

**Patient agency and system constraint: a qualitative thematic study of women in
early adulthood managing chronic illness in Ontario**

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Abstract

This study explored how women in early adulthood living with chronic illness exercised agency in navigating Ontario's health care system. Eight women aged 18 to 35 took part in semi-structured interviews, analyzed using reflexive thematic analysis. Participants were both highly agentic and highly constrained: they researched their conditions, coordinated between providers, sought second opinions and pursued private, alternative or overseas care, while remaining dependent on clinicians for referrals, investigations and treatment. Many concealed their health knowledge to preserve credibility, understood their health relationally through partners, mothers and online communities, and withdrew from care as self-preservation after repeated dismissal. Employment conditions and the cost of uninsured services shaped what participants could manage. The study characterized this as compensatory care, in which patients absorbed the work of a fragmented system, and argued that reducing patient burden and recognizing patient knowledge were distinct objectives.

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Disclosure — Researching from within the system

I am a patient navigating the same health system I am studying, and a peer of the women whose voices I strive to make visible. The selection of this topic for my Major Research Project is deeply personal and affirming of my lived experiences. I am also a policy analyst and system designer, and recognized before this project that the existing mechanisms triggering changes to health care provided in Ontario and in Canada rarely take into account the lived experiences of patients, and when they do, it is often retrospective. However, because of my policy and systems work, I also know that change is possible. This position has shaped what I pay attention to when listening to the experiences of participants and peers, and their expectations of a health system in which patients are at the centre.

Our health system is situated in a broader social, political, and economic context wherein knowledge and realities emerge through friction between people, systems, histories, and beliefs. As a researcher and as a chronically ill person, I recognize that current approaches to evaluating our health system's efficacy and patient experiences fall short in part because these approaches don't recognize lived experience as foundational knowledge missing from the broader body of health research. Beyond this epistemological distinction, my first-hand experience enables analytic attunement to tensions, dissonance, and opportunities that may otherwise remain unarticulated within traditional policy or clinical frameworks.

As a patient-researcher, this work was not without a personal cost. Conducting this study took a major toll on my health; whether it was holding stories of pain and adversity experienced by other women, reminders of my own challenges, or frustrations with the institutions meant to help us, I crashed following my interviews. Because my relational approach does not withhold empathy and prioritizes connection with participants, I felt attached to the stories of my participants and had an overwhelming responsibility to convey their challenges and aspirations in a manner that honoured their voice.

I have come to recognize this as illness work in and of itself; the act of making visible the invisible illness work of navigating chronic illness without material reward, outside the bounds of transactional care and system design. And like many graduate research projects, this work was unpaid. Because of that, I had freedom to steer the interests I would pursue to be in favour of my participants and other women in early adulthood navigating chronic illness in Ontario. This work is personally deeply rewarding and morally aligned. I have also come to learn that it is timely and needed in an era of encroachment on public health care, normalization of misogyny, and collective demand for responsive health care in our province. While I internalized the stories of struggle and suffering, I was comforted by the sheer perseverance, hope and strength emblematic of every single participant.

Introduction

This research explores how women in early adulthood, aged 18 to 35, living with chronic conditions enact agency in navigating fragmented health care systems. Fragmentation has been identified as a barrier to effective chronic illness management, arising from systemic silos, inadequate continuity and gender bias. Women in this age group encounter particular challenges: delayed diagnosis, dismissal of symptoms, and difficulty transitioning from pediatric to adult care. These are often compounded by medical misogyny, understood as the systemic minimization of women's symptoms within biomedical contexts (Samulowitz et al., 2018).

Existing research shows that women with chronic conditions perform extensive illness work — coordinating care, managing medications and interpreting conflicting advice — that remains largely invisible within medical frameworks and unrewarded economically, while also constituting a form of agency and self-management (Corbin & Strauss, 1988). Online communities have extended this work beyond clinical institutions, becoming informal sites of peer education, advocacy and emotional support (Liu et al., 2018).

This study understands agency as the capacity to act within and against systemic constraints. Examining where and how women exercise it makes visible both the constraints they encounter and the ways they informally reconfigure care to meet their needs, offering a basis for health system and service design grounded in lived experience (Bardzell, 2010; Robertson & Simonsen, 2012). A focus on agency does not imply that patients should be responsible for overcoming health system failures. It is precisely the opposite: attending to the work patients undertake reveals where existing systems rely on them to compensate for gaps in care. This is a pressing question as Ontario considers how its health care system can become more responsive to changing patient and community needs.

This research therefore asks how women in early adulthood living with chronic illness exercise agency in navigating Ontario's health care system, and what their adaptations reveal about the conditions that enable or constrain that agency. Three subsidiary questions follow: how participants access and move through care; how their knowledge and credibility are received in clinical encounters; and how they respond when formal systems do not meet their needs.

Research methods

Research approach and epistemological positioning

This study used a qualitative, patient-led research approach to explore how women in early adulthood living with chronic health conditions navigate Ontario's health care system. The research sought to understand these experiences from the perspective of patients themselves, with particular attention to how participants accessed and moved through care, how their knowledge and credibility were received in clinical encounters, and how they responded when formal systems did not meet their needs.

A qualitative approach was selected because the study was concerned not only with what occurred during participants' health care journeys, but with how participants understood and made meaning of these experiences. This allowed for exploration of experiences that may be difficult to capture through administrative or quantitative health system measures, including feeling believed or dismissed, the work involved in navigating care, changing relationships with providers, and the development of patient knowledge and self-advocacy.

The study was patient-led in that the research was conceived, designed, and conducted by a researcher with lived experience of chronic illness and health system navigation. This positionality informed the research questions and provided an experiential understanding of many of the issues explored through the study. Patient-led research was not understood as a replacement for established research methods, but as an approach that influenced which questions were considered important and how patient experiences were understood and interpreted.

This approach also reflects an epistemological position on whose knowledge is recognized in health research. Patient-led research shifts the locus of agenda-setting by recognizing patients as uniquely placed to identify knowledge gaps, develop research questions, gather and interpret data, and mobilize findings. Wilson's (2008) understanding of knowledge as relational and research as a process of accountability to the relationships through which knowledge is produced informed this position. While Wilson's work is situated within an Indigenous research paradigm, his emphasis on relationality provides an important consideration for patient-led research: knowledge of health is produced through relationships with our bodies, providers, health systems, families, communities, and other patients. In this study, lived experience was therefore approached not simply as information about encounters with the health system, but as a form of knowledge produced through sustained interaction with that system.

Research positionality

My relationship to the subject matter was integral to the patient-led nature of the research. My lived experience provided familiarity with many of the processes, frustrations, and forms of illness work described by participants, while also creating the possibility that I could assume similarity between participants' experiences and my own or place greater significance on experiences that resonated with me.

Of course, my experiences, feelings, and beliefs are not universal. Part of the exercise of reflexivity is ongoing observation of assumptions, rejections, and internal amplifications of participants' perspectives and journeys against my own to ensure I am hearing their experiences in their voice. During interviews, it was important to me that most of the time was spent listening and allowing participants to prioritize topics and stories of importance to them, while checking in on my assumptions in real-time.

This reflexivity continued through analysis. I paid particular attention to moments where I strongly identified with, disagreed with, or was surprised by participants' accounts and considered how these reactions could influence coding and interpretation. My lived experience was therefore treated neither as a source of bias to be eliminated nor as a source of authority, but as part of the interpretive position from which the research was conducted.

Literature review and analytic lens

The initial area of inquiry emerged from lived experience navigating chronic illness and the health care system. A review of the literature was subsequently used to situate these observations within existing knowledge, identify where they had previously been examined, and distinguish individual experience from potentially broader health system issues. The review included academic literature related to women's experiences of health care, chronic illness and disability, patient-provider relationships, health system navigation, illness work, patient advocacy, and patient engagement and leadership in health research.

The literature review was iterative and continued alongside the primary research, allowing participant experiences and existing scholarship to inform one another throughout the research process. It was not intended as a systematic or comprehensive review of available evidence, but rather to situate participants' experiences within a broader health system and research context and identify areas where the literature aligned with, differed from, or did not adequately account for their experiences.

The interpretation of findings was informed by critical feminist theory, intersectionality, Sen's capabilities approach, and Lundberg and Chen's (2024) framework of structural

ableism. These frameworks were not used to establish predetermined coding categories, but were introduced during interpretation to consider how participants' experiences were shaped by gendered power relations, intersecting social positions, individual agency, and broader institutional conditions.

Critical feminist theory informed attention to the ways gendered assumptions, power relations, and norms shaped participants' interactions with health care providers and institutions, particularly in relation to credibility, knowledge, autonomy, and the normalization or dismissal of women's symptoms. Intersectionality informed the position that women's experiences of health care are not uniform and that gendered inequities are shaped by disability, socioeconomic circumstances, age, race, sexuality and access to resources. It was used here to resist treating participants as a homogeneous patient population and to remain attentive to the material and social conditions participants themselves identified as consequential, rather than as the basis for a systematic analysis of how these positions differentiated participants' experiences. The study did not collect standardized demographic data on these characteristics, and the sample size would not have supported comparison across them.

Sen's capabilities approach supported examination of the relationship between participants' agency and the conditions that enabled or constrained their ability to achieve desired health and life outcomes. This distinction was particularly relevant to participants who undertook significant illness work, developed knowledge of their health, advocated for themselves, and adapted their approaches to seeking care, while remaining dependent on providers and health systems for access to investigations, referrals, treatments, and other resources.

Lundberg and Chen's (2024) proximate pathways of structural ableism provided a further lens for considering how interactions with health care and other systems could reinforce or compound these constraints, including through disability-incompetent and non-affirming care, chronic stress, trauma, and coping. Together, these analytic lenses allowed participants' individual actions and adaptive strategies to be considered in relation to the broader social, institutional, and structural conditions in which they occurred.

Interview participant recruitment and sample

Eight women aged 18 to 35 living with chronic health conditions and currently residing in Ontario were recruited to participate in the study. This population was selected because women in early adulthood living with chronic illness may experience gender bias, fragmented care, and transitions within the adult health care system, while also taking an increasingly active role in navigating their care and advocating for their health needs.

Participants were recruited through OCAD University's Graduate Studies listserv, social media, and word of mouth. Interested participants completed a brief screening by email or online to confirm eligibility based on three inclusion criteria: being between 18 and 35 years of age, currently residing in Ontario, and self-identifying as living with a chronic health condition. Medical documentation or verification of diagnosis was not required, consistent with the study's emphasis on participants' lived experiences. Requiring medical verification would also have risked excluding experiences of diagnostic uncertainty or misdiagnosis that were directly relevant to the research inquiry. Individuals who met the inclusion criteria were invited to proceed to the informed consent process.

The target sample of 8 to 10 participants prioritized depth and diversity of lived experience rather than statistical representativeness. The objective was not to generalize the findings to all women in early adulthood living with chronic illness in Ontario, but to explore shared patterns, differences, and tensions across participants' health care journeys.

Participants took part in semi-structured interviews lasting approximately 45–60 minutes, conducted online. Semi-structured interviews provided a consistent set of areas for exploration while allowing participants to describe their experiences in their own terms and introduce issues that were important to them. Interviews explored participants' experiences of seeking and receiving health care, including diagnostic journeys, access to primary and specialist care, relationships and interactions with health care providers, continuity and coordination of care, and experiences of advocacy and self-navigation. Participants were also asked about how they understood their own health, accessed health information, made decisions about seeking care, and responded when they felt their needs were not being adequately addressed. Questions also explored the broader contexts in which participants managed their health, including relationships, education, employment, life transitions, and the formal and informal supports they drew on when navigating care.

The interview format was intentionally conversational. Rather than approaching participants solely as subjects from whom information was extracted, interviews provided space for reflection on experiences that were often complex, longitudinal, and difficult to separate into discrete health system encounters. Follow-up questions were guided by participants' responses, allowing participants to place greater emphasis on experiences they considered significant to their own health journeys rather than requiring each interview to follow an identical sequence.

With consent, interviews were audio-recorded and transcribed verbatim. Participants could decline to answer any question or end their participation at any time.

Data analysis

Interview transcripts and fieldnotes were analyzed using reflexive thematic analysis to identify patterns in how women in early adulthood experience and navigate fragmented care. Coding was primarily inductive, with attention to how participants described agency, barriers to care, self-management, and strategies of advocacy and adaptation.

Analysis was iterative and involved familiarization with the data, initial coding, development and refinement of themes, and interpretation in relation to the research questions. Individual accounts were first considered within the context of each participant's broader health journey before patterns were considered across the dataset. Initial codes remained relatively close to participants' accounts before being examined for broader patterns, relationships, and tensions. Themes were subsequently developed and refined through repeated movement between coded material, individual accounts, the broader dataset, and the research questions.

Coding proceeded in two stages. Transcripts were first coded manually, with each transcript coded in full before moving to the next. Approximately 60 codes were generated at this stage, developed inductively from participants' own language and framing and labelled descriptively. Given the volume and richness of the material, and the number of codes to be applied consistently across the full dataset, this codebook was imported into MAXQDA and the software's AI-assisted coding function was used to apply the existing codes systematically across all transcripts.

The codebook was developed manually and was not generated by the software. AI-assisted coding was used to identify further instances of codes already established through manual analysis, rather than to determine which codes existed or what they meant. All software-applied codes were reviewed against the original transcript extracts. The results were largely confirmatory, aligning with the coding already undertaken manually. Where the two diverged, it was consistently through omission: the software applied codes reliably where participants described an experience directly, but missed indirect and implicit statements in which meaning was carried by understatement, hesitation or what participants left unsaid. These instances were retained through manual review. Codes were subsequently clustered into candidate themes, which were reviewed and refined into the eight themes presented below, with theme development, refinement and naming undertaken manually throughout.

In addition to recurring experiences of access, fragmentation, relationships with providers, credibility, and knowledge, analysis attended to participants' emotional tone,

key touchpoints with the health care system, and instances in which participants resisted, adapted to, or informally redesigned aspects of their care. Particular attention was given to how participants constructed autonomy within their health care journeys, including the work they undertook to research their conditions, coordinate care, advocate for further investigation or treatment, and respond to gaps in formal systems of support.

Tensions and apparent contradictions were retained as analytically meaningful rather than requiring resolution into a single account of patient experience. This was particularly relevant where participants demonstrated considerable knowledge, agency, and capacity for self-management while simultaneously describing limited control over the investigations, treatments, referrals, and other forms of care available to them.

The limitations of the software-assisted pass are themselves consistent with the methodological position taken here. Much of what participants conveyed about credibility, resignation and the cost of seeking care was communicated indirectly, and identifying it depended on interpretation rather than on the presence of particular language. Consistent with reflexive thematic analysis, themes were understood as interpretations developed through the researcher's engagement with the data rather than as objective categories that simply emerged from the transcripts. The analysis therefore did not seek thematic consensus or a single representative account of women in early adulthood's experiences of chronic illness. Differences between individual experiences were retained alongside shared patterns to reflect the diversity of participants' care journeys. The frequency of an experience was also not treated as the sole measure of its analytic significance; experiences that illuminated important tensions or features of health system navigation could remain relevant even where they were not shared by all participants.

Following the primarily inductive development of themes, the literature and analytic lenses described above informed their interpretation. Critical feminist theory and intersectionality supported consideration of gender, power, credibility, and the ways participants described their own circumstances as shaping their access to and treatment within care; Sen's capabilities approach supported consideration of the relationship between agency and the conditions required to translate that agency into meaningful outcomes; and structural ableism supported consideration of how health system interactions and institutional conditions could themselves contribute to or compound participants' experiences. This allowed the analysis to move between individual lived experiences and the broader conditions shaping them without requiring participants' accounts to fit predetermined theoretical categories.

Ethical considerations

Ethical approval was obtained from OCAD University's Research Ethics Board. All participants received an information letter and consent form prior to participation. [

Scope and limitations

This study makes interpretive rather than generalizable claims. Reflexive thematic analysis treats themes as produced through the researcher's engagement with the data, so the findings describe recurring patterns and tensions across a specific set of health care journeys rather than their prevalence. Several design features follow from this position rather than constraining it: the sample was small and purposive by intention, and analysis by a single researcher is consistent with a methodology in which themes are not categories whose legitimacy depends on agreement between coders.

Diagnoses were not verified, so that experiences of misdiagnosis and diagnostic uncertainty would not be excluded, and so that participants would not be required to demonstrate legitimacy to a study concerned with how their legitimacy is questioned elsewhere. Participants were interviewed once about journeys spanning years; their present understanding of earlier encounters is treated as the object of analysis rather than as imperfect recall.

Other conditions bound what this study can claim:

- **Self-selection:** Participation depended on self-selection, and recruitment through Instagram, LinkedIn and the OCAD University Graduate School listserv, and word-of-mouth shaped who came forward. Most participants had completed at least one post-secondary degree and most were employed, which matters directly because health literacy, self-advocacy and sustained navigational work are central to the analysis. Women who have disengaged from care entirely, or who are outside the networks the study circulated through, are not represented.
- **Material resources:** Several participants also adapted through private providers, alternative practitioners or care obtained outside Ontario and Canada, which requires money, insurance or the ability to travel. The study documents how patients compensate when they have some means of doing so, and says less about what happens when they do not.
- **Social position:** Data on race, income, insurance status and sexuality were not systematically collected. Intersectionality informed what I attended to, particularly where participants raised their own circumstances, but no systematic intersectional analysis was possible.

- **Software-assisted coding:** Coding was applied across the dataset using MAXQDA's AI-assisted function, working from a manually developed codebook. Review against the transcripts found the application largely confirmatory, though it missed indirect and implicit expressions conveyed through understatement or omission, which were retained manually.

Literature review — What we know about women, chronic illness and health care

This literature review situates the experiences of women in early adulthood managing chronic illness within the broader social, institutional and health system conditions that shape their care. Existing research demonstrates that experiences of chronic illness are shaped not only by symptoms and disease, but also by gender, disability, relationships with health care providers, access to care, and the work required of patients to navigate fragmented systems. The literature reviewed below brings together research on gendered health inequities, illness work and self-management, structural ableism, and experience-based health design to consider how these conditions shape women's agency and experiences of navigating care.

Gendered inequities in health and health care

Women's health inequities persist across diagnosis, treatment, and credibility in clinical encounters (Hamberg, 2008). At the same time, rates of chronic disease are rising among young Canadians, and the prevalence and total of chronic conditions are higher for women than men in all age groups (Sun Life, 2024, Statistics Canada, 2023b). Historically, women's health experiences have been mediated by institutional bias, where pain, fatigue, or reproductive symptoms are dismissed or psychologized (Samulowitz et al., 2018; Hamberg, 2008). This is termed medical misogyny. In this research, medical misogyny refers to the ways gendered assumptions and biases can shape whose symptoms are considered credible, how women's accounts of their bodies are interpreted, and the investigations and treatment they subsequently receive.

However, gender does not operate independently from other social positions and systems of inequality. Intersectionality, first articulated by Crenshaw (1989), describes how multiple systems of power and inequality can interact to shape experiences in ways that cannot be understood by examining gender, race, disability, socioeconomic status, or other social positions independently. In health care, this means that medical misogyny and other gendered inequities may be experienced differently depending on a patient's intersecting identities, social conditions, and access to resources. An intersectional approach is therefore important to understanding differences between women's experiences rather than treating women as a homogenous patient population.

Early adulthood is particularly vulnerable to such patterns, given that women in early adulthood are often negotiating credibility in a system that questions their expertise over

their own bodies and may be experiencing this in tandem with the emergence of new health needs. These gendered epistemologies result in diagnostic delays, barriers to referrals, and a need for patient self-coordination of care (Werner & Malterud, 2003). The existing body of chronic illness literature highlights that women's experiences of illness are often characterized by a tension between dependency on institutional systems and the assertion of personal agency within them (Charmaz, 1991; Lupton, 2013). Thus, women's agency should be studied as a relational and situated practice rather than as individual autonomy, negotiated through advocacy, boundary setting, and the coordination of multiple informal and formal networks of care.

Illness work and the labour of self-management

The need to navigate these institutional barriers extends the work of managing chronic illness beyond the management of symptoms themselves. Living with a chronic condition demands illness work - the daily management of symptoms, appointments and administrative tasks required to stay well - which Corbin and Strauss (1985) situate alongside everyday life work and biographical work as the three lines of labour chronic illness requires (Corbin & Strauss, 1985, 1988). This labour is largely invisible within medical frameworks but essential to health care system functioning. Women are acting on their health through social, digital and other networks that supplement health care. These include tracking applications, online communities, and peer-support groups where women reclaim expertise, share experiential knowledge, and resist epistemic injustice (Ziebland & Wyke, 2012). In the absence of navigational structures and case management for the majority of women with chronic conditions, illness work is intensified during times of diagnostic exploration, acute symptoms and care, and during periods of transition between forms and levels of care.

For many chronic conditions, illness work does not have a defined endpoint, continuing in varying intensity across the course of a person's life (Corbin & Strauss, 1988). Interactions with health care providers can shape outlooks on illness work and whether this work is rewarding to the patient or not. Nonetheless, even if illness work is rewarded with diagnoses, care and supports, patients with chronic illness often experience medical burnout, and experience this at several points along the journey of managing their health.

It is important to note that the amount of illness work required of patients is not only shaped by the complexity of their conditions, but also by the organization of the health care system through which they are attempting to access and coordinate care.

Agency, capabilities and the conditions of health

Amartya Sen's capabilities approach provides a framework for understanding how factors such as health and health care shape an individual's ability to participate in their

life. Rather than evaluating wellbeing solely through the resources or services available to a person, Sen (1992, 1999) distinguishes between resources and an individual's substantive freedom to achieve the ways of being and doing what they value, referred to as capabilities. In the context of chronic illness, this distinction helps illustrate how the formal availability of health care does not necessarily translate into an individual's ability to access appropriate care, manage their health, work, maintain relationships, or pursue other goals. Individual, social, economic and environmental conditions influence whether available resources can be converted into meaningful capacities. Applied to women in early adulthood with chronic illness, this approach provides a way of considering agency alongside the conditions that enable or constrain it. A woman with a chronic illness may undertake significant illness work and demonstrate considerable agency, all while still having limited capability to influence their health outcomes where access to diagnosis, treatment, financial resources, workplace accommodations, or responsive health care providers is constrained.

Fragmentation and the design of health care

From a systems and design perspective, fragmentation is not only an administrative issue, but also a design issue, and a misalignment between institutional logic and the lived realities of patients. Scholars in health design argue that care systems are co-created by providers and users, yet institutional design rarely acknowledges patients' adaptive practices (Bate & Robert, 2006). The navigational and illness work undertaken by patients can consequently be understood as adaptations to the structures and limitations of the systems in which care is provided, and not only as individual responses to chronic illness.

By studying the ways in which women in early adulthood creatively navigate and reconfigure health care, this research foregrounds patient-led innovation as an emerging signal for more participatory and resilient health care systems (Robertson & Simonsen, 2012). This positions lived experience as a source of knowledge about how systems function, where they fall short, and how patients respond to the systems' failings.

Lived experience and patient knowledge

Nonetheless, the extent to which lived experience is recognized as a legitimate form of knowledge is contested within health research and health care systems. Centering lived experience also requires consideration of whose knowledge is recognized as evidence in health research and design. Dominant scientific paradigms reward exogenous research on patient populations, especially quantitative studies with population-level generalizability. This neglects the multifaceted, socio-political dimensions of health shaped by local realities, including health seeking behaviours, beliefs about the role of providers, provider training and quality management, and access to care. Wilson (2008)

challenges the assumption that knowledge can be separated from the relationships and contexts through which it is produced, writing from an Indigenous research paradigm. Instead, he argues that knowledge should be understood as relational and research should be approached as a process of accountability to those relationships (Wilson, 2008). True patient-led research, therefore, should not observe patients, but engages them in the setting of the research agenda, development of proposals, attribution of findings and publication, and respects lived experience as a source of knowledge and truth.

Structural ableism and health

These questions of whose knowledge is recognized, whose experiences are considered credible and how health systems respond to difference extend beyond gender. Structural ableism provides an additional lens through which the experiences of living with chronic illness and disability can be examined. Lundberg and Chen (2024) identify structural ableism as a determinant of health outcomes and disparities among people with disabilities, with its effects potentially compounded for those who live at the intersection of multiple systems of oppression, including those related to gender, race, socioeconomic status, sexual orientation, age and other social identities. Of particular relevance to this research are the proximate pathways through which Lundberg and Chen suggest structural ableism can affect health, including disability-incompetent and non-affirming health care, chronic stress and allostatic load, minority stress and trauma, and health risk behaviours used as coping strategies. These pathways provide a useful lens for considering how interactions with the health care system can themselves contribute to health outcomes. For women in early adulthood managing chronic illness, experiences of dismissal, inadequate or inappropriate care, and barriers to accessing care may therefore have implications beyond whether an immediate health need is addressed, particularly where these experiences are repeated over time.

Disability, income and the material conditions of illness

The conditions shaping how people manage chronic illness extend beyond the health care system to the financial and social supports available to them. Disability is increasingly common in Canada: approximately 27% of people aged 15 and older live with one or more disabilities, and pain-related, mental health-related and seeing disabilities grew most between 2017 and 2022, making them the largest contributors to the rising rate (Statistics Canada, 2023a). Disability is also unevenly distributed by gender, with 30% of women reporting a disability in 2022, compared with 24% of men (Hébert et al., 2024).

Living with disability or chronic illness carries elevated financial risk. Approximately 23% of women with disabilities in Canada live on low incomes, compared with 10% of

women without disabilities (Canadian Women's Foundation, 2025), while people with disabilities require roughly 30% more income to reach the Low Income Measure (Disability Without Poverty, 2025). Income supports have not closed this gap. In Ontario, the maximum amount available to a single recipient of the Ontario Disability Support Program falls \$752 below the official Toronto poverty line (Daily Bread Food Bank, 2023), and the Canada Disability Benefit provides a maximum of \$204.20 monthly for low-income working-age Canadians with disabilities (Government of Canada, n.d.).

Findings — experiences navigating chronic illness

The reflexive thematic analysis of participant interviews found several interconnected themes on participants' experiences navigating health care while living with chronic illness in early adulthood.

Across all participants' interviews, health care navigation emerged as an ongoing process shaped by interactions with providers, structures, expectations and gaps within the health system. Participants described their journeys navigating fragmented systems, how they established their credibility and advocated for themselves in health settings, and how they adapted when formal systems did not adequately respond to their needs.

Participants who disclosed their health conditions described gynecological, endocrinological, rheumatological, musculoskeletal, genetic, mental and neuro-cognitive conditions. Most participants had two or more health conditions. Most participants had completed at least one post-secondary degree, and most participants were employed. Standardized demographic data on race, income, insurance status and sexuality were not collected. Participants raised these and other aspects of their circumstances where they considered them relevant to their care, and those accounts informed the analysis, but the study was not designed to compare experiences systematically across these characteristics. Participant characteristics are described here in aggregate rather than individually to protect confidentiality, given the small sample and the specificity of some conditions.

The findings are presented through eight themes: *Navigating the journey to diagnosis*, *Managing illness while misdiagnosed*, *Physicians as health system gatekeepers*, *Adapting health-seeking behaviours within constrained systems of care*, *Health care navigation across life transitions*, *Health, care and anticipated motherhood*, *Drawing on others to understand and navigate health*, and *Working while managing chronic illness*. These themes are presented separately for analytic clarity, however are closely interconnected across participants' experiences. Findings are presented as analytic summaries across participants rather than through individual illustrative extracts.

Navigating the journey to diagnosis

Participants had non-linear diagnostic journeys, where there was not a clear path from symptom presentation to diagnosis. Their journeys demonstrated that navigating health care involved developing the knowledge and strategies required to move through a fragmented system of care.

For many participants, the emergence of new or worsened symptoms coincided with a change in their primary care provider. Changes in primary care occurred for different reasons, including physician retirement, relocation, or participants intentionally seeking a different provider. For some participants, this meant navigating emerging health

concerns while simultaneously trying to establish a new point of entry into the health care system.

Participants described friction at multiple key points in navigating the health care system. This began with finding an entry point into care, including knowing where to seek help and finding a primary care provider. Once connected to the system, participants described further barriers to accessing care, including challenges obtaining referrals, long wait lists, geographic distance from providers, and thresholds that had to be met before services could be accessed. Participants also described challenges being heard and believed by providers, including having their symptoms minimized, their credibility questioned, or feeling that they had to repeatedly explain or demonstrate the severity of their symptoms.

Friction also occurred as participants moved between providers and services. Participants described care as siloed, with specialists focused on individual conditions and limited consideration of their health as a whole. This often meant repeating their histories, undergoing repeated tests, and navigating between providers who were not always connected to one another. Participants also described the work required to keep their care moving, including tracking referrals, following up on appointments and results, coordinating between providers, researching available options, and determining what steps to take next. When they encountered barriers or felt that their needs were not being met, participants adapted by seeking second opinions, changing providers, accessing private care where possible, educating themselves about their conditions and available treatments, turning to online communities for information and support, and developing strategies to advocate for themselves within the health care system.

During this stage of navigating diagnosis, participants were also actively trying to manage symptoms while formal diagnostic processes played out. Participants often explored different options in parallel with these processes, such as trialling medications, allied health service therapies, lifestyle changes and other approaches to symptom management. This was often described as a process of trial and error, with participants trying different approaches, assessing whether they helped, and adjusting based on their own experiences. In some cases, participants pursued these options based on recommendations from providers, and in other cases, they identified possible management options through their own research, conversations with others with similar experiences, or online communities. Participants were therefore often managing their health before having a diagnosis that could formally organize or explain that care.

Across these journeys, participants took on significant responsibility for keeping their care moving. They described determining possible next steps, identifying appropriate services, following up with providers, and communicating information between different parts of the health care system.

Managing illness while misdiagnosed

Most participants navigated a period of misdiagnosis prior to obtaining their current diagnosis, which prevented them from medical interventions that would appropriately treat their condition. This period was often marked by trialling ineffective treatments, repeatedly raising concerns with providers, and experiencing a worsening of their health. As symptoms persisted or progressed despite treatment, participants began to question their diagnosis and engaged in independent research on their conditions and symptomology. They described trying to understand what might better explain their symptoms, identifying how they could get closer to an appropriate diagnosis, and continuing to raise their concerns with providers, despite facing dismissal. For these participants, questioning an existing diagnosis became part of the work of managing their health rather than a discrete event within their care.

For many participants, the circumstances surrounding their misdiagnosis eroded their confidence in the public health care system, with many subsequently seeking care elsewhere. This included accessing private physicians as well as alternative care providers, such as naturopaths, traditional Chinese medicine providers, chiropractors and osteopaths, and allied health providers, including nurse practitioners, physiotherapists and massage therapists. Participants often moved between different providers and modalities of care while continuing to pursue an appropriate diagnosis through the public health care system.

Two participants were diagnosed with their health condition by physicians abroad, however those diagnoses were not readily accepted by the public health care system in Ontario. In one case, a participant was denied access to insulin by a campus primary care provider for a confirmed case of Type 1 Diabetes Mellitus, despite presenting diagnostic confirmation and presenting with consistent symptoms, due to the testing being conducted outside of Canada. The participant's access to insulin was delayed for several months as a consequence, during which time her health declined.

Participants also described the psychological burden of remaining misdiagnosed while continuing to experience symptoms that were not adequately explained or treated. Having their concerns repeatedly minimized or dismissed led some participants to question their own experiences and perceptions of their health. Over time, this contributed to feelings of exhaustion, frustration, and in some cases, withdrawal from seeking care or raising health concerns with providers. Participants' stories reflected the cumulative effects of repeatedly advocating for recognition of their symptoms, while also managing the physical and psychological consequences of an inadequately treated condition.

Physicians as health system gatekeepers

Across participants' narratives, physicians and other primary care providers functioned as important gatekeepers to diagnosis, referrals, investigations and treatment. Participants could research their symptoms, identify possible conditions or treatments, and develop strategies for navigating care, but acting on much of this knowledge remained dependent on a provider.

Participants exercised multiple tactics to navigate ableism and misogyny at the point of care, but most participants ultimately had to find a provider such as a physician or a nurse practitioner within the public health system to formally diagnose them in order to effectively manage their condition. Participants described trialling multiple treatments without success before their provider conceded that an initial diagnosis or treatment approach had been unsuccessful, or before they sought out a different provider altogether.

Participants described becoming increasingly aware of how their credibility was assessed during interactions with health care providers. Their accounts noted instances where the legitimacy of their symptoms, adherence to treatment, and health literacy were questioned or scrutinized. In response, participants became deliberate about how they presented themselves and their knowledge during clinical encounters. They described assessing what a particular provider would be receptive to, including whether the provider responded positively to detailed medical knowledge or preferred to lead the interaction and plan of care. This was especially evident among participants who identified as having high levels of health literacy. Some described deliberately concealing or minimizing what they knew, rehearsing how they would raise concerns, or allowing providers to arrive at information the participant already knew. Participants described this as necessary to avoid being perceived as difficult, overly informed, or challenging to the provider. In this way, navigating access to care could involve continual assessment of not only what participants communicated, but how their knowledge and credibility might be perceived by the person controlling access to care.

Adapting health-seeking behaviours within constrained systems of care

Health-seeking by participants was not consistent over time. Participants described periods of intensive appointments, testing, research, therapies and attention to their health, followed by periods where they pulled back, often after exhausting or negative experiences. Health-seeking seemed to become more selective and strategic over time; some participants narrowed their interactions with providers to specific aims, such as for referrals or for blood work, some sought private or alternative care, some deferred care until they could access it abroad, and some moved between periods of intense engagement with their health and periods of disengagement or avoidance.

Adaptation occurred both within individual clinical encounters and in participants' broader decisions about when, where and from whom they sought care. As described above, participants adapted their communication with providers, while also becoming increasingly selective about which concerns they raised, which providers they approached, and how much time and energy they were willing to invest in pursuing care.

After repeated encounters with dismissive or unhelpful providers, participants often reported redirecting or withdrawing health-seeking by changing where they sought care. Some sought out new providers within the public health system by finding a new primary care provider, going to a walk-in clinic or visiting an emergency department, while others pursued private or alternative providers, and a few sought care abroad. Across these different circumstances, participants' adaptations could involve not only finding another route to care, but also reducing or stopping their pursuit of it.

Health care navigation across life transitions

Most participants pursued a change in primary care providers upon entering adulthood, either due to personal preference, retirement of their family physician or geographic relocation. Participants who could not be rostered to a family medicine practice sought care on campus or in walk-in clinics, which had variable outcomes. Some preferred this arrangement due to the flexibility of changing providers as needed, while others found that it resulted in a lack of continuity of care.

For participants attending post-secondary education, campus health services provided an additional point of entry into the health care system. Participants varied in whether they accessed care for their health concerns primarily on or off campus, depending on their needs, the services available to them and whether they maintained relationships with existing providers.

Of all the categories of disclosed health conditions (gynecological, endocrinological, rheumatological, musculoskeletal, genetic, mental and neuro-cognitive conditions), mental health concerns appeared to have the clearest pathway to care within the post-secondary environment, with participants describing access to counselling, referrals, and other health supports available through or around their institutions. Upon completion of studies, there were varying experiences with transitions in care. For some participants, continuity of care in the community setting was coordinated by campus health services, while other participants described falling through the cracks.

Geographic relocation appeared to be more disruptive to participants' care than other life transitions. Moving to a new country or region required participants to find a new primary care provider, re-establish their medical history and relationships with providers, restart referral processes, and find new specialists or other health care providers. For

participants already managing chronic conditions, relocation could interrupt care that was already established.

These transitions often coincided with other changes in participants' lives and health. Moving could occur alongside starting a new job, change in relationships or family planning, the emergence of new health concerns, or changing needs and goals for their existing conditions. Participants' health care needs were evolving as their lives changed, changing the type of care they sought and the expectations they had of their providers, as well as their supports and challenges. Participants' relationships with the health system had to be repeatedly renegotiated as their health, location, relationships, education, work and future plans changed.

Health, care and anticipated motherhood

Two of the eight participants had one or more children, while several others expressed desires to have children in the future or how their health shaped their considerations around having children. Participants without children expressed concerns about becoming pregnant or having children while their health remained poorly managed or without adequate care in place. Some felt that their health would need to be in a better place before they could consider having children. These considerations extended beyond pregnancy itself, with participants also questioning how they would manage their health conditions alongside raising children and continuing their careers.

Participants' health also appeared to acquire a different urgency among health care providers when positioned in relation to their reproductive futures. For several participants, raising family planning with health care providers appeared to change the course of their care. Participants described diagnostic processes and referrals moving more quickly once they expressed an interest in having children, and some felt that their concerns were taken more seriously when positioned in relation to a future pregnancy.

One participant who had a child described experiencing discrimination immediately following the delivery of her child on the basis of a well-managed mental health condition, despite having an established plan of care and a clear support network. At the same time, both participants with children described motherhood as an important motivation for continuing to seek care and manage their health. Their children were described as sources of hope and joy, and as an empowering factor in advocating for their health and pursuing the care they needed.

Drawing on others to understand and navigate health

Participants drew on the health experiences of others to inform how they understood and managed their own health concerns. These informal sources of knowledge included people with similar conditions online, family members with shared health experiences, and romantic partners who developed familiarity with participants' health over time.

Online communities were one source of this knowledge, although participants had mixed feelings about their engagement with them. Many participants preferred to observe the participation of others in online communities to gather information and insights for their own self-management and care, while others participated more actively through Facebook groups, Reddit threads, Instagram reels and TikTok videos. For some participants, online communities provided insight into how others with similar symptoms or conditions had navigated diagnosis and treatment. Participants described observing the pathways followed by others to better understand the process of obtaining a diagnosis, identify providers or services they might seek out, learn about different treatment options, and determine possible next steps in their own care. The experiences of others could provide a point of reference when participants were uncertain about what they were experiencing or how to move their care forward.

Participants also drew on the health experiences of people within their families. For many participants, their mothers played an important role in helping them navigate their health concerns, including recognizing symptoms, encouraging them to seek care, and supporting them through diagnosis and treatment. Notably, participants who described their mothers as closely involved in their health often shared the same or similar health issues with them. Their mothers' experiences provided another point of reference for understanding their own symptoms and identifying possible diagnoses, treatments or next steps in their care.

At the same time, participants did not always experience engagement with online health communities as helpful or supportive. For some, exposure to the experiences of others amplified uncomfortable feelings about their own illness or made their health concerns feel more present in their everyday lives. Others found that active participation created additional social demands, including engaging with other users and responding to their experiences. When participants were already managing significant demands related to their health, these interactions could become another source of stress and burden. Some participants therefore chose to withdraw from online communities or engage more passively.

Participants also drew on their romantic partners for support in understanding and navigating their health. Most participants who were in relationships described long-term partnerships, with partners acting as important sources of support and, for some, taking on caregiving roles. Partners were involved in advocating for better care, validating participants' concerns following dismissal by providers, and countering the self-doubt or self-dismissal that could follow these interactions. Over time, partners also developed knowledge of participants' health and engaged in their own pattern recognition, including anticipating changes in symptoms at different points in the menstrual cycle, during flares, or under different social and contextual conditions. In this way, partners

were not only sources of emotional and practical support, but also contributed to the ongoing recognition and interpretation of changes in participants' health.

Across these relationships, knowledge about participants' health was therefore not developed individually or exclusively through clinical encounters. It was also developed relationally through repeated observation, shared experiences, validation, and comparison with the experiences of others.

Working while managing chronic illness

Participants described the structure and conditions of their work as having a significant impact on their ability to manage their health and participate in the workforce. Remote work was highlighted as one of the most significant enablers of continued workforce participation, providing participants with greater flexibility to manage their health alongside the demands of their jobs. In contrast, Return to Office (RTO) requirements experienced by several participants had a negative impact on several participants, particularly where flexibility that had previously allowed them to manage their conditions while working was reduced or removed.

Working from home provided participants with greater privacy and control over how they managed their health throughout the working day. Participants described being able to manage pain through rest, positional changes, heat, or medications that could be sedating or otherwise alter how they felt. Working remotely also allowed participants to better manage their mental wellbeing by controlling their surroundings and avoiding unnecessary triggers. Participants described conserving energy by avoiding a commute, having access to ergonomic setups that accommodated their needs, and being able to access support from caregivers, including partners, parents and friends. Remote work also made it easier to attend virtual or in-person health care appointments with greater discretion and less disruption to the working day. For these participants, remote work did not remove the work associated with managing chronic illness, but provided greater control over when and how that work could occur alongside paid employment.

Some participants engaged with formal workplace accessibility and accommodation processes in order to maintain these or other supports. However, access to accommodations was variable. Some participants did not have a clear entry point into an accommodation process within their workplace, while others were reluctant to seek accommodations because of concerns about how disclosing a disability or chronic condition could affect their job security or future career progression. Participants therefore sometimes had to weigh the immediate benefit of requesting accommodations against the potential consequences they perceived could follow from identifying themselves as requiring them.

Beyond immediate accommodation needs, many participants expressed concerns about their ability to continue working over the long term. The demands of their workplaces, including the structure of the working day and expectations around when and where work should occur, were not always compatible with the ongoing management of chronic illness. Participants questioned whether they would be able to sustain their current ways of working as their careers progressed or if their health needs changed.

More broadly, many participants questioned the sustainability of the conventional 9-to-5 work week, describing its structure as demanding even for people without chronic health concerns. Participants felt that these expectations could be particularly alienating for women, and further compounded for women managing chronic illness alongside other responsibilities and health needs. Their accounts reflected a broader tension between workplace structures that assume a consistent capacity to work and the variable and ongoing demands associated with managing chronic illness.

Discussion — What women's adaptations reveal about the health system

The discussion considers these findings in relation to the three questions set out at the outset: how participants accessed care, how their knowledge was received, and how they responded when the system did not meet their needs.

The limits of patient agency within the health care system

A central finding of this study is that participants were simultaneously highly agentic and highly constrained in managing their health. The forms of work described in the findings, including researching conditions, tracking symptoms, trialling treatments, seeking second opinions, coordinating between providers and travelling for care, were undertaken alongside continued dependence on providers for the investigations, referrals and treatments required to act on any of it.

This dependence is structural rather than incidental. In Ontario, access to prescription medication, specialist care, blood work, imaging and interventional treatment generally requires an order or referral from a physician or nurse practitioner, and participants described referrals being declined, long waits for specialist care, and limited opportunity to obtain a second opinion or transfer their care within the public system. Participants could therefore recognize when an existing approach was not working while having little ability to independently investigate their concerns or change the direction of their care. Much of the agency they demonstrated can be understood as an adaptive response to having limited formal agency within the system.

This distinction matters when considering patient agency through Sen's capabilities approach. Agency was not equivalent to capability: participants demonstrated the capacity and willingness to act on their health, but translating that into outcomes depended on access to providers, referrals, investigations, treatments and financial resources that were not within their control.

The work required to compensate constitutes a form of illness work extending well beyond the management of symptoms themselves (Corbin & Strauss, 1985). System fragmentation therefore did not simply create gaps between services; it transferred some of the work of connecting those services onto patients, who could become responsible for determining what should happen next and communicating information between providers without equivalent authority to act on it.

The ways participants responded to these constraints also have implications for an increasingly plural health care environment. Participants were already responding to difficulty accessing care by seeking private physicians, allied health providers, alternative practitioners and care abroad. While these options can provide access to

care that participants were otherwise unable to obtain, this study did not examine the outcomes of care obtained outside the public system, and greater reliance on it may also introduce new points of fragmentation. Diagnoses and recommendations may differ between providers, information may not cross sectors, and patients may be left to reconcile them. Diversion toward private and alternative care without coordination mechanisms therefore risks increasing the very labour that drove participants to it.

These findings point to an opportunity to provide greater support before a diagnosis is established. The period between recognizing that something is wrong and receiving an appropriate diagnosis was often characterized by considerable work, uncertainty and worsening health. Formalized pre-diagnosis symptom management and navigation supports could assist patients with managing symptoms, understanding available pathways, coordinating referrals and determining appropriate next steps without requiring them to independently navigate this period.

Importantly, the findings do not suggest that the solution to fragmented care is to make patients better navigators of fragmented systems. Participants already demonstrate significant capacity for navigation, research and self-advocacy. Greater recognition of patient agency should therefore be accompanied by attention to the conditions that determine whether that agency can meaningfully influence care.

Health burnout and disengagement as self-preservation

Repeatedly seeking care without adequate resolution had consequences beyond the continued presence or progression of participants' symptoms. Participants described fatigue from trialling unsuccessful treatments, repeatedly explaining their symptoms, attending appointments, following up on referrals and continuing to advocate for further investigation while their health remained inadequately managed. Negative interactions accumulated alongside the physical demands of chronic illness and contributed to self-doubt, demoralization, despair and, for some participants, a withdrawal from medical environments.

These experiences can be understood through the concept of health burnout, which emerged from interviews with participants. Health burnout describes the exhaustion associated with the ongoing work of managing illness and seeking care when that work repeatedly fails to result in adequate support, diagnosis or treatment. Participants' experiences of health burnout included fatigue, gaslighting, self-questioning and, at times, self-abandonment. Withdrawal from care could consequently function as a form of self-preservation rather than an indication that participants no longer regarded their health concerns as important.

Decisions to seek, delay, redirect or disengage from care should therefore be understood in relation to participants' previous experiences with the health care system. Participants often continued to monitor symptoms, research their conditions, manage their health independently or seek other forms of care even when they reduced their engagement with medical providers. In this sense, disengagement from the health care system was not necessarily disengagement from one's health.

Participants' experiences also complicate assumptions that distrust or disengagement necessarily reflect poor health literacy or a rejection of biomedical care. For some participants, distrust developed following repeated experiences of dismissal, misdiagnosis, ineffective treatment or an inability to access care. Some continued to seek biomedical care while simultaneously exploring other providers, treatments and sources of health knowledge. Distrust could therefore develop through interaction with the health system itself, rather than existing prior to those interactions.

Thus, there is a need to better recognize the cumulative impact of seeking care itself. Health systems commonly consider engagement through attendance, adherence and participation in recommended treatment, with less attention to the amount of work required to remain engaged when care is not meeting a patient's needs. Recognition of health burnout could provide a basis for understanding withdrawal or inconsistent engagement differently and for identifying opportunities to intervene before patients disengage from formal care.

Health burnout also demonstrates the limits of relying on sustained patient labour as an informal component of health system functioning. When keeping care moving depends on patients continually monitoring, researching, coordinating and advocating, periods in which patients no longer have the capacity to perform this work can themselves become points of vulnerability

Credibility, patient knowledge and the performance of the patient

Participants' experiences also demonstrate how credibility is negotiated within clinical encounters. Participants described having their symptoms questioned, their adherence scrutinized and their knowledge of their own health discounted. These experiences were particularly consequential because credibility could influence whether their concerns resulted in further investigation, referral or treatment.

At the same time, the conditions under which patients acquire health knowledge have changed substantially. Scientific and health information is increasingly accessible through the internet, open-access publishing, patient communities and digital tools, while electronic medical records and patient portals can provide patients with direct access to their own laboratory results, imaging reports and longitudinal clinical

information. Patients may therefore enter clinical encounters with several forms of knowledge, including lived experience of their symptoms, longitudinal knowledge of their bodies, information from other patients, personal clinical data and scientific literature. These forms of knowledge do not replace clinical expertise, but they complicate a model in which providers are positioned as the primary interpreters of health information.

Despite developing considerable health literacy through years of managing chronic illness, researching symptoms and navigating health services, some participants described concealing or minimizing this knowledge when interacting with providers. Participants rehearsed what they would say, censored the amount or type of information they provided, and at times performed a degree of incompetence or uncertainty in order to appear more palatable to providers. Participants were therefore required to navigate a contradiction in which they needed sufficient health literacy to manage complex chronic illness while sometimes concealing that same literacy to maintain credibility within the therapeutic relationship.

This required a form of surveillance and self-monitoring that extended beyond participants' bodies. Participants monitored symptoms, pain, function and responses to treatment while simultaneously monitoring how they behaved as patients: how strongly to communicate concern, how much knowledge to demonstrate, when to disagree, and when appearing compliant or less informed might better preserve their access to care. The labour of chronic illness therefore included managing not only one's health, but one's presentation as a patient.

Greater access to health knowledge has not necessarily resulted in an equivalent redistribution of authority. Clinicians retain significant power to determine which concerns warrant investigation, which tests or referrals are appropriate, and which diagnoses are formally recognized. This authority has important clinical functions, including protecting against unnecessary investigation and inappropriate treatment. However, participants' experiences demonstrate the tension that can arise when patient knowledge challenges a provider's interpretation of symptoms or proposed course of care.

The expectation of the "informed patient" is therefore contradictory. Patients are increasingly encouraged to understand their conditions, monitor their health and participate in shared decision-making, yet some participants found that demonstrating too much knowledge could itself undermine their credibility. The relevant question is not whether patient knowledge should replace professional expertise, but how different forms of knowledge are received and negotiated when they do not align.

These experiences should be situated within the broader normalization of women's suffering and the persistence of medical misogyny. Women may be expected to continue working, maintaining relationships, caring for others and managing their own health despite significant symptoms. Their ability to continue functioning can then be used, implicitly or explicitly, as evidence that their illness is not sufficiently severe to warrant further intervention. This results in a greater endurance threshold for women, who are expected to sustain considerable physical, psychological and administrative burdens before their inability to continue doing so legitimizes their need for care.

Gender was not the only condition shaping participants' relationships with health care, and these findings should not be read as an account of a uniform set of women's experiences. Disability, socioeconomic circumstances, race, age, sexuality and access to insurance shape both the resources available to patients and how they are perceived within health and social systems, and medical misogyny and structural ableism can intersect rather than operating separately. This study was not designed to examine those differences systematically, and the patterns described here are likely to be experienced with greater force, and with fewer available adaptations, by women with less access to the resources several participants in this study were able to draw on.

Addressing these harms requires more than encouraging patients to advocate for themselves. Participants in this study were already advocating, researching, monitoring and adapting extensively. Further emphasis on patient self-advocacy risks transferring additional responsibility to those already undertaking considerable illness work. There is instead an opportunity for provider education grounded in feminist and anti-ableist approaches that examines how assumptions about credibility, pain, functioning, disability, adherence and health literacy influence clinical decision-making and access to care.

Relational knowledge and informal systems of care

Participants' experiences also challenge an understanding of health knowledge as something produced solely within the relationship between an individual patient and a health care provider. Participants learned about their health through relationships with other patients, family members and romantic partners, as well as through online communities. These relationships supported symptom recognition, comparison of experiences, identification of possible diagnoses and treatments, navigation of health services and validation following experiences of dismissal.

The role of mothers and romantic partners was particularly illustrative of the relational nature of this knowledge. Some daughters drew on their mothers' experiences with

similar health conditions to recognize health patterns, while partners developed knowledge through repeated observation of symptoms, flares, menstrual cycles and other contextual changes. Knowledge of participants' health was therefore produced over time through observation and relationships as well as through discrete clinical encounters.

This finding is consistent with Wilson's (2008) understanding of knowledge as relational, while recognizing that his work is situated within an Indigenous research paradigm. Applied cautiously in the context of patient-led research, relationality provides a way of recognizing that lived experience is not simply an individual account of illness. Patients understand their health through relationships with their bodies, providers, families, communities and other people with similar experiences.

Online patient communities extended these relationships beyond participants' immediate social networks. They could provide access to experiential knowledge from people who had navigated similar symptoms, diagnoses and services, but participants also described limits to this form of engagement. For some, online communities intensified attention to illness or created additional emotional and social demands. Informal networks should therefore not be romanticized as replacements for formal systems of care. Their importance in participants' lives instead demonstrates the range of knowledge and support patients draw on when formal systems do not provide all of the information, validation or navigation they require.

Recognizing relational and experiential knowledge also has implications for patient-led research. The adaptive practices participants developed are not merely individual coping behaviours; they can provide information about recurring friction points within health systems and the ways patients respond to them. Patient experience can therefore function as a source of knowledge about system performance, particularly where similar adaptations recur across otherwise different health journeys.

The hidden work of remaining functional

Participants' experiences should be considered within the growing prevalence of disability in Canada described above. Chronic illness and disability are distinct but overlapping concepts, and many participants described symptoms that affected their daily functioning while they continued to participate in employment, education, relationships, and other aspects of life.

The experiences of participants demonstrate that the presence and impact of chronic illness are not always readily apparent through an individual's level of participation in employment, education and other areas of life. Participants often continued to function while making significant adjustments to their routines, environments and expectations of

their health, careers and lives, all while undertaking significant illness work to manage their health. Continued participation in employment, education or other areas of life therefore did not necessarily indicate that participants were less affected by their conditions.

This is particularly important when considering employment. Most participants described challenges with typical work arrangements and full-time working hours, and identified remote work, flexibility, control over their physical environment and access to accommodations as factors that enabled them to continue working while managing pain, fatigue, mental health conditions and other symptoms. Changes to arrangements that enabled participants to work alongside chronic illness, such as Return to Office requirements following the COVID-19 pandemic, could therefore change their capacity to remain employed without any corresponding change in the underlying chronic illness itself.

Participants' experiences also complicate binary understandings of whether someone is able or unable to participate in employment. Symptoms could fluctuate across menstrual cycles, during flares, in response to treatment, or according to other social and contextual conditions. A participant could therefore be capable of working while still requiring substantial flexibility, accommodations, or adjustments elsewhere in their life to maintain that participation. The ability to work at a particular point in time did not necessarily reflect consistent capacity to work under all conditions.

This distinction is especially relevant during early adulthood, when participants were simultaneously navigating post-secondary education, entering or progressing through employment, developing relationships, relocating, and managing changing health needs. Illness work occurred alongside these activities and required time and energy that could otherwise be directed toward other areas of participants' lives. Attending appointments, managing symptoms, researching conditions, coordinating care, recovering from flares and advocating for access to services could therefore constrain participants' agency beyond the health care system itself.

These experiences can also be understood in relation to structural ableism. Systems organized around expectations of consistent attendance, productivity and functioning may disadvantage people whose capacity fluctuates, even where those individuals remain capable of participating when appropriate conditions are available. The challenges participants experienced were therefore not always produced solely by their underlying health conditions, but by the interaction between their health and environments that offered limited flexibility in how work, education and other forms of participation could occur.

The growing prevalence of disability described above makes this distinction increasingly important. As chronic illness and disability become increasingly common, particularly forms of disability that may be episodic or less readily visible, continued participation should not be interpreted as evidence that existing systems are adequately meeting people's needs. Participants' experiences instead demonstrate the substantial and often invisible work that can make continued participation possible.

The financial conditions of managing chronic illness

The increasing prevalence of disability also raises questions about whether health, employment and social systems are designed for a population in which chronic illness and disability are increasingly common.

Participants' experiences also demonstrate the limitations of existing health and income supports for people managing chronic illness. While physician and hospital services are publicly funded in Ontario, many of the services participants relied on to manage their conditions were not, or were only partially covered. Participants described accessing physiotherapy, massage therapy, psychotherapy and other allied or alternative health services, as well as medications and other health-related expenses that required either private insurance or payment out of pocket. These services were not necessarily peripheral to participants' care. For some, they were among the primary ways they managed pain, maintained function, addressed symptoms, or continued participating in work and other aspects of their lives while awaiting diagnosis or specialist care.

Access to these services was therefore shaped by participants' financial circumstances and, importantly, their access to employment-based health insurance. This creates a tension for people with chronic illness, as maintaining employment can provide access to the very benefits required to manage the health conditions that can make continued participation in the workforce more difficult. Participants who required greater flexibility, reduced hours, leave, or workplace accommodations could therefore face consequences that extended beyond their income if changes in employment also affected access to private health insurance.

Existing income supports similarly do not necessarily reflect the episodic and variable nature of chronic illness. Participants' experiences demonstrate that the ability to work cannot always be understood as a binary distinction between being able or unable to participate in employment. Participants could remain capable of working while requiring substantial flexibility and undertaking significant work outside of their employment to manage their health. A person may therefore be too well to qualify for some forms of disability or income support while simultaneously incurring significant financial and time costs associated with remaining well enough to work.

The insufficiency of these supports also shifts the cost of managing chronic illness onto individuals and their families. Participants relied on partners, parents and other informal caregivers for practical support, transportation, advocacy, symptom management and other forms of care. They also undertook considerable unpaid illness work themselves, including attending appointments, coordinating providers, researching their conditions, tracking symptoms, managing treatments and navigating administrative processes. These costs are largely invisible within a health system that does not account for the time and resources required of patients to access and coordinate their own care.

The costs of illness work are therefore not exclusively financial. Time and energy spent attending appointments, coordinating care, managing symptoms and advocating for access are resources that cannot simultaneously be directed toward employment, education, relationships, caregiving, rest or other aspects of life. In this way, the burden of navigating chronic illness can constrain capabilities beyond health itself.

The findings therefore raise questions about what is considered medically necessary care and who is expected to absorb the costs of maintaining health outside of physician and hospital settings. Where access to allied health services, medications, therapies and other supports depends on employment benefits or the ability to pay privately, the capacity to manage chronic illness becomes partly contingent on income.

These findings raise broader questions about whether health and income supports adequately recognize the ongoing costs associated with remaining well enough to participate in work and other areas of life. The policy implications of this distinction include how allied health services, medications and other illness-related expenditures are covered, and whether supports can better accommodate episodic disability without requiring complete withdrawal from employment as a condition of assistance.

A foresight perspective: two critical uncertainties

The findings describe a present condition rather than a fixed one. Participants were highly agentic and highly constrained at the same time, and both could change over the coming decade. Foresight approaches this by identifying critical uncertainties: forces that will significantly shape how a system develops, that are not controlled by any single actor, and whose direction cannot be predicted. Because they are uncertain rather than merely important, they are treated as axes rather than trends, and the combinations they produce describe futures that are each plausible.

This is offered as an interpretive device rather than a formal scenario development process. The uncertainties below were identified through analysis of a small qualitative sample rather than through horizon scanning or structured driver identification, and situate these findings within a longer time horizon rather than constituting scenarios

developed to a foresight standard. What the framing offers is a means of separating two conditions that were entangled in participants' accounts.

The first concerns patient agency: how much knowledge, capacity and expectation patients carry into their own care. Online health communities, personal health information and self-tracking tools, the use of artificial intelligence for symptom interpretation, and the normalization of self-management all point toward its growth. The cumulative exhaustion participants described, the risks of self-advocacy where credibility is at stake, and the material conditions that make sustained navigational work possible for some patients and not others could equally reduce it.

The second concerns whether the system supplies the conditions that allow action to produce outcomes: access, coordination, coverage and income support. This is the distinction Sen identifies as decisive, and the one participants encountered whenever considerable effort met a referral they could not obtain or a service they could not afford. Its direction is similarly unsettled, shaped by health human resource supply, the pace and structure of privatization, investment in coordination infrastructure, and whether disability and income supports keep pace with the cost of living with chronic illness.

Setting these uncertainties against one another produces four positions, shown in Figure 1 (see page 37). The horizontal axis represents the extent to which the system supplies the conditions required for action to produce outcomes, from constrained to enabling. The vertical axis represents the level of agency patients bring to their own care.

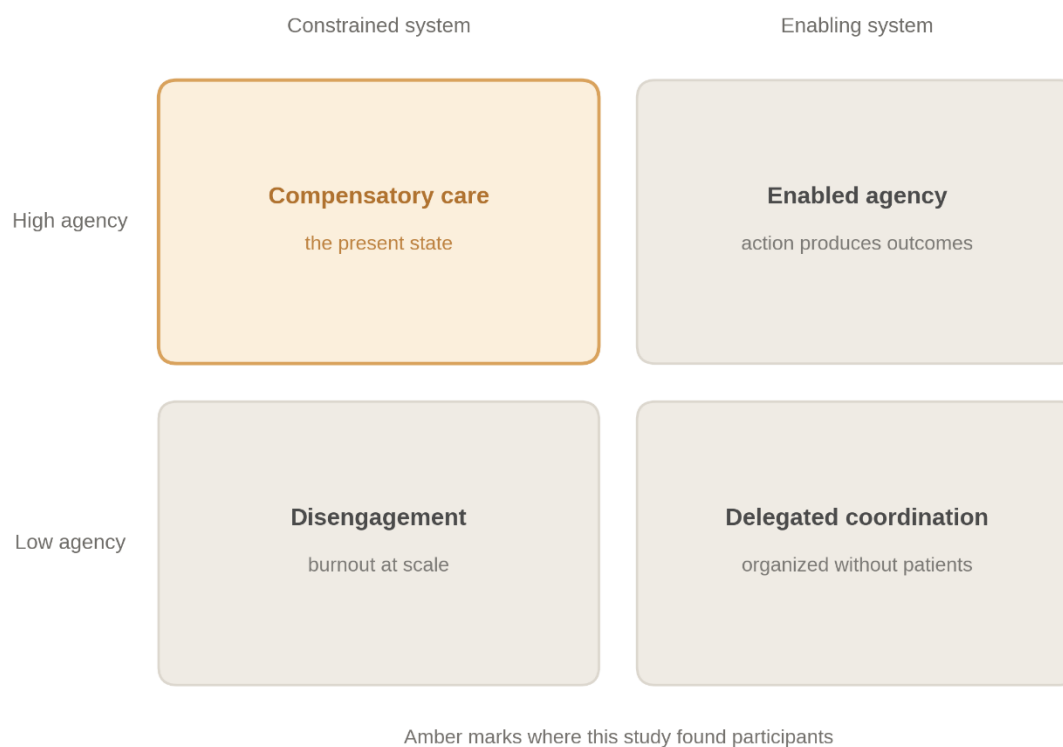


Figure 1. Patient agency and system capability provision as critical uncertainties. The upper-left quadrant describes the conditions participants in this study encountered.

Each quadrant describes a different distribution of responsibility, and the study's findings sit clearly within one of them:

- **Compensatory care** describes high patient agency within a constrained system, and is where this study found its participants. Patients absorb the work of coordination, credibility and access, and the system continues to function in part because they do. Its costs fall disproportionately on those with the time, education, income and support to carry them, and it appears to work until the point at which patients can no longer sustain it.
- **Enabled agency** describes high patient agency within an enabling system, and is the position the recommendations in this study are directed toward. Patients remain knowledgeable and active, and their knowledge produces outcomes because the system supplies the referrals, coordination, coverage and material conditions required to act on it. Agency and capability align.
- **Disengagement** describes low patient agency within a constrained system, and is the trajectory suggested by health burnout occurring at scale.

Withdrawal becomes a reasonable response to a system that does not reward engagement, and the compensatory work currently obscuring that system's failures disappears along with the patients performing it. Conditions progress undetected, and their costs surface later and more severely.

- **Delegated coordination** describes low patient agency within an enabling system, and is the quadrant most easily mistaken for success. Care is coordinated, access is adequate, and patients are relieved of navigational work. But the credibility problem identified in this study is not resolved by improved coordination, and a system that manages care efficiently while continuing to discount what patients know reproduces the dismissal participants described in a more comfortable form

Reducing the burden on patients and taking their knowledge seriously are separate objectives, and only one quadrant achieves both. Compensatory care achieves neither, while registering as functional, because it runs on a capacity participants described running out.

Conclusion — What comes next

This research began with an interest in patient agency: what women in early adulthood do when the health care system does not adequately respond to their needs. What emerged from the findings was a more complex relationship between agency and the systems in which it is exercised. Participants researched their conditions, tracked changes in their health, coordinated between providers, advocated for further investigation, sought care elsewhere when it was not forthcoming, and reorganized their lives to accommodate both their illness and the work of managing it. Their adaptations allowed them to continue seeking care, working, maintaining relationships and planning their futures, while also making visible the considerable work required to compensate for gaps in care.

This distinction is central to how patient agency should be understood. Adaptation can demonstrate resilience, knowledge and resourcefulness while simultaneously signalling that a system is not responsive to the needs of its users. That participants were able to find another provider, coordinate disconnected services, manage how they presented themselves in order to be believed, and reorganize their lives around chronic illness does not make those demands reasonable; it indicates where the health system has transferred its work to patients and where the opportunities to design care differently now lie.

Responsibility for those conditions is distributed across the system, and the recommendations that follow are therefore directed to clinicians, to those who design and organize care, and to the policy and employment systems within which care is provided.

Clinicians and clinical education

Participants developed substantial knowledge of their own health through sustained experience of their bodies, previous clinical encounters, personal health information, independent research and relationships with others living with similar conditions. Some of them concealed it. They rehearsed how they would raise a concern, minimized what they knew, and allowed providers to arrive at conclusions they had reached themselves some time earlier. A patient who must manage how much she appears to know in order to remain credible is not communicating poorly; her knowledge is being received badly.

The response to this cannot be to ask patients to advocate more effectively. Participants were already advocating, researching, monitoring and adapting extensively, and further emphasis on self-advocacy would transfer additional responsibility to those already undertaking considerable illness work. What is required instead is that extraordinary advocacy cease to be a condition of being heard.

- Clinical encounters should make room for experiential and clinical knowledge to be considered together, particularly where a patient's account of her symptoms does not align with an existing diagnosis.
- Provider education grounded in feminist and anti-ableist approaches should examine how assumptions about pain, functioning, adherence and health literacy shape clinical decision-making and access to care.
- Clinicians should recognize that patients develop knowledge of their health relationally, through partners, mothers, other patients and online communities, and not solely within the clinical relationship.
- Disengagement should be understood as a consequence that care can produce rather than as evidence of indifference; participants withdrew after sustained effort to obtain appropriate care, not in place of it.

Those who design and organize care

Participants described friction at every stage of moving through the health system: finding an entry point, obtaining referrals, waiting for specialist care, repeating their histories, and following up on investigations and results. Fragmentation did not simply create gaps between services; it transferred the work of connecting those services onto patients, who became responsible for determining what should happen next without holding the authority to act on that determination.

The period before diagnosis was consistently the most difficult, as participants managed significant symptoms without continuity of care and without a recognized basis on which to receive it. Designing for access therefore requires attention not only to whether a service formally exists, but to the work required of patients to reach it, remain engaged with it, and move between the parts of the system that provide it.

- Symptom management and navigation support should be built into the period before diagnosis, rather than becoming available only once a diagnosis has been established.
- Coordination between services should not depend on patients carrying information, chasing referrals and following up on results themselves.
- The cumulative cost of seeking care should be accounted for in how access is designed; participants' experiences of health burnout followed the accumulation of appointments, referrals and unsuccessful treatments rather than any single encounter.
- Expansion of private and alternative provision should proceed with corresponding attention to coordination, since participants sought care outside the public system precisely to escape navigational work that plural provision may otherwise return to them.
- Recurring patient adaptations should be treated as evidence about how the system is performing, and patient-led research should inform how services are evaluated and designed.

Policy, funding and employment systems

The conditions determining whether participants could manage their health extended well beyond clinical care. Participants relied on medications, physiotherapy, psychotherapy and other allied health services that are not publicly funded in Ontario, so that access depended on private insurance or the ability to pay directly. Because that insurance is generally tied to employment, remaining employed is how many people obtain the coverage required to remain well enough to work; this logic becomes precarious at exactly the point where someone requires reduced hours, leave or accommodation.

Participants' capacity also fluctuated across menstrual cycles, during flares and in response to treatment. Systems organized around a binary distinction between being able and unable to work describe this poorly, and can require complete withdrawal from employment before support becomes available. Remote work was among the most significant enablers of continued workforce participation described in this study, and where Return to Office requirements removed it, participants' capacity to remain employed changed without any corresponding change in their health.

- Income and disability supports should be designed around fluctuating capacity rather than requiring full withdrawal from employment as a condition of eligibility.
- Coverage of allied health services and medications should not depend on employment benefits or the ability to pay privately.
- Workplace accommodation processes require clear entry points, and should account for the fact that participants weighed the benefit of requesting accommodation against its perceived consequences for job security and career progression.
- Flexibility over where and how work occurs should be recognized as a determinant of continued employment for people whose underlying health is otherwise unchanged.

For researchers

This study was small, exploratory and confined to a single province, and several of the questions it raised could not be answered within its scope. The findings point to a set of research directions that would strengthen the evidence base for the changes described above, particularly where the costs of chronic illness remain undocumented and where the work of managing it remains unmeasured.

Much of what participants described has no established measure. The financial cost of living with chronic illness is partially captured in existing estimates of what people with disabilities require to reach an adequate standard of living, but those estimates do not account for the ongoing expenditure participants described on services outside public coverage, on care sought privately or abroad, or on the time and energy absorbed by managing their health. Similarly, the fragmentation participants navigated is well described in general terms but is rarely mapped in detail, with the result that the specific points at which patients lose continuity are known anecdotally rather than systematically.

- Foresight research should examine how patient agency and system capability provision may diverge over the coming decade. This study identified both as critical uncertainties but derived them from a small qualitative sample rather than from systematic scanning of the drivers involved, including health workforce supply, privatization, artificial intelligence in self-directed care, and the adequacy of income and disability supports. Scenario development would be particularly useful for distinguishing futures in which patient burden is reduced from those in which patient knowledge is also recognized.
- Research is needed to cost disability and chronic illness more accurately, accounting not only for direct expenditure on medications and allied health

services but also for privately purchased care, care obtained outside the province or country, lost income associated with reduced or interrupted employment, and the time absorbed by illness work itself. Existing income supports cannot be evaluated against a cost that has not been established.

- Detailed mapping of care pathways and the friction points within them would identify where patients most often lose continuity, where responsibility for coordination transfers to them, and which transitions between primary, specialist, allied and private care are most likely to interrupt care. Mapping of this kind would allow fragmentation to be addressed at specific points rather than as a general condition of the system.
- Research should examine what it would mean to compensate people living with chronic illness at parity with those who are not, in exchange for fewer working hours, treating reduced hours as an accessibility measure rather than as a reduction in contribution. Participants' capacity fluctuated in ways that current employment and disability frameworks accommodate poorly, and a model of this kind would test whether income can be decoupled from hours worked without withdrawing people from the workforce entirely. Such research would need to address both feasibility and the mechanisms through which parity could be funded and administered.
- The relationship between illness work and reproductive labour warrants direct investigation. Both are gendered, largely unpaid, and rendered invisible within the systems that depend on them, and participants in this study both performed illness work for themselves and drew on the unpaid care of mothers, partners and friends. Examining these forms of labour together would clarify whether illness work should be understood as a distinct category or as one expression of a broader pattern in how care is distributed by gender.
- Illness work in motherhood remains largely unexamined. Participants anticipated that pregnancy, birth and parenting would interact with their conditions, their treatments and their capacity, and considered these prospects when making decisions about their care. Research with mothers living with chronic illness would establish how illness work and caregiving work are managed simultaneously, and how existing supports respond when someone is both a patient and a primary caregiver.
- Longitudinal research is needed on whether and how health deteriorates during periods of delayed access and delayed diagnosis. Participants described symptoms worsening, conditions progressing and functioning declining while they waited for referrals, investigations and appropriate treatment, and some described losing years to a diagnosis that was subsequently corrected. Establishing the clinical and functional consequences of these delays would

make the cost of waiting visible in terms that health system planning is able to act on.

Research addressing these questions would benefit from patient-led and patient-partnered approaches. Several of the questions above concern experiences that are not recorded administratively and are difficult to identify without direct experience of them, and this study's own design was shaped substantially by the researcher's familiarity with what she was investigating.

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