Exploring Repeated Clinical Encounters: An Arts-Informed Participatory Project for Women and Gender Minorities Living with Chronic Illnesses

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Abstract

Background: Living with a chronic illness involves frequent interactions with health care professionals and the health care system to manage one's symptoms. Yet, little research conceptualizes health care interactions as a stressor that may exacerbate or contribute to symptoms.

Objectives: This study sought to better understand the health care experiences of women and gender minorities living with chronic illnesses by answering the following research question: Using arts-informed methods, how do women and gender minorities living with chronic illness understand and experience "patienthood?" The project had three objectives: 1) Identify the effects of repeated health care interactions on people living with chronic illnesses and the strategies they use to navigate these interactions and effects; 2) Explore the theoretical concept of "patienthood" through an arts-informed, critical disability lens; and 3) Examine the potential of arts-informed health research as a transformative practice.

Methodology: An arts-informed, patient-oriented lens guided the study. Workshops, involving a multi-media collage activity and focus group discussion, were conducted with ten participants. Data analysis included two phases: first, a reflexive thematic analysis to analyze the focus group transcripts, and second, an interpretive approach informed by critical disability studies to analyze the artwork produced by participants.

Results: Participants often experienced dismissal or disregard for their concerns during clinical encounters, conceptualized as 'medical invalidation.' Experiencing this repeatedly had significant consequences for participants' well-being, willingness to seek care, and the support they sought and received from their social support systems. We emphasize that medical invalidation is not merely a one-off interpersonal interaction, but influences and is influenced by broader sociocultural ideas about illness and disability.

Discussion: Addressing medical invalidation requires a commitment to person-centred, humanist care and critical reflexivity in the medical clinic, as well as a re-imagining of public discourse around illness and disability that affirms and embraces embodied difference.

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Author Contributions

Authorship contributions have been determined in accordance with the guidelines published by the International Committee of Medical Journal Editors. Jennifer Sebring (JS) is the lead author on both manuscripts, having conceptualized the project and led all aspects of the research process. JS wrote the first draft of each manuscript and critically revised the material, approved the final version of each manuscript, and agrees to be accountable for all aspects of the work. Christine Kelly (CK), Deborah McPhail (DM), and Roberta Woodgate (RW) all meet the authorship criteria for the first manuscript and will be named as contributors for the second manuscript as per disciplinary norms. CK contributed significantly to the the conceptualization of the project and supported all aspects of the research process. DM and RW each provided substantial contributions to research design. CK provided initial feedback on the manuscript and suggested revisions for important intellectual content, while DM and RW provided critical feedback after the first round of revisions. CK, DM, and RW all approved the final version of the manuscript and agree to be accountable for the work.

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Introduction

from the other day - I needed to bring my floaty, dissociating bodymind back to earth so badly, and my love knew just what I needed. to the beach it was. to the sand. to the cool water lapping against my calves. to pressing my weight into my heels, my toes; feeling the gritty beach soften underneath me, hold me, remind me of what it feels like to experience life through this body, this flesh.
I've been thinking a lot about this body. what it's asking of me. what it needs. i have two doctors' appointments tomorrow and with all that's been going on this summer, in this body, it feels like a lot is at stake. I usually go into appointments armed with charts and notes and lists and a strategically formed narrative of symptomology.
tomorrow my strategy is to practice vulnerability, and radical honesty, and to hope that my health practitioners will exercise their empathy in response.
even if nothing becomes of it - if medicine cannot offer me the language to describe my current experiences - at least I might be witnessed by another being. And sometimes that's enough.
holding space for everyone looking for answers, while still knowing they might not be there to find 💜

Image and caption by Jen Sebring, Instagram post. July 31, 2019.

Living with chronic illness requires frequent, stressful, and sometimes even traumatic health care interactions. The repeated stress from health care interactions can exacerbate the very symptoms being treated. Chronic illnesses are health conditions with no known cure that "last a year or more and require ongoing medical attention and/or limit activities of daily living."[1] There are many conditions that fall under this umbrella, such as depression, autoimmune diseases, and fibromyalgia. Attention to the experiences of chronic illnesses is important, as advancements in medical technology transform once fatal illnesses into life-long conditions. In turn, an increasing number of people in the global north are living with chronic illnesses. For example, in Canada, 32.7% of people report living with chronic conditions that limit their activities.[2]

Most health research focuses on a specific list of conditions labelled 'chronic disease',[3][i] but this project is less concerned with diagnostic labels. Instead, I focus my study on the shared *experience* of living with chronic illness, recognizing that many people do not (yet) have a diagnosis. As Driedger and Owen note, people with chronic illness become "perpetual patients of

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[i] The chronic diseases most commonly included in this list are: diabetes, cancer, COPD/asthma, heart disease, mood/anxiety disorders, and stroke.

the medical profession, with every aspect of their life examined, researched, and probed"[4(p5)] as a 'problem' in need of medical intervention. In support of this interpretation, a recent study suggests that negative health care encounters experienced by people with chronic illness can have significant consequences for patient's psychological wellbeing and their willingness to seek care.[5]

Chronic illness does not affect all people equally. Women and gender minorities[ii] (transgender, non-binary, or Two-Spirit people) are more likely to live with chronic illnesses.[6,7] While there is considerable research documenting these disparities in women,[8,9] gender minorities remain under-represented in health research. Recent studies, such as that of Abramovich et al. 2020[10] conclude that "transgender individuals [defined in their study as people whose gender identity does not 'match' their sex assigned at birth] are more likely to experience chronic physical and mental health conditions"(p1) as well as increased rates of comorbidities and health service use compared to their cisgender counterparts. Both women and gender minorities also experience systemic discrimination that can contribute to or exacerbate chronic illness.

Health care quality and patient satisfaction are crucial to ensuring people with chronic illnesses continue to seek support for managing these often-complex conditions. Yet women and gender minorities face frequent experiences of sexism,[11] transphobia,[12] or general dismissal of their concerns in health care settings.[13,14] The documentation and dissemination of such experiences, whether through memoir, autoethnographic scholarship, art, documentaries, journalism, or social media, have proliferated in recent years, reflecting the reality that most women with chronic illness, and gender minorities more broadly "expect to experience discrimination"[15(p13)] in health care.[iii]

In particular, this population reports feeling disbelieved and dismissed by their care providers[16,17] – a conundrum I understand through feminist disability philosopher Susan Wendell's concept of epistemic invalidation:[18]

> When a doctor says to a patient who feels terribly ill or has acute pain - 'there's nothing wrong with you' that doctor obliges the patient to choose between discounting her own experience and distrusting the knowledge of someone she may have trusted and respected for years. If the patient receives the same judgement from many doctors…

[ii] I use the term of "gender minorities" as it is the disciplinary norm for health research while acknowledging that some people who fall under this umbrella may prefer different terminology.

[iii] See for example, the genres of 'Crip Lit,' 'Sick Lit,' autopathography, and illness memoirs. Of particular influence to my work: Wendell 1996, Lorde 1997, Driedger & Owen 2008, Hustvedt 2010, Sharman 2016, Hedva 2016, Dusenberry 2018, Clare 2018, Piepzna Samarasinha 2018, Feldman 2021, #HospitalGlam.

> she is forced to choose between asserting her own subjectively based ability to know her own body and discarding her belief in the expertise of medical science (p. 224).

I am compelled to understand what this continued experience of epistemic invalidation *does* to a person,[19] especially in the context of the clinical encounter. Beyond individual encounters, health care operates at a system-level: "health care institutions that are intended to provide services and supports to individuals may themselves be trauma-inducing"[20] through their entanglements with systems of oppression,[21] such as sexism,[11] transphobia,[22] ableism,[23] colonialism,[24,25] racism[26,27] and so forth. Björkman et al refer to this as the 'duality of suffering' where "health care encounters risk adding to rather than alleviating the burden of illness."[28(p2973)]

In previous autoethnographic work, I conceptual this experience as "medical micro-trauma" and in this study, I explore the resonance of this concept through a qualitative, empirical study of others who identify as women or gender minorities and live with chronic illness. Although the basis of this exploration is hinted at in other works, as my literature review shows, it is imperative that health care's role in either exacerbating or protecting against additional stressors be explicitly examined. My work is motivated by my lived experience and affirmed by my continued engagement with critical disability studies (CDS), including those I've already named, but also the writing of Eli Clare, Leah Lakshmi Piepzna-Samarasinha, Sami Schalk, Johanna Hedva, and Alyson Patsavas.[29–34] Through a participatory, patient-engaged framework, my project centers the needs and experiences of women and gender minorities living with chronic illness. I employ arts-informed workshops and focus groups to encourage engagement and collective processes of knowledge construction. It is my hope that this project will help identify solutions that are informed by and responsive to the lived experiences of women and gender minorities with chronic illness in their everyday lives.

Research Question & Objectives

The research question guiding this project is: using arts-informed methods, how do women and gender minorities living with chronic illness understand and experience "patienthood?" In answering this question, this project has three objectives:

1. Identify the effects of repeated health care interactions on people living with chronic illnesses and the strategies they use to navigate these interactions and effects;

2. Explore the theoretical concept of "patienthood" through an arts-informed, critical disability lens; and
3. Examine the potential of arts-informed health research as a transformative practice.

This thesis is organized as follows. First is a review of the literature on my topic, followed by a broad discussion of my methodology and an overview of the research process. I then present my results as two separate manuscripts before ending with a concluding chapter that discusses the study results as a whole.

Literature Review

I conducted a focused, systematized literature review[35] to contextualize my proposed project and identify gaps in the literature. The search strategies are described in detail in Appendix A. What follows is an examination of qualitative, empirical studies that looked at the health care experiences of adults living chronic illness. Through this search, I found four prominent themes: effective communication in patient-provider relationships, models of care and self-management, psychosocial dimensions, and stigma. After reviewing these themes, I present the few studies that begin to consider the effects of repeated clinical encounters in the context of chronic illness, and then discuss the novelty of my study via the limitations of the literature.

Effective Communication

Communication has been a large area of focus in research on chronic illness and health care experiences. Most of the studies look at the interactions between a patient and physician during an appointment, though some studies address communication among care providers and administrative staff, and its implications for patient care.[36,37] The quality of communication between patients and providers has a strong influence on health outcomes,[38] but often patients are dissatisfied with their provider's communication. Reasons for this include divergent perspectives between parties,[16,39,40] overly technical language, and patients feeling like they aren't being listened to or taken seriously.

Continuity of care is brought up frequently as a result of poor communication.[16,41,42] Kvale,[41] who conducted a Norwegian study with 13 interviewees, and Theis,[42] who conducted focus groups with 102 participants in Texas, USA, point to the importance of the provider recognizing *what is at stake*[43] for a patient in an appointment. A quote from a focus group participant included in Theis' study demonstrates this clearly: "*When I'm talkin' to my doctor, is he listening, does he know my fears, does he understand what my needs are when I leave him, what my concerns are?*"[42(p400)] These studies report the importance of building a trusting relationship[44] over time with a provider, as these interactions can "powerfully shape [patient] capacity to make sense of and live with serious illness."[45(p1)] Kvale's narrative interviews stress the importance of feeling heard and attended to, and how difficult it is for patients to find a new provider and build a new relationship, especially when they have a complex medical history, as is the case with chronic illness.[41] At times, as described through interviews with 15 Scandinavian heart failure patients in Ivynian's study,[36] communication breakdown happens because physicians fail to communicate information in an understandable way or do not foster open communication.

Studies attribute breaks in communication to the different knowledges and priorities held by patients and their providers.[16,39,40,46] Piras' study, situated in a regional diabetes clinic in northern Italy, takes a unique approach to understanding this, through examining diabetes logbooks and observing patient-physician appointments. Piras' study finds that medical encounters are often marked by "fragmented systems of knowledge."[39] Lian,[16] through a survey with 431 Norwegian women living with medically unexplained chronic fatigue, and Zizzo,[46] using mixed-methods at a Canadian patient-centered care clinic, found that patients bring with them lived expertise, and physicians, biomedical expertise, but these knowledges are not equally valued. Joensson et al, in a qualitative Danish study on multimorbidity in older adults, find that when patients try to frame their communications in the purview of biomedical knowledge, valuable knowledge is left out, because patients feel it's not relevant, it's too personal, or that it might position them as incompetent.[40]

Few studies link communication issues to their broader contexts, though there are exceptions.[17,47,48] Clochesy et al contribute to this gap by conducting focus groups with "medically and socially disenfranchised groups"[17] in the United States, where they found that communication was hindered by the individual factors discussed above, but also structural factors, such as the time a provider is allowed per patient. Clochesy's participants also note that their health care encounters are marked by discrimination and dehumanization, or they are unable to access care altogether. Townsend extends this finding through interviews with people living with multi-morbidity in Scotland, naming this as “symbolic violence”[47] in that the organization of power in health care and even patient-provider relationships implicitly maintains power differentials. Battalova’s interviews with disabled providers in Canada recognize that first-hand knowledge and disability ‘cultural competence’ enables disabled practitioners to build rapport through shared experiences with patients, and identify structural barriers to health, as well as creative solutions.[48] These findings are important and justify the need for contextualizing communication in the clinical encounter within broader systems of power. The use of arts-informed methods and a critical disability framework will allow for deeper analysis of *how* context informs communication difficulties.

Psychosocial Dimensions

Living with chronic illness comes with many psychosocial challenges.[49–58] Patients with chronic illness have unmet needs in this area because health care services are often limited to concerns that are strictly medical. Still, living with chronic illness is marked by a variety of emotional challenges that influence an individual’s capacity to make meaning of their experience and to cope with stressors.[38,49,54] Certain conditions do come with specific challenges, for example, those conditions that are visible (such as psoriasis) have different impacts than those that are not.[49] It appears though, that chronic illnesses in general, come with psychosocial difficulties such as adjusting to fluctuating health,[49,58] feeling different or isolated from other people,[49,54,58] coping with the demands of self-managing conditions,[54,55,58] and uncertainty around about the future of their health and how it will impact their life.[50–53,56,57]

In many cases, chronic illnesses are acquired conditions. Studies such as that by Rasmussen, which collected survey, focus group, and interview data from young adults with psoriasis in Denmark, explain how the onset of chronic illness came with a significant adjustment period to a drastically changed life.[49] Balfe,[54] in interviews with young people living with type 1 diabetes in Ireland, notes that this adjustment can be an ongoing process as one’s health status fluctuates, whether due to illness or external stressors. For example, in Thomas’ study on Canadians with secondary lymphedema, losses to everyday functioning “were only experienced intermittently or were anticipated if participants’ symptoms worsened.”[58(p5)] Thomas and Rasmussen also find that this loss of ability results in people with chronic illness feeling disconnected from those around them.[49,58]

A social support system is important in maintaining well-being while living with chronic illness. Several studies, all of which focused on diabetes except for one,[58] reflect that patients are often exhausted and frustrated by the demands of constant self-monitoring and management required in their everyday life.[54,55,58] In addition, uncertainty is a prevalent theme. People with chronic illness express fear of the future, of not knowing whether they will develop complications from their condition, and not being able to predict the course their condition, and subsequently, their life, will take.[52,54,57,58] Uncertainty is not only reflected by patients, it also is a challenge to practitioners. For example, in an interview study with older adults with HIV and their providers in the United Kingdom, Rosenfeld describes how aging with HIV is an embodied "experiment of living" with neither patients or providers having any knowledge on what the process might bring.[53] This study, as well as another that looks at post-infectious disease syndrome[56] reflect how the "newness" of chronic conditions means there are still many unknowns. Uncertainty is especially prevalent when a patient has multiple conditions, or when they are seeking diagnosis for complex symptoms/conditions, such as lupus.[50,51] There are many challenges to address with chronic illness and developments in health care to better serve this population are underway.

Models of Care and Self-Management

In response to the acknowledged complexities of managing chronic illness, there has been great attention to improving models of care. While many terms are used in the literature, such as "patient engagement,"[59,60] "person/patient-centered care,"[61,62] and "collaborative or shared-decision making,"[46] most of the interventions aim to better understand patient experiences[37,57] and adapt communication and care to patient needs.[46,55] In a grounded theory study with patients who have heart disease, Barello found that 'full' engagement "features patients who have become co-constructors of their health, capable of enacting meaningful health management."[60(p8)]

Despite this attention to improving the clinical encounter, these models of care have mixed outcomes. In a Canadian study that interviewed 29 patients with chronic pain and/or diabetes, and 34 providers, Lavoie et al found that health care programming, beyond conventional appointments, such as group medical visits, can help facilitate patient-centered outcomes.[61] In tandem with patient-centered care for people with chronic illness, there has been increasing emphasis on the role of self-management. As described earlier, many chronic conditions require monitoring outside of the clinic. This has led to a move to empower patients as active agents in their care.[59,63]

Although these interventions may appear to be helpful strategies, critics argue that they risk simplifying or completely ignoring the role of institutions and structural barriers that shape patients' access to care and the providers' ability to meet patient needs.[51,64–66] For example, Scambler et al (2014)[64] and Hansen et al (2012),[65] who looked at diabetes in the United States, make the case that patient agency is always limited to some extent in the context of medicine, and especially in the clinical encounter, because the care provider retains institutional authority. In interviews with providers conducted by Scambler et al, they found that providers acknowledged that patient empowerment is dependent on "the cultural, social, economic and material resources available to the patient."[64(p550)] As such, empowerment strategies created and implemented by health care as an institution may never be enough to broach the structural barriers patients experience in managing their care.[67] Even when potential solutions do address structural concerns, they have complex implications that can conflict with patient choice and other ethical matters.[68,69]

Stigma

People living with chronic illness often face stigma when interfacing with health care. Most of the literature draws on the work of Erving Goffman, who defines stigma as a negative attribute applied to people who differ from the "norm" and is maintained through interactions with others where their "difference is noted and devalued." [70(p487),71] Stigma is frequently documented in people who live with HIV or other sexually transmitted infections, [70,72,73] or those who live with mental illnesses.[65,74,75] It is also experienced in medical settings by those who occupy marginalized social locations, such as those who are queer[76] and/or racialized.[65,72] When stigma pervades clinical encounters, it has implications for the quality of care received or if patients receive care at all.

Stigma can deter people from seeking help in the first place. For example, in a focus group and interview study on Latino immigrants in the United States living with depression and type 2 diabetes, Hansen et al[65] describe how individuals avoided seeking help so that they could maintain the image of being self-reliant. Stigma can play a role in whether or not individuals follow their treatment plan. Participants in Hansen's study often did not follow treatment plans because they "viewed antidepressants as addictive and harmful and feared taking these medications because they did not want to be labeled as *locos* (crazy)."[65(p9)] Hansen notes how stigma contributes to a negative cycle, where patients avoid care and do not follow their treatment plan, which exacerbates their symptoms, and leads to a decrease in functioning. In some instances, this is recognized and combatted. For example, Cook et al 2012[73] conducted interviews with sexual health clinicians in New Zealand who proactively normalized the experiences of their clients by emphasizing the "epidemiological ordinariness" of their patients' conditions. Although this helped to some extent, Cook notes that the strategies employed did not resonate with patients, as they still experienced stigma in the broader public sphere which had implications for their wellbeing.

In other situations, stigma limits the potential benefits of the clinical encounter, and patients are well aware of this. Patients use performative strategies to downplay the stigmatized aspects of their identity while emphasizing their competence as a 'good patient.'[70,74,77] For example, Crooks[78] interviewed 55 Canadian women with fibromyalgia who described a variety of preparatory practices they undertake before health care appointments, motivated by "desires to take better charge of the illness experience, be more 'in control' of the interaction, and come across as a credible patient."[(p273)] Sacks[77] interviewed 19 American, middle class Black women, and found these strategies were especially prevalent, as the participants reported how they mitigated "stereotyping and dehumanization"[(p65)] through performative strategies such as dressing well and carefully articulating their concerns.

While the role of stigma is recognized in the clinical encounter, the discussion is often limited to specific health conditions. Stigma is also portrayed as if it is a "third party" or elephant in the room, a topic that patients and providers "scoot around"[74(p100)] and not the result of certain structures, policies, and lack of systemic effort to combat stigma. American medical sociologist Kathy Charmaz (2020)[79] has perhaps opened the conversation in this direction, discussing the influence of neoliberal governance in shaping stigma faced by people living with chronic illnesses. Charmaz does so through reflections on fieldwork throughout her career, but more critical attention is needed. None of the studies approach stigma from a critical disability lens, or consider that chronic illness broadly comes with stigma, nor do they speak to the experiences of gender minorities, all of which my project will address.

Considering the Effects of Repeated Clinical Encounters: Gaps in the Literature

In the studies reviewed, very few look specifically at the effects of *repeated* clinical encounters. Still, there are enough indications in the literature to justify that this is an area for further exploration. Given the context of repeated clinical encounters and the potential for epistemic invalidation, it is critical to acknowledge the literature that paves the way forward for understanding how health care, however well-intentioned, can contribute to or exacerbate stressors, and thus, symptom severity. Many patients living with chronic illness may already experience "violence and trauma, poverty, racism, colonization"[69(p1)] in the context of their everyday life, and are subject to vulnerability through institutionalized health care practices.[51]

Some studies document experiences of micro-aggressions - "communications that are brief, commonplace, and contain a hostile message, derogatory meaning, negative slights, invalidation, or insults, directed toward a person belonging to a marginalized group"(p763) among women with invisible or visible disabilities that prevail in encounters with health care providers.[80] Another study explores institutional betrayal in Canadian health care, both within the clinical encounter and in the broader health system.[81] Such work notes how people with chronic illness "frequently use medical services," and as a result, "may be at a greater risk of feeling betrayed by the medical system" which has implications for well-being and future utilization of health care services.[81(p38)] In interviews with people with chronic illnesses in England and Portugal, Bê uses the concept of *impairment effects*[82] such as "pain, fatigue, tiredness or soreness that are actually created or exacerbated by the painful interactions disabled people are required to have with the state, doctors or other institutions"(p14) and notes that this is something "disability studies should also be looking at more carefully."[83(p13)]

This study fills a gap in the literature, as its critical disability studies (CDS) approach works "to centralize bodies that have previously been marginalized by the mainstream disability movement, such as racialized, poor, queer, trans, and sick bodies"[84(p514)], which have also been underrepresented in Canadian health research on chronic illness. Further, it centers lay expertise[67] in the context of health care practices and processes, to illuminate both the micro *and* macro dimensions of navigating health care with chronic illness, with a novel emphasis on the effects of navigating these interactions over a long period of time. Using arts-informed workshops and focus groups enables knowledge to be co-constructed and makes space for collectivity around disability epistemologies, while offering time and space for participants to delve deeper into their experiences and gain rich insights. The awareness of 'the duality of suffering'[28] in this project contributes to deeper understandings of what patient-centered, culturally safe, and collaborative care is, and how women and gender minorities with chronic illness can be better supported.

Methodology

Situating Myself as a Researcher

In line with my feminist epistemological and ontological commitments, I present here an acknowledgment of my positionality as it pertains the research process. While this acknowledgement is only a starting point, I endeavour to reflect, contextualize, and reckon with the implications of my lived experiences throughout the entirety of my thesis. In doing so, I hope to explicate what "reflexivity" in qualitative research looks like in practice while also understanding that writing this thesis in itself is a means of exploring and reflecting on my own role in the research.

My initial interest in this research topic stems from my own experiences, as someone who lives with chronic illnesses and embodies the feminist/queer/crip intersection (see *Theoretical Framework*). In some ways, this gives me "insider status." However, I am wary of generalizing my experiences to the broader population of people living with chronic illnesses. Most notably, this is because of my privileges as a cisgender passing white settler of upper middle-class upbringing, with the financial and social safety net that allows me to obtain higher education and therefore, the space and time to think critically about my experiences. Naming my privileges is not enough to count as reflexivity, and I hope to address the "messiness" of engaging in feminist research and working *with* my biases and social location throughout the reporting and justification of my methodology.

That said, I would never have come to this research question if it were not for my lived experiences: as a queer, non-binary person living with multiple chronic illnesses for eleven years and counting, as someone with contested[85]/yet-to-be-diagnosed illnesses, and someone who has experienced a paradigm shift regarding my relationship to chronic illnesses via my engagement with CDS and the disability justice movement. I would never have come to this research without experiencing an abundance of hardships navigating medical care, without engaging in feminist and disability theory in my undergrad, and thus being motivated to understand and contextualize my personal experiences in the broader political, social, and cultural contexts.

My positionality does not only influence the topic I chose to pursue for my research. It also determines the limits of my methodologies. As in, the questions I am able to formulate, or even imagine, the theory within my grasp, the materials I chose for the art workshop, how I might understand and interpret, or perhaps more importantly, misunderstand or misinterpret participants experiences and so forth. I have made a conscious effort to question how my experiences might be mediating the research decisions I've made and account for these processes throughout my thesis.

Theoretical Framework

Critical Disability Studies (CDS)

Critical disability studies, as an interdisciplinary field, started gaining traction in the late 1980s, largely operationalizing around rights-based issues such as equality and inclusion for people living with disabilities.[86] The aim was to provide a counter-narrative to conventional framings of disability, especially in medicine and education, which understood disability as a "problem" in need of intervention and disability studies as merely the study of disabled people.[86] Critical disability studies takes social justice as a core tenet, and as an epistemology, foregrounds the lived experiences of disabled people as the basis from which to theorize. Ontologically, critical disability studies centers on the idea that disability is a cultural and political category that welcomes and embraces embodied difference as inherently valuable. While earlier disability studies often used physical disability as its reference point, the field has shifted and expanded in recent years to incorporate experiences of mental and chronic illness. So too, given its critical orientation, has it expanded from the taken-for-granted white cis-male subject to generate analyses along the lines of gender, race, sexuality, class and other social categories.

The interdisciplinary nature of the field means there are various branches of critical disability studies, such as feminist disability studies, Black feminist disability studies, postcolonial disability studies, Mad studies and so forth – more than I can do justice to here. That said, I locate my own work in the field within recent efforts to make space for politicized understandings of illness. My epistemological and ontological approach is grounded in the political/relational model of disability put forward by Alison Kafer (2013).[87] Through this model, Kafer outlines a critical disability studies that is feminist, queer, and crip. Feminist here, relates to the "activist commitment of blending theory with practice"(p15) while queer theory invites contestation, dissent, and debate.(p16) Crip theory spirals in and through this framework, understood as an unapologetic politics of reclamation that challenges "everyday understandings of bodies and minds."(p15)

This approach recognizes disability as a contested, expansive category, partly in response to disability activism's earlier history of rejecting medicalization and locating disability in the social environment (social model) rather than in one's embodiment (and, as Kafer notes, rightly so).[88] Still, a feminist/queer/crip approach recognizes that our understanding of disability need not be limited in this way. Claiming a critical 'crip' approach accounts not only for those who experience disability as a primarily social experience, but also "those who *do* 'have' illnesses or impairments, and *who might be recognized by others as disabled but who do not recognize it for themselves*."[87](pp13-14) My project then, continues this conversation by acknowledging the entanglements of politics, materiality, and discourse as they pertain to and shape the experience of living in a body that deviates from the 'healthy', (white, straight, upper-middle class, cisgender, endosex, male) able-bodied norm.

Arts-Informed Research

As noted by Tarr et al 2018, most of the literature on chronic illness reflects a 'heavy reliance' on interviews.[89] Interviews have a few recognized limitations, including that: the researcher sets the agenda through pre-determined questions; some experiences are difficult to represent verbally; and that the power dynamics between researcher and participant will affect the kind of answers participants give.[90] The limits of interviews are more prevalent in certain contexts, such as with people who have difficulty communicating verbally, and when working with marginalized communities where there is a significant power imbalance.[90] Further, recent advances in psychological research conceptualize memory as an emplaced, embodied, relational and sensory-imbued phenomenon.[91] Talk-based interviews, especially in settings divorced from the context of where the relevant experience occurred, may not be enough to recall memories in a meaningful way. I use arts-informed methods in this project as a means of addressing the limitations of interviews and generating in-depth perspectives on chronic illness. Art is increasingly recognized as a valuable method in health research, especially regarding chronic illness, as it allows for "richer exploration of illness journeys."[92] Researchers and participants in arts-informed projects have noted how art helps address the *inexpressibility of illness experiences* through its embodied nature, allowing the communication of experiences that might otherwise remain unvoiced.[89,93] Art not only elicits 'rich' information but supports the aims of participatory research. For example, arts-informed Project Re•Vision focuses on "digital stories as research creation/knowledge mobilization methods; and art as activism"(p.514) and recognizes the potential of "personal and collective transformation"[84](p521) when art and community are brought together. Art then, offers an innovative path for meaningfully engaging patients in research and developing new insights on chronic illness and patienthood.

(Regimes of) Patienthood

"Who gets to be a patient?"

My study explores experiences of navigating health care as a necessary aspect of living with chronic illness. Here, I find the concept of *regimes of patienthood* useful. This concept's intersectional nature and commitment to "engaging in a form of theorizing that builds on rather than dismisses previous theories"[94](p187) fits with the political aims of critical disability studies, while paying particular attention to both the macro and micro level experiences of living with chronic illness.

Although the word 'patient' has been critiqued for its paternalistic connotations,[95] this conceptual approach re-orients the conversation by coupling it with 'hood' to reveal the way 'patient' is socially constructed, experienced, and performed on an individual level.[94] The analytical focus on regimes connects patienthood to "larger social systems of power and resistance" and situates 'the patient' within their broader social, historical, and cultural context.[94](p186)

Regimes of patienthood is a theoretical concept that revisits Parson's sick role while merging two prior concepts – patienthood and regimes of practice. Although there is contentious debate on the value of Parson's insights in medical sociology today,[96] the consensus is that

Parson's sick role is not applicable to the contemporary challenges of the clinical relationship.[97–99] For example, scholars argue that there is not a singular sick role, but a *multiplicity* of practices that make up patienthood.[100] Other shortcomings include its over-reliance on social construction[100] and conformity to social roles. Regimes of patienthood aims to remedy this by attending to gender, sexuality, race, class and so forth, as they pertain to sickness, and considering the ways patients resist and subvert the expectations placed upon them.

As Joyce et al. explain, employing *regimes of patienthood* as a theoretical framework "ensures that the emphasis on the varied cultural construction of self (patienthood) and the focus on power and structure (regimes of practice) are integrated and foregrounded."[94(p187)] Further, "an intersectional approach makes visible the multiple dimensions of power, technoscientific practices, and structure in illness experiences."[94(p187)]

I envision these two approaches in tandem, conceptualizing regimes of patienthood as one way of putting the political/relational model of disability to work. While a feminist/queer/crip orientation reflects my subjectivity, political commitments, and researcher sensibilities, regimes of patienthood contextualizes this particular research inquiry and allows me to catch the granular details. Largely, my research question comes from my engagement with critical disability studies, and its feminist influences, which gave me the tools to theorize from my own lived experience and understand lived experience as inherently valuable and important knowledge.

Critical disability studies emboldens me to ask big questions, to be reflexive, to practice resistance to hegemony and to honour the epistemologies that come from living in non-normative bodies. It connects these lived experiences to broader social phenomena and relationships of power. Regimes of patienthood then, takes up the question of chronic illness in disability studies, and through my data collection and analysis, will shed light on the *how* of these relationships of power – how they are experienced, enacted, navigated, and resisted or subverted. With the integration of these theoretical frameworks, I hope to continue the coalitional work of critical disability studies in understanding the way both people with disabilities and people with chronic illness, and in this case, people of gender minorities, experience medicalization in bodies beyond the norm.

Research Design & Process

In this section, I first briefly describe my methods. Then, I chronologically outline the research process, starting from ethics approval, to demonstrate the “behind-the-scenes” processes that led me to use the methods I did. My methodology is further described and justified in each of the manuscripts as well.

As noted, I employed a qualitative, arts-informed, and patient-oriented approach in my research design. I engaged a research advisory board of people living with chronic illness to help make some of the key research decisions and ensure the research project would be sensitive to the lived experiences of participants. Ten participants were recruited via social media and local community organization email lists to participate in a workshop and focus group discussion. I held three workshops total in November 2021 with 2-4 participants in each workshop. The workshops took place online via Microsoft Teams. Each workshop started with a brief presentation on the research aims and guiding concepts, before jumping into a multi-media collage tutorial where participants created “Portraits of Patienthood.” Following the art activity, participants were invited to share their artwork with the group and discuss what they were trying to portray with their collages. Following this, we engaged in a focus group discussion about their health care experiences more generally. Data analysis was completed in two phases. The first phase sought to explore the concept of “medical invalidation” (explained further in manuscript 1) via focus group transcripts with the aim of writing a manuscript that would educate physicians about the topic and its impact on patients. The second phase focused on reading the art through a critical disability studies lens to develop a better theoretical understanding of patienthood. The results are presented via two separate manuscripts.

Ethical Considerations

This project received ethics approval by the Bannatyne Health Research Ethics Board, University of Manitoba (HS24998 (H2021:234). While there were no physical risks to participants in this study, there were important ethical considerations. People living with chronic illnesses, as this study shows, often have negative experiences in health care or otherwise potentially traumatic experiences living with chronic illnesses.[81] As such, I took great care to try and ensure participants would feel safe and supported throughout the research process. It was important I recognized that safety can never be guaranteed,[101] but still I endeavoured to be as thoughtful as possible in designing the research process. Firstly, this meant engaging a research advisory board as described below to ensure the project was sensitive to the varying lived experiences participants might carry with them. Secondly, I worked to bring a trauma-informed lens to the project. A trauma-informed approach recognizes the pervasiveness of trauma in society, and actively promotes collaboration, empowerment, and feelings of safety to reduce harm.[102] To do so, I attended a webinar on trauma-informed patient engagement, consulted with my advisory board and reviewed literature on the subject. In particular, I turned to scholarly conversations in critical disability studies on trauma and the classroom to guide my process.

The ethics board recommended I have a trained mental health practitioner available due to the potential for my research study to be upsetting for some participants. I was wary about this approach, as many people living with chronic illnesses have experienced harm at the hands of psychologists, psychiatrists, and other mental health professionals. In particular, my study sought to recruit people from marginalized groups, who are even more likely to face harm via the normative perspectives of trained health professionals. I did, however, recognize that my own trauma awareness was not sufficient to support someone experiencing a crisis. In addition to providing a standard list of mental health resources, I consulted with the local queer community to find someone trained in trauma and crisis support with lived experience of chronic illness in hopes of minimizing harm. I was able to find a community health worker with five years experience working in mental health with primarily chronically ill clients who self-identified as queer and lived with chronic illness themselves. They received a $115 honorarium and introduced themselves at the start of each workshop, left their cell phone number, then signed off and remained available through the workshop and two hours afterward if anyone required additional support.

Participants received the consent form at least one week ahead of the workshops, although there was one participant who joined the study last minute and received only a few days to review the consent form. Further, I took time at the beginning of each workshop to review the consent form, highlight parts especially relevant to data collection, and give participants time to ask questions or for further clarification. Data was collected during the second half of the workshop, via the built-in recording feature of Microsoft Teams. Microsoft Teams records video and audio, which I let participants know, and saves recordings to the University of Manitoba server. After completing the first workshop, I found out that Microsoft Teams also generates a transcript. After review, I decided not to use these transcripts as they were not accurate, and instead sent my audio recordings to be professionally and confidentially transcribed by the company Transcript Heroes. I deleted the Teams meeting recording once I had completed the audio editing (approximately two weeks after the workshop). Once I received my professional transcripts and reviewed them, I deleted the auto-generated transcripts.

Research Advisory Board

To ground this project in participatory and patient-oriented principles, I recruited a research advisory board. The advisory board was recruited through my personal and professional Instagram. To manage the selection process, I posed a few questions to all interested individuals in order to assemble an advisory board that reflected diverse social locations and perspectives. Interested individuals were asked to disclose where in Canada they lived, if they had a diagnosis for their chronic illness (this question was asked to facilitate the inclusion of people without a diagnosis) - with no requirement to share what their diagnosis was, their gender identity, and if they identified as Black, Indigenous or a person of colour. Thirty-three individuals responded. In the end I selected three participants as this was what my budget allowed for with $125 honorariums each – following regional guidelines on compensation for patient partners. The group of interested parties was fairly homogeneous in terms of gender and ethnicity, so it was not difficult to select three individuals with different answers to the screening questions. Although I hoped to have representatives from Manitoba, in the end this felt less relevant because the main purpose of the advisory board was to help formulate a trauma-informed approach to the workshop which did not require familiarity with Manitoba health care systems - only familiarity with living with chronic illness and intersecting forms of oppression.

The advisory board met three times. The first meeting was a general introduction to the project and each other and outlined the scope of the work. The second meeting focused on recruitment strategies and brainstorming the workshop activity and how to facilitate it in a way that would be inclusive and supportive for all participants. Then, the workshop outline was collaboratively refined over email and Google Docs. The third and final meeting was used to confirm the workshop design and sort out any outstanding decisions. After the workshops, the preliminary findings and participant artwork were shared with the board via email to get their input on what findings would be important to emphasize in my publications and what they interpreted from the artwork.

Recruitment and Participants

I aimed to recruit twelve participants for the workshops, with a minimum of ten to run the workshops. Eligibility requirements were that participants were 18-35 years of age (broadened from my original goal of 21-30 years old), self-identified as having a chronic illness, self-identified as a woman or gender minority and having received health care in Manitoba. While thirteen participants were initially recruited for this project, only ten ended up participating. Two of the three who did not end up participating were removed from the study due to a lack of response before the workshop dates. The third unfortunately was unable to participate due to a health emergency.

Participants were recruited via online methods. I posted recruitment graphics to my personal and professional Instagram, Twitter, and Facebook accounts. I also posted a Kijiji ad with the same information. Relevant local organizations and patient advocacy groups (both formal and informal) were contacted and received details on the study to share via social media or distribute in their email lists. The organizations included: Rainbow Resource Centre Winnipeg, Epilepsy Manitoba, Celiac Manitoba, ArtsAccessibility Network Manitoba, Artbeat Studio, Canadian Mental Health Association – Manitoba, Multiple Sclerosis Manitoba, Diabetes Canada – Manitoba, Rheumatoid Arthritis – Manitoba, Mood Disorders of Manitoba, Myalgic Encephalitis/Chronic Fatigue Syndrome Manitoba, Fibromyalgia Winnipeg, and TransManitoba. I was not able to confirm if all of the contacted organizations did indeed circulate the materials to their email lists. In some instances, I shared the study details with professional contacts who I thought might be able to support. Finally, I had recruitment support from the Manitoba Primary and Integrated Health care Innovation Network who funded this project, and I presented to government workers at the September 2021 meeting of the Provincial Engagement Community of Practice who offered to circulate my recruitment materials to those they thought might be interested and eligible.

I gave considerable thought to the language and layout of my recruitment materials. As a result, my recruitment materials underwent a few revisions upon feedback from the Rainbow

Resource Centre about the language of “gender minorities” and as I reflected on how to better represent the social justice commitments of my work.

The recruitment materials listed an email and phone number indicating they could text or call the number to promote a variety of contact methods and make it easy and convenient for interested individuals to get more information. Upon contact, I confirmed that they met the above eligibility requirements, and then requested their email to send further details on the study. Upon confirming their interest, participants received a demographic questionnaire. The questionnaire had dual purposes: to help select participants with varied lived experiences, and to collect demographic information to contextualize the data and report in publications.

Once participants had returned the demographic questionnaire and I had confirmed they were accepted into the study, I asked their preferred workshop date, any accommodations they might need, and the address they would like their workshop supplies delivered to. All of the collected information was de-identified and stored in a password protected file on a password protected computer. Any participants who withdrew or were withdrawn had their details deleted immediately.

Participant Demographics

To summarize the demographics of the participants (see also: Table 1 in Manuscript 1), eight participants identified as women, and two identified as non-binary. All participants were born in Canada but had a range of (self-reported) ethnicities, including Guatamalen/White (1 person), Filipina (1 person), and Indigenous (1 person) and white/European (6 participants) while one participant chose not to answer this question. All but one participant lived in an urban region (Winnipeg, MB). In response to how often they struggled to make ends meet, four participants indicated “never/rarely”, while three responded with “sometimes”, two responded “often/always” and one declined to answer. Most participants lived with three or more chronic illnesses (7 participants) while the remainder had two. Additionally, seven participants reported having a diagnosis for their illnesses while three indicated that one of their illnesses was diagnosed but others were not yet. The demographic questionnaire asked if participants had one of the five major chronic diseases to select for representation beyond this category, and asked participants to list their diagnoses if comfortable. All but two participants indicated they had a mood or anxiety disorder and COPD/asthma were also represented out of the major chronic diseases. There was a broad representation of diagnoses, including but not limited to the following: mast cell activation syndrome, chronic migraine, chronic daily headache, fibromyalgia, depression, lupus, arthritis, mixed tissue connective disorder and associated co-morbidities of these conditions. Finally, all participants reported having lived with chronic illnesses for five or more years.

Data Collection

Data collection consisted of three participatory, arts-based workshops. The combination of art and discussion served as means of triangulating the data.[103] Each workshop took place on Microsoft Teams and had two to four participants, and participants noted appreciation for the small group size. The workshops lasted about four hours total with breaks throughout. Each workshop started with brief introductions, a review of the consent form, guidelines for engagement and then time for questions before diving into the art activity, and then a group discussion to follow. Because I chose a participatory approach for the workshop and discussion in that I did not have a focus group guide, I presented briefly on my motivations and conceptual orientation to the project to have an anchor point for our discussion. Participants received art supplies and a participant information kit several days in advance of the workshop. The art activity started with a brief introduction, including to the medium of mixed media collage, the activity theme: *Portraits of Patienthood*, examples of multi-media collage portraits, and the following prompt: What does being a patient mean to you? What is your experience of patienthood? Then, I listed several questions (which were included in the participant information kit) to use to guide their artistic process (see Appendix B). The time dedicated to the art activity varied – I checked in with participants at the one-hour mark and allotted more time as needed.

Once the time was up, participants were invited to share their work with the group if comfortable. It was at this point that I started recording the session. All participants elected to do so, and our discussion started with each participant walking the rest of their group through the collage/artwork they made, and how it related to or represented their experiences of patienthood. I participated in the studio time in the first session to create an example collage, and then started each discussion with my own art to model the art discussion and make participants feel as thought they weren’t the only ones having to share. Following the presentation of the artwork, I invited participants to share any thoughts, reactions, or reflections they had upon viewing all of the work. While I did have questions prepared to prompt discussion, I aimed to stay mostly in the background to allow participants to guide the flow of the conversation. My interjections were mostly to ensure everyone was receiving an opportunity to add to the conversation. Although quite difficult through an online platform, I tried to gauge energy levels and emotional states and offer breaks throughout. I was pleasantly surprised by the comfort everyone displayed in talking in a group setting, and the free-flowing nature of the conversations. I rarely had to prompt for more information or pose a question for the group.

While each workshop touched on many different topics as per the issues participants wished to voice, early on I could see similarities arising in each discussion. The artwork was particularly generative for eliciting conversation, and participants were enthusiastic about the opportunity to make art and share it with each other. Despite the array of collage and other art supplies made available, as participants noted, there were certain images, objects and accompanying themes that came up again and again – pointing to some sort of universality in the patient experience, or at least, a shared resonance with the collage images provided.

Data Analysis

After familiarizing myself with the data, I had a general idea of the two manuscripts I wanted to write. I coded transcripts using Braun and Clarke's reflexive thematic analysis, centered on the question "What story do I want to tell with the data?."[104,105] I engaged in intensive memo-ing as means of being critically reflexive about my data and how I would represent it.

I coded first for the manuscript on medical invalidation, with a kind of deductive approach centered in Susan Wendell's concept of epistemic invalidation.[18] Already having a journal in mind, with a short word length, focused the coding process. I knew the objective of my paper – to illustrate what epistemic invalidation is, its implications, and recommendations from the participants on how clinicians can better their communication with chronically ill patients, and the audience (primarily physicians), and coded with this in mind, while still trying to keep my approach open enough that I coded all relevant material, even if I didn't think it would be published. This allowed me to have enough data coded that I could sharpen my themes and better identify patterns and subthemes. In writing up the data, I decided to use the term "medical invalidation" instead of epistemic invalidation, for the sake of brevity given the intended audience. I also knew there had been a recent burst of interest and scholarship on the similar concept of “epistemic injustice”, and so I reviewed the data with this work in mind as well, taking up Carel & Kidd’s[106] call to identify how stereotypes affect the healthcare experiences of people living with chronic illnesses. I did end up coding the stereotypes and other sociocultural factors participants identified in the discussion and worked these in where possible to both manuscripts.

I coded the second paper with a more open, inductive approach. My focus for this paper was on the artwork specifically, to address the main research question of how patienthood is experienced and how it can be conceptualized through critical disability studies. I returned to the transcripts when necessary to contextualize the artwork and the participants’ intentions to ensure the accuracy of my interpretation. I do not go into further detail on my data analysis here, as it is outlined in the second manuscript.

Knowledge Translation

I used an integrated knowledge translation approach, meaning that the research process was designed to facilitate knowledge-sharing throughout, such as between myself and the advisory board, and between participants in the workshops. At the time of writing, I have presented my research to first year medical students and the Canadian Association for Health Humanities’ annual conference. and will be presenting at the Canadian Sociological Association conference. As mentioned, I have prepared two manuscripts, each aimed at a different audience (physicians and health humanities scholars respectively). Finally, I am working to develop a zine that summarizes the results of the research in an engaging way and can be disseminated with the support of public facing arts and/or health organizations.

Results

The primary findings of the research are presented through two manuscripts that I am preparing for publication. The first is written for a medical audience and focuses on the concept of medical invalidation. I intend it to be a pragmatic introduction to medical invalidation, that emphasizes the importance of this issue by explaining the consequences of medical invalidation on participants' wellbeing. I close the article with a few recommendations from participants on how to avoid medical invalidation in the clinical encounter. The second manuscript is theoretical in nature and aims to develop an account of patienthood through critical disability studies scholarship. This article is intended for a health humanities audience and takes up the participant artwork as the primary data for analysis. In publishing this manuscript, I hope to forge connections between disciplines (medical sociology, health humanities, critical disability studies) while providing an in-depth examination of experiences of patienthood. However, health humanities is gaining traction in medical education and practice, and as such, it may also be relevant for more applied purposes regarding patient care for people living with chronic illnesses.

Manuscript 1

To be submitted to *Canadian Medical Association Journal*

Medical Invalidation in the Clinical Encounter: A Qualitative Study of the Healthcare Experiences of Women and Non-binary People Living with Chronic Illness.

Authors: Jennifer Sebring, Christine Kelly, Deborah McPhail, Roberta Woodgate

Abstract:

Background: People living with chronic illnesses rely on a good working relationship with their physicians to manage their health. Yet, this population is often dissatisfied with their care – citing that they don't feel "heard" or that their concerns are taken seriously by their physicians. We use the term medical invalidation to label these experiences. Our study sought to answer the following question: How is medical invalidation experienced and what is its impact on patients living with chronic illnesses?

Methods: This was a qualitative study. Eligibility requirements included self-identifying as having a chronic illness; self-identifying as a woman or non-binary person receiving health care in Manitoba; and being between the ages of 20 and 35. Ten participants took part in online arts-based workshops and subsequent focus group discussion.

Results: Medical invalidation was experienced by all of participants at different points in their illness journeys and took a variety of forms. We identified several consequences of medical invalidation including: downplaying symptoms or pushing themselves past their limits; avoiding care; and worsening health and wellbeing. We also present recommendations for physicians provided by participants to avoid medical invalidation.

Interpretation: Medical invalidation has the potential to exacerbate patient symptoms and steps must be taken to prevent it from happening. Employing the principles of person-centered care, such as empathy and considering the whole person, may help avoid medical invalidation. We suggest that this may not be enough, and physicians must critically reflect on their assumptions and biases to ensure they are not unintentionally invalidating patient experiences.

Introduction

People living with chronic illnesses frequently interact with physicians to monitor their conditions and manage their health. In this article, we define chronic illnesses as health conditions with no known cure that "last a year or more and require ongoing medical attention and/or limit activities of daily living."[1] We use the term chronic illness instead of chronic health condition, chronic disease, or long-term health condition, as it is preferred and more commonly used by people living with these conditions.[83]

A good working relationship between patients and their physicians is a foundational aspect of care quality.[14,38] The move toward person-centered models of care emphasizes the importance of health care interactions between physicians and patients.[62,107] Yet, people living with chronic illnesses, particularly those from groups who face societal marginalization, often report being dissatisfied with their health care encounters.[17,28,108]

Patient expressions of dissatisfaction and negative health care encounters – especially for those living with chronic illnesses – can have far-reaching implications. Sloan et al 2020 found that negative health care encounters can lead to diminished self-confidence, distrust in the medical profession, and may deter people with chronic illnesses from seeking care when they need it.[5] Tamain et al 2017 find the increased reliance on health care mean that patients with chronic illnesses may be more likely to experience negative health care encounters, and for the same reason, the ramifications of these experiences may be amplified.[81] Björkman et al 2016 refer to this as the 'duality of suffering' where "health care encounters risk adding to rather than alleviating the burden of illness."[28]

There are numerous explanations for negative health care encounters and patient dissatisfaction. Most frequently, such encounters are attributed to communication breakdowns, in that patients and physicians' hold discordant views and priorities;[16,40,46] physicians may use overly technical language;[36] and patients feel as though they aren't being "heard" or taken seriously.[41,42] The latter issue is termed "medical invalidation."[109] We take up medical invalidation in this study, broadly defined as the act of dismissing, minimizing, or otherwise not taking patient concerns seriously. Medical invalidation is of particular concern to the general chronically ill population, for reasons mentioned above, and also for those from groups that have been marginalized and may face unintended prejudice in the clinical encounter.[110]

Given the increased attention to patient-physician dynamics in the context of chronic illness,[14,111–113] our study sought to answer the following question: How is medical invalidation experienced and what is its impact on patients living with chronic illnesses? To that end, we present illustrative examples of medical invalidation as expressed by participants in our qualitative study, the consequences of experiencing medical invalidation, and recommendations for avoiding medical invalidation in the clinical setting.

Methods

We used a qualitative, arts-informed participatory approach[89,114] informed by feminist disability theory, meaning that patient perspectives are foregrounded in the study design and analysis.[18,87] Qualitative methods are helpful for illustrating how a phenomenon is experienced,[115] while arts-informed methods elicit rich discussion that may not be accessible with talk-based methods alone.[92] Due to the COVID-19 pandemic, this study took place virtually over Microsoft Teams, although all participants were residents of Manitoba, Canada and received health care in Manitoba.

Participant eligibility included self-identifying as having a chronic illness; self-identifying as a woman or non-binary person receiving health care in Manitoba; and being between the ages of 20 and 35. Participants were recruited via posts on the lead author's professional social media accounts (Instagram, Facebook, Twitter), the provincial patient-oriented research unit, and the email lists and social media of relevant community organizations (e.g., disease-specific advocacy groups). Participants were then invited to fill out a demographic questionnaire to ensure our sample represented a diversity of experiences (maximum variation sampling).[116]

Participants participated in one of three virtual workshops with two to three other participants, where they were asked to create a visual collage representing their experiences of patienthood.[94] Participants were given an informational booklet ahead of the workshop that framed the study and provided a prompt (*What does being a patient mean to you? What is your experience of patienthood*?) and list of questions to structure their artistic process (e.g., what are some of the pivotal experiences you've had as a patient?). The full list of questions are available in Appendix B. Each participant used their art as the starting point for a broader group discussion. Due to the participatory nature of the research, the discussion was largely unstructured, and the author interjected only to ask for clarification, ensure everyone had a chance to contribute, and to keep the conversation on topic.

The discussion was audio-recorded and subsequently transcribed using a third-party professional transcription company. Data analysis was completed by JS in consultation with CK using Dedoose qualitative analysis software. Braun and Clarke's reflexive thematic analysis was used to code the data, involving a combination of inductive and deductive coding[104,105] informed by the concept of medical invalidation.

The study received ethical approval from the University of Manitoba's Bannatyne Human Research Ethics Board (#HS24998 (H2021:234)).

Results

Eight women and two non-binary individuals participated in the study. Notably, all had more than one chronic illness, including mental health conditions, and had lived with their conditions for five or more years. Further demographic information is available in Table 1.

Table 1: Participant Demographics

Variable	**Number of Participants (n=10)**
Gender	
Woman	8
Non-binary	2
Self-identified ethnicity	
White/European	6
Indigenous	1
Filipina	1
Multiple ethnicities	2
Born in Canada	
Yes	10
No	0
Geographic Location	
Urban	9
Rural	1
Socioeconomic Status*	**Measured by asking "How often do you struggle to make ends meet?"*
Never/rarely	4
Sometimes	3
Often/always	2
Number of Diagnoses	
2	1
3 or more	9

Co-occurring Mood or Anxiety Disorder	
Yes	8
No	2
Years Living with Chronic Illness	
5 or more	10

Theme 1: Experiences of Medical Invalidation

Participants described a number of examples of “medical invalidation.” That is, examples where physicians did not take patient concerns seriously, downplayed or dismissed their concerns, showed casual disregard for their well-being, refused to provide adequate care, would not investigate patient complaints, or refused to refer them to specialists.

Medical invalidation most often occurred during the diagnostic process, however participants also experienced invalidation during follow-up appointments about already established concerns or in regard to new symptoms or seeking better treatment options. Participants expressed that physicians implied their concerns were “all in their head” and described the recurring scenario “where doctors don't believe you and tell you you're crazy and you're like, well I just have this thing that's going on and it's clearly not made up” (P2).

Other situations involved the dismissal of patient concerns based on their social demographics, such as being young, having a rare or poorly understood condition, co-occurring diagnoses of mental health conditions, or being stereotyped for an aspect of their appearance such as their weight, use of mobility aids, or their perceived race (see table 2, quotes 1-5).

The participants described situations in which physicians displayed a casual disregard for their well-being, as is the case of one participant who visited the doctor to try and get help for a severe skin condition. In response, her physician said, “yeah, I don't know, if you survive the summer I'll see you in October’” (P2). Another participant described a similar situation where “doctors have thrown in the towel at me like, ‘well this is your life now’” (P9). The participant attributed this to the fact that her illness was uncommon in young people such as herself.

In contrast, one participant expressed that they had not experienced medical invalidation when seeking treatment for their physical illnesses, explaining that they felt it was because their diagnoses were well-recognized (lupus and rheumatoid arthritis), at times visible (swollen joints) and there was a specific test for diagnosis. Yet, this participant did express that they had experienced invalidation when seeking mental health support.

Theme 2: Consequences of Medical Invalidation

The experiences of medical invalidation were not bound to the clinical encounter. The participants reported lasting implications that affected their personal and emotional well-being, their willingness to seek care, and contributed to worsening health.

As a result of having their experiences minimized by physicians, and others in positions of authority, participants often tested their physical limitations. They expressed scenarios where they internalized medical invalidation, and questioned how sick they really were, and pushed themselves to go beyond their usual limits, which ended up setting them back and sometimes invoking a flare.

The "invisible" nature of some of their illnesses brought certain challenges, in that it was difficult for others to understand participants' experiences, and they felt a certain pressure to act as if nothing was wrong: "They use this term, invisible illness, because it doesn't show up on the scans. It doesn't show up on the blood tests. So it's invisible. And I think them telling me that, almost made me feel that I needed to act that way. I needed to act like it was invisible – because I look fine – so they criticize you for being tired and worn out" (P3).

The internalization of medical invalidation, in combination with broader societal stigma around chronic illness, limited access to support systems – such as asking for help from family and friends. Participants noted that they often felt guilty, like a burden, and overcompensated for these negative repercussions by being hyper-independent, which again, meant pushing themselves past their physical limits.

For example, one participant noted that: "I'm constantly testing myself like, "Am I really that sore? Does my back hurt really that much? Like am I making this, could I go back to work?" And I'm constantly like well I'll just try this and then see, and then the next day I'm suffering and I'm like, "OK yeah, no, still sick." But I've got to that point because so many people have doubted me in the past, had they not my experience would be different" (P9).

The repeated experience of invalidation meant that participants were hesitant to seek medical care, even when they needed it. They cited earlier experiences of invalidation as the reason behind avoiding care. Many expressed a kind of hopelessness, that even if they did seek care, it was unlikely they would get the care they needed, and so, they avoided it altogether: "When I have in the past and when I was young and impressionable sought out care, I just didn't get it. So now I have some more like self-diagnosis, but I just haven't got an official diagnosis yet. I'm sure at some point I'll have to but I'm just super hesitant to go to the doctor ever" (P8).

As a result of this barrier to care, participants opted to self-manage their symptoms via online research or discussions with family and friends who live with chronic illnesses, and sometimes utilized self-diagnosis. Through these strategies they managed to "get what they needed" and cope until they worked up the nerve to seek care.

Medical invalidation had behavioural consequences, but it also at times meant that participants did not receive the care they needed, leading to health consequences. For example, participant 11 described asking for their physician to look into their thyroid, for four years – to no avail. They described their thyroid as "destroyed" as a result (table 2, quote 15).

Medical invalidation had consequences for their emotional and psychological health. Participants emphasized the need for choice and feeling in control of their health as a means of supporting their overall wellbeing. Participants stressed the clinical encounter as a pivotal moment in their illness journeys – driving home the damaging consequences of experiencing medical invalidation. Due to their experiences of medical invalidation, some explained that attending medical appointments caused great anxiety, which meant they were unable to articulate their concerns in a way that would help them get the care they needed.

Table 2: Participant Quotes to Support Findings from Theme 1 & 2

Theme 1: Examples of Medical Invalidation	
Dismissal of patient concerns based on their social demographics, such as being young in age, having a rare or poorly understood condition, or co-occurring diagnoses of mental health	1. "I'm only 20, so I'm very young. And I have the clear brain scan and so a lot of the times it's, "You're so young." And I was an athlete at time, so it's, "You're young. You're athletic. Go have some Advil. You're being a teenager." And now – even now – I'm, "Look. I'm 20 years old and I'm living every single day of my life in pain. And instead of you helping me because I have this long future, I've just learned to get over it in a sense and find my own ways to cope, because the medicine you're giving me isn't helping." And it's very much

conditions or their appearance	that, “Well, you’re young and healthy.” And it’s like, “I’m really not.” And with me being so young, it’s hard to see the healthcare system. And they refer me to new doctors and you wait so long to see this doctor. And then you get told you’re young, and healthy.” P3 2. “In my experience, if it’s anything mental health wise – if you have some kind of mental health issue, most notably anxiety or depression, or even mood disorders – especially if it’s a mood disorder actually – everything you say is filtered through this lens – through the doctor that you probably don’t know what you’re really talking about, at least if your health is concerned. Me, it’s hard for doctors to listen, because I have general – I have health anxiety – for good reason.” P11 3. “I don't really tell my doctors much because when I do then he just tells me that I'm just lying to get attention, that it's too much for him, he's totally told me just stop talking […] Because the first time I saw him he told me, I won't help you until you lose weight. And that was very difficult as I also had struggled with an eating disorder.” P4 4. “I’ll never forget walking into a doctor’s office and I had my aid with me – I was using my cane. And I had someone with me, my daughter. And I was going in because I needed antibiotics for bronchitis. I knew I had bronchitis. Anyways, I walked in with my mobility aid. This doctor had never seen me before. Before she even said, “Hi,” before she said, “Hi, I’m Dr. – anything, anything – she looked at me up and down and she went, “I hope you know we don’t – we don’t do opiate prescriptions here.” P11 5. “I have scoliosis and I’ve been diagnosed with chronic pain too and my doctor said, “Well it’s really not that bad because chronic pain is just all in your head.” And yeah, I was just like kind of flabbergasted because she doesn’t

	understand what it’s like to be in my body and feel pain every second.” P7
Disregard for well-being	6. “The first time I ever approached a doctor about my depression – it was a walk-in clinic so to be fair that's really not a walk-in doctor is meant to do, I went in and finally talked myself up to admitting out loud I think I'm depressed and also I'm suicidal, like I feel like I want to not be here anymore kind of thing. And I remember the doctor – audibly laughed and said, that's not something we deal with at walk-in. Like you'll have to – if you want to be a patient of mine you'll have to go through the same process everyone else does. I'll send you a form and you can come back for an interview and we can go from there. But she never sent me a form, she never called me to make sure I was alive. She never gave me crisis resources. She never did anything – she literally – yeah, literally out loud, I'll always remember, like she laughed at me and was like, that's not what we deal with in walk-in, which might be true. Like maybe there's not enough time or the resources to deal with depression, all that kind of stuff in a walk-in clinic but to her knowledge, like, I never went back to her since, for all she knows I could be not around anymore. And I never got so much as a phone call, a single resource, like that kind of thing. It's like, that was a wild experience.” P6
Theme 2: Consequences of Medical Invalidation	
Downplaying symptoms and pushing themselves past their limits	7. “I’m constantly testing myself like, “Am I really that sore? Does my back hurt really that much? Like am I making this, could I go back to work?”And I’m constantly like well I’ll just try this and then see, and then the next day I’m suffering and I’m like, “OK yeah, no still sick.” But I’ve got to that point because so many people have doubted me in the past, had they not my experience would be different.” P9 8. “I think that perhaps for some people – and especially marginalized people – that just like

	there’s still the stigma that we don’t experience as much pain and so we don’t need as many pain killers…I still like downplay how much in pain I am a lot. I like check with people around me to see like, ‘Oh, is it OK if sit down instead of stand for this conversation?’” P8 9. “I have also imposter syndrome. When you start to feel like – I know that sometimes on my better days I’ll start to be, “Are you really even that sick? What are you doing? No. You could be doing this and that. And then sometimes I’ll get really excited and I’m, “Oh yes. Maybe I’ll be better forever.” And then the next day hits and a flare happens and you’re just – you can barely get out of bed. And you’re, ‘Why did I even think that?’” P11 10. “They use this term, invisible illness, because it doesn’t show up on the scans. It doesn’t show up on the blood tests. So it's invisible. And I think them telling me that, almost made me feel that I needed to act that way. I needed to act like it was invisible – because I look fine – so they criticize you for being tired and worn out. It’s almost like you have to hide that to keep up this persona – that you are fine and you are OK – and that when you are alone and behind closed doors, I think that’s why I put the window on my collage. It’s when you’re alone you have the curtains drawn, that’s when it’s OK to kind of let it out. But as soon as you’re out in the world, it’s presenting this persona and it’s keeping that face – that no-one can see it. And it’s almost like that no-one can see it, so it must not really be there, type of idea.” P3 11. “I’m always super hyper independent. And even when I know I am pushing way too hard and I’m probably not going to make it much longer, I still do it instead of reaching out and asking for help. And I’m getting better at that.” P11

Avoiding care	12. “I feel like since like kind of getting shot down by doctors for the majority of my life, it’s kind of damaging and disheartening to me because sometimes like what’s the point, they won’t even believe me or, you know, it’s different from what they write down in my file than what I say to them and stuff. So it seems like everything gets lost in translation so why would I try, sometimes I’m in that headspace.” P7 13. “Oftentimes people will suggest, “Oh, you should go to the doctor” and stuff and I’m like I can see exactly how this goes, so pass. And like sometimes I’ll wait till it gets either really bad or like it goes away or I’ll self-diagnose […] I’ve done that quite a bit and found like not a cure, but like the answer I’m looking for and then just feel like OK, well this is what I need.” P9 14. “When I have in the past and when I was young and impressionable sought out care, I just didn’t get it. So now I have some more like self-diagnosis, but I just haven’t got an official diagnosis yet. I’m sure at some point I’ll have to but I’m just super hesitant to go to the doctor ever.” P8
Worsening health (& wellbeing)	15. “I have been asking my doctor for probably the last three and a half, four years, to check my thyroid out and not just the basic tests, but like the full panel and go see somebody that’s a specialist. And she just told me for four years, “There’s nothing wrong with your thyroid. Nothing wrong with your thyroid.” Flash forward to last – just this past May – I get an MRI on my thyroid. The thyroid is destroyed. Destroyed. And I get to go see this endocrinologist – the hormone doctor – and she tells me, “This has been going on for so long. Why didn’t your doctor investigate this before?” And I’m, “I’ve been literally asking my doctor for four years to investigate my thyroid.” P11

	16. “I've had doctors before who just assumed because they have the title of doctor I know more about your own body than you do, and it's an incredibly invalidating experience. And it's also very scary – like that's another thing that maybe doctors don't realize, like, it's pretty horrifying when you don't have the backing of a doctor or the validation of a doctor because without that medical validation unfortunately you might not have that diagnosis on paper, and without that diagnosis on paper you might not have coverage, you might not have access to social supports, to medical supports. Like, that can be really, really scary. So yeah, it's pretty scary. It's not just like a one moment interaction, like oh maybe I wasn’t as validating as I needed to be and that's the end of it. Like no, it can really – for me at least it can turn into kind of like a spiraling sort of situation where the person might feel hopeless and like [other participants] have said a very common experience with chronic illness in general is mental health [concerns].“ P6 17. (Referring to the art they made…) “I chose to put it on that background of the coding stuff because I feel like it represents my anxiety dealing with all of it and that’s what my head feels like when I walk into an office. Even though I’ve rehearsed it a thousand times, they throw a bunch of words at me and that’s all I feel and see and I can’t even collect my thoughts and sometimes I don’t say anything because they’ve thrown all this stuff at me. And they ask me if I have questions but, of course, I have none because I don’t know what I’m thinking… I would think of myself as a pretty strong individual outside the clinic and when I walk in, I crumble. I’m always standing up for people in my life and my friends I’m the helper, but when I’m in there I feel completely helpless…

	I have extreme anxiety walking into any medical building ever now. And even when I book a new doctor, like my heart is pounding out of my chest and I pretty much just assume the worst going in because like I can't be hopeful anymore [laughs]. Because yeah, if I assume that they're going to be absolutely terrible and give me no time of day, then if they give me a little bit then I'm better off." P9

Theme 3: Recommendations to Avoid Medical Invalidation

Participants provided a variety of recommendations for physicians working with people with chronic illnesses, informed by their experiences of medical invalidation. Overall, participants recommended:

1. Seeing the patient as the expert of their own experience
2. Recognizing that even amid diagnostic uncertainty, the patient's experience is *real* and impactful to them
3. Practicing humility, empathy, and compassion
4. Help them help you by finding common ground
5. Seeing the whole person

As one participant stated, "I don't need you to give me the world, I just want you to understand that this is hard" (P9).

Table 3: Participant Quotes to Support Findings from Theme 3

Theme 3: Recommendations to Avoid Medical Invalidation	
Seeing the patient as expert of their own experience	18. "Believe your patient, we're coming to you for help…You're the one that studied for this, yes. We've spent our lives in a way studying it ourselves because we live with it." P4
Recognizing that the patient's experience is *real*	19. "I felt that's something that we would all appreciate if healthcare workers took that idea and respect peoples' – even if it's – let's say

and impactful to them	you have schizophrenia and you have – you're explaining something that isn't happening in real life, but to you it truly is happening – give people the respect of understanding that truly is an experience they have. And even if you can't do anything for it, just saying, "OK. It's here. There's nothing I can do for it, but I understand it and I'll listen," is going to help." P14 20. "Recognizing that perhaps they don't think that it's real but recognizing that it is real to us and that it should at the very least be taken into consideration." P8
Practicing humility, empathy, and compassion	21. "And what [other participant] was saying about the like, "You're not in that much pain," yeah, it's like how dare you get to say that. Like unless you literally have been dealing with the same – but even then, every person is different so you can't and that's where the empathy thing comes back into play… I would say radical empathy, yeah. I mean everything else kind of falls into place once the empathy part is there." P9 22. "I think for me it's just like be humble. Like there's nothing wrong with acknowledging that you're a human being and there's no way you know something unless you've experienced it or unless you've learned from someone who has experienced it, or unless you've learned from someone who has studied it, like that kind of thing." P6 23. "P8: And, yeah, it just seems like we're always looking for that like-mind where it's like maybe you don't know but let's figure it out and let's do something… P7: I totally agree. That's more reassuring to have someone to try to figure out what's going on instead of just say like, 'Yeah, I don't know. I'm not going to help you figure it out' kind of thing." 24. "I think empathy is something that a lot lack and whether they have the resources or time or whatever to put in, if someone just honestly

	told me like, “You know what, that sucks. I can’t do this for you but like I can do this or this or this,” or just being there. Like I had a doctor recently and he gave me an honest like, “I don’t know what’s going on but like why don’t we try this,” but it’s like that’s all I wanted. I don’t need you to give me the world, I just want you to understand that this is hard.” P9
Help them help you by finding common ground	25. “Maybe just some education around how like a lay person who's not trained in the medical field might describe an illness or a symptom. Because if it's not – if we don't use the exact medical jargon that they're looking for then they completely write us off. And that can be really, really harmful.” P6 26. “P6: I think it would also be helpful if doctors told patients how to collect data to help them help themselves. Because I come from a family with a lot of STEM people and so if they would help me get in the brain of a doctor, or someone who looks – needs to look at all this data to give a diagnosis, that's how I got my diagnosis, because I tracked literally everything and I presented them…I was like this is what I'm experiencing. So doctors could tell their patients how to collect that data that would be super helpful, because I only knew how to do it because my mom figured it out through research. P4: Yeah, instead of doctors just saying, just track what's going on. It's like, but how? Tell me the information you want.”
Seeing the whole person	27. “I think the thing that I want people to take – or the doctors to get – is just that they need to take the time and they need to listen. That’s it’s kind of like each person is more than just a patient. Because we all could describe – each person’s experience as a patient are just – we’re all individuals – it’s all different. And it’s all of – I hate the labeling and I hate the box – we don’t all fit in the box. There’s so much more. And

	it’s – they really need to take that time and listen, instead of just putting you in the box and giving you that diagnosis and this is you now. They forget – how there’s so much more to you.” P3 28. “I've seen a lot of improvement with doctors lately when I've seen, like, this new allergist and I've seen some other new doctors, and [they’re asking] do you have any treatment plans? Do you see a therapist? Which I think is very good that they're asking that because it's all interconnected, like the body is one system, like your physical health feeds your mental health and your mental health feeds your physical health…like, and you're dealing with – if you have chronic pain or chronic [illness] when you're in the thick of it you literally, like, can't see out of the tunnel, and then it – you start getting more depressed and then when you start getting more depressed you can't do the things that make you feel good. And it's just a spiral.” P4

Interpretation

All participants in this study experienced medical invalidation to some extent. Medical invalidation took different forms but ultimately had lasting implications for participants. Implications included: behavioural consequences such as downplaying symptoms (in the clinic and outside of it), pushing themselves beyond their capacity, and avoiding care even when needed, instead relying on self- diagnosis and management. In some cases, medical invalidation meant arising health issues were missed completely, resulting in worsening health and complications from undiagnosed and untreated issues. Further, the participants emphasized the psychological toll of experiencing medical invalidation repeatedly and how it affected their confidence in the clinical encounter.

Medical invalidation is not a new phenomenon, and the examples described echo that of other studies where patients with chronic illnesses report dismissal of their concerns or having their experiences disbelieved by physicians.[17,80,109,117] The long-term consequences of medical invalidation have been explored to a lesser extent, though our findings are confirmed by Sloan et al 2020, who interviewed 21 people living with lupus and found that negative health care encounters had lasting behavioural consequences, including “self-treating” to avoid care and increased self-doubt.[5]

Bê 2016 conceptualizes the effects of medical invalidation as “externally imposed impairment effects” where “pain, fatigue, tiredness or soreness [are] actually created or exacerbated by the painful interactions disabled people are required to have with the state, doctors or other institutions,”[83(p14)] echoing the aforementioned term “duality of suffering” provoked by health care encounters.[28] These findings reflect Tamaian et al 2017, who found that “negative health care experiences are common” for people living with chronic illnesses, and have implications for patient well-being.[81] Considering the close ties between stress, anxiety, and symptom severity with many chronic illnesses, it is crucial that the impact of medical invalidation be recognized and steps taken to prevent this experience. We suggest, based on our findings, that the impact of medical invalidation has the potential to exacerbate some symptoms, as participants alluded to.

The recommendations provided by participants reflect recent developments in medical education named the “humanist turn.”[118,119] Infusions of the arts and humanities in medical education aim to produce physicians who have greater appreciation for the patient experience. While certainly empathy, good listening skills and other person-centered attributes are necessary to providing good care, some argue it is not enough to create change – and we would agree.[118] We would argue that, as others have, based on participant’s experiences, there is a significant need for critical reflection in the clinic.[120,121] Critical reflection would unearth the assumptions undergirding medical practice – assumptions that discount the embodied experience of patients and do not support those with chronic or hard-to-diagnose illnesses, or those from groups that experience marginalization.[122]

Limitations

While there was some diversity in participants, a larger study with broader representation would provide a fuller picture of medical invalidation and greater understanding of relevant sociocultural factors. Further, the study did not include physician perspectives, which would help to understand why medical invalidation occurs.

Future directions

Further studies on the subject would benefit from larger sample sizes with diverse participants to understand how these experiences differ for different populations. Considering the important role of anxiety and stress in chronic illness, more studies could help identify the relationship between medical invalidation and stress and symptom intensity – this is something that was alluded to in our study but the data was not definitive enough to make a direct conclusion. While the study focused on interpersonal interactions, it is important to further contextualize medical invalidation, paying attention to the system-level factors that may play a role. Finally, participant experiences reflect a need for engagement in reflexivity in clinical practice.

Conclusion

The impacts of negative health care encounters for patients with chronic illness cannot be overlooked. This study provides insight into the phenomenon of medical invalidation, understood as the act of dismissing, minimizing, or otherwise not taking patient concerns seriously. In our study, 10 participants living with multiple chronic conditions experienced medical invalidation to some extent in their illness journey, and some experienced it repeatedly. Medical invalidation had several consequences for patient's overall well-being, their willingness to access care and sometimes resulted in important health issues going undiagnosed. Based on participants' experiences, we offer suggestions for clinical practice such as using a holistic lens to consider the patient, and acknowledging their expertise of their embodied experience, so patients living with chronic illnesses may be taken seriously and the significant health implications of medical invalidation are minimized.

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From the Clinical Encounter to Critical Disability Studies: Linking the Manuscripts

Aside from the direct objectives of my project, I had two secondary goals in completing my thesis related to my professional development. The first is to develop my capacity in being able to speak to two distinct but related audiences: critical health humanities scholars and practicing health professionals. The second is to advance my skills in arts-based research, including methods of analyzing or "reading" art as data in qualitative research.

I wrote the first manuscript with the *Canadian Medical Association Journal* in mind. To meet the journal's requirements and the needs of the audience (mostly physicians), the manuscript had to be quite short, practical, and very focused. In light of the audience, I thought it best to address the issues of epistemic invalidation and clinical invisibility (see Manuscript 2), in a simplified, to-the-point manner. While these theoretical concepts are important, I felt it important to focus the paper on the words and stories of participants rather than delving into theoretical concepts. I chose instead, to use the term "medical invalidation" as an orienting concept for its precision, and the fact that I was able to find another paper in a medical journal that used this concept in the context of chronic illness care.[109] Given ongoing discussions in chronic illness communities of 'medical gaslighting,'[123] medical invalidation as a focused and applied concept, seemed the best way to address this issue using approachable language.

The first manuscript aims to define, document, and discuss participant experiences of medical invalidation and the consequential effects on their health and wellbeing; yet, it leaves a lot of information out for the sake of brevity. In part, due to my personal experiences as a patient, and my commitment as a researcher to do the bridging work of connecting CDS to health care experiences, I knew there was more to say. I wanted to bring more attention to the social, cultural, and power dynamics in the experiences described by participants. Medical invalidation is a central and important part of participants' experiences of patienthood but not the whole story. Something I became acutely aware of, in the workshops, is the way participants described their experiences of medical invalidation as not limited to the clinical encounter. The effects of the experiences crept into their everyday – as I note but do not go into detail in – in the first paper. There were consequences for their relationships with family and friends, self-image and subjectivity, and relationship to their bodyminds and illness perceptions.

The first manuscript also was not able to address my speculation as to why medical invalidation seems to be ubiquitous in the lives of people with chronic illness – particularly those from marginalized populations. And so, the second manuscript takes up the broader experience of living with chronic illness via the concept of "patienthood", importantly emphasizing that patienthood is not only performed in the clinical encounter, but a subjectivity that accompanies people living with chronic illness in their everyday lives. This second paper is directed to a humanities and/or social science audience; however, I hope it also reaches physicians and other health care practitioners as well, and if published in my journal of choice, *BMJ Medical Humanities*, it just might. Like other recent disability work, it aims not only to consider the insights of critical disability studies for health care practices and processes, but to join scholars seeking to bridge between the medical humanities and critical disability studies. My paper takes up patienthood through the lens of critical disability studies while addressing the depth of my broader research question: how do women and gender minorities living with chronic illnesses understand and experience patienthood?

This second paper developed through a round of close reading my data (as described further in the manuscript), specifically looking to make connections between critical disability studies and the participants' artwork. Considering the first manuscript focused only on the transcript data, I felt it important to do justice to the complex and evocative art created by participants in this second paper. As I reviewed and made notes about the art, I noticed many references to both space and time. Given my previous knowledge of critical disability studies, I knew that time was an important and contemporary concept – a 'temporal turn' is underway.[124] I spent time reading work at the intersection of critical disability studies and trauma studies. Through this reading, and I want to specifically name Angela Carter's 2021 paper in *Lateral*, "When Silence Said Everything: Reconceptualizing Trauma through Critical Disability Studies"4, I was introduced to prominent disability studies scholar Margaret Price's notion of *crip spacetime.* Given the reference to spacetime invoked by the word patienthood – 'patient', as a subject location that references medical space, and '-hood' – denoting a relationship to time, it felt a particularly fitting theory for the work produced by participants. Additionally, as Carter explains, both space and time are important to conceptualizations of trauma.

The second manuscript offers a perspective of patienthood that delves into the material, social, cultural, and discursive aspects of living with chronic illness. While I briefly reference medical invalidation, medical invalidation is only one aspect of patienthood. I look more broadly to the contexts that shape participant experiences and seek to understand what factors make medical invalidation both so prevalent and consequential. Although I did try, quite persistently, to work trauma theory into this paper, I ultimately found that it was beyond the scope of the work and focused on conceptualizing patienthood through the notion of crip spacetime. Critical attention to trauma and traumatization in patienthood is still needed, and I address this further my concluding chapter.

My hope is that these two papers work together to provide insights on patienthood that are both conceptual and pragmatic. In completing this work, I have deepened my understanding of patienthood and the necessity of identifying multiple entry points to improving care experiences for people living with chronic illnesses. What becomes evident is that we require not only concrete tools to address the clinical encounter but a re-framing of chronic illness and patienthood in ways that are affirming and empowering, which a critical disability studies approach makes possible.

Manuscript 2

To be submitted to *BMJ Medical Humanities*

Theorizing Patienthood through Critical Disability Studies

Author: Jennifer Sebring

Abstract: Science and technology studies scholars have drawn on the anthropological notion of personhood to develop the concept of patienthood, which highlights the cultural construction of the patient position, and its variations across social contexts, time, and location (Joyce et al 2020). To further conceptualizations of patienthood, I conducted qualitative research to understand how people living with chronic illnesses understand and experience patienthood. Arts-based workshops were held with 10 self-identifying women and non-binary people living with chronic illnesses. Participants were invited to create “portraits of patienthood” using multi-media collage. Following the art activity, a group discussion took place to generate further insights on living with chronic illness and navigating health care. My analysis of the artwork continues the interdisciplinary work of conceptualizing patienthood by reading the art through critical disability scholar Margaret Price’s notion of crip spacetime. In doing so, I illuminate how patienthood is a precarious position - produced and sustained through the entanglement of social, material, and cultural forces.

How can I explain that the equipment and smell of hospitals, the wan light and horrid linoleum floors, are as familiar as memories of my childhood home? That the routine appointments that take up my time—in-home care when needed, twice-a-week physical therapy, weekly psychotherapy, biweekly meetings with my social worker, monthly checkups with my general practitioner, etc.—are as woven into my daily life as work, sleep, and having tea with a friend? In honest, neutral terms, without tragic drama or empowering vindication, I understand that no matter where I sit or sleep in this life, I will be doing it in the house of illness.

- *Letter to a Young Doctor*, Johanna Hedva (2018)

Introduction

In the above excerpt, Johanna Hedva asserts the certainty and centrality of illness in their life – in stark contrast to the dominating narrative that “hospitals are a rare and bizarre interruption of ‘normal’ life” (Hedva 2018). Their poignant description of the medical space and the all-too-familiar trudge of attending appointments outlines the reality of living with chronic illness: even outside the walls of the hospital, one never stops being a patient.

Living with chronic illness[iv] necessitates undertaking and performing the patient role,[v] repeatedly and often frequently for an undeterminable amount of time. The concept of “patienthood” encapsulates this experience quite well, as it invokes a temporal and spatial frame, much like Hedva does in the passage above. While there is a move to abandon the term ‘patient’ in health care contexts for its paternalistic connotations - *patienthood* as Joyce et al. (2019; 2020) explain, highlights the socially and culturally constructed nature of this subject location. In conceptualizing patienthood, Joyce et al. (2019; 2020) write that the “inclusion of the word “patient” retains the analytical focus on individuals’ situated experiences. Adding the word “hood” denaturalizes the word “patient,” highlighting the identity’s social construction and potential precariousness. Who counts as a patient? When? Where? And, what varieties of practices are differentially positioned patients expected to do?” (2020, 186).

In this article, I take up the concept of “patienthood” to contribute to theorizing chronic illness through a critical disability studies lens. At times, I use the term patienthood interchangeably with references to living with chronic illness. I do this to acknowledge the ways the medical clinic, where patienthood is produced, reaches out and becomes entangled in the everyday life of people living with chronic illness. Given the increasing prevalence of patient and public engagement strategies in health care research, policy development, and clinical practice,[vi] it is critical that we think carefully about what it means to be a patient. This includes a refusal of essentialized notions of patienthood, and close attention to the social and cultural

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[iv] Chronic illnesses are defined as health conditions with no known cure that “last a year or more and require ongoing medical attention and/or limit activities of daily living” (Warshaw 2006).

[v] The concept of patienthood may bring to mind Talcott Parson’s theorization of the sick role. Medical sociologists and the broader field of sociology of health and illness have mostly moved away from this concept for a multitude of reasons (see (K. Joyce and Jeske 2019; Burnham 2014). Personally, my employment of patienthood instead of the sick role seeks to foreground a multiplicity of patient perspectives and avoid an overly prescriptive or essentialized notion of what it means to be a patient.

[vi] Increasingly, medicine and health care are integrating patient perspectives into research, policy development and clinical practice. By engaging people with lived experiences of patienthood in health care decision-making, such efforts aim to develop health practices and research processes that are more responsive and relevant to the population they are meant to serve. However, there are concerns that the booming popularity of ‘patient engagement’ strategies may fall short of their aim, resulting in tokenistic practices that do not foster meaningful change (Hahn et al. 2016; Mann et al. 2021; Crockett et al. 2019). Rowland et al note that efforts to mobilize patient perspectives often do so in the singular, as *the* patient perspective or *the* patient voice (2017).

contexts that shape experiences of illness. This article considers the affective, spatial, and temporal practices and processes of patienthood as they relate to power. Just as the concept of patienthood asks, “who counts as a patient?” (K. A. Joyce, James, and Jeske 2020, 186), an affective approach to critical disability studies requires we ask “what subject positions are available for whom and why?” (Jóhannsdóttir, Egilson, and Gibson 2021, 349). By engaging the concept of patienthood, I illuminate the generative potential of thinking through medicine and the embodied, affective experience of illness from a critical disability studies lens.

Through a critical reading of collages produced in the context of an arts-based qualitative research project, I theorize chronic illness and contribute to the conceptualization of patienthood through critical disability studies. I argue that patienthood is marked by a particular orientation to space and time, explored here through Margaret Price’s articulation of *crip spacetime.* Specifically, patienthood is characterized by living both through and in anticipation of what Price calls a “bodymind event.”

I first introduce Price’s theory of crip spacetime and the bodymind event. Next, I consider the elements that make up the “bodymind event” as they are represented in participant artwork. In doing so, I discuss the contributions of the medical clinic, public understandings of illness and disability, and the lived experience of the sick body in producing the bodymind event. Finally, I describe how these elements all interact to produce a particular affective space vis-á-vis research participant metaphors of space and time.

Methodology

I am trained in the humanities and women’s and gender studies with a longstanding interest in disability and cultural studies. I chose, however, to pursue graduate studies in a public health program to bridge this foundational training to an applied research context. As part of my graduate program, I conducted a participatory, patient-oriented, and arts-informed approach study (Jull, Giles, and Graham 2017; Tarr, Cornish, and Gonzalez-Polledo 2018; Government of Canada n.d.; Boydell et al. 2016) in 2021-2022 of the COVID-19 pandemic, grounded in the epistemological and ontological foundations of critical disability studies (Schalk 2017; Minich 2016).

Art is increasingly popular as a method of data collection in health research (Byrne et al. 2018). In this study, I valued the artistic process as a means of generating embodied insights that might otherwise go unrealized. Indeed, a participant remarked that the visual dynamics of the process were “super helpful” and brought to mind insights they had not yet spoken aloud or even acknowledged. As I discuss later in this paper, the experience of living with chronic illness can be difficult to articulate, and art enables another way of seeing and doing, inviting participants to address and represent experiences that may be challenging to speak out loud. Finally, the tactile and interactive nature of creating art can encourage participants to remain grounded while thinking through potentially difficult topics.

Patient-oriented research, as defined by the Canadian Institutes of Health Research, is “about engaging patients, their caregivers and families as partners in the research process… to ensure that studies focus on patient-identified priorities, which ultimately leads to better patient outcomes” (Government of Canada n.d.). As Rowland et al note (2017), patient-oriented or patient-engaged research has some parallels to feminist standpoint theory, however, patient-oriented research often lacks the kind of criticality that feminist theory centers. In my deployment of a patient-oriented framework, I aimed to center the experiences of people living with chronic illness and conduct research in a way that was sensitive to these experiences and allowed participants to set the agenda as much as possible (Shimmin et al. 2017).

Recruitment

Participants were recruited via my professional social media accounts (Twitter, Facebook, Instagram) and email lists of local community organizations and patient-oriented research organizations. The local community organizations included community health centers, 2SLGBTQIA+ resource centres and disease-based advocacy groups (both formal and informal). Eligibility criteria included being 20-35 years of age; self-identifying as a woman or a gender minority (transgender, non-binary, Two-Spirit etc) person living with a chronic illness; and having received health care in Manitoba, Canada. I chose to work with this particular population as 1) young adults experience unique life and health care transitions and are often not represented in the literature on chronic illness and 2) experiences of chronic illness are highly gendered, and women and gender minorities are more likely to live with chronic illness and often face barriers to appropriate care (“Chronic Disease: What Do Sex and Gender Have to Do with It?” n.d.; Progovac et al. 2018). A screening process was used to achieve maximum variation sampling (Liamputtong 2017). As a result, participant demographics varied across race, gender, socioeconomic status, diagnosis, and geographic location. Thirteen participants were recruited but three dropped out for health-related reasons, and as a result, the study ran with ten participants.

Some characteristics of the group of participants should be considered to contextualize my discussion. Beyond the eligibility criteria, all participants had lived with chronic illnesses for five or more years. All lived with multiple chronic conditions and had co-occurring mental health diagnoses. Of note, many lived with "contested" (P. Brown, Morello-Frosch, and Zavestoski 2012), "invisible," or rare illnesses.

The study received ethical approval from the University of Manitoba's Bannatyne Human Research Ethics Board (#HS24998 (H2021:234)).

Data Collection

Ten participants were divided into small groups to partake in a virtual arts-based workshop designed by the author in collaboration with patient partners (see Patient and Public Engagement). Curated art kits were delivered to participants' homes, including various images for collage and multi-media art supplies. The collage materials provided were identical for each participant, including a variety of texts, people, patterns and other imagery such as landscapes, while each participant received a random selection of markers, art tape, watercolour paint, crayons, and art paper. I invited participants to create artwork in response to the following prompts: *What does being a patient mean to you? What is your experience of patienthood?* Further questions were supplied to guide the artistic process (see Appendix B). Following this, we had an unstructured discussion that took the art as a starting point and encouraged participants to delve further into their experiences of patienthood on their terms. The workshop and discussion took place online on Microsoft Teams, and the discussion was recorded.

Data Analysis

Following Riddett-Moore and Siegesmund's articulation of a theory-driven approach to arts-informed data analysis, data were "*constructed*" not found (2012, 109). I took an interpretive, creative approach to data analysis, which meant spending considerable time reviewing and re-reviewing the artwork participants created. This paper represents a second reading of the data: the first reading used common thematic analysis coding techniques and took a more deductive approach to the focus group transcripts for a primarily health practitioner audience. This second reading took the art as its primary data and is my attempt at bridging the work to a humanities audience. The theoretical grounding and influence of critical disability studies allowed me to do a deep reading of the artwork that would not have been possible through my training in health research methods alone.

My reading of the work is informed by my familiarity with the literature on chronic illness, critical disability studies, and my subjectivity and positionality as an artist-researcher and person living with chronic illness. I worked with the notion of the "formative image" to understand how participants used imagery to "expand meanings or allow for new combinations of metaphor" (Riddett-Moore and Siegesmund 2012, 107). The feminist practice of reflexivity (L. A. Brown and Strega 2015) and an iterative process were key to data analysis.

Patient and Public Involvement

Like the participants, I share a history of navigating medical care while living with both chronic and contested illnesses. As is well-known in qualitative research, the researcher and their accompanying subjectivity/ies are as much an instrument in the study as any interview or focus group guide. While, on the one hand, my closeness to the research topic may provide a "better understanding of the subject" (Liamputtong 2017, 26). I acknowledge the risk of universalizing my experiences to that of the participants and people living with chronic illnesses more broadly. I engaged in a patient-oriented research process to make space for multiple perspectives. Three multiply-marginalized individuals with lived experience of patienthood were involved in refining the research question, collaborated extensively to plan and execute data collection, and provided their interpretations of participant artwork which were consulted during data analysis. I will be working with these individuals to disseminate the research results in a publicly available "zine."

Crip Spacetime

Margaret Price developed a notion of crip spacetime (2017).[vii] Price extends the concept of "crip time" (Kafer 2013; Samuels 2017; Samuels and Freeman 2021) to recognize that "space and time are inevitably entangled" and "that it's hard to think meaningfully about space without also involving time…space persists and we inhabit it through time" (Price 2017, 2–3). Critical to understanding *crip spacetime* is that no person ever exists in the same spacetime "and the differences in the spacetimes we inhabit are often a matter of violent inequity, even of life or death" (Price 2017, 10).

Figure 1: Brynn's Collage

Similarly to how Price describes spacetime, I conceptualize space as affective – the particular feelings that one moves through in relation to their illness, and often, in stark relationship to other people (e.g., those who are imagined to be "healthy" and inhabit a normative spacetime). This is illustrated and articulated astutely by one participant, Brynn, who speaks about her decision to tape two pieces of paper together to make an elongated backdrop for her collage (fig. 1) to "accentuate the *distance* [I] *feel*." She explains that she feels this distance in relation to her health care providers ("They're sort of like depersonalized from my experience, they're the furthest away from me in the collage…they're watching my suffering from afar, kind of cold"), the public ("It's almost impossible, in my experience, for people who have never lived with a chronic illness to understand what it's like"), family and friends ("they're trying their hardest to reach for me… but no matter what [they] do [they] can't cure my illness and there's always going to

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[vii] See also her forthcoming book: *Crip Spacetime: A Re-orientation to Disability Studies* (under contract with Duke University Press) and the related project *Disabled Workers in Higher Education* (https://margaretprice.wordpress.com/disabled-faculty-study/).

be that space between us”), and other entities, such as her illness, hope, and finding a solution for managing her chronic illness.

As this participant describes her art to the group, she invokes other experiences that can be understood through crip spacetime. For instance, the dagger positioned below her falling body represents, in her words, the betrayals of her body, a “looming, always-present, impending kind of pain, like I’m eventually going to slam down right on top of it, and it’s always going to be there, and it’s waiting for me pretty much in the darkest depths of my chronic illness.” This – an upcoming flare of her symptoms - can be understood through Price’s description of a “bodymind event”:

> a sudden debilitating shift in one’s mental/corporeal experience. Examples of such events might include a panic attack, being exposed to a toxic chemical or fragrance, abruptly realizing that an interpreter is not interpreting accurately, encountering a dangerous allergen, or hitting an unseen bump with one’s wheelchair and falling over. Bodymind events are not located “in” bodyminds, but rather take place in spacetime; in other words, they arise from the particular conditions of space and time that contribute to the emergent meaning of a situation (Price 2017, 15–16).

The bodymind event is a central component of the particular spacetime of patienthood, as patienthood is lived through or in anticipation of a bodymind event and its repercussions. We can understand patienthood through the concept of precarity, which Price indicates is made up of the “material conditions of vulnerability themselves” and “two other key factors: first, infrastructures designed to sustain the vulnerability; and second, obscurity surrounding the constitutive conditions of vulnerability” (Price 2017, 4). In what follows, I examine contributing factors to the bodymind event via the artistic representations of participants. First, I discuss “infrastructures to sustain vulnerability” in the medical system by examining the concept of clinical invisibility. Next, I consider the broader cultural narratives around illness and disability as contributing to “obscurity surrounding the constitutive conditions of vulnerability” before discussing the “material conditions” of living in a sick body.

Contributing Factors to the Bodymind Event

Infrastructures to sustain vulnerability

The medical clinic is central to the social and cultural construction of patienthood. Despite the increasing prevalence of chronic illness in the global north, health care is not necessarily equipped to account for illnesses that cannot be cured. As Aurora Levins Morales writes, we have "infectious diseases as a model of sickness, and wheelchair users as a model of disability" (2013, 71) relegating patienthood to a liminal, or, as Price writes, "queerly abject spacetime" (2017, 5). Famously, Arthur Frank typifies the spacetime trajectories of illness through his conceptualization of "illness narratives" (2013). First is the quest narrative, whereby the patient is afforded an unexpected positive effect from illness; then the chaos narrative, which is marked by suffering and loss; and finally, the restitution narrative, where the patient is diagnosed, receives treatment, and achieves restoration of their previously lost health. Most of the time, chronic illness does not fit any of these narratives and certainly defies the restitution narrative that medicine is predicated upon. Thus, in the context of medicine and health care, the infrastructures that sustain vulnerability are, in fact, a *lack of infrastructure* across the trajectory of patienthood.

Brynn illustrates discordance between the spacetime of patienthood and the health care system supposedly meant to help her. In her collage, her medical practitioners are depicted as a disembodied eyeball atop an anatomical model of the human body and a hand grasping a pencil – taking notes, surveilling, but never embodying the same spacetime as the participant. To the right of the artwork, she pasted red and yellow pills as if they are falling directly from the medical vignette in the upper right corner. The pink figure in the center of the artwork represents the patient herself - freefalling toward a dagger at the bottom of the collage. The dagger represents her illness, which can be read through Price's *bodymind event* – an "abrupt and debilitating shift in health status." Notably, neither the medical professionals nor the pills come into direct contact with the patient. She describes her interactions with the health system and medical professionals as "depersonalized…purely there just to observe and take notes…watching [my] suffering from afar" and "trying to throw different medications at me [and] *it's never quite right…*". This participant clearly articulates the disjuncture between the spacetime she inhabits as someone living with chronic illness and that of the clinic.

Chronic illness is to the clinic as the "unaccommodatable disability" is to higher education in Price's conceptualization (2017). The unnaccommodatable disability is unpredictable, varying in intensity, and episodic, challenging the checkbox approach to accessibility that universities rely on. Disability scholar and activist Eli Clare writes about the pervasiveness of cure as an ideological force underpinning medicine and broader western society. The goal of medical intervention is to diagnose and remedy the “trouble” of bodyminds, ultimately enabling a “restoration of health” (Clare 2017, 71, 14). Chronic illnesses challenge and complicate the mechanisms of cure: diagnosis, treatment, management and rehabilitation (Clare 2017, 70). Illnesses that cannot be easily diagnosed, treated, managed or rehabilitated defy the very logic of medicine and are met with disbelief - deemed “not real” by those who hold power within medicine and related institutions (Clare 2017, 73). As a result, patienthood is marked by the continued negotiation of power between patients and physicians as patients seek legitimacy for their embodied experience so they might access care (Moss 2016; Rogers 2022). The navigation of the “biomedical apparatus” is marked by a careful and strategic balance of when to assert agency and when to play along to ultimately be taken seriously by a physician (Moss 2016).

The importance of the struggle for recognition is evident when looking broadly at the art generated in this study. Labels abound, though not in the biomedical sense of diagnosis. Instead, phrases like “Liar,” “Patient is sad?”, “Not broken enough” and “fake” indicate the ongoing invalidation of participants’ embodied experiences. In particular, the collages created by Blair and Jenna (figures 2 and 3) paint an intriguing picture of what this experience is like.


Figure 2: Blair’s Collage

Blair (fig. 2), who lives with a rare condition that causes chronic migraines and vision impairments, created a startling collage to represent her experience of struggling to get the care she needed – whether because of fatphobia, invalidation of her symptoms, or physicians not knowing enough about her illness to help. Grounding the imagery of her collage with a skull as the focal point, the localization of pain in their head is highlighted. Eyes are painted into the previously empty sockets of the skull in a bright blue with alarming white accents. What appears to be a red screw is pointing toward the eye on the left, evoking a powerful metaphor of the participant's pain. Similarly, the forehead is layered with smudgy black watercolour topped with chaotic black, white, and blue scribbles and a hand reaching up and out of the skull. The placement of the hand reaching out and beyond the chaos signals the need for relief from the chaotic and painful reality of their condition. The mouth of the skull is coloured over with bright yellow ink and black block letters spelling out "FAKE," reminiscent of taping someone's mouth shut. The words "TOO MUCH TRUTH" are pasted to the right and to the left, "I won't help you." These phrases, combined with a hand-drawn stop sign beside the skull, contextualize the difficult encounters and outright refusals of care this participant experienced. Further, white clouds with question marks point toward the anxiety and uncertainty of patienthood when seeking care seems a futile endeavour. The skull is bordered with colourful flowers, representing the need, as the participant put it, to "put on a face" when attending appointments.


Figure 3: Jenna's Collage

Jenna's artwork is represented in figure 3. Jenna's experience of patienthood is characterized by a sharp divide between who she feels she is as a person, and who she is in the clinic, as she describes: "I would think of myself as a pretty strong individual outside the clinic and when I walk in, I crumble. I'm always standing up for people in my life and my friends I'm the helper, but when I'm in there I feel completely helpless…" Her detailed collage represents this divide, with the top half dedicated to her experiences navigating medicine. A feminine figure sits, legs crossed, holding a sign – the words of which have been pasted over with pink, sparkly paper. The participant described this artistic choice to the group to represent her struggle to be heard in the clinical encounter: “It doesn’t really matter what I say… as long as it sparkles.” To the right, a vignette portrays their understanding of medicine: a faceless figure in a suit; a clock; a mirror; a disembodied eye; two human figures shrouded in safety suits, a pair of dice; and a ruler. Together, these elements convey the participant’s efforts to be recognized in a dehumanizing and detached medical environment.

In chronic illness and the body’s resistance to normative spacetime – or more accurately, medicine’s inability to accommodate crip spacetime, the patient and their embodied experience are denied. Like disability theorists before (Wendell 1996; Mollow 2014), Alex Haagaard considers medical invalidation, or in their terms, *clinical invisibility,* as a formative apparatus in the experience of patienthood (Haagaard 2022). Acknowledging the limits of much disability theorizing to address chronic illness, Haggard draws on medicine’s historical (and indeed, continued) positioning of chronic illness as psychosomatic to “examine how disability is constructed through processes of invisibilization mediated by the clinical gaze” (2022, para. 4). In doing so, Haagaard bridges the work of disability theory around access and accommodation to include the “unaccommodatable” disabilities Margaret Price refers to. Haagaard writes that the clinic “undermedicalizes” invisible disability[viii] and thus, “produces disability through refusal of recognition” (Haagaard 2022, para. 33). By understanding invisible disability in this way, we come to realize that the “embodied suffering of chronic illness is socioculturally produced” through clinical invisibility (Haagaard 2022, para. 33). Clinical recognition paves the way to treatment, social support, and even community and a shared language to describe experience – all of which make it possible to *live well* with chronic illness.

Yet, as Price underscores, we all inhabit different spacetimes, of which the differences are “often a matter of violent inequity – of life and death” (2017, 10). The concept of patienthood asks: “who gets to be a patient?” begging attention to the question of what particular bodies and particular illnesses are made to be *more* invisible than others. For example, Ghaida Moussa’s study of queer, trans, Black, Indigenous and people of colour’s (QTBIPOC) fibromyalgia experiences reflects the ubiquity of invisiblized and medically unexplained illnesses in the

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[viii] Haagaard distinguishes between disability broadly, chronic illnesses and invisible disabilities: “Crucially, not all disabled people are chronically ill, and not all chronically ill people are invisibly disabled (2022, para. 32)” In their articulation, invisible disability as “disability that goes unacknowledged by the clinical gaze” (Haagaard 2022, para. 32).

QTBIPOC community. The individuals interviewed by Moussa concluded that, in their communities, living with medically unexplained or chronic illnesses is “just a part of life” (Moussa 2019). This ongoing invisibility is perpetuated through medical education and research practices that fail to meaningfully engage structural drivers of ill-health and the systematic exclusion of QTBIPOC and other populations facing marginalization (Metzl and Hansen 2014). In my study, this was reflected in the experiences of participants who understood stigma and discrimination as an inevitable part of navigating health care interactions.

The struggle to be visible is part of patienthood and is amplified by institutionalized practices that marginalize people living with chronic illnesses. If medicine cannot recognize us, we remain unrecognizable. This has significant consequences that spill over into all facets of life.

Obscurity surrounding the constitutive conditions of vulnerability

The felt distance between patienthood and normative spacetime manifests in participants' everyday sociocultural contexts. Thus, patienthood, as a concept, works to reflect how medical discourses seep into broader relational contexts. Brynn (fig. 1), whose art was discussed at the outset of this article, articulated “an inherent gap” between herself, her family and friends, and the broader public because of the illness she lives with. In her art, the public is represented by an image in the top left depicting two figures looking out over a cliff, while her friends and family are characterized by a hand reaching down toward her, with the accompanying text “Bigger than your existence.” Like the medical system discussed earlier, the representation of her social support system indicates that even those closest to her are unable to stop her free-fall toward the dagger (representing a bodymind event).

Both the cause and consequence of this “inherent gap” can be understood as the obscurity Price describes surrounding the “constitutive conditions of vulnerability” (2017, 4). An abundance of literature references the *inexpressibility of illness* (especially pain) (Scarry 1987), and chronic illness communities often comment on how no one understands chronic illness unless they live with it too (Whelan 2007). This sentiment came up in my study in that participants relied greatly on the support of friends and family who also lived with chronic illness. In this section, I consider the gap between patienthood spacetime and normative spacetime through cultural theorizations of disability and the material implications of how the broader public imagines disability and illness.

Disability scholars theorize ideologies of cure and compulsory abled-bodiedness that underpin contemporary understandings of disability (Clare 2017; McRuer 2006). Alison Kafer, for example, defines the curative imaginary as “an understanding of disability that not only *expects* and *assumes* intervention but also cannot imagine or comprehend anything other than intervention” (Kafer 2013, 27 (emphasis in original)). The broader failure of imagination to consider disability or chronic illness as a liveable or even desirable (Fritsch 2015) state of being perpetuates the feeling of distance that Brynn alludes to. This insidious form of ableism creates a chasm between crip spacetime and normative spacetime – evidently, a chasm that even the closest friends and family cannot overcome, as Brynn describes. The hand reaching down in the center of her collage, accompanied by the text “Bigger than your existence,” is an intriguing representation of this dilemma. While the participant means this to simply represent that their support system will never be able to cure their illness or do anything to make it better, it brilliantly articulates the general public’s inability to grapple with chronic illness.

Already having spoken to clinical invisibility, one must recognize that a lack of medical/clinical recognition has repercussions outside of the clinic (Moss and Dyck 2003; Johnson 2021). Feminist disability philosopher Susan Wendell (1996) draws on studies of chronic illness to conceptualize the phenomenon of “social abandonment.” Wendell describes how people living with chronic illnesses receive less support from family and friends while undiagnosed than post-diagnosis. Social abandonment, then, refers to the ways family and friends internalize the logic of clinical invisibility and distance themselves from their loved ones living with chronic illness. While Wendell’s theorization applies mainly to undiagnosed or contested illnesses, there is a broader trend of social abandonment happening for people living with chronic illnesses that takes different shapes depending on their specific illness and its sociocultural attachments. While diagnosis (read: clinical validation) plays an essential role as an access point to support from family and friends, we cannot ignore the broader existence and implications of the “queerly abject” spacetime of patienthood that Price references.

Even within disability studies, chronic illness has received limited attention compared to other disabilities. Following the logic of the social model, Oliver (1990) declared that disability is not about the body. However, this approach to disability hinders cross-coalitional ties between those with so-called impairments and those living with chronic illnesses. In some ways, this differentiation was strategic to achieve the aims of the social model and recognize that the "problem of disability" is, in fact located in the social environment and insist that "disability is not suffering, not misfortune, not tragedy" (Mollow 2014, 200). Scholars and activists disavowed chronic illness and the growing literature on sociology of illness, as it was very much about the body and largely referenced suffering and tragedy (Charmaz 2020). Critical disability studies made strides to expand its theoretical lens and attend to chronic illness, but this divide still has lasting effects. Anna Mollow suggests "the covering up of suffering and loss and the removing from view…*exclude ways of knowing*…that might also be described as disabled" (2014, 200). Further, Mollow writes that "disavowals of suffering thus block access to what is most disabling about disability: its unmasterability, its noncompliance, and its radical resistance to meaning" (2014, 200).

Figure 4: Alexandra's Collage

The sort of "removing from view" Mollow writes about is evident in the imagery used in a few participant artworks. First is Alexandra, a young Latina woman living with multiple skin and allergy conditions, (fig. 4), who, in the right upper part of her collage, includes objects such as a window with curtains and a blanket, bringing to mind the notion of being hidden away. Alexandra explained that, in part, these images represented her feelings of "missing out," especially as a teen, as her condition was often triggered by being outdoors or in other public spaces.

Figure 5: Presley's Collage

Presley, who lives with chronic migraines, (fig. 5) uses the same window. Further, two other participants used imagery related to the home – such as a model house and a bed – evoking the experience of being housebound. This containment became all too familiar for disabled people in the time of COVID-19. The imagery of being hidden away can be interpreted in several ways: as being housebound due to the physical limitations of their illness; as a lack of accessibility and active inclusion in public spaces and social events; or as other intangible affects that discourage people living with chronic illnesses from leaving their home (e.g., shame, anxiety). No matter what the cause, these visual representations of being "removed from view" signal how chronic illness becomes contained, limited to the private and personal realm, and fails to be taken up in generative and meaningful ways in the public sphere.

The consequence of the curative imaginary, and the historic failure of disability studies to theorize chronic illness, means that ways of fundamentally knowing chronic illness, of understanding and relating to it, are buried. While the cultural work of reclaiming illness and building collective epistemologies is underway (e.g., Wong 2020), chronic illness and, thus, patienthood remain invisibilized and unspeakable. Illness and all of its discomforts are relegated to the margins so that they might not impose their messy truths on the broader public. Liddiard and Slater describe this phenomenon through the lens of containment: “a dis/ableist desire to contain is to protect the body politic; to remove any threat of contamination and ensure the elimination of burden” (2018, 320). Drawing on Robert McRuer’s pivotal theory of compulsory able-bodiedness, they explain:

> disability haunts the naturalized order of ableism and terrorizes the cultural hegemony of compulsory ‘ableness’ (McRuer 2006, 9): the idea that ‘able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for’. In short, the threat of disability endangers the carefully constructed myth of the ‘able’ body and self which is foundational to a neoliberal social order where multiple forces are in play to keep all bodies ‘tidy’, manageable, and bound” (Liddiard and Slater 2018, 320–21).

Perhaps the COVID-19 pandemic is an illustrative example of the material consequences of our failure to imagine life with chronic illness. In the rush to return to “normal,” public health protections have been abandoned, and an epistemology of ignorance (Whooley and Barker 2021; Einstein and Shildrick 2009) has been assumed. In this rush, people with disabilities, especially those who are immunocompromised and face other intersecting forms of marginalization, are not considered. Nor are the many people who will contract COVID-19 and face long COVID or other post-viral chronic illnesses (Taquet et al. 2021). These kinds of policy decisions reflect a turning away from - a willful ignorance - and ongoing distancing from chronic illness informed by ableism (Sheppard 2021).

Aside from the clinical aspects discussed in the above section, the public (as well as political) inability to *recognize* chronic illness perpetuates the isolation of patienthood and foregoes the possibility of building and accessing any social supports that might ease the pain, incapacity, and suffering that sometimes accompanies living with chronic illness. In considering the ways patienthood and illness are conceived in our cultural imagination, it is possible to understand how the “bodymind event” is not contained to or produced by the sick body alone. In fact, the conditions that obscure the reality of patienthood and vulnerability also exacerbate and contribute to this very vulnerability. With this in mind, I turn to the lived experience of chronic illness in the next section to understand how the sick body shapes and is shaped by the spacetime of patienthood.

The material conditions of vulnerability

Following Douglas et al's call for disability studies to "re-embody its theories, which have tended (albeit for strategic political reasons) to evacuate lived experiences of impairment, pain and illness as matters left for medicine" (2020, 397), I attempt to account for the role of the sick body in contributing to bodymind events while, as Price (2017) notes, being careful not to reduce bodymind events to the body alone. It is also important to note that there are material conditions (e.g., environmental toxins, systemic oppression) that make certain bodies more vulnerable to becoming ill or disabled in the first place. Others have carefully attended to the subject (Smith 2021; Fritsch 2017; Puar 2017) and as such, I will not be going into detail on this aspect of illness here.

Nevertheless, the sick body is a central element of patienthood. The participants in this project, while focusing their art mainly on interactions with health care providers, made frequent reference to the sick body and its affective qualities. For example, participants included images and objects such as a pin-cushion doll - even circling different areas on the doll's body to reference intake forms that ask you to "circle where it hurts," and noting how they would circle almost every area of the body. Others, such as those who experienced migraines or brain fog, collaged atop a skull complete with chaotic, coloured scribbles to indicate the activation of pain in that area, or included dark clouds and other "fuzzy" shapes and textures. While it was clear that the focus of the art was the ways they had been treated due to the illness they lived with, the sick body was ever present. In thinking through crip spacetime and patienthood, a salient theme across the artwork, and indeed, across writing on chronic illness more broadly, is the "destabilization of the material body" (Moss and Dyck 2003). Living with chronic illness means enduring the unpredictable nature of illness, characterized by the fluctuating feelings, sensations, and capacities of the sick body. Elizabeth, a Filipina woman who struggled to receive a diagnosis for her illness, (fig. 6) illustrates these "material shifts" (McKenna 2021). She attached three different colours of stock paper together and indicated the colours are "attributed to the different levels of illness" she experiences. The intention with the art is for the viewer to rotate the artwork, so whichever "level" they want to look at is at the bottom. In this way, the distinctive spacetimes of illness and patienthood are centered and the viewer can fully engage with each level as a contained spacetime, or step back to consider the broader relationship between each level, and the ways they overlap and bleed into one another.

Figure 6: Elizabeth's Collage

In this particular artwork, imagery of the body is prominent. In the green layer, which the participant indicated represents when "I feel really good and picture perfect – and my limbs are working the way I want them to," the television is made to look like a face, with a sunflower for an eye and glossy red lips. Reaching out of the television are a pair of legs, and a hand, both smooth and reminiscent of a 1990s magazine ad. Notably, the hand reaches out and across to the red layer, while a cut-out that features on the blue layer overlaps onto the green, illustrating the impermanence of any given state of illness – the inevitably of shifting to another dimension of embodied experience. Similarly, the blue layer – representing when "things are not great" and the everyday is oriented to simply surviving - features cut-out eyes and lips, an anatomical model of the body, and other references to managing the sick body, such as food, pills, and a cartoon physician. Finally, the red layer is meant to represent their experience of diagnosis – featuring imagery that signals ongoing rupture and repair such as two hands reaching to touch together, except the participant has ripped through the middle so the hands are no longer touching; a body formed by a pincushion doll with a skull affixed to stand in for the head; and the face of a statue with their eyes covered with a slip of white paper with squiggled lines. What this artwork makes clear, is that patienthood is not a linear or predictable experience but an ongoing experience of material shifts that contrast starkly from the taken-for-granted spacetime an able-bodied person might inhabit.

While many of the artworks illustrate suffering and grapple with the pain and negative affects (Price 2015; Patsavas 2014) that are sometimes central to patienthood, the participants also pushback at these “negative ontologies of difference” (Douglas et al 2020) embodying a concept Douglas et al (2020) name “living dis/artfully” with illness. Here, I want to return to Alexandra’s artwork (fig. 4). Her art, in its many layers, textures, and colours, brilliantly recalls the dynamic experience of patienthood. While certainly, pain is alluded to through the imagery of an eye dropping large, blue tears, a face replaced by a skull, and again, the pincushion doll with x’s for eyes, these images are not central to the work, but instead, as much apart of it as everything else. In particular, I want to highlight the legs and hands on the right side of the image. This participant lives with a particularly uncomfortable and complex skin condition, however, she portrays the blemishes and marks on her skin with sparkling pink paper, next to a pink sky with the head of a sculpture and the word “aesthetic” covering its eyes. In the context of her discussion of her journey as a patient, these particular artful choices of portraying illness speak to an embracing of embodied difference, despite the hardships she may face. It is not my intention to romanticize illness or patienthood by highlighting this aspect of the artwork, but instead to recognize the multiplicities of patienthood, and importantly, to attend to the centrality of the body in this experience.

What these collages all make clear, is that the embodied experience of illness is entangled with social contexts, with the systems one must navigate as a patient, and the cultural scripts around illness and patienthood. In Elizabeth’s work, (figure 6), this is illustrated by the dedication of an entire layer of their work to the process and experience of diagnosis. Coyle & Atkinson (2019) understand diagnosis as a *practice of vulnerability* that “is constituted by inherent physical and mental bodily characteristics, from external structures of inequality and through medicine’s own institutional practices of diagnosis in the face of the challenges presented by the ambiguities and multiplicities of those living with a diverse range of symptoms (p. 278).” Some feminist scholars argue that vulnerability is an inevitable and universal feature of being human, inherent to our embodied being (Butler 2004), while also being careful to consider the ways in which policies, practices, and structural systems make certain groups of people *more* vulnerable, stressing that they are not inherently more vulnerable, but vulnerabilized (Tremain 2020; Carel and Kidd 2021). In the particular instance of patienthood, the inherent vulnerability of the body is “amplified” not through embodied difference or embodied difference alone, but importantly, by “external structures of inequality” *and* through the “practices of medicine” (Coyle and Atkinson 2019, 278). In Coyle and Atkinson’s configuration, vulnerability is relational, and present in specific spacetimes, and particularly activated when people have multiple chronic conditions (like all of the participants in this study) which challenge medicine’s understanding of the body as “stable, defineable and solvable”, and expose structural incapacities to provide integrated care that can account for more than one diagnosis (Coyle and Atkinson 2019, 285).

There are triggers external to the body that can incite a flare or exacerbate symptoms – incite a bodymind event. Social and structural systems (such as expectations and norms, stress, lack of supports, access to treatment) have significant consequences for navigating patienthood and may hinder one’s capacity to cope in and beyond a bodymind event. It is not the body alone that incites vulnerability or precarity, or the body alone that contributes to a bodymind event.

The Affective Shape of Bodymind Events

Figure 7: Sam’s Collage

Having thought through the contributing factors of a bodymind event, I now explore the affective shape this bodymind event takes, or how the “emergent meaning” of this situation arises “from the particular conditions of space and time” (Price 2017, 16).

Much as Brynn illustrates a freefall from light to dark, other participants invoked similar patterns of moving through spacetime. Sam, an Indigenous and non-binary individual living with chronic pain depicts, as they describe “a rabbit hole” (fig. 7): a green spiraling line topped with sharp triangular cut-outs. In the center of the spiral is a television, on which the participant has pasted handcut letters to spell out "LIAR". In the bottom left corner, they have pasted an imposing black and white eye.

The "rabbit hole" is a particularly salient spacetime of patienthood – a concept which resonated with many participants - and an apt metaphor to describe the bodymind event. In addition, participants summoned other similar imagery related to their journey of patienthood, such as "spirals", "free falls," climbing mountains or hiking difficult terrain, and cycling or shifting through different affective states. It is the rabbit hole I focus on here, as the embodied and affective shape a bodymind event takes.

A rabbit hole, as a metaphor, has many connotations and my use of the term requires some qualifications. Merriam-Webster defines a rabbit hole as "a complexly bizarre or difficult state or situation conceived of as a hole into which one falls or descends" and "*especially* one in which the pursuit of something (such as an answer or solution) leads to other questions, problems, or pursuits (n.d.)." Writer Kathryn Schulz notes that aside from the popular reference to internet rabbit holes, the original use of the term refers to a "disorienting alternate reality" and in more recent years, has even been used to mean a "downward spiral in mental health" and gained "a largely negative undertone" (2015).

The descent down the rabbit hole might start with a stressor experienced through the medium of the sick body, such as new or worsening symptoms. Participants spoke to the anxiety of a change in their condition and the uncertainty it brought. Often, this spurred them to seek care – *to pursue an answer or solution* – which was an emotionally-laden decision given past experiences of invalidation and invisibility in the clinic. The clinical encounter is a pivotal moment – where a practitioner can witness a patient's testimony or dismiss it. Chronic illness scholar Moss contextualizes this moment, where, a patient, "at the height of their (physical and emotional) vulnerability," is "expected to engage with biomedicine as the authority on health, leaving little, if any, room to resist, challenge, or refuse its dominance" (2016, 227). Jenna illustrates the disorienting affect of having repeatedly experienced invalidation (fig. 3):

> I chose to put it on the background of the coding stuff because I feel like it represents my anxiety dealing with all of it and that's what my head feels like when I walk into an office. Even though I've rehearsed it a thousand times,

> they throw a bunch of words at me and that's all I feel and see and I can't even collect my thoughts and sometimes I don't say anything because they've thrown all this stuff at me. And they ask me if I have questions but, of course, I have none because I don't know what I'm thinking.

Having not received the care she needs, the patient is left to figure out how to manage on her own – engaging in a variety of "desperate" strategies to make her everyday survival possible. In doing so, the original pursuit of an answer from a physician leads to "other questions, pursuits, and problems" (Merriam-Webster n.d.) While family and friends may be able to offer some support, ultimately, as Brynn stated, the rabbit hole is "bigger than your existence" and the cultural chasm as previously explained ensures a certain degree of separation – an "alternate reality" (Schulz 2015) - between the patient and her family and friends.

Participants illustrated the variety of pursuits they undertake to manage in this uncertain time. Reese (figure 8), who lives with chronic migraines and fibromyalgia, and struggled to be taken seriously because of her young age, depicts a vial of medicine, labelled with various methods of healing (therapy, specialists, massage, etc). In addition, a few participants featured food-related imagery to represent the use of specialized nutrition or alternative medicine as a

Figure 8: Reese's Collage

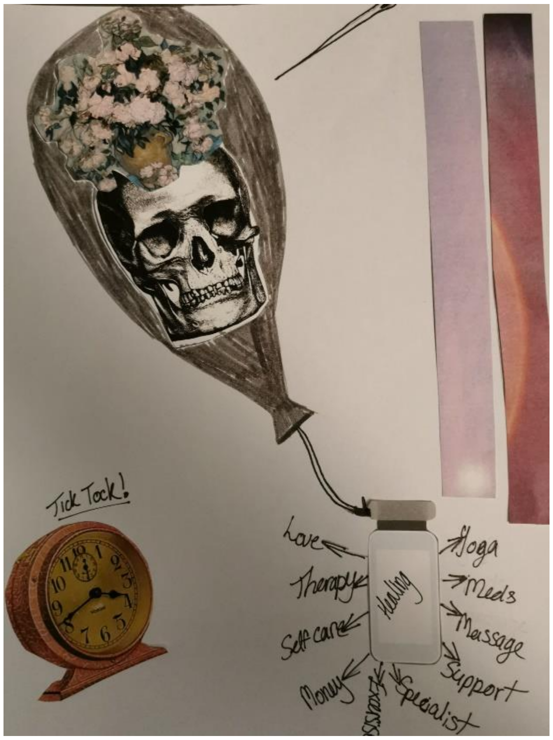

Figure 9: Wren's Collage

support. Others referenced “doing their own research” with the imagery of someone’s head tucked into a book or notepads with possible diagnoses. Such pursuits are necessitated by clinical invisibility and a lack of public supports for people with chronic illness. As Wren, a non-binary individual living with primarily neurological conditions portrays, they were not considered “disabled enough” to receive personal support services (fig. 9). Their collage thus, illustrated the many paths (like that of a rabbit hole) they have traveled in their journey of patienthood – such as the spiritual, the medical, the relational and so forth – in attempt to bring some ease into their life. Ultimately, all participants evoked some sort of imagery of “going beyond” the reality afforded to them through conventional solutions (e.g., medicine), as pictured in fig. 9, representing again, the disjuncture between normative spacetime and patienthood and the lengths one must go to compensate for this distance.

In addition to the practical management of illness, there are considerable “affective impacts” (Price 2017, 10) represented by the rabbit hole. In some ways, having travelled a seemingly never-ending path in search of a solution, the rabbit hole represents feelings of hopelessness and helplessness (Coyle and Atkinson 2018). It invokes a kind of embodied knowing and anxiety – a “complexly difficult state” (Merriam-Webster n.d.) of having experienced this spacetime before and dreading what’s to come - the always looming dagger that Brynn’s collage illustrates. The participants expressed the internalization of clinical invisibility and societal messaging around illness, exacerbating the already existing difficulties of patienthood by perpetuating guilt, anxiety, shame and self-doubt.

Amid the challenge of ongoing marginalization, participants retained a sense of hope for the future, anticipating an end to the rabbit hole. They drew on hope as a means of empowerment and remaining positive, and often, indicated this forward-looking orientation as a core part of themselves. These ‘positive’ aspects are represented throughout the artwork, as participants explained, predominantly through the use of the colour pink, and incorporating pleasing imagery such as sunrises, flowers, and other welcoming landscapes.

The critical point to make about the rabbit hole or bodymind event, is that, if the factors discussed throughout this paper were remedied, the bodymind event would be less of an “event” and the negatively charged rabbit hole might not be the metaphor of choice to encapsulate this experience. If people with chronic illnesses were valued and supported in the clinic and in the broader social sphere, the supports required to manage a destabilization of the material body would exist and be accessible. Much as Haagaard (2022) argues of invisible disability, indeed, the "radical inequities" (Price 2017, 10) of patienthood are socioculturally produced and exacerbated, not merely the result of a malfunctioning body.

Conclusion

In this paper, I argue that patienthood constitutes a particular orientation to space and time. Specifically, this spacetime is shaped by the experiencing of, and ongoing anticipation of, a bodymind event – a "sudden debilitating shift in one's mental/corporeal experience"(Price 2017, 15). A bodymind event is produced and exacerbated by social, cultural, structural and material factors. The first factor I describe is the invisibilization of chronic illnesses in the medical clinic (Haagaard 2022), where participants struggle to be recognized and supported by medical professionals when seeking care. I argue that this lack of regard for individuals with chronic illness extends into the public sphere, resulting in social abandonment and further marginalization of people living with chronic illnesses (Wendell 1996). I then attend to the embodied experience of patienthood via the material conditions of the sick body, noting that structural inequities often produce and sustain bodies as sick. These factors interact to perpetuate patienthood as a precarious and vulnerable social position. Drawing on participants' spatial metaphors, I relay the bodymind event as a "rabbit hole" – an affective spacetime marked by anxiety, isolation, helplessness, and clinging to hope.

Patienthood is not an inherently vulnerable or precarious position due to an unpredictable body. Instead, it is the embodiment of a complex array of social, cultural, and material factors that isolate people living with chronic illnesses and perpetuate precarity. By understanding patienthood through the bodymind event and the metaphor of the "rabbit hole," we can identify a number of entry points to mitigate the contributing factors to vulnerability and precarity. Much of this work can be localized to medicine, and the power of medicine in shaping access to care and support for people living with chronic illness. However, medicine both influences and is influenced by social and cultural forces. A re-imagining of chronic illness – one that moves away from individualizing and isolating discourses – is required to affirm the experiences of people living with chronic illness and facilitate inclusion and access in the broader public sphere.

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Discussion & Conclusion

This study sought to explore how women and gender minorities living with chronic illnesses understand and experience patienthood. While this is a question that might have many answers, in this study, I conclude that patienthood 1) is marked by a particular orientation to space and time that differs from people who *do not* live with chronic illnesses, as well as the normative spacetime medical systems expect patients to inhabit and 2) that medical invalidation is a central experience of patienthood and has significant consequences for people with chronic illnesses both in and out of the clinic. Further, I put forward the illustrative metaphor of the "rabbit hole" as a means of bringing these findings together and demonstrating the embodied, affective experience and impacts of medical invalidation.

The findings of this study reflect many of the themes present in literature on the subject. All of the themes I discussed in my literature review – the importance of effective communication; the unique psychosocial dimensions of living with chronic illness; challenges of self-management; and stigma - came up in my study, though some were more prevalent than others. In this way, my study confirms much of what has been raised as pertinent issues to chronic illness and the clinical encounter previously.

Effective communication is a critical component of health care interactions, and indeed, my study confirmed this. Like other studies,[16,46] feeling "heard" and as though their knowledge was valued by their physician was an ongoing concern for participants. Most of the literature focuses on the "micro" aspects of exchanges between a patient and their doctor, such as explaining concepts in a clear manner. My study, however, pointed to more fundamental issues in the clinical encounter, embedded in power systems inherent to health care – forms of "symbolic violence"[47] and "dehumanization and discrimination"[17] mentioned by Townsend (2012) and Clochesy et al (2015) respectively. What my study showed, is that communication is always already constrained by social norms, cultural discourses, and power dynamics, as well as material forces, such as what resources are available to a physician in any given appointment. These resources can include the time available to a physician per appointment or the demands of their caseload, resulting in participants feeling like they were "just a number" and never had enough time to get to the issue at hand. As a result, participants used careful strategies to maximize their "airtime"[113] and ensure they were taken seriously. Few of the studies in my literature review looked at these strategies in depth, though scholarly attention on the subject is increasing.[113]

The psychosocial dimensions of living with chronic illness were ever present in my study. As is prevalent in the literature, participants expressed being frustrated and exhausted by the demands of managing their health, feeling isolated from those around them, struggling to deal with uncertainty, and the importance of a strong support system. Often, in the literature, these difficulties are presented as an inevitable part of living with chronic illness. However, my study reveals that health care interactions play a role in either mitigating or exacerbating the psychosocial burden of living with chronic illness. The care participants received impacted how they made meaning of their illness experiences and had a direct impact on their emotional and mental wellbeing. While the literature is clear that there are considerable unmet psychosocial needs for people living with chronic illnesses, it pays less attention to the ways inadequate and invalidating care produces unnecessary suffering.

The literature on self-management and models of care emphasizes the importance of “patient engagement” and empowerment in achieving good health outcomes. A small number of articles criticize this discourse for ignoring the structural factors that limit patient agency and empowerment and create barriers to self-management. Like these studies, my research points to the need for a critical consideration of the context in which patient empowerment and self-management is to occur. Participants in my study were well aware of the responsibility put on them for self-management, while noting that there was a significant lack of resources available to help them succeed in this endeavour. While the shortcomings of self-management discourse are present in my study, it also recognizes the creativity, resourcefulness and resistance evident in the ways participants respond to structural and systemic barriers to self-management. Further, it highlights how participants reclaim their agency in small but significant ways, such as sourcing information and care strategies from their community.

Stigma is an ongoing issue and barrier to care for people living with chronic illness. In the literature, stigma is associated with specific diagnoses or social locations. This was the case in my study, where participants from groups marginalized in medicine experienced and expected to experience stigma and discrimination, and it was especially the case for those living with rare or poorly understood diagnoses. Stigma is also cited as a reason patients avoid care, and certainly this was reflected in my study. In the clinical encounter, patients use strategies to emphasize their “cultural health capital”[74,77] and this too was an important part of the health care experiences of participants in my study. My study diverges from the literature in that it considers chronic illness broadly as a stigmatized social position, instead of a phenomenon that is only attributed to specific diagnoses and identities. It pushes the conversation toward consideration for the broader social and cultural systems that shape patient experiences to understand how stigma is produced and perpetuated in the broader public sphere and seeps into medical practice, and vise versa.

Study Contributions

My aim was to move beyond understanding the clinical encounter as a singular interpersonal interaction and situate health care interactions for people with chronic illness as 1) influenced and embedded in the broader sociocultural context and 2) an ongoing, repeated occurrence, reflecting the temporality of living with chronic illness. There are a few other studies who have done similar work, or at least, pointed to the importance of studying the experiences of chronically ill patients in the clinical encounter in this way.[47,51,69,80,81] Still, my study has some unique features and findings to recognize.

First, the population of individuals who participated is important to recognize. Though there are many studies on the health care experiences of populations marginalized in medical research and practice, there are few that conceptualize living with chronic illness as a marginalized positionality. Further, most studies on chronic illness tend to focus on a specific diagnosis while this study took a broader approach in effort to generate findings that can be leveraged as a means of coalition-building across diagnoses, illness experiences, and disability types. Study participants embodied a range of gender identities, race and ethnicities, socio-economic statuses, and diagnoses. All participants lived with multiple chronic illnesses, which has been a focus in other studies and increasingly an important emphasis in research on chronic illness, however, the age demographics of young adults (in this case, ages 20-35) is unique to this study (most studies on multiple chronic conditions look at older adults). As far as I know, this is one of few studies that looks at this specific subset of the population in Canada, and most certainly the only in Manitoba.

Second, the methodological approach sets it apart from other studies on chronic illness and the clinical encounter. While both critical disability studies (CDS) and arts-based/arts-informed methods respectively are gaining traction in health research, there are few that use these approaches in tandem to study the subject at hand – although there are some notable exceptions. The combination of a critical approach with arts-based methods makes space for new ways of understanding and knowing patienthood and chronic illness. The embodied process of creating art, through the careful curation of colours, textures, images, and metaphors, to represent experiences allowed participants to create layered, embodied, and affective representations of their healthcare encounters and illness narratives. In doing so, they accessed insights that they would not have through more conventional methods (as expressed in our group discussion). Framed by my introduction to the project and its crip lens, participants astutely spoke to the implications of gender, the body, disability, illness, race, and power as it related to their experiences of health care and their everyday lives. Concurrently, CDS and arts-informed methodologies generate "cripistemologies"[125] and especially in the gendered context of chronic illness, "criphystemologies"[126] that challenge the normative cultural ideas underpinning medicine's conceptualization and treatment"[127] of embodied difference. In this way, the study did not merely engage with medicine and disability as topics but worked to crip and queer the way medicine conceives of illness and disability altogether.

In terms of findings, this is the only study I know of that sought to empirically study epistemic invalidation in the context of chronic illness. This study explicates the psychosocial consequences faced by people with chronic illness as they navigate *repeated* clinical encounters, with no end in sight. The first manuscript focuses on invalidation in the clinical encounter and is directed to a physician audience, and the second aims to make interdisciplinary ties as it uses critical disability studies to explore the concept of "patienthood" put forward by medical sociologists. Taken together, the papers demonstrate the undeniable power of medicine in the lives of people with chronic illness, and how the management of chronic illness is entangled in sociocultural systems. Further, they emphasize the significant consequences of invalidation, both in the medical setting and the public sphere, that ripple through all facets of the participants' lives. If anything can be taken from this study, it is that we require greater supports for people living with chronic illness, that go *beyond medicine* and involve a fundamental shift of how we imagine chronic illness. What this study reveals, is that creating the conditions to live well with chronic illness is not merely about accounting for the idiosyncrasies of a sick body but addressing the complex sociocultural factors that exacerbate symptoms and isolate people living with chronic illnesses from services and social supports.

This project provides further evidence of the need to integrate – and take seriously – critical health humanities in medical education and practice. The participant recommendations alone speak to the necessity of person-centered care and the importance of so-called soft skills in medical practice, such as empathy, humility, compassion, and critical thinking. Yet, this is not enough. When I first started developing the idea of this project, I thought all that was needed was for patients to feel empowered to advocate for themselves, and for doctors to listen better. In completing this project however, my thinking has certainly changed, and I've come to realize that these 'soft skills' are just the start, and we need to go far beyond them to enact sustainable and meaningful change. Medical practice needs to be able to embrace complexity and uncertainty, to think *with* embodied experiences, and to move beyond the dichotomies that currently characterize diagnostic practice and truly, medicine as a whole (to name only a few factors!). I am not the first to have this realization – there are entire bodies of scholarship; a lineage of activists, community members, academics, cultural workers, and medical professionals dedicated to decolonizing medical practice and undertaking this slow and careful work. I hope to at least have contributed in a small way, through demonstrating the utility of feminist, queer, and crip thinking about chronic illness, patienthood, and medical practice.

Limitations

My study has a few limitations to acknowledge. First, I did not recruit as many participants as I had hoped. Although data saturation did occur, a greater number of participants may have allowed for more depth, and achieve the inclusion of counter-themes and contrasting experiences that I had originally aimed for. As I raised in the first manuscript, the study did not address physician perspectives, and while I acknowledge this would be a valuable addition, in keeping with my critical feminist orientation, I explicitly sought out and foregrounded the perspectives of "patients," as they hold less power in the clinical relationship. Third, although I collected demographic information, I feel short interviews with each participant following the workshops would have been helpful in better contextualizing their experiences, especially pertaining to power dynamics along the lines of race, class, gender, and other salient social factors. Yet, the workshop style of the study was time intensive, and I do wonder if adding interviews would have made the project less feasible for a master's thesis.

Additional Findings & Future Directions

The artwork and group discussions generated many rich insights. It was not possible to address all of the themes and counter-themes that came up in the study in two manuscripts alone, so here I give a high-level overview of what some of these other themes were. In the future, I hope to develop and/or publish some of these findings.

In the artwork, themes of medical surveillance and objectifying/quantifying the human body came up frequently. There is extensive literature that takes up these concepts but it would be worth revisiting to see if the findings of this study may add anything new.

While briefly acknowledged in the first manuscript, participants engaged in a variety of strategies to manage their illnesses amidst inadequate care. They used metaphors in their artwork like “going beyond” to reference the ways that the health care access they had was never enough. Further study of these strategies would reveal the incredibly brilliant ways people with chronic illnesses cope and carry on, as well as point to areas where wraparound services beyond medical care could better support this population. These experiences could also be analyzed through critical disability studies concepts of the “supercrip” and narratives of overcoming and individual willpower that are prevalent in the neoliberal context.[128]

I also found that there were important psychosocial and emotional dimensions, not only to living with chronic illness, but navigating medical care, invalidation, and the consequences of negative health care encounters. Again, I do mention this in my manuscripts, however, the considerable emotional labour required of participants and the mental health repercussions of living with chronic illness and navigating medical care deserve further attention. This ties into the aim of my project to consider how navigating healthcare might be a traumatic experience. Participants framed their experiences as traumatic and a potential participant even withdrew from the study shortly before the workshop, explaining that they weren’t ready to re-visit the traumatic nature of their healthcare experiences.

I spent considerable time analyzing the data through Angela Carter’s crip conceptualization of trauma, which defines trauma as an “embodied, affective structure” that has “attributes of instability” related to time and space, subjectivity, and knowledge.[129] The participants’ experiences of patienthood resonate with this understanding of trauma, and I explore the “affective, embodied structure” of space and time through the metaphor of the "rabbit hole" in my second manuscript. Participant discussions of medical invalidation – as a type of epistemic injustice – make ties to their embodied knowledge and subjectivity as well. Although there was not room to develop this line of analysis in my manuscripts, I hope to write a third paper in the future that addresses trauma more fully.

I aimed, as stated in one of my objectives, to "examine the potential of arts-informed health research as a transformative practice." While I do believe the project achieved this objective, and participants remarked on the incredible value of exploring their experiences via the creative process, a dedicated study to exploring the use of artistic practice and processes in the context of chronic illness would be helpful to generating rigorous data on the subject.

Concluding Thoughts and Reflections

As I alluded to above, undertaking this project, and my master's degree as a whole, has significantly challenged and transformed my thinking. I am grateful to have had the time to think deeply and carefully about chronic illness and all that comes with it, although I still can't help but feel there is so much more to read, to learn, and to think about. The experience of completing my first research project has been both overwhelming and humbling. I am honoured that my participants and patient partners were willing to share their stories with me, so I want to acknowledge this and thank them for their important contributions. I can only hope I did their stories justice, and wish I had more time to spend with their words and images. I was certainly not prepared for the intensity of the workshops: the emotions that welled up when listening to participants' stories, the solidarity felt and expressed among participants and myself, the injustices and needless hardships they endured, and the brilliance of their art and insights.

In completing this research, I was often overwhelmed by the sheer scope of the work that is yet to be done. In the context of COVID-19, this has been made especially clear, as the ableist impulses of medicine, public health, and the broader public have pervasively circulated in public discourse. At the same time, I am heartened by those who are actively challenging such discourse and imagining affirming futures for disabled, sick, mad, and crip folks to flourish. If the alternative is apathy and despair, I am glad to have spent most of my time and energy on this project over the last two years. While I do hope the publications reach their intended audience and beyond, if even one or two people can take something away from what I've written here, that is something. If not, I know I facilitated a meaningful space for fellow chronically ill folks to come together, to be in community, to create, and to bear witness to each other’s stories – an experience that will carry beyond the four hours we were together. Sometimes, that is enough - enough to sustain us as we keep moving toward change.

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Appendices

Appendix A: Literature Review Search Strategy

The following searches were conducted on the University of Manitoba's library database. The abstracts and titles of all searches were scanned for relevance to my study, based on their whether they addressed the experiences of adults with chronic illness in the clinical encounter.

- Search Terms: "chronic illness" AND "disability studies" AND "empirical"
  Filters:
    - Language: English; Type: Peer-reviewed articles; Publication date: 2011-2021
    - Excluded literature reviews.

  = 340 results

- Search Terms: "chronic illness" AND ("arts-informed" OR "arts-based") 296 results
  Filters:
    - Language: English; Type: Peer-reviewed articles; Publication date: 2011-2021
    - Articles related to art therapy, pediatric populations, and caregivers/family members of a person with chronic illness were excluded. Study protocols, literature reviews, and evaluative tools were excluded

  = 296 results

- Search Terms: "chronic illness" AND "clinical encounter" AND "empirical" AND "qualitative"
  Filters:
    - Language: English, Type: Peer-reviewed articles, Publication date: 2011-2021
    - Articles in the field of cognitive science, disease prevention, pediatric populations, or palliative care were excluded, as were study protocols and literature reviews.

    = 252 results

- Search Terms: "gender" AND ("chronic illness" OR "chronic conditions") AND "qualitative" AND ("clinical encounter" OR "patient-provider") NOT "review"
  Filters:
    - Language: English, Type: Peer-reviewed articles, Publication date: 2011-2021
    - Articles focused on pediatric populations, medical education or health professional training, end-of-life care, as well as study protocols and validation of tools were excluded.

    = 128 results

Appendix B: Art Activity Guiding Questions

Art Activity

Portraits of Patienthood - Mixed Media Collage Self-Portrait

Instructions: Using the supplies given to you, and any other materials you might have in your home, create a collage portrait that represents your experience as a patient. There are no rules or right/wrong way to do this! Feel free to experiment and be creative.
Prompt: *What does being a patient mean to you? What is your experience of patienthood?*

Questions to consider while making your art:

- What are some of the pivotal experiences you've had as a patient?
- Does your idea of yourself as a patient differ from your usual self? What is the difference?
- What feelings and memories come to mind when you think about your experiences in healthcare, as a patient?
- What do you want to communicate about your experiences in healthcare? Is there a certain mood, experience, or emotion you want to capture?
- Are there certain colours, textures, or shapes that could represent key aspects of these experiences?
- Are there visual metaphors you could use to illustrate your experience? Objects or images that might relate to your experiences of patienthood?