

Understanding Experiences of Self-Acceptance and Embodiment Among People with Chronic
Health Conditions

by

Madeleine MacDonald
B.A., University of Western Ontario, 2022

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF SCIENCE

in the Department of Psychology

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University of Victoria

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We acknowledge and respect the Lək̓ʷəŋən (Songhees and Esquimalt) Peoples on whose territory the university stands, and the Lək̓ʷəŋən and W̱SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Supervisory Committee

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Abstract

Individuals with chronic health conditions experience greater psychological distress than those without (e.g., Brady et al., 2021). However, much of the existing research relies on quantitative methods that overlook lived experiences, leaving gaps in understanding distress and pathways to healing. This study addressed these gaps by adopting a critical, trauma-informed approach to chronic illness, examining how power structures and societal narratives shape health and well-being. In particular, I explored how individuals with chronic health conditions relate to their bodies and engage in healing for self-acceptance and embodiment (i.e., practices that promote healing from the experience of disembodiment). Participants aged 18 or older ($n = 74$; $M_{\text{age}} = 25$ years) who identified as having any kind of disability completed an online survey which asked about their perceptions of public and internalized stigma, embodiment, self-compassion, and self-esteem. This thesis assessed two open-ended questions, which asked participants about their process of self-acceptance for their disability, as well as what embodiment practices they currently use to stay in-tune/connected to their bodies in a subset of participants who identified as having a chronic health condition. Using both reflexive and codebook thematic analysis (Braun & Clarke, 2021), one overarching theme was identified among participants' responses which depicted disembodiment and disconnection from the body, and four main themes that illustrate the complex relationship between chronic health conditions, embodiment, and psychological distress. Participants described grief, and disconnection from the self, yet also highlighted moments of resistance, self-care, and embodiment, challenging the dominant medical model. Additionally, the codebook analysis examined responses to two research questions: (1) whether individuals described bolstering self-integrity, social support, and embodiment practices in their process of accepting illness, and how they articulated these

processes, and (2) what specific embodiment practices they used to connect with their bodies. Findings suggest that recovery is not a fixed outcome but an ongoing praxis, countering deficit-based narratives that frame chronic illness as inherently detrimental. Integrating perspectives from critical disability studies and critical health psychology, this research advocates for a compassionate, human-centered understanding of chronic health conditions, calling for a shift toward an approach that acknowledges chronic illness as deeply embedded in social and psychological contexts. Ultimately, this study amplifies the voices of people with chronic health conditions who often feel unseen or misunderstood and acknowledges the profound challenges that underly this experience.

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Acknowledgements

I would like to thank my supervisor, Dr. Danu Stinson, for her exceptional mentorship and guidance. Your wisdom, encouragement, and belief in my abilities have been invaluable. Your support has shaped not only this thesis but my academic and personal growth. I would also like to express my heartfelt gratitude to my supervisor, Dr. Paweena Sukhawathanakul, for her continued support and kindness. Your insights and assistance throughout my degree have made this journey more meaningful and fulfilling, and I am deeply grateful for your generosity and encouragement. Thank you both for allowing me to research a topic that means so much to me. Your support has made it possible for me to explore and contribute to a subject that deeply resonates with my own experiences and values. Finally, I want to thank my family and friends, whose love, patience, and belief in me have been a constant source of strength.

Introduction

The current state of the academic literature concerning chronic health conditions is biased by a medical model that is stigmatizing and objectifying, and as such, it fails to accurately represent the complex and multifaceted reality of living with a chronic health condition. There is a critical need for a shift in approaches to studying the lived experiences of people with chronic health conditions which, rather than continuing to perpetuate stigmatizing narratives, instead involves liberating and promoting thriving through reconnecting to the body. Definitions vary across the literature, but chronic health conditions are often characterized by persistent physical symptoms that are attributed to disease or malfunctioning of the body, which typically last for an extended period, often for the duration of a person's life (e.g., Van Der Lee et al., 2007, Goodman et al., 2013). Chronic conditions require ongoing medical attention and management that typically impacts an individual's quality of life negatively. Existing research tends to focus on a deficit model, implying that people with chronic health conditions are somehow deviant or abnormal. Brady et al. (2021), for example, claim that the experience of having a chronic health condition disrupts the "typical" (p.2) developmental trajectory for adolescents, which leads to poor mental health, a framing that negatively contrasts youth with chronic health conditions against their supposedly "typical" peers. It has consistently been suggested in the literature that those with a chronic health condition experience heightened psychological distress, which may be true, but few researchers have attempted to understand the processes underlying this outcome and what it means for people's relationships with their bodies. Thus, in my thesis I will argue that it is essential to adopt a humanistic, critical approach to understanding the experiences of people living with a chronic health condition, to avoid the harmful 'othering,' stigmatization, and objectification that currently exists in the literature. I will focus on the importance of

reconnecting to the body through methods of embodiment and self-acceptance with an aim of understanding how individuals with chronic health conditions attempt to heal from disembodiment and internalized stigma. In a sample of young adults, my research used qualitative methods to understand and validate the realities of living with a chronic health condition, with the long-term goal of supporting research aimed at identifying methods to support the well-being of people living with chronic health conditions. My approach will follow a similar framework introduced by the field of critical disability studies, which provides insight into how societal stigma perpetuates the harmful medicalization and objectification of those with disability or illness. This framework begins with describing health stigma, which is the root of trauma and psychological distress in people with chronic health conditions is. These experiences of stigma, which occur in everyday interactions, in the medical system, and in institutions unfortunately become internalized into one's self-concept, leading to two consequences: internalized stigma and disembodiment. I argue that this is a form of trauma that leads to disconnection from the self and nervous system dysregulation. In my thesis I critique the medical model and current societal perceptions of chronic health conditions that are at the core of health stigma, and to instead understand how people with chronic health conditions heal from their trauma. Specifically, how people are relating to their bodies, and how they are experiencing self-acceptance and embodiment.

Through qualitative methods, a critical, trauma-informed approach is used to understand and illuminate the experiences of people with chronic health conditions with a focus on their relationships with their bodies and how to promote resilience. This critical trauma informed approach necessitates the consideration of how power structures and society affect and shape the experiences of people with chronic health conditions. To understand and represent the

experiences of individuals with chronic health conditions, perspectives from critical disability studies and critical health psychology are used to provide insight into how societal stigma perpetuates the harmful medicalization and objectification of those with disability or illness.

Positionality Statement. Jacobsen and Mustafa (2019) highlight the importance of reflexivity and explicit positionality in critical qualitative research. Reflexivity is a form of critical thinking that involves reflecting upon and questioning one's beliefs, whereas positionality is an aspect of reflexivity, in which researchers explicitly identify their social identities such as values, views and beliefs in relation to the research process (Manohar et al., 2019). Jacobsen and Mustafa argue that reflexivity contributes to transparency and rigor of qualitative research by fostering a deeper understanding of the researcher's backgrounds, experiences, and social locations within the research process. I have therefore included my positionality statement as a critical reflection on my own background, biases, and perspectives.

My drive for wanting to take on this topic of research originally stemmed from a realization that the literature on the chronic health condition experience, specifically related to psychological well-being, is largely dominated by the medical model. Having type 1 diabetes myself, I was personally dissatisfied with research that solely assessed the well-being of people with chronic health conditions using quantitative methods that compared them with "healthy" people. I know from personal experience that the distress that comes with having a chronic health condition is far more complex and multifaceted than these studies depict, and without adequately capturing these experiences it seems impossible to successfully help these people heal.

I position myself as an individual with type 1 diabetes, a chronic health condition I was diagnosed with at the age of two. I recognize that my personal experiences and connection to my

research topic are notable, as my experiences have undoubtedly ignited my passion for this topic and motivation for conducting this kind of research. Throughout my 23 years living with type 1 diabetes, I have personally felt my experiences in the medical system to be very isolating and solely symptom focused. Additionally, I feel a general lack of understanding by close others in my life about the complexities and hardships that I endure while trying to stay healthy and live a “normal” life. This thesis is therefore intended to be a frank and honest examination that illuminates the experiences of people with chronic health conditions. My hope is that it will serve as a reflective resource that authentically captures the lived realities of those navigating these challenges and assists in understanding how they may engage in embodiment to reconnect with the self. I also acknowledge that I am a white, upper-middle class, Canadian, academic woman, and that the complexities of stigma and discrimination that I discuss may be experienced far differently by others who do not have the same privilege that I am fortunate to have. I am adopting a humanistic, critical theoretical approach, and will further elaborate on my theoretical position, and how it informs the lens through which I will examine participants responses, in the remainder of my introduction.

People with Chronic Health Conditions are Stigmatized

Goffman (1963) begins his exploration of social stigma by noting that throughout history and across various social groups, certain human differences have been valued and desired, while others have been feared and devalued. Thus, he argues, stigma is a direct result of social comparisons between desirable characteristic and undesirable differences, or deviations, from an idealized norm. Individuals with bodies that are considered to be unhealthy are often subjected to this kind of stigmatizing social comparison with their healthy peers (Bos et al., 2013). The roots of body stigma in industrialized Western nations can be traced to the 18th century, when anti-

Black racism and colonialism were used to distinguish white European bodies from those of peoples whom Europeans colonized and enslaved (Strings, 2019). Further development of these oppressive ways of thinking about body hierarchies was evident in the popular eugenics movement of the early 1900s (Davis, 2013). From the eugenicist perspective, disabled, fat, chronically ill, and queer people, along with racial and ethnic minorities were all subjected to stigma as a result of their deviate bodies. In turn, stigma fueled and justified prejudice, discrimination and marginalization against such groups in all areas of life (Myerson, 1988).

Although health stigma shares many characteristics with other types of body stigma, fear is a particularly important component of social stigma about illness. People may be fearful of contracting a physical illness, or they may fear contagion, especially when individuals do not know the etiology or predictability of a particular condition (Barbarin, 1986). Weiss and colleagues (2006) define health-related stigma as “an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted” (p.4). In addition to social judgment, health stigma comprises three essential components that involve *negative evaluations, exclusion and ostracism in the form of discrimination, and objectification* (e.g., Be, 2019, Price, 2011, Lewis & Dijkema, 2022). The following sections unpack how health stigma is experienced by people with chronic health conditions in order to emphasize the importance of examining how they recover from these experiences and reconnect to their bodies to instead promote thriving.

Negative Evaluations

Negative evaluations of people with chronic health conditions distort the public identity of the person being stigmatized. Individuals with chronic health conditions are often evaluated as

being unhealthy, or unable to properly care for themselves. But what does it mean to be healthy? The WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948). Yet, many scholars critique this definition and propose that any definition of health must include consideration of social norms. This perspective emphasizes how notions of health are shaped by social, cultural, historical, economic, and political factors. Such a social constructivist perspective may provide insight into the development of negative beliefs about individuals with chronic health conditions. For instance, power dynamics, medicalization, and historical context all contribute to the social construction of health and illness. Power dynamics evident in institutional structures and healthcare systems influence how society views certain conditions and who is marginalized in terms of health outcomes, which obviously influences definitions and experiences of chronic health conditions. Medicalization is the process whereby human conditions and problems are deemed a medical problem in need of treatment, often a process that pathologizes human difference (Sismondo, 2015). It can be argued that this type of pathologization negatively influences the self-concept and well-being of individuals with chronic health conditions, which can impair self-esteem and feelings of self-worth. It is important to discuss how society perpetuates these negative evaluations and how they are often ingrained in social norms to understand how these individuals may attempt to heal from these experiences.

Historical context is important in the conceptualization of what it means to have a chronic health condition, because historical factors such as technological advancements, medical discoveries, and shifts in societal values contribute to evolving perspectives on health. Cultural values like neoliberalism may also shape perceptions of health and illness. Neoliberalism can be defined as the belief in reducing government involvement in economic and social affairs,

promoting individualism, and emphasizing the importance of competition and market forces in driving economic growth (Wilson, 2017). Critics often argue that neoliberal policies exacerbate inequality and prioritize corporate interests over social welfare. Individuals with chronic health conditions may experience a reduced sense of autonomy and a greater reliance on the medical system to maintain well-being. For instance, gaining access to medication and relying on a medical or assistive device such as a wheelchair, an insulin pump, or stoma bag may indicate a sense of impairment. Therefore, these individuals may be perceived as unable to comply with neoliberal social norms whereby productivity and contribution to social capital is of great importance. This perception of impairment to productivity may be a driving force behind both modern definitions of health and the negative evaluation of chronically ill individuals.

A general lack of understanding at the interpersonal and societal level concerning the complexities and hardships endured by individuals with chronic health conditions is yet another driving force behind negative evaluations of people with chronic health conditions. Society perceives that individuals with chronic health conditions are responsible for their illness, and that the illness is a result of a failure on the individual's part to adhere to exercise or hygiene regimens, or appropriate diets (Turner, 1987). People with chronic health conditions often report feeling like there is a general lack of knowledge and understanding of their condition from friends, family, and the general public (Be, 2019). This lack of understanding influences how chronically ill individuals are treated, and the expectations that people have from them. Perhaps it is challenging for others to categorize chronic health conditions when impairment can be so variable and is not in line with other forms of disability that are often more consistent. This lack of understanding seems to prompt a thinking in society, and even in the chronically ill individuals' close relationships, that they are simply not trying hard enough to succeed (in

school, work, etc), or that the symptoms they're experiencing are not 'real'. These processes may be exacerbated when the chronic health condition is *invisible*, and thus not immediately evident to casual observers. Individuals with such conditions report that they suffer a sort of invisibility because they appear physically healthy but feel terrible, helpless, and low energy (Rainer, 2002). Observers may not understand how someone who looks well may in fact be suffering, and thus people with invisible illnesses may find it challenging to disclose how unwell and exhausted they actually feel. But whatever form the chronic health condition takes, when societal or cultural expectations concerning personal responsibility are not met, the body of the individual with the chronic condition is seen as deviant (Be, 2019). This lack of knowledge and acknowledgement of how physically and psychologically demanding it is to care for a condition that has no cure is a significant contributor to distress in everyday interactions, for it is a total disavowal of a person's body, mind, and symptoms (Price, 2011).

Discrimination

Individuals with chronic health conditions face discrimination throughout their daily lives, which means that they are denied equality and treated differently than their healthy peers because of their poor health status (e.g., Allport, 1954). Health discrimination exists across social contexts, such as in the workplace, the medical system, or even in relationships with friends and family.

In a society, health is regarded as a commodity and value is placed on workers who are efficient and productive (Turner, 1987). For individuals with chronic health conditions that are in many cases invisible, "the sufferer lives with a baseline of unwellness that is interrupted by periods of exacerbation and remission, relapse, and remission" (Donoghue and Siegel, 1992, p. 56). As a result, people with chronic conditions may feel the need to hide their illness or will

perhaps face internal conflict to decide whether to disclose their illness or not, often in fear that if they do, they will receive differential treatment or be seen as less capable than their healthy peers. The physical effects of having a chronic health condition are often at odds with workplace norms of success that are defined as speed, productivity, and maintaining a predictable schedule (Beatty & Joffe, 2006). Therefore, people who cannot adhere to such workplace norms and need to take breaks, or who are inconsistent with their levels of productivity when illness is exacerbated, may be seen as lazy or making excuses. Thus, the unpredictability, day to day variability, and invisibility of most chronic health conditions often lead to discrimination in the workplace (Vickers, 1997). For example, employment rates for individuals with disabilities and chronic health conditions remain low, and when they are employed, are offered fewer hours and lower wages, and have a greater likelihood of holding entry-level positions with fewer promotions (Lewis & Dijkema, 2022).

Discrimination is also present in other social contexts like higher education. Students with chronic health conditions are often subjected to ableism and disablism (Be, 2019). For example, ableist or healthist *microaggressions* are common in academia, whereby students with chronic health conditions must suffer a succession of commonplace interactions where their able-bodied or healthy peers and professors express a lack of understanding or invalidate how the chronically-ill person is feeling. The negative attributions about illness described earlier may also lead to denial of academic accommodations to a chronically-ill student, like class notes from a peer, or extra time on exams, because the chronically-ill student's attendance is so inconsistent.

Charmaz (2019) outlines many examples of discrimination experienced by individuals with chronic health conditions or disabilities through an ethnographic analysis with people who have both visible and invisible illnesses. She explains that illness strains public and private

relationships, oftentimes leading to exclusionary behaviour. Exclusion can consist of micro or explicit aggressive acts during interactions. Charmaz uses the example of forcing a person in a wheelchair to look up, which replicates a child-adult interaction. “When illness makes disability explicit, people may become treated as objects in public places” (p. 38, Charmaz, 2019). The visibility of an illness represents a flag for stigma and exclusion that prompts microaggressions and other discriminatory behaviour. For those with invisible illness who may find themselves needing to stay at home on certain occasions to rest and recharge, this temporary strategy may lead friends and family to exclude the ill person. When managing the inconsistent symptoms of a chronic health condition infringes on other people’s time, energy, and commitments, exclusion becomes common. While the British Columbia Human Rights Tribunal, for example, protects individuals against discrimination under the Human Rights Code through acts such as ensuring equal and fair wage and access to accommodation (Human Rights Code, RBSC, 1996), it is hard to enforce anti-discrimination laws when so many of these forms of discrimination occur through microaggressions or interpersonal slights.

With discrimination against those with chronic health conditions existing in the form of micro-aggressions that appear deeply entrenched in societal norms, the inevitability of people with chronic health conditions experiencing this type of maltreatment is high. As such, methods of recovery are incredibly necessary, and I aim to understand what practices people with chronic health conditions are currently using to stay in tune with their bodies.

Objectification and the Medical Gaze

As mentioned earlier, research on and care of chronic health conditions is dominated by a limiting and potentially harmful medical model. When thinking about illnesses such as diabetes, Crohn's disease, or asthma, the medical model focuses on the physical impairments and

symptoms of these conditions, while neglecting to recognize the psychological and social aspects of such diseases, including coping with stigma. Individuals with chronic health conditions consistently report that their doctors and care providers focus solely on the medical aspects of their illness experience but ignore the psychological and social aspects (Greenhalg, 2001). Although it is important to consider the medical aspects of managing chronic health conditions, treating a patient solely as a body with a medical problem, and not as a person with feelings and needs who is embedded within social relationships, is objectifying.

Objectification theory (Fredricksen & Roberts, 1997) describes the process whereby individuals internalize an observer's perspective as the primary view of the self. Originally developed to explain sexual objectification of women, Fredericksen and Roberts (1997) argued that women are acculturated to internalize a heterosexual, male perspective of womanhood, leading women to view themselves from a third-person, sexualized perspective, as if watching a movie about the self that was directed by a sexist man. This *self-objectification* leads to body monitoring and decreased awareness of physical bodily states, which in turn fosters shame and anxiety. That is, when the objectifying male gaze is internalized, women become socialized to treat themselves as sexual objects that exist to meet the needs of a heterosexual observer, leading to psychological distress that poorly impacts well-being. Thus, objectification is inherently tied to social power hierarchies: The higher-powered group's gaze is internalized by the lower-powered group, and the consequences of that internalization serve to reinforce the power hierarchy that fostered the objectification to begin with.

Although devised to explain sexual objectification, since its inception objectification theory has also been adapted to explain the objectification experiences of other groups of people, including those who have a chronic health condition or a disability (e.g., Hayes & Hannold,

2007; Wechuli, 2023). *Medical objectification* occurs when medical professionals see the body as an object, exerting a power differential between the healthcare provider and patient.

According to a critical disability perspective, the medical model embraces the notion of able-bodiedness, which reduces the disabled or chronically ill individual to a dysfunctional body in need of medical care (Hayes & Hannold, 2007). For example, the emotions of individuals with chronic health conditions are medically objectified, because able-mindedness is compulsory in an ableist society. Negative emotions such as sadness are therefore misunderstood and seen as a form of impairment related to the chronic health condition, thus further enforcing the idea that chronically ill individuals are to be regarded as a sick body and not as complex human beings with complex internal lives. Moreover, individuals with chronic health conditions are often subjected to treatment that is designed to help them cope and live as normal a life as possible - a task that seems nearly impossible when chronic health conditions are highly stigmatized and physically unpleasant. When medical objectification is endured, the objectified individuals may adopt a “sick-role” (p. 11) status whereby they see themselves as a patient who is powerless over their health and well-being, which subsequently reinforces the power hierarchy between medical providers and patients (Hayes & Hannold, 2007). Thus, individuals with chronic health conditions experience objectification, such that they are often treated as sick bodies with medical conditions and not as people. This idea of being treated solely as a sick body is concerning enough on its own to warrant an exploration of the complexities in the relationship between chronically ill individuals and their bodies. Especially where disconnection from the body seems inevitable as a result of objectification, focusing on methods that can instead enforce thriving and surviving appears critical.

The Medical Gaze. Objectification theory can also trace its roots back to the work of French philosopher, Michel Foucault. In *The Birth of the Clinic*, Foucault (1963) developed the concept of the *medical gaze* in response to his observations about the exercise of power within medical systems, whereby doctors hold power over the patients whom they view as solely biomedical entities. When applying the medical gaze, doctors modify patients' experiences by filtering out non-biomedical material that is considered to be irrelevant and unsuited to the biomedical paradigm. For example, an individual with Type 1 diabetes might be treated by their doctors as a malfunctioning pancreas rather than a human being with subjective life experiences and complex emotions surrounding their condition. As such, doctors' appointments may center around symptom checklists and rudimentary assessments of daily functioning. Foucault posits that doctors are oriented toward solving medical problems and learning more about biomedicine than about patients, allowing medicine to objectify and stigmatize patients and maintain an abusive power structure. Susan Greenhalg (2001) similarly discusses the power and authority of bio-medicine in her biography, *Under the Medical Gaze*. In a society that deeply trusts and values science, people automatically turn to medicine and doctors for help, because they believe these professionals hold the truth and solutions to their medical concerns. The medical gaze is essentially depictive of the power dynamic between the medical expert and the patient. When applied to chronic health conditions, the medical gaze leads to a reductionist perspective whereby the focus is solely on physiological aspects and neglects the complex interplay between psychological, social, and environmental factors.

Greenhalg (2001) takes an anthropological approach to unpack the complex bio-medical power processes and relations. To illustrate the devastating personal consequences of the medical gaze, she tells the story of a patient whose doctor was convinced that she had fibromyalgia, a

painful and untreatable muscle condition. Despite her hesitancy and after many dismissals of doubt by her doctor, the patient believed the diagnosis, which eventually turned out to be incorrect. The misdiagnosis wreaked havoc on the patient's inner world, bodily health, and well-being, leading the patient to become extremely depressed and physically unwell. The medical model defined the doctor as the expert on the patient's body, leading the patient to lose their sense of pride in their body and agency in their whole self, shattering their self-esteem. Greenhalg explains that for people with chronic health conditions, this kind of medical objectification and its resultant feelings of shame and isolation is unfortunately typical. Further, the symptom discourse in the medical model attributed the patients' symptoms, both mental and physical, solely to fibromyalgia, omitting the patient's deteriorating mental health from the evaluation of the doctor's success. This type of symptom discourse is a common feature of medical objectification, whereby the patients' emotions around their illness are dismissed as irrelevant to their bodily state, positioning the doctor as the expert on the patients' health and well-being. Greenhalg proposes that the tension between the lived reality of bodily experiences and the medical discourses imposed on the body is the key driving force that leads to mental disintegration among people with chronic health conditions. This experience undoubtedly perpetuates a cycle of apathy, hopelessness, and constant reliance on self-advocacy.

The Health Council of Canada (2007) conducted a report on Canadians' experiences having a chronic health condition. This survey's goal was to assess the health of this group of individuals including reports on access to care, quality of care and self-assessments of general health and functioning. Of note for the present study is the fact that more than half of the surveyed adults were almost never given a plan to take care of themselves in difficult circumstances, and less than half reported that their care was tailored to address their lifestyles.

These results suggest that medical care for chronic health conditions tends to follow a formulaic plan that rarely accounts for individual idiosyncrasies. Additionally, the report discussed that too few individuals with chronic health conditions are provided with educational resources and community supports that may be helpful in managing their conditions both psychologically and physically. As such, the present research will be important for identifying how individuals with chronic health conditions are currently working to reconnect with their bodies and increase their self-acceptance.

The Research Literature is Also Stigmatizing

Current research on the experience of having chronic health conditions is also stigmatizing. In describing the mental health of those with chronic health conditions, current studies tend to compare “healthy” versus “non-healthy” individuals. Thus, research on chronic health conditions is stigmatizing because it applies the medical gaze by focusing on group differences without adequate concern for context. For example, a study by Siegel et al., (1990) assessed a sample of non-hospitalized adolescents with chronic conditions to determine whether they differed from their peers on standardized measurements of depression, self-esteem, and life events. The sample consisted of 80 patients between the ages of 12 and 18 who had been dealing with a chronic health condition for at least two years, as well as a control group of 100 “healthy” adolescents (which they define as individuals who have not been diagnosed with a chronic condition), matched for age and socioeconomic status. Results revealed that adolescents with chronic health conditions had higher depression scores and lower self-esteem than their healthy age-matched controls. People with chronic health conditions experience significant mental distress due to the hardships of dealing with stigma, daily medical demands, and general increased stressors due to their illness. Yet, these important factors were not accounted for in the

study. Comparing the psychological well-being of people with and without chronic health conditions means very little when the cause for increased mental health concerns is not adequately examined.

Simply documenting that life is harder for individuals with chronic health conditions because they endure more daily demands does not tell the entire story of what it means to live with a chronic health condition. What specifically causes greater distress and what are the internal processes that lead to the eventual deterioration of mental wellbeing among people with chronic health conditions? Moreover, what can research that documents group differences but fails to account for variables like stigma or discrimination truly tell us about life with a chronic health condition? A more complex consideration of the impact of health stigma on the psychological well-being of people living with chronic health conditions is necessary. Part of that consideration requires researchers to examine their research practices as well. Contrasting healthy versus non-healthy individuals perpetuates objectification by othering those with chronic health conditions, which in-itself may lead to more significant distress among a group that researchers may be purporting to help. Literature that uses terms such as “healthy” versus “unhealthy” (e.g., Seigel et al., 1990), is objectifying. Based on these depictions of individuals with chronic health conditions that I encountered in the literature, it is evident that the research literature is embedded within a society that perpetually stigmatizes people with chronic health condition, and the literature reflects those values.

Additionally, it must be recognized that stigma and objectification are embedded in the use of measurement in these studies and necessitates the use of qualitative methods. Using quantitative measures cannot adequately capture the complexity of people’s experiences when these methods assumes that the extent to which participants agree or disagree with researcher’s

words or standardized measures fully captures their lived experiences. For example, one study used the Multicentre Adolescent Survey on Health to assess chronic health conditions, lifestyle and emotional health in adolescence (Miauton & Narring, 2003). Well-being was globally assessed as responses to the question: “Psychological feeling during the last 12 months?” with the option to select “I feel quite well” either “often” or “rarely” (p.4). These answers were then compared between adolescents with and without a chronic health condition. Using a questionnaire like this to make conclusions about the well-being of people with chronic health conditions oversimplifies and thereby invalidates the chronic health condition experience. How can this method help people with chronic health conditions or promote change within government and mental health supports when the measures provide no opportunity to understand *why* they might be feeling psychologically unwell? There is a clear need for the use of qualitative methods in this area of study to be able to allow for a better understanding of the complexity of these experiences.

The Current Research: A Critical, Trauma-Informed Approach

To improve the current state of the literature around chronic health conditions, I propose a critical, trauma-informed approach to understand how power structures and society affect and shape the experiences of people with chronic health conditions. Taking a human-centered approach to chronic health conditions provides an alternative way of looking at these individuals’ experiences to promote healing and resilience rather than maintaining a deficit model that perpetuates negativity and trauma. While both physical symptoms and internalized stigma lead to a source of trauma for individuals with chronic health conditions, we cannot cure the physical manifestations that accompany certain conditions. We can, however, attempt to assist and understand how individuals break down and recover from the internalized stigma and

objectification. I therefore propose that to heal from the trauma experienced by individuals with chronic health conditions that result from physical symptoms and health stigma, one must increase self-acceptance (or decrease internalized stigma) and increase embodiment (or decrease traumatic disembodiment). This trauma-informed model is depicted conceptually in Figure 1.

To dissect these processes and understand the trauma experienced by individuals with chronic health conditions, I will draw on perspectives from critical disability studies and critical health psychology. Critical disability studies (CDS) is an interdisciplinary form of study that focuses on critically examining social, cultural, political and economic aspects of disability. Further, CDS explores how disability is socially constructed and how it intersects with forms of oppression and discrimination. Power and oppression are a key element of CDS whereby power dynamics are examined to explore how disabled individuals may face discrimination and exclusion in various settings such as education, employment, and healthcare. Thus, the goal of CDS is to dismantle ableism through activism and advocacy to promote more inclusive and accessible environments. Critical health psychology arose out of a dissatisfaction with the positivist paradigm and overemphasis with quantification and generalizability which prevents an understanding of people's experiences of health and illness (Gough, 2017). Critical approaches to health psychology instead are concerned with "a desire to develop a psychological understanding of health and illness that is socially, culturally, politically and historically situated and that contributes to the development of a range of participatory and emancipatory approaches to enhancing health and wellbeing" (Murray & Chamberlain, 2014, p. 845). Moreover, critical health psychology aims to increase awareness of marginalization and stigmatization based on health status that occurs as a result broader systems of power and social norms. Importantly, the work conducted by critical health psychologists is primarily concerned with exploring unique

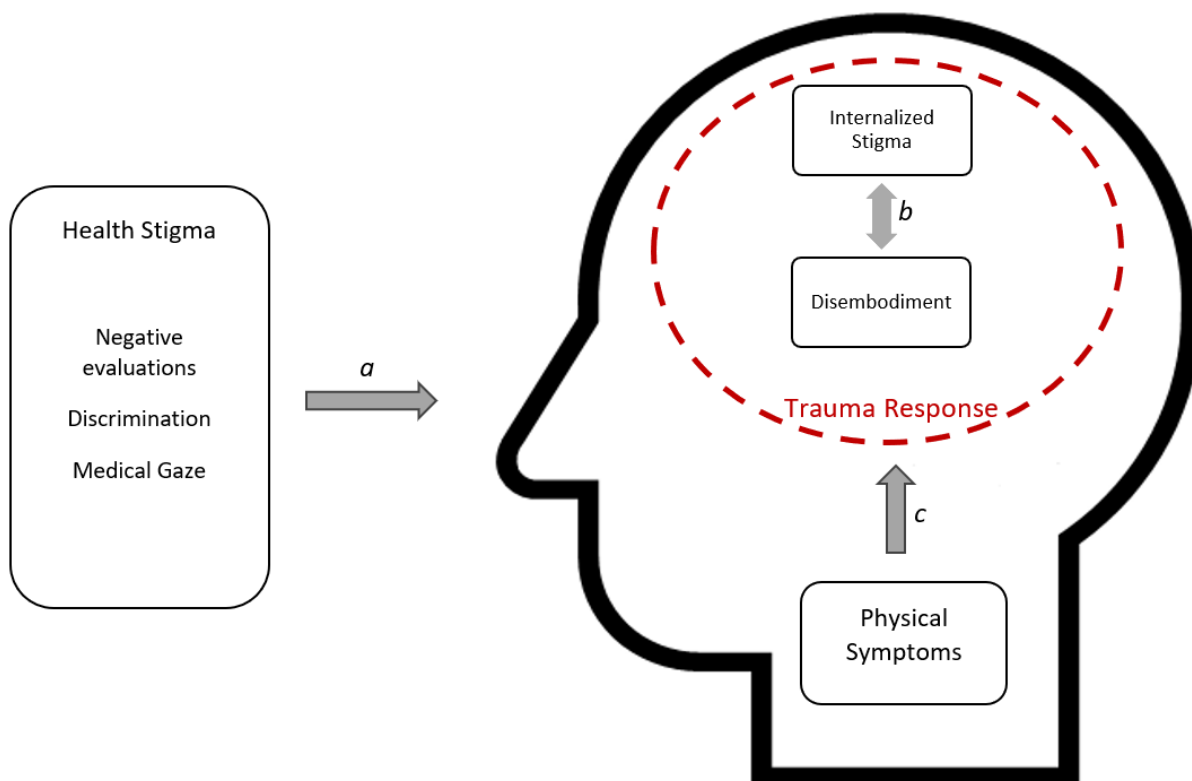
experiences of health and illness through use of qualitative methods and phenomenological methodologies. Using these approaches generates important insights into individuals' experiences with chronic health conditions which can be used to provide better care, as well as lead to the revision of health policies and practices.

Chronic Health Conditions as Trauma: A Conceptual Model

Based on frameworks of critical disability studies and critical health psychology, this research is guided by the assumption that the experience of having a chronic health condition is traumatic, due in part to the combined experiences of health stigma (comprised of negative evaluations, experiences of discrimination, and impact of the medical gaze) and distressing physical symptoms. As shown in Figure 1, internal trauma response is comprised of internalized stigma and disembodiment, which is the primary focus of the present study. Other studies have explored these trauma responses that manifest externally, such as the use of substances or discontinuing treatment adherence among individuals with chronic health conditions (Earnshaw & Quinn, 2012).

Figure 1

A Conceptual Depiction of Chronic Health Condition Trauma



Socially Constructed Health Stigma Becomes Internalized Stigma

Although half of the adult population is living with a chronic health condition (World Health Organization, 2011), society perpetually stigmatizes these individuals. Health stigma has a significant impact on the quality of life of those being stigmatized (Earnshaw & Quinn, 2012). One way that quality of life is diminished by stigma is when people come to perceive that the negative beliefs and attitudes that others hold about them are true and begin to see themselves in this same light, creating a diminished sense of self-worth and feelings of guilt and shame (Person et al., 2009). Thus, people who experience stigma incorporate the stigma into their self-concept, a process that is psychologically damaging which can contribute to devaluation of the self.

Internalized stigma has a significant direct negative impact on quality of life, depressive symptoms, and self-esteem through endorsing socially-constructed negative beliefs and feelings related to the chronic health condition, which then become applied to the self (Link, 1987; Earnshaw and Quinn, 2012). For example, the development of this negative self-image may manifest in feelings that they are not as good as others as a result of their illness, that it is their fault that they have a chronic health condition, and that they are generally less capable as a person because of their chronic condition (Berger et al., 2001; Earnshaw & Quinn, 2012). Kilinc and Campbell (2009) highlight the experiences of individuals with epilepsy who have experienced stigma and explain that they feel “odd” or like a “reject” (p.5). One participant described their internalized feelings: “I don’t feel, you know, as confident as I used to be when I was younger, not at all. I’m very indecisive, yeah, it’s [epilepsy] made me less confident and less decisive. I used to be quite an opinionated person, I try to keep quieter now” (Kilinic & Campbell, p.5).

Earnshaw and Quinn (2012) explain that internalized stigma is therefore an intrapersonal phenomenon which becomes embodied by individuals with chronic health conditions and is then brought into various social contexts as they move throughout their social worlds. Although people who are subjected to social stigma often avoid various social contexts to avoid stigma (e.g., Kinsler et al., 2007, Quinn & Chaudoir, 2009), when those with chronic health conditions endure stigma, they report feeling so shameful and discriminated against that they often avoid accessing healthcare, which may be particularly detrimental to their health (Earnshaw & Quinn, 2012). Many of these individuals who have experienced stereotyping or discrimination in healthcare settings then begin to anticipate that they will receive this same type of prejudicial care in the future and thus avoid accessing care to avoid this kind of negative experience.

Healthcare avoidance is detrimental to anyone's well-being, but it may be especially detrimental to people with chronic health conditions.

As previously described, internalized stigma poses numerous threats to well-being (e.g., Bos et al., 2013), and due to social systems that perpetuate negative evaluations, discrimination and the medical gaze, many individuals cannot escape the internalization process. Sturgess and Stinson (2022) argue that experiencing stigma and the resulting disruption of positive self-identity is actually a form of trauma (see also Stinson et al., 2021). This conceptualization of trauma differs from that of most psychological definitions, which tend to see trauma as resulting from a single isolated life-threatening experience. For instance, Sturgess and Stinson point out that *The Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-5; American Psychiatric Association, 2013) defines trauma as “actual or threatened death, serious injury, or sexual violence”. But the authors also point out that Burstow (2016) claims that “trauma is not a disorder, but a reaction to a kind of wound” (p.10; as cited by Sturgess & Stinson, 2022). This trauma reaction can come in response to a world in which people are routinely wounded, such as in the case for individuals subjected to social stigma. Root (1992) defines this kind of trauma as “insidious”, whereby the accumulation of societal oppression damages marginalized individuals because they are living in a society that is alienating and disparaging. As these scholars discuss, there is also a physicality to trauma. Traumatized individuals, to some degree, become alienated from their bodies, experiencing disconnection between the mind, or sense of self, and the body. This sense of disconnection where mind and body are separated is called *traumatic disembodiment*, which leads to suffering in the form of psychological distress and neglect for the care of the self (Sturgess & Stinson, 2022; Stinson et al., 2021). In the context of chronic illness, traumatic disembodiment may also occur when individuals struggle with the impact of persistent

symptoms or pain, leading them to feel as though their body is an adversary rather than a part of their self.

When individuals disconnect from their bodies to protect themselves from their trauma, they also experience disruptions to their well-being through a process of nervous system dysregulation (Sturgess & Stinson, 2022; Stinson et al., 2021). Nervous system dysregulation is characterized by swings between extreme states of hyper- and hypo- arousal, which leads to emotional volatility and disrupts emotional self-regulation (Van Der Kolk, 2015). This nervous system dysregulation and reduced emotional self-regulation often results in mood disorders and psychological distress, which are common experiences among people who are subjected to social stigma (Sturgess & Stinson, 2022; Stinson et al., 2021). In line with objectification theory (Frederickson & Roberts, 1997), the separation from mind and body that occurs in response to stigma as a defense mechanism also leads to self-objectification and reduced internal bodily awareness. Therefore, it is important to identify what practices individuals with chronic health conditions use to resist, recover, and heal from this type of trauma, which will also be explored in this study.

The Trauma of Chronic Health Conditions. The experience of having a chronic health condition is traumatic as a result of trying to manage the medical demands that come with illness while also living in a world where individuals are persistently oppressed and stigmatized. Especially considering that society perceives chronic health conditions as primarily a medical concern, and not a source of trauma, these internalized societal attitudes (comprised of negative evaluations, discrimination, and the medical gaze) play a significant contributing factor to the feelings of inadequacy and disembodiment these individuals can experience as depicted in Path ‘a’ of Figure 1. Path ‘b’ represents the internal trauma response that results from experiencing

prolonged health stigma and consistent internalization of the medical gaze. In path ‘b,’ there is a reciprocal relationship between disembodiment and internalized stigma, such that the more disembodied an individual becomes, the more likely they are to apply the medical gaze to the self, seeing the self primarily as a sick body and not a fully realized person. Path ‘c’ represents the unique contribution of physical symptoms in the chronic health condition trauma experience which compounds the trauma response.

A Unique Complicating Factor: Physical Symptoms. In addition to the trauma that results from societal implications of stigma and the medical gaze, individuals are also consistently dealing with physical symptoms resulting from their chronic health conditions (i.e., Path ‘c’ in Figure 1). The addition of physical symptoms to this model is unique to individuals with chronic health conditions. While other stigmatized groups may also experience trauma as a result of internalized social stigma, they do not additionally have to manage unpleasant physical symptoms of illness (unless, of course, they also have a chronic health condition, which many members of marginalized and/or stigmatized groups do; e.g., Government of Canada, 2023). Physical symptoms can affect well-being for individuals with chronic health conditions both directly, where symptoms themselves increase distress, and indirectly, through maladaptive coping such as seeking relief with substances (Earnshaw & Quinn, 2012), which in turn, exacerbates disembodiment and mental health concerns.

Physical symptoms increase distress amongst individuals with chronic health conditions as a result of pain, discomfort, and disruptions to sleep and daily life. Further, symptoms may serve as a reminder to individuals of feelings of otherness that are involved in experiencing stigma. Current research suggests that the experiencing of physical symptoms and pain plays a significant role in the relationship between chronic health conditions and self-concept related

outcomes (Ferro, 2016). Importantly, physical symptoms appear to play a significant role in the finding that individuals with chronic health conditions have a higher lifetime prevalence of mental disorders. Specifically, levels of pain or discomfort mediate the association between having a chronic health condition and mental health symptoms, suggesting physical manifestations of the chronic condition are significant in the development of negative psychological outcomes (Ferro, 2016).

Concerningly, relief-oriented substance use is common for teens with chronic health conditions, often because they feel they cannot find other ways to deal with their physical health problems (Bottorff et al., 2009; Wisk & Weitzman, 2016; Suris et al., 2008). People with chronic health conditions sometimes use substances, such as marijuana, to suppress their physical symptoms, and to assist in managing pain, sleep problems, and psychological distress. Teens tend not to see this use of marijuana as excessive and are not worried about the negative impacts of consistent marijuana use. Further, it has been found that chronic users of marijuana who start their use earlier on tend to report more physical symptoms, poorer physical self-concept, less physical activity, poorer eating practices, and less sleep in adolescence and young adulthood (Ames et al., 2020). Thus, there appears to be a negative cyclical relationship between the experiencing of physical manifestations, the use of coping-related substances, and subsequent health risk behaviours. This is undoubtedly detrimental for later health and well-being outcomes, and it is therefore evident that a method of healing that allows individuals to become more in tune with their bodily sensations and recover from traumatic experiences is critical for individuals with chronic health conditions, especially those who feel their only escape from physical symptoms is the use of substances.

Resisting Health Stigma and Healing Internalized Stigma

Healing from this type of trauma will surely be a challenging process, since internalized stigma becomes deeply ingrained into one's sense of self. Moreover, individuals with chronic health conditions have the unique experience of additionally enduring painful and uncomfortable physical symptoms which exacerbate the need to escape the body through disembodiment. Recovery from internalized stigma is likely not linear. The symptoms that individuals face vary tremendously and may range from extreme unwellness to periods of remission. The challenge for the person with the chronic health condition is to adjust to these varied states of unwellness and even to accept it (Donaghue & Siegel, 2000, p. 56). Sturgess and Stinson (2022) suggested various methods of healing from internalized weight stigma that target resisting stigmatizing perspectives, increasing self-acceptance, and increasing embodiment. Further, they proposed that healing through these mechanisms might be achieved through bolstering self-integrity, social support, and embodiment practices. I propose that similar processes may help people with chronic health conditions to resist and heal from internalized health stigma. Further, because people with chronic health conditions face the added component of physical symptoms which inevitably exacerbate disembodiment and the trauma response, I argue that increasing embodiment will play an important role in allowing them to accept and tolerate their physical symptoms. Referring back to Figure 1, one may picture these methods of resistance as a shield between path 'a' and the trauma response, such that they reduce the severity of internalized stigma, disembodiment, and physical symptoms. I acknowledge that many of the resistance and recovery techniques I will describe have shown correlational or experimental effects in quantitative research for their ability to reduce distress and increase mental well-being, but I emphasize the necessity of a qualitative assessment to capture the nuance and complexity that

cannot be attained through quantitative design. My goal pertains to identity, life narrative, and how individuals construct meaning in their lives and thus it is essential to ask these questions qualitatively to see if people with chronic health conditions are discussing these methods in their narrative for recovery and healing.

Bolstering Self-Integrity

Sturgess and Stinson (2022) proposed that in order to resist stigmatizing perspectives and recover from a broken sense of identity, fostering an increased sense of self-integrity is integral. For people with chronic health conditions, I believe this process may be achieved through forging a more positive identity relating to one's disability or illness and resisting stigmatizing perspectives about disability and illness that can lead to internalized stigma. Bolstering self-integrity may also improve embodiment by making the self, and the body, a safer place to reside.

Forging a Positive Identity Related to Illness. As I have already discussed, stigma creates a profound social identity threat that leads to a spoiled self-identity, whereby negative stereotypes, emotions, and beliefs from society are incorporated into the self-concept (Bos et al. 2013). Stinson and Sturgess (2022) discuss healing through strategies that bring awareness to aspects of the self that have been suppressed due to body stigma. Re-invigorating these aspects of the self through self-care and self-compassion may improve well-being (Stinson & Swann, 2017). That is, to recover from a stigmatized identity, individuals need to reject 'self-hate' and embrace 'self-love'. This can be a challenging task for individuals with chronic health conditions who often feel they are at war with their bodies and have internalized illness stigma. Self-blame is salient in people with chronic health conditions (Sirois et al., 2006). To reduce this self-blame, self-compassion and treating the self with kindness rather than harsh judgment may be needed. Adopting more self-compassion has been linked with greater use of adaptive coping strategies,

which in turn decrease psychological distress for individuals with chronic health conditions (Sirois et al., 2015).

Resisting Stigmatizing Perspectives. Individuals may feel a sense of empowerment when they challenge public stigma and engage in activities to break down the systems that create health stigma with others who have endured similar experiences. Research has shown that there are three general strategies for changing public stigma: protest, education, and contact (Corrigan & Penn, 1999). For example, to challenge stigmatizing perspectives, advocacy groups such as the Chronic Disease Coalition or Canadian Health Advocates protest inaccurate representations of chronic health conditions that exist in the medical world and in media. Education involves informing the public of accurate representations of the chronic health condition experience and highlighting false assumptions. For instance, this may include educating employers that despite day-to-day variability in symptoms which may impinge on traditional norms of productivity, chronically ill individuals are not any less capable of achieving success in the workplace. Education could also be provided in the form of brief programs that falsify stigmatizing beliefs and paint an accurate picture of what it means to live with a chronic condition. The final strategy for changing public stigma according to Corrigan and Penn (1999) is contact, whereby members of the community tend to oppose stigmatizing attitudes when they are in close contact with someone who has a chronic health condition. They exemplify this by discussing how when individuals with severe mental illness engage in cooperative tasks with other members of their community such as in an institutional setting, thinking around the individual goes from “them” to “us” (p.771).

Corrigan and Wassel (2008) discuss strategies to reduce stigma through the development of positive group identities, challenging the legitimacy of stigma, and encouraging

empowerment. For example, they discuss how individuals with mental health conditions should work towards creating a collective identity that challenges the negative stereotypes and discrimination that are prevalent in society. Such positive group identity can contribute to a sense of unity, empowerment, and resilience through belonging and shared experience. Challenging the legitimacy of stigma, they explain, can be done through educating the public, raising awareness about the realities of the stigmatized illness, and debunking myths and stereotypes. Moreover, Corrigan and Wassel highlight the importance of encouraging empowerment as a key strategy in addressing the stigma of mental illness, as it involves instilling a sense of control, self-efficacy, and resilience in individuals facing stigma. Strategies may include providing education, support, and resources that enable individuals to advocate for themselves, challenge stigmatizing beliefs, and actively participate in decisions related to their health care. Empowerment is not only a means of improving individual well-being but also a way to contribute to broader social change by challenging the power dynamics that perpetuate mental health stigma (Corrigan & Wassel, 2008). Collective action with communities of people enduring the same or similar illnesses is effective in encouraging this sense of empowerment and may therefore be useful as a method for healing from and accepting one's illness.

While empowerment interventions for people with chronic health conditions exist within the healthcare system, they often do not apply the same activist-oriented perspectives. Traditional empowerment models, while valuable, tend to focus on personal autonomy, education, and self-management, often within the framework of individualized approaches to health care (e.g., McAllister et al., 2012; Stepanian et al., 2023). However, the approach in my research shifts toward a more collective and justice-oriented model that centers shared experiences of oppression, challenging not just personal stigma but the broader social and

systemic forces that marginalize individuals with chronic health conditions. I therefore aim to identify additional methods that empower individuals such as collective action and solidarity.

Social Support can Promote Healing from Trauma

Peers and Community. Social relationships play an important role in nurturing a more positive self-concept and therefore they may also play an important role in healing from trauma and disembodiment. For individuals with chronic health conditions, loneliness is a strong determinant of psychological distress and well-being (Lamu & Olsen, 2018), whereas engaging in greater contact with friends, neighbors, and other community members predicts greater well-being (Maguire et al., 2021). Van Der Kolk (2015) similarly determined that reciprocal social relationships can foster safety, and thus social relationships can be one of the most powerful protections against becoming overwhelmed by stress and trauma.

While having a general sense of community and support in day-to-day life is positive for mental health and self-concept outcomes, the need to feel seen and deeply understood cannot necessarily come from someone who has not had the same first-hand lived experience of a chronic health condition. “People who purposefully affiliate with groups and publicly admit this relationship are less overwhelmed by stigma and are more in control” (Corrigan & Wassel, 2008, p.5). Individuals with chronic conditions may feel more understood and empowered through finding in-person communities of individuals with similar conditions. Lehardy and Fowers (2020) explain that support groups assist with regulating emotions, fostering a sense of belonging, and integrating the chronic health condition experience into one’s identity. The ability for support groups and communities of like individuals to foster a sense of collective identity enables greater acceptance of the chronic health condition identity and more positive psychological outcomes.

Finally, the Health Council of Canada Report on Canadians' experiences with chronic health condition care that I cited earlier discusses the idea of "whole person care" (p.12). In this section, the authors note a general dissatisfaction with the availability of community resources and support groups from individuals accessing healthcare for their chronic health condition. Reading this, I was left with the impression that these individuals were longing for resources like support groups and had a desire for educational resources and programs that would integrate them into a community of similar individuals. The fact that the Canadian Government was thinking about whole person care and including statistics on these areas in need of improvement in 2007 is, however, promising and indicates hints of hope that the medical community might attempt to include these things and move toward more holistic care.

Parents. Parents also play an important role in nurturing and supporting individuals with chronic health conditions. Particularly, parenting style and parent-child attachment have a substantial influence on self-concept formation and adjustment in many areas of life (e.g., Bowlby, 1969). The effects of the parent-child relationship may have an especially pronounced influence when the child has a chronic health condition. For example, parenting style has been found to strongly and negatively affect the self-concept of youth with chronic health conditions (Ahn & Lee, 2016). Further, adolescents with chronic conditions who have more secure attachment relationships with parents have greater beliefs in their own efficacy, and thus employ more frequent self-care practices (Bender & Ingram, 2018). Therefore, it appears that parents have an important influence on the willingness for the child to engage in practices that might help them to resist and recover from internalized health stigma.

Online community. Online communities have the ability to promote resistance and healing from stigma (Burstow, 2003; Gone 2013). Not only do these types of communities

promote the pursuit of social change with others who are a part of the same stigmatized group (van Zomeren et al., 2008), but participating in an online health community also provides benefits for information utility and social support (Johnston et al., 2013). Social groups that form online allow individuals with chronic conditions to find each other, share their experiences, and provide users with a feeling of understanding (Isika & Bosua, 2016). Social media provides an avenue for social support to occur easily among peers. Video blogs, or “vlogs”, have become a common means by which individuals with chronic health conditions share their experiences in an online community (Huh et al., 2014). Others can then comment, offering their emotional support, compassion, or medical advice based on personal experience. Recently, social media has seen a proliferation of chronic health condition and disability “influencers” whose purpose is to share posts and create this sense of online community through attracting individuals enduring similar experiences. Seeing these messages and obtaining this sense of community leaves individuals feeling less alone in their conditions and more positive interpretations of their experiences, leading to greater well-being.

Embodiment Practices Support Healing from Trauma.

Embodiment practices that reconnect individuals to their bodies are essential for healing from the experience of disembodiment and disconnection. To heal from traumatic disembodiment, individuals with chronic health conditions may use practices such as rest (Donoghue, 2000), joyful movement such as yoga (Holte & Mills, 2013), mindfulness (Niazi & Niazi, 2011) and consistent, purposeful self-care (Riegel et al., 2012). Increasing embodiment appears to contribute to decreased anxiety, psychological distress, and depression, and an increase in quality of life amongst those with chronic health conditions. For example, Bolton et al., (2018) found that individuals with chronic conditions who used movement-based

complementary and integrative health therapies such as yoga experienced a reduction in their physical symptoms such as pain, an increased capacity for self-awareness, greater overall happiness, reduced anxiety and anger about their illness, and finally, great improvement in their social-relational realm when classes were taken in a group setting. Further, mind-body therapies like mindfulness and meditation may be particularly important for people who experience traumatic disembodiment, as these practices emphasize the mind-body connection. Mindfulness-based stress reduction (MBSR), for instance, is a meditation technique that combines mindfulness meditation, body awareness, yoga and an inward examination of present experience, which may include body sensations, mental states, emotions, impulses and memories, in an attempt to reduce suffering and increase well-being (Kabat-Zinn, 2013). MBSR has been used as a form of therapy in illnesses such as cancer, diabetes, chronic pain and skin disorders. When used, these individuals experience a decrease in anxiety, psychological distress, and depression, and experienced an enhanced quality of life after MBSR therapy.

The Current Research

The conceptual model in Figure 1 and theoretical exploration of trauma, embodiment, and recovery from internalized stigma poses questions about the comprehensiveness of temporary quantitative approaches to studying experiences of individuals with chronic health conditions. Based on Be's (2016) paradigm of sustained well-being, which asserts that people who are living with a chronic health condition can experience a fulfilling life despite enduring trauma, this research examines how people with chronic health conditions attempt to support their well-being by unlearning internalized stigma. This can be through self-acceptance (i.e., learning to accept their chronic health condition), as well as proactively connecting with their bodies, which is part of the process of healing from traumatic disembodiment. This research will

thus take preliminary steps to determine whether the theoretical framework described fits with some aspects of the lived experience of living with a chronic health condition, and whether embodiment supports sustained well-being among individuals with chronic health conditions.

To examine these processes among individuals with chronic health conditions, I analyzed participants' responses to two opened ended questions which asked them to reflect on processes of self-acceptance and embodiment practices; that is how they come to accept their illness and how they stay connected to their bodies. Participants were part of a larger-scale study concerning resisting and recovering from disability stigma. This subsample consisted of individuals whom identified as having chronic health conditions. First, reflexive thematic analysis was used to analyse responses to these open-ended questions that answer one overarching research question: *How do people with chronic health conditions relate to their bodies?* Reflexive thematic analysis is well-suited to answering this research question because it will allow for an uncovering of the latent meaning in participants' responses in the form of identifying themes within participants' responses, through the use of a more critical analytic approach. This research question explores meaning behind how people are talking about and psychologically relating to their bodies, and how they are relating to the concept of acceptance and recovery.

A qualitative codebook thematic analysis was also used to answer more-specific research questions concerning people's responses to open-ended questions: 1) *When talking about the process of accepting their illness, do people with chronic health conditions describe bolstering self-integrity, social support, and embodiment practices; and if they do, how are they describing these processes?;* and 2) *What specific embodiment practices are people with chronic health conditions using to connect with their bodies?* These methods of self-acceptance and embodiment are likely to represent protective pathways that may reduce the impact of health

stigma in path 'a', diminish disembodiment and internalized stigma in path 'b', and mitigate the trauma associated with physical symptoms in path 'c'. Qualitative codebook analysis is well-suited to answering these questions because this method focuses on identifying broad thematic patterns across participant responses to produce a descriptive analysis of semantic meaning (Braun and Clarke, 2006). The goal of the first research question is to explore whether people with chronic health conditions are using the hypothesized methods of self-acceptance when discussing the process of accepting their illness. As this research is a preliminary exploration, this first research question simply aims to address whether these methods, which have been successful for other stigmatized groups, are applicable to people with chronic health conditions. Further, the codebook thematic analysis will assist with describing which methods appear to be more common and useful in this group, as well as highlighting methods that may not have been initially construed. The second research question will similarly identify what embodiment practices people with chronic health conditions are using, as research that assesses relationships with the body and promotes thriving from a critical activist-oriented perspective are limited.

The goal of this research is to understand more about how people with chronic health conditions are relating to their bodies, and to begin to identify methods that help these people reclaim a more positive self-identity. Internalized stigma, disembodiment, and physical symptoms appear to contribute to trauma for individuals with chronic health conditions, leading to nervous system dysregulation and disembodiment. With such a breadth of literature detailing these negative experiences, the importance of reconnecting with the body for recovery is undoubtedly critical.

Method

Data Collection

Data was collected in February 2021 by Kelby Mullin, a graduate student in my research lab at the University of Victoria (UVic). Kelby's thesis looked at people who self-identified as having some form of disability and focused on responses to quantitative items concerned with internalized stigma, identity, and embodiment. I used a sub-sample of Kelby's original sample who identified as having a chronic health condition and/or a neurological condition and used the qualitative questions which focus on embodiment and self-acceptance. Recruitment occurred through multiple sources including through the SONA psychology research participation system, online UVic channels (e.g., listservs, university newsletters, student-directed social media channels), and through campus-wide posters. The recruitment criteria indicated that participants had to be 18 or older and identify as a person having any kind of disability. Approximately 351 total students were recruited.

Participants completed an online Qualtrics survey which covered demographic information, public and internalized stigma, embodiment, self-compassion, self-esteem, and group interactions. Most questions in the survey were quantitative and were assessed using multiple choice or Likert scales, apart from two long answer, open-ended prompts, which yielded the qualitative data I analyzed. Participants provided informed consent by clicking "I confirm that I am aged 18 or over and that I consent to take part in this study." The questionnaire was administered online and took approximately 30 minutes to complete. Those who participated through the SONA system received course credit, and all other participants were entered into a draw for one of three \$50 gift cards.

Participants

I focused on a subset of the larger study sample who indicated that they had a chronic health condition or a neurological disorder such as epilepsy. I also sorted through the group of participants who selected ‘other’ and chose to include or not include them in my study based on whether they met my definition of chronic health condition; that is persistent physical symptoms that are attributed to disease or malfunctioning of the body, which typically last for an extended period, often for the duration of a person’s life (eg., Van Der Lee et al., 2007, Goodman et al., 2013). Seventy-four total participants met the inclusion criteria ($M_{\text{age}} = 25$ years, $SD_{\text{age}} = 8.1$, range 19 to 63 years; see Table 1 for frequencies for each form of disability). Participants also reported whether their condition was visible (i.e., meaning that the average person would be able to tell that they have a disability just from briefly observing them) or invisible at least some of the time, and the age at which they acquired their condition, and these responses are also reported in Table 1. It is worth noting that while there was a range of visibility and acquisition ages of conditions, we cannot know whether participants were reporting the acquisition of their chronic health conditions or of another co-occurring disability, and I will consider to this issue later in the Discussion.

Table 1*Chronic health conditions and condition characteristics reported by participants*

Condition	Frequency
Condition Type	
Chronic Health Condition	46
Neurological	32
Both	10
Visibility	
Invisible	52 (66.7%)
Visible at least sometimes	25 (32.1%)
Acquisition	
Born with primary disability	14 (17.9%)
Born with disability but did not affect them until later in life	25 (32.1%)
Acquired later in life	37 (47.4%)
Other	2 (2.6%)

Note. Numbers in parentheses are the percent of the total sample for my study.

I chose to focus on this group of participants with a chronic health condition or neurological disorder because I believe their experiences differ from the rest of the sample in terms of physical daily demands, experiences in the medical system, and experiences of stigma. Additionally, the overlapping self-identification of disability and chronic health conditions makes it more likely that this group has engaged meaningfully with the kinds of critical perspectives that I have described in my introduction. I expected this group of people with chronic health conditions to be more aware of disability politics and healthism and to have potentially begun the process of confronting internalized stigma, relative to people with such conditions who did not also identify as having a disability. They may therefore have critical perspectives on their life experiences and experiences in the medical system. As a result of this, I expected the sample to be further along in their recovery process and more likely to have already adopted some of the embodiment or self-acceptance techniques I am studying. Because this is more of an exploratory study in a new area of looking at chronic health conditions, I believe this

sample provides rich preliminary data that will be useful to then later apply to individuals who may not be as radicalized or far along in their recovery process. I also understand that the relationship between disability as an identity and chronic health condition as an identity is complicated, and I will explore this relationship further in the Discussion.

The sample was mostly homogeneous in terms of gender (see Table 2), and ethnicity (see Table 3), but there was also some diversity that should not be overlooked. Still, my sample is disproportionately over-representative of women and white people relative to the UVic student population, which may relate to the cultural politics of identifying as a person with a disability. I will discuss issues relating to gender and ethnicity and self-identification as a person with a disability in the Discussion.

Table 2
Gender identities reported by participants

Gender	Frequency
Women	59 (75.6%)
Men	7 (9%)
Trans and Non-Binary Spectrum	7 (9%)
Additional Gender Identity	2 (2.6%)
Missing Data	3 (3.8%)

Note. Numbers in parentheses are the percent of the total sample.

Table 3
Ethnic identities reported by participants

Ethnicity	Frequency
Black	1 (1.3%)
Chinese	3 (3.8%)
Filipino	1 (1.3%)
Indigenous/First Nations	4 (5.1%)
Latin American	1 (1.3%)
Other	5 (6.4%)
South Asian	4 (5.1%)
Southeast Asian	1 (1.3%)
West Asian	1 (1.3%)
White/Caucasian	66 (84.6%)

Note. Numbers in parentheses are the percent of the total sample.

Materials

I analysed respondents' written answers to two long-answer prompts that were included at the end of the quantitative survey:

1. "How would you describe the process of acceptance for your disability?"
2. "How would you describe the way you experience and stay in-tune/connected with your body now? Include all activities (indoor and outdoor) and body practices (such as eating, self-care, sexuality)."

Reflexive Thematic Analysis

Reflexive thematic analysis was used to address the first research question: "*How do people with chronic health conditions relate to their bodies?*" Reflexive thematic analysis emphasizes meaning as contextual, realities as multiple, and researcher subjectivity as a resource (Braun & Clarke, 2013). This type of analysis is commonly used in critical research approaches like mine that seek to interrogate systems of power and understand socially embedded patterns of meaning (Braun & Clarke, 2013). The purpose of the thematic analysis was to identify patterns

of meaning that were present within the participants' responses, and which were best understood by considering the broader context of the participants' lived realities as people with chronic health conditions. Reflexive thematic analysis allowed me to accomplish this purpose because it is a method for identifying, analysing, and reporting patterns, or "themes," within the responses (Braun & Clarke, 2021). A theme is a pattern of shared meaning that is organized around a core concept or idea that is present in the data. When constructing themes, the researcher maintains an active role in the analytic process and uses their reflexivity along with theory from the literature to interpret the meanings that are present in the data (Braun et al., 2019).

Philosophical and Analytic Orientation

My analysis was both deductive and inductive in that I used my knowledge of theory concerning stigma, traumatic disembodiment, and recovery from internalized stigma to inform the creation of themes, but I was also open to discovering novel patterns of meaning that were present in participants responses. I also relied upon my lived experience as an in-group member to contextualize my analysis through a process of reflexivity. My goal was to create an analysis that resonated with participants' lived experiences but additionally offered new ways of considering and conceptualizing those experiences. Thus, I adopted a critical realist epistemological perspective in my analysis. This meant that I maintained that there is a material reality that exists independent of human perceptions, but that human understanding of that material reality is always mediated by social, cultural, and personal contexts. Applying this epistemology to my analysis meant that I recognized the real, material challenges of the chronic health condition experience, such as physical symptoms and medical diagnoses, but I also acknowledged that participants' meaning-making about their chronic health condition experience was informed by the social, cultural, and personal impact of health stigma. Additionally, my

analysis was both experiential and critical, but leaned more toward a critical orientation. It was experiential because I attempted to make sense of and amplify my participants' voices and experiences. However, I also used a critical disability studies lens to analyse participants' experiences, and as such I may have identified patterns of meaning in the responses that the participants themselves would not have identified on their own if they did not share that theoretical lens.

Analytic Procedure

I followed Braun and Clarke's (2022) six-phase approach to thematic analysis which involves: 1) familiarization with the data; 2) generating initial codes; 3) creating themes; 4) reviewing themes; 5) defining and naming themes; 6) producing the report. Although the phases are listed in order, they are actually recursive, and so I moved forward and backward through the stages as-needed during my analysis. I used MAXQDA (2022) software to code my data and I maintained transparency by keeping records of the entirety of my analytic process. I also used thematic maps to organize my analysis, which served as a visual tool for identifying and depicting my overarching themes, themes, sub-themes, and relationships between each component.

My supervisor was involved throughout the analytic process to provide an additional opinion, and we met weekly to discuss my analysis throughout the process. For instance, she asked me questions about the conclusions I was making or not making, helped me organize my codes, and assisted me with developing themes and theme names. The use of multiple coders in reflexive thematic analysis has been identified as a beneficial reflexive tool to sense check ideas and explore multiple assumptions or interpretations of the data (Byrne, 2022). Collaborating with my supervisor allowed for richer interpretations of meaning rather than supporting a consensus

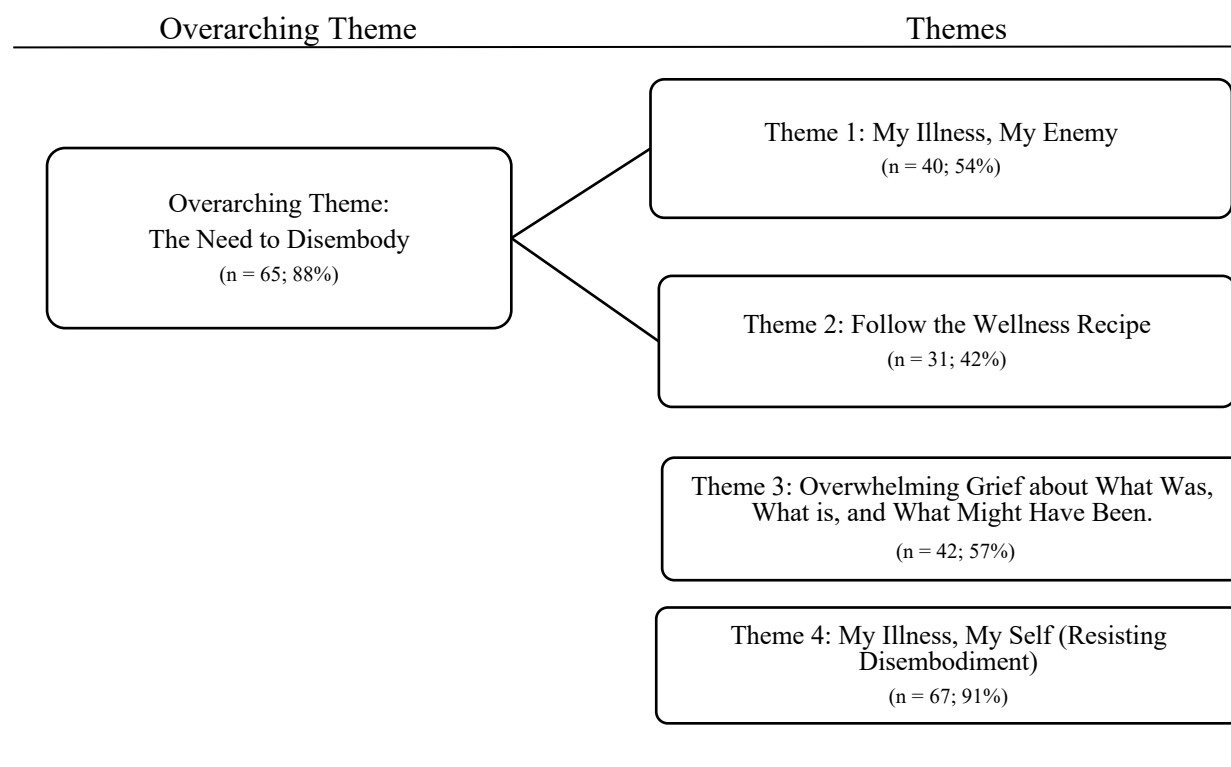
of meaning that might typically be important for generating coder reliability in other types of analysis. To maintain reflexivity throughout the analytic process, I kept a journal of my thoughts, reflections, and realizations, as I recognize that my preconceptions about the data were influenced in part by my own personal experience of having a chronic health condition.

Analysis

My analysis yielded an overarching theme called The Need to Disembody, which comprised two themes: (1) My Illness, My Enemy, and (2) Follow the Wellness Recipe. I also identified two additional stand-alone themes: (3) My Illness, My Self (Resisting Disembodiment), and (4) Overwhelming Grief: What Was, What Is and What Might Have Been. Figure 2 shows the thematic map for my analysis along with the prevalence of each theme within the data. I provide definitions of each theme in the narrative descriptions, below, and example extracts for each theme in accompanying tables.

Figure 2

A Conceptual Depiction of the Themes in the Reflexive Thematic Analysis



Note. Numbers in parentheses represent the number of participant responses that exhibited at least one example of the theme and the percentage of the total sample of participant responses that exhibited at least one example of that theme.

Overarching Theme: The Need to Disembody. My reflexive thematic analysis included an overarching theme called ‘The Need to Disembody’. Braun and Clarke (2021) explain that an overarching theme is a high-level, integrative concept that unifies or organizes multiple, related themes within a reflexive thematic analysis. It captures the broader essence or central thread that runs across a set of themes and connects them to the overarching narrative or core message of the research. *The Need to Disembody* encompasses the overwhelming number of responses that suggested participants felt the need to disconnect or detach from their bodies because of their chronic health condition. These reflections of disembodiment are in line with path ‘b’ in Figure

1, which describes the relationship between internalized stigma and traumatic disembodiment. At their core, the themes contained within *The Need to Disembody* represent avoidance strategies for coping with the distress of chronic illness. Avoidance is a common response to negative thoughts and feelings, and it can be exaggerated when individuals face a significant threat to their self-integrity (as people do when they must live with a chronic health condition that is stigmatized; Gregg, 2013). Avoidance strategies can be maladaptive, as when people with chronic health conditions avoid appointments or use substances (e.g., Earnshaw & Quinn, 2012). But sometimes avoidance strategies can be an adaptive means of achieving short-term relief from pain or distress. This overarching theme represents examples of what might be considered adaptive, or functional, avoidance strategies to alleviate distress, which help people with chronic health conditions temporarily alleviate their psychological distress by disconnecting the self from the body. Thus, this avoidance coping strategy directly reflects my theoretical model, because through these strategies, the mind separates from the body to protect the self from the trauma of existing in a chronically ill body.

The themes *My Illness*, *My Enemy* and *Follow the Wellness Recipe* are both direct reflections of this overarching theme, *The Need to Disembody*, as they demonstrate how participants employ strategies to detach from their physical experiences. In the theme "My Illness, My Enemy," participants describe their illness as something external and adversarial, suggesting that disconnecting from the body through this personification is an attempt to psychologically distance themselves from the pain, isolation, and trauma associated with their chronic health condition. This disembodiment allows them to temporarily cope with the physical and emotional strain, as it separates the self from the illness and the inevitable discomfort it brings. Similarly, the theme *Follow the Wellness Recipe* illustrates how participants try to

maintain a sense of control over their bodies by adhering to a strict regimen of health behaviors. While these behaviors such as exercise, eating habits, and medication adherence are generally aimed at promoting well-being, their rigid and sometimes compulsive enactment often leads to a detached relationship with the body. Participants frame these behaviors not as embodied practices of self-care, but as means of asserting control over their bodies in response to their chronic conditions. These themes illustrate how individuals with chronic health conditions utilize strategies that create distance from their bodies, either by viewing the illness as an enemy or by strictly controlling health behaviors, as a way to manage the distress associated with their conditions.

Theme 1: My Illness, My Enemy. Participants often characterized their illness as a pernicious, parasitic, or malicious force that undermined their sense of autonomy and control in their day-to-day lives (see Table 4 for sample extracts for this theme). For example, P66 illustrated these processes when they said,

“I have not accepted this chronic effect on my health yet and it is difficult to not let “being sick” rule my life and effect how I interact with others.”

Thus, this theme illustrates how having a chronic health condition imposes external control over individuals’ lives, dictating physical capabilities, routines, and choices. Personifying their illness and separating it from the self in this way may allow participants to disconnect from their chronic health condition, and thus allow them to psychologically distance from the pain, limitations, identity disruptions, and general trauma that is associated with their condition. Lazarus and Folkman’s (1984) *Coping and Avoidance Theory* may help provide an explanation as to why people with chronic health conditions view their condition as an enemy that is distinct from the self. When people face a challenging or stressful situation, they undergo a process of

appraisal where they evaluate an event to determine its significance and whether they can cope with it. For people with chronic health conditions, their illness is often appraised as a significant threat to their physical and emotional well-being, sense of self, and daily functioning, which diminishes perceived control and leads to feelings of inadequacy and frustration. This process of appraisal likely leads participants to rely on avoidance coping in the form of traumatic disembodiment or emotional detachment from their chronic health condition to escape the distress that is associated with it. Although this coping strategy likely offers short-term emotional relief, it also underscores the profound challenges having a chronic health condition poses to a sense of autonomy.

Table 4

Example data extracts for Theme 1: My Illness, My Enemy

“I do feel that I will never fully accept my disability because of the strain it has placed on my life trajectory.” (P18)
“My disability really restricts my mobility - which was a HUGE hurdle to overcome - and often left me in bed for weeks feeling left out of the world.” (P242)
“My disability made me have to drop out of high school.” (P328)
“Honestly, it's hard to stay connected to something that brings so much pain to me.” (P46)

Internalized stigma probably lies at the root of this form of detachment, whereby participants conceptualized their illness as an enemy. Most people with chronic health conditions have internalized the stigma of being “sick” or “broken” as a result of societal norms and healthist views that equate wellness with worth (Earnshaw & Quinn, 2011). As a result, for a person who has internalized healthist value systems, it is impossible to maintain a positive sense of self that includes the illness. Viewing the self as “sick” and “broken” is untenable for most people who are motivated to maintain a positive self-evaluation (Abraído-Lanza et al., 2006) and embracing such a negative self-view is antithetical to psychological well-being (Neff, 2003). Thus, compartmentalizing one’s chronic health condition may be adaptive and supportive of

well-being because it is better than the alternative (i.e., self-destructive acceptance of stigma). Furthermore, medicalization and the biomedical model promote the idea that illness must be controlled, defeated, or cured in order to restore a sense of normalcy in life or worth as a person (e.g., Sismondo, 2015). This social discourse is reflected in participants' personification of their illness as an enemy to be fought or overcome, which aligns with medical narratives that focus on curing or defeating disease and leads individuals to perceive their illness as an adversary rather than part of their identity.

Theme 2: Follow the Wellness Recipe. Participants often described how they stayed connected to their bodies by following a prescriptive set of wellness behaviors. They described practices like “healthy eating” (P36), “exercising almost everyday” (P23), and “I take my medications as prescribed” (P7; see Table 5). These practices can support well-being for people with chronic health conditions, but they are most beneficial when they are practiced with a compassionate, caring-based approach to wellness that can support embodiment (Sirois, 2016). When so-called wellness behaviors are practiced with rigidity and over-control, they can lead to a detached relationship with the body (e.g., Elias et al., 2022). The way that participants described their enactment of behaviors associated with the wellness recipe seemed to align with this maladaptive coping style. This was particularly apparent in participants' writing about their eating practices, which were often disordered. Participants often framed their eating habits as either eating too much or avoiding eating as a form of stress management. For example, one participant explained:

“My eating habits are quite poor, not because of the quality of food, but because sometimes if I am feeling overwhelmed I will choose to skip a meal as a way to reduce the load on my metaphorical plate (P254)”.

Table 5

Example data extracts for Theme 2: Follow the Wellness Recipe

“I dealt with an eating disorder as a teen (roughly ages 14 to 19), and while I know it was brought on by a number of factors, I can't help but recognize that my disability and the way others treated me because of it made me desperate for some choice and control, which lead to these self-destructive behaviours.” (P284)
“I try to eat healthy exercise and drink water and take my meds on time.” (P314)
“I started going to the gym when I was diagnosed to prove to people that being diabetic doesn't imply you are unhealthy or overweight. I now go to the gym for 2 hours, 6 days a week.” (P324)
“I try to eat well, but I sometimes stress eat.” (P105)

Participants' descriptions of their exercise habits also seemed compulsive at times.

Disordered eating and compulsive exercise are endemic in Western society, which is pervaded by a diet culture that lionized restrictive eating and punishing exercise habits (e.g., Marks et al., 2020). Often these forms of disordered eating are promoted by health professionals, especially for people with chronic health conditions (Quick et al., 2013). Fitzpatrick (2000) critiques the societal obsession with health and wellness, arguing that it can become a form of tyranny that pressures individuals to constantly monitor, measure, and improve their health, often to a point of obsession. For people with chronic health conditions, the tyranny of health intersects with uncontrollable physical symptoms or bodily changes from the chronic health condition, creating a sense of powerlessness and lack of control. Thus, controlling food intake and engaging in restrictive diets or vigorous exercise may be a way to reassert control over the body. Traumatic disembodiment is an unfortunate side effect of such efforts, because they require people to ignore or override bodily signals of hunger, pain, and tiredness (Sturgess & Stinson, 2022).

Theme 3: Overwhelming Grief about What Was, What is, and What Might Have Been.

Our survey questions did not ask participants about negative emotions. In fact, we asked them about positive experiences of self-acceptance and connecting with their bodies. Yet there was a conspicuous absence of pleasure and joy in their responses. Instead, their responses were

pervaded by deep and overwhelming feelings of grief and sadness as they mourned the loss of their pre-illness body or the life they had imagined for themselves. As P271 said,

“The best way I can describe [the process of accepting my chronic illness] would be the same way one could describe the loss of a loved one. For many years I dealt with grief for the loss of the life I had wanted to live (and had expected to live)”.

Kübler-Ross (1969) suggests that grief has five phases – denial, anger, bargaining, depression, and acceptance – and it seemed that most participants were deep in the first four phases. For instance, denial is likely connected to the types of avoidance coping that I described in Themes 1 and 2. Anger was evident in participants’ feelings of frustration about the hardships that come with having a chronic health condition. Bargaining was present when participants engaged in “if only” thinking by reflecting on how things could be different if they had acted differently or could change the past. Depression was evident in the sadness and shame expressed by many participants. Kübler-Ross explains that grief is often non-linear, which may be especially common for people with chronic health conditions whose conditions may change and new limitations may emerge over time. For example, a flare-up might reignite feelings of anger or sadness, even after a period of acceptance. Societal expectations are likely to also play a role in the grief process, as the pressure to maintain a “healthy” or “normal” appearance can exacerbate grief, making it harder to move through the stages, achieve greater self-acceptance, and uphold a positive relationship with the body. Grief may also exacerbate disconnection from the body as participants attempt to escape contemplating the overwhelming reality of what was, what is, and what might have been.

Table 6

Example data extracts for Theme 3: Overwhelming Grief about What Was, What Is, and What Might Have Been

“For a long time I felt shame and disgust at myself, thinking that nobody would ever be able to love me because the way my body works is disgusting.” (P46)
“I am not able to do most of the physical activities I used to do before my accident.” (P107)
“Currently, I am struggling to [stay connected to my body]. My self-care habits have declined greatly and this has a great impact on how in touch I feel with my body. My sexual drive, motivation to exercise, and eating habits are non-existent.” (P172)
“Because I haven't always been chronically ill, I've had a hard time accepting things that I can no longer do, or have to do differently.” (P184)

Theme 4: My Illness, Myself: Resisting Disembodiment. Positively, 91% of participants responses included codes represented by this theme, whereby people with chronic health conditions expressed a more in-tune and connected relationship with their bodies. As such, it is apparent that not all individuals were stuck in the first four phases of grief, and that some have found ways to find a sense of acceptance, at least some of the time. Resisting disembodiment was achieved through several important strategies. The strategy with the most profound effect on acceptance in the sample was engagement with disability or chronic health communities. As P167 explains,

“Finding a community of people with similar experiences was instrumental in the acceptance of my disability. I primarily have connected with people over social media, which has led to an abundance of new friendships and a real sense of community.”

The ability for community to foster greater self-acceptance aligns closely with ideas from *Social Identity Theory*, which posits that social identification allows individuals to internalize the group's values and perspectives, leading to positive self-affirmation (Tajfel, 1981). Specifically, finding a community where people can share their experiences and see their condition as part of a larger, collective identity rather than an individual struggle validates the chronic health

condition experience and offers opportunity to embrace their identity and feel less alone. The extracts in Table 7 also support this idea, such that participants felt less isolated and more empowered when they were able to engage with people who shared the same struggles. This sense of collective identity is especially useful for those with invisible conditions who may look “normal” but feel sick and misunderstood, whereby engaging with others allows them to feel visible to *each other* (Phillips & Rees, 2017). Online communities, in particular, have revolutionized the illness experience, allowing for ongoing support, advice and solidarity. The ability to engage with these online support groups or forums on a daily basis, offering practical tips and emotional support, stands in stark contrast to the more distant and often stigmatizing experience of bi-annual appointments with medical practitioners. By recognizing their condition beyond the medical gaze, individuals can crystallize their suffering into something more widely understood, reconstructing their identity in a way that feels valid. Undoubtedly this experience leads to a group of more radicalized individuals who encounter critical perspectives and oppose stigmatizing ideologies. A critical disability perspective would encourage this type of community driven resistance, which rejects dominant able-bodied narratives that insist on the need for a cure or normalization.

Finally, while friends and family may not be able to understand or foster a sense of belonging on the same level as community groups, many participants reported that social support was beneficial for their healing. Cohen and Wills’ (1985) social buffering hypothesis explains that emotional or instrumental support provides a sense of relief and promotes better psychological wellbeing. For people with chronic health conditions, this type of support appears to reduce the emotional burden of living with an illness (Maguire et al., 2021). Emotional support involves provision of empathy, understanding, and encouragement which helps people

with chronic health conditions feel validated in their experiences and reduces feelings of isolation and loneliness. For instance, a friend or family member who listens without judgment can provide a safe space for the person to express their fears and frustrations. This emotional connection fosters resilience, helps mitigate feelings of despair, and strengthens the individual's capacity to cope with the challenges of their condition. Instrumental support, on the other hand, involves tangible support, such as helping with daily tasks, transportation to medical appointments, or financial aid for treatments. For individuals managing chronic health conditions, these practical forms of support can significantly ease the logistical and physical burdens of their condition. For example, having someone assist with grocery shopping or meal preparation can conserve the limited energy of a person with chronic fatigue or pain, allowing them to focus on rest and recovery.

Table 7

Example data extracts for Theme 4: My Illness, Myself: Resisting Disembodiment

“I had already accepted it all with the help of others in the community who had to jump over the same hurdles just to be heard.” (P79)
“Getting involved with the type one diabetes community decreased the feeling of being isolated from the rest of the world.” (P326)
“Honestly disability TikTok has been a massive force of positive influence in my life. That has helped me to be more accepting and understanding towards myself.” (P46)
“Having supportive friends and family who educated themselves with IBD gave me a huge sense of acceptance, and I learned to adjust and live well again.” (P252)

Conclusions

In general, the reflexive thematic analysis illuminated participants experiences with self-acceptance and embodiment with a specific focus on their relationships with their bodies. Specifically, findings revealed a complex interplay between disembodiment, identity, and coping in the context of chronic conditions. The overarching theme, *The Need to Disembody*, reflects the emotional and psychological distance that people with chronic health conditions create between

themselves and their bodies as a coping strategy. *My Illness, My Enemy* and *Follow the Wellness Recipe* highlight the pervasive influence of internalized stigma and societal pressures on health behaviors, often leading to emotional detachment and rigid wellness practices. *Overwhelming Grief about What Was, What is, and What Might Have Been* illustrates the profoundly challenging experience of living with a chronic health condition. However, *My Illness, Myself (Resisting Disembodiment)* underscores the importance of community support and social relationships in fostering resilience and resisting traumatic disembodiment. The codebook thematic analysis extends this fourth theme to understand more about the practices people with chronic health conditions identified as being useful for self-acceptance and embodiment when prompted.

Codebook Thematic Analysis

To answer my next research questions -- (1) “*Are people describing bolstering self-integrity, social support, and embodiment practices when talking about the process of accepting their disability?*” and (2) “*What specific embodiment practices are people using?*” -- I used a codebook thematic analysis. This analysis involves using a structured coding framework, often developed in advance of coding, for identifying patterns of shared meaning that are present across the dataset (Braun and Clarke, 2021). Braun and Clarke explain that a codebook approach represents a degree of compromise of qualitative principles because research is driven by pragmatic demands around pre-determined information needs. Specifically, data are often concrete, and the output is a descriptive analysis of semantic meaning. This analysis was appropriate for addressing my second and third research question because I was explicitly interested in identifying concrete categories or types of practices that people use to come to terms with their chronic illness. For this analysis, I adopted a more post-positivist theoretical

approach, which involved including a reliability test with a second coder, as the goal of this analysis was to validate the themes I had proposed based on the theoretical background of my study. This analysis is what Braun and Clarke call a ‘small q’ qualitative approach, which often reflects a more structured and less reflexive engagement with data, generating findings that are seen as more objective or closely aligned with realist assumptions. As such, issues like reliability are valid considerations and so a second coder was involved in the analysis.

Codebook thematic analysis follows a more structured process where predefined codes are developed before interacting with the data and are used to guide the analysis to systematically identify themes within the data (Braun & Clarke, 2021). This approach allows themes to be developed in a more systematic manner while still leaving room for the researcher to engage with the data and adjust the codes if necessary. In contrast to reflexive thematic analysis, which places greater emphasis on researcher subjectivity and the co-construction of meaning with participants, codebook thematic analysis is more focused on organizing data according to a clear set of categories. This deductive analysis allowed me to code for semantic meaning in participants’ responses to determine (1) whether they were describing self-integrity, social support, and embodiment practices as methods for self-acceptance, and (2) identify the embodiment practices participants were using to stay in-tune and connected to their bodies.

Analytic Procedure

I used a top-down, *a priori* coding approach based on the theory outlined in my introduction to develop my codebooks. Codebook 1 identified methods for accepting one’s chronic health condition, like bolstering self-integrity and social support, and focused on responses to the first prompt: “*How would you describe the process of acceptance for your disability?*” Codebook 2 identified embodiment practices and focused on response to the second

prompt: “*How would you describe the way you experience and stay in-tune/connected with your body now? Include all activities (indoor and outdoor) and body practices (such as eating, self-care, sexuality)*”. These initial draft Codebooks are presented in Appendix A. However, the codebooks evolved throughout the coding process to include methods of self-acceptance and embodiment practices that I had not anticipated based solely on my theory. Thus, my coding process also involved a bottom-up, or inductive, element to code generation. The Final Codebooks are presented in Appendix B.

Once again, I used MAXQDA software to code the data, highlighting words and phrases that fit my coding frameworks. First, I coded responses to the first response using Codebook 1, and then I coded responses to the second prompt using Codebook 2. After multiple rounds of coding, I grouped each code into themes based on their shared meaning. For Codebook 1, codes were grouped into themes based on methods of self-acceptance, and for Codebook 2, I grouped codes into embodiment practices. To assess the reliability of my themes, a practice that is valid when conducting ‘small q’ qualitative research, a trained research assistant coded a random 30% of my sample. Because I was most interested in affirming the reliability of the categories of practices I identified (i.e., the themes), rather than the specific practices that comprised each category (i.e., the codes), the research assistant rated whether each theme was present or absent in each participant’s response. Inter-rater reliability was exceptionally high, with kappa values ranging from .50 to 1.00 and percentage agreements ranging from 76.92% to 100% (see Tables 8 and 13).

Analysis

Methods of Self-Acceptance. Table 8 reports the themes I identified in this analysis, their prevalence, and inter-rater reliability. The analysis confirmed three of the methods of self-acceptance proposed by Sturgess and Stinson (2022) – Social Support, Bolstering Self-Integrity, and Embodiment Practices -- and another method that they did not anticipate, called Treatment to Alleviate Symptoms.

Table 8

Themes concerning methods of self-acceptance including definitions and inter-rater reliability scores

Theme	Definition
Social Support Prevalence: n = 49 (66.00%) Inter-rater reliability: $k = 0.92$ (96.15%)	Meaningful connections with people or communities that have assisted individuals in their acceptance of their chronic health condition.
Bolstering Self-Integrity Prevalence: n = 23 (31.00%) Inter-rater reliability: $k = 0.50$ (76.92%)	Engaging in practices that re-invigorate aspects of the self that have been suppressed due to internalized stigma.
Treatment to Alleviate Symptoms Prevalence: n = 11(15.00%) Inter-rater reliability: $k = 1.00$ (100%)	Seeking and using tools that reduce psychological and physical suffering and/or increase well-being.
Embodiment Practices Prevalence: 7(9.00%) Inter-rater reliability: $k = 0.52$ (88.46%)	Meaningful engagement of the body with the world via any combination of sensory processes through methods such as positive body connection, embodied agency, and self-care.

Note. Prevalence values represent the number (n) of coded documents including at least one instance of the theme and the percent of the total sample of documents including at least one instance of the theme. Inter-rater reliability includes the kappa value and the percentage agreement between coders (in parentheses).

Theme 1: Social Support. The most frequent method of self-acceptance identified by participants was social support. Participants accessed and benefitted from social support from healthcare providers, family, and other close relationships, but as the quote for P266 illustrates, below, communing with chronic health condition groups, especially online, identity-based support groups, was particularly important for participants:

“Joining TikTok and finding an abundance of people with the same conditions has helped me feel confident that I am not making things up for ‘attention’ and that I hold value as a human regardless of my physical and cognitive shortcomings.”

As P266 noted and the extracts in Table 9 reinforce, engaging with others with similar chronic conditions made people feel accepted, understood, and that they could move forward together in their illness journeys (e.g., Linkiewicz et al., 2023). Lehardy and Fowers (2020) explain that support groups assist with regulating emotions and fostering a sense of belonging and collective identity. Online groups are particularly beneficial for people with chronic health conditions because they are anonymous, thus alleviating shame, and provide a space that is more accessible both in terms of time and geographic proximity (van Uden-Kraan et al., 2009). These features of online access are especially important for people with chronic health conditions who experience inconsistent symptom flare ups. This theme also suggests that disability and chronic health groups can be a potent source of radicalization about disability politics, which is another method of self-acceptance that I describe in the next theme.

Table 9

Example data extracts for Theme 1: Social Support

“I primarily have connected with people over social media, which has led to an abundance of new friendships and a real sense of community.” (P167)
“My mother was very influential. Giving me tools at a young age and supporting me throughout my childhood/adolescents.” (P84)
“My mother and my friends have been very helpful and supportive because most of my disability is invisible until I have a flare-up or my back starts the seize up. My friends and family started to do activities that I could be included in that were less physically active.” (P107)
“Honestly disability TikTok has been a massive force of positive influence in my life.” (P46)

Theme 2: Bolstering Self-Integrity. Participants in my sample worked to heal from internalized stigma by attempting to root out their internalized negative self-views and beliefs and replace those self-stigmatizing perspectives with more positive identities, a process called *bolstering self-integrity*. Extracts illustrating this theme are presented in Table 10. This method of self-acceptance often began with re-education, which shifted perspectives on the individual’s identity group and their stigmatizing experiences. This process was best exemplified by P288, who wrote:

“By about year 4-5 after I started experiencing symptoms associated with my disability, I was more vocal about diversity and inclusion. By focusing on how stigma affects others with disabilities, I became much more self-compassionate. Advocating for individuals with disabilities shifted my perspective from “others should not have to struggle this way” to “we should not have to struggle this way”. It took time for me to extend the kindness I expressed towards others towards myself, but advocacy played a key part in this.”

This quote illustrated what I would call a process of radicalization, whereby beliefs and values about health shift away from stigmatizing perspectives and come to align with critical health and disability perspectives that promote breaking down stigma and advocacy or collective

action as a means for self-acceptance. The passage and the extracts in Table 10 also illustrate two other mechanisms of bolstering self-integrity that were evident in my participants' descriptions. First, newly radicalized perspectives can be directed inward, prompting greater self-acceptance and self-compassion. Second, radicalization can be directed outward, prompting actions such as advocacy and activism. Involvement in disability activism, such as challenging stigmatizing perspectives and participating in advocacy efforts, can empower people with chronic health conditions to reclaim their identities and combat internalized stigma (Smith & Mueller, 2021).

Table 10

Example data extracts for Theme 2: Bolstering Self-Integrity

<p>“I attended a Disability Pride event in Vancouver and then created one in Calgary. I enjoyed "Disability politics and theory" by A.J Withers and the film "Crip Camp" Joining disability advocacy groups with people from various disability communities helps the journey of acceptance.” (P292)</p>
<p>“I just need to learn that yes it will be a little harder but it is possible!” (P150)</p>
<p>“My mother and my friends have been very helpful and supportive because most of my disability is invisible until I have a flare-up or my back starts the seize up. My friends and family started to do activities that I could be included in that were less physically active.” (P31)</p>
<p>“i found that it did not define me but it it has made me who I am today. the challenges I have overcome have made me a better person” (P192)</p>

Theme 3: Treatment to Alleviate Symptoms. Several participants discussed various treatments that helped alleviate their symptoms, allowing them to achieve a greater sense of self-acceptance (see Table 11). This included pursuing medical treatments, therapies, accommodations, and using assistive devices. While I had not anticipated this as a theme in my a-priori coding framework, this theme shares similarities with Sturgess and Stinson’s (2022) argument that seeking and demanding accommodations can be an approach to resisting and healing from weight stigma. Further, finding accommodations or taking medication may increase embodiment by making the body a more hospitable place to reside, thus reducing the necessity to disconnect from the body. The following quote from participant 2 exemplifies this process:

“Once I started taking proper medication, I became less embarrassed because bowl issues were controlling less of my life and interfering less.” Research affirms that addressing physical symptoms of chronic health conditions through treatment, symptom management, and medical support can significantly increase self-acceptance (e.g., Delmar et al., 2005). It is possible that people’s engagement with the methods encompassed in this theme vary by health condition and the degree of responsibility for symptom management that a person possesses.

Table 11

Example data extracts for Theme 3: Treatment to Alleviate Symptoms

“Finding mobility aids that work for me and look the way I want them to has been such a huge part of accepting my disability.” (P242)
“In school, it took me 4 years to reach out to CAL about my struggles but the support of a mental health practitioner encouraged me to make this shift and it has been so needed.” (P172)
“Getting medicated, has changed my life for sure. I am able to focus and get things done I was unable to before. Before I was doing so much extra work just to live.” (P309)
“It wasn't till I joined UVic and got help from the Wellness centre that I learned not only are my symptoms valid but there are diagnosis, medicine, and other accommodations available.” (266)

Theme 4: Embodiment Practices. Very few participants spontaneously mentioned embodiment practices as a method of self-acceptance. Of those who did, meditation was the most common practice used, which is consistent with previous findings that link mind-body therapies such as mindfulness, meditation, and yoga with reduced suffering amongst those who experience traumatic disembodiment (Kabat-Zinn, 2013). For example, participant 135 wrote: “staying active in things that help me physically and mentally such as yoga. climbing and meditating.”

Table 12

Example data extracts for Theme 3: Embodiment Practices

“I came to accept my disability through art related to disability” (P292)
“Working out became a very beneficial activity for me, not just for "looks", but also because it made me stronger” (P318)
“dress up, do my makeup” (P283)
“I have practiced meditation” (P240)

Embodiment Practices

Table 13 reports the themes I identified in this analysis using my second codebook, their prevalence, and inter-rater reliability. I identified five embodiment practices: mindfulness and meditation, caring and tending to the body, connecting to nature, exercise, and sense and sensuality.

Table 13*Themes concerning embodiment practices including definitions and inter-rater reliability scores*

Theme	Definition
Exercise Prevalence: n = 36 (49.00%) Inter-rater reliability: $k = 1.00$ (100%)	Any form of structured movement or physical activity with a focus on reconnecting with the body in a mindful and intentional way.
Caring and Tending to the Body Prevalence: n = 32 (43.00%) Inter-rater reliability: $k = 0.72$ (85.71%)	Practices that involve physically nurturing and caring for the body in a way that is more meaningful and intentional than simply satisfying basic human needs. For example, eating, rest, or bathing.
Mindfulness and Meditation Prevalence: n = 12 (16.00%) Inter-rater reliability: $k = 1.00$ (100%)	Mindfulness involves bringing one's attention to the present moment to foster awareness of thoughts, feelings and bodily sensations without judgement, promoting a deeper connection to the self. Meditation involves focused techniques which cultivate a state of relaxed attention and awareness and may include various practices such as breath awareness, body scans, or loving-kindness meditation.
Connection to Nature Prevalence: n = 12 (16.00%) Inter-rater reliability: $k = 1.00$ (100%)	Immersing oneself in the natural environment through activities such as hiking, walking, or swimming, to connect with aspects of the outdoors (e.g., beaches, wilderness, birds).
Sense and Sensuality Prevalence: n = 10 (14.00%) Inter-rater reliability: $k = 1.00$ (100%)	Activities that invigorate the senses. This may be through tactile activities such as art or massage, experiencing physical affection from others, or listening to music.

Note. Prevalence values represent the number (n) of coded documents including at least one instance of the theme and the percent of the total sample of documents including at least one instance of the theme. Inter-rater reliability includes the kappa value and the percentage agreement between coders (in parentheses)

Theme 1: Exercise. Exercise was the most common embodiment practice described by participants. Many people with chronic health conditions discussed the practice of adjusting exercise routines based on their physical abilities on any given day, such as P288:

I stay in-tune with my body by altering my schedule for physical exercise based on my abilities that day. I try not to be strict about what I "should" do (ie. go to the gym, bike to school instead of drive), instead I try to respect that my body and disability are dynamic, and the activities I do should reflect that. On good days, I try to take advantage and do more intense activities like running/biking/climbing. On harder days, I choose more gentle activities like stretching, walking, yoga.

This ability to meet the body where it's at in the moment is suggestive of an embodied approach to exercise or intuitive movement, in that individuals were listening to and respecting their body's needs as a dynamic and evolving practice (e.g., Alleva & Tylka, 2021). People with chronic health conditions also explained that physical activity like yoga, walking, or more intense workouts helped them engage with their bodies in meaningful ways. Bolton and colleagues (2018) provide support for this finding in their study which found that when people with chronic health conditions engage in movement-based health therapies such as yoga, they experience reduced physical symptoms, increased capacity for self-awareness, overall greater happiness, and reduced anxiety or anger about their illness. More generally, regular physical activity can enhance body awareness and improve mental health by fostering greater mindfulness and self-regulation, and therefore it makes sense that this was the most frequently reported practice (Raedeke & Bernard, 2007).

Table 14*Example data extracts for Theme 1: Exercise*

“I do some form of physical activity everyday, usually a walk or two along with a workout.” (P44)
“When I am able to walk short distances I work hard to be in the moment and appreciate the little gift my body gave me. I am able to exercise in water - which lets me move almost like I did pre-disability and connect to the self I find most comfortable.” (P242)
“Exercise is super important for my relationship with my body. I like to feel strong so I really enjoy weightlifting” (P211)
“I am quite physically active and I would say that exercise is the primary way I stay in tune with my body. I try to go for a walk or bike ride of at least an hour everyday where I can forget about my problems and enjoy what I'm doing and the environment I'm doing it in.” (P254)

Theme 2: Mindfulness and Meditation. Mindfulness and meditation practices were highlighted as tools for enhancing body awareness and fostering a sense of embodiment (see table 15), which I had expected to be an important practice based on the embodiment literature for various stigmatized groups including those with chronic conditions (e.g., Niazi & Niazi, 2011, Kabbat-Zinn, 2013). Participants emphasized the role of mindfulness and meditation in grounding them, especially during times of distress or physical discomfort. For example, P320 wrote: “I stay connected with myself by doing affirmations, and checking in with/listening to my body, especially when I am distressed or not doing well, then doing what I can to give it what I need.” By using mindful breathing, body scans, or focused reflection, individuals reported greater awareness of bodily sensations, helping them to better manage their physical and emotional states. Meditation also appeared to serve as a method for cultivating a deeper connection to the physical self, enabling participants to respond to their body's needs in a more attuned and intentional way.

Table 15*Example data extracts for Theme 2: Mindfulness and Meditation*

"I practice meditation and reflection as an ongoing process." (P7)
"I meditate, and do deep breathing in the morning time after I wake up." (P320)
"Practice meditation and breathwork occasionally." (P284)
"Meditation was very helpful to me, even the first time that I tried it I could feel the effects." (P199)

Theme 3: Caring and Tending to the Body. P309 describes how they care and tend to their body by practicing "self-love and staying present and respecting my body for where it is at". Participants described engaging in self-care rituals that involved both physical and emotional attention to their well-being including practices like taking baths, applying skincare routines and creating a peaceful atmosphere with candles. These practices all shared undertones of self-love and self-respect. For example, participants highlighted the importance of listening to their bodies, such as through choosing to nourish themselves with food that felt comforting or through engaging in activities that promoted relaxation and mindfulness, such as listening to music or taking time for quiet reflection. Considering people with chronic health conditions may be influenced by societal pressures to "push through" and accomplish more and may also compare their abilities to what they might have been pre-illness, these loving, gentle expressions of self-care are reassuring. The ideas in this theme are supported by Cook-Cottone and colleagues' (2017) paper on trauma-informed yoga and embodiment, whereby they discussed the prioritization of self-regulation through activities such as body awareness, mindful movement, and grounding practices. Living with a chronic health condition means living with certain limitations, and therefore emphasizing choice and ownership in how we expend our energy to nourish the body is critical. This theme exemplifies this process in that participants were able to prioritize self-care practices that involve gentle pleasure toward the body.

Table 16

Example data extracts for Theme 3: Caring and Tending to the Body

“I have stayed in tune with myself by doing self care like going for walks using essential oils and candles, taking long baths and showers using face masks and having a skin care routine.” (P31)
“Self-care: time to myself to listen to music!” (P318)
“Something I started doing was washing my body in the shower with my hands instead of a luffa. That I guess helped me feel like my body was something tangible.” (P291)
“not denying myself what I need because I need it and deserve to eat yummy food.” (P155)

Theme 4: Connection to Nature. The natural world, whether through walking outside, sitting by water, or birding, seemed to offer a space for participants to focus on their senses, and cultivate a deeper awareness of their bodily sensations. P274 exemplified this process in their response:

“I go Birding! It allows me to be outside but also focus my attention on the environment around me. I feel connected to my body (Listening and looking) and to the surrounding area. It's an act of centering myself and meditation without really meaning to.”

Time in nature can reduce stress and enhance well-being (e.g., Berman et al., 2008). For people with chronic health conditions, the peaceful and soothing environment that nature provides may offer a break from the stress associated with managing illness. Connection to nature may also function as an embodiment practice by creating a sense of connection to something larger than the self, which is a facet of self-compassion (Neff, 2011). Participants’ connection to the world around them may help to reduce feelings of isolation and otherness, providing a sense of peace and acceptance they may not otherwise feel in everyday environments.

Table 17

Example data extracts for Theme 4: Connection to Nature

“I love to be outside. I work in a job where I am outdoors in the wilderness most of the time. I also make sure I get fresh air every day while in school and I love hiking and swimming in lakes and rivers.” (P211)
“I also appreciated going for walks and being outside, where it's quiet.” (P342)
“I also like to walk, and I try to go out a few times a week to do this.” (P87)
“nature walks” (P84)

Theme 5: Sense and Sensuality. Sense and Sensuality practices such as beautification, listening to music, connecting with animals, massage, sex, and art, go beyond mere self-care — they are means of nurturing the body and fostering a deeper sense of self-compassion, acceptance, and comfort through engaging with different aspects of the senses. As P60 noted:

“I work with animals and I find that the hard work allows me to channel my energy somewhere, and the ability to have an animal connection, which is just unconditional love, puts me at ease when I need it.”

For individuals with chronic health conditions, Sense and Sensuality practices allowed participants to find solace in external sources of comfort that engage their senses in loving and pleasurable ways. Moreover, the sensory practices mentioned in table 18 – such as listening to music or receiving affectionate touch – create spaces where individuals can focus on sensations of pleasure, relaxation, and love, rather than pain or limitations. These practices help to center them in the present moment, fostering a positive relationship with their bodies and a sense of acceptance. Research supports these practices and their therapeutic effects for individuals with chronic health conditions. For example, research supports the many emotional, social, and physiological benefits of human-animal bonds, particularly in reducing stress and improving overall well-being (McConnell et al., 2011). In a qualitative study on art as a healing practice used by individuals with chronic conditions, Lynch and colleagues (2012) also discuss how art-

making allowed participants to develop a sense of self-worth and feel like they were taking back a sense of control. Overall, these practices reinforce the importance of pleasure and body-centered practices in fostering a positive relationship with the body through embodiment.

Table 18

Example data extracts for Theme 5: Sense and Sensuality

“healthy sex life and lots of physical affection” (P252)
“animal relationships a.k.a fur baby, action” (P292)
“take care of my appearance” (P124)
“I listen to music frequently” (P23)

Conclusions

This codebook analysis identified concrete methods of self-acceptance and embodiment practices, complimenting the reflexive thematic analysis by addressing more specific research questions. The findings confirmed key concepts such as social support, bolstering self-integrity, and embodiment practices were useful for self-acceptance, while also revealing symptom treatment as an unexpected method. Participants expressed engagement in a range of embodiment practices, including exercise, mindfulness, self-care, nature connection, and sensory experiences. These insights underscore the diverse and nuanced ways individuals navigate their process of self-acceptance and engagement with embodiment practices, highlighting the importance of agency, adaptation, and community in fostering well-being.

Discussion

The present study provides valuable insight into the lived experiences of people with chronic health conditions by qualitatively exploring how participants described their process of self-acceptance, embodiment practices, and relationships with their bodies. Using a reflexive thematic analysis, I identified four key themes related to how individuals with chronic health conditions relate to their bodies. Additionally, a codebook thematic analysis was conducted to

explore the strategies participants used for both self-acceptance and embodiment. I will expand on these findings below, discussing the study's strengths and limitations, future directions, and implications.

The reflexive thematic analysis yielded one overarching theme, *The Need to Disembody*, and four main themes: *My Illness, My Enemy*, *Follow the Wellness Recipe*, *Overwhelming Grief about What Was, What Is, and What Might Have Been*, and *My Illness, Myself (Resisting Disembodiment)*. These themes highlight key aspects of how individuals with chronic health conditions engage with their bodies. The themes that are captured within the overarching theme *The Need to Disembody* highlight the overwhelming number of responses that suggest a disconnected relationship with the body. I believe that this occurs primarily through internalized stigma, feelings of isolation, and subscribing to medical narratives. Having a chronic health condition requires outsourcing decisions about the body, such as relying on healthcare professionals for treatment advice, and I argue that this can weaken trust in one's ability to understand and care for the body independently. The combination of these experiences thus understandably leads to avoidance coping strategies that subconsciously attempt to make the body a more hospitable place to reside. As mentioned, these strategies likely only work in the short-term and will end up in more pronounced traumatic disembodiment.

Under this overarching theme was my first main theme, '*My Illness, My Enemy*', which illustrates how participants appear to separate their illness from their sense of self as an adaptive coping mechanism to avoid integrating it into their identity. '*Follow the Wellness Recipe*' reflects participants' engagement in restrictive wellness culture behaviors, such as controlling eating and exercise, which may contribute to traumatic disembodiment, rather than fostering compassionate, body-centered care. '*Overwhelming Grief*' is a theme that comprises part of the

chronic health condition experience which has been critically underexplored in the literature. The experience of grief appears to be central to the trauma of having a chronic condition such that many individuals describe grieving a body that might have been, their pre-illness bodies, or even their sense of autonomy. Finally, the theme '*My Illness, Myself (Resisting Disembodiment)*' explains how participants resisted disembodiment by engaging in healing or embodiment practices, such as community group involvement. The findings from this theme were further supported by the codebook thematic analysis, which provided a deeper understanding of the specific practices participants used to cultivate self-acceptance and embodiment.

The methods of self-acceptance identified through the codebook thematic analysis -- Bolstering Self-Integrity, Social Support, Embodiment Practices, and Treatment to Alleviate Symptoms -- offer important insights into how individuals with chronic health conditions navigate their journeys toward self-acceptance. These strategies empower individuals to challenge internalized stigma, build positive identities, foster meaningful connections, and strengthen community, contributing to an enhanced sense of self-worth. The codebook analysis also helped to highlight the embodiment practices participants used to engage with their bodies in physical and sensory ways, offering strategies such as mindfulness, exercise, and sensory experiences to deepen the connection with the body. By allowing participants to speak freely about their experiences and self-care practices, this qualitative approach complements and enriches quantitative findings, capturing the nuanced and individualized ways in which people cultivate self-acceptance and maintain a connection to their bodies. This approach provides a more holistic understanding of the coping strategies employed by individuals with chronic health conditions.

The Role of the Healthcare System in Promoting Disembodiment.

Throughout my analysis, I kept thinking about how engaging with the medical system, which is necessary for survival, may also perpetuate the processes of disembodiment that I was observing in my participants' responses.

Medical Language and Disembodiment. Several responses from the sample suggested that people with chronic health conditions have internalized the medical gaze (Foucault, 1963), and as such I will expand on potential sources of medical objectification for people with chronic health conditions. Common social discourses concerning "person-first" versus "disease-first" language to describe chronic health conditions (e.g., "person with diabetes" vs. "diabetic") are an example of how the medical system encourages people with chronic health conditions to detach from their disease. Medical professionals are encouraged to use person-first language (e.g., "person with diabetes") to minimize stigma by communicating that the disease is separate from the person. While the intention behind this type of language intervention is positive, it indirectly reinforces the stigma surrounding chronic health conditions because it is that very stigma that necessitates the distinction between patient and health condition. This phenomenon is deeply embedded in the broader conceptual and linguistic distinction between "illness" and "disease" (Fleischman, 1999, p.7). Medical language is largely abstract and focused on disease and organs, rather than patients' lived experiences of illness (McCullough, 1989). The "medicine-as-war" metaphor, intrinsic to biomedicine, emphasizes combatting disease rather than caring for the individual, reinforcing the idea of illness as an adversary (Fleischman, 1999, p.8). McCullough (1989) argues that while patients inherently speak the language of illness, physicians, due to their training, rely predominantly on the detached, disease-focused language of biomedicine. By framing illness as an external entity to be fought and conquered, the medical system

inadvertently reinforces this objectification, leading patients to internalize a view of their condition as separate from their identity. This can make it more difficult for patients to integrate their condition into their sense of self and cultivate self-compassion in the context of chronic illness. When patients' attempts to self-advocate within this framework are repeatedly met with resistance or dismissal, it can result in learned helplessness, as they begin to feel that their efforts to influence their care or well-being are ineffective.

Furthermore, this language likely exacerbates the disembodiment described by participants in their responses and captured in the overarching theme from my reflexive thematic analysis, particularly because it occurs in a context where individuals with chronic health conditions are often subjected to objectification. According to objectification theory (Fredericksen & Roberts, 1997), objectification involves internalizing an observer's perspective as the primary way of viewing oneself. This process of self-objectification was outlined in path 'a' and 'b' of my trauma model in Figure 1. In a significant study by Boudreau and colleagues (2008), participants with chronic health conditions reported feeling objectified by their physicians. They felt their illness was treated as a "research project" or a "problematic body part," rather than being recognized as part of their identity as unique individuals. This experience can force individuals to view their illness as an enemy, as externalizing their condition increases the sense of disconnection from it. This sense of separation encourages a mindset in which individuals feel the need to "fight" or "conquer" their illness, further deepening traumatic disembodiment.

State Sanctioned Disembodiment. The experiences of participants identified in *Follow the Wellness Recipe* are also representative of a sort of "state sanctioned disembodiment" whereby medical professionals often prescribe "healthy" behaviors as methods of treatment to

combat chronic illness symptoms. Healthcare systems can unintentionally reinforce disordered eating habits by overemphasizing health behaviors as a primary strategy for managing chronic conditions. People with chronic health conditions may feel pressure to engage in extreme dieting or orthorexia (obsession with "clean eating") as part of their treatment plan, blurring the line between medical advice and disordered behavior. This prescription of wellness culture, I argue, leads to a heightened state of disembodiment when reliance on health behaviors becomes a maladaptive source of control. This was exemplified in my participants' responses, as although we did not ask them anything to do with their eating behaviors, many responses depicted complicated relationships with food and exercise. Especially where people with chronic health conditions may already feel a lack of control over their bodies because of their condition, the ability to control eating and exercise behaviors can understandably become disordered. Further, for a group who is constantly outsourcing information on their bodies, this reliance on external prescriptions can deepen the disconnection between mind and body. Adhering to wellness norms and medical recommendations to manage chronic health conditions—such as prescribed diets, exercise routines, and other “healthy” behaviors—may inadvertently reinforce the objectification of the body, treating it as something to be controlled rather than something to be understood and listened to. This dynamic can contribute to a cycle of self-objectification, where individuals internalize the belief that their worth is tied to their ability to meet these external standards.

Franzoi's (1995) theory on the body-as-object versus the body-as-process is particularly relevant here, as it helps to explain how people with chronic health conditions may engage with their bodies in ways that reinforce disembodiment. The theory draws attention to the objectification of the body, where it is seen as something to be controlled, evaluated, and scrutinized (the body-as-object), versus a more integrated, dynamic view of the body as part of

one's lived experience (the body-as-process). In the context of chronic illness, the external prescriptions around wellness and health behaviors can intensify the objectification of the body, encouraging individuals to see their bodies as entities to be fixed or manipulated. Ultimately, this "state sanctioned disembodiment" further isolates individuals from their authentic experiences and emotional connections to their bodies, exacerbating the psychological and emotional toll of living with a chronic health condition. In contrast, the responses represented in *"My Illness, Myself (Resisting Disembodiment)"* align more with the body-as-process view, as participants resist disembodiment and attempt to reconnect with their bodies through self-acceptance and healing practices. This reflects the more holistic perspective where the body is seen as a process, constantly changing and interacting with the environment, rather than an object that must be controlled or fixed.

Rethinking Embodiment in People with Chronic Health Conditions

A primary aim of this research was to apply embodiment theory to a new group of stigmatized individuals. I therefore assumed that people with chronic health conditions experience traumatic disembodiment. While my themes clearly reflect behaviors and efforts to separate one's illness from their identity (such as viewing the chronic health condition as an 'enemy'), an important question remains: *is this behavior adaptive for individuals with chronic health conditions?* It is possible that embodiment practices, such as joyful movement, do not offer the same genuine pleasure in the body for these individuals, especially since their conditions often manifest in physical symptoms that are difficult to ignore. Chronic pain research has examined the choice between coping and acceptance as strategies for managing pain (e.g., McCracken & Eccleston, 2003). The experience of chronic pain, and many other chronic health conditions, is often framed as a struggle to master or overcome adversity (Jackson, 2000). This

narrative reinforces the idea that acceptance or the ability to cope with symptoms is achieved through a struggle to alter or control an aversive experience. From this perspective, “coping” becomes defined by the extent to which individuals with chronic health conditions can persevere with often unsuccessful attempts to control symptoms that are ultimately uncontrollable (Aldrich et al., 2000).

This emphasis on struggle in the narrative of chronic illness highlights a core challenge faced by individuals with chronic health conditions: the constant tension between accepting their reality and attempting to alter or control it. The prevailing medical and societal narratives often prioritize the idea of "mastery" or “control” over illness, which can reinforce feelings of inadequacy and failure when symptoms cannot be conquered. This framing may inadvertently discourage individuals from embracing a more accepting approach to their condition that allows for coexistence with symptoms rather than an ongoing battle against them. Furthermore, the focus on control and mastery in chronic pain and illness research may overlook the nuanced ways in which individuals with chronic health conditions engage with their bodies in more subtle, embodied ways. Perhaps incorporating embodiment practices into the lives of those with chronic health conditions requires a reframing of what "wellness" and "healing" mean. Rather than focusing on the absence of pain or the eradication of symptoms, a more holistic approach might center on self-compassion, presence, and the gradual process of reconnecting with the body in its entirety (Kılıç et al., 2021). For some, this may mean redefining what it means to feel pleasure in the body, especially when physical symptoms persist. Thus, understanding how people with chronic health conditions navigate the embodied tension between disembodiment and acceptance, could be key to developing interventions that foster long-term psychological and emotional well-being. By broadening the conversation beyond traditional models of coping and

control, we may begin to understand more fully the rich, complex ways in which individuals with chronic health conditions relate to their bodies and their health.

Studies in the body image literature have begun to address this concept. For example, the concept of body self-unity has been discussed as a method to combat the experience of seeing the body as a separate adversary (Bode et al., 2010). Specifically, Bode and colleagues (2010) discuss how people with rheumatic conditions face challenges to their maintenance of positive self-esteem due to consequences of the disease like pain and limited physical functioning. Their intervention focused on training women with rheumatoid arthritis to focus holistically on their body functionality and reflect on the functions that their body can perform despite experiencing symptoms of their chronic condition. This concept is referred to in the body image literature as *functionality appreciation*, which is defined as “appreciating, respecting, and honouring the body for what it is capable of doing, extending beyond mere awareness of body functionality (e.g., knowing the body can digest food versus being grateful that the body can digest food)” (Alleva et al., 2017, p.29).

Limitations

One limitation of this study is the challenge posed by theorizing in the face of overlapping identities among participants. Many participants identified broadly within the disability community, which encompasses a diverse range of experiences and conditions. As a result, it is unclear in some cases whether participants were discussing their chronic health condition specifically, or referring to other disabilities, as these identities can often overlap or be comorbid. This ambiguity limits our ability to draw conclusions specific to the lived experiences of individuals with chronic health conditions. To address this limitation, future research would benefit from recruiting participants who primarily identify as a person with a chronic health

condition, rather than relying on broader disability-based samples. This targeted approach would allow for a more nuanced understanding of the unique challenges and experiences associated with chronic health conditions, leading to more precise and actionable insights. Additionally, it would help disentangle the specific impacts of living with chronic health conditions from those of other types of disabilities, providing clearer guidance for interventions and support strategies.

Further, critical disability perspectives discuss how the relationship between identifying as someone with a disability versus chronic illness is complex and often contentious (e.g., Meekosha & Shuttleworth, 2009). For instance, people with chronic health conditions may not see their illness as part of their identity or may resist identifying as disabled due to societal stigma or a desire to maintain “normalcy” (Shakespeare, 2006). Since chronic health conditions, by definition, may not always lead to significant physical impairment or disability, and often involve fluctuating symptoms and varying degrees of severity, individuals may struggle with how to perceive themselves and their conditions when disability is typically framed in societal discourse as permanent, often visible, and limiting ability to participate in “normal” activities. On the other hand, some individuals with chronic health conditions find it empowering to adopt a disability identity as it can provide a sense of solidarity and advocacy within the larger disability community (Brown & Zasler, 2011). This identity may, for example, help to combat internalized ableism or discrimination people with chronic health conditions face as a result of societal norms that value productivity and “normal” functioning. As such, adopting a disability identity may provide a form of self-empowerment, offering a way to challenge the biomedical model of health and illness that is often isolating. These tensions are important to recognize as a limitation, as my sample is inevitably representative of people who have adopted a disability identity, making

them more likely to have engaged in advocacy or activist groups and are thus more likely to have done work to combat internalized stigma.

Intersectionality theory is a framework for understanding how different aspects of a person's identity such as race, gender, class, sexuality, disability, and other social categories interact and intersect to shape their experiences of privilege, oppression, and discrimination. The theory emphasizes that people are not defined by a single aspect of their identity; instead, the intersections of multiple social identities create complex layers of experience and social position (Crenshaw, 1989). Applying this to chronic illness experience, collective social identities intersect in interconnected systems of power, leading to differing experiences of oppression. The experience of having a chronic health condition is unequal across different groups because of systematic social inequities like income, power, race, and discrimination. Most research on health conditions is based on white middle-class samples, which creates knowledge that doesn't reflect the real diversity of experiences and can actually reinforce inequities (Meekosha & Shuttleworth, 2009). Researchers therefore need to embrace justice-oriented research that centers lived experience and acknowledges the fluid, contextual nature of people's experiences.

I recognize that my sample was very homogenous and comprised mostly of white women. Therefore, it is probable that I've missed important differences in how illness is experienced at the intersections of race, class, and gender identity. While I have attempted to engage in intersectionality by critiquing individualistic and medicalized views of chronic illness, recognizing that experiences are deeply shaped by social context, stigma, and power structures, and highlighting the importance of lived experience, I acknowledge that future research should intentionally recruit more heterogeneous samples to allow for a deeper understanding of how race, class, gender, and disability status intersect to shape stigma, embodiment, and

psychological well-being. For example, ideals of health and mind-body philosophies differ across cultures, and Western perspectives, such as the one I adopted in this study, may not apply universally. In many non-Western cultures, health is often seen as a more holistic and interconnected concept, where the mind and body are not viewed as separate but as integral parts of a whole. This cultural variation highlights the need for caution when applying Western frameworks to diverse populations.

Additionally, my sample was primarily women, and men and other genders might have different attitudes toward healthcare, self-care, or emotional expression, which could influence how they respond to survey items or qualitative interviews. Gender norms and societal expectations around masculinity (e.g., emotional stoicism, independence, or reluctance to seek help) could shape how men engage with the research topic, for example. An additional consideration is that the sample was exclusively comprised of University of Victoria (UVic) students. UVic, as a liberal institution, likely cultivates an environment that encourages critical thinking, social justice engagement, and activism. As such, participants may be more attuned to or actively involved in perspectives that advocate for the rights of marginalized groups, including those with disabilities, leading to a potentially skewed representation in how participants discuss disability and chronic health conditions.

Finally, post-secondary education is widely recognized as a period of heightened stress and significant transition, even for individuals without chronic health conditions (Marcotte et al., 2018). For students with chronic health conditions, this already challenging phase can be further complicated by the additional demands of managing their health. These demands may include adjusting to living independently for the first time, managing changes in activity levels due to illness-related fatigue or pain, and navigating complex accommodation systems within the

university. These layered stressors can intensify feelings of disconnection and disembodiment, potentially skewing the findings to reflect a unique subset of experiences tied to the intersection of chronic illness and student life. Future research should consider diversifying the sample by including individuals with chronic health conditions from various life stages and contexts, such as those in the workforce, retirees, or individuals in non-academic environments. This broader perspective would provide a more comprehensive understanding of the experiences of people with chronic health conditions beyond the university setting.

Future Directions

The results of the present study highlight the importance of continuing to understand the lived experiences of people with chronic health conditions. It is clear that having a chronic health condition presents significant and profound challenges, and as such, finding ways to minimize the disembodiment and internalized stigma experienced by these groups is essential. Notably, many participants emphasized the role of online communities, particularly platforms like TikTok, in their healing journeys. These spaces allowed them to feel seen, understood, and supported, fostering a sense of self-acceptance and relief from the isolation often associated with chronic health conditions. This emerging reliance on online communities highlights a crucial area for future research, as understanding how these digital spaces influence coping and self-perception could inform strategies to enhance support for people with chronic health conditions.

An important extension of this study would be to compare results across different ages of diagnosis. It is possible that feelings of disembodiment lessen over time as individuals become more accustomed to living with their illness and discover practices that enhance self-acceptance. To further explore this, future research could involve using focus groups or one-on-one interviews to gain a deeper understanding of the lived experiences of individuals with chronic

health conditions. These qualitative methods would provide rich, detailed insights into how stigma and disembodiment are navigated, as well as the specific practices that promote healing and self-acceptance. Focusing specifically on individuals who identify solely with chronic health conditions, rather than a broader sample that includes other disabilities, would allow for a more concentrated exploration of the unique challenges they face.

Kitzinger (1995) highlights the value of qualitative focus group research, noting that it is particularly inclusive, as it does not exclude individuals who may struggle with reading or writing. Furthermore, focus groups encourage participation from those who may be hesitant to engage in one-on-one interviews or feel they have little to contribute. By providing a space for individuals to share their experiences, researchers could explore how factors such as the visibility of a condition, the role of social support, and engagement with embodiment practices affect self-acceptance. Ultimately, these methods would offer a more holistic understanding of the emotional and psychological processes involved in living with a chronic health condition.

Implications

Giving Voice to People with Chronic Health Conditions

This qualitative examination of the lived experiences of people with chronic health conditions aims to give individuals with chronic health conditions and disabilities a sense of being seen and understood. The theme ‘*Overwhelming Grief about What Was, What Is, and What Might Have Been*’ clearly captures the challenges and sense of loss associated with having a chronic health condition. The hope, therefore, is that people with chronic health conditions will feel less isolated and more empowered by reading narratives that authentically capture the difficulties they face. By recognizing and validating the challenges inherent in living with a chronic health condition, this research underscores the immense emotional and physical toll

these individuals endure. It also serves as a reminder that their experiences are real, complex, and worthy of attention beyond the reductionistic conclusions often found in current literature, which fail to address the underlying processes contributing to heightened mental distress. This study helps to amplify their voices and offers recognition of the resilience they demonstrate daily. Furthermore, this research represents a first step in applying embodiment theory to chronic health conditions and hopes to be a catalyst for identifying the most effective practices for those who have experienced traumatic disembodiment and continue to endure the physical symptoms of illness. By exploring how individuals can reconnect with their bodies and find healing, this study aims to guide future work in helping people with chronic health conditions feel more empowered, validated, and supported in their journey toward self-acceptance and well-being.

Medical Care

Although providing recommendations for major changes in healthcare policy is beyond the scope of this study, understanding the realities of living with chronic health condition more holistically can help healthcare providers better meet the psychological needs of the patients their care. While many medical practitioners often only see their patients on a bi-annual basis, these interactions hold significant weight for people with chronic health conditions, often shaping one's illness identity. For example, during a routine bi-annual visit, a doctor may mention, "Your A1c is a bit high, you need to work on lowering it." While the intention is to provide health guidance, such comments can feel overwhelming and demoralizing for a person managing diabetes. This one remark can intensify the already constant mental load of living with a chronic condition. The patient likely does not need to be reminded that their condition requires attention, as they are living with it every day. For them, diabetes is not just something they think about in the doctor's office; it is a constant part of their identity and daily life. As such, people with

chronic health conditions would benefit significantly from their practitioners adopting a more compassionate and empathetic approach to care to foster more awareness around not reinforcing the medical gaze. Compassion-based interventions have been shown to significantly reduce anxiety and fear in individuals managing chronic conditions, creating a supportive environment that fosters emotional resilience and self-efficacy (Austin et al., 2020). Compassionate care also improves health outcomes, patient safety, and engagement by addressing not only the clinical aspects of chronic health conditions but also the emotional and relational needs of patients (Ahmed et al., 2024). By actively listening to patients, acknowledging their experiences, and tailoring care to their unique circumstances, practitioners can build trust and create a therapeutic alliance that enhances patient well-being, reduces internalized stigma, and ideally leads to a more positive, embodied relationship with the self. Along with a more general compassionate care approach, medical professionals could make use of the specific information expressed by participants in the '*My Illness, Myself (Resisting Disembodiment)*' theme. For example, knowing that people with chronic health conditions indicated that community and support groups were influential in promoting self-acceptance, practitioners and public health workers could compile a list of support groups or online community platforms for their patients.

Conclusion

This thesis highlights the profound and often overlooked trauma experienced by individuals with chronic health conditions. In developing my trauma model, I initially hypothesized that healing would occur through increasing self-acceptance or decreasing internalized stigma, alongside promoting embodiment or decreasing traumatic disembodiment. However, my findings revealed that this process is not as linear or straightforward as anticipated. Rather, healing appears to be a fluctuating journey. A qualitative assessment of participants'

relationships with their bodies revealed themes of disembodiment, grief, and complex bodily relationships, emphasizing how difficult it is to feel connected to a body that seems to betray you. However, while disconnection was prevalent, participants also described moments of resisting disconnection from the body and engaging in self-care, suggesting that it is possible to cultivate a compassionate caregiving relationship with the body, even if full embodiment, where body and self are one, may not always be achievable. Instead, embodiment for those with chronic illness may be an adaptive, fluctuating process, where disconnection coexists with efforts to nurture and reclaim bodily presence.

A key takeaway of this thesis is the notion that the body is not just a source of pain, but also a window to experience. While disembodiment may serve as a coping mechanism, shutting out the body also means shutting out pleasure, a theme deeply intertwined with the perception of illness as an “enemy.” This underscores the importance of reframing chronic illness beyond purely medical narratives and recognizing the role of pleasurable, affirming experiences in fostering a more compassionate relationship with the body. Social support was another vital coping mechanism, with online communities such as those on TikTok playing a crucial role in helping participants feel validated and less alone. This finding reinforces that people with chronic health conditions should not have to navigate their experiences in isolation, and that connection, whether through advocacy, shared experiences, or peer support, can be a powerful mechanism for self-acceptance. For healthcare providers, this research calls for a more empathetic, patient-centered approach. Current medical discourse often reinforces disembodiment, failing to acknowledge the psychological toll of chronic illness. Providers may exacerbate this problem by overlooking patients’ lived experiences and expertise in their own conditions, prioritizing disease management over holistic well-being. Greater awareness of the

inseparable nature of psychological and physical experiences in chronic health conditions is necessary. While future research is needed to refine these approaches, this study is an important step in bridging embodiment literature with chronic illness experiences. Concepts like functionality appreciation (Alleva & Tykla, 2021) provide promising frameworks for promoting genuine care and pleasure for the body, paving the way for more affirming and inclusive models of chronic illness care.

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Appendix A

Research Question #1: A Priori Codebook Table

Categories	Definition	Codes
Bolstering Self-Integrity	Engaging in practices that re-invigorate aspects of the self that have been suppressed due to internalized stigma through actions such as advocacy and increasing self-compassion.	Positive self-identity Self-compassion Self-love Challenging stigmatizing perspectives Educating community members Protesting Contribution to social change
Social Support	Meaningful connections with people or communities that provide individuals with greater feelings of belonging, acceptance, emotional comfort, and empowerment.	Positive role models Engagement with in-person community Engagement with online community Supportive close others (parent, partner, siblings) Healthcare team Miscellaneous
Embodiment Practices	Meaningful engagement of the body with the world through methods such as positive body connection, embodied agency, and self-care.	Meditation Yoga Mindfulness Self-care Joyful Movement Dance Massage Sex Sexuality Eating Outdoor activities Swimming Miscellaneous

Research Question #2: A Priori Codebook Table

Categories	Definition	Codes
Embodiment Practices	Meaningful engagement of the body with the world through methods such as positive body connection, embodied agency, and self-care.	Meditation Yoga Mindfulness Self-care Joyful Movement Dance Massage Sex Sexuality Eating Outdoor activities Swimming Miscellaneous

Appendix B

Research Question #1: Final Codebook Table

Themes	Definition	Examples
Bolstering Self-Integrity	Engaging in practices that reinvigorate aspects of the self that have been suppressed due to internalized stigma. This process begins with re-education, which shifts perspectives on the individual's identity group and their stigmatizing experiences. This can be reflected inward, through increasing self-compassion, or outward through actions such as advocacy and radicalization.	“I only recently began to identify as someone with a disability, and acknowledge the fact that some things are genuinely hard for me and I'm not necessarily being lazy.”
Social Support	Meaningful connections with people or communities that have assisted individuals in their acceptance of their chronic health condition. People may access and benefit from different sources of support such as healthcare providers, close relationships, or chronic illness communities. In addition, individuals may benefit from different types of support, specifically empowerment, acceptance, and belonging.	“Joining TikTok and finding an abundance of people with the same conditions has helped me feel confident that I am not making things up for "attention" and that I hold value as a human regardless of my physical and cognitive shortcomings.”
Embodiment Practices	Meaningful engagement of the body with the world via any combination of sensory processes through methods such as positive body connection, embodied agency, and self-care.	“I came to accept my disability through art related to disability.”

Treatment to Alleviate	Seeking and using tools that reduce psychological and physical suffering and/or increase well-being. This could include pursuing medical treatments, therapies, accommodations, and using assistive devices.	“Finding mobility aids that work for me and look the way I want them to has been such a huge part of accepting my disability.”
Symptoms		

Research Question #2: Final Codebook Table

Embodiment Practices	Definition	Codes
Mindfulness and Meditation	Mindfulness involves the practice of intentionally bringing one's attention to the present moment to foster awareness of thoughts, feelings and bodily sensations without judgement, promoting a deeper connection to the self. Meditation involves focused techniques which cultivate a state of relaxed attention and awareness and may include various practices such as breath awareness, body scans, or loving-kindness meditation. Together these practices serve to promote compassionate awareness of the body to better understand physical experiences and encourage healing or emotional regulation.	(No subcodes)
Caring and Tending to the Body	Practices that involve physically nurturing and caring for the body in a way that is more meaningful and intentional than simply satisfying basic human needs. For example, eating, rest, or bathing.	Eating, rest, bathing
Connection to Nature	Immersing oneself in the natural environment through activities such as hiking, walking, or swimming, to connect with aspects of the outdoors (e.g., beaches, wilderness, birds).	(No subcodes)

Exercise	Any form of structured movement or physical activity with a focus on reconnecting with the body in a mindful and intentional way.	Joyful movement, yoga, dance
Sense and Sensuality	Activities that invigorate the senses. This may be through tactile activities such as art or massage, experiencing physical affection from others, or listening to music.	Beautification, music, touching animals, massage, sex, art
