2016). While some platforms operate on an 'all-or-nothing' basis, where funds are only released if a campaigner-specified goal is reached, others are incremental and campaigners receive all funds donated, irrespective of whether or not they reach their target goal (Snyder et al., 2016). In-built search tools enable potential donors to refine their searches (Young & Scheinberg, 2017), with some platforms specific to particular models of crowdfunding or types of campaigns, such as Kickstarter, which is used to fund creative works (Medic et al., 2016). Other platforms, such as GoFundMe, are general-purpose platforms, spanning a range of causes, such as emergency relief, memorial funds and health-related fundraising.

1.3 Health-related crowdfunding

Fundraising for health-related costs has become ubiquitous on donation-based crowdfunding platforms. Crowdfunding may be used more broadly in the health sector to fund commercial health innovation and research, or to fundraise for health-related organisations (Renwick & Mossalios, 2017; Young & Scheinberg, 2017); however, at the individual level, crowdfunding is increasingly used to cover personal health expenses. For instance, personal health-related campaigns now comprise the largest category on GoFundMe, the world's largest donation-based crowdfunding platform (Dressler & Kelly, 2018; van Duynhoven et al., 2019). In a similar vein, NZ's only dedicated donation-based platform, Givealittle, reported that in 2018 the top three most-funded campaigns were fundraising for individual health-related costs (Stanton, 2018). In the NZ context, health-related campaigns dominate donation-based crowdfunding, raising significant volumes of funding and attracting considerable media attention in the process. News articles reporting on individual crowdfunding campaigns

are omnipresent, sporting attention-grabbing headlines such as "Cancer shock: Kiwis raise $150k for 6yo's treatment, then medical team drop bombshell" (Henry, 2019) and "Wanaka mum Kate Callaghan raises funds to travel to Mexico for cancer treatment" (Stuff, 2019). The ubiquity of such articles reflects both the human interest of these narratives, but also the incentive for campaigners to seek out media coverage that platforms encourage (Murdoch et al., 2019). As such, these campaigns are increasingly commonplace not just within crowdfunding platforms themselves, but within wider public discourse.

People seek care from the 'crowd' through campaigns for a variety of reasons. In some cases, the campaign beneficiary simply cannot afford the costs of healthcare and may construct an online appeal for assistance. This can stem from inadequate private insurance coverage, as has been well documented in the United States context (Berliner & Kenworthy, 2017; Gonzales et al., 2018; Paulus & Roberts, 2018; Sisler, 2012). In other cases, frustration with the public healthcare system may motivate people to seek private treatment even where publicly-funded options are available, or to seek offshore care in a form of 'medical tourism' (Snyder et al., 2018; Snyder & Caulfield, 2019). While campaigns frequently seek funds to directly cover the costs of treatments, many also seek compensation for time off work or to cover living, travel and/or after-treatment costs (Snyder et al., 2016; Palad & Snyder, 2019). Personal health-related crowdfunding may therefore be used to cover the cost of treatment itself, whether domestically or abroad, or to cover associated costs.

Across a range of funding uses, campaigners seek to construct appealing pages in order to trigger caring responses, and consequently, donations, from the 'crowd'. While sometimes initiated by the funding recipient themselves, crowdfunding campaigns are most frequently set up by friends or family members of those who are in need of financial assistance (Palad & Snyder, 2019; Paulus & Roberts, 2018; Snyder et al., 2018). In setting up campaigns, users must communicate their or their loved ones' circumstances through the use of text, images and/or videos (Berliner & Kenworthy, 2017; Snyder, 2016; van Duynhoven et al., 2019). Such design decisions can be pivotal in shaping the relative success of the cause, as need is only able to be assessed by the 'crowd' insofar as it is effectively communicated. For instance, those constructing crowdfunding campaigns must determine the degree to which they

disclose intimate details of personal illness and hardship through the page, juggling privacy concerns with the need to prove the legitimacy of their cause (Dressler & Kelly, 2018; Palad & Snyder, 2019). For this reason, campaigners play a central role in the crowdfunding process, with their practices and experiences crucial to understanding the phenomenon more broadly.

Representations of health-related crowdfunding on platforms themselves and in mainstream media tend to be optimistic, with crowdfunding widely framed as a "new tool for empowering charitable giving", in spite of the stories of hardship that often motivate and inform campaigns (Snyder, 2016, pp. 40). Murdoch et al. (2019) argue that among media reports, crowdfunding is often implicitly or explicitly endorsed through its positive framing of campaigns. This framing tends to overlook inequities in who is able to capitalise on these platforms, and what types of norms are reified by this practice (Dressler & Kelly, 2018; Snyder, 2016). For instance, in a media statement from Lynne Le Gros, then-General Manager of the foundation that owns Givealittle, she expressed of the platform, "We see all types of people [running campaigns]. Need doesn't differentiate against socio-economic status or age. Our givers are equally lots of different people, and also groups" (Wiggins, 2015). Such a framing of crowdfunding as 'open' and non-discriminatory warrants further interrogation. I seek to do just that in the following chapters.

1.4 Research objectives and thesis structure

In the context of its rising popularity and widespread endorsement as an 'empowering' and accessible tool, scholars have begun to investigate the nature and implications of health-related crowdfunding. In spite of recent scholarly attention paid to this phenomenon, however, and as this thesis argues, further critical analysis is needed to extend understandings of this increasingly ubiquitous phenomenon due to its potential implications for equity in access to healthcare (Dressler & Kelly, 2016; Palad & Snyder, 2019; Snyder, 2016). Specifically, in light of limited research that engages directly with users (Berliner & Kenworthy, 2017), this research aims to examine the practices and experiences of campaigners using Givealittle, a NZ-based crowdfunding platform. In addressing this aim, my research is guided by the following two related objectives:

Objective 1: To explore campaigners' perceptions of how care is necessitated and experienced in a crowdfunding context;

Objective 2: To explore how deservingness is understood among campaigners, and how these understandings shape experiences of care in a crowdfunding context.

In order to address my research objectives, this thesis is divided into five chapters. In the chapter that follows, I canvass existing literature on crowdfunding and care, highlighting three key contributions of this thesis. Firstly, I seek to make a theoretical contribution to scholarship on health-related crowdfunding by applying a care ethics framework, which, I argue, provides a useful articulation of the caring process, and further, is attentive to how caring processes operate across different scales. Secondly, this thesis makes an empirical contribution to the health-related crowdfunding literature by grounding some of the more abstracted claims within this scholarship using insights gained from engaging directly with campaigners through semi-structured interviews. Thirdly, I endeavour to make an empirical contribution to the care ethics literature by exploring experiences of commodified care in a recently emerged marketised space (Cox, 2013a), namely crowdfunding platforms, a caring context that has not yet been examined through this lens.

Before discussing findings, Chapter Three outlines the methodology and context that have informed this research. Having taken a qualitative approach to examine the case of health-related crowdfunding in NZ, this chapter justifies and discusses my reflexive thematic analysis of semi-structured interviews with campaigners, and their respective online campaigns, to inform a discussion of the practices and experiences of crowdfunding. Conducting interviews enabled me to allowed me to elicit rich accounts of lived experiences of those using crowdfunding platforms (Berliner & Kenworthy, 2017), insights that were complemented by the analysis of secondary data (Braun & Clarke, 2013). In discussing my research design, I also reflect on some of the challenges of online research, both ethically and emotionally, as well as difficulties I encountered in navigating boundaries when engaging with participants over sensitive topics (Bergman Blix & Wettergren, 2015; Dickson-Swift et al., 2006).

Chapter Four analyses the practices and experiences of Givealittle campaigners. Addressing my first research objective, I argue that care is understood as being necessitated in a crowdfunding context through gaps in state-funded care, meaning that many campaigners do not feel they have a choice in 'choosing' to crowdfund. Crowdfunding responsibilises the funding recipient and their loved ones by placing the onus for *taking care of* unwell individuals on their friends, family and wider social circles, a responsibilisation that can place stress on those involved, and pose difficulties in the face of changing treatment plans. Such challenges may reinforce the scholarly argument that care in a commodified context is inherently problematic (Cox, 2013a; Green & Lawson, 2011). Yet, as this chapter highlights, crowdfunding campaigns can also be understood as a catalyst for genuine experiences of care. In spite of the process being a source of significant emotional support for some, however, those who do not raise sufficient funds may be unable to secure the *care-giving* that they require in the context of gaps in public funding.

Perceptions of the relative 'deservingness' of funding recipients are central to the varied ability of campaigners to successfully crowdfund their care. In addressing my second research objective, Chapter Four examines how funding recipients are positioned as 'deserving' subjects of care, and how these implicit criteria of deservingness shape experiences of the crowdfunding process. I argue that funding recipients must both 'embody' and 'enact' the ideal *care-recipient* through visual and written cues that communicate their conformity to implicit criteria of deservingness. Despite its online nature, the funding recipient's body and their embodied experiences remain central in triggering caring responses from the crowd. I argue that the continued salience of pre-existing social ties in attracting funding, but also the importance of visual representations of the funding recipient's body within campaigns, may serve to constrain those that are already disadvantaged in accessing care. Moreover, in 'enacting' the deserving recipient of care, campaigners engage with discourses of neoliberal subjectivity, meaning that those who are unable to frame their circumstances according to ideals of hard work and self-responsibility may struggle to be *taken care of* in a crowdfunding context.

Chapter Five concludes by arguing that crowdfunding is likely to undermine efforts to improve equity in access to healthcare. Through extending scholarly understandings

of health-related crowdfunding and the commodification of care, this thesis contributes to two previously separate bodies of literature that have levelled parallel critiques at the application of market values to the realm of healthcare provision. Despite the experiences of care and support through crowdfunding among some participants, the distributional outcomes of these campaigns, as well as the values they reinforce, are of concern as this phenomenon continues to grow (van Duynhoven et al., 2017). In the context of calls for greater policy efforts in aligning healthcare resources with need (Goodyear-Smith & Ashton, 2019), and in light of the skills and traits necessary to run a successful campaign, I therefore argue that the propensity for these platforms to benefit those who are already in a position of privilege is particularly problematic where crowdfunding is used to fill gaps in government-funded care.

Chapter Two: Literature Review

2.1 Introduction

This chapter canvasses scholarship within Geography and the broader social sciences to argue for the importance of examining the practices and experiences of users of health-related crowdfunding. In doing so, I bring together literature on care ethics with literature on crowdfunding, highlighting three key contributions of my research. Firstly, I seek to make a theoretical contribution to the literature on health-related crowdfunding, arguing for the relevance of applying care ethics as a framework to understand the complex caring practices and relations facilitated through crowdfunding platforms. Introducing Fisher and Tronto's (1990) four phases of care, I argue that care ethics scholarship provides a useful analytical framing for articulating how these practices and experiences fit into the caring process, but further, that this scholarship is attentive to how processes of care operate across different scales (Atkinson et al., 2011; Cox, 2013; Milligan & Wiles, 2010). As such, the extensive care ethics literature is useful in drawing connections between embodied experiences of care and wider social and economic processes in a crowdfunding context. In light of a relatively under-developed and under-theorised body of scholarship on health-related crowdfunding (Berliner & Kenworthy, 2017; Renwick & Mossialos, 2017; Snyder et al., 2016), I engage with two key themes in the literature, namely the commodification of care and understandings of deservingness respectively to draw connections between individual-level practices and experiences, and wider discourses and processes.

Secondly, I seek to contribute to the literature on health-related crowdfunding by filling an empirical gap. Scholarship on health-related crowdfunding suffers from being somewhat abstracted in its claims, with existing literature largely consisting of analysis of online campaigns and media coverage, or commentary with no empirical component. With few studies engaging face-to-face with users of crowdfunding platforms (for exceptions, see Fritz & Gonzales, 2018; Gonzales et al. 2018; Kneese, 2018), more direct engagement with campaigners is needed in order to tease out some of these more abstracted claims and ground them in lived experience, a call made by Berliner and Kenworthy (2017) to which I respond through this research. Engaging

with care ethics as a framework provides an impetus for engaging face-to-face with campaigners due to its emphasis on embodied practice and experience (Held, 2006; Robinson, 2018). In combining an emphasis on individual experience with a focus on wider social and economic processes, this research therefore fills an empirical gap in the health-related crowdfunding literature, meanwhile drawing on the strengths of the care literature in its ability to connect, for instance, micro-level representations of the body with macro-level shifts in structures of care provision (Dyck et al., 2005; Vaittinen, 2014; Wiles, 2011).

Thirdly, this research endeavours to provide an empirical contribution to the care ethics literature by advancing understandings of the commodification of care through a focus on a novel and contemporary caring context. I argue that crowdfunding reflects the emergence of a new marketised space (Cox, 2013a), which enables me to respond to Green and Lawson's (2011, pp. 65) call for research that explores "particular expressions or renegotiations of the commodification of care". While much existing literature on commodified care focuses on waged caring labour, or the commodification of *care-giving* practices, in the crowdfunding context, market values shape who is *taken care of* earlier in the caring process (Fisher & Tronto, 1990). As such, this project advances understandings of the experiences and practices of using crowdfunding, but also the skills and traits necessary to secure *care-giving* in a commodified context.

In developing these three arguments, I begin in 2.2 by providing an overview of debates within the broader crowdfunding literature, in particular debates over the degree to which crowdfunding reflects a 'democratising' and 'transformative' funding model. I argue that while crowdfunding may provide opportunities for subverting traditional public 'gatekeepers' of finance, existing studies demonstrate that funding is likely to reinforce existing patterns of distribution (Davidson & Poor, 2015; Hunter & Bartolomeo, 2018; Kromidha & Robson, 2016). Section 2.3 moves on to engage with debates within the health-related crowdfunding literature more specifically. Similar reservations exist in this smaller body of literature about crowdfunding as an allocator of resources in the healthcare context; however, as Paulus and Roberts (2018) explain, such concerns are especially salient in the context of individual health-related crowdfunding, as the stakes of access, or a lack thereof, can be a matter of life or

death for the funding recipient. For this reason, and in the context of relatively sparse academic attention, various authors have called for further research into the use of these increasingly ubiquitous platforms for health-related expenses (Berliner & Kenworthy, 2017; Renwick & Mossialos, 2017; Snyder et al., 2016).

In order to understand practices and experiences of health-related crowdfunding, I introduce scholarship on care ethics, an expansive interdisciplinary literature that has theorised the changing nature of caring relations within the wider social sciences, including Geography. I examine the development of care ethics in section 2.4, arguing that this framework provides insights into how interdependence and relations of responsibility pervade social and political life (Brown, 2003; Robinson, 2018; Tronto, 1993). In section 2.5, I explore some of the empirical applications of care ethics in the geographic literature, using the five phases of care introduced by Fisher and Tronto (1990) and Tronto (2003) to structure my discussion. Section 2.6 examines a theme within broader care ethics scholarship on the commodification of care, exploring how the adoption of market logics within realms of care provision have often been read as 'corrupting' the nature of caring relations and exacerbating inequalities (Green & Lawson, 2011; Held, 2002; Hoppania & Vaittinen, 2015). Consequently, section 2.7 discusses notions of 'deservingness', examining how constructions of the morally 'legitimate' recipient of care have been understood in care ethics scholarship. While scholars writing on health-related crowdfunding have levelled cursory critiques at the market-based allocation of healthcare that these platforms facilitate, and who is able to benefit from them, I conclude by arguing for the usefulness of the care literature in teasing out the nuances of this commodification process, and who is read as 'deserving' within this context.

2.2 Crowdfunding as transformational?

Among mainstream pundits and the scholarly community alike, crowdfunding has been praised for its 'transformational' potential. Whether used for getting a start-up initiative off the ground or fundraising for a charitable cause, crowdfunding platforms have often been held up as a "novel, digitally rendered economic space" (Langley & Leyshon, 2017, pp. 1019), as they are technically open to all, and enable users to subvert traditional funding sources. Where, previously, individuals and organisations

were reliant on conventional financial 'gatekeepers' in accessing funding (Borst et al., 2018; Davidson & Poor, 2015; Gray & Zhang, 2017; Kromidha & Robson, 2016), crowdfunding enables 'everyday' individuals to determine which projects get funded. Some argue that this 'democratisation' reflects the "potential for a power shift" away from conventional investors (Paulus & Roberts, 2018, pp. 66).

The ability to source funding from the 'crowd' may therefore facilitate the success of initiatives that have otherwise not been viable or received attention. For instance, in the case of business ventures, accessing funding through the 'crowd' may enable smaller firms to access funding in instances where they may have struggled to compete with larger firms (Gray & Zhang, 2017; Kromidha & Robson, 2016). Similarly, for individuals seeking to raise funds, Gray and Zhang (2017, pp. 601) argue that crowdfunding "can function as effective and alternative capital accumulation channels for people who come from lower income backgrounds and who might have difficulty in raising capital or accessing credit through traditional means." Locational biases associated with existing geographies of finance may be overcome by the ability of such platforms to connect donors with geographically-distant projects, diminishing the barriers for raising capital (Agrawal et al., 2015).

Crowdfunding has also been conceptualised as democratising in its ability to empower 'everyday' citizens. In the cultural sector, for example, Borst et al. (2018) explain how the power is shifted from so-called 'experts' to a number of everyday consumers of art in determining the financial viability of a venture. Where creatives might have once been beholden to the likes of corporate sponsors, government grants and patronage from wealthy donors, crowdfunding platforms enable them to elicit funding from a number of non-specified donors who wish to see the end product, thus turning 'fans' into 'fan-patrons' (Borst et al., 2018; Brabham, 2017; Navar-Gill, 2018). Campaigns can also be used to challenge the status quo and empower people to form a 'movement' around a particular issue. Some scholars have argued that cases of grassroots organising through crowdfunding platforms demonstrate crowdfunding's potential in challenging mainstream neoliberal ideologies of individualism, private ownership and personal responsibility (Braben, 2017; Brent & Lorah, 2019; Doan & Toledano, 2018; Gonzales Cacheda, 2018; Stiver et al., 2015). In a NZ-based example of civic crowdfunding, over two million dollars were raised on a crowdfunding platform

to purchase a private beach for public use, an initiative which Doan and Toledano (2018) argue demonstrates successful community activism. Taking a stand against the private ownership of Awaroa Bay, two New Zealanders crowdfunded to 'buy back' the beach into public ownership, demonstrating how crowdfunding platforms can be used to promote civic engagement. Hunter and Bartolomeo (2018) provide another example of the use of crowdfunding campaigns to form a 'movement'; they demonstrate how those seeking funds for alternative feminist media content can mobilise their campaigns to create a sense of community, bringing women together under the cause of challenging negative portrayals of femininity in mainstream media. In this way, crowdfunding may present opportunities for democratic participation as well as fostering a sense of collectivism and community.

However, other scholars have questioned the 'democratising' potential of crowdfunding, arguing that such platforms more usually reinforce existing patterns of capital distribution. Claims of crowdfunding as 'transformational' are often underpinned by the assumption that crowdfunding meritocratically allocates resources, whereby those with the 'best' and 'most deserving' causes will receive the most funding (Brabham, 2017). Yet, factors beyond the apparent 'worthiness' of a particular campaign determine its success. While crowdfunding platforms are intentionally designed to overcome geographic boundaries in funding projects, the ability of an individual or organisation to stimulate donations or investment from strangers has been demonstrated to rely on initial financial support from pre-existing offline social connections such as friends and family (Agrawal et al., 2015; Borst et al., 2018; Davidson & Poor, 2015; Gomez-Diago, 2016; Kromidha & Robson, 2016; Langley & Leyson, 2017). In order to mobilise funders beyond their immediate social circles, campaigners must first establish a solid base of funding from people known to them. In a form of 'herding behaviour' (Borst et al., 2018), members of the public may interpret the early support of friends and family as signalling the quality and trustworthiness of a campaign, and therefore be more likely to donate (Kneese, 2018). Thus, while crowdfunding may "enable artists and other entrepreneurs from anywhere to access capital globally … in reality, only those with a sufficient base of offline support may be able to do so" (Agrawal et al., 2015, pp. 257). Many have therefore argued that the process of 'capitalising on the crowd' is an uneven process (Langley

& Leyshon, 2017), as campaigners may require pre-existing social networks that are both willing and able to contribute in order to be successful.

Further, beyond social networks, crowdfunders must mobilise certain skills in order to be able to successfully construct a compelling narrative. Crowdfunding is a highly competitive process, and campaigners must have refined marketing capabilities in order to attract the attention and money of the 'crowd' (Braben, 2017; Hunter & Bartolomeo, 2018; Kneese, 2018). As Braben (2017, pp. 995) puts it, those projects with the most "sex appeal" are the ones that get funded. Even where initiatives may challenge the status quo, therefore, campaigners are encouraged to adopt marketing and advertising strategies that conform to mainstream economic logics in order to be successful in crowdfunding. As Hunter and Bartolomeo (2018, pp. 13) explain in the context of crowdfunding countercultural journalistic endeavours,

> At the same time that [campaigning journalists] are challenging the existing media structures through crowdfunding, they must also become entrepreneurs themselves and adopt many of the same strategies as media organizations that survive through subscriptions and advertising.

The skills required to conduct a successful crowdfunding campaign therefore not only problematise the purportedly transformative impact of crowdfunding as 'alternative' finance, but also highlights the exclusive nature of these platforms.

The extent to which such platforms can be understood as 'transformational' is often further undermined by the volume of funding that can be accessed. As campaigns are generally a 'one-off', they may be effective in funding one-time initiatives, but do not necessarily provide a sustainable and regular income (Gonzales Cacheda, 2018; Hunter & Bartolomeo, 2018; Stiver et al., 2015). For this reason, crowdfunding may not be a suitable funding source for certain types of projects, particularly those that require ongoing maintenance or support. As various scholars have highlighted, donations- and rewards-based crowdfunding are unlikely to ever grow to a scale such that they become a feasible replacement for traditional philanthropy or state funding (Brent & Lorah, 2019; Gonzales Cacheda, 2018). While some have framed the ability of campaigners to bypass traditional financial 'gatekeepers' as productive, therefore,

others have argued that in appealing to the 'crowd' for funding, these platforms may incentivise and justify further public funding cuts (Braben, 2017; Galuszka & Brzozowska, 2015; Gonzales Cacheda, 2018). In this way, crowdfunding may not only *reinforce* but further *exacerbate* existing inequities in funding distribution patterns.

The broader crowdfunding literature therefore foregrounds some of the ways in which crowdfunding may be transformative, and yet also highlights the ways in which this purportedly 'alternative' mode of financing initiatives may entrench conventional funding inequities. Through canvassing some of the literature engaging with this debate, it is evident that disparities in outcomes are at least somewhat contingent on the model of crowdfunding and context of usage. As Gray and Zhang (2017, pp. 586) explain, the work of previous researchers "suffers from the tendency to examine one particular model … or one particular industry … with the assumption that their findings apply to the entire crowdfunding field." With this in mind, I now turn to a specific subset of the crowdfunding literature, namely donation-based health-related crowdfunding, in the interests of drawing conclusions about this particular type of crowdfunding.

2.3 Health-related crowdfunding

Campaigns seeking to cover individual health-related costs have become a subject of academic interest in recent years. Scholars across various social scientific fields, particularly media studies and health sciences, have begun to engage with the nature and implications of this nascent phenomenon. This rise in interest is perhaps due to the broader ethical questions such campaigns pose for access and equity in the health sector (Barcelos, 2019; Berliner & Kenworthy, 2017; Palad & Snyder, 2019; van Duynhoven et al., 2019). Indeed, where crowdfunding is used for personal medical costs, the stakes of accessing funding are particularly high, especially when platforms are used as a last resort (Paulus & Roberts, 2018).

Existing research suggests that health-related crowdfunding holds some potential in generating financial and social support for its users. The accessibility of these platforms is undoubtedly beneficial for those who are able to run successful campaigns, as it can provide "interim financial relief" during times of hardship (Renwick & Mossalios, 2017, pp. 54; Gonzales et al., 2018; Snyder et al., 2016; van Duynhoven

et al., 2019). Beyond instrumental assistance, crowdfunding may also provide social support for those experiencing illness, and/or their friends and family, even where financial support is limited (Fritz & Gonzales, 2018; Gonzales et al., 2018). For instance, Fritz and Gonzales (2018) find that the process of crowdfunding was affirming for transgendered individuals in their study who sought to crowdfund their gender-reassignment surgeries. Their participants talked of strengthened relationships with friends and family, as well as the affirming role of support from strangers. Farnel (2015) similarly argues in the context of transition surgery that crowdfunding has potential to affirm and legitimise transgendered lives by creating a sense of community. In this sense, crowdfunding may serve to provide both financial and emotional support through the healthcare experience of campaigners and/or their loved ones.

However, scholars have also highlighted a range of concerns associated with the rising use of crowdfunding for health-related costs. In a similar vein to criticisms raised in the broader crowdfunding literature, research on health-related crowdfunding has demonstrated how existing social networks play a significant role in determining the success of a given campaign (Berliner & Kenworthy, 2017; Gonzales et al., 2018; Paulus & Roberts, 2018; Young & Scheinberg, 2017). Campaigners are frequently encouraged to connect to social media platforms through in-built sharing features, meaning that those with well-established networks are able to mobilise existing connections (Snyder et al., 2017; Snyder et al., 2018). In Kenworthy et al.'s (forthcoming, pp. 16) study of 822 GoFundMe campaigns, they find that "the vast majority of campaigns do not go viral", and that "the 'crowd' with whom crowdfunders are interacting is often an intimate, densely connected social assemblage". In all but a few cases, individuals must possess extensive social networks with sufficient discretionary income to donate in order to be successful in crowdfunding for health-related costs, highlighting the class-based inequities that such a model exacerbates (Berliner & Kenworthy, 2017). While crowdfunding platforms may hold some potential in generating a sense of support and solidarity, existing research suggests that campaigns generally rely on existing online networks and not on the creation of community through the site itself.

Further, campaigners craft – and even 'package' and 'market' - their illness narratives in a particular manner in order to attract funding, a process which builds on the possession of a range of relevant competencies and resources. While the general crowdfunding literature highlights that those campaigns with "sex appeal" are the most likely to get funded (Braben, 2017, pp. 995), such concerns are particularly pertinent in the health-related crowdfunding context whereby those in genuine medical need may be overlooked as they have not narrated their illness in a way that is coherent with cultural norms of 'deservingness' (Berliner & Kenworthy, 2017; Brabham, 2017). In constructing campaigns, users must carefully craft stories about their or their loved one's illness and hardship in order to negotiate the taboo of asking strangers for financial support (Palad & Snyder, 2019; Paulus & Roberts, 2018; Snyder et al., 2018). In doing so, successful campaigners frame their challenges in a "culturally coherent manner" that emphasises 'self-help' and 'hard work' in order to legitimise and justify their appeal for funding (Paulus & Roberts, 2018, pp. 65; Berliner & Kenworthy, 2017). The ability to narrate one's story in this way requires a certain degree of basic literacy, but also requires possessing more refined medical, cultural and social media literacies, as well as the sheer time necessary to establish and maintain the campaign (Gonzales et al., 2018; Snyder et al., 2016).

In light of these barriers to access, various scholars have denounced the resources and competencies required to run a successful crowdfunding campaign, and the implications of this in terms of access to health-related funding. In their quantitative analysis of cancer campaigns on GoFundMe, van Duynhoven et al. (2019) find that persons in positions of relative socioeconomic privilege with higher educational achievements are disproportionately represented among those that use crowdfunding to address health-related needs. Health-related crowdfunding has therefore been criticised for exacerbating inequities in accessing healthcare, and in the process, some have argued, obscuring structural challenges. In the same way that scholars in the broader crowdfunding literature have raised concerns that platforms may justify further public funding cuts (Braben, 2017; Galuszka & Brzozowska, 2015; Gonzales Cacheda, 2018), some have argued that health-related crowdfunding serves to undermine pushes for systemic reform of social assistance and healthcare systems (Berliner & Kenworthy, 2017; Sisler, 2012; Snyder, 2016; Young & Scheinberg, 2017). By providing the opportunity for financial assistance, however minimal, crowdfunding

may distract from the broader failures of public systems, individualising the burden of what many would argue should be collective responsibilities. Campaigners frequently market personal illness and hardship as the product of 'exceptional' circumstances or 'bad luck', meaning that they often lack any explicit critique of the broader structural causes of their personal hardship (Farnel, 2015; Snyder, 2016; Young & Scheinberg, 2017). As such, crowdfunding may be increasingly embedded in health systems as a legitimate alternative to collective care provision (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018), which is of concern to many scholars due to its inefficient and inequitable priority setting.

The need to effectively market one's illness has implications for which kinds of healthcare treatments are successful in a crowdfunding context. As Snyder et al. (2016) explain, the most marketable illnesses are those that are seemingly 'solvable', arising from 'unexpected' circumstances. Illnesses such as cancer, where framed as exceptional or curable, may be more enticing for donors as they arguably provide more instant gratification than those which might be seeking assistance with more complex and chronic challenges (Berliner & Kenworthy, 2017). This desire for a 'feel good' story may further disadvantage lower socio-economic groups in utilising these platforms, as their health needs tend to be compounding and seemingly more difficult to address (Snyder, 2016). For instance, in their comparison of two GoFundMe campaigns, Berliner and Kenworthy (2017) contrast the success of one campaign that fundraised to cover the costs of cancer treatment with a less successful campaign, which listed a range of needs including compounding health issues among multiple family members and general financial distress. The imperative to neatly package and clearly communicate one's predicament therefore disadvantages those with compounding challenges, as "the more generalized one's distress or the more complex one's needs, the more difficult they become to represent" (Berliner & Kenworthy, 2017, pp. 240).

Along these lines, campaigns relating to stigmatised health needs are less likely to be successful in a crowdfunding context. Research into the use of crowdfunding websites to fund gender-affirming procedures among transgendered individuals (Barcelos, 2019; Farnel, 2015) and addiction-related services (Palad & Snyder, 2019) demonstrates how crowdfunding campaigns are largely financially unsuccessful for those with marginalised health needs. In some cases, platforms may even censor

conditions they deem 'inappropriate' (Snyder, 2016); for instance, Kneese (2018) explains how a woman's abortion procedure was censored from GoFundMe following right-wing push-back. Crowdfunding is therefore likely to best serve those deemed 'deserving' recipients that have 'palatable' health needs, which may serve to further marginalise already-vulnerable groups.

Scholars have further raised concerns over the potential harms associated with privacy given the level of personal disclosure health-related crowdfunding necessitates. Platforms encourage campaigners to provide as much detail as possible, and to share this information as widely as they can, in order to improve chances of success (Gonzales et al., 2018; Snyder et al., 2016). Indeed, to establish a sense of legitimacy and deservingness, campaigners must provide extensive detail about the funding recipient's illness story, particularly in light of donor scepticism due to cases of fraud (Fritz & Gonzales, 2018; Snyder et al., 2016; Palad & Snyder, 2019; Renwick & Mossalios, 2017; Zerone & Snyder, 2018). In the case of medical campaigns, the need to forego personal privacy raises questions about agency and consent; the barriers faced in obtaining funding and gravity of need in some cases may compromise the extent to which individuals can consent to this loss of privacy, as they may feel they have no other options (Paulus & Roberts, 2018; Sisler, 2012; Snyder et al., 2017; Snyder et al., 2018). Such privacy-related challenges are compounded when a third party establishes a campaign on behalf of the fund-recipient, as is most common (Fritz & Gonzales, 2018; Paulus & Roberts, 2018; Snyder et al., 2016).

However, the need to divulge personal information in publishing and updating a crowdfunding campaign is not necessarily always detrimental for the individual involved. As Gonzales et al. (2018) and Fritz and Gonzales (2018) found through semi-structured interviews with campaigners, the process of constructing and circulating illness stories can be empowering, resulting in the active reconstruction of one's identity. Where campaigns seek to raise funds for an individual afflicted by a rare condition or disease, crowdfunding may serve as an opportunity for raising awareness about neglected health issues, with opportunities for the individual in question to redefine themselves as more than a victim, but a health spokesperson for their given illness (Gonzales et al., 2018; Renwick & Mossalios, 2017). Further, some may find the process of personal disclosure as constructive in helping them come to terms with

their illness and become more open about their condition (Gonzales et al., 2018). Existing research therefore suggests that while there are ethical challenges associated with the compromised privacy that health-related crowdfunding demands, for some, the fundraising process may be emotionally and psychologically beneficial.

Literature on health-related crowdfunding thus highlights some of the challenges associated with this nascent phenomenon. While the broader crowdfunding literature raises equity-related concerns due to, for instance, the need to successfully market one's cause and possess existing networks, the use of these platforms to fill gaps in healthcare and welfare systems intensifies such concerns (Berliner & Kenworthy, 2017). Despite the salience of these challenges, however, health-related crowdfunding is still relatively under-studied and under-theorised, as many scholars have identified (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018; Renwick & Mossialos, 2017; Snyder et al., 2016; Young & Scheinberg, 2017). For instance, Renwick and Mossialos (2017, pp. 48) argue that health-related crowdfunding has been "inadequately explored", while Young and Scheinberg (2017, pp. 1624) state that further research in this area is "long overdue, and will only increase in importance". In a similar vein, Snyder et al. (2016, pp. 30) describe a "lack of understanding on the motivations and experiences of users [as] extremely troubling." While research in this field has gained momentum since 2016, when Snyder and colleagues argued that "virtually no scholarly attention has been paid to these health-related crowdfunding campaigns" (pp. 27), significant work remains in understanding how crowdfunding for health-related purposes is experienced and understood.

In particular, further inquiry is needed into the experiences and practices of those constructing health-related crowdfunding campaigns. As Berliner and Kenworthy (2017) highlight, there is limited research that engages face-to-face with users of these platforms. With the exception of three recent studies (Fritz & Gonzales, 2018; Gonzales et al. 2018; Kneese, 2018), existing scholarly work in this area consists of literature reviews, commentary, or documentary analysis of online campaigns and media coverage. This project seeks to fill this gap by engaging in semi-structured interviews, a method of enquiry that enables me to go beyond examining online representation to also examine reported experiences and perceptions. In speaking directly with campaigners, I bring to bear the epistemological arguments advanced by

care scholars on crowdfunding research. As will be discussed next, care ethics as a framework was developed as a rejection of abstracted and universalised ontologies, instead emphasising the importance of context and embodied knowledges (Brown, 2003; Lawson, 2007; McEwan & Goodman, 2010). Through engaging with this framework, therefore, this research seeks to advance the literature on health-related crowdfunding beyond polarised debate that may be abstracted from the lived experiences of those engaging with these platforms.

Moreover, in engaging with campaigners, I seek to connect individual experiences with wider processes and discourses. Without this face-to-face engagement with users, existing research on health-related crowdfunding has largely been limited in its ability to draw such connections. In order to do so, I mobilise care scholarship, which, as a body of literature, is attentive to the relations, practices and processes of care across various scales, from the micro-geographies of experiences of health-care spaces to the macro-geographies of structures of global care provision (Conradson, 2003; Milligan & Wiles, 2010; Wiles, 2011; Parr, 2003). This attentiveness is useful in situating the understandings and experiences of campaigners within the wider socio-political context in which crowdfunding has emerged, connections which I seek to tease out through engaging with two key themes, namely the politics of deservingness and the commodification of care. I now turn to introducing this broader body of care literature.

2.4 Theorising care

In order to further develop understandings of health-related crowdfunding, but also to extend scholarship on contemporary caring practices, this thesis mobilises literature that engages with care ethics as a framework. Once overlooked as a private and 'pre-political' concern, there has been an increased recognition of the social, political and economic salience of care in recent decades (Green & Lawson, 2011; Parr & Philo, 2003; Robinson, 2011). Within this trend, geographers have had much to contribute in examining how care is understood, practiced and experienced across a range of spaces and scales (Conradson, 2003; Milligan & Wiles, 2010; Wiles, 2011). Crucial to this rise in analytic interest has been the development of 'care ethics' as a theoretical framework. While initially proposed as a moral theory, care ethics has come to be

influential across a range of disciplines, including Geography, as a way of understanding how interdependence and relations of responsibility permeate social and political life (Brown, 2003; Robinson, 2018; Tronto, 1993).

Care ethics in the academy emerged out of debates within Western psychology over the nature of moral reasoning and development. The work of moral psychologist Carol Gilligan initiated the momentum of the 'ethic of care', which emerged as a response to the privileging of 'justice' as a 'rational' guiding principle, with care marginalised due to its 'emotional', and therefore purportedly 'irrational', status (Brown, 2003; Lawson, 2007; McEwan & Goodman, 2010). Gilligan sought to challenge the ideas of associate Lawrence Kohlberg, whose theory of cognitive development appeared to prove that boys generally had superior moral reasoning abilities (Held, 2006; Tronto, 1987, 1993). Contesting this finding, Gilligan explicated the 'ethic of care', which she argued reflects a 'different voice' in moral reasoning. Rather than deriving moral judgements from abstracted and universalised rules, this alternative form of moral reasoning is principally concerned with care and interpersonal responsibility, making judgements based on contextual circumstances.

Gilligan's work has been highly influential. While many feminist scholars have been wary of the way in which Gilligan's work may entrench essentialisms, and in particular, embed stereotypes of women as 'innately' caring (Hamington, 2004; Haylett, 2003; Robinson, 2018; Tronto, 1993), elements of Gilligan's framework have influenced debates from a range of disciplines, including Geography. The key contribution of the ethic of care has been its 'relational ontology', foregrounding and normalising interdependency as central to all human lives (Brown, 2003; Green & Lawson, 2011; Held, 2006; Raghuram et al., 2009). Rather than a discrete intervention in the lives of those who are ill or incapacitated, care ethics frames the giving and receiving of care as a crucial feature in the lives of all people, from birth to death (Haylett, 2003). Such an understanding serves as an explicit challenge to dominant liberal political and economic theories that frame individuals as 'moral' agents who apply universalised and purportedly 'rational' principles in their decision-making practices (Bartos, 2018; Held, 2006; Smith, 2005; Robinson, 2011). According to the ethic of care, we make moral judgements as interdependent beings, justifiably affected by our sense of care and responsibility for those around us. In this sense, care ethics is attentive to context

and resists abstraction or universalisation, highlighting how all humans think and act according to the social relations in which they are undeniably embedded.

While care ethics was initially developed as a moral theory, it has also come to be understood as a political theory, due to the inherently political nature of 'care'. Feminist political scientist Joan Tronto argued in her watershed text *Moral Boundaries* (1993) that the divisions frequently demarcated between morality and politics are fallacious, as moral arguments always emerge within a political context (Ticktin, 2011). In the case of care, despite being feminised and associated with intimate spaces and practices, relations of care are not only of 'private' or 'pre-political' significance (Popke, 2006; Robinson, 2011; Tronto, 1993, 2013; Vaittinen, 2015). Indeed, care affects, and is affected by, the distribution of power and resources, and for this reason, various scholars have come to engage with the 'politics of care' that emerge from care ethics.

Care ethics therefore centres care as a pervasive and essential element of all social life, justifying and necessitating its explicit analysis (Green & Lawson, 2011; Popke, 2006; Robinson, 2011). Such an understanding stands in stark contrast to conventional constructions of care as a "spatially and temporally bounded practice" enacted as a means to an end of restoring independence in the lives of dependent others (Atkinson et al., 2011, pp. 564). Fisher and Tronto's (1990, pp. 40) widely-cited definition describes care as "a species activity that includes everything that we do to maintain, continue, and repair our "world" so that we can live in it as well as possible." Such a definition is useful insofar as it captures the centrality of care to the human condition, but also leaves room for the diversity of relations and practices that constitute care. Nonetheless, the breadth of this definition means that further deconstruction of the notion of care is useful in mobilising this concept analytically. With this in mind, I turn to Fisher and Tronto's (1990) explication of the process of care to develop an analytical framework for articulating how health-related crowdfunding can be understood in terms of caring practices.

2.5 Care as process and the geographies of care

Notions of 'care' and 'caring' are contested, with significant scholarly attention paid to unpacking the concepts themselves (Atkinson et al., 2011; Conradson, 2003; Meah &

Jackson, 2017). Care has been widely acknowledged as both a disposition and a practice, incorporating affective responses, as well as activities undertaken to maintain or restore something or someone (Brown, 2003; Haylett, 2003; Held, 2006; Fisher & Tronto, 1990; Tronto, 1993). However, as various scholars have emphasised, engaging in caregiving practices does not necessitate experiencing feelings of care, and nor does a caring disposition necessitate action (Milligan & Wiles, 2010; Shaw et al., 2016; Tronto, 2013). For this reason, care is perhaps best understood as a *process* involving both disposition and practice. In their discussion of the process of care, Fisher and Tronto (1990) explicate four analytically distinct, yet interconnected, phases, namely *caring about*, *taking care of*, *care-giving* and *care-receiving*. In 2013, Tronto amended this list to include a fifth phase, *caring with*. While not all caring relations involve all phases of the care process, Tronto (1993, pp. 109) argues that these phases reflect an 'ideal' that describes *"an integrated, well-accomplished, act of care."* Through deconstructing these phases, we can analyse disruptions in the care process, highlighting where care may lead to uncaring outcomes or conflict (Bartos, 2018; Shaw et al., 2016).

Care frequently begins by noticing the existence of another being, with some sort of emotional reaction, reflecting a caring disposition towards something or someone (Cox, 2010; Milligan & Wiles, 2010; Pitt, 2018). Fisher and Tronto's (1990) first phase of care is therefore *caring about*, which involves the initial recognition that some need exists, and that care is necessary in order to address this need (Meah & Jackson, 2017; Tronto, 1993). This emotion may move someone to act on something, though *caring about* in itself does not necessitate action. If some action is taken, one is said to be *taking care of*, moving to the second phase of the caring process which involves assuming some degree of "responsibility for initiating and maintaining care activities" (Fisher & Tronto, 1990, pp. 42). Beyond an emotional response, the shift from caring about to taking care of requires "the recognition that one can act to address these unmet needs" (Tronto, 1993, pp. 106). This transition from *caring about* to *taking care of* therefore necessitates not only possessing some knowledge of the other, but also having the capacity and resources to act in response.

Consumption practices have been an important entry point for scholars seeking to understand the relationship between these first two phases of the caring process

(Barnett et al., 2005; McEwan & Goodman, 2010; Popke, 2006; Smith, 1998). Some consumers may demonstrate *care about* the environment or 'third world' producers through their consumption choices; yet, among others, inconsistencies between attitudes and behaviours highlight a discontinuity between *caring about* and *taking care of,* rendering the care process incomplete (Shaw et al., 2016). For instance, Meah and Jackson (2017) examine the unlikely pairing of convenience foods and care to argue how among some, the selection of pre-prepared foods may demonstrate a disposition of care towards the environment through a desire to avoid wasting resources. Among others, a lack of resources may restrict their ability to exercise a purportedly 'ethical' consumption choice, despite caring about the issue at hand (McEwan & Goodman, 2010).

Other scholars have examined *caring about* and *taking care of* others in the context of activity on online platforms. Lancione (2014) analyses public social media comments in response to a picture of a police officer assisting a homeless man in New York which went 'viral'. He argues that while comments are not explicitly addressed to anyone in particular, they demonstrate benevolent care *about* the issue; however, Lancione (2014) finds that no comments took a critical approach to what was happening in the image. Describing what he argues is a 'spectacle of the poor', he explains that these expressions of care deliberately maintain a distance between 'us' and 'them', without asking viewers to engage with, or *take care of*, the issue of poverty itself. Hawkins (2008) levels a similar critique at online performances of *care about* others in her examination of a 'click-to-commit' style campaign for an international development organisation. She argues that through encouraging participants to like or share content in order to 'help' girls in Malawi, such a campaign is a case of 'slacktivism', providing an opportunity for participants to perform an 'ethical' identity. Such studies therefore raise questions about our capacity to truly care about, and consequently, take care of, unknown 'others' at a distance.

The second two phases of care according to Fisher and Tronto's (1990) four-part framework are more closely aligned to the practice of care, namely *care-giving* and *care-receiving*. Care-giving involves "the direct meeting of needs for care … involv[ing] physical work, and almost always requir[ing] that care-givers come in contact with the objects of care" (Tronto, 1993, pp. 107). While some scholars (e.g. Milligan & Wiles,

2010; Smith, 1998) subsume *taking care of* and *care-giving* under 'caring for', Fisher and Tronto (1990) distinguish between the two, arguing that care-giving requires "more continuous and dense time commitments than taking care of". The final phase of care, care-receiving, acknowledges the agency of the care recipient in responding to the care extended to them. As caregiving practices are contingent on the evaluation of needs, which is a subjective process, care may not always be received in the way it was initially intended (Fisher & Tronto, 1990; Meah & Jackson, 2017). An attentiveness to the final phase is therefore important, as without it, we "lose the ability to assess how adequately care is provided" (Tronto, 1993, pp. 106).

Within healthcare contexts, relations of care-giving and -receiving have been extensively researched, albeit with an emphasis on the former over the latter (Wiles, 2011). Indeed, various health geographers have examined the socio-spatial dimensions of care-giving relationships across diverse spaces of healthcare provision, including hospices, emergency rooms, and primary care clinics (Andrews & Evans, 2008; Cox, 2010; Donovan et al., 2011; Moore et al., 2013; Wellstood et al., 2005). Within such research, 'care' is commonly understood as sets of discrete practices associated with particular spaces (Green & Lawson, 2011). For instance, the 'home' as a site of care has been extensively examined in the context of deinstitutionalisation processes (Hughes et al., 2013; Lee & Gramotnev, 2007; Milligan, 2005; Quinn, 2010). Scholars such as Brown (2003) and England (2010) argue that while home-based care may be preferable among care-recipients over institutional care, the burden of informal care work is disproportionately carried by women, which means that gains in patient flexibility frequently come at the expense of the freedom of the (female) carer. Such dynamics highlight the tensions inherent in caring relations, and demonstrate the analytical usefulness of distinguishing between care as experienced by the giver and the receiver.

Beyond the micro-geographies of healthcare, experiences of care-giving and -receiving have been examined at the macro-scale in the context of labour markets and the welfare state. In advanced economies, structures of care provision are significantly affected by the configuration of the welfare state. State welfare regimes frequently reinforce the gendered distribution of caring labour by assuming women to be the primary carers in the home (Knijn & Kremer, 1997; Lawson, 2007; Milligan & Wiles,

2010). Knijn and Kremer (1997), for instance, discuss how the reliance on unpaid female caring labour is challenging the organisation of care within welfare states as women increasingly participate in the formal labour market; however, this increased participation of women in formal work has not led to the degendering of care. Care work is outsourced to paid caregivers, who are generally female, and among those who cannot afford to hire paid caregivers, there remains a 'gap' in care provision (England & Henry, 2013; Lutz, 2018). Welfare systems that emphasise 'work-readiness' and compel socio-economically deprived women into formal employment may therefore constrain the ability of working-class mothers to be care-givers for their offspring, leaving care deficits within poor families (Haylett, 2003).

Studies examining the nature of and relationship between *care-giving* and *-receiving* have largely conceptualised care as labour and practice. While understandings of 'care' within examinations of the socio-spatial dimensions of care-giving and -receiving have undoubtedly become more nuanced over time (Conradson, 2003; Milligan & Wiles, 2010), this research has been limited in its unpacking of the nature of care itself and its role within broader social relations. The practice of care is crucial for care ethicists, as it grounds discussions of morality that otherwise become abstracted into language of rights and principles, as is the case with the ethic of justice (Tronto, 1993); yet, within care ethics, care is more than practice alone. As Robinson (2018, pp. 331) argues, care ethics scholars have been "less concerned with care as a practice or form of labour, and more with care as a way of 'being in the world' that disrupts and fractures the existing order." In this way, scholars engaging with care ethics have tended to extend examinations beyond care as labour or activity, in order to understand how care structures social relations and the allocation of power therein (Green & Lawson, 2011; Meah & Jackson, 2017).

Some scholars engaging with care have taken this a step further to examine, in a normative sense, how care should be mobilized to *re*structure social relations and *re*allocate power in society. In her book *Caring Democracy*, Tronto (2013) advocates for a re-conceptualisation of democratic politics, arguing that care presents opportunities for reshaping and revitalizing contemporary political life. Here, she proposes a fifth and final phase of care, *caring with*, that, she explains, "requires that caring needs and the ways in which they are met need to be consistent with democratic

commitments to justice, equality, and freedom for all" (Tronto, 2013, pp. 23). Such normative questions of the 'transformational' capacity of care have reverberated throughout the geographic literature, for instance among scholars who have examined our capacity to 'care at a distance', and how we might extend the spatial boundaries of our care (Barnett et al., 2005; Lancione, 2014; Popke, 2006; Smith, 1998). Popke (2006) for instance examines the potential for care to 'defetishise' the economy through ethical trade movements that seek to expose the social relations that underpin global chains of production and consumption. As Bartos (2019, pp. 774) argues, however, "when care is analyzed within wider structural systems of oppression, care's normative assumptions become murky". As many scholars have highlighted, caring practices can result in violence or conflict, complicating normative claims of care's ability to radically transform social and political life for the 'better' (Bartos, 2018; Narayan, 1995). In light of these criticisms, and in light of the empirical context of this research, this thesis engages with care ethics as a descriptive, rather than a normative, framework.

As has been demonstrated, the care literature is attentive to connections across scale through the caring process. From the relationship between individual consumption practices and global environmental degradation (Meah and Jackson, 2017), to the connection between wider shifts in the welfare state and lived experiences of the caring 'gap' (England & Henry, 2013; Lutz, 2018), this body of scholarship is useful in highlighting the interrelatedness of individual practices and broader processes, meanwhile providing an analytical framing for articulating how these practices and experiences fit into the caring process. This application of a care ethics frame to the empirical context of crowdfunding enables me to examine lived experiences, but also to situate these experiences within wider discourses. In order to do so, I focus on two key themes within the broader care scholarship to provide analytical focus, the first of these I turn to now.

2.6 The commodification of care

The commodification of care has been a central theme in the care ethics literature, with scholars examining the nature and consequences of care entering the market across a range of contexts. From the rise of commercial childcare (Boyer et al., 2013;

Gallagher, 2018; Schwiter, 2013) to home-based elderly care work (Pelzelmayer, 2018; Schwiter et al., 2018; Stolt & Winblad, 2009), geographers have examined the emergence of new marketplaces for care, as well as instances where existing spheres, such as the home, are transformed into marketised spaces (Pelzelmayer, 2018). Indeed, commodification processes have profoundly shaped how relations of care are organised, experienced and understood, a manifestation of which has been the emerging use of crowdfunding platforms for health-related costs, as I examine through this research.

Services once deemed public – such as healthcare, education and childcare – have increasingly come to be run by for-profit and non-profit private entities, with a reduced role for the state in care provision (Gallagher, 2018; Hoppania & Vaittinen, 2015; Stolt & Winblad, 2009). Even where the state has retained control over service provision, the language and goals of free market economics have come to inform models of care. Neoliberal discourse emphasises autonomy and individualism, seeking efficiency and productivity through maximising individual choice and increasing competition (Held, 2002; Lawson, 2007; McDowell, 2004). In the context of care provision, 'service users' have therefore come to be understood as 'consumers' (Gesler & Kearns, 2002, pp. 143), 'free' to select their own care provider according to their own wants and needs (Gallagher, 2018; Held, 2002; Tronto, 2013). Such neoliberal framing pervades crowdfunding platforms, which, through their very premise, foster an understanding of healthcare as a "good properly governed by the norms of the marketplace rather than as a basic human entitlement" (Snyder, 2016, pp. 40), a framing I interrogate through my analysis of health-related crowdfunding.

These transformations in understandings and structures of care provision have been the subject of significant scholarly critique. Some authors have challenged the principle of assigning monetary value to caring activities, arguing that the application of market values compromises the essential nature of care by facilitating the provision of "care-less" care (Atkinson et al., 2011, pp. 569), or "care without caring" (Green & Lawson, 2011, pp. 646). By treating care as a service that can be freely and openly exchanged among self-determining individuals, Tronto (2013) argues, we distort how we understand caring relations throughout our social worlds. Market values reinforce understandings of care as a discrete and hierarchical intervention designed to

maximise autonomy, overlooking our responsibility for, and interdependence on, one another (Green & Lawson, 2011; Staeheli & Brown, 2003). The 'logic of choice' which prevails in neoliberal discourse, it is argued, is at odds with the 'logic of care', which frames care as an open-ended and ongoing process, responsive to the needs of the care-recipient (Hoppania & Vaittinen, 2015). For this reason, scholars such as Held (2002, pp. 32) have argued for the need to "shrink rather than to expand the market, so that other values than market ones can flourish."

Beyond these philosophical objections, pragmatic critiques have also been levelled at the marketisation of care. The atomistic understanding of human nature that market rhetoric promotes may serve to undermine more relational approaches to care (Hoppania & Vaittinen, 2015; Held, 2002; Tronto, 2013). In terms of care provision, scholars have raised concerns about the ways in which emphasising the rights and responsibilities of individuals to self-determine their own care may serve to undermine more collective models, even if the latter is proven to be beneficial (Boyer et al., 2013; Green & Lawson, 2011; Schwiter, 2013). For instance, Hall (2011) examines the restructuring of care provision for people with learning disabilities through his case study of 'Personal Budgets' in the United Kingdom, which shifted the management of care funding from local governments to the individual. Here, he argues that this focus on maximising individual autonomy necessarily diminished funding for community-based services; services that, in many cases, provide indispensable support and solidarity for its users (Hall, 2011). In this sense, while a 'market logic of choice' can maximise individual autonomy in seeking care (Green & Lawson, 2011; Schwiter, 2013), models informed by this logic may fragment collective structures of care provision.

Further, the commodification of care has been critiqued for exacerbating inequalities in access to care. The logic of choice conceptualises the market as 'flat', with individuals 'free' to make their own decisions (Green & Lawson, 2011; Tronto, 2013); however, such an understanding of the market overlooks historical injustices and social inequities that shape individual 'choice'. As Tronto (2013, pp. 126) explains, a key tool of neoliberal thinking is "creating structural inequalities through past interactions and then declaring them formally irrelevant for the next transaction". By conceptualising individuals as autonomous while simultaneously emphasising

personal responsibility, neoliberal discourse permits widening inequalities in access to resources, by individualising what are, in fact, structural challenges (Cox, 2013b; Hall, 2011; Schwiter, 2013). Framing care as a transaction therefore permits situating those who have limited resources "outside the social and hence beyond the scope of obligation" (Green & Lawson, 2011, pp. 651).

While market-based models may maximise freedom among some, for those who have constrained resources, their reality is far from meeting the ideal of the autonomous actor who can freely select the care they need. Such outcomes are evident in Brazil, where an inability to access privatised healthcare has, in extreme cases, driven some poorer families to disown their own kin (Biehl, 2005, as cited in Green & Lawson, 2011). Where providing care becomes a financial burden that cannot be met, individuals may be abandoned out of desperation. Even in contexts where complete privatisation of services has not occurred, neoliberal discourses increasingly inform who is considered a legitimate recipient of public care, exacerbating inequalities in access (Cox, 2013b; Schwiter, 2013). Commodified care is therefore generating "new geographies of inequality" (Cox, 2013a, pp. 493), with distributional challenges exacerbated in marketised contexts where care is conceptualised not as a social responsibility, but as an individual choice.

Despite significant critique of commodification processes, some scholars have challenged the notion that market values necessarily 'corrupt' care and lead to undesirable outcomes, a debate I engage with in the crowdfunding context. Some scholars have argued that the assignment of monetary value to caring services is not, in itself, objectionable. As Cox (2013a, pp. 494) explains,

> In academic work and popular opinion, the idea that the market is in some way a priori unsuitable or incompatible with the activity of caring can be taken for granted and there is the idea that caring activities are corrupted when a monetary value is attached to them. However, it is worth questioning whether there really is a principled objection to payments for care. There is much evidence that paid-for care is often deeply caring.

Indeed, many have highlighted the binary framing of marketised care as problematic and non-marketised care as unproblematic, which overlooks the complexity of lived caring experiences (Boyer et al., 2013; Cox, 2013a; Pelzelmayer, 2018). For instance, this dualism is complicated by evidence of paid caregivers who express 'heart-felt love' for their care-recipients, as Pelzelmayer (2018) discusses in the context of live-in carers in Switzerland. Equally, care that is non-commodified is not necessarily 'uncorrupted' or 'pure'; for instance, gendered expectations can make unpaid familial care oppressive for women (Cox, 2013a). Further, some have raised concerns that critiquing the commodification of care may simply reinforce the devaluation and underpayment of waged caring labour (Held, 2002; Pelzelmayer, 2018). For this reason, Cox (2013a, pp. 494) among others argue that "payment itself is not the problem, but the context and organisation of commoditised care can be highly problematic."

There is therefore an existing scholarly debate over the nature and implications of commodified care. While market-based models of care have been widely critiqued, some have also raised concerns about dominant conceptualisations of commodified care as "almost-wholly negative" (Boyer et al., 2013, pp. 519). This thesis engages with this debate, contributing to existing literature that destabilises this binary and engages with the tensions of caring in a commodified context. While some existing work has begun to unpack these complexities, many authors have called for further research that explores the extension of market logics into realms of care (Gallagher, 2018; Green & Lawson, 2011; Lawson, 2007).

In doing so, this thesis seeks to contribute to literature on health-related crowdfunding, but also to further develop understandings within the broader care literature. Empirical examinations of commodification processes within the care literature have largely focussed on the nature and implications of the shift from unpaid to paid caring labour, with a consequent emphasis on *care-giving* practices (for exceptions, see discussions on commodification and consumption practices, e.g. Barnett et al., 2005; Goodman & Boyd, 2011; Popke, 2006). In the case of crowdfunding, market values come to influence who is *taken care of* in the caring process. By engaging with a novel marketised space that has emerged in a commodified context, this thesis therefore

seeks to respond to Green and Lawson's (2011, pp. 650) call for further research that "analyses particular expressions or renegotiations of the commodification of care."

Some scholars engaging with health-related crowdfunding have begun to situate this phenomenon within the context of broader commodification processes (Dressler & Kelly, 2018; Snyder, 2016). Such discussions have levelled cursory critiques at the market-based allocation of healthcare that crowdfunding facilitates, without teasing out the nuances and complexities of this process. The abstracted nature of these claims is perhaps unsurprising given the limited empirical research within this body of scholarship, and more specifically, the lack of face-to-face engagement with campaigners. In particular, as raised in section 2.3, conducting semi-structured interviews with campaigners allows me to go beyond a commentary on how these individuals present themselves online to explore how they describe their experiences of this process, and what these described experiences have to say about the implications of the commodification of care. In engaging with these debates and acknowledging the nuanced experiences of care in a commodified context, I also seek to unpack how understandings of who is a 'deserving' care-recipient are implicated in these experiences. As such, I now turn to engage with a second key theme within care ethics scholarship on the politics of deservingness.

2.7 The politics of deservingness

Scholars have widely discussed understandings of deservingness, and the political implications of these understandings, in relation to care. Many have argued that our understandings of who is 'deserving' of our care is predominantly shaped by proximity and personal ties. Physical and social proximity has often been understood as the foundation for ethical and moral relationships, as we care for those close to us, both physically and emotionally (Atkinson et al., 2011; Lancione, 2014; Milligan & Wiles, 2010; Moosa-Mitha, 2016; Pitt, 2018). In her widely cited article on relational space and geographies of responsibility, Massey (2004, pp. 8-9) describes a "hegemonic geography of care" within the Western world, which she argues resembles a "nested set of Russian dolls". By this, she refers to the way in which our sense of care and responsibility for others is organised territorially and hierarchically, with the prevailing assumption that we care most for those within our home, then community, then nation,

and so on. This reality, Massey (2004, pp. 9) argues, reflects the "still-remaining impact, in this world sometimes said to be increasingly virtual, of material, physical proximity". Despite technological advances – of relevance to this project, for instance, the rise of crowdfunding platforms – that have enabled knowledge of, and interaction between, 'distant' individuals, Massey (2004) contends that social ties, whether they be familial or identity-based, remain important in determining our understandings of who deserves our care.

However, scholars have also examined how individuals beyond our 'nearest and dearest' can be understood as 'worthy' care recipients, and thus trigger caring responses. Many have challenged the notion that caring processes necessarily rely on proximity (Cox, 2010; Lancione, 2014; Lawson, 2007; Milligan & Wiles, 2010; Raghuram et al., 2016). The potentialities of caring for distant 'others' has been examined in the context of, for instance, online campaigns that raise awareness of the 'plight' of distant 'third world' others (Hawkins, 2008), or through ethical consumption practices aimed at alleviating the harms of global production chains (Barnett et al., 2005; Popke, 2006). By generating caring responses from 'first world' consumers, such cases perhaps reflect our ability to stretch the "boundaries of our caring" (Milligan & Wiles, 2010, pp. 744) beyond those within our immediate circles to include those who are socially and physically distant to ourselves. Such debates over the 'boundaries' of our care raises questions as to how social and physical proximity shapes understandings of deservingness on crowdfunding platforms, a setting which is often framed as 'transforming' existing patterns of distribution (Langley & Leyshon, 2017; Paulus & Roberts, 2018).

Care ethics as a framework places an emphasis on embodiment. Care is understood as a concrete corporeal relation, "rooted in our body and our bodily practices" (Hamington, 2004, pp. 5; Robinson, 2018). Processes of care involve embodied responses to our surroundings, *caring about*, on which we may or may not act, or *take care of* (Vaittinen, 2014; Wiles, 2011).This centring of the body as a political subject within the ethic of care is part of the challenge posed to traditional justice-based ethical frameworks which have privileged the 'rational' thinker and devalued embodied knowledges (Hamington, 2004; Robinson, 2018). The myth of autonomous and rational subjectivity that pervades Western ideology has devalued 'dependency', and

consequently, 'dependent' bodies (Wiles, 2011); but far from being politically inconsequential, care ethicists have highlighted how 'needy' bodies hold significant power as they necessitate and motivate caring labour (Hoppania & Vaittinen, 2015; Robinson, 2018). As such, using a care ethics lens to understand deservingness in a crowdfunding context enables an attentiveness to how particular bodies trigger caring responses in particular contexts.

However, not all 'needy' bodies prompt caring responses, and as such it is important to examine how bodies are read and interpreted. This is particularly useful in understanding health-related crowdfunding, where, in the context of large numbers of campaigns centred on the funding recipient's body and its malfunctions, donors must evaluate which causes are 'worthy' of their money. As Dyck et al. (2005, pp. 176) argue in their article on home-based care, bodies may (or may not) be inscribed with norms that deem them "in need of and deserving of care". In order to trigger care, one's 'neediness' must therefore be constructed in ways that are congruent with what Ticktin (2011, pp. 10) describes as "regimes of care", or accepted and established discourses and practices that are rooted in the moral imperative to alleviate suffering. Based on her fieldwork examining the construction of "the morally legitimate suffering body" in the context of asylum seeking in Paris, Ticktin (2011, pp. 3) argues that asylum seekers must perform their suffering according to two regimes of care – namely, humanitarianism and the movement against gender-based violence – in order to be recognised as 'deserving' of care by the French government. In a similar vein, crowdfunding campaigners must effectively perform their suffering according to established discourses and practices, a performance that I seek to deconstruct through this research.

The political construction of the 'deserving' subject has also been examined among care scholars in the context of welfare provision. Since the late 20th century, neoliberalism has become political orthodoxy across the Western world, with its emphasis on the free market as the most efficient and effective allocator of resources reverberating beyond economic policies to shape models of social service provision (Cox, 2013a; Green & Lawson 2011; Staeheli & Brown, 2003; Tronto, 2013). Scholars have therefore examined how the proliferation of market values has led to an accompanying scepticism towards universal benefits, under the assumption that

universal welfare "prices people out of work" (McDowell, 2004, pp. 151). Increasingly, eligibility for welfare benefits has become contingent on the 'work-readiness' of individuals, with those who do not seek work and/or pursue jobs proposed by welfare officials deemed 'undeserving' recipients of state support (Green & Lawson, 2011; McDowell 2004). Calling for further interrogation of how individuals are situated within broader political narratives of deservingness, Robinson (2018, pp. 327) argues that "[the] task for scholars, then, is to ask why particular bodies in particular encounters can trigger political relations of care, whereas others elsewhere elicit only relations of neglect." This connection of lived experience – "particular bodies in particular encounters" – and the wider processes that contextualise this experience – the "political relations of care" – is a connection that I seek to engage with in the crowdfunding context.

Indeed, the corporeal focus of care ethics therefore enables an interrogation of which bodies fail to receive care, revealing how care can serve to reproduce a violent or unjust status quo. While 'care' is often romanticised, particularly when discussed in normative terms (Bartos, 2019), caring processes can serve to justify relations of oppression whereby particular groups or individuals are subject to cycles of a lack of care (Bartos, 2018; Narayan, 1995; Robinson, 2011). Such was the case in colonial discourse, where Narayan (1995) argues that rhetoric of paternalistic care was deployed to conceal relationships of domination between the colonisers and colonised. For this reason, Bartos (2018) argues that it is important to be attentive to whose understandings of 'living well' are enacted over others (Bartos, 2018; Brown, 2003). In her examination of care and conflict in the context of campus-based sexual assault, Bartos (2018, pp. 69) demonstrates how discourses of care were deployed to "maintain a criminal's world and a larger world of structural privilege", where care for the perpetrator was prioritised over care for the victim. To dismantle idealistic representations of care, scholars have therefore demonstrated how the framing of particular bodies as more deserving than others can serve to reproduce wider systems of oppression and domination.

Existing literature on deservingness and care therefore provides a framework for analysing understandings of who constitutes a 'legitimate' recipient of care. This scholarship is attentive to the micro-level politics of how bodies are 'read' and

interpreted, but also to how wider discursive shifts in who is constructed as a worthy care-recipient, as is evident in approaches to welfare provision. Issues of deservingness have been raised in existing literature on health-related crowdfunding; as was explored in section 2.3, scholars have highlighted how campaigners must craft narratives that carefully negotiate cultural norms of 'self-help' and 'hard work' in order to justify their appeal for funding (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018; Snyder et al., 2018). Engaging with the comparatively expansive discussions on the 'deserving' subject within the care ethics literature enables further development of these ideas, in particular through capitalising on the ability of this literature to draw connections across scales. As such, I seek to mobilise this literature by drawing connections to the embodied understandings and experiences of who constitutes a 'worthy' care-recipient, meanwhile examining the wider discourses of deservingness that campaign(er)s seek to perform.

2.8 Conclusion

While health-related crowdfunding has begun to receive scholarly attention in recent years, there is significant work to be done in examining the practices and experiences of those engaging with these platforms. This review has examined existing literature on crowdfunding more broadly, and health-related crowdfunding specifically, arguing that broader critiques of these platforms as allocators of resources are especially salient in the context of fundraising for health-related costs. Indeed, in the context of inadequate public healthcare cover, the ability of individuals to raise funds can be consequential. In the context of calls for further research in this area (Berliner & Kenworthy, 2017; Renwick & Mossialos, 2017; Snyder et al., 2016), I argued for the value of care ethics as a framework for conceptualising and articulating the process of care, in particular due to its ability to connect practices and experiences of care across different scales. I examined literature on the commodification of care and the politics of deservingness, key themes within wider care ethics scholarship, demonstrating their usefulness in extending under-theorised and under-developed arguments from within the health-related crowdfunding literature.

Beyond this theoretical contribution, I also highlighted the empirical gap in the scholarship on health-related crowdfunding that this thesis seeks to address. Through

conducting semi-structured interviews with campaigners, I not only engage with the epistemological position of care ethics scholars, but further seek to examine individual experiences of securing care in a crowdfunding context, grounding the relatively abstracted arguments put forth in existing literature on health-related crowdfunding to date. Finally, I built a case for the empirical contribution of this research to care ethics literature, within which debates over the nature and implications of the commodification of care have largely centred around the transition from unpaid to paid caring labour across various contexts. The rise of health-related crowdfunding presents an opportunity for examining a novel marketised space (Cox, 2013a), through which insights can be gained as to who is *taken care of* in a commodified context.

Chapter Three: Methodology and Context

3.1 Introduction

This chapter discusses the methodological approach, context, and methods that inform this thesis. I begin in section 3.2 with a discussion of how my methodology has been informed by care ethics, in particular through embracing an emphasis on embodied experience and context, out of which I have developed a qualitative case study methodology. The case study that this thesis engages with is health-related crowdfunding in NZ. Section 3.3 discusses the research context, providing an overview of healthcare provision in NZ. To examine this case study and answer my aim and related objectives, the design of this project involves both primary and secondary data collection, the details of which are overviewed in section 3.4. I conducted interviews with those constructing health-related campaigns on Givealittle, a NZ donation-based crowdfunding platform, alongside collecting interviewees' online campaigns. Section 3.5 outlines my recruitment process, discussing some of the implications of this process for me as the researcher, and what this means for understandings of online research more broadly. Sections 3.6 and 3.7 consequently discuss the proceedings and ethical implications of conducting interviews and gathering secondary data from Givealittle, before I detail the process of reflexive thematic analysis in section 3.8 that I used to construct my analysis in Chapter Four.

3.2 Methodological approach

This project takes a qualitative case study approach (Baxter, 2016; Flyvberg, 2006) in order to examine the practices and experiences of crowdfunding campaigners. As highlighted in Chapter Two, mobilising care ethics as an analytical lens necessitates engaging with lived realities and experiences in order to understand how context-dependent notions of responsibility for others shape our social and political worlds (Couper, 2015; Tronto, 1987; Pitt, 2018). Indeed, key to the challenge that the ethic of care poses to conventional Western moral philosophy is the rejection of abstracted principles, instead emphasising the importance of concrete practices in shaping our decision-making processes (Held, 2006; Robinson, 2018). This shift in emphasis from abstracted principles to practice and experience is accompanied by a shift in who is

understood as an expert, and whose knowledge is valued. Whereas a moral theory of justice may privilege, for instance, the 'rational' expertise of a politician, taking care 'seriously' involves paying attention to those involved in caring processes on-the-ground (Brown, 2003; Robinson, 2011; Tronto, 1995). In light of this approach, and informed by care ethics as a framework, my research design enables engagement with the understandings and constructions of care among those who have themselves crowdfunded for the health-related costs of a loved one. In doing so, I collected both primary and secondary data, seeking to tap into the concrete circumstances of care (Pitt, 2018; Tronto, 1987) and tease out nuances in meaning and experience, a necessarily qualitative endeavour.

Research within a qualitative paradigm investigates meaning and meaning-making, with an explicit acknowledgement of the involvement of the researcher in the knowledge-production process (Crang, 2005; Winchester & Rofe, 2016). Unlike a positivist epistemology often associated with quantitative research, qualitative researchers do not understand there to be an objective world that is able to be impartially observed and measured (Braun & Clarke, 2013; Kitchin & Tate, 2000; Valentine, 2005). Instead, all knowledge is understood to be socially produced and shaped by the experiences and interpretations of those doing the research. This explicit acknowledgement of the social production of knowledge undermines any critiques of 'subjectivity' levelled at qualitative research, as a qualitative approach highlights that all knowledge, whether retrieved through qualitative or quantitative techniques, is wedded to human interpretation.

Operating within the qualitative paradigm, this project has engaged with a case study approach. Qualitative case study research assumes the importance of in-depth and context-dependent research of a particular manifestation of a phenomenon of interest (Baxter, 2016; Flyberg, 2006). For researchers engaging with this approach, a case is treated holistically as something which cannot be understood properly when divorced from its context, lumped together with multiple other cases and/or deconstructed into many sub-units. This emphasis on depth and close observation makes it a useful approach for expanding, corroborating or falsifying theoretical concepts (Baxter, 2016; Flyvberg, 2006). The 'hallmark' of case study research is engaging with data from multiple sources, as this enables depth in understanding a phenomenon through

different access points (Baxter, 2016; Baxter & Jack, 2008). In the context of the present project, adopting this approach has enabled me to engage with the experiences of care and understandings of deservingness using the case of health-related crowdfunding on the Givealittle platform in NZ. Through analysing both primary and secondary data, this approach facilitated an engagement with care ethics as a theoretical framework, enabling me to expand understandings of health-related crowdfunding as a phenomenon, but also further conceptualise the nature and implications of commodified care.

Qualitative case study research is closely aligned with a social constructionist approach to knowledge creation (Baxter, 2016; Baxter & Jack, 2008). Social constructionism emphasises the social processes that shape our knowledge of the world, seeking to deconstruct 'truth' claims by uncovering incoherencies and inconsistencies. Such an approach emphasises the role that language plays in constructing our realities, as the way we think, act and speak actively shapes the world around us (Couper, 2015; Winchester & Rofe, 2016). This thesis takes a regular social constructionist approach, which, rather than denying the possibility of a reality independent of human consciousness, acknowledges that we can only ever come to know this reality through socially constructed concepts (Couper, 2015; Winchester & Rofe, 2016). I am interested in how campaigners engage with social structures of meaning around care, seeking to uncover the ways in which campaigners situate their understandings of the politics of who gives and receives care within broader narratives of, for instance, 'responsibility' and 'deservingness', and how campaigners frame their understandings and experiences of commodified care in a crowdfunding context.

3.3 Research context

This thesis engages with health-related crowdfunding in NZ, a national context that has not yet been examined in the existing health-related crowdfunding literature. NZ is a novel context for this research as it is a country with a history of strong welfare provision (Gauld, 2013; Goodyear & Ashton, 2019). Existing research on health-related crowdfunding has largely focused on the United States (e.g. Barcelos, 2019; Barcelos & Budge, 2019; Berliner & Kenworthy, 2017; Kenworthy et al., forthcoming; Gonzales et al., 2018; Murdoch et al., 2019; Paulus & Roberts, 2018), where it is

arguably less surprising that crowdfunding is being used to substitute for publicly funded care due to its lack of universal health cover. NZ is widely understood as providing a high standard of care; following the establishment of the Social Security Act of 1938, NZ was one of the first in the world to develop a universal, tax-funded health service (Gauld, 2013; Goodyear-Smith & Ashton, 2019). Unique features of the NZ health system are lauded internationally, such as the Pharmaceutical Management Agency, or PHARMAC, which, since its establishment in 1993, has successfully kept drug expenditure low meanwhile expanding access to medicines (Cumming et al., 2010; Goodyear-Smith & Ashton, 2019). Similarly, NZ's no-fault accident compensation scheme is praised for its ability to provide injured patients with timely assistance and avoiding medical litigation (Bismark & Paterson, 2006). As such, with the universal orientation of its health system, NZ is understood to produce relatively good health statistics, particularly when compared with a country like the United States (Gauld, 2013; Goodyear-Smith & Ashton, 2019).

NZ has had a long-standing relationship with neoliberal ideology. Coined the 'New Zealand experiment', NZ became infamous in the 1980s for its extensive adoption of neoliberal policy and widespread economic restructuring, mirroring that of structural adjustment programmes implemented in the global South (Aimer, 2015; Kelsey, 2015; Larner, 1997; Prince et al., 2006). The manner in which the government at the time embraced wide-reaching deregulation and privatisation across a short time frame meant that NZ was held up by global economic organisations such as the World Bank and the Organisation for Economic Co-operation and Development (OECD) as an international 'success' story and a model for the rest of the world.

In spite of the ubiquity of neoliberalism in the NZ context, healthcare has remained relatively sheltered from neoliberal reform compared to other domains of social service provision, albeit with a period of health restructuring that was later reversed. The 1990s in NZ saw what Gauld (2009) describes as one of the most 'radical' health sector restructurings witnessed anywhere in the world. The government sought to adopt private sector management practices by introducing market principles into the health sector and seeking to stimulate competition between service providers (Easton, 2002; Goodyear-Smith & Ashton, 2019); however, these reforms did not deliver, and were largely softened and/or reversed by the turn of the century, in part responding to

significant public outcry about spending cuts (Barnett & Barnett, 2004; Gauld, 2009; Prince et al., 2006). Indeed, despite diminished public support for income redistribution and increased support for tax cuts among the NZ public since the 1980s, healthcare is still understood by the majority as a social good that ought to be provided by the state (Humpage, 2011).

Today, despite providing a relatively well-regarded standard of care, gaps remain in healthcare provision. For instance, access to modern cancer drugs has been a source of significant contention in recent years, with many stakeholders criticising the limited and delayed access to new cancer medications compared to nations such as Australia and the United Kingdom (Desmarais, 2019; Wonder & Milne, 2011). In another recent example, highly publicised debates have unfolded over the rights of individuals to be paid for their labour in caregiving for disabled family members (Bell, 2019; Johnston, 2018). The NZ context thus presents an important opportunity for examining the use of crowdfunding for health-related costs. Although it presents a less extreme case than the United States, where access to healthcare is widely recognised as uneven, shortfalls prevail in NZ that are perhaps more easily overlooked given the existence of a relatively comprehensive public health system.

3.4 Research design

In examining the practices and experiences of crowdfunding campaigners, this project engaged with users of Givealittle, a NZ donation-based crowdfunding platform established in 2008. Givealittle was selected as the platform of study as it is the only dedicated donation-based crowdfunding platform in NZ. Other crowdfunding platforms used are either international, such as GoFundMe, or are designated for other types of crowdfunding such as equity- or lending-based. The platform is said to be "New Zealand's most popular crowdfunding website" (Spark Foundation, 2020), with $136.4 million (New Zealand Dollars) raised through its campaigns since its inception (Givealittle, 2019b). The platform is owned by the Spark Foundation, a charitable organisation affiliated with major telecommunications company Spark New Zealand. Givealittle enables individuals, charities or businesses to create campaigns for a cause or project, with users determining the duration of the campaign. Users can set a specific monetary goal, or they can leave their goal as open, with donations to the

cause paid out irrespective of whether a goal is set and/or reached. Donors are able to contribute any amount they wish and can choose whether or not to display their name and/or leave a message. While establishing a campaign is free, in 2016, Givealittle introduced a 5% fee on the amount raised on each campaign, stated to be for administrative purposes.

To examine practices and experiences of health-related crowdfunding campaigners, I collected both primary and secondary data. Primary data collection involved 15 semi-structured interviews with people running crowdfunding campaigns on Givealittle. Interviews remain the most commonly used qualitative technique in geographical research, despite a plethora of qualitative research methods available (Dowling, 2016; Kitchin & Tate, 2000). This popularity among researchers is perhaps attributable to the way in which interviews enable an in-depth examination of opinions, understandings, and the negotiation of identities and/or feelings in a way that more rigid methods such as surveys may fail to capture. As a method, their interactive nature provided me with an opportunity to gain insights into how participants make sense of their experiences (Cloke et al., 2004). As an intensive – rather than extensive – data collection method, interviews are not used to produce statistically generalisable findings. Rather, they are useful for examining how processes operate in a particular case, or a number of particular cases, making them well-suited to qualitative case study research (Stratford & Bradshaw, 2016; Valentine, 2005).

To complement understandings gained through interviews, I combined primary data collection with secondary data collection by gathering the online Givealittle campaigns of interviewed users. Preliminary analysis of online campaigns helped to inform questions during the interviews themselves, but also later provided useful insights into how participants presented their causes and/or the funding recipient to the 'crowd'. As Braun and Clarke (2013, pp. 153) explain, the use of pre-existing data sources enables "access [to] people's experiences and perspectives without shaping their responses through our data collection questions and methods". Engaging with the online user-generated content of my interviewees was useful, as it enabled me to identify tensions and inconsistencies between interview accounts of participants' lived experiences and online representations, in essence having "a foot in both virtual space and material place" (Morrow et al., 2015, pp. 532). Combining primary and secondary data in this

way enabled me to explicate both 'behind-the-scenes' experiences of interviewees and the framing of their public-facing campaigns.

3.5 Participant recruitment and navigating online research

In beginning the data collection process, I recruited interview participants by conducting searches for active health-related campaigns on the Givealittle website (https://www.givealittle.co.nz). Searches were initially conducted by filtering those categorised under 'Health'. Through this process, it became evident that some campaigners had categorised health-related campaigns under other categories, for example 'Kiwi Kids' or 'Community'. For this reason, searches were also conducted under other such related categories in order to reach those that were health-related but categorised otherwise.

In order to address my research aim, campaigns were excluded that were raising funds for either funeral costs, an organisation, or someone based overseas. I interpreted funeral costs to be beyond the scope of 'health-related expenses', while campaigns fundraising for an organisation were excluded on the grounds that the funds were not used for individual costs. As the specified case study of this thesis is health-related crowdfunding in NZ, campaigns that were raising funds for individuals who were declared as being based overseas were also seen to be beyond the scope of the study. Pages with fewer than fifteen donations were excluded on the grounds that the campaigners' level of engagement with the crowdfunding process was likely to have been limited.

A locational filter for Auckland- and Christchurch-based campaigns was also applied in recruiting participants. This decision was made for logistical purposes to enable me to conduct face-to-face interviews where possible. Auckland and Christchurch are the two biggest urban centres in NZ (Stats NZ, 2013), and as such, this decision confined my sample of campaigners to those residing in large urban areas. As existing research suggests that crowdfunding is largely an urban phenomenon (van Duynhoven et al., 2019), I felt this locational specificity to be appropriate; however, future research many benefit from specifically examining the experiences of those campaigners based in rural areas.

Participants were limited to those campaigning *on behalf of* the specified funding recipient (i.e. third-party campaigners). Existing research suggests that the majority of campaigns are created by someone other than the funding recipient themselves (Palad & Snyder, 2019; Paulus & Roberts, 2018; Snyder et al., 2018), and indeed, anecdotally, this trend was consistent with the campaigns I encountered on Givealittle. While the decision to exclude those who managed their own campaigns may have precluded some unique insights from those filling the role of 'campaign manager' and 'funding recipient' concurrently, it provided a degree of specificity in the focus of the project. Beyond the specificity this criterion enabled, this decision was also made to create distance between the individual experiencing illness or disability, and I as the researcher. I hoped that this degree of separation would mitigate some of the ethical risks the research project would entail, and lessen some of the emotional labour of conducting interviews.

Coming into this project, I anticipated that conducting interviews might be emotionally taxing due to the context of conversations, in particular discussing the hardships facing interviewees and their loved ones. Emotion management, a form of emotional labour, has been well-documented in the social sciences as a necessary element of developing rapport with interview participants (Bergman Blix and Wettergren, 2015; Carroll, 2013). In hindsight, however, I underestimated the emotion management that I would have to enact while recruiting participants online. Given the in-depth disclosure that crowdfunding campaigns often elicit (Gonzales et al., 2018; Paulus & Roberts, 2018), scrolling through pages of crowdfunding campaigns, many with tragic stories of suffering or distressing images, was somewhat taxing, and at times, confronting. For instance, one page I encountered contained graphic images of bloodied cysts, lined up against a ruler to emphasise their size, that had the campaigner described as having been removed from the funding recipient's body. In another case, a campaigner described in vivid detail being a victim of domestic violence, appealing for financial assistance to seek medical help.

My experiences reinforce the extent to which online research must be understood as embodied and relational. Morrow et al. (2015, pp. 534) argue that much existing literature on online research methods has overlooked the complexity of the "virtual-

material interface", and in doing so, the online researcher has been positioned as a "disembodied, outside observer". They argue that much feminist geographical research privileges or assumes embodied, face-to-face contact, and join other scholars such as Crang et al. (2007) in arguing for a more nuanced way of thinking through the co-constitution of online and offline interactions. While I may not have had any face-to-face interaction with the aforementioned campaigners who posted images of their cysts, or were victim to domestic violence, spending time on their Givealittle pages gave me a window into their lives in a way that felt intrusive, or even voyeuristic, due to the level of intimate detail provided. The complex relations between virtual and material worlds are therefore pertinent not only in terms of my empirical focus in this thesis, but also in relation to my experiences of conducting research, where my online recruitment process at times resulted in embodied, visceral reactions to the realities of distant 'others'.

In order to recruit campaigners who met my selection criteria, I posted tailored advertisements to the 'Question and Answer' tab of eligible campaigns in early July 2019 following approval from the University of Auckland Human Participants Ethics Committee (reference number 023116). My post invited page constructors to make contact by email if they wished to participate in an interview. I posted to a total of 97 campaigns, which spanned a range of health conditions, intended use of funds, length of campaign and amount of funding received. Of the pages that were posted to, page constructors from 22 campaigns made contact. I responded by email to all campaigners who contacted me, attaching a Participant Information Statement and a Consent Form (see Appendices A and B). Seven individuals did not respond to my follow-up email, and as such, 15 interviews were arranged.

3.6 Conducting interviews, enacting boundaries

Following recruitment, I conducted 15 interviews over a two-week period in mid-July. Five of these involved face-to-face conversations, with ten conducted over the phone. While it was somewhat harder to establish rapport with participants over the phone, phone interviews were offered as an option to be flexible in accommodating participants' existing commitments (Braun & Clarke, 2013; Kitchin & Tate, 2000). Many interviewees were otherwise occupied juggling work, fundraising and/or caregiving

demands, an issue pertinent to my analysis in Chapter Four. Participants were offered the opportunity to suggest a location for a conversation, in an attempt to maximise convenience for interviewees, but also to facilitate a more relaxed conversation (Elwood & Martin, 2000; Valentine, 2005). Face-to-face interviews were therefore conducted at participants' homes, at cafes, or at workplaces. Interviews were semi-structured, which involved preparing some questions prior to meeting with participants (see Appendix C for interview schedule) but leaving the format of the interview relatively flexible to enable me to pursue unforeseen areas of interest as they arose (Dunn, 2016; Kitchin & Tate, 2000; Valentine, 2005). Preliminary analysis of participants' online campaigns informed the interviews themselves by providing background information on the context of their particular campaign, as well as highlighting some points of interest for conversation. All interviewees signed consent forms prior to participation, and were provided with a $30 supermarket voucher in recognition of their time and contribution to the research project. Both face-to-face and phone interviews were audio-recorded, enabling me to focus on the conversation at hand without being preoccupied by taking notes.

Despite the imperative to keep conversations on-topic, I found myself on many occasions listening to participants describe their struggles to a degree that was far beyond the scope of my research interest. Given the precarious circumstances that many of these individuals found themselves in, I felt it necessary to provide participants with the space to voice their feelings and experiences, even if they were not explicitly 'relevant' to the project at hand. However, doing so meant that I was having to negotiate boundaries in a way that would perhaps have been easier had I followed a more scripted approach. While I was only conducting one-off interviews, it nonetheless felt at times that the boundaries between my role as a researcher and that of a new-found friend became murky (Bergman Blix & Wettergren, 2015; Dickson-Swift et al., 2006). As Dickson-Swift et al. (2006) explain, qualitative researchers investigating sensitive issues can find themselves caught between seeking to encourage openness from their participants, meanwhile avoiding the interview turning into a counselling session. In one particular instance of boundary-blurring, a participant was eager for me to go with her to visit the funding recipient, a child, who was in hospital. Despite my initial attempt to politely decline, she suggested the excursion again. While I ultimately managed to communicate why I felt it was not my place to go – both in terms

of my own personal discomforts with what felt like a voyeuristic visit with a sick child, but also in terms of the scope of my research objectives and ethics approval – I found negotiating this boundary difficult, as I did not want to come across as rude or ungrateful for her time. As Bergman Blix and Wettergren (2015, pp. 691) put it, the researcher/researched boundary is "situationally contingent", and as such, making these judgement calls is not always straight-forward.

More broadly, I felt a certain degree of discomfort during some of these interviews, akin to what McGarrol (2017) describes in her discussion of the emotional labour of conducting interviews with terminally ill individuals. While none of my participants were terminally ill, a distance that was afforded by interviewing third-party campaigners, many of them were in difficult circumstances, leaving me with a sense of guilt as I fleetingly entered and exited their lives. At times, providing a $30 voucher felt somewhat uncouth given the level of financial need some were describing, particularly among those that had been relatively unsuccessful in raising funds through crowdfunding. These experiences of discomfort highlight the extent to which an interview is a "complex social encounter" (Kitchin & Tate, 2000, pp. 213; Valentine, 2005), which, beyond a mere question-and-answer session, involves negotiating the emotions and identities of both the researched and the researcher.

I noted down these initial reflections following interviews to be collated alongside interview transcripts for analysis. Interview recordings were manually transcribed verbatim in order to tap into the thought processes behind the words spoken (Braun & Clarke, 2013). In order to maintain confidentiality, the names of participants were changed in transcription, as well as any other names discussed in conversation and/or potentially identifying details, such as workplaces or locations.

3.7 Secondary data collection and the ethics of online data use

To prepare for analysis, online campaigns were downloaded and converted into Portable Document Format (PDF) files before being printed for manual coding alongside interview transcripts. The use of crowdfunding campaigns as secondary data raises ethical questions around the use of online data and informed consent in research. Participants explicitly consented to engaging in an interview through signing

a consent form, but I did not seek consent to use their online content. The ethics of online data use has been widely discussed in the social sciences, with many highlighting the inadequacy of extant ethical guidelines in informing how researchers should proceed with data collection in 'public' online forums (Braun & Clarke, 2013; Elgesem, 2002; Zimmer, 2010). While some have argued that anything publicly available online is 'fair game' for social researchers, others have raised concerns about the use of online content that is published with an assumption of privacy, even if it is technically publicly available (Bruckman, 2002; Hookway, 2008).

This decision to use the online content of interviewees without explicit permission was, I argue, ethically defensible, as the premise under which those posting a crowdfunding page share (sometimes intimate) information, is that it will be publicly available beyond their immediate social networks. In their widely-cited report, the Association of Internet Researchers argue that it is important to consider the venue of information provision in online research, stating that the "the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality, right to informed consent etc." (Ess & the AoIR Ethics Working Committee, 2002). In the case of crowdfunding campaigns, the publicly-accessible nature of pages is assumed in the process. A 'private' crowdfunding campaign that was not available for members of the public to access would undermine the purpose of fundraising in such a forum at all.

In spite of the acknowledged publicity of these campaigns, I still deemed it necessary in my analysis to maintain some level of confidentiality so as to not unknowingly implicate individuals in my research. As such, I applied what Bruckman (2002) describes as 'moderate disguise'. Verbatim quotes from online campaigns have been used, however names and other identifying details have been changed, such as specific workplaces or locations (Bruckman, 2002). While there is a chance that quotations could be traced back to their original author with some investigation, the potential harms associated with this risk are, I argue, minimal given the explicitly public nature of campaigns.

3.8 Data analysis

In order to interpret data, I engaged in reflexive thematic analysis (Braun & Clarke, 2019; Braun et al., 2019) of interview transcripts and online campaigns. More broadly, thematic analysis involves the identification of codes as the basic units of analysis, from which patterns can be identified (Braun & Clarke, 2013). In particular, thematic analysis is useful for "capturing the complexities of meaning within a textual data set" (Guest et al., 2012, pp. 11) as the researcher can identify both semantic, or data-derived, but also latent, or researcher-derived, codes (Braun & Clarke, 2013). As Braun et al. (2019) explain, thematic analysis is perhaps best understood as an umbrella term rather than a single analytic approach, and indeed, one which is often poorly defined. Many scholars, they argue, describe themes as simply 'emerging' from the data, a depiction which overlooks the active role of the researcher in the process of knowledge production. For this reason, they propose a 'reflexive thematic analysis' approach, which emphasises the situated and contextual nature of meaning-making, highlighting the researcher's input and subjectivity as not only valid but a useful tool in making sense of data (Braun & Clarke, 2019; Braun et al., 2019).

In the context of my research, reflexive thematic analysis began with familiarising myself with my data. Reading and re-reading transcripts and written campaigns enabled me to 'immerse' myself in the data, out of which I was able to generate initial codes which I applied manually to the data (Braun & Clarke, 2019). Initial codes were largely semantic codes, in that they captured the explicit meaning of the text (Braun et al., 2019), such as 'reconnecting with loved ones' and 'feeling emotionally supported'. In order to develop these codes into candidate themes, I combined some codes, while others I deemed substantial enough to be 'promoted' to a theme. For instance, 'control over circumstances' and 'hard working' were combined to form the theme 'deserving neoliberal subject', whereas I saw 'gap filling for state support' as significant enough to form a standalone theme. Reviewing the themes that I had developed led to a process of refinement and rearrangement in order to form a coherent narrative out of the data, through which I referred back to my raw data to ensure the story I was presenting reflected the data itself (Braun & Clarke, 2013; Braun et al., 2019). As such, the discussion presented in Chapter Four does not reflect a process of 'retrieving' pre-

existing themes from within the data, but rather is an output of an iterative process through which I, as the researcher, played an active role.

Chapter Four: Findings and Discussion

4.1 Introduction

This chapter presents and discusses findings from a reflexive thematic analysis of online Givealittle campaigns and semi-structured interviews, through which I examine the practices and experiences of third-party crowdfunding campaigners. In discussing my findings, I argue that many campaigners understand care as necessitated in the crowdfunding context through gaps in state funding. In the context of these shortfalls in publicly-funded care, crowdfunding can pose significant challenges for its users, and yet it can also function as a catalyst for experiences of care and support; however, experiences of care are constrained by the ability of campaigners to engage the 'crowd'. As such, the extent to which users can position the funding recipient as 'deserving' profoundly impacts experiences of the crowdfunding process.

In developing these arguments, section 4.2 begins by exploring how care is necessitated in a crowdfunding context, arguing that despite its common use to gap-fill for state-funded care, crowdfunding encourages an understanding of care as a voluntary offering extended by 'generous' individuals to other individuals who 'choose' to crowdfund. The market logics of independence and choice that underpin such a framing (Green & Lawson, 2011; Held, 2002; McDowell, 2004) are complicated by narratives of desperation where campaigners feel they have little other choice in ensuring their loved one is taken care of in a commodified context. In exploring how care is experienced through crowdfunding, section 4.3 consequently discusses how health-related crowdfunding responsibilises the funding recipient and their social networks, placing the onus for *taking care of* the funding recipient on those who are often already grappling with difficult circumstances.

Such findings, I argue, might suggest that experiences of care in a commodified context are 'corrupted' (Green & Lawson, 2011; Held, 2002; Hoppania & Vaittinen, 2015); however, in section 4.4, I go on to examine some of the articulations of care through crowdfunding among participants, reflecting how campaigns can also function as catalysts for the extension and receipt of support. Experiences of care through the

crowdfunding process are multifarious, varied, and at times, contradictory, reinforcing the argument advanced by some care ethics scholars that binary framings of (un)commodified care are too simplistic (Boyer et al., 2013; Cox, 2013a; Pelzelmayer, 2018).

Funding recipients must both embody and enact the deserving subject through their crowdfunding campaigns in order to be *taken care of*. Examining the former, section 4.5 examines the centrality of the body to understandings of who constitutes a deserving recipient of care. I argue that despite the online nature of crowdfunding, pre-existing (offline) social ties remain central in shaping who gets taken care of through platforms such as Givealittle. Even where campaigners attract donations from people unknown to them, visual representations of the body remain crucial in encouraging strangers to donate, precluding those with privacy or other concerns associated with the funding recipient's wellbeing from capitalising on these platforms. Beyond the need to embody the deserving subject, section 4.6 explores how campaigners must also enact the funding recipient's deservingness through a demonstration of their behavioural and attitudinal conformity to the ideal neoliberal subject (England, 2010). Campaigners seek to position the funding recipient as hard-working and self-responsible through their justifications for crowdfunding, but also through various narration techniques within their online campaigns. When these implied criteria of deservingness come to determine who is *taken care of*, I conclude that inequalities in access to care are likely to be exacerbated.

4.2 Gap-filling: choosing to crowdfund

Crowdfunding for health-related costs requires campaigners to market their illness narratives in order to encourage online networks to *take care of* them through donating money to their cause. In doing so, crowdfunding consolidates market norms in the realm of healthcare allocation (Snyder, 2016). Neoliberal values of individualism and competition are inherent in the set-up of a crowdfunding platform, whereby campaigners seek to appeal to the 'crowd' in order to attract funding for their particular cause. For instance, on the Givealittle platform, the template on which individuals construct their campaigns encourages campaigners to "*Get people's attention* with a brief title" and "*Win donors over* with a clear explanation", alluding to the competition

for donors' attention, and ultimately, money (Givealittle, 2019e, emphasis added). Further, the framing of donors throughout the Givealittle site encourages an understanding of extending care to others as a 'choice' (Green & Lawson, 2011; Hoppania & Vaittinen, 2015), rather than a collective responsibility and social good (Held, 2002; Lawson, 2007). A panel on the right-hand side of each campaign enumerates donors and the amount raised, reading "[X] donated: Given by [X] generous donors in [X] days" (Givealittle, 2019f; see Figure 4.1). In framing donors as 'generous', the platform reinforces understandings of care as something that can be freely exchanged among self-determining individuals (Held, 2002; Tronto, 2013), as opposed to a mutual obligation and responsibility. Donors are situated as examples of "awesome Kiwi kindness" (Givealittle, 2019a), acting beyond the scope of what is expected.
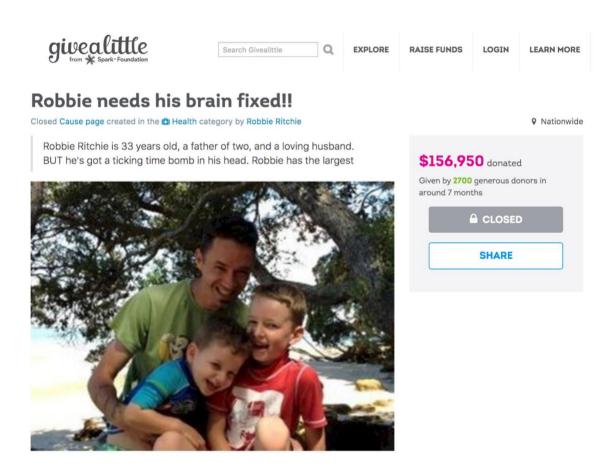

Figure 4.1: Example of health-related Givealittle campaign, as featured on Givealittle's timeline of "10 years of facilitating Kiwi generosity". The box on the right-hand side enumerates donors and the amount of money raised, framing donors as "generous". Source: Givealittle, 2019f.

In interviews, participants explained that Givealittle is used to fill public funding gaps, highlighting the salience of these market logics in determining access to healthcare and welfare funding in NZ. Existing research in the North American context has highlighted how crowdfunding is often used to bridge the gap between publicly-funded care and funding needed for particular treatments and/or associated costs (Snyder, 2016; Snyder et al., 2016). Consistent with these findings, 13 of 15 interviewees described their fundraising efforts as providing essential support in the face of insufficient funding in the public system. Uses of funding ranged from subsidising paid caregiving hours, to seeking overseas treatments otherwise unavailable in NZ, and fundraising for disability equipment (see Table 4.1 for an overview of declared funding uses). Three participants were seeking to finance unfunded cancer drugs that were funded in comparable nations such as Australia and the United Kingdom, highlighting the uneven global geographies of healthcare that motivate crowdfunding campaigns. Michelle, whose husband had advanced lung cancer, needed to source $10,000 per month for medication to extend his life beyond the three-month prognosis he had been given. Exasperated by having to source such a large volume of funding, she stated,

> You shouldn't have to do this, I feel … It's literally, if he doesn't have this drug, then he will die within six months. I think from that point of view, it's really hard to accept that it's not funded. Especially when it's funded elsewhere in the world, you know?

Table 4.1: Details of participants and their respective funding recipients and campaigns

Participant (pseudonym)	Relationship to funding recipient	Illness or condition of funding recipient (child/adult)	Declared use of funds	Funds raised and number of donors at time of interview	Perceived support from strangers through campaign	Time elapsed on campaign at time of interview	Funds raised over time elapsed (average $ p/w)
Pat	Aunt	Cancer (child)	Overseas treatment	$86,931 from 1347 donors	Significant	3 weeks	$28,977 per week
Aimee	Friend	Motor Neurons Disease (adult)	Professional caregiving	$48,485 from 158 donors	Some	8 months	$1,346.80 per week
Michelle	Wife	Cancer (adult)	Unfunded cancer drug	$28,295 from 228 donors	Little to none	1.5 months	$4,715.83 per week
Bex	Mother's colleague	Cancer (child)	Living costs	$21,841 from 219 donors	Significant	11 months	$496.39 per week
Scott	Husband	Multiple Sclerosis (adult)	Overseas treatment	$18,050 from 217 donors	Little to none	1.5 months	$3,008.33 per week
Desiree	Wife	Cancer (adult)	Unfunded cancer drug	$13,797 from 106 donors	Some	4 months	$574.88 per week
Rachel	Daughter	Multiple Sclerosis (adult)	Overseas treatment	$12,164 from 85 donors	Some	2.5 months	$1,216.40 per week

James	Friend	Cancer *(adult)*	Unfunded cancer drug	$11,154 from 87 donors	Little to none	1.5 months	$1,859 per week
Vanessa	Mother	Cerebral Palsy *(child)*	Overseas treatment	$9,476 from 118 donors	Significant	1 month	$2,369 per week
Ellyse	Daughter	Cancer *(adult)*	Living costs	$4,155 from 37 donors	Little to none	4 months	$259.69 per week
Chelsea	Mother	Anorexia Nervosa *(child)*	Overseas treatment	$3,540 from 36 donors	Little to none	6 months	$147.50 per week
Tracy	Friend	Cancer *(adult)*	Living costs	$2,945 from 26 donors	Little to none	2 months	$368.13 per week
Zayn	Brother	Autoimmune disease *(adult)*	Domestic treatment for non-resident	$2,030 from 20 donors	Little to none	7 months	$72.50 per week
Nancy	Friend	Paraplegia *(adult)*	Unfunded disability equipment	$1,403 from 31 donors	Little to none	1 month	$350.75 per week
Grace	Niece	Cancer *(adult)*	Living costs	$920 from 30 donors	Little to none	3 months	$76.67 per week

For others, while the costs of their treatment may have been covered by the public health system, crowdfunding was seen as a necessary means of subsidising living costs, including loss of income, accommodation and transport. Ellyse was crowdfunding for her father, who lived alone and was undergoing intensive chemotherapy. She expressed frustration at the limited amount of government support he was receiving, stating:

> He's been put on a benefit for the rest of his life, however long that may be, but you can't live off that. It's ridiculous. It's like $300 a week or something, you know? A grown man that's 62 years old and being told that he's gonna die from this, and you've given him $300 a week. That's ridiculous.

Similarly, Tracy, who set up a page for her friend Sharon who was suffering from multiple types of cancer, described Sharon's difficulties in accessing financial support to supplement her living costs. Tracy explained, "She's been to WINZ [welfare office], they're not gonna help her. She's been to ACC [state-funded accident cover], they turned her down. There's not really any other options."

Talk of a lack of options was common among participants, with crowdfunding framed as a last resort in securing care for loved ones. Existing literature has raised concerns about the compromised ability of crowdfunders to make free and informed decisions about disclosing private medical information by crowdfunding when they are faced with desperate circumstances (Gonzales et al., 2018; Snyder et al., 2016). This perception of having no alternative but to crowdfund is at odds with the market logics of freedom and independence, within which all exchanges are framed as 'voluntary' within the marketplace (Green & Lawson, 2011; Held, 2002; McDowell, 2004). As one participant, Desiree, who was crowdfunding for an unfunded cancer drug for her husband, explained, "We'd just run out of options. … It was our only chance really to try and buy some more time." Vanessa similarly expressed that "we always knew [crowdfunding] was gonna be uncomfortable, but we don't have many other choices, so you kinda just have to roll with it." While Michelle felt that it was "tough to stick your stuff out there", she saw such a public appeal as the only way to keep her husband alive. She stated,

> For us there was only really one route to go, which was to say 'well, we'll find a way to fund this', and that means you've gotta stick your stuff out there and let everybody know what's going on in your lives and how serious the situation was.

The framing of campaigner participation as voluntary within a crowdfunding context is therefore undermined by a backdrop of public funding gaps and personal financial constraints. While campaigners might technically be 'free' (Beckmann, 2013; Held, 2002) to make the decision to compose a public appeal, the constrained agency wrought by financial hardship complicates this framing.

In its use to fill gaps in public funding, health-related crowdfunding reflects the detachment of care from "broader, inclusive notions of the social through its commodification" (Green & Lawson, 2011, pp. 639). Where healthcare and welfare needs might once have been understood to be a collective responsibility, the locus of responsibility is increasingly focused on the funding recipient and their loved ones (Lawson, 2007; McDowell, 2004). The transactional nature of care in the crowdfunding context undermines understandings of care—in this case, healthcare specifically—as a good best distributed according to medically-evaluated need, instead encouraging individuals to become entrepreneurs in marketing their degree of need to the crowd (Berliner & Kenworthy, 2017; Dressler & Kelly, 2018; Snyder, 2016). As I will discuss next, this devolution of responsibility has implications for funding recipients and their loved ones through the caring process.

4.3 Experiences of responsibilisation in commodified care

Using crowdfunding to gap-fill for health-related costs reflects a responsibilisation of the funding recipient and their social networks. As care scholars have argued, the term 'responsibility' has become appropriated within neoliberal discourse to reflect neoliberal values of individual choice and autonomy (Clarke et al., 2007; Raghuram et al., 2009; Trnka & Trundle, 2014). Responsibilised citizens are understood to be those that are self-determining and self-managing, engaging in 'self-care' (Murray, 2007), with any sense of social responsibility individualised (Beckmann, 2013). In a context

where care is commodified, crowdfunding encourages an understanding of *taking care of* those with health needs as the responsibility of the funding recipient and their loved ones. Beckmann (2013, pp. 171) argues in her discussion of care provision for people with HIV/AIDS that a focus on responsibilisation places "an undue burden on people who are barely able to survive". In a similar vein, the devolution of responsibility for *taking care of* funding recipients results in significant burdening of the time and energy of these individuals and their loved ones. For participants such as Tracy, fundraising for Sharon, a friend outside of her own household, the compounding stressors Sharon was facing were a key motivator in establishing the page on her behalf. Tracy stated,

> I set up a Givealittle page just to try and get her some extra money, because I know what it's like when you're going through health issues and you should really be focusing on that and getting better, not how you're gonna pay the rent and eat and put petrol in the car.

Where third party campaigners are those within the funding recipient's household, the labours of taking care of the funding recipient through managing a Givealittle page was seen to further compound the existing challenges of having a loved one facing serious health challenges. As Michelle explained,

> You should just be worrying about having to get this person well and healthy and make the most of every day with one another, not having to try and struggle to raise funds and lead a campaign so to speak. Your time and energy and efforts should be going into really having quality time together as a family, rather than having to spend hours on end emailing, sending texts and that sort of thing to try and encourage them to support you.

In constructing an effective campaign, users must be able to present a coherent and appealing narrative to captivate the attention of the 'crowd' (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018). Indeed, the imperative to produce a well-crafted narrative can place significant demand on the time and energy of those managing campaigns for their loved ones, reflecting the devolved responsibility for securing care that crowdfunding entails. One participant, Michelle, described the time it took to piece

together a story that she and her husband were happy to share on Givealittle. She stated:

> It actually took us about 10 days from the time we decided to structure the Givealittle page to put it out there, because we wanted a very clear message. We didn't want to oversupply information, but we wanted people to have sufficient information to know what it was being used for.

Michelle speaks to imperative to disclose personal details in order to make their story compelling, while also seeking to maintain some degree of privacy (Dressler & Kelly, 2018; Gonzales et al., 2018), a balancing act that can result in a lengthy campaign crafting process.

Such demands are exacerbated for those who have difficulties with written literacy. Indeed, existing research has flagged how the need to 'sell' one's story in an online context in order to be taken care of privileges those with fine-tuned writing skills (Berliner & Kenworthy, 2017; Kenworthy et al., forthcoming). This heightened burden was evident in the comments of one participant, Nancy, who sought assistance from the funding recipient in writing the campaign due to her dyslexia, as well as her propensity for swearing. She explained:

> I had her beside me [while I was writing the campaign], because I have a learning disability and I'm dyslexic so I needed her to help with the format of the paragraph about what's happened, and also in a way where if it was me just speaking there probably would have been a lot of 'fucks' and 'shits' (laughs). … I thought I was back at uni doing a 3,000-word essay!

As such, through requiring campaigners to piece together a coherent and compelling campaign, crowdfunding responsibilises funding recipients and their loved ones, which can pose particular challenges for those who may not have the refined story-telling skills that such a medium is designed for.

Intensifying the time and energy that campaigning consumes, many interviewees talked of their perceived responsibility in remaining answerable to their donors. A

sense of accountability, Trnka and Trundle (2014) argue, is a crucial component of becoming a responsiblised individual, involving displays to broader audiences of the extent of one's ability to self-manage. In the crowdfunding context, accountability to donors involves a public demonstration of 'self-surveillance' (Trnka & Trundle, 2014), enacted through posting updates to prove their legitimate use of funds. Many participants were conscious of these issues of transparency in their dedicated use of funds throughout the crowdfunding process, a concern that was exacerbated by a consciousness of highly publicised cases of fraud in crowdfunding (Snyder et al., 2016; Zenone & Snyder, 2018). As such, many took steps to reassure donors of the legitimacy of their cause and their use of funds, for instance through posting regular updates. As Nancy expressed:

> There has to be accountability in everything. You're asking this of people, so I need to be accountable, and giving updates on it is a way of being accountable and going 'hey', you know, 'this is it, her progress is this, we're getting this much closer'.

Other strategies included getting an accountant involved to authenticate the use of funds. As Michelle explained,

> I think one of the most important things was to be able to give people reassurance that it was only gonna be used towards his medication. It's not gonna be used for overseas holiday or that sort of thing. That's why we decided to get an accounting firm involved, to use our accountant, who does our business accounts and auditing, so that he will verify that all the money was only used towards the drug and medication.

This perceived need to establish accountability through the crowdfunding process increases the labours of what is, already, a time- and energy-consuming process, but also poses difficulties in the face of evolving caring needs. Scholars have discussed how the commodification of care has led to the expansion of the monitoring and documentation of care practices. Hoppania and Vaittinen (2015, pp. 85) argue in the context of paid care work that this "limits the carers' ability to listen and respond to the actual needs at hand". By creating a fixed care 'product', care processes are sliced up

and fragmented into transactable units, making this commodified care less flexible and responsive to the needs of the care-recipient (Cox, 2013a; Hoppania & Vaittinen, 2015; Mol, 2008). This reduced flexibility was evident in the narratives of campaigners, who had to negotiate disparities between their 'advertised' use of funds and the changing realities of funding recipients' needs. Partway through raising funds for a targeted cancer drug for her husband Hone, interviewee Desiree learned that this drug would no longer work for him. She posted an update on the Givealittle page, notifying donors and asking permission for the funds to be diverted to a naturopathic treatment plan; the post read, "We would appreciate it if funds could be used towards funding alternative treatments" (Campaign, Desiree). Of this process, she explained,

> [Making that post] was really hard, because we didn't know what was happening over that time. … I was fine with the possibility that people would take their money back, because it is much easier to donate to something when it's for something specific and you know what's going to happen with it, as opposed to our airy fairy alternative therapies, which we whole heartedly believe in. But yeah, that was really hard. It's just like our world popped again, our whole little bubble. Just keep building it and it keeps getting shredded.

A sense of accountability to donors creates an added layer of uncertainty due to the possibility that people might want their 'money back', as they have donated under the assumption of funds being used for a particular purpose that may no longer be suitable in the context of fluctuating care needs. This "incompatibility between care as a corporeal relation and open-ended process on one hand, and the neoliberal logic of choice and commodification that necessitates clearly defined products and services on the other" (Hoppania & Vaittinen, 2015, pp. 84) can therefore exacerbate the sense of liability to donors among those seeking care through crowdfunding pages.

Beyond the practical labours of crowdfunding, many participants spoke of the emotional implications of the process. The affective backdrop of optimism, built into Givealittle as a platform, stands in stark contrast with some of the narratives of desperation, humiliation and vulnerability that participants described in interviews. This positive framing has been discussed in the context of crowdfunding campaigns (Berliner & Kenworthy, 2017) but also within market discourse more broadly; as Mol

(2008, pp. 28) argues, "the language of the market contains only positive terms." In the case of Givealittle, this optimism is evident in the platform itself. The homepage that reads "A simple way to give and share the Kiwi spirit", prompting visitors to "Get Inspired with Givealittle" and follow a link to read "Inspiring stories" (Givealittle, 2019b). However, such an affective atmosphere of inspiration, generosity and spirit is juxtaposed against some of the experiences of interviewees, such as Vanessa and Tracy, who respectively described feeling "raw and vulnerable" and "embarrassed" through the process. Similarly, Desiree said of campaigning, "It was humiliating … When you're desperate, and we're really desperate, desperate to get more time for your husband, that desperation does funny things."

In particular, asking networks to 'price' their care through donating was a source of discomfort for some participants. Hoppania and Vaittinen (2015, pp. 81) argue that the commodification of care reconstitutes the "social fabric of society", such that "existing care relations [are] severed so as to re-create them in a commercial context". Care comes to be commodified in the crowdfunding context as networks are asked to show their support for the funding recipient through the form of a financial donation, to which they may or may not attach a message of encouragement. For Desiree, this transposition of caring relations into a commercial context was key to her sense of anxiety in crowdfunding for her husband's treatment. She explained,

> I was worried about putting up the page because the people that I thought might want to help were the people that had helped already. I was worried that our family and friends would be stretching their own resources, and we really didn't want that to happen.

For others, beyond a *fear* of burdening friends and family, the process of crowdfunding was seen to put an *actual* strain on close relationships. Vanessa describes the tensions that emerged through the crowdfunding process, which she saw as related to the discomfort of asking friends for money:

> Sadly, this is probably a side issue, but we've actually had people that we're very close to, and one instance of a best friend, that have basically disappeared … I think they just don't know how to do anything or what to do, you know?

Whereas for us, a lot of it's just about being there. We're not actually asking you for money, you know? Because we're not the type of people that will go and be like 'hey give us money, we need your money', like even though that's what we're doing on one hand, we're also like, it's absolutely up to you. We're never going to be someone to pressure other people into making them give us money kind of a thing, you know what I mean?

Vanessa's description alludes to the ways in which framing care "as a transaction, rather than as social relations" can lead to the re-categorisation of people as beyond the scope of care (Green & Lawson, 2011, pp. 651). In turning to crowdfunding, she felt that she had indirectly alienated a close friend, which she saw as resulting from the friend's discomfort in being asked to *take care of* her son through donating to the online campaign. This abandoning of close relationships resembles the disowning of kin that Green and Lawson (2011) describe in the context of the privatisation of healthcare in Brazil among family members who feel they cannot provide support in the face of caring costs. Such experiences of disrupted ties with family and friends across different contexts reflect the strain on relationships that can be experienced as a result of the commodification of care, in this case through campaigners "turning their social network into a safety net" (Sisler, 2012, pp. E123).

The responsibilisation of funding recipients and their loved ones can undermine the capacity of campaigners to address wider structural challenges that have necessitated crowdfunding in the first instance, thus perpetuating systems of devolved responsibility. One participant, Chelsea, had started a petition calling on the Minister of Health to further develop what she argued were inadequate treatment facilities for children with eating disorders in NZ. The link to this petition was embedded in her crowdfunding page, which she established to fund her daughter's attendance to an overseas treatment centre. Such an action, one might argue, reflects an explicit critique of broader structures of care provision, and a resistance to this devolution of responsibility, countering the arguments of various scholars who frame crowdfunding as inherently depoliticising issues of access to care (Berliner & Kenworthy, 2017; Snyder, 2016). Chelsea explained, however, that she was unable to commit sufficient time and energy to the cause in the context of shortfalls in publicly-funded care. She expressed:

When you're a parent already having to care and cope with a child being severely ill, that is a handful enough. You literally do not have the mental or physical time or energy to also fight for things that you should be entitled to, such as just the [carer] benefit. So throw poor treatment into the works as well, and you're struggling with three fronts. Hence the petition has gone on the backburner, which actually really needs to go across to help the many other thousands of families that are affected by this.

Even in instances where campaigners endeavour to address structural inadequacies through their campaigns, momentum in achieving wider changes can be overshadowed by the realities of immediate needs in *taking care of*, and *care-giving* for, the funding recipient.

The responsibilisation that crowdfunding entails therefore has significant implications for the funding recipient and their loved ones. Where platforms such as Givealittle are used to gap-fill for government funding, responsibility for securing adequate care is devolved to those who are already facing difficult circumstances, in some cases juggling *care-giving* responsibilities with trying to *take care of* their loved one through assuming the role of 'campaign manager'. A perceived imperative to remain accountable to donors and demonstrate 'self-surveillance' (Trnka & Trundle, 2014) can intensify the energies required in managing a campaign, but further, may pose challenges in the face of changing healthcare needs (Hoppania & Vaittinen, 2015). The time and energy required to manage a campaign may undermine the ability of those affected to address the gaps in provision that necessitate crowdfunding in the first instance, thus perpetuating systems of devolved responsibility.

Some participants described the emotional difficulties they faced through the crowdfunding process, with negative implications for relationships with friends and family. The practical and emotional demands of crowdfunding that result from responsibilising the funding recipient and their social networks can trigger experiences of disappointment, anxiety and/or neglect for campaigners and/or funding recipients. Such experiences appear to suggest a broader incompatibility between the market values embedded in the crowdfunding process, and the need to secure care for those

with precarious health conditions, resonating with conventional scholarly arguments about care in a commodified context. Indeed, many scholars writing about the commodification of care have argued that market values 'corrupt' care (Green & Lawson, 2011; Held, 2002; Hoppania & Vaittinen, 2015), with the introduction of market norms of independence and choice into realms of care seen to produce "some serious distortions in how we think about caring responsibilities in society as a whole" (Tronto, 2013, pp. 119). However, experiences of care in the crowdfunding context are not uniformly unfavourable, reflecting some of the complexities in this commodification process.

4.4 Care in spite of responsibilisation?

Far from a simple binary, experiences of securing care in a commodified context through health-related crowdfunding are multi-faceted, and at times, contradictory. Despite dominant conceptualisations of commodified care being "almost-wholly negative" (Boyer et al., 2013, pp. 519), various scholars have sought to complicate this simplified narrative of commodification as 'corrupting' care (Cox, 2013a; Pelzelmayer, 2018). While market-based care has commonly been framed as 'bad', and non-marketised care as 'good', Cox (2013a, pp. 494) argues in the context of waged labour that "it is worth questioning whether there really is a principled objection to payments for care". As the stories of many participants demonstrated, the fact of having to secure health-related expenses through campaigning did not preclude authentic experiences of care in the crowdfunding process.

Receiving money was understood and experienced by some as a legitimate and appreciated means of being *taken care of*, thus challenging notions of commodified care as necessarily less authentic than 'non-commodified' care. Irrespective of concerns around the sustainability and longevity of financial support provided, various participants talked of the immediate financial relief enabled by crowdfunding (Gonzales et al., 2018; Renwick & Mossalios, 2017). In some cases, this financial support can have significant implications in making certain treatments obtainable, with more affluent networks *taking care of* funding recipients to the extent that they can ultimately receive the care they need. For example, of the campaign for her mother's overseas treatment, Rachel explained, "It's just been amazing. Like that's just taken

so much strain off, and it's made [the surgery] so much more attainable and more tangible." Others spoke of valuing money to the extent that receiving it felt like a boost, regardless of its instrumental use in securing *care-giving* further down the line. As Aimee mused,

> Money is a big deal for Josh. It is something he's always cared about, and you know, never quite had enough of, or struggled with a little bit, so it's kinda cool to be able to do that, because it is a currency that matters to him.

Beyond money raised, many participants saw their crowdfunding campaign as a useful tool with which to notify networks of the funding recipient's health status, and in doing so, overcome spatial barriers to reconnect with friends and family. In some cases, the funding recipient's networks were largely unaware of their condition or illness prior to creating the campaign. This meant that online disclosure opened up the possibility of receiving messages of care and support. For instance, Scott explained of his wife, Sarah, and the campaign for her overseas treatment:

> As her mobility got less, we just don't go out that much anymore, and you know, some people haven't seen us for a few years. It's sort of a bit hard on friendships sometimes, because you just make excuses not to see people all the time. So for some people that haven't seen much of us in the last wee while, they're kinda like 'oh, that's why' sort of thing. So it's been a conversation starter and a reconnector for some friendships and families as well.

Rather than precluding experiences of genuine care, therefore, in Scott's instance, his Givealittle campaign acted as a catalyst for triggering wider caring responses from those they were able to 'reconnect' with, thus strengthening relationships with friends and family (Fritz & Gonzales, 2018). In particular, the campaign enabled Sarah to circumvent the difficulties of navigating space with limited mobility, instead reuniting her with extended social networks in online space.

Irrespective of the level of instrumental support provided, participants widely described a sense of connectedness to wider networks provided by the campaign. Grace, who had raised the least amount of money of all participants at the time of interviewing,

explained that her campaign had been worthwhile regardless of funds raised, as it got word of her aunt's illness out to wider networks and encouraged them to show support in other ways, even if they did not donate. She explained:

> The page wasn't necessarily a huge money-maker or anything like that, but it was the fact that the knowledge of it was out there, and her illness was out there, so it sort of encouraged everybody else to pull finger and do something about it as well.

Such experiences are consistent with the findings of Gonzales et al. (2018, pp. 649), who argue that the capacity to connect with wider networks is "often a very salient part of the crowdfunding experience". For individuals such as Desiree, the Givealittle campaign facilitated experiences of support and care from wider networks, as well as strangers who had personal connections with her husband's type of cancer. She expressed,

> People come out of the woodwork and have done things for us, and it's just shocking. It's just unbelievable how kind and how loving people are. Some of these people are strangers, some are friends he hasn't had a whole lot of interaction with since high school, family from overseas, and especially a whole network of people that have suffered from cancer or have lost a loved one. Those people are just amazing. The support, the advice, the understanding that they have, it's huge.

In a similar vein, Ellyse described of her father's campaign: "Old friends have reached out to him on Facebook because of it and stuff, which has been really nice for him." Experiences of care among campaigners therefore demonstrate that the transactional nature of extensions of care in a crowdfunding context does not necessarily result in "care-less care" (Atkinson et al., 2011, pp. 569), or "care without caring" (Green & Lawson, 2011, pp. 646).

The accounts of various participants demonstrated how their Givealittle pages played an important role in helping them to cope with the illness of a loved one. Vanessa recounted the boost provided by words of support from strangers, making reference

to "those days where you're having down days about things, and people are basically giving you a kick up the bum, which is great." Gonzales et al. (2018) argue that online disclosure through crowdfunding can help campaigners come to terms with their circumstances. In a similar vein, Desiree explained that being able to share updates and respond to messages of support through the page was therapeutic and helped her to cope with the demands of day-to-day *care-giving*. She stated:

> When it's a bad day, I can't talk about it, but I can type. It's quite good to have those people there, and even that page, to be able to have a voice when my own voice is just focused on looking after Hone and the kids and keeping the household together.

Beyond the perceived experiences of care-recipients, many campaigners felt that establishing a Givealittle page was an important way to empower friends and family who were grappling with how to demonstrate care for the funding recipient. In her discussion of the phases of care, Tronto (1993, pp. 106) explains that the shift from *caring about* to *taking care of* requires "the recognition that one can act to address these unmet needs". In the context of crowdfunding, establishing a Givealittle campaign was seen as important not only for the funding recipient, but also for their wider networks, who were provided with a tangible way to act on their *care about* a loved one in crisis. As Aimee explained, "[The campaign] empowered people to show their love for him through their donation, and equally, the site set up a medium for a small note of encouragement and support, and that was really heartening to Josh." Similarly, Pat stated,

> Once I started [the campaign], I got lots of messages from like aunties, family friends we've known our whole life, being like 'I'm so glad you've put this page up, because now we feel like we can help, we haven't known what we can do.' … 'We know you've probably got a freezer full of food from friends, but if I can chuck 100 bucks on this Givealittle page, I feel like I'm helping in some way.' So it gave people an avenue to make people feel like they aren't so helpless.

These accounts demonstrate the multidirectional and relational nature of care, as both the *care-recipient* and those *taking care of* are seen to benefit from the practice of

donating (Milligan & Wiles, 2010; Fisher & Tronto, 1990). While relations of care have conventionally been conceptualised as unidirectional, with an independent individual extending care to a dependent other, the perception of donating as a mutually gratifying experience for both reiterates the interdependence of all involved in caring practices.

In particular, crowdfunding campaigns were understood as providing a way for wider social networks to overcome location-related limitations in demonstrating care for the funding recipient. Indeed, compared to other fundraising alternatives, the online nature of crowdfunding provided a way to circumvent geographical barriers, enabling friends and family to provide support 'at a distance'. As James described:

> We thought about doing something like a bike ride or some sort of event, but we thought with a lot of his family in Coromandel and up North and things and overseas, this would be the quickest, easiest way to tell everyone that if they wanted to help, now would be a good time for the family to take a bit of the burden off.

Beyond donating, establishing and managing a Givealittle campaign on behalf of a loved one was articulated by some as a way to *take care of* the funding recipient (Berliner & Kenworthy, 2017). For Bex, running the campaign provided a way to act on her *care about* her friend Kate in the face of day-to-day time constraints. She explained, "We're all so busy. [She's my] best friend, but I don't have time to take dinners to her house every night or arrange other people to do it. At least it felt like I've contributed." In this sense, various participants saw Givealittle as an important catalyst in the caring process not only for the care recipient, but for those seeking to overcome a sense of 'helplessness' by providing a convenient and tangible way to *take care of* a loved one.

In this way, crowdfunding campaigns were understood by many as an important medium for expressing, and receiving expressions of, care. For various participants, receiving donations and/or the messages of support that accompanied these provided a sense of encouragement, enabling them to reconnect with wider circles of friends and family through notifying people of their circumstances. Some campaigners

experienced the process of constructing and managing a campaign to be cathartic in itself, enabling them to come to terms with the health-related challenges faced by their loved ones. For others, the campaign was understood to be an important way of empowering friends and family to demonstrate their care at a time where they may otherwise have felt helpless, demonstrating the multidirectional nature of extending and receiving care in a crowdfunding context (Milligan & Wiles, 2010; Fisher & Tronto, 1990).

In the context of filling gaps in public care, however, funding recipients and their loved ones are ultimately reliant on sourcing money to access the *care-giving* that they require. Among those participants that were seeking to raise funds for a life-extending medication, for instance, receiving words of encouragement could only go so far in keeping their loved one alive and "buy[ing] some more time" (Interview, Desiree). Notwithstanding the significance of campaigns as a source of emotional support for many participants, therefore, the extent to which people experience care through crowdfunding is constrained by the realities of the context in which these platforms are used. In accordance with Cox's (2013a, pp. 494) argument, therefore, commodified care is not in itself inherently 'corrupted', but rather "the context and organisation of commoditised care can be highly problematic". The constraints on these positive experiences of crowdfunding are particularly apparent when examining who is deemed 'deserving' in a crowdfunding context, an issue which I turn to now.

4.5 'Embodying' deservingness: social ties and the 'sick' body

Despite its online nature, the body and embodied experience remain central to practices of care in a crowdfunding context, shaping understandings of who constitutes a 'deserving' recipient of care. Crowdfunding platforms have been framed by some as transforming existing geographies of funding due to their purportedly 'placeless' nature, able to connect physically and socially distant individuals (Gray & Zhang, 2017; Langley & Leyshon, 2017). However, consistent with findings from existing research on health-related crowdfunding (Berliner & Kenworthy, 2017; Gonzales et al., 2018; Paulus & Roberts, 2018; Young & Scheinberg, 2017), most participants in this research understood their Givealittle campaign as attracting support predominantly from pre-existing networks. Of fifteen participants, nine described

receiving little to no support from strangers, while three described receiving some support, and three described receiving significant support, from people unknown to them (see Table 4.1). For many users, therefore, engagement between donors and campaigners in the Givealittle context is very much rooted within existing (offline) social ties, reinforcing Massey's (2004, pp. 8) "hegemonic geography of care".

It could be argued that the support received from strangers by some disrupts conventional scholarly narratives of the importance of physical and social proximity to our sense of care and responsibility for others (Atkinson et al., 2011; Lancione, 2014; Milligan & Wiles, 2010; Moosa-Mitha, 2016; Pitt, 2018). Some care ethics scholars have discussed the potential for extending the spatial boundaries of care beyond our 'nearest and dearest' to include those who are physically and socially distant to ourselves (Barnett et al., 2005; Lancione, 2014; Popke, 2006; Smith, 1998); yet, the experiences of participants suggests that even where the 'crowd' *takes care of* people with whom they have no personal connection, the relative 'worthiness' of a cause may be evaluated according to the (imagined) social ties of nationhood. Indeed, further reflecting the territorial and hierarchical organisation of care in the Western world (Massey, 2004), the ability of campaigners to capture funding from people unknown to them was perceived to be affected by understandings of national identity. In the context of health-related crowdfunding, the "morally legitimate suffering body" (Ticktin, 2011, pp. 3) is therefore 'read' as one that falls within the legally and imaginatively constructed borders of the nation.

The potency of national identity in shaping understandings of who is 'worth' *taking care of* in a crowdfunding context became particularly apparent in the story of participant Zayn. Zayn had previously immigrated to NZ from a neighbouring Pacific Island, and was fundraising for treatment for his sister's autoimmune disease. In light of limited access to medical treatment in some Pacific Island nations, NZ offers public health cover for Pacific Island nationals that meet certain eligibility criteria (Ministry of Health, 2009). In Zayn's case, despite no available treatment in his country of origin, his sister Tina, resident of a Pacific Island nation, was deemed ineligible for public cover in NZ, He and his family needed to source $32,000 for her NZ medical bills. Having launched a Givealittle campaign in response, Zayn's appeal gained little traction beyond immediate networks, much to his disappointment. He stated in an interview, "I think

there were a couple of strangers [who donated], but they donated 5 or 10 dollars."
Discussing the possible reasons for his perceived lack of success in campaigning,
Zayn offered, "If you are not a resident of New Zealand, it is tough." Despite "staying
here … working and paying taxes", Zayn's experiences perhaps reflect the 'crowd'
locating his sister beyond the scope of caring obligation (Green & Lawson, 2011), as
a non-resident connected to the country by Zayn, a recent migrant.

The choice of whether to *take care of* funding recipients was therefore understood as
being shaped by notions of nationhood, and the associated (imagined) ties with those
who are deemed 'within' the borders of the nation. Scholars writing on the geographies
of care have reiterated how notions of place matter in shaping caring processes
(Brown, 2003; Conradson, 2003; Milligan & Wiles, 2010), and indeed, Zayn's
experiences reflect the extent to which place matters, even in an online setting. This
influence of the national imaginary is perhaps unsurprising given the frequent appeals
to a national identity made by Givealittle as a platform. Givealittle firmly situates itself
as NZ-based, making frequent reference to the "generosity of New Zealanders"
(Givealittle, 2019c) and describing itself as an "online platform for all of New Zealand"
(Givealittle, 2019b). However, as Zayn's experiences highlight, there are particular
bodies that are 'read' as sufficiently 'Kiwi' to be deserving of care, demonstrating how
"particular bodies in particular encounters can trigger political relations of care,
whereas others elsewhere elicit only relations of neglect" (Robinson, 2018, pp. 327).

Health-related crowdfunding can therefore be understood as reinforcing existing
inequalities in access to care through the allocation of donations according to existing
and imagined social ties, as opposed to necessarily distributing according to medical
need. Scholars engaging with health-related crowdfunding have argued that these
platforms are likely to exacerbate structural inequalities through privileging those with
extensive social networks and disadvantaging those who are already marginalised in
their circumstances (Barcelos, 2019; Berliner & Kenworthy, 2017; Palad & Snyder,
2019; Paulus & Roberts, 2018). These concerns resonate with broader critiques
levelled at the provision of care in a commodified context (Green & Lawson, 2011;
Hall, 2011; Schwiter, 2013; Tronto, 2013). Many scholars engaging with care ethics
have highlighted how an emphasis on personal choice and individual autonomy within
market-based models of care provision may result in exclusion for those who do not

have the capacity to engage as care 'consumers'. Individuals such as Zayn are likely to already face significant discrimination in accessing social services by virtue of their immigrant or non-resident status (Berliner & Kenworthy, 2017). This marginalisation reverberates through the crowdfunding process, as such campaigners are likely to be doubly disadvantaged through their less-extensive social networks (Snyder, 2016), but also their challenges in locating themselves and/or the funding recipient within the imagined borders of the nation.

Even where donors have no pre-existing social ties with the recipient of their care, the body, and inscriptions therein, remain crucial in shaping understandings of deservingness in the crowdfunding context. As was argued in Chapter Two, care ethics as a framework emphasises the political salience of the body as part of its explicit challenge of conventional Western understandings of ethics and responsibility (Hamington, 2004; Robinson, 2018). Needy bodies hold significant power in that they motivate caring labour; however, in order to be recognised and interpreted as 'in need', bodies must resonate with established norms and practices that deem them 'worthy' of care (Dyck et al., 2005; Ticktin, 2011). Beyond locating oneself within the national imaginary, the ability of campaigners to trigger caring responses from the 'crowd' is affected by the visibility and presentation of the body within the online campaign. Scholars writing on health-related crowdfunding have discussed how individuals must present a visually appealing campaign and effectively mobilise social media platforms in order to attract funding (Berliner & Kenworthy, 2017; Gonzales et al., 2018; Snyder et al., 2018). Due to the nature of health-related fundraising – the premise of raising funds centred on illness, disability, or disease of an individual body – the body of the funding recipient becomes a critical symbol within this broader strategy of campaign construction and dissemination.

Visual representations of the body are therefore salient in encouraging the 'crowd' to 'read' the funding recipient as deserving. This salience was communicated implicitly by many participants, who understood that without posting images of the funding recipient to the campaign, their ability to ensure that the funding recipient is *taken care of* was limited. Bex, for instance, described how she initially launched the campaign for her friend Kate's daughter without an image of the daughter on the Givealittle page. While Kate was initially dubious about uploading photos, over time, she came to

understand the wider reach that the page was capable of, later adding various pictures of her daughter both before and during her illness to the campaign. Bex explained:

> Originally we didn't add a photo. We just had [a stock image]. We knew the people who were going to see it, it was only colleagues and everybody understood. But then when Kate started warming up to the process, she understood, there's so many people [that wanted to help], and she was overwhelmed by the support.

However, some may not wish to disseminate images of the funding recipient in order to protect their wellbeing (Palad & Snyder, 2019), compromising their ability to be *taken care of*. Such was the case for Zayn's campaign, where constraints associated with his sister Tina's depression, and in particular, shame associated with her illness, were seen to limit his ability to produce an 'appealing' campaign. Tina's mental health challenges meant that he and his family chose to refrain from putting any images of her face on the Givealittle page, and decided not to share the page on social media. He stated,

> She didn't want her face [on the page] and stuff like that. She was going under depression and stuff, so it's hard for us to convince her to create a page. That's why we didn't share on Facebook and other social media, because her friends and colleagues would know [about her illness], and she didn't want that.

While the campaign included images of Tina's hands and feet, evidence of her autoimmune condition, Zayn recognised that without any images of her face, her campaign was less compelling. He felt that "most of the people won't believe [her story], because her face is not there probably, so it's very tricky." Existing health-related crowdfunding research has highlighted the importance of presenting personalised images in campaigns in order to secure success (Berliner & Kenworthy, 2017; Palad & Snyder, 2019; Paulus & Roberts, 2018); yet Zayn's reflections would suggest that beyond merely presenting customised images, one must quite literally 'face up' to their campaign in order to be *taken care of*. Privacy concerns or other constraints associated with the funding recipient's wellbeing, such as fear of stigmatisation, therefore might preclude particular people from capitalising on these

platforms, thus generating inequities associated with the need to perform one's deservingness in a crowdfunding context.

In spite of its online nature, embodied encounters between those *taking care of* and *receiving* care, as well as interpretations of the body, thus remain central in informing practices of care in a crowdfunding context. Understandings of deservingness are shaped by existing or imagined social ties between the donor and funding recipient, and are likely also informed by more diffuse social knowledge about whose lives are valuable. While most participants found support on Givealittle through pre-existing networks, notions of nationhood, and belonging therein, were seen to shape the perceived deservingness of funding recipients among people unknown to them. Further, accounts of campaigners highlight the importance of online presentations of the body within crowdfunding campaigns in communicating the worthiness of a cause. Beyond their ability to 'embody' the deserving subject, individuals must also perform their worthiness of care through the way they narrate their circumstances, an issue which I turn to now.

4.6 'Enacting' deservingness: performing the ideal neoliberal subject

In appealing to the crowd, crowdfunding users engage with dominant constructions of neoliberal subjectivity in order to frame their cause as 'deserving' of funding. Through their justifications for publicly appealing for money, users frame funding recipients as hard-working and responsibilised, in other words the 'ideal' neoliberal subject (Barcelos, 2019; England, 2010). Such a framing was evident in statements made on participants' Givealittle pages, including "As a striving young Auckland family, Kate and John are both working full time" and "As a young hard working family in a house of their own anything received will be an enormous help" (Campaign, Bex). Many campaigns also foregrounded the dedication of funding recipients to their line of work through statements like "Sharon has been a passionate teacher for around 20 years" (Campaign, Tracy) and "Sarah is a teacher of 20+ years and loves her job, but is on the verge of not being able to manage that anymore" (Campaign, Scott). Emphasising the economic productivity of individuals reinforces the idea that caring activities are designed to support the economically engaged, in order to restore autonomy and

reproduce the labour force (Green & Lawson, 2011). As such, those who do not 'choose' to be productive individuals, and are not able to perform their deservingness as such, may be interpreted as illegitimate care recipients.

The notion of choice, or indeed, lack thereof, was emphasised through interviewees' campaigns. By stressing a lack of control over circumstances, campaigners frame the funding recipient's predicament as a product of 'bad luck' (Snyder, 2016; Young & Scheinberg, 2017), thus distancing the recipient from any judgement of personal irresponsibility (Gillespie & Lawson, 2007). For instance, Scott's campaign explicitly emphasised that his wife's circumstances were beyond her control by stating that "Unfortunately, through no fault of her own, Sarah has developed the debilitating disease, Multiple Sclerosis." Lack of control was also communicated through narration techniques that emphasised a sudden change in the lives of the funding recipients. Describing her nephew's cancer diagnosis, Pat's campaign read "The past 8 weeks has seen the Smith family's world flipped upside down, but even through adversity this beautiful family's strength and love has never shone so bright." Similarly, Michelle wrote of her husband's cancer, "This diagnosis came as a huge shock to him and his family as well as all who know him well in the community."

Beyond positioning within online campaigns, constructions of the neoliberal subject as the morally 'legitimate' funding recipient were also evident in campaigner's justifications for their decision to crowdfund. Many campaigners emphasised the degree to which they and/or the funding recipient were taking steps to address their own hardships, reflecting neoliberal dogmas of individual responsibility and hard work. Scholars have discussed how rhetoric of 'responsible citizenship' increasingly informs care provision, for instance in job-seeking requirements for welfare eligibility among the unemployed (England, 2010; Green & Lawson, 2011; Hoppania & Vaittinen, 2015). These values were foregrounded as implied criteria of 'deservingness' in the comments of participants. Vanessa, for instance, who was fundraising for an overseas procedure for her son, felt that her online appeal for funding was justified because of the extra effort she and her family were putting in on the side to host events and other fundraisers. She explained:

I feel fine about it, knowing that we're actually putting on all these other events. We're doing lots of things ourselves as well. Not just 'oh we're gonna sit here and do nothing and wait for people to give us some money', you know? I don't agree with that, but the fact that we are working our arses off as well, I feel okay about it.

In a similar vein, Pat, who was fundraising for her nephew's overseas treatment, felt the need to have a defined time period for her campaign in order to avoid the perception that they were passively taking advantage of the generosity of others. She explained, "It's not something that we want to just keep milking, or be perceived as milking. It'll have a timeline, and then we can start giving back or whatever."

Such justifications reflect a discursive distancing of crowdfunders from someone who is 'dependent'. By juxtaposing their approach to crowdfunding against those who would "sit here and do nothing" or "just keep milking", these interviewees therefore bury their need for money in assertions of the independence and self-determination of the funding recipient and/or their family. In doing so, they distance the funding recipient from those who are seen to be 'morally illegitimate' recipients of assistance, such as the homeless or welfare beneficiaries, who are commonly framed as lazy and passive (Gillespie & Lawson, 2017). For instance, Tracy, fundraising for her friend Sharon, explained Sharon's desire to distance herself from the archetype of a 'beggar':

She was a bit reluctant [to crowdfund] because she didn't want people to think she had her hand out and was begging for money. … And then I think she was so desperate that she agreed. I can see where she's coming from. You don't want people to think 'oh gosh, look at poor Sharon, she's struggling'. You don't want people to feel sorry for you.

Here, Tracy suggests that a public declaration of (financial) dependence on others is perceived to trigger responses of pity. In the 'language' of neoliberalism, dependency is a trait that has come to be devalued and understood as the antithesis of self-actualisation (McDowell, 2004; Wiles, 2011). Such a devaluing of dependency is at odds with the relational ontology foregrounded within care ethics, which highlights how people are irrevocably interdependent throughout their lives (Brown, 2003; England,

2010; Raghuram, 2009). By reiterating their independence and positioning themselves as self-responsible individuals, campaigners therefore play into an understanding of care as a discrete intervention during abnormal circumstances, rather than a pervasive and necessary feature of social life (Haylett, 2003; Held, 2002).

These understandings of the 'morally deserving' individual as the ideal neoliberal subject shaped the ability of campaigners to capitalise on donations from strangers. Scholars discussing health-related crowdfunding have previously raised concerns as to what types of health needs are likely to attract funding, and what the implications of this are in contexts where crowdfunding becomes a substitute for public funding (Barcelos, 2019; Berliner & Kenworthy, 2017; Farnel, 2015; Palad & Snyder, 2019). Among the pool of 15 participants, the five campaigns that received the most funding were for individuals with cancer and neurological diseases (see Table 4.1). Campaigners such as Pat, whose two-year-old nephew Toby had a rare form of cancer, received significant support from strangers, raising almost $87,000 in three weeks. She explained, "Absolute strangers reached out. I think it's people who mostly have kids themselves or whatever and think, 'holy shit', you know, 'this could happen'." Similarly, Bex managed to raise $21,841 from wider networks and strangers to support her friend Kate, whose daughter had cancer. She stated,

> I found it was especially elderly ladies [that donated to the campaign]. The kids are all overseas, they don't have grandchildren, and this is the beauty of New Zealand eh. It is for me the fact that there's people out there that just wanna give.

While the successes of campaigning for a child relative to that of an adult in the crowdfunding context have been acknowledged (Kenworthy et al., forthcoming, pp. 17; Snyder et al., 2017), contrasting experiences of participants suggest that factors beyond the "broad sympathy" that campaigns for children elicit shape the ability of campaigners to trigger caring responses in a crowdfunding context. Chelsea, who was crowdfunding for treatment for her daughter's Anorexia Nervosa, managed to raise $3,540 over six months, significantly less than the three other interviewees campaigning around a child's illness. She described in an interview that the money she had managed to raise was a "bare minimum" and came from "some very good

friends and local community only". She recounted what she felt was an "uphill battle" in trying to raise funds for a stigmatised sickness:

> As soon as you mention the Child Cancer Trust, people go 'oh yeah, I'll put money into that', but if you say eating disorders, it doesn't have the same sexy ring to it, does it? People still well-and-truly see it as a personal choice, but it's not. It's no more a choice than anyone having Type One Diabetes thrown in with Bipolar.

Chelsea felt that misunderstanding of eating disorders as a personal 'choice', and thus a consequence of personal irresponsibility, precluded her and her daughter from fully benefiting from the use of Givealittle by attracting donations from strangers. She expressed that as a result of a lack of "public awareness and understanding of eating disorders, the page has attracted very little in the way of support." An inability to convincingly 'package' Anorexia Nervosa as the product of 'bad luck' and uncontrollable circumstances (Snyder, 2016; Young & Scheinberg, 2017) therefore may hinder the ability of individuals like Chelsea's daughter to be *taken care of* in a crowdfunding context, irrespective of medical need.

Crowdfunding campaigners therefore engage with dominant discourses of neoliberal subjectivity in order to enact the deservingness of their cause, and, ultimately, ensure their loved ones are *taken care of*. Through their framing both within their online campaigns and in discussion of these campaigns, campaigners appeal to values of hard work, self-responsibility and economic productivity when describing the funding recipient. In this way, the behaviours and attitudes of the funding recipient become implied criteria of deservingness that ultimately shape experiences of care in a crowdfunding context. For those who cannot easily narrate their circumstances in such a manner, for instance due to the nature of their illness and associated stigma, they may therefore struggle to demonstrate the worthiness of their cause in a way that is congruent with the crowd.

4.7 Conclusion

This chapter has examined the practices and experiences of health-related crowdfunding among 15 individuals running campaigns on Givealittle, a NZ-based platform. In doing so, it has argued that the extension of care through the crowdfunding process can be both beneficial and fraught for funding recipients and their loved ones. Where campaigns are initiated to address shortfalls in public cover, users may feel compelled to turn to crowdfunding, and the process may pose difficulties, for instance in burdening their time and energy and putting strain on relationships. Nonetheless, despite such challenges, many participants also emphasised feelings of care and support through their campaigns, with Givealittle a catalyst for reconnecting people and empowering friends and family to demonstrate their *care about* the funding recipient. Ultimately, however, in a commodified context, the ability of funding recipients to access the care they need is contingent on raising the money required, and their ability to do so is shaped by how 'deserving' they are deemed by donors. As such, in order to be *taken care of* through health-related crowdfunding, one must embody and perform the deserving subject, a reality that is likely to exacerbate inequalities in access to healthcare in NZ.

Chapter Five: Conclusion

This thesis has examined practices and experiences of health-related crowdfunding campaigners. Specifically, it engaged with the online campaigns of, and semi-structured interviews with, 15 people campaigning on Givealittle, a NZ donation-based platform. In doing so, I mobilised both care ethics literature and research on crowdfunding in order to extend scholarly understandings within both bodies of literature, meanwhile seeking to address two related objectives.

The first research objective sought to explore campaigners' perceptions of how care is necessitated and experienced in a crowdfunding context. In engaging with this objective, Chapter Four examined how many campaigners saw crowdfunding as a tool used to facilitate access to care in a commodified context where gaps in public funding prevail. Campaigners seek to produce an appealing and captivating representation of the funding recipient's circumstances to convince the 'crowd' to *care about*, and consequently, *take care of*, the funding recipient. The imperative to market their medical needs results in the responsibilisation of the funding recipient and their loved ones (Barcelos, 2019; Beckmann, 2013; England, 2010), which can put significant burden on the time and energy of these individuals, but also strain relationships with friends and family who may be uncomfortable with being asked to *take care of* them. As part of this responsibilisation, many campaigners described a sense of duty in remaining accountable to their donors, an accountability that may exacerbate these demands of crowdfunding, but also reduce flexibility in meeting evolving caring demands.

Despite such challenges, running a crowdfunding campaign was understood by many as an important component of coping with illness or disability among the funding recipients themselves, but also among their loved ones. Far from a universally 'corrupted' care experience (Boyer et al., 2013; Cox, 2013a; Pelzelmayer, 2018), many participants felt that their crowdfunding campaign reconnected the funding recipient with wider networks and empowered friends and family to tangibly contribute at a time where they may have otherwise felt 'helpless'. Such divergent narratives of tensions and anxieties on the one hand, and feelings of care and support on the other, highlight some of the contradictions in experiences of care in a commodified context. While

crowdfunding may provide significant emotional consolation for its users, against a backdrop of gaps in state-funded care, funding recipients and their loved ones ultimately must source money to secure the *care-giving* that they need. As such, these positive experiences of the crowdfunding process are, in the long run, constrained by the realities of whether campaigners are able to successfully attract funding.

The ability of campaigners to attract funding is contingent on their ability to position the funding recipient as a 'deserving' care-recipient. As such, the second objective of this thesis was to examine how deservingness is understood among crowdfunding campaigners, and how these understandings shape experiences of crowdfunding. In addressing this objective, Chapter Four explored how the body and embodied experience are central to being recognised as a 'worthy' recipient of care. I highlighted the prevailing importance of social ties, both real and imagined, reinforcing the extent to which perceptions of deservingness continue to be shaped by social and geographical proximity in spite of the online nature of crowdfunding. Further, I demonstrated how the ability of funding recipients to literally 'face up' to their campaigns by including photographs is imperative to being recognised as a deserving recipient of care.

Beyond their ability to 'embody' the deserving subject, I also explored how campaigners frame the funding recipient as 'enacting' the deserving subject through demonstrating their behavioural and attitudinal conformity to neoliberal subjectivity. In their verbal justifications of their decision to crowdfund, and in their online framing of the funding recipient, many campaigners reiterated traits of hard work and self-responsibility as implied criteria of deservingness. For some, their circumstances mean that they are easily recognised as worthy recipients of the crowd's care; however, among others, their inability to tap into these understandings of deservingness may preclude them from capitalising on the 'generosity' of the crowd. These varied experiences therefore highlight how "particular bodies in particular encounters can trigger political relations of care, whereas others elsewhere elicit only relations of neglect" (Robinson, 2018, pp. 327).

In answering the aforementioned research objectives, this thesis has made three important contributions to the literature. The first of these is a theoretical contribution

to scholarship on health-related crowdfunding. Examining this phenomenon through a care ethics lens – a novel application of the care ethics literature to the crowdfunding literature – provided an analytical vocabulary for framing how the process of care is renegotiated through crowdfunding practices. Deconstructing the caring process using Fisher and Tronto's (1990) phases of care facilitated an articulation of who is *taken care of* in a crowdfunding context, how this relates to the crowd's *care about* particular funding recipients, and who is able to access the *care-giving* they require. For example, breaking down these elements enabled me to explore how crowdfunding was perceived by some to be empowering for friends and family, as it provided a mechanism with which to translate their *care about* a loved one into a tangible action to *take care of* them.

Moreover, as part of this theoretical contribution to health-related crowdfunding scholarship, I highlighted the attentiveness of care ethics literature to processes of care operating across different scales (Atkinson et al., 2011; Cox, 2013; Milligan & Wiles, 2010). The ability of this body of work to connect embodied experiences of care to wider socio-economic processes is useful in understanding crowdfunding as a phenomenon that has implications for both lived experiences of illness, but also broader questions of resource distribution and access. Engaging with literature on the politics of deservingness, for instance, enabled me to draw connections between experiences of significant support through crowdfunding among particular participants, and how these participants fit within wider discursive framings of control and responsibility within neoliberal discourse.

Beyond a theoretical contribution, this thesis has also provided a second, empirical contribution to the health-related crowdfunding literature. While scholarship on health-related crowdfunding is nascent, many have called for further research that engages with these platforms (Berliner & Kenworthy, 2017; Paulus & Roberts, 2018; Renwick & Mossialos, 2017; Snyder et al., 2016), and indeed, much existing literature is somewhat abstracted in its claims, lacking an empirical component. Even where existing studies have conducted empirical analysis, few have engaged face-to-face with users of crowdfunding platforms (for exceptions, see Fritz & Gonzales, 2018; Gonzales et al. 2018; Kneese, 2018). Through conducting semi-structured interviews with campaigners, I have been able to nuance some of the more abstracted debates

within this scholarship by grounding them in the lived experiences of users. For instance, while scholars have broadly denounced the time required to establish and maintain a campaign and the structural implications therein (Gonzales et al., 2018; Snyder et al., 2016), this thesis has teased out how users articulate the *experience* managing a campaign, and how this relates to the responsibilisation of individuals within neoliberal ideology. In this sense, I have been able to simultaneously fill this empirical gap in the crowdfunding literature, meanwhile drawing on the theoretical strengths of the care ethics literature in connecting embodied experiences of care with macro-level discursive shifts.

Finally, this research has also provided an empirical contribution to care ethics scholarship. As a recently emerged marketised space (Cox, 2013a), an empirical focus on crowdfunding has enabled further development of understandings of who is *taken care of* in a commodified context, beyond the conventional emphasis on commodified *care-giving* practices within existing literature. In responding to Green and Lawson's (2011, pp. 65) call for research that explores "particular expressions or renegotiations of the commodification of care", this thesis has provided insights into the skills and traits necessary to be *taken care of* in a commodified context, but further, how this care is experienced. Contributing to the growing body of scholars that are problematising the dominant narrative of commodification as 'corrupting' caring practices (Boyer et al., 2013; Cox, 2013a; Pelzelmayer, 2018), engaging directly with campaigners through this project has enabled me to further disrupt this simplified narrative, highlighting how crowdfunding can simultaneously be perceived as a catalyst for expressions of care, and yet a fraught means of securing care for loved ones.

By engaging with campaigners fundraising for individuals with a diverse range of illnesses and conditions, this research has provided insights into the broader experiences of health-related crowdfunding. In doing so, it has identified common themes among participants raising funds for a wide range of health-related purposes. In order to make more specific policy recommendations, future research in the NZ context could usefully focus on particular 'gaps' that are being filled by crowdfunding platforms. For instance, narrowing in on those campaigns raising money for unfunded cancer drugs would enable a more specific engagement with how Givealittle is being

used in the context of PHARMAC's funding process. Further, while this thesis has focused on the perspectives of campaigners, future research that engages with donors, for example through online surveys, could also be beneficial in gaining insights into understandings of deservingness and experiences of commodified care in a crowdfunding context. Beyond understanding how campaigners seek to position the funding recipient in order to be 'read' as a legitimate recipient of funds, for instance, engaging directly with donors could extend the findings presented in this thesis to examine how the 'crowd' interprets campaigns.

Collectively, the findings presented in Chapter Four demonstrate the various ways in which health-related crowdfunding is likely to exacerbate inequities in access to care. From the labours of managing a campaign to the precise discourses of deservingness that one must be able to navigate in order to capture the funds of strangers, the various experiences of participants demonstrate the disposable time, resources and culturally-specific knowledges – and arguably, identities – that one must possess in order to be *taken care of* in a crowdfunding context (Gonzales et al., 2018; Snyder et al., 2016). Discourses of deservingness may serve to reward those who already have privileged access to resources and services, and medical need is only able to be evaluated in so far as it is effectively and convincingly narrated. Health systems scholars such as Goodyear-Smith and Ashton (2019) have recommended that in the NZ context, future policy shifts must focus on addressing equity in outcomes, and in particular, aligning resources with need; however, the distributional outcomes that the findings of this study allude to are at odds with such objectives, demonstrating the difficulties of the rise in prominence of this phenomenon.

The experiences of conditional care in a crowdfunding context, as discussed in this thesis, therefore broadly support the contention that market-based alternatives are patchy in their ability to compensate for the social provision of care. Various researchers have emphasised the incompatibility of markets with equitable healthcare provision; Gauld (2009, pp. 77) for example argues that "in health care, there are limits on the extent to which the market alternative is a viable substitute for government intervention." In her discussion of care and markets, Held (2002) advocates for not demonising market logics altogether, but rather recognising domains of social life where they are appropriate, and consequently domains where they are not. While in

some spheres, conceptualising people as self-sufficient and autonomous individuals may be appropriate (Held, 2002), in the context of this research, I conclude that healthcare provision is not one of these. Against a backdrop of limited government support, the emphasis on 'choice' within a commodified context of care provision may perversely limit the options of people seeking to secure appropriate care for their loved ones, as care is not guaranteed (Green & Lawson, 2011).

As was highlighted in Chapter Three, an examination of health reforms over the previous three decades highlights a broader grappling with the role of market values in the realm of healthcare provision in NZ. Despite being one of the first countries to develop a universal national health service, neoliberal restructuring in the 1990s resulted in a system that emphasised competition and efficiency (Easton, 2002; Goodyear-Smith & Ashton, 2019). While many of these changes were later reversed (Gauld, 2009), this series of structural reforms highlights the unfixed and ever-changing nature of health policy, and in particular, the pervasiveness of neoliberal ideology. Unlike in other developed countries such as the United States, where the design of the political system necessitates thorough scrutiny of policy proposals, Gauld (2009, pp. 77) argues in the context of the health reforms of the 1990s that "New Zealand's political system allowed the new health structures to be hastily implemented." In light of a history of attempted neoliberal restructuring, and the swift manner in which these policies were able to be implemented, it is therefore prudent to interrogate the normalisation and establishment of market values within the realm of healthcare. Through foregrounding individualism, choice and independence, crowdfunding reinforces an understanding of healthcare as best allocated by the market, a framing that is sympathetic to such attempts to reform NZ's universal national health service.

The findings of this research therefore speak to the need for expanded, rather than reduced, public cover for healthcare and welfare-related expenses. While some scholars have called for tighter government regulation of crowdfunding (Snyder, 2016; Zhao et al., 2019), prioritising strengthened public healthcare and welfare provision would address the gaps that necessitate this type of use of these platforms in the first instance. While the cover provided by the national health system in NZ is undeniably more comprehensive than in some other national contexts—such as the United States,

where concerns related to health-related crowdfunding have been widely raised—gaps in provision persist. Policy makers might view platforms such as Givealittle as a "living archive" (Berliner & Kenworthy, 2017, pp. 234) of faults in the contemporary health system, which could be effectively mobilised for gap identification. As crowdfunding for health-related purposes is expected to continue to grow (van Duynhoven et al., 2019), such concerns will only become more pertinent in years to come.

Appendix A: Participant Information Statement

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

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PARTICIPANT INFORMATION SHEET
for the research project
'Crowdfunding care: examining the use of crowdfunding platforms for health expenses in Aotearoa New Zealand'

Who is conducting the project?
My name is Caitlin Neuwelt Kearns. I am a Masters Student in the School of Environment at the University of Auckland. My supervisors are Dr. Tom Baker, a Senior Lecturer in Human Geography at the University of Auckland, and Dr. Octavia Calder-Dawe, Research Officer at Massey University.

Why is the project being conducted?
Health-related expenses are a key cause for which crowdfunding campaigners seek funding both internationally, as well as in New Zealand. In 2018, *Givealittle*, New Zealand's largest crowdfunding platform, reported that among the top 10 most-funded projects, eight were health-related campaigns. In recent years, the popularity of crowdfunding has increased exponentially. This emerging trend raises questions about the broader context in which such campaigns have become commonplace, as well as how people experience the process of crowdfunding care for their loved ones. In the absence of any New Zealand-based studies, this project seeks to examine experiences and understandings of crowdfunding in Aotearoa New Zealand among those constructing campaigns for friends and family members.

How is the project being conducted?
The project is being conducted over 10 months from March 2019 to January 2020 as my Masters thesis. I aim to collect data in two ways:
- Documentary data collection of online *Givealittle* campaigns
- Approximately 15 interviews with individuals who have administered health-related campaigns on *Givealittle*

Why have I been invited to participate in the project?
You have been invited to participate in the project as you have been identified, based on searches on the *Givealittle* site, as actively running a health-related crowdfunding campaign in Auckland.

What does participating in the project involve?
You are invited to participate in an interview conducted by me at a location and time convenient to you. The interview will last for between 30 and 60 minutes, depending on your availability and how much we have to discuss. Topics of conversation will include your experiences of establishing a crowdfunding campaign, your relationship with the funding recipient, and your understanding of strategies for a successful campaign. The interview will be semi-structured and is intended to be conversational. With your consent the interview will be electronically audio-recorded. You will be offered a written transcript of the interview, which, if requested, will be sent to you within a month of the interview date. Following this, you will have the opportunity to make alterations to the transcript up to two weeks after I send this to you.

How will my comments be identified in the research results?
Your comments will be assigned a pseudonym in any analysis or write-up of research results. Any other names that may arise in discussion will also be changed so as to maintain confidentiality.

What are my rights as a participant in the project?

Participation in the project is voluntary; you are free to decline to participate in the project, and can withdraw at any stage up until two months after the date of your interview, or two weeks after receipt of transcript, whichever is the latest. If you wish to receive a copy of your transcript, you can indicate so on your consent form. You can make alterations of your transcript for up to two weeks after it is provided to you.

What are the potential benefits and risks of participating in the project?
I hope that the interview will provide a beneficial opportunity for you to discuss and reflect on your experiences of running a crowdfunding campaign. Your participation will help to further understandings of how crowdfunding platforms are used and engaged with in Aotearoa New Zealand. You will be able to access any publications that result from the project. Please note that as pseudonyms will be used to attribute your comments, this process will not generate publicity for your individual campaign. Koha will be provided in the form of a $30 shopping voucher in recognition of your time and contribution to the research.

I don't expect that there are any risks of participating in this project, however the interview and/or recording device can be stopped at any time if you no longer wish to continue. If the interview raises any concerns or issues for you, you can contact a service such as these for information and support:
> Lifeline 0800 543 354 (0800 LIFELINE) - for counselling and support
> ·Samaritans 0800 726 666 - for confidential support for anyone who is lonely or in emotional distress
> Depression Helpline 0800 111 757 or free text 4202 - to talk to a trained counsellor about how you are feeling or to ask any questions
> Healthline 0800 611 116 - for advice from trained registered nurses

What will happen after my participation in the project?
Interview recordings will be transcribed and analysed. The data collected will form the empirical basis of my Masters thesis. Material may also be used for presentations and publications. You can request a copy of publications by indicating so on the Consent Form. All data will only be available to myself and my supervisors. All records will be stored securely for six years before being destroyed.

How do I contact the researcher/primary supervisor?

Caitlin Neuwelt Kearns	**Dr Tom Baker**
MA Student	**Senior Lecturer in Human Geography**
School of Environment	**School of Environment**
University of Auckland	**University of Auckland**
E: cneu868@aucklanduni.ac.nz	**T: +64 9923 8554**
	E: t.baker@auckland.ac.nz

For any concerns regarding ethical issues you may contact Associate Professor Julie Rowland, Head of the School of Environment, at the University of Auckland. Telephone +64 9923 7412. Email: j.rowland@auckland.ac.nz

Alternatively you may contact: Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone +64 9373 7599 ext. 83711. *Email:* ro-ethics@auckland.ac.nz

Appendix B: Consent Form

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

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INTERVIEW CONSENT FORM

Project title: Crowdfunding care: examining the use of crowdfunding platforms for health expenses in Aotearoa New Zealand

Name of Researchers: Caitlin Neuwelt Kearns (cneu868@aucklanduni.ac.nz)
Dr Tom Baker (t.baker@auckland.ac.nz)
Dr Octavia Calder-Dawe (O.Calder-dawe@massey.ac.nz)
Dr Ann Bartos (a.bartos@auckland.ac.nz)

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected.

I have had the opportunity to ask questions and have them answered to my satisfaction.

I agree to take part in this research by participating in an interview.

I agree to have the interview audio recorded.

Koha in the form of a $30 shopping voucher will be provided in recognition of my contribution to the research, whether or not I withdraw, which I am free to accept or decline.

I understand that:
- I can ask for the recorder to be turned off at any time, refuse to answer a question and/or leave the interview without having to give a reason
- My interview comments will remain confidential, which means that any reproductions of my statements will be assigned a pseudonym and names within my comments will be changed
- I can request a copy of my audio recording and a transcript of my interview, both of which will be provided to me within one month of the interview date
- I am free to edit the transcript for up to two weeks from the date of the receipt of the interview transcript
- I am free to withdraw participation at any time during the interview process without any reason. After the interview, I can withdraw up until two months after the interview, or two weeks after receipt of the interview transcript, whichever is the latest
- the interview recording and transcript will be kept for 6 years, after which it will be destroyed.

☐ I would like to receive a copy of my audio recording after my interview. *[Please tick the box if you agree to this]*

☐ I would like to receive a copy of the transcript of my interview. *[Please tick the box if you agree to this]*

☐ I would like to be notified at some point in the future when the outcomes of the research are available. *[Please tick the box if you agree to this]*

If you have ticked 'yes' to any of the above, please provide the email address at which you would like this information to be sent:

_____

Name _____   Signature _____

Date _____

Approved by the University of Auckland Human Participants Ethics Committee on 11th June 2019 for three years, Reference Number 023136

Appendix C: Generic Interview Schedule

Could you please tell me a bit about what motivated you to establish a Givealittle campaign?

Did you consider other forms of raising funds? If so, what were these? If not, why was Givealittle your primary consideration?

How did you go about constructing your campaign? What were some of your key considerations in deciding what photos to upload, or what details to include?

How have you felt about the campaign creation process?

If funding recipient is an adult: How much involvement did *(recipient of funding)* have in the design of this page?

Did you have any discomforts in creating the page? Have these shifted at all as time has gone on?

How have you felt about disclosing personal details about *(recipient of funding)* in constructing a campaign?

How much contact have you had with people who have donated to your campaign?

How often have you been checking the page? To what extent have you felt the need to maintain ongoing communication with donors through this page?

Who do you see as your target audience with this page?

What do you think motivates donors to contribute to your cause?

What proportion of those who have donated to your campaign would you say have pre-existing personal connections with *(you/the recipient)*?

Have you been in contact with any family/friends/acquaintances that are supportive of your cause but don't feel like they're in a position to contribute financially?

Have you been receiving donations from strangers through this campaign? If so, how has this felt to have people unknown to you engaging with your cause?

How, if at all, has this fundraising process shaped your relationship with *(recipient of funding)*?

How do you think *(recipient of funding)* has felt about the fundraising process?

How has the success of your campaign so far compared to your expectations? What are your plans for financing the cost of care if you find you can't raise sufficient funds?

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