

**Hype, Heresy, Healthism, and Hope around “Healing”: Constructing Chronicity and Cure(s)**

Amy R. Hogan

Master of Science in Psychology

School of Psychology/ Te Kura Mātai Hinengaro

University of Auckland/ Waipapa Taumata Rau

Prof. Virginia Braun

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## Abstract

Driven by a neoliberal sociopolitical climate, concepts of health in contemporary New Zealand society emphasise a process of becoming healthy through healthist responsabilisation. An individual's ability to achieve a healthy lifestyle and cure chronic conditions is seen as something that can be achieved with the right balance of technology, medicalisation and individual effort. Using a critical qualitative orientation and drawing on Critical Disability Theory I examine how people understand cures and treatments in the context of chronic conditions. This master's research incorporated two datasets; online content around chronic condition treatment and management which formed the basis for a vignette study in which 188 participants answered questions about fictionalised characters. In a reflexive Thematic Analysis of both datasets together, I identified two overarching analytic stories. First, chronicity was constructed as something that was hostile to individuals, whānau and society as a whole. Secondly, chronic illness was constructed as needing to be defeated through a curative process. Together these construct a "hostile ecosite", where a relentless search for "cure" is the only way a "responsible" person with a chronic condition can be socially acceptable. By promoting a more inclusive and accepting perspective, we can recognise that a life with chronicity can be just as acceptable and meaningful as any other. By valuing the lived experiences of those with chronicity and elevating their voices, we can work towards a society that embraces diversity and recognises the inherent worth and dignity of every individual, regardless of their health status.

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## Preface

As a scholar who lives with neurodiversity, I am confronted with both the general challenges of reflexivity and specific obstacles in constructing narrative structures within an academic context, described as disability labour, legitimacy and vulnerability (Sheldon, 2017). The interplay between academic requirements and the unique perspective that neurodiversity brings to all aspects of academia creates a complex embodiment and tension (Siebers, 2013). In this preface, I will explore this complexity through various elements. Firstly, I will provide a brief history of lived experience scholarship. Secondly, I will examine the tension between individual scholarship, academic legitimacy, and the appreciation of disability theory in broader academic contexts. Thirdly, I will discuss my own perspective as a neurodiverse academic. Lastly, I will highlight approaching my thesis through a neurodiverse lens. The recognition of neurodiversity and being neurodivergent has grown in recent years, partly due to the proliferation of popular books about the brain and its functions (Cobb, 2021). However, with this recognition often comes the tendency to stereotype individuals under this broad term, usually based on "classic" community groups that were the first to have access to testing or early theoretical discussions about thinking "differently" (Price, 2022). In framing my neurodiversity, I refer to the way in which I perceive, understand, produce, and reproduce sensory input and information.

The history of positioning individuals with "lived experience" as scholars, recognising their attributes and perspectives, is lengthy and complex (Davidson, 2016). While the notion of "lived experience" and "consumer engagement" is increasingly valued and ethically required, by ethics bodies and government health initiatives, the presence of a researcher or medical professional living with and expressing their condition, rather than "overcoming" it, remains



relatively novel (Meeks et al., 2018). Inaccessible elements exist within all areas of education, but tertiary courses, studies, and research can be particularly exclusionary (Hodgkin, 1996). These exclusionary elements include physically inaccessible spaces, academic material that cannot be adapted and work requirements. In my studies, I have needed to adapt my office workspace, and get support with reading inaccessible resources such as photocopying, websites and PDFs. Efforts have been made to centre the experiences and scholarship of individuals with lived experiences, including disability, in various domains, from *Lancet* articles to extensive ethnographies (Schalk, 2017). Still, there is considerable labour in individuals and groups being willing to initiate these processes.

The core issue within explicitly acknowledging lived experience is the issue of "legitimacy" and the challenges of openly integrating one's disability or condition into academia (Sheldon, 2017). Many individuals feel unsafe to disclose their disability, even if they have managed to overcome the barriers outlined earlier (Dolan, 2021). This difficulty often stems from two concerns: the fear of jeopardising their own academic safety and progression, and the desire to avoid being perceived as tokens or engaging in diversity labour (Siebers, 2010). There is also the concern that their research in the field may be dismissed as overly biased (Davis, 2006). These concerns are often referred to as "blurring the lines" (Mogendorff, 2013), although the metaphorical lines between professional and personal are arguably artificial and come with their own theoretical foundations and underpinnings.

Due to my combination of disabilities, completing projects, research, and teaching without considering accessibility is simply not feasible. Additionally, I have little interest in pursuing topics unrelated to health or disability, as suggested by a joking colleague during my

undergraduate studies. The disability and critical health space is not somewhere I wish to escape from in order to pursue "legitimacy" through distance and objectivity. To the best of my knowledge, I am the only individual using a manual wheelchair accompanied by a service dog, in the Faculty of Science at Waipapa Taumata Rau. For me, "passing" as able-bodied was never an option, even if I desired such a state. Physical challenges arise from the accessibility of rooms and spaces, as well as digital environments that are difficult to navigate, and the information processing required for tasks like ethics forms.

If quantitative researchers have nightmares about their qualitative counterparts, then both I and my thesis likely embody those fears. One of my supervisors once humorously informed me that I was "drowning" in bias, which provided an amusing mental image. My childhood and adolescence were largely shaped by health-related elements, such as treatments and management, which were marked by varying degrees of success in relation to the assumed goal of "cure". By paediatric neurorehabilitation standards in the 1980s and 1990s, my primary reliance on a wheelchair was often classified as a failure. Neurodiversity and processing differences only became significant features of my life during early adulthood. However, I believe this background informs both my interest in and criticism of power structures, without overshadowing everything else in an assumption of unbiased truth. I have both an academic and professional interest in how these concepts are understood within the tension surrounding health narratives.

Every thesis needs to adhere to certain conventions for publication, and I have been working diligently in recent months to meet these requirements. However, every element of this thesis and the process of producing the final product has been influenced and shaped by

neurodiversity, from the initial mind maps to planning writing sessions based on my processing and sensory needs. It was a requirement to hire a proofreader (a considerable investment) to ensure I was able convey messages and meaning within the strict rules and conventions of producing a final academic product. A neurodiverse lens is present in every cell, convention, and twist of this thesis, and this lens makes this work stronger and more deeply embedded within the academic tapestry, complete with writing quirks. In the truest sense of the word, a master's thesis represents the process of mastering skills and concepts, which will subsequently inform my future research and professional projects. I have laid the foundation for understanding how to shape, write, and articulate an argument while bringing together different perspectives. Moreover, for me, achieving mastery involves embracing the differences and diversities that shape my unique research lens. My thesis has a critical orientation as part of that foregrounding of dynamics and structures that influence approaches and power dynamics. Many of the same influences occur in academic and the neuro normative conventions in producing every aspect of a thesis and the “final product” has many normative conventions that can be difficult to adapt. This work represents my finished point with the best support and “neurodivergent” translation options available to me to meet all the needs of scholarship.

## Chapter 1: Introduction - Situating Chronicity and Cure Narratives

Patients and people who identify (or more commonly are identified by others) as being ill have historically occupied and continue to occupy a contentious place within society, considering the current wider sociocultural demarcations of health status as they connect to good citizenship (Carney, 2020). Individuals and the medical professionals who assist in this process are often venerated in heroic language (Kim, 2017). The promotion of “health” as a moral social imperative becomes even more complex when we consider individuals who do not and/or will not fit the “default” norms or “factory settings” of health recognised by conventional health measurement (Davis, 1995). When “healthy” becomes the normalised expectation, then so does an expectation that those who deviate from healthy must shift into normalcy (Cassuto, 2020).

The focus of my project is to critically investigate and interrogate the intricate relationship between chronicity and cure narratives. In a broad sense, I am interested in how “achieving health” is normalised and promoted within this New Zealand<sup>1</sup> context. Specifically, in this chapter I will delve into three key aspects of chronicity and cure narratives and set up a broader understanding for the connection between these three. The first aspect is how health narratives become influential guiding forces and promoted ideals. The second aspect is around the processes by which chronic illness and disability are comprehended and given meaning.

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<sup>1</sup> Within current debates about Māori sovereignty and upholding Te Tiriti o Waitangi I considered naming this country Aotearoa/New Zealand throughout the thesis. However, here I am referring to the national construct we currently work within (and that I critique), which is the one created by Pākehā/White settler New Zealanders called New Zealand.

Lastly, I will explore how the context of health and healthism promotes cures within New Zealand, including the systems and processes that shape and sustain cures as priorities.

The scope of the thesis will investigate the underlying assumptions around how the ideas of treating and managing a condition are understood and put into practice. The scope will include both conventional and experimental treatments, as every standardised health process was once an experiment, and through conventionalising methods becomes standard. Broadly speaking my parameters around what counts as an experimental treatment are that they are largely unproven in wider literature or not widely tested for things like efficacy or implementation. Thus, these experimental treatments often exclusively utilise direct to consumer marketing and require privately raised funds to access.

Throughout Western medical history, health narratives have consistently been constructed to emphasise the pursuit of a cure (Seedhouse, 2004). The importance of cure has been intertwined with a more recent rise of wellbeing constructs where “being well” is a conscious and controllable act. These ideas around health are deeply embedded at the macro level, in ideologies, theoretical foundations, and socio-political power structures (Alderson, 2021). This connection persists despite claims that health is apolitical and universally virtuous (Kim, 2017). Individuals living with chronic conditions often bear negative impacts within these dominant paradigms and paradigm shifts (DasGupta, 2020). The tension between chronicity and the pursuit of cures is manifested locally in New Zealand across various mediums, academic disciplines, clinical settings, and community practices (Podsiadlowski & Fox, 2011). Hence, it is important to critically review this tension through a reflexive lens.

The thesis comes in part as a reflection on constructions of healing that have been presented and promoted insidiously throughout all aspects of life (Lupton, 2013). Individualised constructions of health and efforts to be healthy have gained far greater prominence in both public and socio-political discourses in recent decades, due in large part to the fact that tools for measuring health are becoming more economical and readily available (Whitson, 2013). Almost every level of the health experience, from the body's daily rhythms to optimal performance of the mind, are discussed in detail within social platforms. Therefore, it has been increasingly difficult to even define what people mean when they say somebody is "healthy" or "unhealthy". Constructions of health are no longer simply a reflection of biological or physiological medical measures, which categorise individuals or groups into a perceived range (Alderson, 1998), but can now be anything from medical records to more holistic commentary on overall health including the spiritual and social realm.

An underlying element of constructions of health in public discourse is how these messages are presented to the public, in various forms and formats. These include advertisements, infographics and online resources. For example, messaging that includes underlying constructs about self-discipline drive measures around self-improvement projects (Rail & Jette, 2015). A monolithic approach around "doing health" presents health as a state that can be reached only through the right amount of energy, engagement and enthusiasm (LaMarre et al., 2019). New Zealand, in particular, presents an almost unique way of disseminating public health information, which has a consequential impact on the framing of chronicity and cures. At the time of this thesis, New Zealand is one of only two countries that allows direct-to-consumer marketing for health, such as pain medication and prenatal health

regimens (Every-Palmer et al., 2014). This is routinely framed as a “pro consumer” activity that allows choice, although much of the regulation of this health marketing industry is self-directed and inconsistently applied (Coney, 2002), despite the protest of many industry bodies (Every-Palmer et al., 2014). This legislative “quirk” (in allowing and promoting medical advertising) lays the foundation for expectations that achieving health should be done through right and conscious health choices. This wider sociopolitical backdrop occurs even if people are not actively seeking information on health care decisions (e.g., watching the news or YouTube advertising).

Neoliberalism, and its many ideological offspring, is a useful framework for researchers, clinicians and activists to recognise and critique constructions of “health” as a discoverable pathway (Schrecker, 2016). Neoliberalism means many often contradictory things, depending on how the underlying economic philosophy is contextualised, it is not a malevolent force in isolation (Bell & Green, 2016). In the simplified application to health, the connection to neoliberalism centres around championing individualism and the retreating of the government states responsivity to health inequality and responsibility (Whitson, 2015).

When it comes to considering health and cure it is important to consider *why* being healthy has taken up such importance. There are long and tangled roots within these constructions which develop from the neoliberal idea that there are “uses” for every member of society in how they behave, socially engage, and model family life (Andrews et al., 2019). When societal influences construct an ideal, the opposite is often produced in default, in this case, those that are considered “useless” to society. People who experience chronicity are frequently constructed as lacking in the measures that enable an ideal subject (Vallelly, 2021).

“A retreating state” when it comes to health achieves one of the rare feats of unifying the left and the right political spectrum, with each centring the idea of individual power and control, albeit for different reasons.

The way we measure and understand health is intrinsically linked to our understanding of curing and the curative ideal. The current dominant discourse surrounding health often frames finding an "alleviation" for chronic illness as an unquestioned positive outcome, with the ultimate goal being the restoration of the individual to an imagined or idealised version of their life before illness (Schrecker, 2016). Despite decades of discourse and debate, there is still a persistent desire to reduce health to a formula (Rysst, 2010). The concept of a cure is socially constructed as the ultimate and unquestioned path to a better, enlightened life (Kim, 2017), conflating the ideas of reprieve from illness and becoming healthy. Both achieving health and ameliorating illness are subject to the dominance of verbs such as “being” or “becoming” healthy or “seeking” a cure. This reductionist view of health presents health as a goal that all humans should unquestionably strive towards, regardless of the diversity of individual experiences and needs.

Throughout sociocultural history, health has been associated with progress and enlightenment, characterised by a transition from illness to a state of wellness, facilitated by advancements in medical technology, tests, and measurements (Fitzgerald, 1994). This perspective is widely accepted as objective, but “medical neutrality” masks the power dynamics at play (Kronenfeld, 1979). Underlying this view is the assumption that doctors and medical professionals are neutral agents of cure, objectively disseminating knowledge and following the Hippocratic Oath (BMJ, 1998). However, this is a mythologised and misquoted representation



of the medical profession that fails to recognise the role of power and subjectivity in medical practice (Crawford, 1980). From a critical perspective, health as an embodied concept is constructed through societal, cultural and socioeconomic factors (Crawford, 2006). There are almost unending examples of the ways these produce prejudice and discrimination in health, such as qualifying for insurance, housing and renting codes (Cheek, 2008).

The moral imperative of health and the citizen seeking to become healthy was brought together in Robert Crawford's (1980) concept of healthism. His influential paper, *The Medicalisation of Everyday Life* sparked interest in the concept of healthism (Crawford, 1980). Crawford defines healthism as "the transfer of responsibility for sustaining health from state-led initiatives and institutions onto individual communities" (p.1). This perspective suggests that everyday life becomes subsumed by efforts to attain and maintain good health. Recent scholars have expanded on this idea, examining trends such as the promotion of healthy eating, the gamification of health, and the impact of healthism on patient-practitioner interactions (Greenhalgh, 2004). Healthism, according to Crawford, is the preoccupation with personal health as the primary focus for defining and achieving well-being, primarily through lifestyle modifications (Crawford, 1980). However, the ability to be a "healthy citizen" has been criticised as an insidious obligation rather than a voluntary benefit (Cheek, 2008). Crawford argued in 1980 that healthism was a problematic yet largely inevitable outcome of broader political and societal constructions in preceding decades. Particularly, he highlighted as problematic the notions of individual responsibility for health and the production of individuals for the benefit of the nation. A general way to understand this perspective is to recognise that notions of health apply to everyone and intersect with all aspects of society, permeating

everyday life and becoming medicalised (Crawford,1980). This study specifically focuses on the experiences of communities considered “unhealthy” according to standardised and normalised criteria of well-being. It raises questions about the criteria for inclusion and participation in society when being healthy and cessation of illness assumes an all-encompassing significance.

In this section I give a broad overview of disability and chronic illness scholarship and how the meanings of such concepts are constructed and contested in contemporary debates. Firstly, I cover how living with a condition long term has come to exemplify far more than a medical health measure. Secondly, I introduce the wider, often frantic, health imperative to bring a particular style to life and living (Yodar, 2022). Thirdly, I outline how these imperatives play out in everyday life examples of responsibility in common health practices.

Chronic illness and disability are contested concepts, depending on your ideological leanings, however in their simplified form they refer to the experience of living with an illness or disability over an extended period of time (Yeo & Sawyer, 2006). Though uncertainty and inconsistency remain around how these concepts are applied across all health domains (Mishel, 1999), chronic illness and disability are frequently associated but are not automatically the same (Wendell, 2001). Chronic illness needs to be acknowledged as having many disabling elements that do not necessarily mean the person has a disability in the way that the term is commonly understood (Wendell, 2001). I use the terms chronic illness and chronicity primarily because those are the terms that signify a sense of unwellness that are perceived to be in need of betterment. The perceived unwellness embedded and embodied within disability is frequently what is contested and pathologised in the neoliberal atmosphere (Ayo, 2012).

The experience of chronicity has become far more than the objective fact of living with a condition over time. The dominant ideologies around being chronically unwell are inextricably linked to how health processes are enacted because many markers of health are ones that people living with chronicity cannot meet (Adams et al., 2020). The framing within this thesis extends from the concepts that I have outlined in previous sections that inform the interplay between the different forms of identity that stem from living with a diagnosis. Dominant constructions of chronic illness centre around the presentation of the condition, as opposed to the identity of the person and all the many subtle and complex interplays between the two (Williams, 1984). These dominant constructions also position people who are chronically unwell as problematically not actively in the process of “getting better”, and therefore wasting time (Davis, 2014). Time has an unusual role to play in how people living with long term conditions are perceived, in terms of making acceptable progress or lagging (Kim, 2017).

These nuances around how chronicity is constructed directly impact the wider health imperative to exert control over health and all life domains (Campbell, 2020). In recent decades, there has been a particular shift, reflecting wider neoliberal beliefs, towards individuals taking up the mantle of a healthy lifestyle through pursuing specific and measurable targets such as Body Mass Index (BMI) and “ideal” weight ranges (Hokowhitu, 2014). “Lifestyle” has become a ubiquitous term for individuals taking control of their lives (Rose, 2020), and specifically promotes the idea that people can systematically find the building blocks to health (Cairns & Johnston, 2015). There is increasing ability to monitor every aspect of a person’s biological and physiological reality with specificity and intensity (e.g., smart apps; Dobransky, & Hargittai, 2014). This holds true for measurements that were previously exclusive to the

domain of hospitals and medical professionals. Faith Fitzgerald (1994) describes the overarching paradox between seeking to divest responsibility for health to individuals and in turn, wanting to control the ways in which people seek health alternatives.

This tendency towards and expansion of responsabilisation and lifestyle surveillance can be viewed through Foucault's theory of architecture of governance and measurement of worthiness, or as Whitson (2014) phrased it: "Foucault's Fitbit". In relation to this topic, it presents the idea of bio power, where the measurement of biological facts such as function have tremendous power over the health of society and thus need to become a measurable commodity throughout society (Foucault, 1982, Tremain, 2009). In principle, the idea is that every aspect of our life and health are gamified and measured in ways that can be both empowering and disempowering, depending on ways in which the information is framed, utilised, and disseminated (Whitson, 2014). Given medicine's uneasy historical roots, these aspects of medicalisation, surveillance and measurement look further stigmatising to those outside the acceptable ranges, such as those who are chronically ill (DasGupta, 2020).

People living with chronic conditions have often been at the centre of these contested points around health, such as housing and respiratory illnesses like asthma (Live, 2021), and public health measures such as dental care and sexual health education (Devinsky et al., 2020). There is a recognised need for attention and support in health measures for vulnerable populations but often community groups are left out of the dialogue and negotiations (Bérubé et al., 2015). These examples highlight the way people with chronicity are stigmatised within discussions surrounding health and well-being, by placing the responsibility on the individual to surveil and modify themselves (Hughes, 2009). The experiences and needs of those with

chronicity shape policy debates and interventions, changes are often predicated on social understandings of contributing health factors (Brown et al., 2019). It is important to recognise that these issues are not neutral; they reflect broader societal and political constructions. The prioritisation of individual responsibility for health and the drive to produce healthy individuals for social benefit underpin these debates (Eysenbach, 2009). By critically examining these ideologies and understanding their implications, we can gain a deeper understanding of the complexities surrounding chronicity, health, and the pursuit of well-being.

Individuals living with chronic conditions face growing pressure to constantly evaluate and improve their well-being, both in terms of personal achievements and social expectations. This complex issue carries theoretical debates, as striving for wellness can have direct and indirect effects on individuals and their families. These constructions influence their ability to fully engage in and contribute to society in ways that hold significance for them (Kim, 2017). The prevailing environment often encourages seeking personalised solutions, with this expectation ingrained both internally and externally.

The principles and practices of responsabilisation and privatisation give rise to the perfect environment for cure narratives to thrive and expand (Galvin, 2002). By cure, I mean the orientation to chronicity (and disability) which frames these as problems in need of a solution, a cure. Therefore, finding the cure (or some way towards it) is framed as the ultimate purpose of health engagement and healthcare seeking (Martini & Bragazzi, 2021). Cure is a construction that means to “significantly treat” or eradicate a person’s experience of any given condition (Pantazakos, 2019). Becoming cured is becoming seen as the most unquestionably important outcome in many narratives around health decision making (Kim, 2017).

Furthermore, the standards of what it means to become cured are created to resonate within a person on a physical, psychological, and emotional level (Adams et al., 2020).

Healthism positions cure and curative narratives as a logical extension of the three main tenets of individualism, privatisation, and decentralisation (McGregor, 2001). A person that is actively seeking a cure is thus one step closer to minimising the burden, whereas a person that does not conform to these expectations becomes invisible (Davis, 2014). Furthermore, this construction of cure conceals the many inequalities that sustain people's inability to access certain services and opportunities, such as long-term sustained treatment.

As science and scientism has gained prominence and attention, so too has the tantalising notion that a cure maybe "out there" for people to find if they have the right level of enthusiasm and tenacity. Cure has become an all-encompassing metaphor for offering a "life reset", meaning that the escape of the condition will be the golden ticket to a new life of happiness and contentment (Beauchamp-Pryor, 2011). A related construction is around the gamification of health and lifestyle (Johnson et al., 2016), where a person's daily life and biorhythm can be cured by way of hacking the body's systems to make the best out of every moment, minute, hour, and day. More colloquially, such notions come under the broad umbrella of "life hacks" or as one magazine describes it, it represents a lifelong available cure and measurement connected to devices (Whitson, 2015). Therefore, (it is assumed) there are no aspects of life or existence that cannot be micromanaged and controlled to produce a healthy and well life. The willing control and surveillance that people execute over themselves in the quest for betterment, does not find its roots in playful gaming but in escalating measures of "brokenness", "success", "failure", and "control" (Neuwelt-Kearns et al., 2021).

The expanding field of science and advancements in technology have enabled the development of what falls under the broad category of “personalised medicine”. Essentially, this concept refers to interventions or approaches that are precisely tailored to an individual's unique needs, requirements, and measurements (De Grandis & Halgunset, 2016). This is made possible by the Western medical system that emphasises the necessity for the most precise measurements possible, positioning it as the “future” of medicine (Savard, 2013). In practice, the claims surrounding personalised medicine continue to evolve, with more intricate assertions being made about available options, such as individual DNA mapping and personalised approaches to understanding and optimising the endocrine system for ideal diets (Broom et al., 2014). This work is presented as being extremely specific, surpassing everyday knowledge, and consequently, non-personalised medicine is perceived as inadequate and inferior. To a certain extent, personalised medicine can be seen as a rebranding of a long-standing concept, as most healthcare professionals strive to be responsive and attentive to the individual needs of their patients (De Grandis & Halgunset, 2016). However, the challenge lies in the belief that the power of biomedicine and self-measurement can bring about comprehensive changes without recognising the existence of broader political and structural inequalities.

Eunjung Kim (2021) highlights the potential dangers of an individualised curative narrative that allows little to no room for alternative approaches, which she terms “curative violence”. This concept suggests that rights, understandings, and access to services become contingent upon subscribing to curative efforts at a state level, being a good healthy citizen with a moral health compass (Kristensen, 2016). This perspective aligns with advocacy and

critical work illustrating the immense and often unsupported efforts to resist and disrupt narratives of responsibility (Galvin, 2002), as well as the examination of cure as a prejudiced force (Thomas, 2009). Understanding the underlying assumptions surrounding cure in the context of chronic conditions is crucial due to their increasing influence on public and societal perceptions (Turner & Knoepfler, 2016). One prominent assumption is that individuals with chronic illnesses are automatically disabled by their conditions, thus unable to live fulfilling lives (Wendell, 2001). Such attributions and the medicalisation of illness have a long history, positioning sickness as a personal failing rather than a facet of life (Ullrich, 2012).

An example that illustrates the influence of curative narratives and their connection to violence on individuals is the growing phenomenon of cosmetic limb lengthening procedures (Gayomali, 2022). This practice involves individuals who are of average height or short, within “standard parameters” seeking these procedures, rather than individuals with severe growth restrictions needing to correct a limb discrepancy (Catagni, 2005). A lack of height among the general population is not inherently a deficiency requiring medical intervention. However, the ability to measure oneself against societal norms has constructed being tall or of average height as a necessity, particularly for men, in various contexts of masculinity such as business, social interactions, and romantic relationships. There is an intersection between societal pressures and the field of medicine that deems the breaking and rebreaking of leg bones as an acceptable and even encouraged prospect (Vishwanathan & Nimbalkar, 2017), precisely because the perceived benefits in terms of social acceptance outweigh the financial, physiological and psychological costs and risks involved.



The concept of cure and the pursuit of symptom alleviation are not value-neutral concepts; they carry influences and theoretical foundations. As scientific technologies and testing become increasingly sophisticated, precise, and economically driven, there is a growing expectation for individuals to incorporate this knowledge into an ongoing quest for self-improvement and personal betterment (LaMarre et al., 2019). This perspective emphasises the importance of striving to become "normal, improving, and productive selves" (LaMarre et al., 2019, p. 1). Within this framework, the question of who is responsible for one's health has a clear and uncomplicated answer: the individual (Layton, 2009). Consequently, measures aimed at enforcing and achieving cure may exert a form of violence on the individual, but they become perceived as worthwhile endeavours by the affected individuals themselves, as well as their families and society as a whole.

The New Zealand healthcare system provides a unique context for examining the interplay between chronicity and cure narratives. It is unique not only in terms of how the healthcare system in New Zealand functions but also in terms of the accurate or inaccurate assumptions regarding New Zealand's broader contributions to the global healthcare landscape and its perceived international standing) This section will shed light on the New Zealand system and its processes through the following approaches. Firstly, it will explore the guiding principles and systems in place concerning individuals experiencing chronic conditions. Secondly, it will examine the key elements that shape contemporary health scholarship in New Zealand, including the healthcare reforms implemented during the timeframe of this thesis. Thirdly, it will highlight specific examples that have influenced the narratives around the experience of

healthcare in New Zealand. Lastly, it will delve into the constructions of health in New Zealand, particularly in relation to experimental treatments.

While there is limited specific research on healthism, cures, and chronicity within the context of New Zealand, the underlying constructions of healthism and individual responsibility for health are acknowledged as influential factors in shaping various populations within New Zealand and their health messaging (Jenkin, 2010). These constructions have been used to justify why certain populations are perceived as unhealthy or why they fail to utilise available healthcare services. New Zealand, often regarded as an egalitarian country, underwent a significant shift towards neoliberal economics and privatisation starting in the 1980s, transitioning from a welfare-focused approach to a competitive framework (Laner, 1997). The adoption of these individualised privatisation principles has exacerbated health inequities and rendered access to healthcare, employment, and education more precarious (Barnett & Bagshaw, 2020). These narratives often gain traction and become reinforced during election seasons. For example, right-leaning political parties like the National and ACT parties in New Zealand have frequently critiqued young individuals, often with disabilities, who rely on long-term job-seeking benefits, emphasising the expectation of productivity for all (Chapple, 2013). Health and welfare reforms remain a constant topic of political discussion, generating substantial debate from both left and right perspectives (Laner, 1997).

The healthcare system in New Zealand, as it relates to people experiencing chronic illness, has many of the challenges endemic to countries and regions that are preoccupied by the idea of creating healthy citizens (King, 2000). There is perceived to be a constant tension between the availability of resources and the idea that New Zealanders are falling into broader

global trends, such as increased cases of Type Two Diabetes and escalating needs for expensive treatments such as dialysis (Gounder & Ameer, 2018). The cost of long-term conditions is frequently framed in terms of individuals with reduced quality of life, unbearable pressures on families, and a government with finite resources (Hogan & Song, 2022).

However, clinicians and academics are also (if imperfectly and not without resistance) working to develop a more strengths-based approach in framing chronic illness and disability, or at least beginning those conversations (Reynolds, 2018). There is particular work to centre Indigenous knowledges<sup>2</sup> around wellbeing and resistance (Penehira, 2014).

The New Zealand health system is also making progress on shaping and prioritising long-term health elements such as rehabilitation; (McPherson, 2015). In the textbook *Rethinking Rehabilitation*, influential New Zealand rehabilitation specialist Kathryn McPherson and her colleagues (2015) examine the epistemological underpinnings of rehabilitation and the management of chronic conditions. Many of the critiques in this textbook focus on healthism as a root ideology that underpins many discourses, including the long history of rehabilitation as a tool for producing a “productive patient”. In the book, Karen Walley Hammell (2015) examines the problematic but frequently unacknowledged assumptions that underlie the principles of “quality of life” as they relate to seeking treatment and management of illness. It particularly problematises the idea that there is somehow a quality life state that people can aspire to that

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<sup>2</sup> As a Pākehā researcher and advocate working within the framework of a broader health reforms and centring te Tiriti o Waitangi, there are ways to enact allyship that need to be reflective and recognise the positionality, limits and assumptions that I carry. For example, in my work, this includes the introduction of te reo terms for different conditions of disability, that emphasise strength, complexity and resilience over medicalisation (Opai, 2022). This was gifted to our community by a scholar and linguist who spent a year within different disability communities. The Pākehā advocate’s responsibilities lie in using and centring this knowledge and the principles that underly the new meanings.

remains permanent. The book also examines the tensions that are created for individuals living with chronic conditions or disabilities. From their earliest beginnings, health theories, often sociological in nature, have struggled to situate the individual as both a recipient of health and the agent of change (Lupton, 1993). These academic tensions are frequently embodied in clinical practice and how the patient perceives themselves.

Another important feature of the New Zealand health system as it is currently envisioned is the idea of centring and developing strategies for the recognised inequities within the system. While tackling promoting equity may have many noble intentions, it can be difficult to achieve without also drawing on wider narratives of “vulnerability” and the perception of inherent problems within a group of people that may not exist (Jenkin, 2010).

During the writing of this thesis, the New Zealand healthcare system has gone through a period of considerable change and development. In particular, the District Health Board has been replaced by a singular health authority, joined by a new Māori health authority (which is viewed by the right wing as problematic). Furthermore, there are systemic changes in the way health initiatives are funded and the ability of individuals to access the said funding (Lupton, 2013). In theory, these new changes will centre the voices of individuals, accommodate needs more completely, and reach the areas of greatest needs (Broom et al., 2014). These proposed alterations and ideological shifts influenced the information I accessed, the official framing of chronicity on government websites, and the focus of the most reports and guidelines. Furthermore, the health system from 2024 onwards may play a role in shaping future research into experimental treatments because information may be more readily available within New Zealand and accessing them may be framed differently.

A New Zealand example of this trend in accessing information is contention when it comes to the “high-cost treatment pool” (MOH, 2020). This refers to a limited fund that the government provides for experimental treatments not available in New Zealand. However, there are strict criteria and guidelines for accessing this money. Running in parallel to the intensity of these conceptions of health is what Deborah Lupton (1997) refers to as the “de-throning” of medical professionals as the (perceived) sole providers of health knowledge and the authorised navigators of a health landscape. Individuals, community groups, and lay experts are developing increasing dominance within health discourses, particularly when it comes to the concept of restoring people to prized positions such as full health (Storni, 2015). People are practicing and constructing the idea of being a patient and patienthood in entirely different domains and making health choices accordingly (Sosnowy, 2014).

My research is situated at the intersection of multiple factors influencing the New Zealand context, exploring how the healthcare system is understood and how diverse elements of health are conceptualised for individuals living with long-term conditions. Specifically, I aim to examine the backdrop of individualisation, which can significantly shape how people engage with various opportunities for symptom management, treatment, and potential cures. Through this investigation, my goal is to provide insights into the experiences and perspectives of individuals navigating the intricacies of healthcare within New Zealand's distinctive healthcare landscape.

Another key aim of this thesis is to explore how to reframe chronicity within the context of cure. I aim to explore the nuance between the discursive binaries that frame people as chronically ill, chronically seeking wellness, or a “lazy drain on society”. Through an optimistic

lens, nuanced spaces for chronicity are occurring, thanks largely in part to long-standing activism (Davis, 2014). These include movements that centre around condition specific pride and the many campaigns championing neurodiversity in the workforce (with varying degrees of success), such as (without turning to clichés) the impossibly talented savant (Simonton, 2017). Much like efforts to build sculptures out of sand, these attempts “wash away” easily without constant efforts to create a permanent impression. However, here I want to specifically focus on critiquing the constructions of treatment and health management. My perspective is that cure is a construct that should not have the power to shape every aspect of a person’s existence.

New Zealand has a long history of patient advocacy. This advocacy builds resistance to the dehumanising way the dominant health institutions frame their patients. There are a number of active spaces in New Zealand that are shaping dialogues with MedSafe and Pharmac on drug funding rounds and sourcing generic drug alternatives for different lifelong conditions (Hep C Action Aotearoa, n.d.). For example, social media groups have shared an iterative way of sifting through the claims that are made online (Heath Pages, n.d.). Patient positionality within New Zealand is a vital part of the tapestry. One of the best examples is the advocacy work for access to experimental treatments (New Zealand Clinical Research, n.d.). Collective advocacy spaces worked to change government policy when it comes to allowing access to different treatment pathways, such as bringing the regional centres to a standard of excellence around providing generic medications. These efforts did not lie exclusively on the shoulders of a few individuals or interactions but were multi-pronged and extensive (Baumann et al., 2017). As

Deborah Lupton (1996) wrote, the dethroning of a singular narrative has many advantages and positive framings. Lay expertise and official sources do not need to be binary concepts.

In this thesis I explore the idea that constructions of chronicity should be far more complex and nuanced than the way healthism frames it. The notions of illness and cure were always multi-faceted and contradictory, and deeply political (Fitzgerald, 1994). Health and seeking a cure both remain constructs that are steeped in deeply rooted ideologies and theoretical backdrops, even if the paradigm's contextual background and influence remain largely unacknowledged (Yeo & Sawyer, 2005). The shadow that is cast is a long one. Reaching the prized "healthy" remains a construction that is subject to scrutiny from wider society, measured through social health morals, which are the ways society understands doing the act of health (Crawford, 1980). This shifts and frames the notions of responsibility, wellness, and how to locate control. A variation of the Hippocratic Oath could say, "First, recognise the tangled mess that produces the contested notion of illness and recovery before producing the change narrative". Therefore, this thesis looks at the shifting underlying frameworks of meanings of health and cure narratives at a societal level, specifically in the space of chronicity.

## Chapter 2: Methodology

My overall research question looks at how healthism potentially shapes health information online as well as expectations around health and chronicity. As I occupy a positionality of both a former “good patient” *and* a health researcher, I will expand beyond a personal sense of disempowerment. I use an academic toolkit to critically examine meanings around consumerist health and cures, informed by but not defined by my own experience. I draw on a range of critical health scholarship to inform my theoretical positioning, topic development, qualitative methodology, and critical analysis.

In this chapter, I will discuss my understanding of and rationale for my theoretical approach. Under the general umbrella of critical qualitative theory, I utilise the more specific theoretical approach of Critical Disability Theory (CDT), which brings together an intersectionality of social constructionism, social justice, and critical realism (Davis, 1995). This theoretical position is useful because it allows for the foregrounding of lived experience within the broad systemic structures of health care (Alderson, 2021). I will ground my theoretical approach by exploring the core elements of CDT, which include centralising lived experiences as subjectively “real” and therefore meaningful in the context of health research, as well as challenging constructions of illness, chronicity, and “compulsory able-bodiedness”. Overall, the theoretical approach I use is aimed at developing a deeper understanding of health information, specifically the construction of “brokenness” in individual bodies, and the related emphasis on achieving and maintaining wellness.

In this section of my thesis, I will also cover my development of a robust methodological design including two data sources – online data and participant generated data from vignettes



– which I analyse utilising a reflexive thematic analysis (TA). My first data source, online health information, captures how things are presented to (potential) health “consumers”. With my second data source, vignettes, I explore how people engage with and make sense of (other) people’s health and chronic illness (and cure) experiences. For this research, I decided RTA would be an effective approach, as it involves challenging dominant social structures and power dynamics (Braun & Clarke, 2019), in this case providing a framework for deconstructing and analysing online health information and participant generated data from vignettes of fictional health consumers. Overall, this chapter covers my theoretical position as one of CDT-informed critical qualitative research, the rationales and collection methods for my two studies, and my rationale and process for conducting a reflexive TA.

## **2.1 Theoretical Positioning (Using the Idea of the Body and “Brokenness”)**

A researcher’s decision-making in relation to their theoretical approach involves a mixture of personal values, ideologies, and practical realities (Braun & Clarke, 2022). My theoretical approach as a researcher comes out of my research into the ways different theories make sense of bodies, and different ways of constructing meaning from the way they do or do not function. As I aim to critically examine constructions of meaning in the context of online health information, a critical qualitative design was most appropriate for my research, as it encompasses an overarching concept of examining patterns of meaning and their implications (Braun & Clarke, 2013). Developing confidence in your theoretical approach can be the work of a researcher’s professional lifetime, certainly longer than the length of a master's thesis, even if the importance of this process is often under-acknowledged or omitted completely in mainstream academia (Alderson, 1998). There are many personal, practical, social, and societal

perspectives that help shape the approach that a student or researcher connects with to form a particular approach (Freyer, 2020).

A fundamental consideration when approaching research is that no engagement with knowledge is entirely atheoretical or neutral, even if years of conditioning make it feel like it is the case (Alderson, 2021). On a broad level, all research is situated around two overarching questions, what “reality” of the world exists to be known (ontology), and what knowledge can actually be accessed or studied (epistemology)(Braun & Clarke, 2022). The two main schools of thought are divided between whether there is a singular objective reality to find/study with the right set of tools by an objectively situated researcher (empirical positivism) (Freyer, 2020), or that multiple realities are constructed through language production, social experiences, and societal expectations (social constructionism)(Gergen, 1992).

Positivism centres around the assumption that there is a singular, objective reality and it is up to the neutral researcher to find a way to measure and report on it for the purposes of neutrality and legitimacy (Alvesson & Skoldberg, 2009). The majority of research within the field of psychology still heavily favours these realist assumptions. Even in the context of a wave of “post” realist ideals, the “positivist creep” can be both appealing and subtle (Braun & Clarke, 2022). Unless the work is explicitly and intentionally in the “critical” space, examining theoretical assumptions is frequently neglected or considered a “luxury” (Alderson, 1998). Researchers and schools who adhere to different theoretical assumptions or backgrounds often see serious flaws in the other (Shakespeare, 2004). For example, in a simplified way, medicalism denies the social factors of health, while social construction denies the fundamental and often

important role of individual bodies and the personal “reality” that comes with experiencing illness (Gergen, 1992).

### **2.1.1 *Positivist Medical Models vs Social Constructionist Models***

Quantitative health research based on positivist assumptions is largely reductionist and generally overlooks broader sociocultural and environmental contributions to the ways in which illness and disability are constructed or made sense of (Love, 2020). For example, medical models of health and disability locate the concept of “brokenness” in the individual, with the goal of “fixing” them via treatments and cures. This is problematic because it constructs the person as measurably “broken” without considering the broader context (Galvin, 2002).

Social constructionism situates the disablement of a person into wider societal constructions and frameworks, such as the lack of accessible build environment (Andrews et al., 2019). Within the context of chronic illness and disability, the division between the medical and social models of disability provides a loose framework for conceptualisation (Oliver, 2013). The foundations of these distinctions can be traced back to early social justice movements, which sought to address the question of where resources should primarily be focused: on alleviating medical issues within individuals or addressing the broader societal and structural disabling factors (Shakespeare, 2004). Particularly in the early stages, there was often limited space for both models to coexist simultaneously, as they represented different approaches and priorities in understanding and addressing disability injustice and discrimination (Oliver, 1984).

An illustrative example of the tension between different perspectives is evident in Brian Watermeyer's (2009) examination of disablement and loss. Watermeyer highlights the social resistance to framing disability and illness solely as experiences of loss and vulnerability.

However, he also acknowledges the internalised trauma and loss that individuals may experience, which is intricately linked to their individual bodies and not necessarily part of a wider social resistance or construct. This example underscores the complexities involved in understanding disability and illness.

Critical realism offers an understanding of “real world consequence” and inhabits a kind of “middle-ground” within the theoretical continuum between positivism and social constructionism (Braun, Clarke & Hayfield 2023). It acknowledges the inability to directly access reality, and the limitations involved in attempting to know an all-encompassing truth (Freyer, 2020). It allows for the speculation of personal realities, and “real world” experiences/consequences for individuals, while also providing a framework for deconstructing broader systems of knowledge production and normalisation (Thomas, 2004). Although it is not a “perfect unicorn” (rare blend of everything we need), the theory involves an acknowledgement of the discord between what is “real” and what can be known. It allows for an attempt at understanding an approximation of individual realities as well as broader sociocultural contexts, while also acknowledging the incompleteness/inaccessibility of knowledge and the need for ongoing research and discussion (Thomas, 2004). Priscilla Alderson (2021) advocates critical realism as a way to integrate critical thinking to biomedical spaces and create a richer set of orientations for healthcare. If not a unicorn, it is a useful tool to consider. I use critical realism as a starting point to situate different elements of disability theory, in the way it positions disability and the body.

### ***2.1.2 Critical Realism, CDT, and Social Justice in the Health Context***

The branch of CDT that is my focus is based in, but moves away, from critical realism, but it is

focused more specifically on social justice in the context of health and disability, in particular, the deconstruction of disability, chronicity, and compulsory able-bodiedness (Campbell, 2008). CDT provides a developed framework for these aims. A complicating factor in my decision on a theoretical approach is where I am in the “real world” – the place where I am planning to situate the research and knowledge while carrying it into clinical or community settings (Gergen, 1992). My work as a researcher and an advocate, and the provision of my master’s funding, are predicated on the ability to translate my work into a lever for change, and to do so in a relatively quick timeframe. However, seeking change at a government level can be distressingly quantitative and reductionist, in the sense that they predominantly ask us to give them both the problems and the answers, and all within the allotted budget. Many of the assumptions in government and the health context more broadly are fixed and not receptive to general criticism (which focusses on the need for change) or academic constructions (which focus on broader factors that influence a situation) (Wilkerson, 2020).

Feminist theories and scholarship have done much of the “heavy lifting” when it comes to challenging theoretical conventions and moving them quickly into the social justice fields (Ahmed, 2017). This is particularly so when it comes to challenging notions of bodies and how those are often predicated on (often patriarchal) ideals of what a woman’s body is and should continue to be (Butler, 2004). This foundation in resistance influenced the feminist movements within disability studies (Garland-Thomson, 2002). In more recent times feminist and disability scholars have charted and challenged the creeping rise of the political, cultural, and societal contexts (Sointu, 2005). An illustrative example of action with feminist roots is considering the healthist way weight is constructed (Gibson, 2022). Many of the ideals around weight have normalised assumptions that health measures are entirely objective. Such parallels are most apparent when considering ideal behaviours and maintaining a “healthy” lifestyle within prescribed parameters. Fatness is considered a form of chronicity that is constructed as draining to society in a similar way that disability and chronicity are. Gemma Gibson (2021) critiques the concept of the “good fat person”, who is persistently striving to lose weight or maintain health, thereby reducing their supposed burden on the healthcare system and society.

For both groups (those with chronic illness or disability and those deemed overweight), there is a societal pressure to align with idealised standards, which often fosters and perpetuates prevailing narratives of overcoming conditions or impairments. This is epitomised in widely endorsed slogans such as “overcoming diabetes” and “being in charge of your body” (Morrison, 2020). My project delves into how these narratives of “overcoming conditions” are presented in both conventional and experimental contexts.

In a similar way to the experience of body positivity and the wellness culture, every element of living with a chronic condition can be measured and evaluated, therefore subject to change. Living openly with a disability, impairment or illness is considered a largely transgressive act (Beauchamp-Pryor, 2011). Feminist scholarship has not always had the strongest connection to disability embodiment and constructions, due in part to different approaches to language and terminology around illness and health (Samuels, 2002). However, the challenging of categories that underpins feminism is foundational to centring difference, which is influential in this thesis.

Disabled Studies (distinguished here with a capital 'D'), is a field that emerges from the struggle for disability rights and has navigated its own identity crisis (Watermeyer, 2012). In its early stages, Disabled Studies was viewed as too fragile to challenge the established constructs that characterise disability through a critical orientation with reflexivity and theory and analysis. (Lazard & McAvory, 2020). CDT and Disabled Studies (Davis, 1995) represent two distinct but related avenues of scholarly exploration. They both arise from a desire to unpack and critique social perceptions of disability and health; however, they differ in their historical contexts and the scope of their analytical lens (Watermeyer, 2012b). CDT, a relatively new field,

primarily focuses on identifying and challenging social constructions of disability, including the framing of controversial concepts like “recovering from a disability” and “finding a cure” (Samuels, 2020; Watermeyer, 2012a). Drawing upon the broader landscape of critical scholarship, feminist theory, and critical health theory, CDT has evolved as a hard-won scholarly discipline (Campbell, 2008; Thomas, 2004). It has instigated thought-provoking debates and discourses in a society often resistant to them, thereby championing an integral shift in our understanding of disability (Watermeyer, 2012a).

I will draw from feminism and patient advocacy which centres action research and seeking change to inform my RTA. RTA integrates reflexivity into all processes and every aspect of the Thematic Analysis (Braun & Clarke, 2023). The focus of this analysis will be on how online health information and its potential consumers interpret patients and possible cures. As someone who was once a “good patient”, I will scrutinise meanings surrounding consumerist health and cures, employing the rigorous academic tools of critique as opposed to a generalised sense of disempowerment. By utilising a critical lens, this research aims to unravel the complexities and ambiguities inherent in the discourse surrounding health, chronicity, cure narratives and experimental treatments.

One of my supervisors' favourite sayings is “hold things lightly” and allow for change and flexibility. In this way my theoretical approach is grounded firmly in the many threads that weave the critical design and approach. Health may occupy a considerable amount of the public consciousness, but that does not mean that that health is a prize that people can acquire with effort (Fitzgerald, 1994). I am particularly interested in how these issues are navigated online,

because this is where a growing number of individuals in New Zealand seek their health information (Cheek, 2008).

## **2.2 Study One: Online Materials**

My first study centred around an analysis of website content. Studying website content and the online patterns of engagement, information sharing, and presentation is becoming more prominent in both quantitative and qualitative research (Wilkinson et al., 2017). Websites are particularly important in the area of health, chronicity and cures because online is where much of the “direct to consumer” narratives, marketing and community building occurs (Murdoch et al., 2018). Online spaces create a unique environment for people to enact patienthood, with high levels of interaction and engagement (Sosnowy, 2018). This section will provide an overview of my approach to selecting websites from different health connected sources, reviewing these and analysing the data.

All public facing health organisations need some presence online due to the wider demands of digitalisation in nearly all aspects of Western society (Zhao, 2019). The online environment creates opportunities due to its high volume of accessible and democratised information, and simultaneously terror, due to the enablement of misinformation (Lupton, 2021). The online space is still a relatively new platform for health information that is connected to hospitals, government and conventional medical approaches, with evolving sets of regulations (van der Eijk, 2013). Experimental treatments are more naturally situated within the processes and particularities of online platforms, this is due to their reliance on direct-to-consumer marketing and less connection to wider health infrastructure and regulation (Sipp, 2013). Online data is rich with reflections and constructions that reflect social understandings



(Sosnowy, 2014). Many health care providers or marketers are investing large portions of their budgets to expanding their digital footprint and employing people specifically to curate online content (McLean et al., 2015). Discussion of management, treatment and cures in online spaces contextualises and theoretically democratises health information away from singular authoritative structures. The online space may present difficulties and challenges as a delivery mechanism but will remain a permanent part of health exploration (Lupton, 2021).

### **2.2.1 Data Collection**

I designed a robust protocol for online data collection. I selected search terms based on both my research interests, and knowledge and concepts that were popular in public health discourses, such as stem cells, and neuro-regeneration (See Table 1). I set a timeframe for the search results between March to June 2021 and used a set list of the most popular and frequently searched websites. I selected my data sources from pages 1 to 3 on Google because generally, those searches retain the most relevance to the general search (Google, n.d.). The websites I included were those that fit within the public domain and were not behind a paywall or requiring a social media group membership, and as such did not require ethical review (Roberts, 2015). The importance of archiving all website information as collected became increasingly clear as clinics would often shut down or change their websites, necessitating their preservation in their current form. The process I adopted is detailed in the following paragraphs, with examples of the websites, including screenshots, detailed in Appendix A. The algorithms are sensitive and easily manipulated to create a particular kind of result (Balaji et al., 2021), therefore, it was not as simple as defining search terms and plugging them into Google. I work as a health advocate, adviser, and lecturer so my browser history has previous searches

around this topic, including but not limited to New Zealand public health sites such as Health Navigator New Zealand, which can alter the search outcome. Therefore, it was important to make sure the searches were as clean as possible, for example, ensuring search prompts and autofill did not impact the search. This was done through using private and incognito searches as well as utilising other people's laptops in the university offices. The sample data were selected based on popularity and frequency of occurrence when mapping across different search terms. An example of this incorporated methodology is in Table 1.

**Table 1***Overview of Search Terms and Parameters*

Search Engine	Term	Results/Parameters
Google	Cure + Chronic Illness	Pages 1-3
Google	“Cure chronic illness New Zealand”	First page searches
	Overcoming multiple sclerosis	
Bing	Overcoming motor neurone disease	Pages 1-3
	Overcoming muscular dystrophy	
Google	Reversing neurological conditions	Pages 1-3
Google	“Experimental treatments New Zealand”	Pages 1-3

Within this data collection process, there were many challenges I faced to my wider belief system which I had to interrogate when decision-making. Once I had my list of search results, I felt the need to categorise these results to make them manageable and provide some meaning to the variation inherent within the data items. However, there was no neat way to do this. Some websites have little to no oversight and some private clinics have extensive website management processes. Similarly, I needed to largely abandon the use of the term “regulation” entirely because it served no practical purpose and was not reflected in the wider discourses. It was proving too tempting to present a false dichotomy of “good” versus “evil”. (Bauml et al., 2015).

The websites were selected using a variety of Google and analytic tools and marketing software. As my area of interest was in publicly available and highly findable websites, it

became necessary to develop a systematic approach to creating an online search “snapshot”. First, I conducted the searches on a new computer that did not have all my browsing history. Secondly, I temporarily erased the browsing history and cookies/caches from my university computer. Lastly, I constructed my search terms not based on my knowledge of current health trends and curative efforts, but the concepts and information that were popular searches on analytic platforms such as Google Analytics.

One deliberate exclusion from the dataset was medical crowdfunding, such as those from the New Zealand site Givealittle. Givealittle is consistent with international crowdfunding sites in seeing an increase of medical fundraising requests (Neuwelt-Kearns et al., 2021). Including these sources would have provided a rich source of information and fit well with my research topic, especially when it comes to seeing how members of the community shape and juxtapose conventional and experimental treatments with the expressed intention of seeking cures or a “normal life”. However, there were too many factors around the inclusion of these sources to consider for this project. Reviews of medical crowdfunding have been done before (Neuwelt-Kearns et al., 2021), but, in the context of New Zealand and in particular the small chronic illness and disability communities, the risk of identities being uncovered was too great, even if extensive anonymising procedures were implemented. The challenges would be across both the ethics process for identifying information, and a moral obligation around people’s privacy and dignity (Kenworthy, 2019).

Once I identified a potential data source, I began with a thorough review of the website's homepage. This involved a search for key terms or concepts that would form the backbone of the analysis. It was crucial to have a deep understanding of the primary ideas the

website presented, as this would serve as the framework for the subsequent steps. Following the initial review, the next step involved capturing a screenshot of the first or second page of the website. The choice of page depended on the content; if the first page only provided an introduction, the second page was used instead. The aim here was to have a tangible reference to the initial appearance of the website, offering a visual anchor for the ongoing work. The text was the main focus of data collection, however, images and other website features were also collected to demonstrate how potential patients might receive the information. The key descriptive elements were itemised in a table. These elements included details such as the date of upload and the geographical location of the clinic. The inclusion of these elements in the table provided a quick reference point and contributed to the creation of a comprehensive dataset. Finally, the images from the website were catalogued separately. This was done with the intention to potentially enhance the descriptions and to have a visual database to refer to during analysis. Cataloguing the images individually ensured that they could be accurately associated with their corresponding descriptions, thus enriching the overall analysis. The websites were captured both in Microsoft Word and in the NVivo storage facility. For examples, see Appendix A.

I initially differentiated the data into the following types of information:

- Public Health Information (PHI): The PHI included a selection of government related or regulated information sources that specifically referenced long-term conditions and neurological disorders. In particular, the Ministry of Health website and MedSafe.

- Local Patient Resources (LPR): These comprised the Ministry of Health information in practice, including the information that was specifically designed for patients to take home and action in the community. Examples of this included Health Navigator and Kids Health.
- Media Constructions (MC): These involved a selection of media articles that related to the search terms, “experimental treatments”, “regenerative medicine”, and several specific neurological disorders. They were sourced from three of the main news websites that permit articles outside the pay wall. These were the New Zealand Herald, Stuff, and Newsroom, and were the most popular and well-read articles within the search parameters.
- Private Clinic Information (PCI): The PCI were sourced from Google searches using the most popular search terms for “curing” and experimental treatments for neurological disorders. These websites and associated advertisements were collected between June and August 2021. They were searched both through Google ads and the conventional Google search engine. The most important aspect of the search was that the data items were readily available to the public, meaning they were not behind a paywall nor was there any requirement to sign up for more information.

These original loose categories were useful for gathering the depth and breadth of data for constructing chronic illness and potential cures. However, the categories quickly become reductive and constrictive, both in terms of the practicality of connecting with and thinking about the data, and in terms of allowing shifts in the research question and focus as data

engagement progressed. As I worked with the data it became increasingly apparent that treating it as a single dataset allowed for both descriptive and latent analyses that were not constrained by preconceived structures, with the potential to reveal continuities that might have been obscured with a pre-separated dataset. Individual data extracts were no longer linked to certain others based on where they originate from, such as whether they were regulated or unregulated. From that point, all familiarisation, coding, and then analytic development was done on the complete dataset. A seemingly simple decision had a profound effect on my framing and connection to the study and data extracts. Once I had collected all the online data, I named each data item with a D, then a number, for example, D1.

### **2.2.2 Analysis**

In analysing the online material my objective was to understand how sense was made around the topic of chronic illness. The two analysis techniques that I used (which I outline below) share a common focus: examining the language used and understanding how it positions the individual, their specific condition(s), and their potential pathway for treatment or management.

The first technique involved a detailed analysis and mapping of the language. This included studying the choice of words, tone, and structure of the sentences, all of which can provide valuable insights into how both the condition and the available treatment options are constructed (Martini & Bragazzi, 2021). For instance, specific terms or phrases may indicate a preference for certain treatments or a particular perspective on living with a chronic illness. One that is interesting to consider was the prominence of cure and treatment pathways within the websites. The second technique focused on the positioning of a potential individual patient

within the narrative. This understanding could shed light on ways these treatment or management strategy resources could be picked up and read by a potential online user.

These techniques helped me to understand the potential pathways for treatment or management. This was achieved by analysing how the language used in the material framed the different options. For example, the choice of words could reveal a tendency towards conventional medicine, experimental treatment, holistic approaches, or a combination of these. By comparing and contrasting these narratives, I was able to draw a more nuanced picture of how individuals may make sense of living with chronic illnesses and navigate their treatment options.

### **2.3 Study Two: Vignettes**

My second data set was designed to provide a way to get at how people make sense of chronicity and cure, using the insights from data source one. It involved using four vignettes about fictionalised characters, Mara, Jay, Tāne, and Alice. The vignette approach has been defined by Tremblay and colleagues (2022) as hypothetical scenarios that provide a way to explore implicit meaning without attaching to individual people or scenarios. Vignette studies are well known for their ability to provide insights into complex and contradictory ideas (Finch, 1987). I felt this made vignettes ideal for looking at the controversies and complexities of chronic illness and the path towards treatment. This section will provide an overview of the ethics, vignette design and recruitment processes. I also describe efforts to make this study accessible for members of the disabled/chronic community.

#### **2.3.1 Data Collection**



### 2.3.1.1 Developing Vignettes

The design and rationale for each of the vignettes was based on a combination of insights from the literature and from the analysis in study one. In particular, the themes were around the different ways people experience seeking treatment systems at different life stages and common demographics and difficulties that people encounter while making these decisions (Joseph-Williams et al., 2014). The vignettes went through considerable revisions and changes to the demographic information to best reflect the concepts I wanted to explore. There are many diverse opinions on concepts of treatment options, empowerment and healthcare systems (van Wilgen et al., 2018). Within the online analysis there were different points where people could enter or engage with the health care system which underpinned the fictionalised scenarios, and underscored the difficult questions of who controls health decision making (Layton, 2009).

Following each vignette were a set of questions that asked participants to reflect on the fictionalised characters' motivations for making their health decisions and the impact these decisions may have on their lives. I kept most of the questions generic, but for several of the scenarios I wanted to have questions which signalled how changes could potentially be "positive" as another possible construct of chronicity. People were also given the opportunity to offer additional comments on the scenario in general. Each of the vignettes were designed to reflect an aspect of chronicity and the situational pressures to "manage" living with chronic illness. Specific demographic descriptions were added to reflect and acknowledge the multiple people and communities that navigate the health system, either with conventional or experimental goals. I wanted to use the potential of the different possible scenarios to promote

reflection on and possibly reframing of the underlying concepts like perceptions of chronicity. Two vignettes used a name gendered female, and two a name gendered male; two names were more or less culturally marked (Alice and Tāne), while two were more or less culturally ambiguous (Jay and Mara).

Mara is at the beginning of her process for getting experimental treatment, a retiree because she is experiencing the beginnings of a condition that affects her mobility and lifestyle. The vignette included having fundraised on GiveALittle for the cost to get a procedure that was not available in New Zealand. See Appendix E1 for full vignette and questions. Jay is a young man living with a physical disability as well as a “mild” intellectual impairment. Terms like mild, moderate and severe are problematic due to inconsistent measurement, however, this categorisation provides a useful discussion point when constructing an understanding of living with a chronic illness and navigating the health system as a young person. See Appendix E2 for full vignette and questions. Tāne was positioned as somebody living with a condition that is likely to get worse. He and his family are working to understand his new life as somebody who is no longer a CEO and adjusting to other changes. There are specific details about what the family wishes to achieve within this new experience and navigating the health system. See Appendix E3 for full vignette and questions. Alice has just had a funded experimental treatment, and her “conspicuous symptoms” (needing to rely on a cane for general mobility and walking) are returning after initial improvements. This vignette includes details about the changes both physically and psychologically and the potential responsibility towards the people that provide financial backers. See Appendix E4 for full vignette and questions.

### **2.3.1.2 Ethics**

Vignettes provide an anonymous and potentially low-risk method of research (Finch, 1987). However, they are not completely without risk, because the hypothetical scenarios are still within a potentially sensitive topic area and ask questions that illicit (potentially) both personal and professional insights from the people that are responding (Azman & Mahadhir, 1997). This online format provided no clarification or mediation of any effects the narratives might be having on the participants. Therefore, in constructing the vignettes, I needed to consider minimising the risk of harm in the form of providing support materials and a process for seeking help. Ethical approval was sought and granted by the University of Auckland Human Participants Ethics Committee (UAHPEC24289, 27/5/202), after going through the standard ethics process for the University of Auckland at a postgraduate level. All vignette materials that were required for ethics are in Appendix B.

### **2.3.1.3 Recruitment**

I aimed to over-include participants who were connected to or had some experience or investment in the disability and chronicity space. In order to target people who had a connection with disability or chronicity, one recruitment method involved developing connection opportunities (my recruitment material advertisement is available in Appendix K). I also felt a responsibility to recruit outside my immediate networks because there was a risk of the information being too identifiable. Therefore, I relied on networks that I was not as familiar with to make those connections, such as my local neuro-rehabilitation facility. I have outlined my recruitment process below.

The first step in my process was to compile a list of potential community or clinical settings that would be relevant to my study. Once this list was compiled, I reached out to these locations to inquire about the possibility of advertising in their clinics or community spaces, typically where other advertisements were already displayed. In addition to these physical locations, I extended my outreach online. I placed an advertisement on my personal social media platforms and workspaces to cast a wider net. Recognising the value of extended networks, I solicited the help of my friends and colleagues, asking them to distribute the advertisement within their respective networks, particularly in areas where I had limited contact or influence. Finally, I ventured into general community spaces that permitted research advertisements, such as libraries. These comprehensive measures ensured that the advertisement reached a wide and diverse audience, but also was skewed towards people who had some experience with the disability or chronicity space.

My recruitment strategy targeted different layers of chronic illness experience. For example: people living with chronic conditions; family members/whānau; allied health professionals, e.g., physiotherapists, occupational therapists, doctors, nurses, and social workers; health policy advocates; community groups; and training institutions and schools. The purpose of my recruitment strategy was to target a broad range of individuals and groups who are connected to chronic illness in some way. I consciously did not define what I meant by chronic illness or experimental treatment so that people could bring their experiences to the hypothetical scenarios. New Zealand has a relatively small population to draw from when considering specific population demographics, however, long-term health conditions intersect with many sectors of New Zealand society.

#### **2.3.1.4 Participants**

In total, 188 people completed the data collection, although only 80 of these provided demographic information (which was requested at beginning before the completion of the vignette questions). Of the 80, 92% identified as female, 5% identified as male, and the rest were divided amongst other self-identifiers such as intersex or non-binary. Ages ranged from 20 to 81 with the mean age being 32. Nearly half (46%) self-identified as having a disability; just over half (58%) said that they or a family member lived with a chronic illness. Participants were asked if they had considered or sought experimental treatments for themselves or others (which were not defined), 20% reported they had. These experiences ranged from seeking insights from a New Zealand based naturopath to travelling overseas for an extensive treatment.

Vignettes were delivered online via *Qualtrics* which is a popular survey delivery tool. After reviewing the information sheet and demographic data questions at the beginning, participants were asked to review the vignettes and answer the questions on all the scenarios. They viewed each vignette before scrolling to the subsequent questions, and there was capacity to save the questions and come back later to give them opportunity for reflection. As the data was all in written form, it did not need transcription. The data was named using the following protocol: the first letter of the name of the character of the vignette, the question number, then the last number refers to the particular participant, for example, M (Mara)-Q3-30.

#### **2.3.1.5 Reconciling Accessibility**

I felt that it was necessary for this study to be as accessible as possible due to the community I was engaging with, including disability. The data collection method was limited by

both ethics and the restraints of the software, for example, the recording capability within the survey software. Typically, this is a good disability option for those with restricted writing (**See Appendix B1** for accessibility options). I needed to ensure that the study was compatible with basic computer accessibility features such as screen readers and dictation. While there was no capacity to do a pilot study, the questions were tested by individuals with a range of conditions and neuro-diverse experiences, to gather their opinions on the length, tone and specific features of the vignettes. There were several revisions done to capture the different elements that these individuals noticed, and potential societal pressures. The small group also provided a list of story elements to avoid, for ease of reading, for example, not listing too many characteristics at once.

### **2.3.2 Analysis**

The vignette methodology proved to be an effective approach for exploring the underlying assumptions that inform people's beliefs about patienthood, identity, treatments, and rights. The wide range of data I collected served as a proof of concept, demonstrating the utility of vignettes as an effective tool for eliciting deeply held views. The method allowed me to construct hypothetical patients for participants to form opinions about, and the participants did not hold back in their responses.

At the outset, I was drawn to, and became quite attached to the idea of treating the two datasets (media and participant generated) as separate studies. This preference was driven partly by practical considerations, including timing constraints. However, another factor was the need for time to digest and respond to the more extreme elements encountered within the vignette study. As a compromise, I embarked on separate familiarisation processes across each

individual dataset before finally integrating the two datasets. This approach meant that I was more able to fully comprehend and interpret the nuances within each set of data. In the end, this method proved invaluable, allowing for a more comprehensive and holistic understanding of the data as a whole.

The next part focused on examining how participants comprehended and reacted to specific treatment options or pathways presented in the vignettes. This involved analysing their responses and attitudes towards various treatment options. By employing this dual approach, I was able to delve deeper into how participants perceive and understand the complexities of living with chronic illness, and how they view and respond to different treatment options. This provided me with valuable insights into the subjective experiences and decision-making processes related to chronic disease management.

#### **2.4 Analysis of Conjoined Dataset**

The data was reviewed using reflexive TA as defined and articulated by Virginia Braun and Victoria Clarke (2022) in their practical guides to doing thematic analysis. In particular I placed emphasis on familiarisation and analysis with conscious and explicit decision making at each phase. Below I outline the core elements to my analysis, and want to note that these do not entirely map onto the phases Braun and Clarke (2006) outline, as there is no recipe or instruction manual for analysis, it is an iterative process that moves back and forth between the phases.

The first element of the analysis involved making decisions about how I was going to review and physically manage the data in a way that accommodated both my neurodiversity and physical access. I opted for a hybrid approach, firstly printing out physical copies of the data

connected to each of the four vignettes, and secondly, I set up Miro (2022) – a virtual whiteboard mind mapping tool – boards to capture the first initial ideas and how they connected, along with several word tables which were a useful way to capture first data impressions (examples of these are in Appendix D and E). In the second stage I worked on becoming familiar with the data, focusing on each vignette as a single data set. In this first reading I simply wanted to get the first impression of the data and notice what caught my attention without seeking any particular idea. These areas of interest included points of emphasis, strong language and different lengths and styles. This was where I allowed myself brief permission to “argue” with the data (where I did not agree with it or found it objectionable), which is an acknowledged part of the process but not something for the final document (Fryer, 2020).

In the third stage I highlighted and signposted elements that may form the start of codes or groupings for the data. I started using all four vignettes as a singular dataset at this point because it made better sense when connecting back to the original questions around making sense of treatments. The fourth stage involved finalising my coding notes and tables around key concepts, and identifying codes that could potentially merge. This was especially relevant when it came to the many different framings of control and choice that were drawn explicitly from the questions for Mara and Alice because they were the ones who were pursuing an experimental and arguably “unsanctioned” path.

The fifth stage involved creating broad theme ideas and plans using online tools such as Miro and Microsoft Word (See Appendices D and E). These themes drew on the codes and contextualised them within broader systems of meaning. For example, finding a way to



encapsulate the concept of hope, which required several iterations, because there were many contradictory elements that made finding a narrative around this challenging. Mapping was useful in reworking the links and relationship points. The final stage involved deciding on the final themes that would form the basis of my analytic chapters. Several themes lacked specificity and presented a “bucket” style of category (rather than a code), which was too wide to retain specific connections to the data (Braun & Clarke, 2022). Others were overly specific and could more clearly be told as part of the wider narrative, for example, the weaving of a story rather than subthemes.

### Chapter 3: Chronicity in a “Hostile Ecosite”

My first analytic chapter centres around how experiencing chronic illness and chronicity are constructed across the datasets. Living with a chronic condition is often defined by what one can or cannot achieve. The narratives of “burden” frequently occur in the data; this is represented by the pressure that the individual feels, and in response actively works towards not imposing on people in their surroundings (family/community/society). The concepts of burden and chronicity are naturalised to encompass all aspects of life - personal, familial, and societal, with limited resistance from the mainstream (Davis, 2010). These are often problematically framed in terms of regaining “quality of life” and the concept of self-actualisation (Thomas, 2004). Chronicity is a contested concept and as such is subject to disease hierarchies, where value and legitimacy are placed on different conditions depending on wider perspectives (Mishel, 1999). Chronicity is very often connected to the idea of deficit, however alternate discourses that frame it in more empowering ways are building in legitimacy (Swoboda, 2005).

In this chapter, I will begin by explaining the terms “hostile ecosite”, “chronic” and “illness” I will then introduce the framework of this chapter and the overall story that scaffolds a chronicity narrative. This narrative covers three themes that illustrate different perceived aspects of living with a condition long term. The three themes capture and revolve around various aspects of living with a chronic condition, these are: 1. Chronicity as the Enemy of Life; 2. Body Struggling: Form, Function and Control; 3. Chronically Ill = Chronically Underserved by the New Zealand Healthcare System. Each theme is constructed around individuals'

understandings of living with a long-term condition and the responsibilities marketed and internalised through wider literature and societal expectations.

The term hostile ecosite that gives name to this chapter is both an extension (as a new idea) and shrinking (as narrow focus) of an ecosystem as a metaphor. Chronicity and its perceived impairment are viewed with hostility within various societal contexts (Ayo, 2012). There are few, if any, discourses of acceptance in the wider neoliberal atmosphere of public health messaging, and health in public domains/demands. New Zealand researcher Carrie-Anne Morrison and colleagues (2020) have written on the sense of not belonging and “emotional geographies”. They identify that the sense of connection to spaces, places and community is shaped and influenced by the ability to access and engage in related physical locations (e.g., access to community event/central areas). The contention, through this research, is that living with chronicity can be perceived as hostile. The geography and mapping of both “physical” and “emotional” elements of society struggles to and ultimately does not allow chronicity (Morrison, 2020). The core concept of this chapter, encapsulated in the metaphor “Navigating the Hostile Ecosite” suggests that an individual's environment persistently reframes and reinforces the pursuit of wellness (the myth that wellness can/should be achieved/achievable; Morrison, 2020). Whether an individual stands still within their chronicity or tries to move within the system then they are still subject to a hostile ecosystem, forces that construct a specific meaning of chronicity as unacceptable.

The terms “chronic” and “illness” hold varied meanings and interpretations (Mishel, 1999). In this analytical framework, I explore the pressures and forces that shape our understanding of chronic illness as a condition requiring meticulous, long-term management

and treatment. The idea of “curing” is inherently associated with living beyond the conventional confines of illness and achieving recovery (Wasserman & Asch, 2013). I consider the diverse elements of realising the potential for health, given sufficient effort and engagement towards life-sustaining outcomes from the individual and families. These experiences of health care are largely dictated by broader forces of individualism and healthism, defining the ideal patient as someone who does not excessively depend on or burden the healthcare system (Vallelly, 2021). In the context of my data, in this chapter, people living with chronicity with the datasets were “in the middle” of their conditions, meaning they were at different points in the process of diagnosis but grounded in a sense of deterioration which means they were constructed as acutely affected by a sense of limitation and dissatisfaction with their circumstances. The testimonials, media articles, website articles and fictionalised vignettes constructed individuals as centred within their condition and contesting a daily struggle (Gonsalves et al., 2016).

In this work I was seeking how people made sense of and understood long-term conditions *rather* than why and how people introduced social justice movements. It was challenging to explore chronic illness and disability without encountering numerous offers to treat, manage, or alleviate the symptoms of these conditions (Beauchamp-Pryor, 2011). This prevalence can be attributed, in large part, to the popularisation of self-improvement and the contested notion that transformative wellness is not only achievable but actively pursued by many as a moral imperative (Crawford, 2006). This pervasive discourse of self-improvement, personalised medicine and wellness has shaped the broader landscape and narratives around chronic illness and disability.

The first theme, "Chronicity as the Enemy" investigates how chronicity is perceived as a foe to both individuals and institutions that must be "overcome". This perspective shapes future considerations of treatments and/or cures. The idea that chronicity is an adversary to one's life and future happiness fuels and sustains the quest for active and constant management of chronic conditions. The second theme, "The Body Struggling: Control, Form and Function," illustrates the body and the struggle for function as a core element in shaping chronicity and cure narratives. This theme carries a dual significance, concerning both the broader perception of the "body" in general and the interpretation of chronically ill individuals. Living with an untreated, "broken" body is considered a largely transgressive act necessitating active resistance (Campbell, 2008). There is a struggle within individuals and aspects of society for everything from betterment, to cure or resistance.

The third theme, "Chronically Ill = Chronically Underserved by the New Zealand Healthcare System", illustrates the perceived inadequacies and tensions within New Zealand's healthcare system. This theme posits that if you are suffering from chronic illness, the current health system is ill-equipped to serve you. As an extension of the hostile ecosite metaphor, in this theme, "New Zealand" (country and health system) is representative of conventional systems and has multiple perceived "failures" to address. These perceived inadequacies of the conventional system fuel the desire for change, in the form of individual choices to seek treatment elsewhere, and ways to provide more options within New Zealand.

### **3.1 Theme 1: Chronicity as an Enemy**

Within this dataset, the experience of chronicity and living with a chronic illness was portrayed as a transformative process that profoundly impacts an individual's life and their

sense of connection and community. Chronicity was depicted as having life-altering consequences, not only for the self but also for others. The concept of life was often framed or understood in terms of a "before and after" paradigm or as a loss of what could never be reclaimed. This theme aims to explore the overarching concept of chronicity as an enemy to be confronted and overcome. It will provide a general description of the chronicity experience and offer specific examples highlighting the role it plays in individuals' lives.

The insights demonstrated in the extract below shed light on how chronicity was portrayed and framed throughout the dataset. The person's depiction of the scenario highlights the notion that living with a chronic condition hinders every aspect of daily life and participation in life. This observation illustrates the strong association between chronicity and a life that is constrained and restricted at a fundamental human level.

Day by day, year by year, many people with MS lose a small part of themselves in that daily struggle against constant but invisible neurological fatigue and pain. Many of us see our hopes and ambitions die, and all too often lose our jobs, marriages and closest relationships. Living with a partner who's always exhausted - and whose ability to see, speak or walk can vary from day to day - is rarely easy. Many relationships break up thanks to MS, including my own. For me, that small chance of death following chemotherapy was infinitely preferable to the certainty of further silent decline (D74).

The website extract above further delves into the profound sense of loss, trauma, and impact experienced by individuals living with chronic conditions, particularly in relation to their decision to pursue experimental treatments. The narrative constructs a haunting reality where every aspect of the person's life is being eroded and seemingly "dying" in the relentless face of

the condition. In this construction, chronicity creates the opposite of a worthwhile life and therefore is an enemy. This erosion extends to their relationships, career ambitions, and even their sense of self. Physical death is constructed as infinitely preferable to enduring what is perceived as a "silent decline" in which the individual's essence and identity seem to wither away.

I think that she hoped to gain a way out of the condition that is holding her back from doing the things that she wants and needs to do throughout her daily life. She wants to be able to participate in life and her chronic illness is holding her back from doing so (M-Q2-2).

This emotional account constructs chronicity as taking an immense toll on a person's life and frames desperate measures some may be compelled to take in search of relief and hope for a better future. In this construction the experience of chronic illness shapes life and takes elements away. The profound impact of chronic illness is keenly and acutely constructed in every aspect of the individual's existence, leaving them grappling with the weight of a life that feels diminished and overwhelmed by the condition's relentlessness. The extract captures the intensity of emotions experienced by individuals in the face of such adversity, underscoring the urgent need for understanding, compassion, and improved support for those living with chronic conditions (Campbell, 2014). The foundation of sense making around living with a chronic illness, stems from the implicate and expected sense that living in this new or old reality creates a sense of burden for the individual (in relation to themselves and others). Consider the following extract, where the sense of burden is explicitly tied to his family, and this is framed as having direct impact to his value as person.

He will begin to feel the burden increasing on his family and consider his worth in life (T-Q1-19).

It would affect him hugely. He's the one living through degenerative condition that is slowly taking everything he once loved away. I imagine he feels like a shadow of his former self (T-Q1-04).

The concept of a "shadow self" and the longing for an explicit "former life", as expressed in the extracts above, echoes throughout various narratives in different forms. At the heart of this notion is the belief that a life lived with chronicity, impairment, or disability is one marked by disruption and distraction. This principle is vividly illustrated in the vignette of Tāne, where his experience of losing his role as a CEO becomes a poignant example of the profound impact of chronicity on a person's life trajectory. This is further explored in the following excerpts which reference the reliance on others and physicality.

He is not of the same value if he can't do his sport or be physically active with family and friends (T-Q1-10).

He will have to get used to relying on family and friends to help him, which will be difficult because he is used to being very independent and being the one who supports other people (T-Q1-18).

The "shadow self" represents the person who Tāne once used to be or aspired to become. The "former life" signifies the life that has been dramatically altered by the challenges of chronicity. The desire to either regain or attain that former life resurfaces in various



accounts, reflecting the yearning for a sense of normalcy, fulfilment, and achievement unencumbered by the constraints of chronic conditions.

Being a male and wanting to be the breadwinner in the relationship and look after my family, I was very depressed about life and now (after treatment) the outlook is totally different and totally positive (D40).

Tāne's story exemplifies how the loss of a significant role, such as that of a CEO is constructed as having a profound impact on a person's identity, self-worth, and overall well-being. The disruption caused by chronicity can upend one's established trajectory, leading to a reassessment of life goals, aspirations, and the search for new sources of meaning and purpose. Furthermore, on a broader scale, in extract D40 above and below in T-Q1-16, there is disruption in the overall sensemaking of what it means to be a "typical New Zealand male". This is exemplified in the designated role of being the "breadwinner"

He will grieve his previous abilities. He will worry about the drain his dependency and need for help will be on his loved ones. He will struggle to accept his dependency. He will worry about finances, his inability to earn, the cost of his needs (T-Q1-16).

This theme of striving to reconcile one's present self with a perceived former self intertwines with the broader narrative of living with chronicity. It underlies the deeply felt construction of the impact that chronic conditions can have on various aspects of an individual's life, prompting the search for ways to reclaim a sense of agency, autonomy, and fulfilment amidst the challenges posed by chronicity, impairment, or disability. An often overlooked and seldom challenged aspect of chronicity is the perception that it places a burden

on the neoliberal state which influences wider public health messaging, emphasising individual responsibility for health (Fitzgerald, 1993). The extract below paints a picture of chronicity actively impacting the state, creating challenges, and resulting in increased utilisation of the healthcare system. While it may be tempting to attribute this burden solely to the conditions themselves, an argument can be made that the successive loss of preventative elements could also play a contributing role (Rysst, 2010). These viewpoints are prevalent and easily accessible on public-facing websites, which is where the below extract is derived from.

Multimorbidity is associated with reduced quality of life, higher mortality, polypharmacy, high treatment burden, higher rates of adverse drug events, and greater health services use. Multimorbidity affects 1 in 4 NZ adults" (D61).

This framing of chronicity as a burden to the state reflects broader constructions of individual responsibility and self-reliance in health matters. This perspective often overlooks the structural and systemic factors that contribute to the prevalence and impact of chronic conditions in society (Chin et al., 2018). This infers that while individuals may bear the burden of managing their health conditions, there is a need to critically examine the broader societal factors that influence the development and management of chronicity (Adams et al., 2020)

In my data, Long-term conditions were described as “the healthcare challenge of the 21st century” (D14) by the World Health Organisation. This is due to the increasing burden of disease and mortality attributable to long-term conditions not only in developed countries but increasingly in developing countries. Also in the data, a 2018 report commissioned by the Australian and New Zealand College of Anaesthetists estimated the total annual cost to New Zealand of chronic pain was between \$13 billion and \$14.9 billion (D3).

Addressing chronicity and its associated burdens requires a more comprehensive and holistic approach that acknowledges the complex interplay between individual health choices, social determinants of health, and healthcare system support, however this is frequently missing in discussions of chronicity (Barnett & Bagshaw, 2020). A broader understanding that considers the multifaceted factors influencing the health and well-being of individuals and communities can be achieved by challenging and deconstructing the prevailing narrative that chronicity is a burden solely on the individual. By doing so, we can pave the way for more inclusive and effective approaches for managing chronic conditions and promoting overall health and without imposing singular notions of wellbeing (Sointu, 2005).

I highlight below a metaphor that several participants used to describe the fictionalised scenarios, shedding light on how chronicity is framed in their perspectives. One extreme example compared chronicity to an overwhelming burden that may lead one to consider suicide as the "best option" to spare their family and children from the strain of their condition.

He may conclude that suicide is the best option for his young family because he doesn't want to erode all family resources for his needs, he wants to know his children will have financial resources (T-Q1-16).

Furthermore, the construction of chronic illness as a "hellish existence" or a "hellscape" serves as a powerful metaphor depicting the overwhelming challenges and sense of entrapment that chronic conditions are constructed as having. Hell, in sociocultural terms, represents an untenable and agonising situation that one desperately seeks to escape from to avoid being trapped in misery indefinitely. Chronicity is often depicted as an unacceptably heavy burden in the narratives explored within this study. This kind of description potentially

acts as an extreme case formulation (ECF). An ECF is a discursive technique which constructs a thing in an exaggerated way so as to convey a type of messaging (Pomerantz, 1986), in this case, around suicidality and likening illness to hell. In this situation, the ECF constructions are employed to illustrate the overwhelming weight that individuals with chronic conditions are perceived to bear. In this construction, no one should have to deal with such challenging circumstances, implying that chronicity is an unacceptable state that needs to be eradicated at all costs. This perspective places the burden of responsibility on the individual to seek a complete cure as the only viable option to alleviate this perceived misery.

The metaphor of hell is commonly used to convey the ultimate misery experienced by those living with chronicity. In our collective consciousness, hell serves as shorthand for a state of perpetual suffering, and equating chronic life with this level of despair paints a dire picture of the condition. This ECF (Mitchell & Snyder, 2020) adds drama to the narrative, further accentuating the idea that there is no room for adaptation or compromise in the face of chronicity. The notion of adapted space is dismissed, and the prevailing belief is that it is an all-or-nothing scenario where only a complete cure can offer relief.

Sometimes with chronic unwellness short term relief is like a vacation from hell! Its about quality of life and sometimes if all you gain is a 'moment' in time its a moment of joy in a otherwise miserable existence (A-Q5-8).

Having a chronic illness can be like being given a living hell sentence. I fully support fundraising like this but would rather see the option of treatments provided local treatments (M-Q4-20).

Stereotyped language plays a significant role in shaping public perception and can create a singular notion about what makes a “worthwhile” life and citizenship (Gernsbacher, 2017). The continuum of experiences and possibilities within chronic conditions is often erased, leading to an oversimplified understanding of the complexities individuals face (Charmaz, 1994). By perpetuating the narrative of chronicity as an unbearable burden, the lived experiences and potential for adaptation are overshadowed, reinforcing the need for a complete cure as the sole solution.

Challenging these dichotomous underlying assumptions around life’s quality (Davis, 1999) and the erasure of any kind of intermedial alternatives can foster a more nuanced and empathetic understanding of chronicity. Embracing a more inclusive and adaptable perspective can create space for the diverse experiences of individuals living with chronic conditions, acknowledging their agency in navigating their unique paths towards well-being. By rejecting the all-or-nothing approach, we can work towards a more compassionate and supportive society that values the complexities of chronicity and promotes a broader range of health narratives internally and externally (Campbell & Campbell, 2009).

Comprehending the ways chronicity has been constructed constitutes the foundational pillar of my analytical approach. The overarching perception of a hostile ecosystem is born from the construction of chronicity as standing as an adversary to both individuals and those encircling them. Specifically, within this ecosystem, living with a chronic condition systematically erodes an individual's role within their family unit, portraying them as a perceived drain on the broader societal framework. Individuals are positioned as grappling with a succession of losses that are deemed unacceptable, akin to navigating a treacherous

hellscape. The subsequent two themes will further elaborate upon the notion of chronicity as an unwelcome burden. Firstly, by delving into how the body functions as a yardstick for understanding how chronicity is constructed. Subsequently, by exploring how the broader New Zealand environment contributes to, perpetuates, and exacerbates the lived experience of chronicity.

### **3.2 Theme 2: The Body Struggling: Control, Form and Function**

Within the data, at the core of these constructions of chronic illness lies the body, the locus where various forms and functions are measured. The data provides a critical qualitative perspective that sheds light on the perceived reality of individuals living with chronicity, offering deep insights into the challenging and demanding aspects of their daily lives. A constant struggle to fix the aspects of the body that are failing is constructed. It is primarily through this measurement that the extent and precise nature of illness within the framework of the chronic label are determined (Samuels, 2002). The body becomes the site where medicalisation occurs (DasGupta, 2020), and where wellness, physical success, or failure are assessed (Nicholls et al., 2015). The title of this theme encapsulates how the "chronic body" was perceived and comprehended. It represents the struggles faced by the body in terms of form and function, while also emphasising the notion of individuals having "100% control". This was a recurring phrase used to define the perceived importance of the individual being able to make *their own* decisions concerning their bodies.

Everyone always should have the right and control over their body and mind. It is her basic human right (M-Q3-30).

The extract above vividly illustrates the overarching emphasis placed on the idea of control as central to everything. Within this context, human rights are perceived and addressed as a fundamental element necessary for individuals to not only survive but also thrive in society. The notion that the body is controllable, and one's inability to control their body is considered an unacceptable reality, underscores the significance attributed to individual control over health and well-being. This emphasis on control extends to the notions of able-bodiedness and wellness, which are often equated with the fulfilment of human rights (Samuels, 2002). Those who do not exercise control over their body or mind are often “othered” (Steinberg, 2015), pushed to the periphery of societal norms. Therefore, the consequence of not conforming to this control construction is stigmatisation or marginalisation (Love, 2020). In this construct, functioning and maintaining control over the body is seen as paramount, with little room for alternative perspectives or experiences. By recognising and challenging the overemphasis on control, we can create a more inclusive and compassionate understanding of health and well-being that acknowledges the complexities of human experiences (Feder Kittay, 2020). Emphasising human rights as a broader concept, beyond the narrow lens of individual control, can open the door to more diverse narratives and empower individuals to navigate their unique paths towards health and fulfilment.

The data highlights two distinct forms of control: the first pertains to the control of the body's functional abilities, particularly the ability to perform basic actions like walking. In this context, the body's perceived level of control is linked to its capacity to independently and unaidedly carry out these actions. The following extract provides an example of this. The second element is the idea that people, if they are deemed capable, have the “100% right” to

be in charge of the decision-making process when it comes to what happens to their body. If something can be said to be codified as a truism, at least in terms of this data, it would be that idea. Consider the range of responses below and the points of emphasis when it comes to questioning Mara as a potential decision maker. If 100% control was not partially possible the notion was idealised as the best option for Mara as shown in how the data below frames rights.

“Without treatment, there will come a time when I will no longer be able to walk or drive and that prospect is terrifying,” she writes (D27).

“I left my pride at the door and I just put myself out there because I thought it was my one chance to get my life back,” she said (D8).

I’ve got two little children and if I hadn’t done this, I would have been in a wheelchair in a couple of years (D24).

As outlined above, the concept of full control over bodily functions is highly prized as an ultimate achievement demonstrated in a person's (perceived) ability to shower, walk, and move independently. Participants expressed a right to expect their bodies to perform optimally, most or all the time, given the right intervention. The body is constructed as a central battleground in the discussions surrounding chronicity. It serves as a symbol of control, where individuals assert their right to make decisions about a body that deviates from societal norms of “normalcy”. Throughout the data, there is a clear emphasis on maintaining full control over their body, reinforcing a sense of autonomy and agency. The physical body becomes a focal point for measuring successes and failures in health experiences, intertwining notions of identity, acceptance, and conformity.



An inherent and persistent narrative thread within this data is the promotion and acceptance of bodily autonomy, particularly when framing the notion that individuals have the right to determine their treatment paths. The concept of autonomy is one that the participants were vehemently passionate about defending, as reflected in the fictional case of Mara, a retired nurse who had discovered a promising experimental treatment abroad. Mara, being at the heart of it all, was viewed as deserving of the ultimate decision-making power. The body, in this perspective, is the site where all “struggles” and presumably future hopes are situated.

She could barely walk across a room unaided – if she was even able to get out of bed – struggled to concentrate enough to read and felt robbed of a normal life she desperately wanted (D44).

The term struggle in the extract above gains deeper significance when viewed from the perspective that a body is expected to possess and maintain these functional abilities autonomously, constructing an emotional space of longing to return to a state of full independence and self-sufficiency. In the data, the desire to regain control over the body and its functional processes is intricately tied to the idea of personal agency and the pursuit of a life where individuals can fully exercise their basic rights and freedoms.

The construction of chronicity often revolves around the defined and benchmarked ability to walk, symbolising the perceived severity of an individual's condition. It becomes “Ground Zero” - a central focus of disablement, where the fear of losing the ability to walk looms large, often equated with ending up in a wheelchair, which is seen as a significant loss of independence and autonomy. The pressure to maintain the ability to walk becomes a benchmark of success, reinforcing the notion that normality is defined by one's physical

capabilities. Within this construct, the prevailing message is to "reason or adapt your way" through the challenges of chronicity. The emphasis is on finding solutions, rather than accepting or sitting with the reality of living with chronic conditions. The belief that individuals should shape their reality and overcome obstacles may overshadow the recognition of the complexities and limitations inherent in chronicity. The loss of mobility extends beyond the physical realm and permeates various aspects of daily life. It affects individuals' capacity to engage in exercise, perform routine tasks, and maintain a sense of bodily integrity. The inability to stand or even "reach the letterbox" signifies a retreat from the world, a loss of independence and the erosion of a once-solid foundation for navigating life (McPherson, 2015). This focus on walking and the quest for independence and autonomy can overshadow other valuable aspects of life and personal fulfilment. It narrows the perspective of what constitutes success and normalcy, potentially overlooking the diverse ways individuals can find meaning and joy in their lives. The ability to walk, or the loss thereof, becomes a powerful symbol that encompasses a broader sense of autonomy and control over one's life. Walking is often the first aspect highlighted when discussing the impact of a person's condition, serving as a tangible yardstick by which they measure their abilities and limitations as an individual in their daily routine.

Within the data, respondents explicitly and implicitly referenced the constant struggle between managing the demands of their changing bodies and the demands of their lives and future. As illustrated below, there is the idea that the future hinges on regaining control and making the right decisions.

I feel she should have full control. It's her body, her future, she's the one who is struggling so she has the right to make decisions (M-Q3-27).

The excerpt above describes the participant's difficulty in walking a short distance to take their children to school, and it constructs a profound impact of chronicity on their mobility and independence. In this construction, the perceived reality revolves around an incessant battle with exhaustion, severely limiting their capacity to perform everyday activities.

Moreover, the data constructs a harsh reality of physical limitations, turning once-easy tasks into daunting challenges. The perceived struggle of the body to perform its basic and "normal" functions, centres around the belief that people should be able to rely on their body to be and remain within their own control. Secondly, they should exert 100% control over their healthcare decisions such as actively seeking experimental treatments. Charmaz (1993) aptly articulates the notion that people living with chronic conditions often experience a profound loss of identity, as they grapple with what she terms "biographical disruption". This disruption is intricately linked to the shifts in their sense of self, which become closely tied to their physical functioning and ability to navigate the world independently.

The narratives within the data depict a powerful and emotive struggle, where individuals express a deep yearning for autonomy and independence. The loss of mobility is constructed as not merely a physical limitation; it permeates every aspect of a person's existence, influencing their emotional and psychological well-being. This emphasis on physical functioning as a defining factor in one's sense of self reveals the societal assumption that ability and disability determine a person's worth and place in society. The pursuit of a fulfilling life is often contingent upon the ability to perform everyday tasks without hindrance, perpetuating the belief that those with mobility challenges are somehow "less than" or incomplete (Kenworthy, 2019). These societal assumptions lead to a collective expectation that individuals

should aspire to regain their previous abilities as a means of returning to a state of normalcy (LaMarre et al., 2019). This narrow perspective neglects the diverse and unique experiences of individuals living with chronic illness. The narratives highlight a desperate longing to reclaim what was once taken for granted, reinforcing the societal pressure to conform to able-bodied norms. This unyielding focus on regaining lost abilities inadvertently marginalises and stigmatises those who may not fit the conventional notions of physical functioning (Kersten et al., 2015).

Understanding the perceived reality of chronicity is vital for advocating for more comprehensive support systems and targeted interventions. It compels us to critically examine existing healthcare structures and societal attitudes, urging transformative changes that provide meaningful support and empowerment for those living with chronic illnesses. The insights of this analysis prompt us to confront the complex and often overlooked realities of chronicity, urging us to create a more compassionate and inclusive society that acknowledges and addresses the profound impact of chronic conditions on individuals' lives.

### **3.3 Theme 3: Chronically Ill = Chronically Underserved by the (New Zealand) Healthcare System**

If the body and its functioning is the contested space where chronicity is measured then participants made sense of “New Zealand” as the ecosystem that shapes and reshapes the wider chronicity experience (King, 2000). The title of this theme summarises that general feeling. Within the data, New Zealand is a substitute and catch-all term for our society, health system, geopolitical positioning and community as a whole. This theme will cover the perceptions of what the New Zealand Health System is, how it interacts with patients and the

perceived motivations for health decisions. New Zealand as a country, society and healthcare system bares a kaleidoscope of different constructions and understandings through this dataset. Fundamentally, the perception in the wider data is that there is no “place” for individuals experiencing chronicity. This is articulated by Morrison and colleagues (2020) in the idea of being displaced by an environment that is largely inaccessible. These underpinnings of environmental hostility will be discussed in the following ways. Firstly, an overview of how New Zealand is made sense of within the data. Secondly, the different ways health in New Zealand is made sense of by people. Thirdly, the idea of there being no other option than working to move out of chronicity.

### ***3.3.1 Making Sense of New Zealand***

The overarching theme of navigating the hostile ecosite called for an in-depth analysis and understanding of the adversarial forces individuals face while navigating the healthcare system. One complexity I grappled with was the myriad of perceptions of the conventional system and New Zealand as a socio-political entity, constantly shifting and being reframed through various lenses such as the Ministry of Health or rural general practitioner’s (GP) motivations. These dynamics led to the final theme in which the healthcare system is constructed as being chronically unfit for purpose.

In analysing New Zealand both as a country and as a source of a “healthcare system”, it was necessary to comprehend and reconcile multiple, often contradictory representations about its underlying motivations and competencies. The term “underserved” was constructed as a unifying thread, encapsulating the sense of individuals feeling they had no choice but to seek assistance outside the traditional healthcare system.

The way the healthcare system is funded is set to save the most amount of lives possible with the least amount of money. This means it routinely discriminated against folks who are not the average person...So yes. They should be able to seek care in other places. Bc the best care is absolutely not here (M-Q5-13).

The vignette extract above encapsulates this sentiment of the health system underserving those with chronic illness. It also alludes to an image of the New Zealand health system as callously disregarding the needs of those living with chronic conditions, seemingly eroding their human rights. This perception is further reinforced by respondents who see the healthcare system's funding model as inherently discriminatory. They argued that it prioritises saving the most lives with the least expenditure, thereby failing to cater to those who deviate from the “average person”.

This sense of being underserved also hints at systemic issues within the New Zealand healthcare system, such as actual inequalities in access to care, perceived inadequacies in the delivery of services, or dissatisfaction with conventional treatment approaches. These factors contribute to creating a “hostile ecosite” where individuals feel compelled to explore alternatives, fostering a healthcare landscape where unconventional or experimental treatments may gain traction.

### ***3.3.2 What does New Zealand do (or not do) for People with Chronicity?***

If we return to the concept of disease hierarchy (Album & Westin, 2013), within the framing of New Zealand as a health ecosite or system, there is a perception in the data that people experiencing chronicity are at the bottom of this hierarchy. It is perceived that the chronically ill do not have a place within the constraints of the health system, the scope of

current medical knowledge and the “attention” that current medical practitioners are perceived to provide. This theme portrays the healthcare system as fundamentally failing in its mission to serve the needs of all citizens. This sense of systemic failure is particularly prominent when discussing long waiting times and lack of specialists, creating a stark contrast between the perceived capabilities of conventional and experimental treatments.

For many of those suffering indescribable pain caused by Osteoarthritis, they are led to believe surgery is the only option. The lack of surgeons to carry out replacement surgeries in NZ can mean being placed on a waiting list. This on top of recovery times and rehabilitation means that some are reluctant to undergo joint replacement surgery (D36).

The depiction of New Zealand as a place of medical neglect resonates powerfully through the data, casting a sobering light on perceived systemic failures. Respondents often express a sense of desperation, painting stark images of patients left with no other option but to seek medical refuge abroad due to a perceived lack of viable treatments in New Zealand. These sentiments highlight a profound level of frustration and disillusionment with New Zealand's healthcare system. The impression formed is of a system that is not only inadequate but potentially harmful to those who fall outside the parameters of “average”. New Zealand is constructed as a place of medical neglect and apathy, seemingly unconcerned with the well-being of its citizens. This narrative drives attention towards the potential relief offered by unregulated systems or overseas clinics.

The construct between the perception of the conventional New Zealand pathway and the overseas clinics goes some way to explain the centring of knowledge from doctors that

trained overseas or accessed specialised or exclusive knowledge (Hokowhitu, 2014)). These surgeons are not bound by a system that is perceived to be underfunded and constrained by budgets and staffing as described in the extracts (D36 and D17) which frame two different possible scenarios with joint pain and the need for a replacement.

When can I bounce back into my daily routine? You can get back the next day with the same-day operation, although after the injection you may feel a bit sore. Again, you may be able to resume ordinary tasks quickly depending on the therapy site. For some moment you should not be engaged in exhausting physical activity (D17).

The experience of individuals in the health system is constructed as slow and offering little to no sense of relief. Contrastingly, treatment options outside of New Zealand's conventional healthcare system seem to seductively promise much faster recovery times. Patients are often told they can return to their normal routines as early as the day following their procedure. This stark difference in expected recovery times further amplifies the allure of overseas clinics and unregulated systems. This comparison underscores the frustrations expressed by respondents, emphasising the perceived failings of the New Zealand healthcare system while highlighting the perceived advantages of seeking treatments abroad or outside regulated systems.

### **3.3.3 *The Medical Encounter***

An intriguing expansion of the framing of New Zealand in relation to people experiencing chronicity lies in the exploration of how medical encounters are perceived within the data. An important aspect of the concept of being underserved by the New Zealand



healthcare system involves examining how people in the data made sense of their interactions with medical professionals.

Potential improvements of symptoms. Someone “medical” who see their struggle, seems to listen & is willing to try help. Miracle cure/hope (M-Q2-37).

These professionals are framed as agents responsible for delivering health within the bounds of what is considered the conventional treatment approach. This often pertains to GPs and the experience of waiting for services within the public healthcare system. By delving into these perceptions, we gain valuable insights into how the healthcare system is perceived, to either meet, or fall short of, the needs of those living with chronic conditions.

They are trained to treat illness as cheap and easily as possible. They are only interested in managing not exploring or fixing because budgets don't allow time or energy to go into individuals. There always seems to be a sense of there could be more that will improve your life but it doesn't fit in their budget. If you don't advocate for yourself, doctors and specialists won't either (M-Q1-25).

Most GPs do not have time to talk about condition progression, illness in 15min, they barely have time to write prescriptions! Not a single GP in (my) partner's life ever did and we have travelled NZ and he has had over 100 (GPs), this is a very common report from most with similarly chronic illness in support groups and studies (J-Q1-8).

At best GPs are perceived in the data to be reactive and cannot handle patients with degenerative progressive medical conditions adequately. Hence patients with these conditions are constructed as forced to educate themselves (they often know more about the conditions than GPs ever do). The patient is positioned as pursuing their own education on their condition, and that they would be lost in a neglectful system. Participants framed GPs as not having the required knowledge, nor educating themselves on chronic conditions.

The above extract provides an impression of how GPs are perceived to be ill-prepared to handle the complexities of chronic conditions, either due to a lack of education or unwillingness to learn. The data suggests that there are more critical considerations that shape the perceived quality of the interaction and engagement with healthcare providers. Additionally, there seems to be a notion that life is reduced to a mere financial value, which fails to align with the broader and more holistic aspects that should be considered in medical encounters (Lupton, 1997). In a specific sense if people like Mara do not advocate for themselves then the medical professionals will not either.

There were also small 'defences' of the medical encounter and specifically GPs in the data. In the following quote, GPs are depicted as providers of established and proven medical knowledge, offering treatments and interventions that are known to be effective and carry minimal perceived risk. This defensive stance may arise from the need to maintain trust and confidence in the medical profession and to reinforce the credibility of evidence-based practices within the realm of medicine in the data below.

As a professional working with people who live with a chronic illness, I get that seeking any treatment is better than feeling that no one is helping or supporting them.

However, I do also think that the GP in this case wasn't going out of their way to be obstructive but offer the advice of what is proven to help (M-Q5-1).

The concept of the medical encounter has become a significant topic of discussion and contemplation within the public sphere (Lupton, 1993). While there exists an idealised notion of how these encounters should unfold, the reality often falls short, leading to a sense of frustration and dissatisfaction (Lupton, 2013). GPs were perceived as lacking time, lacking effective communication, and as disconnected from the knowledge they seek. These perceptions contributing to the participant's diminishing faith in the New Zealand medical system. As a result, individuals may feel compelled to explore alternative options, as they perceive no other viable choice within the current medical setting.

#### **3.3.4 *Medical Refugees: Leaves no Other Option***

With cystic fibrosis or SMA muscular dystrophy the NZ government already identified that it would rather they died young. So we already have medical refugees moving to Australia, my family with auto immune conditions were forced to the UK, and Australia. There is no NZ options and if NZs answer is death due to medical negligence for which there are no legal avenues for justice or redress (my past dead family members) or suicide due to denial of basic living needs like housing, ability to bath, eat cooked food, have clean clothes then yes LEAVE NZ ASAP TO ANY COUNTRY THAT WILL HAVE YOU (M-Q4-10).

The concept of “medical refugees” and the notion of a healthcare system that seemingly permits people to die can be seen as evocative ECFs, capturing the idea that New Zealand offers no other viable options. These extreme concepts serve to demonstrate the perceived severity

of the situation and forcefully convey a point (Pomerantz, 1986). The term medical refugee implies that individuals are left “stateless” within their own country, unable to access the appropriate treatment and feeling neglected by healthcare authorities. This conceptualisation sheds light on the desperation and helplessness that some people may experience when seeking medical care and the perceived lack of support from the healthcare system. This notion of being stateless in one's own country raises questions about the adequacy of the healthcare system's response to the needs of those living with chronic illnesses and the potential gaps in providing accessible and effective treatments.

The perception of the conventional healthcare system suggests that individuals often feel they have no other option but to seek treatment through private means or advocate for services overseas. The specific treatment sought may vary, from seeking stem cell treatment in Mexico to simply seeking “hope” in a broader sense. Individuals are often in search of a care provider who will listen, validate their concerns and align with their values and belief systems as they navigate the healthcare system.

If someone is willing to travel overseas for a treatment option then they are desperate. The physical, emotional and psychological trauma that a chronic condition gives you is awful, and will often lead you to seek unconventional methods. If anything she's seeking closure as she has clearly exhausted all options in NZ (M-Q2-27).

An underlying concept in the portrayal of conventional medicine is its tendency to offer “management” rather than true remediation. In contrast, overseas clinics are viewed as offering hope for effectively addressing their health issues – a perception that starkly contrasts with local options. Conventional medical providers and specialists are portrayed as unable to

meet their needs and expectations of the vignette patients Mara and Alice, who are depicted as having exhausted all other options. Consequently, these individuals are framed as having no other choice but to venture into uncharted territories of unconventional or overseas treatments.

The overseas clinic offered hope for effectively managing the issue which was not available from the local options. We need to get some of these options available (through trials?) locally within NZ (M-Q2-15).

New Zealand's healthcare system, in all its iterations, is portrayed as hopeless, and as a hostile environment that creates medical refugees. The insurmountable challenges it presents compel individuals to seek any and all potential opportunities elsewhere. Any change is perceived to be worth the struggle against this hostile ecosystem. Advancing from the unacceptable status quo and achieving success in navigating the system, despite the financial and personal burdens, is seen as a triumph, whereas a contrast is found in unregulated or overseas alternatives that offer hope of improvement and relief.

Having no options at all and no hope of improving but only deteriorating would be devastating. If there was an approved treatment in another country that is getting results, it would be worth trying if you could afford to financially. Any increase in functionality and any reduction in pain would be worth trying something that may work (A-Q1-6).

In expanding upon this theme, it is important to examine the complexities within the New Zealand healthcare system and its perceived deficiencies, as well as the impacts on

individuals' healthcare-seeking behaviours. This examination could encompass everything from policy decisions to localised healthcare practices, allowing for a more nuanced understanding of why some feel underserved and how this perception influences their interactions with the healthcare system. This chapter has explored what I am characterising as a hostile ecosite within which people with chronic conditions live/navigate their health. The hostile ecosite is my construction, based in CDT, critical health psychology and similar frameworks, for understanding what is at stake for people. It is not based so much on the hostility but more the demands on the individuals and the consequences of health surveillance. These three themes evidenced aspects of this hostile ecosite by demonstrating the seeming disposition of the individual from the places, roles, and activities that they value because of chronic conditions. In particular, there was the repeated construction of a hellscape that needs to be escaped from.

### **3.4 Chapter 3: Summary**

This analytic chapter concentrated on two areas of focus, the different ways chronicity is made sense of and the backdrop of health in a neoliberal context. Firstly, it examined the constructs of individuality and personhood in daily life and communal experiences, focusing on the language and nuances prioritised in these narratives. The second focus was on how individuals navigate the search for treatment for their conditions. It particularly underscored the pressure to persistently seek new and improved measures to counter the challenges of chronicity. This reflects the foundational question of my master's thesis, which is to understand the role and context of healthism in the presentation of treatment and potential cures online. Healthism, in its many modern forms and iterations, exerts a significant, albeit largely unnoticed, influence on our understanding of chronic conditions (Cheek, 2008). The emphasis

on personal responsibility frames the way individuals are expected to navigate their treatment and cure journey, regardless of the chosen path to maintain wellness.

#### Chapter 4: The Responsibilised Cure Quest: Ultimate Prize, Normalcy

The second analytic chapter centres around the positioning of patients and the expectations placed on them to seek and achieve a cure or cure pathway. Each theme in this chapter illuminates different aspects of the pursuit of normality and unpacks the demands it places on individuals and their families. This chapter outlines how the *potential* for a cure is made sense of. The sequence of themes reflects the various stages of this quest, starting with hope and concluding with discussions of resistance to such narratives.

Central to and running throughout all themes is the idea of situating the personal at the centre of cure efforts and health management. Personalised medicine is defined within medical and clinical concepts as “tailoring” the approach for the individual (Sánchez & Fuentes, 2002). A less well known but equally salient phenomena is the pressures within health to find “the best fit for you”, not just as a one-time exchange but as an internalised embodiment and value that shapes every decision and reading of information (Cheng & Dunn, 2015). There is an assumption that there are personalised ways to seek health, if you look, study, and gain enough insights. The way health is sought is constructed as needing to align with these values. Normalcy is a prize that is worth fighting for and thus requires effort and investment, from all sides.

The first theme, "Idealised Patienthood: Doing and being the "Good" Patient" examines how the hostile ecosystem constructs and reinforces the concept of an ideal patient who actively manages their health. The notion of being good or “well-behaved” is a controversial, yet inevitable, outcome of the framing that those with chronic illnesses need to actively pursue change. There are various ways to alleviate the health burden, and individuals are deemed



good if they navigate the system with the goal of minimising the impact on themselves, their families, and society. The second theme “Perception of Hope: A Wonderful and Weaponised Force”, illustrates the ways in which the quest for normality is underscored by hope. This hope is not only the foundation of the journey, but also becomes commodified within the context of chronic illness, suggesting that there are specific steps one can take to cultivate and maintain both hope and health (Lohne, 2022).

The third theme “Doing (Good Health) as the Ultimate Investment for the Unwell” reflects the concept that whatever the individual or family invest in health is worth the cost because of the perceived payoff. This idea is framed as a significant step towards achieving normality and becoming a good patient. The pursuit of normalcy requires the right attitude and commitment, manifested not only in financial terms but also in emotional and physiological investments. Fourthly, the theme “Individuals and Family Are Agents of Wellness” explores the concept that agency plays a crucial role in determining the success or failure of health outcomes. Normality is constructed as not concluding with the receipt of treatment; it remains an ongoing challenge for those living with chronic illnesses. Lastly, the final theme “(The Expectation of) Performative Normality” identifies the expected evidence and performance of normality. Returning to the state of normal is framed as not being something that is done quietly, there are key signifiers which I will discuss in this theme. Individuals not only recover, but also engage in explicit acts that demonstrate their progress along the path to normality, often in terms of physical strength and endurance (e.g., people with multiple sclerosis being able to run marathons; Kersten et al., 2015). Before engaging with the themes and their narrative, I believe it is important to give a broader overview of how the data constructed and

staked normalcy as a core concept. This permeated all the themes and played an important role in scaffolding this thesis and its connection to broader literature and scholarships (Puar, 2013).

#### **4.1 Choosing and Staking Normalcy and Cure**

Societal norms often encourage individuals with chronic conditions to engage in activities that reduce the visibility of their condition, promoting a semblance of normality (Mitchell & Snyder, 2015). Once they have embarked on a treatment journey, there is an implicit expectation to present the outcome in the most favourable light (Allen, 2009). One enduring metaphor often used by medical institutions is that of the patient being in the "driver's seat", maintaining control even in the aftermath of the active treatment process. The process' supposed endpoint, cure, is often characterised as a return to normalcy, as though this state encapsulates something fundamentally essential (Titchkosky, 2020). This chapter will further unpack these narratives, examining their origins, implications, and the broader constructions that lies beneath.

Because at the end of the day you just want to be able to function normally and do the things you want to do without limitations (A-Q1-31).

Building on the metaphor from the previous chapter, a significant portion of the data in this set reflects a prevailing belief that individuals can triumph over their health conditions. Thus, they reach the pinnacle of the "health mountain" therefore permanently conquering chronicity through sheer determination and effort. Assistance is constructed as being available for those willing to traverse unfamiliar terrains and potentially challenge traditional norms. The narrative of the body needing to restore itself to health remains a persistent narrative across all

data sources and literature (Campbell & Campbell, 2009). Implicit in these data extracts is an understanding of a “normal life”, and its role and implications for both the individual and wider society. For example, in describing Mara’s actions, one participant wrote:

Because she is desperate at a chance to live a normal able-bodied life (M-Q1-41).

Normalcy, a mythical idea rooted in statistics (Davis, 2010), sociocultural norms (Sointu, 2005), and societal preoccupations (LaMarre et al., 2019), becomes the yardstick by which patients measure their success, using phrases such as "back to normal" and "I am normal." The pervasive notion of “returning to normal” significantly impacts clinical and rehabilitation settings, influencing the goals set and determining perceived successes or failures (McPherson et al., 2015). This concept is particularly evident in an individual's ability to meet predefined rehabilitation objectives, such as walking a certain distance or demonstrating stamina. For instance, within this dataset, individuals noted achievements like "swimming 23 laps" or "standing throughout the day", highlighting the perceived impact of chronicity across physical, emotional, and psychological domains. They are examples of a wider psycho-social trend that shifts health away from merely an absence of disease into a system or construction of being completely well and absent of all symptoms (Porter, 1985). This in turn reinforces the notion that wellness is possible for everyone, including the chronically ill if they just navigate the system better and take individual responsibility for their health.

Normality is a construct that has as many definitions as detractors, even if staying within the concept of health normality and within normal ranges (Davis, 1995). There was little conflict within the responses about how people perceive the idea of wanting to be normal regardless of

the consequences. The ability to “display” normality was seen as the endpoint to many quests and achievements both for individuals and families. I would argue that normality has been positioned in a similar way to health, in the sense that the individual is often responsabilised to produce it. The work for normalcy becomes emblematic of a whole life where people achieve goals that centre around the “freedom” to be “normal”. This concept is articulated in the extract below, where every part of this person’s life is constructed as being free now, including mind and body.

I have a life now, there is so much to catch up on and I am able to do simple things – I want to paint a chest of drawers. I have freedom now, in my body and mind (D1).

This modern understanding of what it means to seek a cure is reflected in my chapter title which posits the idea of a “Noble Quest for Normality”. The idea of being and presenting as normal is something that sits with great tension amongst people who live with chronic illnesses (Campbell, 2008). The statistical measure of value compared to an idealised average has come to saturate every aspect of life in both implicit and explicit ways. The concept of being in (close to total) control of your life is a normalising act (Basas, 2014). Normal encompasses the understanding of health, how we measure and present ourselves. There was a persistent belief in the data and wider society that it is perfectly “natural” and “understandable” to want to seek and achieve these goals. People are constructed as not only being on the noble quest for normal, but in doing so they are acting in a completely normal and understandable way. For example, within the vignette studies, I asked people the question in various forms, “why would people want to seek experimental treatments?”. The idea of having a go at and wanting to gain

opportunities toward a cure is naturalised and normalised in different ways. The extract below (A-Q2-30) is an example of how the concept of normality is woven throughout the perception of both chronicity and the cure paradigm.

I think it's a natural and normal response to have. I think this is especially the case when we don't paint a picture of how life can still be fulfilling and wonderful with or without disabilities. We focus on the deficits, and it's natural to not want to lose things that are so important to our life and how society sees/treats us (A-Q2-30).

Throughout the themes, I demonstrate how the quest for a cure or significant improvement is constructed as a noble quest to seek normality, and how the concept of being normal is framed and enforced as a motivation for changing the chronically ill body. The five themes will look at both the abstract concepts when seeking interventions and the expectations placed on people after they seek treatment. It is against this backdrop of "normalcy naturalised" that seeking treatment can be understood as a noble quest. An individual is positioned as admirable and virtuous for their efforts to manage and navigate their illness with the expressed intent of lessening the obvious and conspicuous impact of such a state. There are many and varied ways to act out the effort to seek this elusive goal (e.g., conventional verses experimental), however, the unifying element remains the notion of being on "the path" and expressing a commitment to the cause of seeking something that is impossibly valuable.

When I was first weaving together the tapestry of my analysis, I kept reworking how I was going to understand and frame the link between seeking a cure and "desperation". In a sense, all noble quests in fictionalised context, such as high fantasy, are often predicated on

desperation (e.g., to save the realm and the princess). In a similar way, the quest for *something* to alleviate suffering was framed in similar terms, as giving back “life force”, and worth so many sacrifices. The normality at the end of the noble quest for normal was the water at the end of an adventure in the desert. In the critical qualitative analysis, the notion of seeking a cure is framed as a profound desire to not only alleviate symptoms but to undergo a transformative journey towards a new life, free from the constraints of chronicity. The extracts below illustrate how individuals envision the curative process as an opportunity for profound change, not only for themselves but for everyone involved. The focus shifts towards the enhancement of the quality of life, allowing individuals to engage in activities that were previously idealised or seemingly out of reach, now made possible through the pursuit or attainment of a cure.

A better life (M-Q2-16).

This transformative view of cure reveals a deeply rooted longing for a life unburdened by chronic illness, where the individual can experience newfound freedom and possibilities. It goes beyond merely addressing symptoms, encompassing a holistic shift towards regaining a sense of agency, control, and empowerment over one's health and well-being.

To get better (M-Q2-30).

The concept of cure, in this context, becomes intertwined with notions of hope, agency, and the promise of a better future. Individuals view the curative potential as an avenue to reclaim their identity and pursue dreams that were once deferred by chronicity.

Feel better - results - outcomes (M-Q2-36).

Alleviation of symptoms and better quality of life (M-Q2-39).

“Get my life” (D6 ).

However, it is important to critically examine the construction of a cure as a panacea, as the idealised notion of complete eradication of chronicity can overshadow the reality of living with chronic illness. While the pursuit of a cure may be empowering and hopeful, acknowledging that it may not be attainable for everyone or may not lead to the anticipated transformative outcome(s) promotes transparency and a foundation that underscores complexity. In doing so, a more nuanced understanding of cure can be developed, recognising the multiple dimensions of living with chronicity and the importance of embracing a diverse range of experiences and outcomes.

#### **4.2 Theme 1: Idealised “Patienthood”: Doing and Being the "Good" Patient**

The term "patienthood" refers to the state or condition of being a patient (Sosnowy, 2014). A patient is an individual who is receiving medical care or treatment from healthcare professionals due to an illness, injury, or medical condition (Huxtable, 2018). Patienthood entails the role and responsibilities of the person seeking and undergoing medical care, which may include following treatment plans, adhering to medical advice, and actively participating in the management of their health condition (Sosnowy, 2014). It is a temporary state during which an individual seeks medical attention to address their health needs and works towards recovery or improved health outcomes. The process and procedures of being a patient are not neutral, instead patienthood is situated within many complex ideologies and belief systems (Davis, 2014). There have been many iterations of the role of the patient and what it means to engage

with the healthcare system when the medical professional's authority is no longer absolute (Lupton, 1993), meaning that people are getting multiple and different narratives within the health experience. In conjunction with the wider movements of "better health". This theme will be explored in the following ways; firstly, the problematic understanding of the "driver's seat" and empowerment and secondly what the good patient does and is.

The driver's seat position represents an idealised construct, aligning with the principles of neoliberalism and individual empowerment (Archer, 2008). In this context, being a good patient implies an understanding of one's condition, a willingness to adhere to recommended treatments, an ability to communicate effectively with healthcare providers, and a readiness to participate actively in the decision-making process (Jørgensen, 2015). However, this construct can create an undue burden on individuals, as it demands constant adaptation to the evolving landscape of healthcare and sets high standards for successful navigation (Liebenberg et al., 2015). Yet, the notion of taking full responsibility for one's health is not without its paradoxes. As Vallely (2021) points out, health outcomes are often influenced by factors beyond the control of individuals and families. Despite a patient's intent to take the wheel, other forces – such as the healthcare system, socioeconomic factors, and underlying health conditions – may have significant control over the treatment processes direction (Satz, 2020).

More control of her life and to reduce fear of what could happen with the progression of the condition. People are problem solvers who are wired to survive, so she is looking for ways of overcoming the condition. It could be related to family being worried, as she has family support - her family could also be worried and looking for



solutions, in addition to Mara being worried about how her condition will impact them (M-Q2-40).

The term good patient encapsulates a myriad of actions and attitudes that individuals are expected to embody when navigating the health system (Carey, 2020). This involves adherence to the responsabilised steps toward an idealised state of health and well-being (Sointu, 2005). This active navigation process is, however, subject to continuous change as it reflects ongoing scientific advancements and societal shifts (Dirth & Branscombe, 2018). The duties of being a good patient permeate not only daily life but also interactions with healthcare professionals (Kersten et al., 2015).

Patients are encouraged to take charge of the things they can change, they are advised to be active, eat well, connect with others, and get enough sleep (LaMarre et al., 2019). Notably, this advice is not about imposing strict diets or strenuous workouts, but about achieving balance and maintaining connections with loved ones (Rail & Jette, 2015). This approach embodies the shifting dynamics of the patient-practitioner relationship in modern healthcare, where an informed, empowered patient is at the heart of decision-making (Thorne et al., 2003). It involves the notion of the good patient actively and persistently navigating towards the destination of “health”. Consider this illustrative quote:

Step by step my body is healing itself. I’m also working hard to be as healthy as possible. I’ve still got a long way to go but I’m definitely moving in the right direction. Never give up hope for a better tomorrow! (D69).

This quote depicts a patient demonstrating an unwavering commitment to the journey towards wellness, no matter how arduous the path may be. The idea of asserting control over one's treatment and self is seen as an active process, meaning seeking and finding information and options to feel better. This quote is about patients placing themselves at the centre of their healthcare, viewing themselves through a focus point of responsibility. This is particularly evident in the characterisations of Mara and Alice, who embody the perceived actions and attitudes of the good patient, taking charge of their healthcare engagements (Storni, 2015). For instance:

I think it's very brave, and I love that she wants to feel in charge of her own life and her own treatment (M-Q1-8).

This characterisation aligns with the idealised notion of the “consumer in charge” (Layton, 2009). The extract above frames this concept by emphasising the unique viewpoint of the consumer. However, it also suggests that to qualify as a health consumer (Veinot et al., 2010), one needs certain skills and attributes (Adams et al., 2020). There is inherent “value” in individuals taking responsibility to assist the health agenda and to form an idealised partnership within the health system (Jørgensen, 2015).

Are you a 'health consumer'? The Health Quality & Safety Commission defines a consumer as a person who has accessed or is currently using a health or disability service, or is likely to do so in the future. As a health consumer, your unique experiences can provide valuable input on improving services, setting priorities, and identifying quality issues in the delivery of health services. The commission further underscores the importance of consumer engagement in the decision-making process about their treatment, services, and care (D44).

The (perceived) ability to demonstrate health and the concept of wellbeing is an expectation in many social and societal domains (Shakespeare, 2004). The concept of conspicuous patienthood means being a patient that is taking and reading measurements while working towards improvement, based around increasing responsibilisation and the rise of the ideal person (Sointu, 2005). This will be explored with several examples of health and wellbeing in practice in this section.

The individuals depicted in both in media accounts and fictitious scenarios are often held to conflicting standards. On one hand, they are asked to assume responsibility, to make informed decisions, and to sit in the driver's seat by adhering to healthy lifestyles (e.g., maintaining a balanced diet and regular exercise). Simultaneously, however, these individuals are portrayed as susceptible to exploitation from disreputable sources and in need of protection.

I think it's great that Jay is trying to taking control of his condition by researching ways to help himself and come up with his own plan. However they information online can be overwhelming as their is so many differing opinions on what is the right thing to do. Also their is a lot of people are trying to take advantage of unwell people by offering expensive treatments that often don't work (J-Q1-44).

Further exploring the concept of a conspicuous responsibilised patient, one can see that it includes those who proactively engage with healthcare discourses, whether with their own healthcare providers or with the system as a whole. For instance, in New Zealand. Patients are encouraged to challenge their doctors to justify or explain the necessity of certain tests, such as CT scans or X-rays. The following data extracts from New Zealand's Health Navigator website, a

highly recommended resource among health professionals, emphasise a range of “patient and consumer” engagement strategies. This consumer advocacy/engagement perspective places significant responsibility on individuals, who may already be grappling with health challenges, without fully acknowledging the power dynamics that exist between patients and practitioners, where power resides in those who make decisions (Lupton, 1993). In such a scenario, empowerment and responsabilisation almost become synonymous, blurring the line between a medical virtue and a neoliberal obligation.

What do I need to consider when judging evidence?

Understanding and interpreting the evidence can be quite complex. Your healthcare professional will be able to discuss the pros and cons of different options with you. When sifting through evidence, it is important to remember that: different people respond differently to treatments. Not all people have the same risk or chance of experiencing a benefit or an adverse effect, the evidence may not always be in line with your personal preference, if a disease or condition is rare, or unusual, there may be very little good quality evidence (D49).

The Choose Wisely campaign envisions a culture where the patient defines the parameters of their own health care. The ability to gain a sense of which aspect of their health is valuable. The positioning is centred around a sense of health as an act of information and consumerism.

Low value and inappropriate clinical interventions are avoided, and patients and health professionals have well-informed conversations around their treatment options, leading to better decisions and outcomes (D53).

Do I really need to have this test/procedure?

What are the risks?

Are there simpler safer options?

What happens if I do nothing? (D53).

The Choose Wisely campaign also invites critical examination. While it aims to empower patients to make informed decisions, it places the onus on individuals to navigate complex healthcare choices. This approach assumes that patients have equal access to information, resources, and support, which is often not the case (Sen, 2002). The campaign's focus on avoiding low-value clinical interventions is important, but it must be accompanied by a recognition of the social determinants of health that contribute to the overuse or underuse of medical procedures. A patient's ability to "choose wisely" is frequently contingent on what the medical community broadly refers to as lifestyle factors (Steinberg, 2015). Within the data lifestyle was used as a motivating factor and a contention point as something that may limit a person's suitability for a particular treatment. This upholds the notion that science has the tools to quantify and shape every conceivable aspect of health, given the right opportunities (Whitson, 2015). The journey towards responsibility is marked by the ability to recognise and demonstrate measurable states that render one a suitable candidate for specific treatments. Ideally, this would also involve crafting a compelling narrative of transformation marked by "before" and "after" states. This process not only emphasises personal agency but also raises questions about the complex intersections between health, societal expectations, and individual identity.

The ways in which people enact patienthood is a core element of how chronicity and cure narratives are understood by people. People within my data were at various stages of being patients. There is a particular formula and blueprint for doing patienthood the right way, which works within the backdrop of healthism and responsabilisation. The patient taking the right control is an idealised understanding about what it means to be a good patient who is in the best position to make change. There is a need for deeper understanding of what it means to live with a chronic condition beyond the standard medical framework, which is primarily oriented towards acute modelling - injury, treatment, recovery, and return to normalcy (Basas, 2014).

#### **4.3 Theme 2: Perception of Hope: A Wonderful and Weaponised Force**

The treatment in Mexico gives Mara hope of lessening pain and symptoms. So she is chasing that - the Drs obviously have told her that there is nothing more they can do for her. Hope- of a cure - of less pain and symptoms is a very enticing and seductive force (M-Q1-30).

One intriguing aspect of this analysis revolves around how hope and the prospect of regaining health are articulated. Hope is made sense of as a valuable commodity, offering individuals relief from their symptoms and serving as a worthwhile investment. Hope is an important feature often a “lighthouse” (Lohne, 2022), either through conventional pathways or experimental treatment. It is often couched in economic terms, implying that the emotion and sensation of hope possess intrinsic power and value (Perez et al., 2016). The acquisition of hope is seen as a commodity in itself, offering people a guiding light to navigate through the

challenging landscape of chronic illness. This concept is vividly portrayed in the following excerpt, where a participant describes Mara's experience during treatment.

First is hope. One of the defining features of humanity is our capacity to remain hopeful for the future, often in the face of adversity, or, in Mara's case, scientific evidence. To follow conventional advice, it would seem, is to lose hope and resign to a life Mara fears. For Mara, the hope she feels transcends any conventional advice that general or specialists alike may espouse. The second is empathy (SMQ-10).

Hope takes centre stage especially in decisions related to experimental treatments. The pursuit of hope is framed as a transformative experience, providing individuals with the light they need to navigate the complex and challenging landscape of chronic illness. The allure of hope is palpable, as people actively seek treatment options that promise the possibility of regaining health and a renewed sense of "life". This concept is vividly illustrated in a poignant excerpt below, where a participant outlines Mara's experience during treatment, capturing the profound impact that hope can have on the journey towards healing and recovery.

What was flowing through my veins was hope, for the first time in a very long time (D76).

One of the first ways hope is constructed is giving people the ability to face the difficulties of their conditions. As articulated in the extract below, hope was a "major benefit", even if the actual experimental treatment was not overly successful. The person in question retains the dream of walking without having experienced "dramatic" or transformative results. Therefore, hope can be a commodity even more so than the outcome of treatment itself.

Because of her age Wood had not seen results as dramatic as some younger people but said one of the major benefits from the treatment was the hope it brought. "I'll never give up the dream (of walking) (D36).

The concept of hope, along with the anticipation of change, is intricately interwoven throughout the entire dataset, both explicitly and implicitly. This is especially notable in metaphorical depictions of “escaping darkness” and heading towards a “brighter future”. Moreover, many reflections on how individuals should manage and treat their conditions embrace a formulaic approach. This notion is closely tied to neoliberal and healthism ideologies, promoting the idea of being a responsible citizen for the collective wellbeing of society (LeBesco, 2012). It unifies various ideas and metaphors, such as people navigating turbulent seas (risks) to find a lighthouse - a metaphor for the cure they seek, as reflected in the opinion below.

Hope and possibility and because the alternative is worse than not taking the risk (A-Q1-7).

While hope is universally considered a virtue intrinsic to human nature, in the data it assumes an especially potent, influential, and somewhat omniscient role. Hope becomes a flexible marketing formula capable of being wielded for both beneficent and detrimental purposes. Despite this, hope generally bestows more than it exacts, necessitating its recognition and central placement within discourses around cures.

The excerpt below reflects a sentiment commonly expressed within New Zealand's healthcare circles: despite being trapped by one's condition, the potential to bring about



transformative changes through lifestyle modifications remains within one's grasp if they remain diligent and seek change.

You can't modify your genes but you can make lifestyle changes that can reduce your overall risk (D4).

The promise of an improved (or ultimately, condition-free) life is perceived to be contingent on these changes. However, the recurring theme of lifestyle changes within public health discourse is problematic and frequently rife with undertones of healthism and responsabilisation (Crawford, 2006). Genes and lifestyle are often contrasted in a manner that obscures the more intricate aspects of disability such as complex health conditions with no modifiable path (Watermeyer, 2012). Despite the limits of hope to (always) materially transform, hope was framed as a psychological and emotional tonic. For example:

For the first time, I really feel hopeful – there is a treatment that may completely halt this disease and let me live a more normal life and be there for my family (D46).

For someone staring into the darkness of a future of pain and disability, that's an amazing light of hope," writes Melody Holmes on her decision to go without treatment, there will come a time when I will no longer be able to walk or drive and that prospect is terrifying," she writes (D25).

These accounts offer evocative portrayals of the uplifting power of hope, described as an "amazing light". Hope serves as a motivational catalyst, spurring individuals to persist in their treatments and self-care efforts. Strikingly, hope is often contrasted with the encroaching darkness of a person's reality, particularly when this reality is framed by psychological fears and

the struggle to make sense of their condition. In this narrative, the untreated condition is constructed as a frightful “monster” lurking beneath the bed, a looming threat that calls for intervention and support.

Hope was not always framed in positive ways. There was a response amongst many of the participants that people and families were taken advantage of by “false hope”. In this construction, hope did little more than play on people's “desperation” as they were “uneducated” in the face of misinformation. In this construction, the appearance of hope, is a mirage and people often are vulnerable and naïve to the effects.

Simply put, desperation, backed up by confirmation bias. When faced with a hopeless situation, people will look for any option that appears to offer hope. And the tendency is to focus on the positive messages (carefully managed by the experimental clinic, backed up by patients who are emotionally and financially invested in the apparent benefits) and to minimise the potential downsides. And, well ... it might work. Probably not, but sometimes, the experimental treatments turn out to be effective. Hope is a potent drug (M-Q1-13).

Parents who have a child with a disability, especially a severe disability that significantly limits function and/or quality of life, may want to consider any therapy that offers hope of a cure or significant improvement. There are many claims on the internet of dramatic improvements following stem cell treatments. There are real concerns about exploiting vulnerable families who only want to do the best for their children. Find out as much information as you can and talk to your healthcare team before planning to travel for treatment (D27).

The capability of individuals to discern between valid and deceptive health claims were perceived to be a recurring issue in the data. In this context, hope was often perceived as a detriment rather than an asset. There was a genuine concern that these individuals and families were rendered susceptible due to the hope that these treatments (usually located overseas and of experimental nature) promised. There was a prevalent sentiment that these individuals and families needed to solicit advice and guidance from individuals less emotionally invested in the situation, typically their healthcare provider or a specialist, such as a neurologist. This was often presented as if these interactions could be an unbiased exchange of information.

I struggle with it as I often think people are being given false hope (M-Q4-21).

From a more critical perspective, the notion of false hope takes on a deeper significance within the context of experimental treatments. It reveals the power dynamics and societal assumptions that underpin the pursuit of medical interventions for chronic illness (Chu-Hui-Lin Chi, 2007). The emphasis on avoiding false hope often stems from a paternalistic attitude, where medical professionals and society at large believe they know what is best for the individual seeking treatment (Lohne, 2022). In this framework, individuals are positioned as vulnerable and incapable of making informed decisions about their health. The emphasis on scientific reasoning and education can inadvertently dismiss or invalidate the hopes and desires of those living with chronic illness (Fitzgerald Miller, 2007). It perpetuates the idea that certain treatments are “right” or “wrong”, ignoring the complex and personal nature of healthcare decisions.

Medical knowledge to date does not have all the answers. There are millions worldwide that cannot get cured or even treated for their condition(s). If the research has not been done or has not yet provided a treatment or medication that the GP or specialist can prescribe then as patients we either have to accept the 'we can't offer you anything' or we have to go outside mainstream medicine for possibilities.

Unfortunately this exposes us to high risk of false hopes and wasted money (M-Q1-21).

We are desperate for hope that the situation we are in is not our forever place.

Businesses are created to feed our hope. An awful lot of people make money from our despair (M-Q2-20).

The concept of false hope has become a "catch-all" concept to imply that alternatives to conventional medicine lack legitimacy within a health context. It reinforces the dominant narrative of conventional medicine as the only valid path to health, disregarding the diversity of experiences and approaches to well-being (Vehmas & Watson, 2014). A critical perspective also questions the unequal distribution of resources and opportunities when it comes to experimental treatments (Basas, 2014). Access to such treatments often depends on financial means, geographic location, and social networks. This creates a system where some individuals have greater access to potentially life-changing interventions, while others are perceived to be left without viable options.

The perception of hope emerges as a pivotal element in how individuals navigate the landscape of chronicity management and grapple with the prospect of a potential cure. Throughout the data, hope consistently manifests as a seductive force, exerting its influence in

both positive and detrimental ways, in particular, when it comes to choosing experimental treatments over conventional. People are made both vulnerable and strong by the process of feeling and hope that sustains them through health decision making.

#### **4.4 Theme 3: Doing (Good Health) as the Ultimate Investment for the Unwell**

Investment in yourself (financial and physical) in your health, as a person who is needing treatment and betterment, is a mainstay of wider health promotion and dialogues. Self-care is constructed as a virtual panacea for all that ails you and society (Kronenfeld, 1979). This theme centres around the notion that health care decisions are driven by a broad set of “investments” in your health that provide an ultimate future payoff. In this theme I will outline a definition of investment from the data, the positionality of those who invest and the different types of investment and investment payoffs.

A definition of health investment can be constructed from the data, both from the perspectives of individual narratives or the instructions given in the online health information (Chu et al., 2017). Investment in your health is constructed as doing everything systemically to be “better”. This construction follows a narrative where, if you or your family does not advocate and take the time to do your “own research”, no one else will, and taking the time, money and emotional labour is a crucial element for both surviving and thriving. The extract below demonstrates the construction of investment as a life-or-death consequence.

The research online enabled us to recognise the warning signs that were deadly e.g. choking and stopped breathing at night, we could get referral to the right specialist for testing. Doctors are very rarely proactive and it is the same for specialists. If we waited he would be dead instead (J-Q1-8).

In this excerpt, the pursuit of health goals is regarded as noble and brave, particularly for those who embraced cutting-edge scientific advancements, positioning themselves on the frontier of healthcare.

The value is the feeling of having turned over every stone. If she hadn't had the opportunity or didn't know if the symptoms would have likely stayed the same.

Nothing ventured nothing gained (A-Q3-26).

Additionally, it is worth considering that certain forms of an individual's health investment, such as training for a marathon, may have a perceived endpoint or finish line. However, when it comes to chronic conditions and maintaining overall well-being, the investment required is ongoing, even infinite, with no definitive conclusion (Veinot, 2010). This is especially true when considering the changes that accompany aging and other life circumstances (Minkler, 1999). Regardless of the specific actions individuals take or don't take for their health, what is constructed as mattering more is the evidence that they are actively seeking ways to alleviate their situation. Accepting the status quo of (chronic) health is often deemed unacceptable by all parties involved.

Throughout my analysis, I followed the thread of investment, identifying its multifaceted meanings encompassing physical, psychological, and financial aspects. Agency in health contexts for the individual is often determined by a person's perceived suitability for treatments, whether they be conventional or experimental (Thorne et al., 2003). This suitability is frequently predicated on an array of qualifications that necessitate a certain level of commitment or investment from the individual. I refer to this as the "wall of investment", drawing a parallel to the proliferating use of websites that require a financial commitment or

the provision of personal details to gain access to specific materials or personalised plans. This wall of investment acts as a gatekeeper, influencing access to specific treatments or interventions. It aligns with the neoliberal framework, which emphasises personal responsibility, individual choice, and market-based solutions (Broom et al., 2014). Within the realm of experimental treatments, the path to accessing treatment often begins with taking the initiative and making personal investments. One such example is the act of providing personal information, such as an email address in exchange for what is considered an “individual consultation” In this process, individuals willingly share their details to explore potential treatment options. Another form of investment in pursuit of experimental treatments is paying for 30-minute visits to doctors or practitioners who have the authority; during which the individual's suitability for the cutting-edge science is assessed. These consultations may involve additional costs, as individuals seek specialised expertise and guidance in their quest for potential cures or treatments. The journey to accessing experimental treatments can also involve an element of being “selected”. Individuals may have the opportunity to be part of a select group of participants receiving the experimental treatment. This aspect introduces a sense of anticipation and hope, as individuals eagerly await the possibility of being chosen to receive a potentially life-changing intervention (MacGregor et al., 2021).

If you have osteoarthritis or injury that has not recovered and continues to cause pain, you may be. While there is a lot of information on our site, it may be best to ring the clinic and talk through your own requirements. We can advise whether a consult with Dr Matti would be beneficial. If you are pregnant or have active cancer, stem cell therapy is contraindicated and we cannot treat you (D37).

Earlier in this chapter, the concept of the driver's seat highlighted the significance of agency and control in the context of chronic illness. Individuals are positioned as active decision-makers, taking control of their treatment processes, and navigating through the complexities of managing their health. This agency is reflected in various types of investment made by individuals, each playing a role in their pursuit of improved health and well-being. One form of investment is the allocation of time, where individuals dedicate significant efforts to researching treatment options, consulting with medical professionals, and engaging in self-care practices. Time becomes a valuable resource in navigating the intricacies of chronic illness and seeking potential solutions.

Change your life, for life

Exercise

Vitamin C

Medication

Meditation

Connection with Self and Others (D20).

Can stem cells be stored and how much does it cost?

Yes. As part of your treatment package, we store your cells in cryopreservation for 1 year free of charge. We can keep them securely stored for up to 20 years at an annual cost of \$350 incl GST billed annually. The upside is that the younger you have your original treatment, the younger your cells remain in cryostorage and these younger stem cells will be available if needed in the future (D37).



Financial investment is another aspect, with individuals constructed as willing to spend their resources on various healthcare interventions, conventional treatments, or experimental therapies. The constructed belief in the potential payoff of these investments drives their decisions to pursue different avenues in hopes of finding relief and improvement. Furthermore, the emotional and psychological labour invested by individuals should not be overlooked (Dolan, 2023). The emotional toll of living with chronic illness and the constant pursuit of hope and escaping disablement can be profound. The psychological investment in maintaining a positive outlook, coping with uncertainties, and managing the emotional impact of their condition plays a pivotal role in their perceived well-being (Ungar, 2011). Overall, the driver's seat metaphor captures the perceived empowering nature of agency and control, and the diverse forms of investment illustrate the depth of commitment individuals are positioned to take on in their pursuit of health and a better quality of life.

Conventional medicine emphasises conspicuous health measures (e.g., BMI), which means the ability to actively engage in the processes of getting and staying well will foster less reliance on the state (Lupton, 2015). Also, the promotion of individual control over well-being warrants critical examination from a psychological health orientation (Moore, 2010). The measures in the data extract below are presented as a means to stabilise and enhance wellness, placing the responsibility squarely on the individual. However, this framing overlooks the broader social, economic, and environmental factors that significantly impact health outcomes (Andreassen & Trondsen, 2010). The "Take Charge Toolkit" (D18) exemplifies the prevailing narrative of self-management, urging individuals to monitor and control various aspects of their health.

Being active

Early warning signs plan

Feeling good

Healthy eating

Making changes

Medicines

Medicines list

My check-ups

My food diary

My goal and action plan

My plan

My medicines

My progress

My weekly activity diary

Pace yourself

Pain

Problem solving

Relaxation and breathing

Sleep

Sleep tips tracker

Sleep, relaxation and breathing

Staying on track

Talking with friends and family

Weekly activity diary

What could I do

What's important to me

What's stopping me

Who can help me (D18).

The promotion of self-management may divert attention away from broader systemic issues that perpetuate health inequalities (Jenkin, 2010). While these resources ostensibly provide simple and useful guidance, they also assumptively position individuals and (possible) health outcomes. They assume a level playing field and overlook the structural barriers that can hinder individuals' ability to adopt and maintain these practices. The toolkit's emphasis on adherence to certain standards of health may contribute to feelings of guilt or inadequacy for those who are unable to meet these expectations.

The field of regenerative medicine, hailed as the next revolution in medicine by some scientists (van Wilgen et al., 2008), offers promising advancements in treating diseases at their source rather than merely alleviating symptoms (Frow et al., 2019). This concept has sparked interest and investment in experimental treatments, with individuals, families, and even states considering these options as potential solutions to the challenges of chronic illness. The idea of operating health care more like a free market aligns with neoliberal ideologies (Bell & Green, 2016), presenting opportunities for individuals to take control of their health and bypass public system waiting lists. In this context, the notion of investing in yourself or investing in your future is frequently employed by websites promoting experimental treatments. In the data I identify a common narrative where individuals or families make what is portrayed as a relatively small financial investment with the promise of lifelong benefits. This narrative is often

accompanied by images of renowned medical professionals and portrays a sense of renewed connection with one's community and loved ones. The dataset includes examples of parents banking cord blood as a precautionary measure for a potentially secure future, showcasing the notion of investing in health as a means of securing a better quality of life.

My dream was to develop robotic technology so people like Robbie could continue to stand up and walk as their disease progressed – and keep enjoying a better quality of life. In 2014 he public listed the company in the UK and then sold it to private investors. Little says there is growing demand for technology in medicine as humans live longer. As we live longer, our expectations have gotten higher as well. We expect to be cured and fixed "I'm not a doctor, I can't cure diseases, but I can build devices that will help make those humans more efficient and give them more time (D8).

The focus on individual investment and self-empowerment may divert attention from broader systemic issues and the need for equitable access to healthcare for all. In conclusion, the concept of investing in experimental treatments as a means of improving health outcomes is prevalent in the discourse surrounding chronic illness (Satz, 2020). The idea of health functioning as a free market, with individuals empowered to make choices and investments in their well-being, is promoted through various platforms. However, these narratives should be approached with a critical lens, considering the potential benefits, risks, and broader societal implications of such approaches (Sen, 2002).

At the heart of the concept of investment in health is the anticipation of a significant "payoff." Individuals are framed as willingly committing themselves to various actions and decisions, perceiving them as essential costs with the expectation of yielding valuable returns.

The framing of investment in health is inherently linked to the belief that the outcomes will justify the efforts and resources invested. It encompasses a sense of hope and optimism, as people actively engage in actions and decisions that they consider beneficial for their well-being and future quality of life.

#### **4.5 Theme 4: Individuals and Families as Agents of “Wellness”**

Mara would do anything to be able to walk and move around again. Mara feels that as her GP and specialist have not personally experienced this condition then they cannot truly understand her experience (M-Q1-62).

In this extract, control and agency are assigned significant importance in how individuals navigate life with chronic illness or disability (Wallston, 1982). In the data, these terms exist on a kind of continuum, reflecting the varying degrees to which individuals are positioned to assume control and make decisions regarding their health and future trajectory. This perspective is predominantly viewed positively, encompassing notions of patient empowerment and the fundamental right of individuals to assert autonomy over their own bodies. The following accounts underscore the idea that individuals like Alice and Mara are exemplifying the actions that any person would take in similar circumstances.

Alice, much like every other human, probably needed to feel in control of her life.

Going overseas to get treatment for her condition, that is otherwise unavailable in her own country, is empowering. Further, there may be some asinine political reasons that prohibited Alice from getting the best treatment, which she was likely aware of (A-Q1-9).

A chance to make her life a little easier. Get back some things she's lost. Feel like she is in control. Gain some of herself back (M-Q2-3).

In the vignettes, some people were seen as knowing their own bodies and are positioned as naturally able to find the right pathway.

Most people do know what their body is saying to them. Some ignore the signs and accept the diagnosis's of specialists. I think she is entitled to choose her own path (M-Q2-35).

Health is frequently portrayed as the ultimate prize, attainable only through maintaining control over every aspect of one's life. This perspective emphasises the importance of taking active steps rather than accepting the unacceptable status quo. Such framing aligns with broader notions of responsabilisation and healthism, as discussed by Robert Crawford (2006) in the context of medicalisation extending into everyday life. The pursuit of control over health has significant historical and contemporary influences, with health improvement efforts directed towards achieving this goal (DasGupta, 2020). While attaining 100% control is an idealised impossibility, it remains a persistent motivator that drives marketing strategies and decision-making processes, positioning individuals in the metaphorical driver's seat of an uncertain domain (Charmaz,1983)

She would have been looking for a treatment option where she feels she is in control and actually doing something towards finding relief from symptoms (M-Q2-26).

This notion of control and agency was debated and contested within the regulated and unregulated website data, where the decision-making process was framed as a matter of

agency and making the right choices. Consequently, the idea of control over both health and lifestyle choices positions individuals as the ideal heroes or heroines embarking on their quest for relief and improved well-being.

Often health problems can slowly change your lifestyle and stop you from doing some of the things that are important to you. Many people have found that little changes in their day-to-day routine can have good results that allow them to get more out of life (D65).

Some individuals even referenced specific indigenous concepts or models to conceptualise grief, family, and the process of building a new life. However, despite these variations, there remained an almost universal belief that control holds immense significance in navigating life with chronic illness or disability.

It's wonderful to hear that his family are supportive of Taane. The best way to approach it is through strengths-based collaboration. Taane's family should only support him in ways he feels comfortable, such as always underscoring his agency when possible, by including him in decisions concerning his life (T-Q5-9).

For instance, Mara, as a retired nurse, was often viewed as an ideal candidate for navigating the complexities of the healthcare system, her professional background implicitly lending her credibility and expected competency.

Mara is a strong and wise woman to not settle for the level of care her GP and specialist have dished out to her if the care has not been helpful and they are unable to offer alternatives. There may be a time when Mara will have to accept that her

illness cannot be improved but she will need to try many alternatives before getting to that decision. As a nurse she will have done thorough research and a risk analysis on this intervention and decided that the benefit outweighed the harm before proceeding (M-Q1-20).

Conversely, Jay was depicted as lacking the requisite executive functioning needed to effectively deal with such complex realities.

Challenge would be to break old habits and the challenges he already faces through his cognitive impairment. He may also find it difficult to stick with a new habit and not fall back to the old one (J-Q3-10).

This perceived deficiency seemed to be a predetermination that he would fail and be vulnerable, as if his inability to fulfil certain biological markers negated his potential for success within the system. The emphasis placed on these biological markers as qualifiers for success or failure reinforces the concept of a medicalised body, where an individual's health status and treatment outcomes are largely determined by their biological characteristics and how well they align with predefined medical standards (Jørgensen, 2015).

Within the data, the processes of receiving treatment seeking medical information were personalised. There was a perceived value in seeking treatment in a way that gives people a sense of value and achievement. This was seen in the extract below in the construction of a sense of connection for Mara in a new community.

To be heard To have her essential needs and previous ability recognised To have her life valued as a human being To be treated as more than a \$60 a week income To be



able to get a diagnosis accurate to the condition to identify further pathways forward  
Treatment options with informed consent To halt further decline in condition and  
ability To be able to return to work and to remain living in her home with the ability to  
perform basic household tasks (M-Q3-04).

It is important to understand that the treatment is not a guaranteed cure for every  
disease. The patient may be denied for various reasons. The effectiveness of the  
therapy for a particular disease depends on multiple factors: duration of the illness,  
age of the patient, the existence of chronic conditions, hereditary predisposition,  
lifestyle, etc (D15).

One of the features of agency in the data were how people positioned and  
conceptualised the idea of lay expertise. Mara was seen as a person with the ideal level of  
agency when navigating health decisions and difficulties. She therefore was constructed as  
having the right to seek alternative pathways and trust her values as a guiding principle for  
health decision making.

There are many potential factors as to why Mara would go against both her doctor's  
advice. A more, detailed anecdote might shed greater light. However, based on the  
limited information above, there could be two main reasons. Because the  
recommendations come from a support group that understands Mara's experience,  
she may feel that their suggestions—tempered by a shared understanding of a unique,  
lived experience—hold much more weight than medical professionals' traditional,  
objective knowledge. In truth, Mara may feel that because her support group are well-  
versed in both the lived experience, and the assumed research that such members

have also undertaken, that they understand the risks much better than medical professionals (M-Q1-10).

100% control - it is her body, her life and she has every right to find people that want to help her in ways that align with her values. Not everything is explained by our current knowledge of medicine and sometimes healthcare practitioners need to acknowledge this (M-Q3-2).

It is beneficial to critically consider the potential tensions that personalised advocacies may carry. While personalised perspectives can be deeply insightful and encouraging, they may not always represent a comprehensive understanding of chronicity and its complexities. There is a risk of oversimplifying the experiences of individuals or overgeneralising specific treatment outcomes (Charmaz, 2002). The increasing prevalence of personalised advocacies also raises questions about the power dynamics involved in the decision-making process (Doble et al., 2016). There is a tension between those whose voices are amplified, and whose experiences are underrepresented or overlooked. How do these advocacies interact with broader health systems, policies, and institutional structures?

Agency is a contested idea and construct. However, within a society that is becoming increasingly more neoliberal (Ayo, 2012) the process of agency has become actively encouraged and sustained in many different forms. Individuals and families are positioned as agents when interacting with services and the medical system as a whole, regardless of the outcome. Furthermore, they are expected to pick up the mantle for finding their own sources of information, which gives rise to the prominence of lay expertise and the positing of different expertise (Lupton, 2013).

#### 4.6 Theme 5: (The Expectation of) Performative Normality

The section will explore the constructions of normalcy, particularly the expectations on people to reach standards of functioning and normalcy. Firstly, I examine the link between normalcy and the concept of able-bodiedness as a compulsory feature of society (McRuer, 2010). Secondly, I explore the concept of passing as a normal person (Sammels, 2015). Thirdly, I explore the regaining of the conspicuous role of presenting health achievement. Lastly, I outline what I call “performative” normality, the ways in which people are expected to conspicuously move from the state of sickness into “promotive” feats (a classic example being no longer relying on a wheelchair or mobility device) (Kim, 2017). The concept of performative normality closely resonates with Robert McRuer's (2010) notion of compulsory able-bodiedness, or the need to present yourself as the societal benchmark, which while unacknowledged as a whole, means being abled bodied. The data suggested that individuals were not only expected to experience improvement but also actively demonstrate their recovery in normative and often physical ways, such as effortlessly performing daily routines or even running a marathon.

The concept of performance within the realm of disability is a widely recognised phenomenon that reveals the intricate ways individuals living with disabilities navigate their lives across various spheres (Davis, 1995). These individuals often find themselves engaging in a range of rituals and actions as they traverse both private and public domains. A telling example can be observed in scenarios where individuals are required to “make a case to qualify for funding” (Kuppers, 2011). In such situations, there exists a compelling need for these individuals to meticulously present their circumstances in a manner that aligns with certain socially dominant expectations.

Within this complex landscape, a distinct set of norms and anticipations are constructed. Depending on the context, individuals may feel a pressure to represent themselves as either more or less disabled, a phenomenon that Bérubé (2015) has astutely highlighted. This dynamic interplay between the individual's genuine experience and the external perceptions and assumptions surrounding disability underscores the performative nature of disability.

Robert Bryden's brain injury was so bad he could barely see or remember his parents' names. Now he's talking clearly and getting his vision back after trying an unconventional oxygen treatment (D33).

My thesis seeks to delve deeper into the intricate interplay of illness and disability performance, specifically examining how notions of cure are enacted and discussed. By exploring these performative dimensions, a deeper understanding can be gained about the transformative and potentially reductive effects of such performances, particularly within the context of chronic illness and the pursuit of curative solutions. Consider the extract above which outlines the distinct "before and after" elements.

Robert McRuer (2005) explores the intersections between queer theory and disability theory, highlighting the parallels between able-bodiedness and heteronormative ideals. In his work *Crip Eye for the Normative Guy* (McRuer, 2005), McRuer posits that the able body is normalised and naturalised in society, much like the measurement of many things against a heterosexual ideal. In a reductionist sense, one is either deemed to have an able body and can function in society, or they do not. This concept permeates both the online and vignette narratives in my data where questions arise about the necessity of returning to normal and the

limited choices individuals have in navigating their conditions. McRuer (2005) also points out that while able-bodiedness is poorly understood as a concept, it infiltrates everyday constructions of people and their ability to connect with their communities. There is often an expectation that individuals must demonstrate a transformation from a disabled state with limited function, to a state of being able to perform all the necessary tasks to be a productive and valued member of society. This notion aligns with the concept of compulsory ableism, which intersects with the obligations and opportunities presented by chronic illness and its treatments, reflecting healthism and responsabilisation (Vallelly, 2021a).

Because at the end of the day you just want to be able to function normally and do the things you want to do without limitations (A-Q1-31).

The data exemplified a concept by Samuels (2020), who frames the achievement of normalcy as “passing”. This is the process by which individuals minimise their disability with a conscious or subconscious desire to appear non-disabled, and to avoid societal pressures and the stigma of living with a disability. This in turn precipitates the negative perceptions of people who cannot or will not resist the urge to pass as able-bodied. Passing is a concept that underpins many aspects of performative normality. An example is doing “abled things” that are considered regular and normal in everyday settings. Being like everyone else and looking normal is an important social value (Rysst, 2010). In the vignette of Tāne much of the discussion is framed around the loss of the ability to pass in the form of a traditional working role. The data focusses on tension between his new life and the old one.

Many of the success markers in the socioeconomic environment, hinge on passing or invisibilising a disability in high-status environments like work (Rose, 2020). Throughout the dataset, there was a prevalent focus on physical normalcy, which heavily influences discussions around the motivations for seeking treatment and post-treatment experiences. The notion revolves around the opportunity to live a life that embodies physical normalcy, including fulfilling roles like taking care of one's family. While the term "abled-bodied" may spark debate among scholars (Trnka & Trundle, 2014), in the data it served as a frequent benchmark for the concept and expectation of normalcy. In the data featuring Alice, there was a sense that a life free from chronicity, with limitless possibilities, justifies enduring potential setbacks associated with treatments that may offer only temporary relief. The prospect of being able to perform tasks without limitations is closely tied to functioning in a normal manner, serving as the standard against which the efficacy of the treatment is measured. There is a belief that the ability to engage in activities and "catch up on life" is intrinsically connected to the ultimate sense of normalcy and the freedom it brings to both the body and mind.

The extract below featuring Mara ties quality of life to functionality in the physical sense, for example doing things and the reliance on aspects such as prescription medication.

A reduction in debilitating symptoms resulting in an improvement in functionality and quality of life. If her pain is reduced then she would also be able to reduce her use of prescription medication (M-Q2-7).

An integral component of passing, revolves around the resolute avoidance of dependency (McRuer, 2005). Within this framework, independence emerges as the pinnacle of accomplishment, a pivotal facet of performative normalcy. This paradigm becomes even more

evident when examining examples like “ground zero loss” (Charmaz, 1983), to achieving profound milestones such as “standing on my feet” (Kersten, et al., 2015), being able to walk, bidding farewell to “brain fog”, and triumphantly declaring the ability to “do things myself”.

The concept of normalcy has been extensively explored by various theorists, especially as it relates to measurement and success (Kersten et al., 2015). It has transitioned from being a statistical term denoting a numeric curve to becoming a yardstick that measures almost everything in society and underpins the notion of a qualified body (Lupton, 2013). As Lenard Davis (2016) points out, the construction of normalcy plays a significant role in shaping the ways in which the disabled body is deemed to “fail”. In the context of my data, the success of treatments or management strategies is often measured by the ability to regain a sense of normalcy or to “get life back”. This achievement is frequently tied to specific tasks or roles. A successful “quest” entails not only feeling better or being free from illness but also performing health and well-being in a visible and performative manner, as exemplified by headlines that highlight individuals with conditions like multiple sclerosis running after receiving stem cell treatment and experimental outcomes (Lupton, 2021).

Ground-breaking treatment for multiple sclerosis has man running again

MS sufferer Hamish Bockett-Smith discusses undergone HSCT treatment in Singapore.

Two years ago he could hardly walk, now he is mountain-biking and running. "Now I can walk the kids to school, I don't have any pain, I'm off most of my medication. I'm out biking, I did a 10km run last year... it's awesome to kind of get my life back (D36).

Over recent years, with the rise of social media, it has become easier and more prevalent to demonstrate and perform health. This is particularly noticeable in areas like body

weight policing and showcasing dramatic before-and-after weight loss transformations (Gibson, 2021), or when showcasing someone's first steps or being back to running again (McPherson et al., 2015). This concept can be exemplified in New Zealand's strong emphasis on sports and the popularisation of physical activities such as surf lifesaving and rugby, which represent hyper-physical moments (Chin et al., 2018). A thesis titled *Mangos, Beaches, and Fitness* (Howson, 2019) aptly explores the dynamics of healthism in New Zealand, specifically examining how young women perceive fitness and health. It highlights the pressures to both appear and live a fit lifestyle, leaving little room for more subtle healing or quiet transformations. In my data, several companies offering experimental treatments in New Zealand have former All Blacks athletes endorsing their services, emphasising the idea of regaining one's life and freedom after receiving treatment for conditions like osteoarthritis and other age-related ailments.

Sports stars regularly seek us out to repair a reoccurring injury or to elongate careers.

We have treated All Blacks to golfers, martial arts to timbersports world champions

(D37).

Over time, health discourse has evolved from focusing on the absence of disease or disability to emphasising individuals' ability to perform notable acts of what can be termed "performative recovery". Performative recovery goes beyond the mere absence of illness and instead centres around physical accomplishments like cycling or walking long distances, as well as resuming societal roles as indicators of wellness (Greenhalgh, 2004). The concept of performative recovery aligns with the critiques of resilience and the expectation for individuals to "bounce back" after adversities. There is internal and external pressure to embody the image of a successful recovery, typically characterised by the complete eradication of symptoms. The



individuals in the data are not simply quietly living out their recovery; they are performing extraordinary acts of health and reclaiming their lives. Media articles often highlight "miraculous improvements," which usually involve individuals actively engaging in normal activities like running or biking (Dobransky & Hargittai, 2012).

Throughout the data, there is a recurring theme of aspiring to return to normal and a desire to perform tasks considered normal. The construction of normalcy has a complex and contentious history, transitioning from a statistical average to an ideal standard that allows little room for deviation (Davis, 2014). This belief system deeply influences the perception of the body and its appearance, actions, and performance (Davis, 1997). The data constructs individuals as willing to invest significant efforts and resources in the pursuit of attaining this standard of normalcy, both for themselves and/or others. Hope becomes a driving force, as the possibility of achieving a normal life is seen as invaluable. The value of normalcy is a strong theme in the data, permeating societal values, notions, and belief systems, with individuals aiming to perform and embody the concept of normal.

The concept of performative normality serves as the cornerstone that unites the core concepts and narrative constructions derived from the data. The time and timelapse towards recovering from chronicity involves a deliberate process of enacting transformation, punctuated by measurable milestones and strategic presentations of the rejuvenated self. This often entails a juxtaposition between a stereotypical image of one's former self and the envisioned shape of the newly embraced life. This idea is vividly illustrated through a compelling example of an individual who once relied on mobility aids, yet now triumphantly participates in running marathons.

#### 4.7 Chapter 4: Summary

The construction of chronicity and the pursuit of cure are deeply entrenched in societal structures, financial incentives, and scientific achievements (LeBesco, 2011). There is considerable focus on framing and fixing long-term health issues, which often overshadows alternative perspectives on living with chronicity (Davis, 2010). The real challenge lies in providing a platform for the transformative and individualised narratives that acknowledge and embrace the complexities of living with chronic conditions (Campbell, 2008). These narratives should not seek to erase or diminish the experiences of chronicity, but rather to create space for individuals to lead fulfilling lives that incorporate their conditions while still participating fully in society. By promoting a more inclusive and accepting perspective, we can challenge the dominant notion that a life with chronicity must solely revolve around the pursuit of a cure (Kim, 2017). Instead, we can recognise that a life with chronicity can be just as acceptable and meaningful as any other, celebrating the diverse ways in which individuals navigate and find purpose within their unique circumstances (Davis, 1999). To achieve this, we must continue to raise awareness, challenge stigmatising narratives, and advocate for policies that support individuals with chronic conditions in all aspects of life. By valuing the lived experiences of those with chronicity and elevating their voices, we can work towards a society that embraces diversity and recognises the inherent worth and dignity of every individual, regardless of their health status.

## Chapter 5: Discussion

### 5.1 Positioning Chronicity in New Zealand

Chronic conditions and the interventions targeting their associated perceived deficits continue to shape and reshape political and public health debates (Hogan & Zong, 2022). Individuals experiencing chronicity find themselves entangled within a complex network of appointments and referrals, often navigating both the broader healthcare system and the National Health Insurance system. Extensive efforts have been made to define and reframe how the public health system perceives and addresses chronicity, determining the balance between functional, social, and holistic aspects of care (McPherson, 2015). While there has been considerable attention given to the self and the experience of loss of identity through chronic illness and disability, with some degree of acknowledgement (Thomas et al., 2015), the wider system's reckoning with these identities remains less well-understood. This includes how messaging and narratives are constructed. This knowledge gap is applicable to well-known long-term conditions like diabetes (Gounder & Ameer, 2018) as well as recently identified conditions such as Long COVID (Wardell, 2021).

Within the collected data, it became apparent that the New Zealand health system was often perceived as chronically underserving individuals living with chronic conditions (as seen in Chapter 3, Theme 3). The language used in some instances portrayed the system in extreme terms, describing it as responsible for creating "medical refugees" (Chapter 3, Theme 3) and neglecting towards New Zealand citizens (Chapter 3, Theme 3). These examples provided detailed accounts of the current state of the system, highlighting the perceived lack of available options and the necessity for individuals to seek experimental treatments overseas.

Additionally, there was a sense of placing emphasis on international experts as the ones capable of meeting the "real need" in addressing chronic conditions. However, there have been considerable developments within different areas of the New Zealand health system. This includes a reprioritisation of diagnosis pathways and efforts to address systemic inequities when it comes to Ministry of Health and ACC funding (Jenkin et al., 2011). Existing discussions around the framing of chronic illness as "deserving" less attention, especially if the illnesses are contested (Swoboda, 2005), are reflected in both literature (Beauchamp-Pryor, 2011) and the data. However, patient advocacy groups and collaborative advocacy have begun systematic efforts to give chronic and rare conditions equal opportunity to access funding and resources utilising lay expertise (Storni, 2015).

New Zealand's public health systems are expanding access to different health resources and decision pathways in line with many international counterparts, as a result of "health globalisation" (meaning the exporting of health ideals and principles across borders; Barnett & Bagshaw, 2020). There are a considerable and ever-expanding array of choices when it comes to navigating health discussions. Some concepts are seen as so universal that they are derisively termed as such, for being anywhere and everywhere, the world's problem (Purser, 2019). For example, 'McMindfulness'. The labels I have termed conventional and experimental treatments are deceptively self-explanatory. Conventional treatments are interventions that are attached to public health systems, and experimental treatments are those that are entirely privatised without any regulation (Novak, 2017). However, positioning them in opposition can create a false dichotomy. In my data, many of the conventional and experimental treatment websites that were public, bore similar elements within their messaging. Both contained messages

centred on the idea that the reader could be in control of the life and lifestyle they wanted. The distinction between conventional and experimental lay in the results these websites were offering, for example, the conventional websites emphasised a lifetime of management, while often the experimental were framed around a singular dose or pill (usually in an exotic location), that promised freedom from the condition in question.

The exploration of constructions of living with a chronic illness deserves thorough examination, especially within publicly accessible online resources. Being a good and idealised patient requires more than just personal determination and willpower (LaMarre et al., 2019). It necessitates stronger connections with available structural supports that acknowledge the complexities of chronicity and allow sufficient time for exploration. Using resilience and strength-based language (e.g., “being in the driver’s seat of your health”; Chapter 4), should not become a mere catch-all phrase and tactic for venturing into uncharted medical territories and being conventionally (Ball, 2021), chronically well (Yoder, 2002). Instead, patient empowerment should be a call to recognise the multifaceted aspects of chronic conditions and therefore should provide adequate resources and support for individuals on their health journey. This concept of integrating health messaging from all avenues draws on wider studies of chronic illness and studies into wellness control (Kristensen et al., 2016). For example, considerable work has been done to shape the space when it comes to the experience of cancer and messages around oncology (Thorne et al., 2005). The tensions between complex diagnoses, health directives, navigation and decision-making have many different aspects (Thorne, 2006). The language around cancer is carefully scrutinised and the construction of language around chronicity could benefit from the same attention (Chu-Hui-Lin Chi, 2007). A comprehensive

understanding of living with chronic illness should be fostered in public-facing online resource (Foroughi et al., 2016). Emphasising the importance of structural support and avoiding oversimplification through resilience language leads to more meaningful and informed discussions about chronicity, and the experiences of those affected by it (Introne & Goggins, 2019).

Questioning authorities and medical influences are slowly no longer becoming the exclusive domain of critical researchers (Lupton, 1993). A tension that has always existed, but is growing in influence within the lifestyle ecosystems, is determining who is responsible for health decision-making (Layton, 2009). Individuals and families are expected to be in the “Driver’s Seat” (see Chapter 4, Theme 1), while simultaneously experiencing many different authorities' voices, from lay expertise to medical experts, within direct-to-consumer marketing. New Zealand’s constructions of public health give rise to a “choir” of different points of authority in a person’s life (Jenkin et al., 2011). In my data, the concept that online support groups were giving the best advice because they come from a place that aligns with the person’s values resonates strongly. At different points within the healthcare interaction, the patient, parent, family and doctor are expected to play different roles (Lupton, 1996). The concept of investing in oneself extends beyond seeking and achieving good health. There exists a multi-billion-dollar industry catering to what has sometimes been condescendingly labelled as the “worried well” (Fitzgerald, 1994). However, within the realm of chronic conditions, the combined forces of responsabilisation and decentralisation steer individuals away from long-term state-provided services and towards more experimental paths (McGregor, 2001). The act

of having “turned over every stone”, is a way to actively seek every possible solution before accepting defeat.

## **5.2 Responsibilisation**

The increasing capability to monitor and adjust micro and macro health elements creates expectations that individuals should actively engage with these opportunities. Those living with chronicity often encounter various forms of measurement, which often come with the expectation of regular measurement as an indicator of wellness. These measurements include sleep cycles, nutrition and food profiles and exercise patterns with circadian rhythm (Kersten, et al., 2015). Measurements have a pervasive presence, having become normalised and ingrained into Western society (Wasserman & Asch, 2013). The pressure to constantly measure and optimise health can add an additional burden to individuals already navigating the challenges of chronic conditions. This expectation of continuous self-monitoring and improvement may cause the complexities and unique experiences of each person's health process to be glossed over (Howson, 2019). In my data, people within the dataset were considered worthy of health navigation depending on their ability and perceived willingness to weigh the pros and cons and keep themselves in the most ideal health category. This attitude was constructed as the means to qualify for experimental treatment or to give the best chance for the conventional process to show measurable results.

Critical theorists and activists resist this narrative through contending that the overt resourcing of individual surveillance connects strongly with authority figures and health as a function of society (Fitzgerald, 1994). Instead, academics in this space are more in favour of introducing concepts such as the Labour government's Wellbeing Budget (Coney, 2002), which

examines the societal obligations in health. It is essential to critically examine the implications of such pervasive measurement practices and consider the potential impacts on individuals' well-being. Striking a balance between utilising health monitoring technologies and respecting individual autonomy and well-being is crucial in providing meaningful support to those living with chronicity.

A patient's interactions with medical professionals are considered vital, regardless of whether they follow conventional or experimental health approaches (DasGupta, 2020). The nature of these medical encounters is evolving, with research increasingly recognising their collaborative nature (Sosnowy, 2014). Deborah Lupton's (1993) concept of “dethroning” illustrates the shift away from the monolithic, one-sided authority figure in these interactions. In analysing my data from both participant and website sources, I identified the construction of an idealised version of medical encounters, whereby each party has equal ability to comment, and knowledge is neutrally exchanged. However, it is important to note that these idealised expectations may not always be met in reality (Stone, 2018). The complexity of healthcare systems, varying approaches, and individual circumstances can influence the actual outcomes of these encounters, especially in contested illness spaces, where legitimacy is debated (Charmaz, 1983). Recognising the changing nature of medical encounters, and the expectations surrounding them, can inform discussions on how to foster more effective and patient-centred interactions between individuals and medical professionals. Emphasising collaboration, communication, and understanding the complexities of each patient's needs can lead to more fulfilling and productive healthcare interactions (Campbell & Campbell, 2009).



The data is consistent with a concerning aspect of personalised medicine (Greenhalgh, 2004), and the notion of a personalised question for health, where not only medicine but also seeking health information can be personalised for health (Sosnowy, 2014). While in theory, personalised medicine has the potential to be more cost-effective and readily available, several significant barriers stand in the way of achieving this goal. One of the primary concerns is the high cost associated with developing and implementing personalised treatments (Murdoch et al., 2018). Cutting-edge technologies, genetic testing, and tailored therapies can be prohibitively expensive, making them accessible only to those with substantial financial resources or comprehensive health insurance coverage. This creates a stark divide between those who can afford personalised healthcare and those who cannot. Additionally, the availability of personalised medicine relies heavily on advanced technological infrastructure and specialised expertise (McLean et al., 2015). Access to these resources may be limited in certain geographical regions or underprivileged communities, further exacerbating health disparities (Turner & Knoepfler, 2016). Personalised medicine heavily relies on extensive and diverse datasets to develop accurate and effective treatments (Sánchez & Fuentes, 2002). However, issues related to data privacy and consent can hinder the collection and utilisation of such datasets, impacting the quality and inclusivity of personalised health options (Love, 2020). The focus on individualised treatments can sometimes overshadow broader public health initiatives and preventive measures (LeBesco, 2011). While personalised medicine may offer targeted treatments for specific conditions, it may neglect the importance of addressing broader social determinants of health and systemic factors that influence health outcomes for populations (Ayo, 2012).

Critics argue that this idea of personalised health inadvertently or deliberately exacerbates existing inequalities (Jenkin, 2010). While the concept of tailoring healthcare to individual needs may sound empowering, it assumes that everyone has equal access to resources and information necessary to make informed decisions. In practical terms, this is far from the truth. Individuals from marginalised communities or lower socioeconomic backgrounds may not have the same level of access to healthcare options, cutting-edge treatments, or even basic health education. The burden of navigating complex healthcare choices and understanding personalised medical information can fall disproportionately on those who are already facing multiple barriers (Ayo, 2012). Moreover, the expectation of individuals to integrate health decisions into their lifestyles may not consider the social and economic realities they are navigating. For some, juggling work, caregiving responsibilities, and financial constraints may leave little room to prioritise personalised health exploration, unless there are elements of desperation (Berger et al., 2016).

It is crucial to recognise that the pursuit of personalised health should not perpetuate existing inequalities. Instead, there needs to be a concerted effort to ensure that resources and information are accessible to all, irrespective of their background or socioeconomic status. Additionally, healthcare systems must prioritise addressing systemic barriers and inequalities to ensure that personalised health options are genuinely empowering and inclusive for everyone. To truly harness the potential of personalised medicine and ensure equitable access, efforts must be made to address these barriers. This includes advocating for policies that promote affordability of personalised treatments; investing in healthcare infrastructure, fostering data privacy and consent frameworks, and maintaining a balanced approach that integrates

personalised medicine within comprehensive public health strategies. Only then can personalised medicine fulfil its promise of improving health outcomes for all individuals, irrespective of their background or means.

### **5.3 A Place for Chronicity**

By adopting a critical psychology lens, we can challenge the individualistic paradigm and advocate for a more holistic understanding of health. This includes recognising the influence of social and environmental factors, advocating for equitable access to healthcare resources, and fostering collective efforts to address the structural determinants of health disparities. By doing so, we can move towards a more inclusive and transformative approach to health in public information that values the well-being of individuals and communities (Davis, 2014). Once I finished the first stage of the analytic chapters an idea around what might be possible in the future began to “haunt” my writing process. In weaving the threads together for the final analytic lens (which is frequently known as *Discussion*), was there a way to “soften” the edges of neoliberalism? The shift towards “compulsory cure” constructions reflects the idea that chronicity almost always represents a financial, physical, and relationship drain (Gounder & Ameer, 2018), or what I refer to as the hostile ecosystem. Making space for chronicity to exist, with the work to alleviate suffering, and the shades of “betterment”, should not be framed as mutually exclusive exercises or exclusively within the domain of critical academics.

A softer ecosystem may encompass several defining elements, such as the language that is used to construct ideas and practical elements in the space of activism and advocacy. A softer ecosystem would not have the concept of cure as its lifeblood and would challenge the condensed narrative of chronicity. There is no simple and single progression between the

stages of being unhealthy to “complete wellness”, and there is a need to acknowledge that people’s experiences of health are not linear (Charmaz, 1991). As an example, specific work has gone into reframing how people understand the notions of “recovering”, away from framing chronic illness as something that needs “normalising” (e.g., the principles of mobility and movement, in between wheelchairs and walking as the ultimate and frequently measured elements; (Nicholls et al., 2015). Also, there is a specific need to grapple with the constructions of illness that are presented within media, popular science and wider society (Davis, 2014; 2016). Promoting and sustaining a softer ecosystem brings together many of the constructions that I shape and begin to understand within this thesis. The idea of broadening the constructions of health able to be drawn upon, within multiple mediums, by people under the chronicity umbrella does not require the internalising of a singular model of experiencing health.

The second element of a softer ecosystem is to be cognisant of, and weaken the automatic connection between, chronicity and illness (Radcliffe et al., 2013). The two notions can and should often be seen as working separately, instead of the current automatic association between disability/sickness and disability/illness. People can come under the umbrella of chronicity without experiencing illness and people who are ill are not always in a state of chronicity. This automatic rhetoric embeds itself within the contours of ableism because it creates expectations of meeting socially prescribed wellness standards (Campbell, 2008). The third way the ecosite might be made softer is through reframing and repurposing generic descriptions of conditions as well as other movements towards inclusive and encompassing languages. An illustrative example is the ways in which people are given the

choice to freely frame how they scaffold their condition. This involves changing from condition-first language toward person-first, and a move towards systematic and governmental change when it comes to shaping health and illness narratives.

A fourth way the ecosite could become softer is through challenging how people define and understand the prospect of cure. Cure is currently a singular and monolithic construct which works to erase any alternative constructions through overtly claiming them to be “wrong” (Porter, 1985). Instead, cure could be broken down into smaller or more realistic components, such as a lessening of intensity or to meet a different threshold other than complete alleviation of symptoms (Wasserman & Asch, 2013). This would allow for a different dimensionality in approaching notions of cure and symptom management (Basas, 2014).

The metaphor of being in the driver’s seat (Chapter 4, Theme 1) and the suggestion that “you” need to be a good patient (Chapter 4, Theme 1) to feel better is an idea that needs to be challenged and resisted. Currently many documents that outline ways for a person to manage their condition are presented in health settings, with self-motivated detail around their whole lives. Instead, based on the data, it would be easier to frame suggestions like sleep diaries/activities schedules as small snapshots in an overall life that may wax and wane. Furthermore, there should be more efforts to communicate the need for institutional support that live up to the expectations of New Zealand’s international and national obligations such as Code of Health and Disability Services Consumers' Rights.

The narrative of responsabilisation and self-empowerment is deeply intertwined with the belief that each person, regardless of their circumstances, possesses a lifestyle that significantly impacts their overall health (Unger, 2011). In the realm of online information

lifestyle is frequently depicted as a crucial determinant of success or failure in both conventional and experimental treatments. A noteworthy commonality between the two datasets is the recognition that individual factors play a role in shaping treatment outcomes. However, within critical discourse, there has long been an acknowledgement of the limitations of the "lifestyle" and the promotion of a "healthy lifestyle" constructions, as they tend to place an undue burden on individuals while overlooking broader societal factors (Ulrich, 2003). This critique highlights the tendency within these constructs to blame individuals for their health outcomes, attributing outcomes solely to personal choices and behaviours, while neglecting the influence of structural and systemic factors (Layton, 2009). Therefore, critical tools can be utilised to resist the messaging around the lifestyle construction and to include the consideration of larger socio-cultural, economic, and environmental contexts that shape individuals' health opportunities and decisions (LeBesco, 2011). A compelling illustration of the lifestyle construction can be found, when revisiting the fictionalised accounts of Jay and Tāne, two men living with different forms of disability. Both individuals are constructed as needing to navigate the complexities of living with chronic conditions while being encouraged to take control of their health through lifestyle choices. This narrative reflects the broader societal emphasis on individual agency and the belief that personal choices hold the key to improved health outcomes (Vallelly, 2021). While lifestyle factors can play a role in health management, they do not exist in isolation, and broader systemic factors must be considered to address health disparities and promote health equity (Crawford, 1980).

Seeking betterment of symptoms play an important role in how people understand their experience of chronicity. However, cure as a transformative act reflects the neoliberal

environment. One form of individualism within health is the prevailing belief that individuals are responsible for seeking and “investing” in their own health (Chapter 4, theme 3). As scientific advancements and medical technology continue to expand and become more accessible in everyday life, the expectation of attaining complete symptom-free health also increases (Porter, 1985). The fictionalised scenarios in the vignette study explore this concept and revolve around the quest for knowledge and understanding of health-related matters. The aspiration to find a cure for any identified problem, as defined by scientific, medical, and other disciplines, was a common and pervasive theme in my data. Throughout history, whenever a problem has been identified, there have always been individuals, companies, or organisations willing to offer solutions and assert their legitimacy (Lee, 2007). However, the concept of a cure can vary, and it may not necessarily be a prerequisite for obtaining full New Zealand health citizenship. An important theme within the data was “finding control” (Chapter 3, Theme 2). This theme conceptualises negotiating health and navigating the challenges of chronicity and highlights the multifaceted and nuanced nature of health experiences, where individual agency and control play significant roles in the pursuit of improved health outcomes.

The media data from the experimental treatments websites is predominantly shaped by a transformative narrative, wherein individuals with long-term conditions seek to become perceived as someone who experiences little or no impact from their condition. Advertisers, medical authorities, and advertisements often present a narrow and idealised portrayal of individuals after undergoing treatment, showcasing only a snapshot of their lives in "paradise" under the care of "the best doctors" (Chapter 4, Theme 3). The construction of chronicity at its core raises questions about how individuals, families, communities, and the state contend with

long-term conditions (Charmaz, 1991). While neoliberalism undoubtedly exerts significant influence in various spheres, it is essential to explore alternative perspectives and frameworks to understand "chronicity and comorbidities" (Sointu, 2005).

By centring and embracing the concept of "crip time" (Kuppers, 2014), we can challenge the binary approach that juxtaposes living with a long-term condition against the need for a cure and a transformation to a new state. Embracing crip time acknowledges that an average life can include individuals who may not be in perfect health, just as there are other variations in life. This perspective encourages a more inclusive portrayal of individuals with chronic conditions, one that goes beyond medical advertising stereotypes and recognises the diversity of experiences and identities within the chronicity spectrum. By delving into the nuances and complexities of chronicity, we can move away from the singular focus on cure and highlight the importance of valuing individuals for their unique abilities, needs, and experiences. Embracing a broader perspective on chronicity can promote a more inclusive and compassionate understanding of individuals living with long-term conditions, fostering a society that respects and supports their diverse ways of living and thriving (Jorm et al., 2005).

In examining the concept of walking and achieving physical independence, it is important to challenge the assumption that walking is the ultimate signpost of recovery and "promotive normality" (Chapter 4, Theme 3). While walking is undoubtedly a significant aspect of mobility and independence for many individuals, disability and chronicity can manifest in diverse ways, and not all individuals may have the ability to walk or weight bear conventionally (Rimke, 2000). Promoting the idea that walking is the ultimate indicator of recovery can (in)advertently perpetuate ableist notions and further marginalise individuals with different



forms of disability or limited mobility. The premise that well-being is defined by the ability to walk is pervasive and problematic (Kersten et al., 2015). Embracing a more inclusive perspective that values the diverse experiences and capacities of individuals living with chronic conditions encourages the weaving of diversity into society (LaMarre et al., 2019). A nuanced approach to weight bearing and mobility acknowledges that well-being can be achieved, and life can be lived fully without having conventional “full” mobility. Different forms of mobility aids, adaptive technologies, and support systems can enable individuals to lead fulfilling lives, actively participate in society, and achieve a sense of “normalcy” that aligns with their unique circumstances (Davis, 2014). By embracing a critical perspective and moving away from a narrow focus on walking as the goal, we can foster a more inclusive and compassionate understanding of chronicity. This approach values individual autonomy, acknowledges the diverse experiences of those living with chronic conditions, and advocates for an inclusive society that accommodates the varied needs and capabilities of all its members.

The prevailing perception of “patient-hood” within the general public and society at large often revolves around the virtues of individuals and families who are perceived to assert agency and take control of their health. Unfortunately, this emphasis on agency can inadvertently lead to stigmatisation of those who cannot meet these perceived standards due to various reasons (Coleman Brown, 2013). However, there are alternative models that focus on health, resiliency, and community connectivity that are gradually gaining more attention, resources, and recognition (Right & Mastern, 2015). These models challenge the individualistic perspective and instead prioritise the collective well-being of communities and the role of social connections in fostering health and resilience. By embracing and promoting these alternative

models, we can create a more inclusive and supportive environment for individuals and communities that may face challenges in meeting conventional standards of patient-hood (Sosnowy, 2014). These approaches acknowledge the diversity of experiences and circumstances that people encounter in their health processes, fostering a society that values and uplifts all members regardless of their ability to conform to societal expectations of agency and control (Pantazakos, 2019).

Indeed, within the New Zealand context, there are existing examples that illustrate how physical health and perceived abilities are just one part of a much larger societal narrative (Jenkin, 2010). Initiatives like Whaikaka (n.d.), driven by the Ministry for Disabled People and Enabling Good Lives, emphasise the need to address broader societal issues and work towards creating a more inclusive and equitable environment (Barnett & Bagshaw, 2020). The challenge lies in sustaining the momentum towards addressing inequalities and promoting alternative perspectives. Concepts like crip time (Kuppers, 2014) and CDT (Hall, 2019) are already influencing practices in various ways, even if they are not always formally recognised by name. The real test is in giving these notions, causes, and structures equal recognition and consideration alongside more easily digestible concepts like responsabilisation, which often masquerades as empowerment without critical examination (Juhila et al., 2016). To create lasting change, it is essential to challenge the prevailing narratives and power structures that perpetuate inequalities and advocate for a more inclusive and diverse understanding of health, ability, and well-being. By amplifying the voices of marginalised communities and promoting meaningful participation in decision-making processes, we can work towards building a society that truly values and respects the uniqueness of each individual's experience and needs (Jenkin

et al., 2011). This requires ongoing effort and commitment from all stakeholders, including government agencies, healthcare providers, community organisations, and the broader public (Love, 2020).

#### **5.4 Methodological Reflections**

One of the more challenging aspects to unlearn when it comes to understanding the distinctions between quantitative and qualitative research is the abiding attachment to a singular scientific method (Alderson, 1998), which typically includes study limitations and weaknesses. In line with my critical qualitative orientation, I have focused on specifically tracing the decision process and the reasoning behind it (Alderson, 2021), and so now reframe limitations and methods in the form of a methodological reflection, highlighting the key decisions within the methods. This will indicate where decisions may have an influence on the outcome and the possible learnings for future research on a similar topic or method combination. I will also situate my research and methodological decisions within the broader concepts of the research field and theoretical frameworks. I am not attached to the quantitative ideas of replication, generalisation, and highlighting limitations. This area of navigating conventional and experimental research study and community activism will become increasingly relevant as technology and medical innovations are more economical and accessible (Novak et al., 2016). The context of chronicity or any research project needs careful consideration and has many inherent contradictions. These are the aspects that came into play in my methodological process.

##### **5.4.1 Reflections on Study One: Online Content Analysis**

My decisions around the search parameters for my research seemed relatively straightforward at the time I was making them. However, in hindsight, after completing my analysis, there were decisions that could be made differently that would provide different understandings of chronicity and its consequences in public health domains. One of the aspects that I was not anticipating was the shifting website landscape, which impacted how I shaped my definition of the different types of information. The experimental treatment websites regularly shut down and shifted, and these needed to be taken into account carefully when building the methodology and methods. One of the elements I would incorporate into a search of health information is a system or orientation that allows for framing and understanding of testimonials and personal narratives within the online health information, which may have identifying aspects or work differently. Understanding testimonials will play an important role in the understanding of personalised methods in health decision making and their interactions in New Zealand (Coney, 2002). This is particularly relevant because testimonials are allowed as part of medical advertising within New Zealand. In future research, I would have a dedicated document to highlight any likely changes to website information that I include as part of my data in case this changes during the search process. Furthermore, I would also take extensive screenshots as I move through the process, so any changes were documented.

#### ***5.4.2 Reflections on Study Two: Vignette Study***

To an extent, my choice to conduct a vignette study remains one of the more difficult decisions in my entire thesis. In the second part of my research, I considered many different methods and iterations before settling on the idea of fictionalised chronic illness scenarios. Of course, one of the harder realities of this kind of qualitative research is that you cannot rely on

secondary sources alone (Gray et al., 2017). A student researcher, with the help of a supervisor, needs to be willing to put their skills and interpersonal dynamics potentially at risk by engaging with people and for the most part, communities that they have a level of connection to, and investment in (Wendell, 2001).

It became increasingly apparent that I could not simply rely on participants discussing and dissecting the online content because that would not capture the constructions of chronicity and cure narratives, and many of the websites were not user friendly. I wanted to include data that more directly addressed how people make sense of chronicity and the cure pathway. Therefore, it became important to build the second study so that participants could weave their understanding of chronicity into whatever they were reading or reviewing. In this sense, framing everything onto the stem of the vignette created far more opportunities for exploration and understanding. At first, I considered offering a story stem with key differences in each scenario. This story completion method has a reputation for allowing individuals the space to explore explicit meanings and different approaches towards a particular collective topic (Atzmüller & Steiner, 2010). However, through a process of iteration, it became apparent that the areas I wished to explore around chronicity potentially needed more richness of detail than a story completion task could easily accommodate. This is especially the case when considering that I would not be there for follow-up or to explain any ambiguities in the scenarios. A vignette study shares many of the same characteristics as a story completion but allows more details and reflecting on contested topics (Finch, 1987), which is particularly useful when there are so many ways to explore treatments with multiple scenarios.

An element that I could not explore fully but became important to the study was the degree to which the participants were wanting to engage with me as a researcher about their experiences during the study. The premise of the online vignette study was that people could remain anonymous and that the demographic data would be deidentified. However, a number of participants emailed me directly with feedback, engagement and specific examples of their lives and intersectionality within areas of health and advocacy, in a way that could potentially be identifying. Participants wanted to use the vignette characters as starting points for dialogues with me about their experiences, however, I did not have the capacity or scope within the research to incorporate interviews or focus groups, or extensions to the vignettes.

I think future research that allows people to construct or deconstruct chronicity using these kinds of methods would offer ways to explore the intersection between chronicity and cure narratives in more depth. Had there been more time, I would have incorporated more consultation from the different communities about their perspectives on both chronicity and cure, to shape the foundations of the study directions. Providing space for such narratives and discussions remains an important part of my academic values and theoretical approach.

Framing the vignette study within the context of an online survey involved a series of small decisions that had profound impacts. One of the biggest challenges was that I, as the researcher (who knew the topic intimately), was not there to provide clarification or insight unless participants contacted me directly with queries. Therefore, the content needed to be self-contained, especially because the topic connected with personal experiences and there may have been a temptation to go off-topic. My careful crafting of both the scenarios and questions involved finding a midway point between providing enough specificity and not

implicitly guiding any potential “correct” answer to the questions. The vignettes were carefully rendered to construct a narrative of the experiences of people and families in ways that were considered typical scenarios, supported by the literature around how people engage with treatment options (Gray et al., 2017). I had to carefully strike a balance between too much and too little information, and also take care not to unintentionally provide leading questions, while centring chronicity and the idea of seeking treatment and cures. The vignette responses provided extensive commentary on many different treatments that were considered appropriate for different conditions, either for the whole body or for specific problems such as swallowing. Because there is greater diversity in what people consider “against the grain” treatments than I first thought, in the future I would highlight a more strength-based model and include different elements of treatment, rather than only experimental or conventional overseas treatments.

One aspect of the fictionalised scenarios that had an impact was the framing of gender and the role that both men and women played in making sense of chronicity. The experiences of Tāne were underpinned by ideas and assumptions around the masculine roles of being the provider and a former CEO. Career or vocational pathways were not present in the data for the fictionalised accounts of Mara and Alice. In hindsight, presenting such a career change was unintentionally a gender normative signpost. He could have just as easily been a stay-at-home father who become ill. Similarly, Mara or Alice could have been the former banking official who self-funded treatments. In a similar concept the perspective of youth and “intellectual impairment” of Jay become something that people focused on, rather than the fact that gaining a sense of independence is common for everyone, regardless of the perceived or actual

impairment. There remains a preconceived notion around youth and people living with intellectual capacity that is perceived to be “below average” (Davis, 2010). Within the data from the scenario of Jay there was a distinct intersection between constructions of the “folly of youth” and the pathologising of impairment and cognition. The perception of competency is something that warrants its own vignette or research topic when it comes to health navigation and decision-making. In the data, Jay was made vulnerable in a way I was not necessarily expecting. In hindsight, I would have constructed the vignette so that the different aspects of health navigation and perceived competency were addressed more directly alongside what is thought of as “hard life aspects” like gaining independence and self-directed health decisions.

### **5.5 Personal Reflections on Accessibility**

As a researcher who lives with a physical disability, I am acutely aware of the many barriers that people living with different forms of impairment face when wanting to participate in research. Researchers and clinicians have ethical obligations to provide meaningful consultation (Bérubé, 2020). However, in practice, such exercises often remain as little more than a checkbox (Wilkerson, 2020). Within the context of this thesis, I have done my best to strike a balance between the practicalities of a part-time master's thesis and my professional insights when it comes to removing barriers. I cannot judge the success or failure of such efforts beyond participant feedback. However, within this section, I will outline some ideas around accessibility and inclusion that came from my experience, in case it is of use for future studies at the master's level and beyond. Reflections on accessibility have long been absent from general research unless there is a specific reason for including the intersectionality of disability or the discourses around it (Schalk, 2017). In that sense, I may be perpetuating the stereotype



that only within studies around disability are such things considered (Lazard & McAvoy, 2020). But I still felt this concept was important to include or consider within wider reflections. Therefore, I will list some aspects that I considered which may be useful when framing a topic with accessibility elements. Accessibility should not always be an afterthought or considered a luxury when measuring against other competing requirements. Making work accessible does not need to be intimidating or burdensome, but more an opportunity for innovation.

As previously mentioned, I am in the uncomfortable position of being labelled an “expert” in this area, frequently providing the “lived experience” perspective for health initiatives and company policies. One way I do this is through being on panels that review and give assessments on research concepts, however, an individual cannot account for the needs of multiple communities. There needs to be precision and accuracy when claiming what is needed from lived experience. In this thesis, I am not able to do justice to the nuanced constructions and positioning of lived experience and expertise, which deserve much more interrogation. The inclusion of lived experience elements within research is growing inconsistently and slowly, but it is starting to mean more than a check box on an ethics form to demonstrate community engagement or diversity (Davis, 1995). I would like to consider this section a “lived experience snapshot” with all the limitations that a particular moment and dimension in time implies. These I have reinforced throughout the different elements of this research, including group discussions, community outreach, literature reviews and wider reading.

The first consideration is physical accessibility to spaces, in the case of interviews or focus groups, such as entering buildings, or accessing any interview or focus group spaces. Elements to consider include clarity for directions, height of tables and access to writing

material or recording spaces. These things do not need to be “perfect”, but the important point is acknowledging that these difficulties may occur. People who experience access needs can frequently offer suggestions or insights on what would be best to meet their needs, either before the interview or after.

The second element to consider is digital accessibility. There are limits to how many things you can manipulate in software tools. Factors to consider include Zoom capability for people with eyesight impairment, voice-over features, and foreground and background manipulation. This means settings in the computer tackle accessibility needs, for example, reading text out loud or having appropriate contrast points or cursor size at appropriate sizes. Most companies that are run through university services have “accessibility” policies or options in places such as Survey Monkey, Qualtrics, Zoom and dictation services. Again, accessibility can be an iterative process with trial, error, and mistakes.

The third consideration is building flexibility into your timing. It is tempting to frame research task timing in neat increments such as surveys taking 15 minutes or interviews, an hour. To make participating in research more accessible, allow for extra time or breaks into the process for people that have communication, writing differences, pain and physical or cognitive fatigue. It is important to acknowledge that not all conditions are visible or signposted in an obvious way, participants may be doing everything they can to “pass” as non-disabled. Within the context of any research, it is important to consider equity without demanding disclosure of impairment. Where possible, tend towards advertising more time than less, so that people can have the opportunity to take breaks in person or come back if the study is online without feeling like they are being a burden to the researcher or research process (Titchkosky, 2020).

## 5.6 Implications for Research and The Community

This research contributes to the broader understanding of experiences of chronic illness and disability within New Zealand. Specifically, it looks at how experimental treatments are understood by examining discourse and language around this. This was done via two sites: online spaces and participant generated responses to fictionalised scenarios. What this analysis demonstrates is that both conventional and unconventional health messaging is shaped by the concept of individual responsibility for health, and promote constructions around living a person's "best life". Change is not simply a matter of providing more regulation around seeking experimental treatments, but seeking to understand the compulsory normality that motivates many health discourses. Within the context of people living with chronic illness and disability, this has implications for how their conditions and the sense of "burdenhood" is often constructed and understood. If the wider forces of neoliberalism, healthism, and individual responsibility are given more attention outside of critical spaces, then huge efforts to seek individual cures may be considered more of a negotiation than an absolute necessity (Kim, 2021).

A worked example of this comes from my professional life working in paediatric neurology and patient advocacy. Many families feel pressure to go overseas for "pioneering treatment" even if the treatment is not considered risky. This involves considerable financial, emotional, and physical investment. Frequently, these experts are situated within a particular context, for example, reducing the neurological impulses when there is overactive nerve condition. Living with these conditions is a lifelong experience and treatments such as these provide "snapshots", meaning that they deal with symptoms in that moment but ignore the

reality of living with chronicity long term (Kim, 2021). Conversations and discourses need to broaden so that it is more widely understood that the experience of chronic illness and disability has wider implications than a simple pathology or “problem-set” indicates. A conversation drawing on this research would include explanations of this difference and why it matters.

There are also implications for clinicians, researchers, and people who specialise in science communication when it comes to automatic language around “patient empowerment” and them having the “driver’s seat”. The resources that are widely circulated and the conversations that occur can be more considered when they acknowledge concepts like patient choice, consumer engagement, and empowerment. Many of these messages implicitly or explicitly reinforce the idea that the individual is taking on these experiences alone. A worked example is the well-circulated and popularised Health Navigation (Barnett & Bagshaw, 2020), which makes suggestions around lifestyle changes to be a “good patient” and to “see change” (Steinberg, 2015). Frequently in these resources, constructions of lifestyle are seen as a panacea, whereas in reality for many people there is a definite limitation to what “lifestyle” can achieve. It would be more practical for these online resources to centre around making connections to the broader community and healthcare systems while learning that particular language is inherently weighted and does not come from an entirely neutral place (LeBesco, 2011). In the future I would like to see the idea of a softer ecosite for chronicity embedded into everyday patient resources and wider conversations about treatment, cures, and management. Specifically, the idea that it is possible to live with conditions without pressure to actively seek

treatments within cure narratives, or that the alleviation of symptoms is not singularly the responsibility of the individual but also the state (Vallelly, 2021).

## **5.7 Future Research**

Throughout this study and particularly as I was revising and reshaping the discussion section, several thoughts for useful future research struck me as, at the time of writing, a hopefully graduating master's student and community advocate. The research questions and method of my study worked practically to identify dominant understandings about chronicity and cure, however, it did not allow for an exploration of some of the nuances around this topic. A focus group design would enable a study of more collective or collaborative constructions of chronicity and cure narratives in New Zealand, and the subtleties underpinning them (Wilkinson, 1998) Focus groups could include participants who have gone through experimental or conventional treatments, finding out about their experiences with any perceived social expectations or beliefs about chronicity.

Future directions for exploring this topic further could consider elements that are not so general. For example, data could be derived from online information from advocacy community groups, foregrounding their perspective on how chronicity and cure narratives affect their work, or how they make sense of conditions on their websites. Research questions could encompass the distinction between general health navigation for being 'healthy' and specialised searches for specific conditions when it comes to interacting with sources of information. For instance, the experiences are likely very different if a person's condition is comparatively well known and given wider societal legitimacy, versus "contested" conditions (Swoboda, 2006). After completing this study, my own future research interests are around

how health status can be weaponised and lead to curative hostility and violence, and how that violence can have profound implications on individuals. Another is how resisting the powerful influence of healthism may bring insights into advocacy and clinical spaces. This process could be fostered by bringing a softer ecosystem to the starting point of discourses around chronicity, therefore any constructions of cures would be embedded in a context of chronicity as an acceptable and normal human state that needs work (Titchkosky, 2020).

## **5.8 Conclusions**

My area of research interest explores how treatments and cures are understood in the context of chronic illness, foregrounding the possible influence of neoliberalism and its offshoot, healthism. There is a sharp distinction between cure as a way to alleviate symptoms, and cure as a complete transformation that incorporates a “new life” (Novak, 2017). A critical qualitative orientation, drawing on CDT allowed me to illustrate the dual construction of chronicity as unacceptable, and responsibilised curative transformation and self-management as the answer to this problem afflicting individuals and society. The idea of a cure as a necessity, not a negotiation, across mainstream discourses, tends to thrive because the alternative is poorly resourced and understood (Jenkins, 2020). Chronicity as a concept is literally defined by a certain length of time (Yeo & Sawyer, 2005). Still, in order to soften the hostility within ecosites and different geographic locations (Morrison, 2020), chronicity itself needs to be challenged as such a one-dimensional concept. This thesis seeks to show that constructions of chronicity can have a dimensionality and depth that is rarely seen within dominant discourses but could play an important role in health decision making and understanding.

## References

- Adams, R., Reiss, B., & Serlin, D. (2020). Introduction. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 1–5). New York University Press.  
<https://doi.org/10.18574/nyu/9781479812141.003.0003>
- Alderson, P. (1998). Theories in health care and research: The importance of theories in health care. *BMJ*, *317*(7164), 1007–1010. <https://doi.org/10.1136/bmj.317.7164.1007>
- Alderson, P. (2021). *Critical Realism for Health and Illness Research: A Practical Introduction*. Policy Press.
- Anālayo, B. (2020). The Myth of McM mindfulness. *Mindfulness*, *11*(2), 472–479.  
<https://doi.org/10.1007/s12671-019-01264-x>
- Andreassen, H. K., & Trondsen, M. (2010). The empowered patient and the sociologist. *Social Theory & Health*, *8*(3), 280–287. <https://doi.org/10.1057/sth.2010.9>
- Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., Pilarski, C. R., & Balter, R. (2019). #SaytheWord: A disability culture commentary on the erasure of “disability”. *Rehabilitation Psychology*, *64*(2), 111–118. <https://doi.org/10.1037/rep0000258>
- Archer, L. (2008). The new neoliberal subjects? Young/er academics’ constructions of professional identity. *Journal of Education Policy*, *23*(3), 265–285.  
<https://doi.org/10.1080/02680930701754047>
- Atzmüller, C., & Steiner, P. M. (2010). Experimental Vignette Studies in Survey Research. *Methodology*, *6*(3), 128–138. <https://doi.org/10.1027/1614-2241/a000014>
- Ayo, N. (2012). Understanding health promotion in a neoliberal climate and the making of health conscious citizens. *Critical Public Health*, *22*(1), 99–105.

<https://doi.org/10.1080/09581596.2010.520692>

Balaji, T. K., Annavarapu, C. S. R., & Bablani, A. (2021). Machine learning algorithms for social media analysis: A survey. *Computer Science Review, 40*, 100395.

<https://doi.org/10.1016/j.cosrev.2021.100395>

Ball, S. (2021). The Making of a Neoliberal Academic. *Research in Teacher Education, 11*(1), 15-17. <https://doi.org/10.15123/UEL.8Q506>

Barnett, P., & Bagshaw, P. (2020). Neoliberalism: What it is, how it affects health and what to do about it. *The New Zealand Medical Journal, 133*(1512), 76–84.

Basas, C. G. (2014). What's Bad about Wellness? What the Disability Rights Perspective Offers about the Limitations of Wellness. *Journal of Health Politics, Policy and Law, 39*(5), 1035–1066. <https://doi.org/10.1215/03616878-2813695>

Baumann, S., Engman, A., Huddart-Kennedy, E., & Johnston, J. (2017). Organic vs. Local: Comparing individualist and collectivist motivations for “ethical” food consumption. *Canadian Food Studies / La Revue Canadienne Des Études Sur l'alimentation, 4*(1), 68–86. <https://doi.org/10.15353/cfs-rcea.v4i1.191>

Bauml, J. M., Chokshi, S., Schapira, M. M., Im, E. O., Li, S. Q., Langer, C. J., Ibrahim, S. A., & Mao, J. J. (2015). Do attitudes and beliefs regarding complementary and alternative medicine impact its use among patients with cancer? A cross-sectional survey: Attitudes and Beliefs About CAM. *Cancer, 121*(14), 2431–2438. <https://doi.org/10.1002/cncr.29173>

Beauchamp-Pryor, K. (2011). Impairment, cure and identity: ‘Where do I fit in?’. *Disability & Society, 26*(1), 5–17. <https://doi.org/10.1080/09687599.2011.529662>

Bell, K., & Green, J. (2016). On the perils of invoking neoliberalism in public health critique.



- Critical Public Health*, 26(3), 239–243. <https://doi.org/10.1080/09581596.2016.1144872>
- Berger, I., Ahmad, A., Bansal, A., Kapoor, T., Sipp, D., & Rasko, J. E. J. (2016). Global Distribution of Businesses Marketing Stem Cell-Based Interventions. *Cell Stem Cell*, 19(2), 158–162. <https://doi.org/10.1016/j.stem.2016.07.015>
- Bérubé, M. (2020). Representation. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 151–155). New York University Press. <https://doi.org/10.18574/nyu/9781479812141.003.0053>
- BMJ. (1998). The hippocratic oath. *BMJ: British Medical Journal*, 317(7166), 1110. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1114108/>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. SAGE.
- Braun, V., & Clarke, V. (2014). What can “thematic analysis” offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, 9(1), 26152. <https://doi.org/10.3402/qhw.v9.26152>
- Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.
- Braun, V., Clarke, V., & Hayfield, N. (2023). *Thematic analysis: A reflexive approach*. SAGE Publications.
- Brown, R. C. H., Maslen, H., & Savulescu, J. (2019). Against Moral Responsibilisation of Health: Prudential Responsibility and Health Promotion. *Public Health Ethics*, 12(2), 114–129. <https://doi.org/10.1093/phe/phz006>

- Butler, J. (2004). *Undoing Gender*. Routledge
- Cairns, K., & Johnston, J. (2015). Choosing health: Embodied neoliberalism, postfeminism, and the “do-diet.” *Theory and Society*, *44*(2), 153–175. <https://doi.org/10.1007/s11186-015-9242-y>
- Campbell, F. K. (2008). Refusing Able(ness): A Preliminary Conversation about Ableism. *M/C Journal*, *11*(3). <https://doi.org/10.5204/mcj.46>
- Campbell, F. K. (2014). Ableism as transformative practice. In C. Cocker & T. Hafford Letchfield (Eds.), *Rethinking anti-discriminatory and anti-oppressive theories for social work practice* (pp. 78–92). Palgrave Macmillan.  
<https://research.usq.edu.au/item/q37wy/ableism-as-transformative-practice>
- Campbell, F. K., & Campbell, F. K. (2009). Internalised ableism: The tyranny within. In F. Campbell (Ed.), *Contours of Ableism: The Production of Disability and Abledness* (pp. 16–29). Springer. <https://doi.org/10.1057/9780230245181>
- Carey, A. (2020). Citizenship. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 37–39). New York University Press.  
<https://doi.org/10.18574/nyu/9781479812141.003.0014>
- Cassuto, L. (2020). Freak. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 85–88). New York University Press.  
<https://doi.org/10.18574/nyu/9781479812141.003.0030>
- Chapple, S. (2013). Forward liability and welfare reform in New Zealand. *Policy Quarterly*, *9*(2), 56-62. <https://doi.org/10.26686/pq.v9i2.4449>
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology*

- of Health and Illness*, 5(2), 168–195. <https://doi.org/10.1111/1467-9566.ep10491512>
- Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers University Press.
- Cheek, J. (2008). Healthism: A New Conservatism? *Qualitative Health Research*, 18(7), 974–982. <https://doi.org/10.1177/1049732308320444>
- Cheng, C., & Dunn, M. (2015). Health literacy and the Internet: A study on the readability of Australian online health information. *Australian and New Zealand Journal of Public Health*, 39(4), 309–314. <https://doi.org/10.1111/1753-6405.12341>
- Chin, M. H., King, P. T., Jones, R. G., Jones, B., Ameratunga, S. N., Muramatsu, N., & Derrett, S. (2018). Lessons for achieving health equity comparing Aotearoa/New Zealand and the United States. *Health Policy*, 122(8), 837–853. <https://doi.org/10.1016/j.healthpol.2018.05.001>
- Chu, J. T., Wang, M. P., Shen, C., Viswanath, K., Lam, T. H., & Chan, S. S. C. (2017). How, When and Why People Seek Health Information Online: Qualitative Study in Hong Kong. *Interactive Journal of Medical Research*, 6(2), e24. <https://doi.org/10.2196/ijmr.7000>
- Chu-Hui-Lin Chi, G. (2007). The role of hope in patients with cancer. *Oncology Nursing Forum*, 34(2), 415-424.
- Cobb, M. (2020). *The Idea of the Brain: The Past and Future of Neuroscience*. Hachette UK.
- Coney, S. (2002). Direct-to-Consumer Advertising of Prescription Pharmaceuticals: A Consumer Perspective from New Zealand. *Journal of Public Policy & Marketing*, 21(2), 213–223. <https://doi.org/10.1509/jppm.21.2.213.17592>
- Crawford, R. (1980). Healthism and the Medicalization of Everyday Life. *International Journal of*

- Health Services*, 10(3), 365–388. <https://doi.org/10.2190/3H2H-3XJN-3KAY-G9NY>
- Crawford, R. (2006). Health as a meaningful social practice. *Health*, 10(4), 401–420.  
<https://doi.org/10.1177/1363459306067310>
- DasGupta, S. (2020). Medicalization. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 120–121). New York University Press.  
<https://doi.org/10.18574/nyu/9781479812141.003.0041>
- Davidson, M. (2016). Crippling Consensus: Disability Studies at the Intersection. *American Literary History*, 28(2), 433–453. <https://doi.org/10.1093/alh/ajw008>
- Davis, L. J. (1995). Enforcing normalcy: Disability, deafness, and the body. Verso.
- Davis, L. J. (1999). Crips Strike Back: The Rise of Disability Studies. *American Literary History*, 11(3), 500–512.
- Davis, L. J. (2010). Constructing normalcy. In L.J. Davis (Ed.), *The Disability Studies Reader*, (4<sup>th</sup> ed., 3-19). Taylor and Francis.
- Davis, L. J. (2014). *The end of normal: Identity in a biocultural era*. University of Michigan Press.
- De Grandis, G., & Halgunset, V. (2016). Conceptual and terminological confusion around personalised medicine: A coping strategy. *BMC Medical Ethics*, 17(1), 43.  
<https://doi.org/10.1186/s12910-016-0122-4>
- Devinsky, O., Boyce, D., Robbins, M., & Pressler, M. (2020). Dental health in persons with disability. *Epilepsy & Behavior*, 110, 107174.  
<https://doi.org/10.1016/j.yebeh.2020.107174>
- Dirth, T. P., & Branscombe, N. R. (2018). The social identity approach to disability: Bridging disability studies and psychological science. *Psychological Bulletin*, 144(12), 1300–1324.

<https://doi.org/10.1037/bul0000156>

Doble, B., Schofield, D. J., Roscioli, T., & Mattick, J. S. (2016). The promise of personalised medicine. *The Lancet*, *387*(10017), 433–434. [https://doi.org/10.1016/S0140-6736\(16\)00176-8](https://doi.org/10.1016/S0140-6736(16)00176-8)

Dobransky, K., & Hargittai, E. (2012). Inquiring Minds Acquiring Wellness: Uses of Online and Offline Sources for Health Information. *Health Communication*, *27*(4), 331–343. <https://doi.org/10.1080/10410236.2011.585451>

Dolan, V. L. B. (2023). ‘...but if you tell anyone, I’ll deny we ever met:’ the experiences of academics with invisible disabilities in the neoliberal university. *International Journal of Qualitative Studies in Education*, *36*(4), 689–706. <https://doi.org/10.1080/09518398.2021.1885075>

Every-Palmer, S., Duggal, R., & Menkes, D. (2014). Direct-to-consumer advertising of prescription medication in New Zealand. *The New Zealand Medical Journal*, *127*(1401), 102–110.

Eysenbach, G. (2009). Infodemiology and Infoveillance: Framework for an Emerging Set of Public Health Informatics Methods to Analyze Search, Communication and Publication Behavior on the Internet. *Journal of Medical Internet Research*, *11*(1), e11. <https://doi.org/10.2196/jmir.1157>

Feder Kittay, E. (2020). Dependency. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 54–58). New York University Press. <https://doi.org/10.18574/nyu/9781479812141.003.0020>

Fitzgerald, F. T. (1994). The Tyranny of Health. *New England Journal of Medicine*, *331*(3), 196–

198. <https://doi.org/10.1056/NEJM199407213310312>

Finch, J. (1987). The Vignette Technique in Survey Research. *Sociology*, 21(1), 105–114.

<https://doi.org/10.1177/0038038587021001008>

Fitzgerald Miller, J. (2007). Hope: A Construct Central to Nursing. *Nursing Forum*, 42(1), 12–19.

<https://doi.org/10.1111/j.1744-6198.2007.00061.x>

Foroughi, F., Lam, A. K. Y., Lim, M. S. C., Saremi, N., & Ahmadvand, A. (2016). “Googling” for Cancer: An Infodemiological Assessment of Online Search Interests in Australia, Canada, New Zealand, the United Kingdom, and the United States. *JMIR Cancer*, 2(1), e5.

<https://doi.org/10.2196/cancer.5212>

Foucault, M. (1982). The Subject and Power. *Critical Inquiry*, 8(4), 777–795.

<https://doi.org/10.1086/448181>

Frow, E. K., Brafman, D. A., Muldoon, A., Krum, L., Williams, P., Becker, B., Nelson, J. P., & Pritchett, A. (2019). Characterizing Direct-to-Consumer Stem Cell Businesses in the Southwest United States. *Stem Cell Reports*, 13(2), 247–253.

<https://doi.org/10.1016/j.stemcr.2019.07.001>

Fryer, T. (2020). *A short guide to ontology and epistemology: Why everyone should be a critical realist*. <https://tfryer.com/ontology-guide/>

Galvin, R. (2002). Disturbing Notions of Chronic Illness and Individual Responsibility: Towards a Genealogy of Morals. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6(2), 107–137. <https://doi.org/10.1177/136345930200600201>

Garland-Thomson, R. (2002). Integrating Disability, Transforming Feminist Theory. In C. McCann, S. K. Kim, & E. Ergun (Eds.), *Feminist Theory Reader: Local and Global*

- Perspectives* (5th ed, pp. 181-191). Routledge. <https://doi.org/10.4324/9781003001201>
- Gayomali, C. (2022). *Inside the World of Leg Lengthening*. GQ. <https://www.gq.com/story/leg-lengthening>
- Gergen, K. J. (1992). The social constructionist movement in modern psychology. In R.B Miller (Ed.), *The restoration of dialogue: Readings in the philosophy of clinical psychology* (pp. 556–569). American Psychological Association. <https://doi.org/10.1037/10112-044>
- Gernsbacher, M. A. (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58(7), 859–861. <https://doi.org/10.1111/jcpp.12706>
- Gibson, G. (2022). Health(ism) at every size: The duties of the “good fatty.” *Fat Studies*, 11(1), 22–35. <https://doi.org/10.1080/21604851.2021.1906526>
- Google (n.d.). *Google Trends*. <https://trends.google.com/trends/>
- Gonsalves, C. A., McGannon, K. R., Schinke, R. J., & Michel, G. (2016). Are you ‘woman enough’ to control your leading cause of death?: An ethnographic content analysis of women’s cardiovascular disease and identities in media narratives. *Qualitative Research in Psychology*, 13(2), 130–148. <https://doi.org/10.1080/14780887.2015.1121309>
- Gounder, F., & Ameer, R. (2018). Defining diabetes and assigning responsibility: How print media frame diabetes in New Zealand. *Journal of Applied Communication Research*, 46(1), 93–112. <https://doi.org/10.1080/00909882.2017.1409907>
- Greenhalgh, T. (2004). “Health for me”: A sociocultural analysis of healthism in the middle classes. *British Medical Bulletin*, 69(1), 197–213. <https://doi.org/10.1093/bmb/ldh013>
- Guerreschi, F., & Tsididakis, H. (2016). Cosmetic lengthening: What are the limits? *Journal of*

- Children's Orthopaedics*, 10(6), 597–604. <https://doi.org/10.1007/s11832-016-0791-z>
- Hall, M. C. (2019). Critical Disability Theory. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Winter 2019 Edition).  
<https://plato.stanford.edu/archives/win2019/entries/disability-critical/>
- Hammell, K. W. (2015). Rethinking rehabilitation's assumptions: Challenging "Thinking-as-usual" and envisioning a relevant future. In K. McPherson, B. E. Gibson, & A. Leplege (Eds.), *Rethinking Rehabilitation* (pp. 66–89). CRC Press.
- Health Pages (n.d.). <https://healthpages.co.nz/>
- Hep C Action Aotearoa. (n.d.). <https://hepc-action.nz/>
- Hodgkin, P. (1996). Medicine, postmodernism, and the end of certainty. *BMJ*, 313(7072), 1568–1569. <https://doi.org/10.1136/bmj.313.7072.1568>
- Hokowhitu, B. (2014). If you are not healthy, then what are you?: Healthism, colonial disease and body-logic. In K. Fitzpatrick & R. Tinning (Eds.), *Health education: Critical Perspectives* (pp. 31–47). Routledge. <https://doi-org.ezproxy.auckland.ac.nz/10.4324/9780203387993>
- Howson, M. (2019). *Mangoes, Beaches and Fitness: Healthism Among Young Women in New Zealand* [Thesis, ResearchSpace@Auckland].  
<https://researchspace.auckland.ac.nz/handle/2292/49360>
- Hughes, A. L. (Fall 2012). The folly of scientism. *The New Atlantis*, 37, 32–50.
- Huxtable, R. (2018). Clinic, courtroom or (specialist) committee: In the best interests of the critically ill child? *Journal of Medical Ethics*, 44(7), 471–475.  
<https://doi.org/10.1136/medethics-2017-104706>



- Introne, J., & Goggins, S. (2019). Advice reification, learning, and emergent collective intelligence in online health support communities. *Computers in Human Behavior, 99*, 205–218. <https://doi.org/10.1016/j.chb.2019.05.028>
- Jenkin, G. (2010). Individuals, the Environment or Inequalities: Industry and Public Health Framing of Obesity and its Presence in New Zealand Government Policy on Food and Nutrition [Unpublished PhD thesis]. University of Otago.
- Jenkin, G. L., Signal, L., & Thomson, G. (2011). Framing obesity: The framing contest between industry and public health at the New Zealand inquiry into obesity. *Obesity Reviews, 12*(12), 1022–1030. <https://doi.org/10.1111/j.1467-789X.2011.00918.x>
- Johnson, D., Deterding, S., Kuhn, K.-A., Staneva, A., Stoyanov, S., & Hides, L. (2016). Gamification for health and wellbeing: A systematic review of the literature. *Internet Interventions, 6*, 89–106. <https://doi.org/10.1016/j.invent.2016.10.002>
- Jørgensen, M. W. (2015). Patient-centred decision-making? Biocitizens between evidence-based medicine and self-determination. *Evidence & Policy, 11*(3), 311–329. <https://doi.org/10.1332/174426415X14381755121530>
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling, 94*(3), 291–309. <https://doi.org/10.1016/j.pec.2013.10.031>
- Juhila, K., Raitakari, S., & Hall, C. (Eds.). (2016). *Responsibilisation at the Margins of Welfare Services* (0 ed.). Routledge. <https://doi.org/10.4324/9781315681757>
- Kenworthy, N. J. (2019). Crowdfunding and global health disparities: An exploratory conceptual

and empirical analysis. *Globalization and Health*, 15(S1), 71.

<https://doi.org/10.1186/s12992-019-0519-1>

Kersten, P., Lundgren-Nilsson, Å., & Batcho, C. S. (2015). Rethinking measurement in rehabilitation. In K. McPherson, B. E. Gibson, & A. Leplege (Eds.), *Rethinking Rehabilitation* (pp. 230-247). CRC Press. <https://doi.org/10.1201/b18118>

Kim, E. (2017). *Curative violence: Rehabilitating disability, gender, and sexuality in modern Korea*. Duke University Press.

Kristensen, D. B., Lim, M., & Askegaard, S. (2016). Healthism in Denmark: State, market, and the search for a “Moral Compass.” *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 20(5), 485–504.

<https://doi.org/10.1177/1363459316638541>

Kronenfeld, J. J. (1979). Self care as a panacea for the ills of the health care system: An assessment. *Social Science & Medicine. Part A: Medical Psychology & Medical Sociology*, 13, 263–267. [https://doi.org/10.1016/0271-7123\(79\)90044-0](https://doi.org/10.1016/0271-7123(79)90044-0)

Kumari Campbell, F. (2020). Ability. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 12–14). New York University Press.

<https://doi.org/10.18574/nyu/9781479812141.003.0005>

Kuppers, P. (2014). Crip Time. *Tikkun*, 29(4), 29–30. <https://doi.org/10.1215/08879982-2810062>

LaMarre, A., Smoliak, O., Cool, C., Kinavey, H., & Hardt, L. (2019). The Normal, Improving, and Productive Self: Unpacking Neoliberal Governmentality in Therapeutic Interactions. *Journal of Constructivist Psychology*, 32(3), 236–253.

<https://doi.org/10.1080/10720537.2018.1477080>

Layton, L. (2009). Who's Responsible? Our Mutual Implication in Each Other's Suffering.

*Psychoanalytic Dialogues*, 19(2), 105–120.

<https://doi.org/10.1080/10481880902779695>

Lazard, L., & McAvoy, J. (2020). Doing reflexivity in psychological research: What's the point?

What's the practice? *Qualitative Research in Psychology*, 17(2), 159–177.

<https://doi.org/10.1080/14780887.2017.1400144>

LeBesco, K. (2011). Neoliberalism, public health, and the moral perils of fatness. *Critical Public*

*Health*, 21(2), 153–164. <https://doi.org/10.1080/09581596.2010.529422>

Liebenberg, L., Ungar, M., & Ikeda, J. (2015). Neo-Liberalism and Responsibilisation in the

Discourse of Social Service Workers. *British Journal of Social Work*, 45(3), 1006–1021.

<https://doi.org/10.1093/bjsw/bct172>

Lohne, V. (2022). 'Hope as a lighthouse' A meta-synthesis on hope and hoping in different

nursing contexts. *Scandinavian Journal of Caring Sciences*, 36(1), 36–48.

<https://doi.org/10.1111/scs.12961>

Love, H. (2020). Stigma. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies*

(pp. 173–176). New York University Press.

<https://doi.org/10.18574/nyu/9781479812141.003.0060>

Lupton, D. (1993). Risk as Moral Danger: The Social and Political Functions of Risk Discourse in

Public Health. *International Journal of Health Services*, 23(3), 425–435.

<https://doi.org/10.2190/16AY-E2GC-DFLD-51X2>

Lupton, D. (1997). Consumerism, reflexivity and the medical encounter. *Social Science &*

*Medicine*, 45(3), 373-381. [https://doi.org/10.1016/S0277-9536\(96\)00353-X](https://doi.org/10.1016/S0277-9536(96)00353-X)

Lupton, D. (2013). Quantifying the body: monitoring and measuring health in the age of mHealth technologies. *Critical Public Health*, 23(4), 393-403.

<https://doi.org/10.1080/09581596.2013.794931>

Lupton, D. (2015). Health promotion in the digital era: A critical commentary. *Health Promotion International*, 30(1), 174–183. <https://doi.org/10.1093/heapro/dau091>

Lupton, D. (2021). ‘The internet both reassures and terrifies’: Exploring the more-than-human worlds of health information using the story completion method. *Medical Humanities*, 47(1), 68-77. <https://doi.org/10.1136/medhum-2019-011700>

MacGregor, C., Petersen, A., & Munsie, M. (2021). From the margins to mainstream: How providers of autologous ‘stem cell treatments’ legitimise their practice in Australia. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 25(1), 51–68. <https://doi.org/10.1177/1363459319846927>

Martini, M., & Bragazzi, N. L. (2021). Googling for Neurological Disorders: From Seeking Health-Related Information to Patient Empowerment, Advocacy, and Open, Public Self-Disclosure in the Neurology 2.0 Era. *Journal of Medical Internet Research*, 23(3), e13999. <https://doi.org/10.2196/13999>

McGregor, S. (2001). Neoliberalism and health care. *International Journal of Consumer Studies*, 25(2), 82–89. <https://doi.org/10.1111/j.1470-6431.2001.00183.x>

McLean, A. K., Stewart, C., & Kerridge, I. (2015). Untested, unproven, and unethical: The promotion and provision of autologous stem cell therapies in Australia. *Stem Cell Research & Therapy*, 6(1), 33. <https://doi.org/10.1186/s13287-015-0047-8>

- McPherson, K., Gibson, B. E., & Leplege, A. (Eds.). (2015). *Rethinking Rehabilitation: Theory and Practice*. CRC Press.
- McRuer, R. (2005). Crip Eye for the Normate Guy: Queer Theory and the Disciplining of Disability Studies. *PMLA/Publications of the Modern Language Association of America*, 120(2), 586–593. <https://doi.org/10.1632/S003081290016794X>
- McRuer, R. (2010). Compulsory able-bodiedness and queer/disabled existence. In L.J. Davis (Ed.), *The Disability Studies Reader*, (4<sup>th</sup> ed., 383–392). Taylor and Francis.
- Meeks, L. M., Herzer, K., & Jain, N. R. (2018). Removing Barriers and Facilitating Access: Increasing the Number of Physicians with Disabilities. *Academic Medicine*, 93(4), 540–543. <https://doi.org/10.1097/ACM.0000000000002112>
- Minkler, M. (1999). Personal Responsibility for Health? A Review of the Arguments and the Evidence at Century's End. *Health Education & Behavior*, 26(1), 121–141. <https://doi.org/10.1177/109019819902600110>
- Miro. (2022). *Miro online whiteboard* (no version provided). RealTimeBoard, Inc. [www.miro.com](http://www.miro.com).
- Mishel, M. H. (1999). Uncertainty in chronic illness. In J.J Fitzpatrick (Ed.), *Annual Review of Nursing Research: Vol. 17. Focus on Contemporary Health and Pain Management* (pp. 269–294). Springer
- Mogendorff, K. (2013). The Blurring of Boundaries between Research and Everyday Life: Dilemmas of Employing One's Own Experiential Knowledge in Disability Research. *Disability Studies Quarterly*, 33(2). <https://doi.org/10.18061/dsq.v33i2.3713>
- Moore, S. E. H. (2010). Is the Healthy Body Gendered? Toward a Feminist Critique of the New

Paradigm of Health. *Body & Society*, 16(2), 95–118.

<https://doi.org/10.1177/1357034X10364765>

Morrison, C. A., Woodbury, E., Johnston, L., & Longhurst, R. (2020). Disabled people's embodied and emotional geographies of (not)belonging in Aotearoa New Zealand. *Health & Place*, 62, 102283. <https://doi.org/10.1016/j.healthplace.2020.102283>

Murdoch, B., Zarzeczny, A., & Caulfield, T. (2018). Exploiting science? A systematic analysis of complementary and alternative medicine clinic websites' marketing of stem cell therapies. *BMJ Open*, 8(2), e019414. <https://doi.org/10.1136/bmjopen-2017-019414>

Neuwelt-Kearns, C., Baker, T., Calder-Dawe, O., Bartos, A. E., & Wardell, S. (2021). Getting the crowd to care: Marketing illness through health-related crowdfunding in Aotearoa New Zealand. *Environment and Planning A: Economy and Space*, 0308518X2110095.

<https://doi.org/10.1177/0308518X211009535>

New Zealand Clinical Research (n.d.). *Join our research community*. <https://www.nzcr.co.nz/>

Nicholls, D. A., Gibson, B. E., & Fadyl, J. K. (2015). Rethinking Movement: Postmodern Reflections on a Dominant Rehabilitation Discourse. In K. McPherson, B. E. Gibson, & A. Leplege (Eds.), *Rethinking Rehabilitation* (pp. 118-137). CRC Press.

<https://doi.org/10.1201/b18118>

Novak, I., Walker, K., Hunt, R. W., Wallace, E. M., Fahey, M., & Badawi, N. (2016). Concise Review: Stem Cell Interventions for People With Cerebral Palsy: Systematic Review With Meta-Analysis. *Stem Cells Translational Medicine*, 5(8), 1014–1025.

<https://doi.org/10.5966/sctm.2015-0372>

Oliver, M. (1984). The politics of disability. *Critical Social Policy*, 4(11), 21–32.

<https://doi.org/10.1177/026101838400401103>

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28(7), 1024–1026. <https://doi.org/10.1080/09687599.2013.818773>

Olssen, M. (1996). In defence of the welfare state and publicly provided education: A New Zealand perspective. *Journal of Education Policy*, 11(3), 337–362.

<https://doi.org/10.1080/0268093960110305>

Opai, K. (2022). Words have great power: Creating Māori concepts of disability. *Developmental Medicine & Child Neurology*, 64(10), 1182–1182. <https://doi.org/10.1111/dmcn.15266>

Pantazakos, T. (2019). Treatment for whom? Towards a phenomenological resolution of controversy within autism treatment. *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, 77, 101176.

<https://doi.org/10.1016/j.shpsc.2019.04.001>

Penehira, M., Green, A., Smith, L. T., & Aspin, C. (2014). *Māori and indigenous views on R and R: Resistance and Resilience*. 3(2), 96–110.

Perez, S. L., Kravitz, R. L., Bell, R. A., Chan, M. S., & Paterniti, D. A. (2016). Characterizing internet health information seeking strategies by socioeconomic status: A mixed methods approach. *BMC Medical Informatics and Decision Making*, 16(1), 107.

<https://doi.org/10.1186/s12911-016-0344-x>

Podsiadlowski, A., & Fox, S. (2011). Collectivist Value Orientations among Four Ethnic Groups: Collectivism in the New Zealand Context. *New Zealand Journal of Psychology*, 40(1), 5-18.

Pomerantz, A. (1986). Extreme case formulations: A way of legitimizing claims. *Human Studies*,

- 9(2–3), 219–229. <https://doi.org/10.1007/BF00148128>
- Porter, R. (1985). The patient's view: Doing medical history from below. *Theory and Society*, 14(2), 175–198. <https://doi.org/10.1007/BF00157532>
- Price, D. (2022). Unmasking autism: Discovering the new faces of neurodiversity. Harmony.
- Puar, J. K. (2013). The cost of getting better: Ability and debility. In L.J. Davis (Ed.), *The Disability Studies Reader*, (4<sup>th</sup> ed., 177–184). Taylor and Francis.  
<https://ebookcentral.proquest.com/lib/auckland/detail.action?docID=1125176>
- Radcliffe, E., Lowton, K., & Morgan, M. (2013). Co-construction of chronic illness narratives by older stroke survivors and their spouses: Co-construction of chronic illness narratives. *Sociology of Health & Illness*, 35(7), 993–1007. <https://doi.org/10.1111/1467-9566.12012>
- Rail, G., & Jette, S. (2015). Reflections on Biopedagogies and/of Public Health: On Bio-Others, Rescue Missions, and Social Justice. *Cultural Studies - Critical Methodologies*, 15(5), 327–336. <https://doi.org/10.1177/1532708615611703>
- Richardson, C. L., & Reynolds, V. (2012). “Here We Are, Amazingly Alive”: Holding Ourselves Together With An Ethic Of Social Justice In Community Work. *International Journal of Child, Youth and Family Studies*, 3(1), 1. <https://doi.org/10.18357/ijcyfs31201210471>
- Rimke, H. M. (2000). Governing citizens through self-help literature. *Cultural Studies*, 14(1), 61–78. <https://doi.org/10.1080/095023800334986>
- Roberts, J. L., & Leonard, E. W. (2015). What Is (and Isn't) Healthism. *Georgia Law Review*, 50, 833-868.
- Rose, S. F. (2020). Work. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies*



(pp. 187–190). New York University Press.

<https://doi.org/10.18574/nyu/9781479812141.003.0065>

Rysst, M. (2010). “Healthism” and looking good: Body ideals and body practices in Norway.

*Scandinavian Journal of Public Health*, 38(5 suppl), 71–80.

<https://doi.org/10.1177/1403494810376561>

Samuels, E. (2002). Critical Divides: Judith Butler’s Body Theory and the Question of Disability.

*NWSA Journal*, 14(3), 58–76.

Samuels, E. (2020). Passing. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability*

*Studies* (pp. 135–137). New York University Press.

<https://doi.org/10.18574/nyu/9781479812141.003.0047>

Sánchez, A. O., & Fuentes, M. T. M. (2002). Consumer orientation of public hospital websites in

Spain. *Journal of Medical Marketing*, 3(1), 20–30.

<https://doi.org/10.1057/palgrave.jmm.5040099>

Satz, A. B. (2020). Vulnerability. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability*

*Studies* (pp. 185–186). New York University Press.

<https://doi.org/10.18574/nyu/9781479812141.003.0064>

Savard, J. (2013). Personalised Medicine: A Critique on the Future of Health Care. *Journal of*

*Bioethical Inquiry*, 10(2), 197–203. <https://doi.org/10.1007/s11673-013-9429-8>

Schalk, S. (2017). Critical Disability Studies as Methodology. *Lateral*, 6(1).

<https://www.jstor.org/stable/48671697>

Schrecker, T. (2016). Neoliberalism and Health: The Linkages and the Dangers: Neoliberalism

and Health. *Sociology Compass*, 10(10), 952–971. <https://doi.org/10.1111/soc4.12408>

- Seedhouse, D. (2004). *Health promotion: Philosophy, prejudice and practice*. John Wiley & Sons.
- Sen, A. (2002). Why health equity? *Health Economics*, 11(8), 659–666.  
<https://doi.org/10.1002/hec.762>
- Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research*, 6(1), 8–21. <https://doi.org/10.1080/15017410409512636>
- Sheldon, J. (2017). Problematizing reflexivity, validity, and disclosure: Research by people with disabilities about disability. *The Qualitative Report*, 22(4), 984–1000.
- Siebers, T. (2013). Disability and the theory of complex embodiment—For identity politics in a new register. In L.J. Davis (Ed.), *The Disability Studies Reader*, (4<sup>th</sup> ed., pp. 278–297). Taylor and Francis.
- Simonton, D. K. (2017). Creative Geniuses, Polymaths, Child Prodigies, and Autistic Savants: The Ambivalent Function of Interests and Obsessions. In P. A. O’Keefe & J. M. Harackiewicz (Eds.), *The Science of Interest* (pp. 175–185). Springer International Publishing.  
[https://doi.org/10.1007/978-3-319-55509-6\\_9](https://doi.org/10.1007/978-3-319-55509-6_9)
- Sipp, D. (2013). Direct-to-Consumer Stem Cell Marketing and Regulatory Responses. *Stem Cells Translational Medicine*, 2(9), 638–640. <https://doi.org/10.5966/sctm.2013-0040>
- Sointu, E. (2005). The Rise of an Ideal: Tracing Changing Discourses of Wellbeing. *The Sociological Review*, 53(2), 255–274. <https://doi.org/10.1111/j.1467-954X.2005.00513.x>
- Sosnowy, C. (2014). Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise. *Societies*, 4(2), 316–329. <https://doi.org/10.3390/soc4020316>
- Steinberg, D. L. (2015). The Bad Patient: Estranged Subjects of the Cancer Culture. *Body &*

- Society*, 21(3), 115–143. <https://doi.org/10.1177/1357034X15586240>
- Stone, L. (2018). Disease prestige and the hierarchy of suffering. *Medical Journal of Australia*, 208(2), 60–62. <https://doi.org/10.5694/mja17.00503>
- Swartz, L., Hunt, X., Watermeyer, B., Carew, M., Braathen, S. H., & Rohleder, P. (2018). Symbolic violence and the invisibility of disability. *African Safety Promotion: A Journal of Injury and Violence Prevention*, 16(2), 2. <https://doi.org/10.4314/asp.v16i2>
- Storni, C. (2015). Patients' lay expertise in chronic self-care: A case study in type 1 diabetes. *Health Expectations*, 18(5), 1439–1450. <https://doi.org/10.1111/hex.12124>
- Swoboda, D. A. (2005). *Embodiment and the Search for Illness Legitimacy Among Women with Contested Illnesses*. MPublishing. <http://hdl.handle.net/2027/spo.ark5583.0019.004>
- Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research*, 6(1), 22–36. <https://doi.org/10.1080/15017410409512637>
- Thorne, S. E., Kuo, M., Armstrong, E. A., McPherson, G., Harris, S. R., & Hislop, T. G. (2005). 'Being known': Patients' perspectives of the dynamics of human connection in cancer care. *Psycho-Oncology*, 14(10), 887–898. <https://doi.org/10.1002/pon.945>
- Thorne, S., Paterson, B., & Russell, C. (2003). The Structure of Everyday Self-Care Decision Making in Chronic Illness. *Qualitative Health Research*, 13(10), 1337–1352. <https://doi.org/10.1177/1049732303258039>
- Titchkosky, T. (2020). Normal. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 130–132). New York University Press. <https://doi.org/10.18574/nyu/9781479812141.003.0045>
- Tremain, S. (2005). Foucault, governmentality, and critical disability theory: An introduction.

The University of Michigan Press.

Tremblay, D., Turcotte, A., Touati, N., Poder, T. G., Kilpatrick, K., Bilodeau, K., Roy, M., Richard, P. O., Lessard, S., & Giordano, É. (2022). Development and use of research vignettes to collect qualitative data from healthcare professionals: A scoping review. *BMJ Open*, *12*(1), e057095. <https://doi.org/10.1136/bmjopen-2021-057095>

Trnka, S., & Trundle, C. (2014). Competing Responsibilities: Moving Beyond Neoliberal Responsibilisation. *Anthropological Forum*, *24*(2), 136–153. <https://doi.org/10.1080/00664677.2013.879051>

Turner, L., & Knoepfler, P. (2016). Selling Stem Cells in the USA: Assessing the Direct-to-Consumer Industry. *Cell Stem Cell*, *19*(2), 154–157. <https://doi.org/10.1016/j.stem.2016.06.007>

Ullrich, P., Kausch, S., & Holze, S. (2012). The making of the healthcare self. State metamorphoses, activation, responsibilisation and healthcare reforms in Germany. *Hamburg Review of the Social Sciences*, *7*(1), 52–72. <https://doi.org/10.14279/depositonce-4735>

Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American Journal of Orthopsychiatry*, *81*(1), 1–17. <https://doi.org/10.1111/j.1939-0025.2010.01067.x>

Vallely, N. (2021). *Futilitarianism: Neoliberalism and the production of uselessness*. Goldsmiths Press.

Van Der Eijk, M., Faber, M. J., Aarts, J. W., Kremer, J. A., Munneke, M., & Bloem, B. R. (2013). Using Online Health Communities to Deliver Patient-Centered Care to People With

Chronic Conditions. *Journal of Medical Internet Research*, 15(6), e115.

<https://doi.org/10.2196/jmir.2476>

Van Wilgen, C. P., Van Ittersum, M. W., Kaptein, A. A., & Van Wijhe, M. (2008). Illness perceptions in patients with fibromyalgia and their relationship to quality of life and catastrophizing. *Arthritis & Rheumatism*, 58(11), 3618–3626.

<https://doi.org/10.1002/art.23959>

Vehmas, S., & Watson, N. (2014). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & Society*, 29(4), 638–650.

<https://doi.org/10.1080/09687599.2013.831751>

Veinot, T. (2010). Power to the Patient? A Critical Examination of Patient Empowerment Discourses. In R. Harris, N. Wathen, & S. Wyatt (Eds.), *Configuring Health Consumers: Health Work and the Imperative of Personal Responsibility* (pp. 30–41). Palgrave

Macmillan UK. [https://doi.org/10.1057/9780230292543\\_3](https://doi.org/10.1057/9780230292543_3)

Vishwanathan, K., & Nimbalkar, S. (2017). Cosmetic limb lengthening in a patient of normal stature: Ethical considerations. *Indian J Med Ethics*, 2(1), 45–48.

Wallston, K. A. W., Strudler, B. (1982). Who Is Responsible for Your Health? The Construct of Health Locus of Control. In G. S. Sanders, & J. Sullis (Eds.), *Social Psychology of Health and Illness* (pp. 65-95). Psychology Press.

Wardell, S. (2023). To wish you well: The biopolitical subjectivities of medical crowdfunders during and after Aotearoa New Zealand's COVID-19 lockdown. *BioSocieties*, 18(1), 52–78. <https://doi.org/10.1057/s41292-021-00251-7>

Wasserman, D., & Asch, A. (2013). Understanding the relationship between disability and well-

- being. In J.E. Bickenbach, F. Felder, & B. Schmitz (Eds.), *Disability and the Good Human Life* (pp. 139–167). Cambridge University Press.
- Watermeyer, B. (2009). Claiming loss in disability. *Disability & Society*, 24(1), 91–102.  
<https://doi.org/10.1080/09687590802535717>
- Watermeyer, B. (2012a). Is it possible to create a politically engaged, contextual psychology of disability? *Disability & Society*, 27(2), 161–174.  
<https://doi.org/10.1080/09687599.2011.644928>
- Watermeyer, B. (2012b). *Towards a Contextual Psychology of Disablism*. Routledge.
- Wendell, S. (2001). Unhealthy Disabled: Treating Chronic Illnesses as Disabilities. *Hypatia*, 16(4), 17–33. <https://doi.org/10.1111/j.1527-2001.2001.tb00751.x>
- Whaikaka – Ministry of Disabled People. (n.d.). *Whaikaka*. <https://www.whaikaha.govt.nz/>
- Whitson, J. (2015). *Foucault's Fitbit: Governance and Gamification*. In S.P. Walz, & S Deterding (Eds.), *The Gameful World: Approaches, Issues, Applications* (pp. 339–358). MIT Press.  
<https://doi.org/10.7551/mitpress/9788.003.0023>
- Wilkerson, A. (2020). Embodiment. In R. Adams, B. Reiss, & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 67–70). New York University Press.  
<https://doi.org/10.18574/nyu/9781479812141.003.0024>
- Wilkinson, S. (1998). Focus groups in feminist research. *Women's Studies International Forum*, 21(1), 111–125. [https://doi.org/10.1016/S0277-5395\(97\)00080-0](https://doi.org/10.1016/S0277-5395(97)00080-0)
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness*, 6(2), 175–200. <https://doi.org/10.1111/1467-9566.ep10778250>
- Yeo, M., & Sawyer, S. (2005). Chronic illness and disability. *BMJ*, 330(7493), 721–723.

<https://doi.org/10.1136/bmj.330.7493.721>

Yoder, S. D. (2002). Individual Responsibility for Health: Decision, Not Discovery. *The Hastings Center Report*, 32(2), 22-31. <https://doi.org/10.2307/3528519>

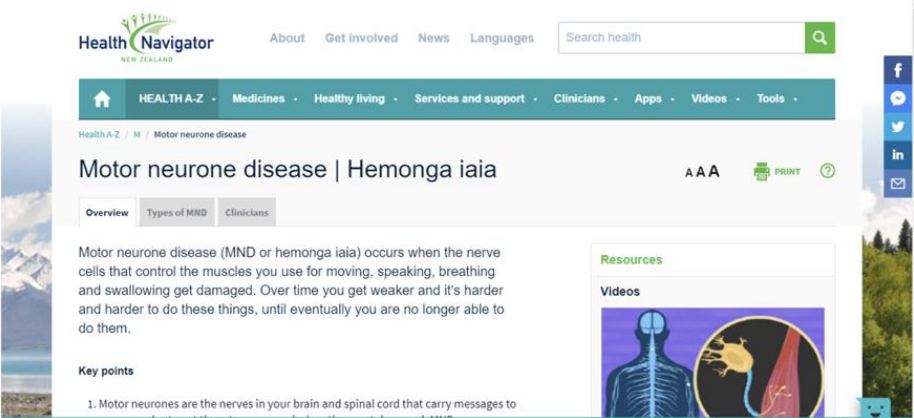
Zhao, Z. (2019). Cashless society: Consumer-perceived value propositions of mobile payment [Unpublished Master's Thesis]. Tampere University.

## Appendix A

### Website Examples

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<https://www.healthnavigator.org.nz/health-a-z/m/motor-neurone-disease/#Overview>



Health Navigator  
NEW ZEALAND

About Get involved News Languages Search health

HEALTH A-Z Medicines Healthy living Services and support Clinicians Apps Videos Tools

Health A-Z / M / Motor neurone disease

### Motor neurone disease | Hemonga iaia

Overview Types of MND Clinicians

Motor neurone disease (MND or hemonga iaia) occurs when the nerve cells that control the muscles you use for moving, speaking, breathing and swallowing get damaged. Over time you get weaker and it's harder and harder to do these things, until eventually you are no longer able to do them.

Key points

1. Motor neurones are the nerves in your brain and spinal cord that carry messages to

Resources

Videos

Motor neurone disease (MND or hemonga iaia) occurs when the nerve cells that control the muscles you use for moving, speaking, breathing and swallowing get damaged. Over time you get weaker and it's harder and harder to do these things, until eventually you are no longer able to

Figure A1. Health Navigator website example.

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<https://www.gesundheitsindustrie-bw.de/en/article/news/regenerative-medicine-curing-rather-than-simply-treating-diseases>

## Regenerative medicine: curing rather than simply treating diseases

Some scientists refer to the latest developments in the field of regenerative medicine as the "next revolution in medicine". With the help of gene therapies or stem cells, regenerative medicine aims not only to treat disease symptoms, but to cure them at source. Some approaches are already being used to treat patients and several others are close to application. However, there are concerns that certain social and political issues could have a negative effect on regenerative medicine. Big pharma, which is currently less active in this field than other players, would be well advised to think about becoming involved in the field of regenerative medicine to ensure that it does not miss out on the many opportunities.

Figure A2. Gesundheitsindustrie website example.



## Appendix B

### Vignette Study Pages

#### Figure B1

##### *Landing page – Welcome*

#### **Introduction to the project**

This project asks you to read a series of vignettes (briefly described scenarios) and respond to a series of questions about each vignette. The vignettes have been designed and developed based on real world examples presented in the media and on online platforms. Please respond to the questions based on the information provided, and any experience you may have had with the different health scenarios. You don't need to have specific *experience* of certain chronic illnesses to respond to the questions. We are more interested in understanding your general impressions.

#### **Instructions**

- Please read each vignette, and then respond to each of the questions listed below.
- There are no right or wrong answers, and we encourage you to respond from your own perspective.
- We encourage you to write as much as you wish, for each question.
- You can type your answer or use voice-to-text dictation software.
- You *can* go back and add to past answers if you wish to, but there's no expectation to do that.
- You are able to start the survey, save it, and return at another point if need be.
- When you get through the vignettes, there are some brief demographic questions to complete before submitting. Submitting indicates consent to participate.

**Accessibility Options:** Making the study as accessible as possible is important to us. Qualtrics is compatible with most accessibility software on both Windows and Mac including Zoom In, Dictation and VoiceOver. However, accessibility is an evolving field. If there is anything that needs to be added altered or considered feel free to contact Amy.

## Figure B2

### *Participant Information Sheet*

#### Participant Information Sheet

**Project Title:** *Understanding perceived opportunities and obligations around chronic illness*

**Name of Principal Investigator/Supervisor (PI):** Professor Virginia Braun

**Name of Student Researcher:** Amy Hogan

Tēnā koe,

My name is Amy Hogan, and I am from Tāmaki Makaurau along with my whole family for several generations. I am a Pākehā New Zealander who has lived with a lifelong neurological disorder and has extensive experience with the healthcare system. My professional work involves working with individuals and their families on understanding the complexity of chronic illness, disability, and connecting to communities. I am currently completing my Master's thesis in Psychology at the University of Auckland. My Master's topic reflects an interest and observation about the increasing popularity of experimental treatments and the claims that they make about living with chronicity and searching for "cures" online.

#### **Project Description**

For my Master's research, I am exploring how people understand the idea and impact of chronic illness, and the opportunities and obligations available to those with chronic conditions, and navigate the different health information available. In the context of a mass of online information, and internationally available experimental treatments, I'm interested in understanding how these sorts of decisions might be navigated.

Our understanding how living with chronic illnesses and disabilities is undergoing a period of change as science and research understands more about the brain and how it works. People in Aotearoa New Zealand are presented with a wide range of options for managing their condition, from conventional treatments to more experimental ones. There is an increasing number of experimental treatments that make expansive claims about what they can achieve. However, much emphasis is placed on the individual and their whānau to navigate these spaces and make decisions. This project explores how people understand the typical experiences of navigating these spaces, using hypothetical scenarios and characters (vignettes) developed around common experiences or situations. These vignettes are developed around real-world scenarios New Zealanders might face navigating health information and systems at different stages in their lives and chronic illness.

#### **Invitation to Participate**

If you meet our participation criteria (18+, living in Aotearoa New Zealand, with an interest in or connection to chronic illness), we invite you to participate in our study.

#### **Project Procedures**

A vignettes study presents the participant with short hypothetical scenarios, and then asks a series of questions about the characters in the vignette, and your own responses to aspects of the vignette. Participating in this study will involve reading four short vignettes, each about a person who is making health-related decisions on the context of a chronic condition. Then you will be asked a series of open-ended questions about the scenarios, and what you think might happen in the future or in situations that are like the one provided. These require you to think about and describe things in your own words, from your perspective. There are no right or wrong answers! There will also be space at the end for you to provide any additional comments.

We anticipate this will take around 30 minutes, but it could be longer if you have a lot to say (or likewise, shorter). There is no limit on length of response, and we encourage detailed and thoughtful responses. You will have the opportunity to type your responses or deliver them in another accessible format. You will be able to move back and forward if you wish to go back to previous responses (though this is not expected); you will also be able to save your responses part way through and return later if need be.

**Risks and Benefits**

Although there are no direct benefits to you of involvement in this study, we hope you find the experience interesting. There is no particular risk involved in participating, and we do not anticipate that it will cause distress or harm. However, topics like this can bring up issues or concerns for some people. We provide a link to a downloadable page of support resources, should you feel you wish to seek support after this study. This link is both provided [HERE](#), and again will be listed upon completion of the study.

**Confidentiality, Data Use and Storage**

This study is anonymous – which means no identifying information is collected during the data collection process. You will be asked to provide some demographic information at the end, but this will not be identifying. This information is primarily gathered so we have a descriptive understanding of our participants, to contextualise our data. This is both an ethical and analysis quality measure.

Segments of your written responses may be used as quoted data in the thesis and any resulting presentations or publications. Excerpts may also be used in research group sessions. If any aspects of your responses contain potentially identifying aspects, we will anonymise these in any instance where we quote the response.

The data for this project will be stored securely on personal computers and in the cloud using password protection. Only the researchers will have direct access to this information. The information will be kept for at least 6 years.

**Consent and Withdrawal**

On the next page, you will be shown a brief consent form. This indicates that completing and submitting this study indicates your informed consent to participate. Due to the anonymous nature of the study, you will not be able to withdraw once your responses have been submitted. However, if you change your mind once you have started, you can withdraw from the study simply by not submitting.

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Email: [ahog010@aucklanduni.ac.nz](mailto:ahog010@aucklanduni.ac.nz)

**Supervisor**

Professor Virginia Braun  
School of Psychology, The University of Auckland  
Email: [v.braun@auckland.ac.nz](mailto:v.braun@auckland.ac.nz)

The **Head of School of Psychology** is:

Professor Suzanne Purdy  
Email: [sc.purdy@auckland.ac.nz](mailto:sc.purdy@auckland.ac.nz)

**For any queries regarding ethical concerns:**

You may contact the Chair, the University of Auckland Human Participants Ethics Committee, Office of Strategy Research and Integrity, University of Auckland, Private Bag 92019, Auckland 1142.  
Telephone 09 373-7599 ext. 83711.  
Email: [humanethics@auckland.ac.nz](mailto:humanethics@auckland.ac.nz)

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A link to a downloadable version of the PIS will be added to this part of the site.

## Figure B3

### *Vignette Instructions*

#### **Introduction to the project**

This project asks you to read a series of vignettes (briefly described scenarios) and respond to a series of questions about each vignette. The vignettes have been designed and developed based on real world examples presented in the media and on online platforms. Please respond to the questions based on the information provided, and any experience you may have had with the different health scenarios. You don't need to have specific *experience* of certain chronic illnesses to respond to the questions. We are more interested in understanding your general impressions.

#### **Instructions**

- Please read each vignette, and then respond to each of the questions listed below.
- There are no right or wrong answers, and we encourage you to respond from your own perspective.
- We encourage you to write as much as you wish, for each question.
- You can type your answer or use voice-to-text dictation software.
- You *can* go back and add to past answers if you wish to, but there's no expectation to do that.
- You are able to start the survey, save it, and return at another point if need be.
- When you get through the vignettes, there are some brief demographic questions to complete before submitting. Submitting indicates consent to participate.

**Accessibility Options:** Making the study as accessible as possible is important to us. Qualtrics is compatible with most accessibility software on both Windows and Mac including Zoom In, Dictation and VoiceOver. However, accessibility is an evolving field. If there is anything that needs to be added altered or considered feel free to contact Amy.

**Figure B4****Vignette 1: Mara****Mara**

In her early 50s, Mara has been diagnosed with a life-altering chronic condition that affects her ability to walk and move around. Mara is a former nurse, so she has some knowledge on how the condition will impact her life. She finds the conventional advice she is given from her GP and specialist to be lacking. During her regular scrolling online, she finds a support group that is recommending an experimental treatment in Mexico. The testimonials from patients describe specific advantages and reduction in symptoms she experiences, such as pain, chronic tiredness, and “brain fog”.

Mara becomes increasingly excited about this opportunity and feels that she has enough knowledge to make a decision to seek such treatment. With the support of her friends and family, she has set up a GiveALittle to raise the \$100,000 for the treatment, travel and follow-up appointments. Her GP is nervous about her expectations and provides her with some questions to ask. Mara is frustrated by his doubts, and with the support of her family, raises enough money to go to the clinic.

**Questions**

- Please explain *why* you think Mara would go against the conventional advice of her GP and specialist.
- What do you think Mara hoped to gain from the overseas clinic? Please describe anything relevant, from physical through emotional aspects.
- How much control do you think Mara should have over her own healthcare, her options, and her choices?
- How do you feel about patients fundraising like this, to seek treatments abroad, if they are not offered or approved locally?
- Are there any other thoughts you'd like to add about this scenario?

## Figure B5

### Vignette 2: Jay

#### Jay

Jay is a young man who lives with a lifelong condition that is relatively well-controlled with medication for now, but will get worse. He lives with a significant physical disability and some intellectual impairment, which has been classed as mild. He graduated high school and is starting a computer course. Now he is a young adult, making decisions for himself has been encouraged. Jay's parents are trying to give him more independence, but he is struggling to navigate the health system on his own. He has a good relationship with his GP, but most GPs don't have specific experience with Jay's condition, including his current one.

Jay has sought information online... The support groups seem to be mostly for older people. As Jay likes to eat junk food and stay up late, the general recommend advice he's found, like eating right and staying healthy, doesn't appeal. However, Jay doesn't want his condition to worsen. Given none of the information seems right for him, he decides to try and develop his own health plan. His first action is to go to Google and start searching for both his condition and young people.

#### Questions

- What do you anticipate the likely outcome of Jay's decision to develop his own health plan?
- What *opportunities* might Jay encounter as he navigates through this new phase as a young man taking responsibility for his health?
- What *challenges* might Jay encounter as he navigates through this new phase as a young man taking responsibility for his health?
- What role do you think Jay's parents and loved ones should have while he navigates this new time in his life?
- Any other thoughts you'd like to add about this scenario?

## Figure B6

### *Vignette 3: Tāne*

#### **Tāne**

Tāne is a former business owner and CEO, used to making hard decisions with professional and personal support around him. He has recently been diagnosed with a lifelong chronic condition that will eventually require breathing support, and in-home caregiving or residential care. Right now, Tāne uses a manual wheelchair to get around and can do most of his personal care, with a little support for things like shaving and brushing his hair. His family support him, and want to make sure he is as healthy and happy as possible. He is struggling with the fact he can no longer do sports, and wants to keep up as many of his pre-diagnosis routines as he can.

It's very important for him and his family that he remains under family care, stays connected to community, and enjoys key aspects of his life, like being a father to his three young kids and going out with his friends to the rugby. His doctors have given them lots of information and resources about the condition, and what to expect, but they want to do more than just make sure Tāne is medically stable. There is nothing that seems specifically targeted at helping Tāne's symptoms get better, and helping him live a worthwhile life, and the family has started to explore options online.

#### **Questions**

- How do you think the changes in his health will affect how Tāne feels about himself and his life?
- What are some of the likely challenges Tāne may encounter in the next year, as he and his family adapt to the condition?
- Might Tāne's diagnosis offer any positives for Tāne and his family?
- How might Tāne maintain community connections, now that he lives with a physical disability that means he cannot participate in his previous activities?
- What do you think about the family seeking ways to maintain or enhance Tony's health and wellbeing? How do you think they might best tackle this?
- Any other thoughts you'd like to add about this scenario?



**Figure B7***Vignette 4: Alice***Alice**

Alice has a deteriorating condition. Although it has been progressing relatively slowly, Alice has recently completed an experimental medical treatment in Thailand. She loved the idea that she was in control of the help she would receive and was hopeful about the procedure. The doctors asked her opinion on every step, which gave her a sense of empowerment and achievement to be making these decisions – she hadn't had many options in New Zealand. Despite some side effects – things she was warned about on the website and in consultation – Alice saw some immediate positive effects, including being able to walk further than before, and a reduction in chronic symptoms like pain and fatigue. Her local newspaper ran an article on her treatment and success.

However, Alice's longer-term recovery did not go as well as the clinic doctor predicted, and her symptoms are starting to return. She is worried about telling people it may not have worked and so is 'putting on a brave face' and doing new things. But she has started to rely on a cane again.

**Questions**

- Why might Alice have sought experimental treatments that wasn't medically approved and offered in her own country?
- What do you think of people in a situation like Alice's making choices like hers?
- What might count as the value or success of such treatments? *How* might it matter if Alice's symptoms return?
- What might Alice be thinking and feeling about the experience of having sought an experimental treatment that may not have worked longer term?
- Any other thoughts you'd like to add about this scenario?

## Figure B8

### Demographics Page

Please provide us with a little bit of information about you, so we can understand who has taken part in our project. This information will be used to provide a descriptive overview of the participants, an ethical and quality measure for our project.

How old are you?			
I identify as (select all that apply):	Woman	Man	Non-binary
	Gender fluid	Trans	Intersex
	Another way (please specify): _____		
How would you describe your race/ethnicity?			
Do you identify as disabled?		Yes / No	
What experience do you have with chronic illness? Select all that apply:		My own personal experience Within my family Within my friendship groups/close community Professionally	
Have you ever engaged with online health information sources related to chronic illness?		Yes / No	
If yes, I have looked at:		Conventional/mainstream approved. Complimentary and alternative medicine. Experimental treatments not approved here.	
Have you or someone you know considered experimental treatments?		Yes / No	
If yes, please tell us a bit about why and what happened			
Is there anything else you'd like us to know?			

**[CLICK HERE TO SUBMIT YOUR RESPONSES TO THIS STUDY](#)**

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**Figure B9***Study Endpage/Thank You***Thank You**

Ngā mihi nui! Thank you so for taking part in our study. If you would like to receive a summary of the information and findings, please add your email in the space provided.

We hope you found the experience interesting and possibly even enjoyable. If you did find it distressing in any way, you can download a list of support services.

We are offering all participants the opportunity to enter a draw for a \$100 Prezzy card. If you would like to be entered to this draw, please email Amy [ahog010@aucklanduni.ac.nz](mailto:ahog010@aucklanduni.ac.nz) with 'please enter me in chronicity study prize draw' as the subject line. This will not connect to your particular responses to this study, and therefore not impact anonymity.

## Appendix C

### Participant Advertisement

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*UNDERSTANDING PERCEIVED OPPORTUNITIES AND OBLIGATIONS  
AROUND CHRONIC ILLNESS*

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#### RESEARCH PRACTICIPANTS WANTED



Do you have a connection to, experience of, or an interest in chronic illness?

We (Amy Hogan and Prof Virginia Braun) are seeking people to read and respond to questions about a series of vignettes. The vignettes explore the current context of information, treatment options, and life choices for people with chronic conditions.

If you're 18+, live in Aotearoa New Zealand, and have interest, connection or experience related to chronic illness, you're eligible to take part.

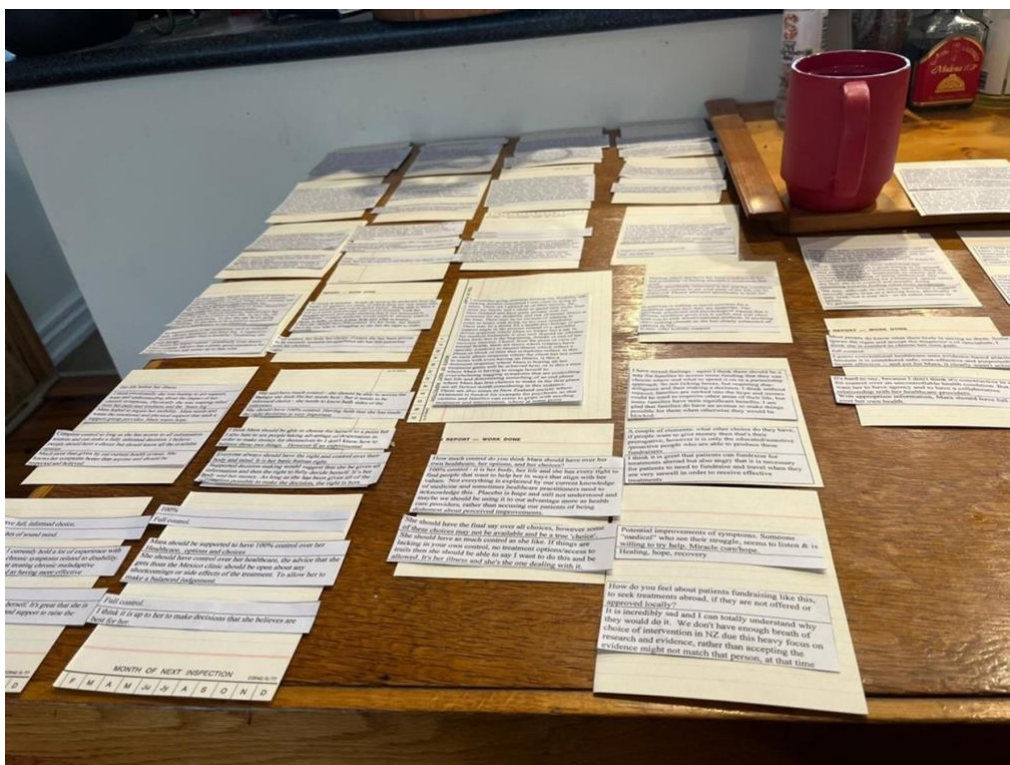
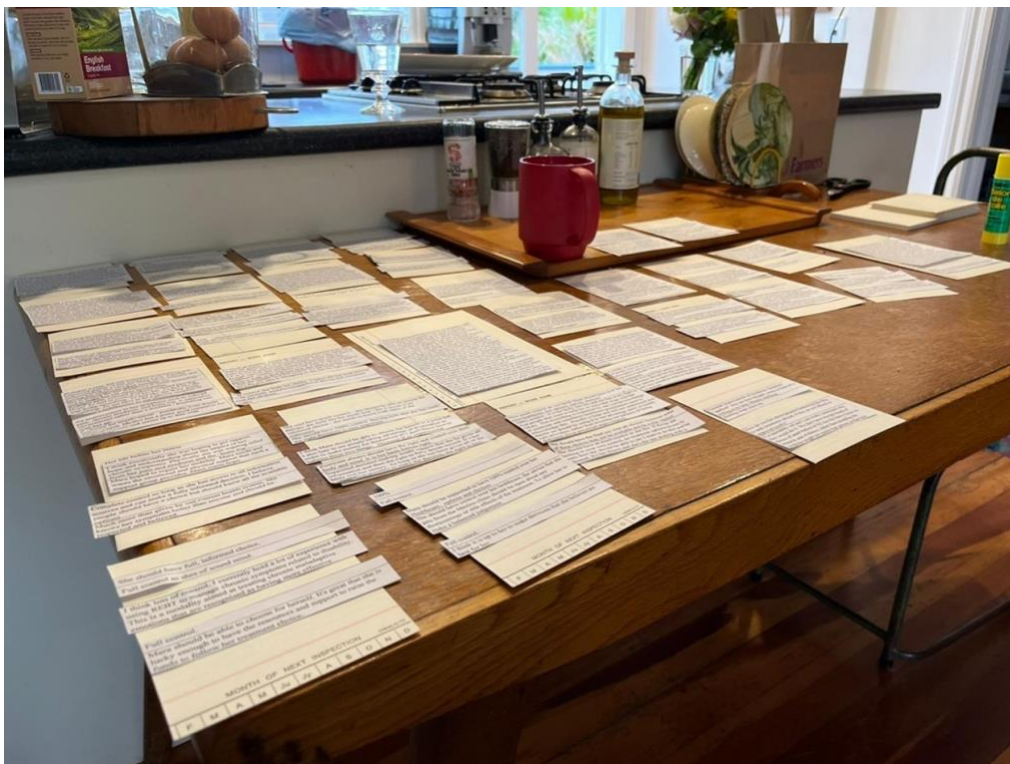
Responses are completed online and are anonymous. It should take around 30 minutes to finish the study. You will also be asked some brief demographic questions.

This research is for Amy's Master's thesis, in Psychology at Waipapa Taumata Rau (the University of Auckland), supervised by Virginia Braun.

To find out more, go to [Chronicity Study Qualtrics](#) or email Amy Hogan at [ahog010@aucklanduni.ac.nz](mailto:ahog010@aucklanduni.ac.nz)

### Appendix D

### Code Mapping and Initial Spreadsheets



Data Extract	Amy Codes
<p>She is not finding the answers she is looking for in traditional approaches that are heavily based on biomedicine. The treatment approach she has been offered does not align with her own values and needs from healthcare.</p> <p>She already has some knowledge but her views do not agree with the GP's and probably other people so she is trying to find her "tribe" that have had similar experiences with good outcomes. Ultimately she is probably just looking for a bit of hope and positivity.</p>	<p>New Zealand Health System failures</p> <p>She needs to find a system, approach and people that align with what she wants to gain.</p>
<p>Hope - I think many people living with a chronic illness are often seeking the nugget that gives them hope that their lives will have a change for the better.</p>	<p>Motivation situated around the hope for a better life</p>
<p>To gain some control and say with what is happening. Take a chance on something that could help her.</p>	<p>Gaining a sense of control – 'help'</p>

1	<b>Amy Codes</b>		
2	The Role of Adaptations and Adapted Resources		
3	Abilities' restrict health navigation success		
4	Adjusted Life Still Has Value		
5	Adjustment of Role and Self		
6	Agency and Support = Delicate Balance		
7	Breakdown of Social Relationships		
8	Capacity Needs To Be Navigated		
9	Change Is Hard!		
10	Change of Role and Status		
11	Chronic Illness and Mental Health -Connects		
12	Chronic illness is a slow progression – fighting against it is noble?		



## Appendix E

### Theme Miro Mapping

