


Women's experiences of navigating chronic pain within the context of living with an episodic disability

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Abstract

Objectives: Of the 6.2 million Canadians aged 15 years or older who live with disability, 61% have disabilities that are not static or continuous. These dynamic conditions are known as episodic disabilities and many disproportionately experienced by women. Chronic pain is also a common feature associated with many episodic disabilities. The purpose of this article is to explore the experience of chronic pain for women living with episodic disabilities.

Methods: This qualitative study draws on the tenets of interpretive description. Thirty women, with one or more episodic disabilities and chronic pain, participated in a semi-structured interview and answered questions about their chronic pain levels, using Von Korff et al.'s graded chronic pain scale.

Results: Women experienced gendered treatment within the healthcare system and reported that they were frequently dismissed by their healthcare providers, most often physicians. Healthcare professionals' practices around pain assessment were another common challenge for women. Women who were able to access financial support from government disability programs were more likely to access allied health professionals. Many of the holistic strategies that women researched and used to treat chronic pain were self-enacted. While diet, exercise, and other self-care activities are general health promotion strategies for all, they were seen as *essential* aspects of living that helped women have control over chronic pain and modifying the course of their episodic disability.

Conclusion: Living with chronic pain and an episodic disability is complex. The findings of this study present the impact that gendered treatment in the healthcare system has on women who live with an episodic disability and experience chronic pain. It is evident that the current system did not meet the needs of the women in our study and system changes could result in better experiences, more disclosure of alternative therapies, and increase women's agency in their care.

Keywords

chronic pain, episodic disability, lupus, multiple sclerosis

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Introduction

Of the 6.2 million Canadians aged 15 years or older who live with disability, 61% have disabilities that are not static or continuous.^{1,2} These dynamic conditions are known as episodic disabilities. Often chronic or lifelong conditions, episodic disabilities are characterized by fluctuating periods of good health interrupted by disabling limitations.^{1,3–6} Unlike many permanent disabilities, episodic conditions are often cyclical and unpredictable in their severity, duration, and potential for recovery.^{1,7} Chronic pain is also a common feature associated with

many episodic disabilities.^{6,7} The purpose of this article is to explore the experience of chronic pain for women living with episodic disabilities.

Living with disability is a gendered experience. The prevalence of all disability is higher for women than men

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and is most significant among working-aged adults (25–44 years),² which is also a common time for the onset of many episodic disabilities. While a variety of chronic health conditions are classified as episodic, some of these disabilities are disproportionately experienced by women. Multiple sclerosis (MS), fibromyalgia, lupus, Ehlers–Danlos syndrome, rheumatoid arthritis, and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) are episodic disabilities that impact women significantly more than men.^{8–12} Rates of inflammatory bowel diseases, such as Crohn's disease and ulcerative colitis are also slightly higher in women.¹³ Gender roles can affect experiences of episodic disability. Specifically, women continue to assume more responsibility for child-care, eldercare, and household work; this contributes to increased stress that can aggravate symptoms and exacerbate disease progression.^{14–16}

The nature of episodic disability is largely misunderstood, including by employers, policymakers, and many health professionals, who may not understand the negative effects these conditions have on the lives of individuals and their families.^{6,17–19} Social constructions position episodic disabilities as less legitimate than permanent disabilities, leading those with episodic disability to experience heightened stigma and discrimination based on their condition.²⁰ These experiences can negatively impact quality of life and interfere with an individual's ability to engage in meaningful employment and build social networks. In the context of episodic disability, women lack access to important income supports that are designed to assist people with permanent disabilities.^{6,18,21} These structural barriers create and sustain social and economic inequities that enhance stress and may make it more difficult to access needed support.

Chronic pain, defined as persistent pain lasting more than 3 months, is a common feature of many episodic disabilities.^{5,22–24} Pain frequently interferes with many aspects of women's lives including participating in social activities, working, exercising, or even basic activities like getting out of bed.^{6,17,22,25} Like episodic disability, chronic pain is a gendered experience such that women are at a greater risk of chronic pain and consistently report higher pain intensity and disability than men.^{1,2,26,27} Among women, various types of social disadvantage have been associated with pain conditions, including poverty.²⁸ A history of gender-based violence, including child maltreatment, intimate partner violence, or sexual assault is also common in women living with chronic pain.^{29–31} Social inequities increase women's risk of chronic pain while simultaneously alienating them from many treatment options.^{27,32–34}

The relationships between episodic disability, chronic pain, gender, and social and structural inequities are complex. For management of chronic pain to be effective, it must consider the complex biological, psychological, and social dimensions of pain and consider how it functions

within the larger context of dealing with an episodic disability.³⁴ Yet many people experience stigma and discrimination in healthcare encounters,³⁵ which can be heightened when therapeutic relationships between women and their healthcare providers are ineffective, lack empathy, or where providers fail to legitimize chronic pain symptoms that are part of the episodic disability.³⁶ Women living with episodic disability struggle with chronic pain, yet how they attempt to navigate their pain experiences in the context of gender norms and social and structural inequities is poorly understood. The purpose of this study was to explore how women navigate chronic pain within the context of living with an episodic disability. The primary research question was: What can be learned from women living with an episodic disability and experiencing chronic pain?

Method

This qualitative study draws on the tenets of interpretive description, an applied research approach developed with the specific goals of creating clinically relevant knowledge.³⁷ Interpretive description is particularly suitable for this study because of its focus on identifying healthcare challenges and using disciplinary logic to generate new knowledge. The techniques used are drawn from social sciences research (e.g. grounded theory or phenomenology) but it allows for nuanced modifications that are pertinent to applied qualitative health research.³⁸ The use of predetermined theories or frameworks is not required for this type of research but the thoughtful application of relevant theoretical or conceptual perspectives is encouraged when it supports answering the research questions.³⁷ While interpretive description is largely a qualitative research approach, its pragmatic orientation allows for the collection and integration of various types of data needed to produce clinical insights. This study draws primarily on in-depth qualitative interviews with women who are living with both an episodic disability and chronic pain. To contextualize these data, selected quantitative data were collected during the interview including a brief measure of chronic pain³⁹ and demographic characteristics.

This form of inquiry is not intended to generate definitive claims.³⁸ The conclusions drawn from an interpretive description qualitative study do not represent the experiences of all women with all episodic disabilities, or the relationships they have with healthcare providers. We recognize that the women who self-selected to participate in this study may have experiences unlike others. However, this type of methodology *does* allow for examination of the patterns and themes within the dataset that can generate insights that are particularly helpful for clinicians and healthcare professionals who practice in this area,³⁸ and ultimately for women living with episodic disabilities and chronic pain.

Table 1. Characteristics of study participants.

Characteristic	% (n)
Age	Range 20–62 years Mean age 40 years
Education level	
Less than college diploma	16 (5)
College/university	77 (23)
Graduate degree	7 (2)
Employment status	
Unemployed	60 (18)
Full-time employment	17 (5)
Part-time employment	23 (7)
Difficulty living on current income	
Not difficult	33 (10)
Somewhat difficult	20 (6)
Difficult	10 (3)
Very difficult	10 (3)
Extremely difficult	27 (8)
Receiving disability assistance	
Yes	27 (8)
No	73 (22)
Community size	
Rural (<1000)	10 (3)
Medium city/area (30,000–99,999)	23 (7)
Large city (>100,000)	67 (20)
Born in Canada	
Yes	90 (27)
No	10 (3)

Sample

Women were eligible to participate in this study if they were 18 years of age or older, had experienced pain lasting 3 months or longer, were living in and/or accessing healthcare in Ontario, Canada, and self-reported a diagnosis of one or more of the following episodic disabilities: MS, lupus, fibromyalgia, Ehlers–Danlos syndrome, rheumatoid arthritis, inflammatory bowel disease, and/or ME/CFS. Purposive sampling strategies were used to intentionally recruit a sample of women living with different episodic disabilities and with varied socioeconomic backgrounds. These strategies included recruiting through multiple channels, such as national organizations (MS Society of Canada and Lupus Ontario), social media (Instagram and Facebook), Kijiji, chronic pain groups, and women’s shelters. As illustrated in Table 1, these strategies were successful in that the 30 participants varied in age (range 20–62 years, average 40 years), socioeconomic factors, geographic location, and diagnosis (Figure 1). Of interest, although 84% of participants had completed college or university, the majority (60%) were unemployed and almost half (47%) found it difficult, very difficult, or extremely difficult to live on their current incomes.

Data collection and analysis

This study was approved by the Western University’s research ethics board (Approval No. 118031). Participants were able to provide written and/or verbal consent. Because none of the interviews were in-person, participants were able to sign, scan, and email written consent. If that was a barrier, participants could provide verbal consent, which was recorded on a Documentation of Verbal Consent form, signed by the interviewer, and emailed to the participant if desired. After obtaining informed verbal and/or written consent, semi-structured, individual interviews were conducted over telephone or Zoom videoconference (within the context of the COVID-19 global pandemic) with 30 women who had experienced chronic pain and were diagnosed with one or more episodic disabilities. Interviews were loosely structured by a qualitative interview guide (Appendix 1) and lasted between 22 and 82 min, with an average length of 51 min. Interviews were conducted between March 2021 and July 2021 by two nurse-researchers (K.A.C. and K.K.), who both had training and/or experience in qualitative interviewing. Questions from Von Korff et al.’s³⁹ graded chronic pain scale revised (GCPS-R) were integrated into the interview guide (see Appendix 1) and are reported in Table 2. The GCPS-R is a brief, validated tool that supports identification of chronic pain based on pain severity and pain-related disability.³⁹ Chronic pain is differentiated into three categories: mild, bothersome, and high-impact chronic pain.³⁹ Items are based on self-assessment of experiences over the past 7 days to 3 months and assess impact of pain on life activities.³⁹ Quantitative data were analyzed using a mixture of descriptive statistics and nonparametric inferential statistics, using SPSS Version 27. Participants were free to answer, or not answer, questions in a way that was meaningful to them. All interviews were audio-recorded and transcribed using a professional transcription service. All identifying information was removed prior to analysis.

In keeping with the pragmatic and flexible approach of interpretive description, various data analysis strategies were used to bring rich interpretation and rigor to the findings.³⁷ Data collection and analysis occurred concurrently. In interpretive description, the goal is not to reach *data saturation* but rather to collect and analyze data that can provide a logical, original, and meaningful contribution to clinicians and others interested in the phenomena.³⁷ The primary strategy followed Research Talk’s[®] *Sort and Sift, Think and Shift* analytic method, which encouraged continuous movement between engaging with the data and engaging in reflective thought.⁴⁰ This method is consistent with interpretive description because it allows researchers to establish their own understanding of the data while exploring their relationship to the data. Primary activities included reading and reviewing transcripts for powerful quotations and data segments, recognizing topics, themes,

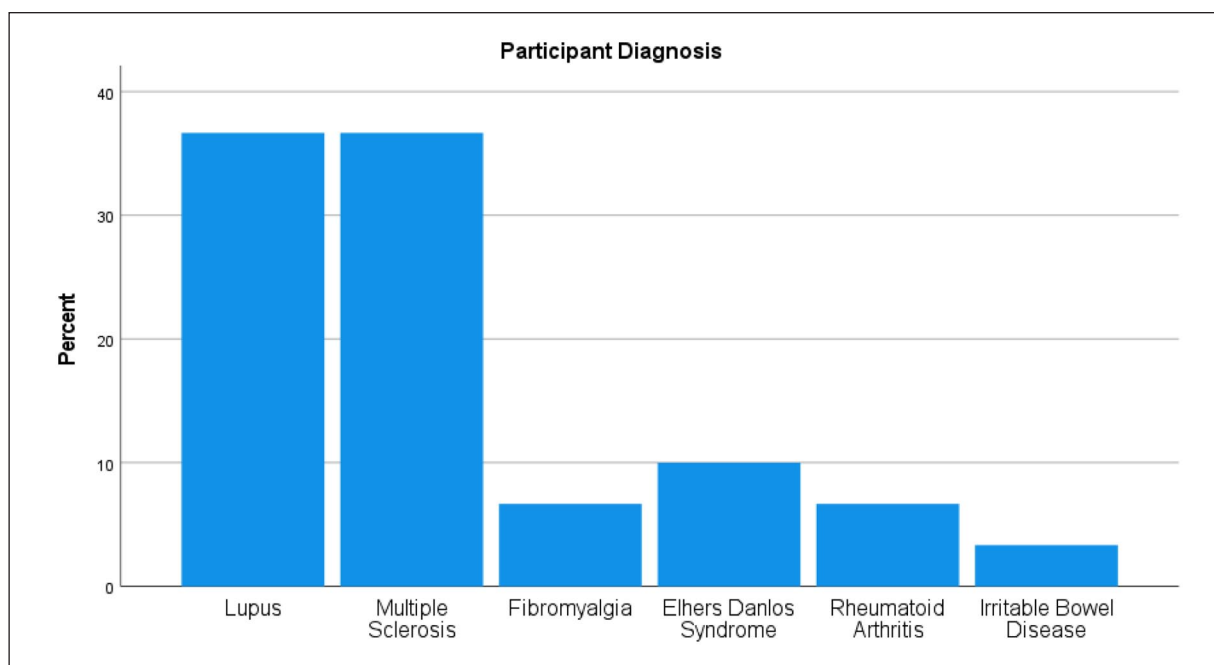


Figure 1. Diagnoses of participants.

Table 2. Participant's results from the Graded Chronic Pain Scale, Revised.

Grading	% (n)
Grade 0 Chronic pain absent	0 (0)
Grade 1 Mild chronic pain	10 (3)
Grade 2 Bothersome chronic pain	20 (6)
Grade 3 High-impact chronic pain	70 (21)

and attributes of the data, recording memos, and developing diagrams and visuals that helped bridge key ideas.^{40,41}

Results

The women who participated in this study described their experiences of navigating chronic pain within the context of living with an episodic disability. Overall, this involved dealing, as women, with the limitations existing within the healthcare system. Nurses and physicians were the primary gatekeepers to the commodities needed to manage the chronic pain associated with their diagnoses. As they navigated their pain management, participants described their need to take control of their treatment plan by enacting their own agency and finding complementary treatments to medical care that represented a holistic approach to their well-being. Findings related to *navigating and*

responding to the healthcare system are presented below as four inter-related themes.

Navigating and responding to the healthcare system

The power of being dismissed. Overwhelmingly, women experienced gendered treatment within the healthcare system and reported that they were frequently dismissed by their healthcare providers, most often physicians. To a lesser extent, nurses in hospital disregarded women's symptoms, which was problematic when they controlled access to medications. Being dismissed occurred at many points, including while seeking testing and diagnoses, treatment for symptoms, or referrals. When women experienced dismissive behavior, it led some to question their own judgment or knowledge of themselves, "When a physician cannot find inflammation present in the blood or there isn't anything tangible as an identifier, they automatically dismiss the pain as psychological." Some found these experiences to be triggering. Feelings of shame and embarrassment were also evident when no biomedical markers could "prove" their pain, as suggested in this quote:

It's easier to put the onus on the patient and say, "well we couldn't find anything wrong with you" . . . Then the patient feels that instead everything is turned on them. So then, you know, the patient feels, "well they can't find out what is wrong with me"; then the patient feels shame, you know, there's nothing *concrete*.

The response of feeling gaslit or being triggered should not be surprising given the high number of women who disclosed a previous traumatic or abusive event in life.

Most women in this study experienced patriarchal or gendered communication from their physicians. In some instances, this included speaking to their male partner (or parent of a former pediatric patient) rather than addressing the woman directly during specialist appointments. The sexist communication was often overt, particularly for one woman who required her physician fill out government forms that would provide access to disability income supports:

A long time ago, when I was trying to get onto housing and disability [financial support], I had some really terrible doctors who gave me bad advice and they just left me hopeless. They were old school doctors which, you know, I can't believe this one psychiatrist even told me "you're better off marrying a rich man than getting on disability." And I'm like, "are you kidding me? Don't say something like that to a client." I've had some bad experiences with some doctors.

Other women in the study had their pain experiences dismissed and blamed on them being overweight:

I actually lost 150 lbs—my doctor told me that it would help me so much with my pain, which wasn't exactly true. Because I'm still in the same amount of pain, but I did lose a lot of weight to try to help that.

Generally, women reported that they did not have the energy to address these inappropriate comments because they were already dealing with pain and other symptoms caused by their concurrent episodic disability: "You know, I am a fighter. I mean I feel like that's the only way we get change. It's just I don't have any energy left to fight at the moment." Others feared the consequences that challenging their healthcare provider would have on their care.

The quality of healthcare received and how it was communicated also impacted participants' experiences of chronic pain within the context of living with an episodic disability. Participants' encounters with healthcare professionals, particularly in acute care settings, led to frustration and anger, as one woman shared:

And one doctor there who was an internist said to me two days in a row, well you have lupus why would you expect to get better? If I wasn't so sick on that bed, he'd have lost a body part.

This type of dismissal affected participants' plan of care and made it more challenging to get their pain treated, "You kind of fall through the cracks. And unless you have a huge gaping wound or something that they can see, it's really hard to be treated for pain."

All participants sought out healthcare professionals who were effective communicators and had compassionate attributes. When participants had compassionate health providers involved in their care, they had more trust in the healthcare system, even when they could not control pain or other related symptoms. This was primarily because regular providers could see changes, trusted, and respected the women's experiences when they complained of pain, and had recall of past treatments and their level of success. One woman living with lupus who had a long-term relationship with an understanding and compassionate physician noted:

I had had that same doctor for 20 years, and he understood how my illness worked almost as well as I did. So, like I know the first signs of flaring, and he—we would have a way of communicating where I was able to say this and this, so this is triggering this, and, OK, this was the plan. You know, there was an understated agreement—he had also given me ways of just upping my Prednisone when I needed without actually consulting him.

Where long-term relationships could be maintained with compassionate providers, women were able to be active participants in navigating their treatment and controlling their pain and associated symptoms. As these relationships ended, primarily caused by retirements, women went back into situations where healthcare providers (mainly physicians) were in control.

(Dis)respecting medical advice. Influenced by gendered treatment within healthcare settings, women experiencing chronic pain and an episodic disability navigated the tensions between trusting healthcare providers and avoiding interactions that would not meet their needs. At times, this involved becoming more passive in their own care and deferring to medical advice. As a consequence, women described feeling powerless around being "put on" medications and fearing significant adverse effects, particularly from the use of steroids but followed physicians' directives hoping for better management of their episodic condition, "I don't like the way it makes me feel when I first take it, but yet I'm dependent on it. Because if I don't take it I have a very hard time walking." Women, often reluctantly, trusted the medications prescribed by their healthcare providers.

Many women attempted to control pain and manage exacerbations of disability by using a variety of natural supplements or vitamins that did not require a physician prescription. For example, the majority of women were open to trying cannabis in an attempt to control chronic pain symptoms, and some were actively using cannabis or cannabidiols. Physicians' responses to cannabis ranged from supportive to cautious, with some doctors avoiding the discussion entirely. Anticipating or fearing disapproval from their physicians, and also exerting

agency where they could, some women did not discuss these self-selected treatments with their physicians, while others were proactive in consulting with their physician as part of their own decision-making, “[I do] my own research and then I discuss that with healthcare providers.” While some women made decisions about their own self-care, a few noted that they would not attempt any medication or supplement that was not *approved* or *suggested* by a physician.

Seeking personalized care in an unpersonal system. Women navigated the rigidity of a healthcare system that inherently lacked continuity in care, thus creating instability. Many participants were connected to teaching hospitals, where general practitioners were residents replaced every 2 years. Despite the disruption that this caused, women in this study remained in these arrangements because specialist care was associated with a particular clinic or hospital, and specialists were difficult to access. Those who had healthcare providers retire were disheartened because no one was available to fill the void. For one woman with lupus, chronic pain, and multiple other health concerns, a physician retiring meant that she could not access a variety of needed medications, “The biggest problem when everybody on your team retires is that you have nobody to do [prescribe] medications. So, when you have to go off your 14 medications because nobody can prescribe, that causes issues.” Frustrated by the lack of continuity in care and succession planning, women’s confidence in their ability to manage their health was often eroded.

Healthcare professionals’ practices around pain assessment were another common challenge for women in the depersonalized system. In particular, women reported that pain assessments based on a few questions and requiring women to report their pain on a 1–10 scale were common and limiting. These types of pain assessments were generally ineffective in capturing the everchanging nature of the pain experienced by participants, particularly when healthcare providers were unfamiliar with the woman’s history. While many women reported frustration with these practices, one explained how she attempted to help the nurses conduct assessments that better captured the nuances of her experiences with lupus:

In my case, I find a lot of times when I go into the pre-assessment and the nurse comes in, she’s like, “How’s your lupus, are you stiff?” And I find it so irrelevant to me because stiff is not how I would describe my joint pain. So, often I’ll say “No,” and then they’re like “Oh, good.” But I’m like, “No, I mean my joints hurt a lot but they’re not stiff, and I know what you mean by stiff, but that’s not how I’d describe it.” So, a lot of times I think there’s like a set of questions that they have to ask, but if you don’t fit in those questions, you kind of have to be able to adapt how you’re explaining your pain, or how you’re feeling the pain, you know? My joints just feel like they’re *eroding*.

Both the language and the structure of standardized pain scale assessments were reported by women as problematic and out of touch with their experiences, particularly when asked to assign a numerical rating to their pain over a longer timeframe (e.g. Thinking about the pain you had in the last 7 days, what number best describes your pain, on average, where 0 is “no pain” and 10 is “pain as bad as it could be”?). For women who never experienced a day without pain, a score of 0 was outside their reality. Others had difficulty even quantifying the episodic nature of their pain. In an effort to make these numeric ratings more meaningful, study participants attempted to *interpret* their pain score for healthcare providers, as described by this woman:

When I’m talking to a new person or a new doctor about pain and they do the one to ten [pain scale], I’m always like, “Look, here’s how I’m calibrating it. I’m calibrating it with an eight being childbirth.” So, like, my six is still frigging serious, right?

When women in this study rated pain on a numeric scale, these ratings were often lower than their narrative accounts would suggest. One woman’s account of the significant impact of her pain on activities of daily living illustrates this *disconnect* with her pain rating:

If I’m barefoot, the time to take a shower, it’s too painful. Standing is painful, you know, little things . . . Like cooking, if I’m peeling vegetables I have to sit down. So, I mean that, in terms of the kind of pain—it’s just like it’s everything you do. So, six, seven at worst.

In general, the constant need to qualify and explain how pain was being experienced to new or disbelieving healthcare providers was common and exhausting for women and used up already limited energy reserves.

The “cost” of well-being. Financial constraints were a significant barrier to accessing healthcare not covered by the provincial insurance plan. Women were often interested in accessing care from a wide range of allied health professionals and believed they would benefit from such care. However, these services were not affordable, even with private insurance, due to the high (co)payments required. The list of practitioners that women were interested in accessing ranged from allied health professionals (e.g. massage therapists, psychologists, and physiotherapists) to holistic healers (e.g. acupuncturists, and naturopaths), and even to paraprofessionals (e.g. fitness instructors and personal support workers (PSWs)). Women did not necessarily seek out the same types of treatments or have success with the same type of practitioner, even when they had the same episodic disability. For example, one participant said, “I meditate while I’m getting the acupuncture. I find that it does work,” while another said, “Acupuncture? No,

because I heard it's not good for people with MS, so I just didn't do it." When women lacked knowledge about the impact of these therapies on their episodic disability, they were more likely to be interested but cautious, and often unwilling to risk further pain or disability by using these allied health or holistic professionals.

Women who were able to access financial support from government disability programs were more likely to access allied health professionals. Given that finances were a constraining factor for most women in the study, finding a licensed professional who was flexible enough to bill them in way that fit with the conditions of their extended health benefit was critical in securing therapies that women perceived as helpful:

I would go to an osteopath. I call it a tune-up. When I could go to him. He did all three [osteopath, physiotherapy, and acupuncture] and had it billed as physio. If I'd spent the money, I could stay functional enough to work because I've had three periods in two years where I could not work. I used to go every two weeks to three weeks. I'd go to physio and we wouldn't do anything there that I couldn't do at home. So, all the exercises I could do at home. It was the hands-on stuff. Things like the osteopathic movements that were critical to me. I haven't been able to get one for a year and a half. I think this headache that hasn't left for six months might just go away if I could see an osteopath for one or two appointments.

Yet, most women could not afford these therapies. Even PSW services to help everyday needs (such as bathing, exercises, cooking, errands, and housework) were difficult to access. In response, some women hired friends who could provide this type of support to benefit from PSW services in a cost-effective manner, "I have a friend that is a PSW, and she actually comes in once a week and does what my kids can't do [cleaning, cooking, or helping with bathing]." Occasionally, charitable organizations (e.g. MS Society of Canada) were helpful in providing financial support for housecleaning and support in bathing or other activities of daily living by PSWs. Finally, despite all of the participants describing the need to find ways to cope with fatigue and its impact on pain, only one woman mentioned an interest in working with an occupational therapist, despite their expertise in energy conservation techniques.

Regardless of interest, cost was also a barrier for women being able to access professional support for exercise. As women's level of disability increased, their convictions about the need for professional exercise support also increased. For example, participants sought out support from physiotherapists or fitness professionals, particularly those who had knowledge of episodic conditions and chronic pain, to preserve or regain ability. One woman shared her desire to work with a physiotherapist to regain function, "Getting the muscle strength back, like exercising, with somebody who could be there with me to guide

me. But you know, I can't afford something like that." The fear of doing harm or causing more pain through exercise often interfered with regular physical activity. If cost was not a factor, women indicated that they would use professional services to remain active.

Seeking the essentials of living, beyond healthcare. Facing challenges presented in their interactions with the health-care system, the women in this study enacted their own agency to navigate chronic pain management alongside medical care. They often began with "research" to identify the specific therapies and medications that would best support their own unique approach to managing their episodic condition and, in turn, help with pain. Many of the women described the extensive work done to learn more about their options:

Sometimes, it can be a giant mess and it becomes a struggle—you're not just struggling to deal with the chronic pain and the illness and the disease and the takedown and the comorbidities and the constant information, you have to become your own doctor, I swear. You've got the three years medical school, but you don't have the certificate hanging on your wall.

While this research included information about disease modifying drugs, women were also eager to try holistic modalities to address chronic pain, including diet, exercise, and other self-care measures.

Various approaches to diet for disease management were mentioned by participants. Although women primarily used their diet to manage episodic conditions, they noted that this also lowered pain levels. The women who discussed diet had done extensive research into different nutrition plans, "I went back to school to become a holistic nutritionist because I wanted to not set off my body with diet, because if I eat acid producing foods my pain goes bananas." Few of the participants discussed dietary plans with healthcare providers, including registered dieticians or nutritionists. However, for one university student with lupus, the school nutritionist helped to develop a plan to support healthy eating on campus; another student moved out of her family home to have more autonomy with her diet, which she researched herself.

Many of the holistic strategies that women researched and used to treat chronic pain were self-enacted. Getting adequate sleep, taking supplements, conserving energy by scheduling activities, limiting stressful events or people, taking baths, or using hot or cold compresses were all strategies used to manage pain. Other approaches included prayer, mindfulness, meditation, and practicing gratitude. Surrendering to the pain experience was necessary at times, and despite growing more despondent, it was also used as a method of pain management. One participant shared how she came to accept pain as part of her life:

When I'm in really bad pain, or really down—like fatigued, I'll just cry. I don't know what else to do. Because I can't really help myself, I just have to wait it out. But the longer I wait it out, the more the years go by and the next thing you know 10 years have gone by and what the hell did you do with yourself.

These types of self-enacted activities were the most common strategies used to manage pain because they came at no significant cost to the participants. While diet, exercise, and other self-enacted approaches are general health promotion strategies for all, they were seen as *essential* aspects of living that helped women have control over chronic pain and modifying the course of their disease. One participant described the necessity of these activities:

Self-care now is necessary for *survival* and self-care could be grooming yourself or eating. Simple showering and cleaning and cooking and socialising and chilling and the 100 other things I'm not mentioning. Those become, I would say *essential to living*; self-care that some people just take for granted.

Discussion

The findings of this study highlight the gendered treatment of women who live with episodic disabilities and navigate chronic pain within the healthcare system. We found that lasting relationships with understanding and compassionate caregivers were required for women to be supported and connected to their healthcare providers. Despite the need for consistency in healthcare providers, system issues often interfered, causing women to expend limited energy reserves on building short-term relationships, particularly with new physicians. In addition, financial barriers often precluded women from seeking out allied health professionals for support with chronic pain. Yet many women sought out strategies that they could enact themselves as a method of maintaining or promoting their health and limiting pain. These types of self-care measures were essential for managing episodic disabilities resulting in better pain management. While it is important to know that women with a variety of episodic disabilities had similar experiences, it may be a limitation of this study that these conditions were collectively researched. As such, we did not isolate the nuances of any one episodic disability from others in this analysis.

Women and healthcare providers

For decades, the chronic pain literature has recognized the stigma and treatment of women to be gendered and that women are frequently dismissed in healthcare.^{42–44} Women *being dismissed* by healthcare providers happens across multiple areas of healthcare, including women with

chronic health conditions,⁴⁵ during childbirth,⁴⁶ and women who are overweight,^{47,48} among others. This was not different in our study as we found that gendered treatment most often occurred through interactions that were dismissive or misogynistic and that it negatively impacted women's experiences of navigating pain management. Similarly, Thorne et al.¹⁹ found when communication with healthcare providers was dismissive or unhelpful, quality of care for people with MS, an episodic disability, was negatively impacted.

Research reviews have suggested that effective patient-provider communication is positively related to patients' satisfaction, and improves their view of their own health.^{49,50} Indeed, there have been many calls for positive patient communication in healthcare because it is foundational for therapeutic relationships.^{19,49,50} Based on their study, Thorne et al.¹⁹ even provided a taxonomy of helpful and unhelpful communication patterns for physicians treating people with MS. Beyond communication, our findings extend this research to include the entire healthcare interaction, inclusive of interpersonal relationships and system issues.

One significant finding in our study was the importance that women placed on trust and continuity of relationships with healthcare providers in the face of many system barriers. Horn et al.⁵¹ also found that patients valued continuity of care as a distinguishing feature of family medicine. The lack of continuity of care had some dire outcomes in our study, including a disruption in medications and women having to re-establish an understanding of how to manage their chronic pain with their healthcare provider and within the context of their episodic disability. Other research has also noted the preferences that patients have for a partnership in decision making and the importance of trust in the patient-provider relationship.⁵²

Treating chronic pain is difficult and effective pain management begins with a comprehensive biomedical, psychosocial, and behavioral assessment.^{6–8,39,50,53} The need for a comprehensive history as part of the assessment⁵⁰ reinforces the need for continuity of care. Similar to other research, we recognized the difficulty in assessing chronic pain and found that assessments that did not contextualize the women's experiences were disaffirming. We used Von Korff et al.'s³⁹ self-reported revised graded chronic pain scale. The results (see Table 2) were that 70% of the women ranked as high impact chronic pain, which was defined by Von Korff et al. as “sustained pain-related limitations in work, social, and self-care activities” (p. 2). There are a variety of self-reported tools⁵⁰ that could provide women with more agency in assessing chronic pain when used in conjunction with a thorough history.

It is well recognized that the chronic pain experience is associated with histories of trauma and/or violence.^{29,30,54} Although this study did not explore the phenomenon of trauma and violence, women spontaneously revealed

many incidences of trauma. This finding highlights the need for approaches that encourage effective communication, but also consider other barriers that may reinforce disadvantage or trauma for women with episodic disabilities and chronic pain. When women's pain concerns are dismissed, health professionals could be missing opportunities to assess for and respond to situations of trauma.

Financial burdens and chronic pain

Our study revealed that financial barriers interfered with women being able to access additional health services, despite their interest or preferences. An extensive body of literature has examined the cost-of-illness for a variety of episodic disabilities, and indicate an economic burden on the healthcare system, society, and the individual.⁵⁵⁻⁵⁸ These findings are consistent with our study, where almost half (47%) of the participants indicated that it was difficult, very difficult, or extremely difficult to live on their current income. To put this in context, in Canada, people with post-secondary degrees are more likely to be employed;⁵⁹ therefore, the high unemployment rate among women in this study (60%) is particularly noteworthy given that 84% of participants had completed post-secondary education. Also, only 27% were accessing provincial disability income support that could provide access to additional health services.

Poverty is considered to be both a cause and a consequence of disability.⁶⁰ This continuous and cyclical relationship can have a negative impact on women's ability to access health professionals that are not covered by provincial health insurance programs or medications or other therapies that may support optimal health. Findings from Yaphe et al.'s⁶¹ qualitative study revealed the financial burden of accessing medications and called for policies that support universal, government funded pharmacare programs in order to reduce this burden. Pharmacare programs could help women with episodic disabilities by reducing the burden of medication costs; however, more research is needed to understand the benefits of pharmacare for women with episodic disabilities and chronic pain.

Our study finding that financial burdens limited women's access to allied health professionals is significant for the development of meaningful public policies that have potential to reduce health inequities. This may require further research to identify the effectiveness of allied health professionals in treating women with episodic disabilities and pain. Concurrently, economic strategies and policies that make access to costly therapies financially viable, such as bringing these professionals into the public insurance system or having access to flexible dollars for government funded therapies are worth considering. In addition, using Medicare in novel ways to support women with episodic disabilities to access allied health professionals should be explored. In Australia, for example, one

initiative for chronic disease management integrated access to 13 allied health professionals into a primary care program.⁶² While these types of innovations require rigorous evaluation, they may be promising approaches for reducing financial burden for women while increasing access to health professions, beyond physicians.

Self-management

As the women in our study sought out more information, they enacted agency and identified holistic treatments to self-manage their episodic condition and help navigate their chronic pain. This is an important finding given that an Ontario study suggested that people with MS had unmet healthcare needs, and that self-treatment led to service avoidance until a health crisis occurred.⁶³ In our study, there was a lot of variation in how much women sought advice from their healthcare providers. This ranged from unquestioning deference to consultation to making decisions entirely on their own. Similarly to our participants, Petrin et al.⁶³ also found that the majority of patients in their study were receiving healthcare services from physicians, and few received care from other health providers, including nurses.

Another unique finding of our study was the importance of self-care behaviors as effective measures for controlling disease progression and treating pain for women with episodic disabilities. It was of interest that women who had previously been dismissed by health professionals were more hesitant to discuss decisions around natural supplements, diet, or cannabis use with their physicians. This finding could have an impact on their plan of care and reinforces the importance of open, respectful, and trusting relationships with care providers. Increasingly, evidence is supporting the effectiveness of non-pharmacological treatments for episodic disabilities, which may also impact chronic pain experiences.^{64,65} Research that identifies modifiable lifestyle factors that reduce chronic pain, without the negative side effects of medications typically used to treat episodic disabilities or chronic pain, should be a priority. Self-management strategies could also be a method of increasing women's active participation in their pain management which, in this study, was related to more positive experiences with health professionals.

Implications

This study has implications for future education, practice, and research. First, Von Korff et al.'s³⁹ GCPS-R is a promising tool for measuring chronic pain in women with episodic disabilities. If the GCPS-R is effective with this population, it may facilitate communication about chronic pain between health practitioners and women.

To further enhance communication, trauma- and violence-informed care (TVIC) approaches could be embedded

directly into education programs for healthcare providers. TVIC approaches to care go beyond interpersonal communication and illuminate the broader social conditions that impact health, including structural and systemic violence.⁶⁶ Practicing from this perspective enhances safety and trust, which could have an impact on how women utilize healthcare services. Practitioners working with women who are living with chronic pain may be better able to support their situations without re-traumatizing and perpetuating gendered treatment in the healthcare system when applying TVIC. Education programs from students and practicing nurses and physicians, as well as allied health professionals, could benefit from TVIC training across all healthcare settings.⁶⁷

In addition to TVIC healthcare environments, enhancing the role of registered nurses working with women experiencing chronic pain and episodic disabilities could provide increased consistency in healthcare providers and allow women to build trusting relationships. The development of community health nursing interventions that support women living with chronic pain and episodic disabilities could have positive outcomes with decreasing pain and slowing disease progression for women; however, such programs need to be developed, piloted, and evaluated. Finally, the impact of self-management strategies on women's well-being is an under researched area that could have significant implications for women with episodic disabilities and should be further explored.

Conclusion

The findings of this study present the impact that gendered treatment in the healthcare system has on women who live with an episodic disability and experience chronic pain. It is evident that the current system did not meet the needs of the women in our study and system changes could result in better experiences, more disclosure of alternative therapies, and increase women's agency in their care. Living with chronic pain and an episodic disability is complex and may also be associated with experiences of past trauma and/or violence. Thus, embedding TVIC practices into primary healthcare and acute care settings may be a strategy that addresses ineffective communication on a systemic level, while being responsive to not re-traumatizing women. Finally, living with an episodic disability and chronic pain may be a lifelong situation; when women can identify and implement strategies that support their own health, it may support well-being and increase satisfaction with their health.

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Marilyn Ford-Gilboe: Conceptualization; Formal analysis; Funding acquisition; Methodology; Supervision; Validation; Writing—original draft; Writing—review and editing.

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Supplemental material

Supplemental material for this article is available online.

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Appendix I

Semi-structured interview guide

1. Thinking about the pain you had in the last 7 days, what number best describes your pain, on average, where 0 is “no pain” and 10 is ‘pain as bad as it could be’? (That is, your usual pain when you were experiencing pain)

0	1	2	3	4	5	6	7	8	9	10
No									Pain as Bad	
Pain									as Could Be	
2. It might help me to understand what is going on with your pain if I knew a bit about your living situation. Could you tell me about your living situation?
 - a. Probes:
Does anyone live with you? Have you moved in the past 12 months? If yes, how many times? Is your current housing meeting your needs?
3. Who are the important people in your life that help you to cope with your pain?
 - a. Probes:
Do any health professionals that help with your pain? How does that work with each condition (i.e. chronic pain and episodic disability)? Are there any other paid people who are involved in

- treating your pain? Family? Friends?
Co-workers?
4. How does your chronic pain currently affect your life?
 - a. Probes:
Does your pain interfere with your ability to work or go to school? Have a social life? Does it impact your ability to do household chores or impact your family?
 5. Over the past 3 months, how often did pain limit your life or work activities?
Never Some days Most days Everyday
 6. Over the last 7 days, what number best describes how pain has interfered with your general activity?
0 1 2 3 4 5 6 7 8 9 10
No Pain as Bad as Could Be
 7. Can you tell me a bit about how you have tried to manage your chronic pain?
 - a. Probes:
What have you tried to do on your own?
How did you find out about that? Did this help you? how?
Have other people helped you? (e.g. healthcare providers, family members, friends. Can you tell me about that? [who? how did they know you needed help? what did they offer? how effective was their help?])
 8. Are there other things you would like to try to better manage your pain?
 - a. Probe:
What would you like to try? What keeps you from trying this? (e.g. (social inequities, against medical advice)
 9. During the past 7 days, what number best describes how pain has interfered with your enjoyment of life?
0 1 2 3 4 5 6 7 8 9 10
No Pain as Bad as Could Be
 10. How would your life be different if you didn't have chronic pain?
 - a. Probes:
What are you not getting to do enough of because of your chronic pain?
How would your episodic disability be different if you didn't have chronic pain?
 11. Are there any parts of your life make it harder to cope with having chronic pain and <Name of the episodic disability>?
 - a. Probe:
If money was not a concern, is there anything that you would do differently to deal with your pain or treat your <name of episodic disability>?
 12. Is there anything else that you would like us to know about living with chronic pain and <name of episodic disability>?

Section 2: background questions

Before we end, I would like to ask a few questions about your background.

What year were you born?

How would you describe the community where you live?

- Rural Community—with less than 1000 residents
- Small Town or Area—with between 1000 and 29,999 residents
- Medium-Size City or Area—with 30,000 to 99,999 residents
- Large City or Area—with 100,000 or more residents

What is the highest level of education you have completed?

- Some elementary school
- Elementary School
- Some Secondary School/High School
- Graduated from Secondary School/High School
- Some College or University
- Graduated from College or University
- Other:

Do you work outside the home?

If employed: Are you employed full-time or part-time?

If unemployed: Are you not working or unable to work due to you pain?

Are you receiving disability assistance?

If YES, since when (approximately)

Are you receiving social assistance?

If Yes, since when (approximately)

Overall, how difficult is it for you to live on your TOTAL household income right now?

- Not at all difficult
- Somewhat difficult
- Difficult
- Very difficult
- Extremely difficult or impossible

Has this difficulty living on your income changed in the past 12 months?

If so, was it easier or harder to live on your income?

This study is for women of all backgrounds. What were the ethnic or cultural origins of your ancestors?

(Note: An ancestor is usually more distant than a grandparent. Examples are: Canadian, English, French, Chinese, East Indian, Italian, German, Scottish, Irish, Cree, Mi'kmaq, Salish, Métis, Inuit, Filipino, Dutch, Ukrainian, Polish, Portuguese, Greek, Korean, Vietnamese, Jamaican, Jewish, Lebanese, Salvadorean, Somali, Colombian, etc.) Please specify as many origins as you want.

Do you identify as Indigenous (First nations, metis, inuit)?

Were you born in Canada?

If NO: In which country were you born? _____

How long have you lived in Canada? _____

Before we finish up, I just want to take a few minutes to check in with you. Should you feel distressed as a result of participating in the study, we encourage you to follow up with your primary healthcare provider (doctor or NP), speak to a nurse at your local health department or call a mental health support line. Are these things that you would be able to do? Would you like me to provide phone numbers or web addresses you can use to reach a public health nurse or mental health support line?