

Medical invalidation in the clinical encounter: a qualitative study of the health care experiences of young women and nonbinary people living with chronic illnesses

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Abstract

Background: Medical invalidation is a well-documented phenomenon in the literature on chronic illnesses, yet there is a paucity of research capturing the perspectives of young adults living with chronic illnesses, and especially of those who are gender diverse or from groups that face broader societal marginalization. Our study sought to answer the following question: How do young women and nonbinary adults living with chronic illnesses characterize their experiences of medical invalidation and its impact on their health and well-being?

Methods: This was a patient-oriented qualitative study informed by feminist disability theory. Eligibility requirements included self-identifying as having a chronic illness, self-identifying as a woman or nonbinary person receiving health care in Manitoba, and being between the ages of 18 and 35 years. Participants took part in online arts-based workshops and subsequent focus group discussion in November 2021.

Results: Eight women and 2 nonbinary individuals participated. Medical invalidation was experienced by all of the participants at different points in their illness journeys and took a variety of forms depending on their social location and their particular illness, positioning invalidation as an issue of in/visibility. We identified several consequences of medical invalidation, including internalizing invalidation, overcompensating for their illness, avoiding care and, ultimately, symptom intensification. We also present participants' recommendations to avoid medical invalidation.

Interpretation: This study provides insight into the phenomenon of medical invalidation, understood as the act of dismissing, minimizing or otherwise not taking patient concerns seriously. We suggest person-centred care may not be enough, and critical reflexivity may help avoid unintentionally invalidating patient experiences.

Medical invalidation, whereby health care professionals dismiss, minimize or otherwise do not take patient concerns seriously, is a well-documented phenomenon in the literature on chronic illnesses — particularly expressed by women, people with poorly understood or contested conditions, or those from other groups who face marginalization in health care.¹ Medical invalidation has far-reaching implications. For example, Sloan and colleagues found that negative health care encounters can lead to diminished self-confidence and distrust in the medical profession, and may deter people with chronic illnesses from seeking care when they need it.² Quantitative research is beginning to confirm the relation between invalidation and worsening mental health.^{3,4} Yet, most of the research on medical invalidation focuses on the experiences of middle- and older-aged women, leaving out the perspectives of young adults living with chronic illnesses, and especially of those who are gender diverse or from groups that face broader societal marginalization.

Early adulthood can be a difficult time for youth living with chronic illnesses as they navigate a variety of life changes

and increasing responsibility.⁵ Critical to this period is a supportive relationship with their health care provider. Given this, our study sought to answer the following question: How do young women and nonbinary adults living with chronic illnesses characterize their experiences of medical invalidation and its impact on their health and well-being?

Methods

This article reports focus group findings from a broader qualitative, arts-informed and patient-oriented project^{6,7} that explored the health care experiences of young women and

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nonbinary adults living with chronic illnesses. The broader study involved arts-based workshops followed by focus groups, and we present the findings from the focus group transcripts here. The study was informed by feminist disability theory,^{8–11} which is amenable to the principles of patient-oriented research. In practice, this meant the study was by and for the population of interest (J.C.H.S. is a young, nonbinary adult living with multiple chronic illnesses, and patient partners helped design the workshops); the focus groups were largely unstructured to allow for participants to lead the discussion; and an ethos of collective access^{12,13} informed our study design overall (e.g., intersectional approach to recruitment,¹⁴ trauma-informed approach to facilitation and engagement,¹⁵ active offer of accommodations and providing information ahead of time on the workshops). Further, we strove to achieve the quality markers of reflexivity and integrity,¹⁶ which meant maintaining dialogic engagement throughout,¹⁷ continually interrogating and revisiting our assumptions, keeping a journal of our thought processes during data analysis, and ensuring that study design, data collection and analysis were rooted in the established theoretical and methodological literature, the lived realities of people living with chronic illnesses and the participants' experiences and intentions (e.g., consulting with patient partners). Because of the COVID-19 pandemic, this study took place virtually over Microsoft Teams, although all participants were residents of Manitoba, Canada, and received health care in Manitoba. The study took place in November 2021.

We report our results in accordance with the Standards for Reporting Qualitative Research.

Participants and recruitment

Participant eligibility included self-identifying as having a chronic illness, self-identifying as a woman or nonbinary person receiving health care in Manitoba, and being between the ages of 21 and 30 years, which was expanded to 18 to 35 years to allow for more participants. The study focuses on this particular population because women and nonbinary people are more likely to live with chronic illnesses and experience gender-related discrimination in care than their cisgender, cissex male counterparts.^{18–20} As mentioned earlier, young adults are less represented in the literature on chronic illness than middle-aged or older adults, and this life stage represents an important transitional period both in terms of shifting health care services (pediatrics v. adult care) and establishing one's independence. Participants were recruited via posts on the lead author's professional social media accounts (Instagram, Facebook and Twitter), through outreach with the provincial patient-oriented research unit, and the email lists and social media of relevant community organizations (e.g., disease-specific advocacy groups and local resource centres).

Data collection

Participants were invited to fill out a demographic questionnaire online. Participants took part in 1 of 3 virtual workshops with 2 to 3 other participants. The small group size reflects our commitment to collective access and inclusion in that it allows

more time for participants to create their work and discuss their experiences. J.C.H.S. conducted the workshops, in which participants were first guided to create a collage representing their experiences of patienthood and then a group discussion took place to contextualize the artwork created and link these to broader experiences in health care and their everyday life with chronic illness.²¹ Three patient partners assisted in designing the workshop. Participants were given an informational booklet ahead of the workshop designed by J.C.H.S. so they knew what to expect coming into the workshop. The booklet framed the study, provided an agenda for the workshop, a prompt (What does being a patient mean to you? What is your experience of patienthood?) and list of questions to structure their artistic process (e.g., What are some of the pivotal experiences you've had as a patient?). The full list of questions is available in Appendix 1 (available at www.cmajopen.ca/content/11/5/E915/suppl/DC1). J.C.H.S. interjected only to ask for clarification, to ensure everyone had a chance to contribute and to keep the conversation on topic. A list of local mental health resources was available to participants, and a mental health support worker was made available during and after the workshop if participants needed support.

Data analysis

The discussion was audio-recorded and subsequently transcribed using a third-party professional transcription company. Using Dedoose software, J.C.H.S. completed the data analysis using qualitative thematic analysis²² and a combination of inductive and deductive coding informed by feminist disability theory, including the concept of invalidation as articulated by feminist disability philosopher Susan Wendell.²³ Wendell highlights how invalidation may lead to negative effects on one's self-esteem and confidence in their ability to know their body. After deductively coding instances of medical invalidation and such consequences, we inductively coded these excerpts to better understand how participants characterized their experiences. Feminist disability theory informed how we conceptualized themes, in that it shaped what we found meaningful to develop and report on (e.g., how participants related invalidation to aspects of their identity, including disability but also race and body size). J.C.H.S. met with C.K. several times throughout the analysis process to review codes and develop themes. Informed by the concept of information power,²⁴ we determined that our sample of 10 participants was sufficient to achieve the aims of the research study and did not complete further data collection or analysis.

Ethics approval

The study received ethics approval from the University of Manitoba's Bannatyne Human Research Ethics Board (no. HS24998 [H2021:234]).

Results

Eight women and 2 nonbinary individuals participated in the study, out of 13 participants who initially expressed interest but were ultimately unable to participate owing to health-related

reasons. Notably, all had more than 1 chronic illness, including mental health conditions, and had lived with their conditions for 5 or more years. Example diagnoses included chronic migraine, mixed connective tissue disease, fibromyalgia, asthma, anxiety and depression. Further demographic information is available in Table 1.

Theme 1: Invalidation as a problem of in/visibility

Whereas all participants experienced medical invalidation, how they characterized their experiences varied based on their specific embodiment. Participants were keen to contextualize and make sense of the invalidation they experienced, and they often referenced visible or invisible characteristics of themselves or their illnesses as a way of explaining why they experienced invalidation. The extent to which visibility or invisibility affected the treatment they received differed depending on the context.

Visibility could be helpful and buffer against invalidation, as was the case for one participant who had not experienced medical invalidation when seeking treatment for their physical illnesses. They felt this was the case because their diagnoses were well-recognized (lupus and rheumatoid arthritis) and at times visible (swollen joints), and there was a specific test for diagnosis — a biomarker that served to make their illness visible. Yet, this participant had experienced invalidation when seeking mental health support for their longstanding depression.

Visibility could also be harmful and fuel invalidation when doctors mobilized harmful and reductive assumptions based on an aspect of a participant’s appearance, such as their weight, perceived race or physical disability. Sometimes, this meant they were dismissed before they even had a chance to voice their concerns. One participant (P10) who used a mobility aid explained,

I’ll never forget walking into a doctor’s office and ... I was using my cane ... I was going in because I needed antibiotics for bronchitis. This doctor had never seen me before. Before she even said, “Hi,” before she said, “Hi, I’m Dr. — anything, anything — she looked at me up and down and she went, “I hope you know we don’t — we don’t do opiate prescriptions here.”

A common factor across all participants was their young age and having a mental health diagnoses alongside other invisible illnesses. This intersection came with an experience of simultaneous invisibility and visibility in that they were obviously young, but their illnesses were “invisible” (P3). As one participant (P3) with chronic migraines eloquently put it, this exacerbated their vulnerability to invalidation:

I’m only 20, so I’m very young. And I have the clear brain scan and so a lot of the times it’s, “You’re so young.” And I was an athlete at time, so it’s, “You’re young. You’re athletic. Go have some Advil. You’re being a teenager.”

Further, the inclusion of a mental health diagnosis in their medical record alongside their young age made them, in some ways, hypervisible, as someone who might be read as having illnesses that were “all in their head” (P7) or even “lying to get attention” (P4):

Table 1: Participant demographic characteristics

Variable	No. of participants <i>n</i> = 10
Gender	
Woman	8
Nonbinary	2
Self-identified ethnicity	
White/European	6
Indigenous	1
Filipina	1
Multiple ethnicities	2
Born in Canada	
Yes	10
No	0
Geographic location	
Urban	9
Rural	1
Socioeconomic status (Measured by asking, “How often do you struggle to make ends meet?”)	
Never or rarely	4
Sometimes	3
Often or always	2
Missing	1
No. of diagnoses	
2	1
≥ 3	9
Co-occurring mood or anxiety disorder	
Yes	8
No	2
Years living with chronic illness	
≥ 5	10

In my experience, if it’s anything mental health wise — if you have some kind of mental health issue, most notably anxiety or depression, or even mood disorders — especially if it’s a mood disorder actually — everything you say is filtered through this lens — through the doctor that you probably don’t know what you’re really talking about, at least if your health is concerned (P10).

In this way, the visibility of their youthfulness, which in the case of more physically obvious or acute illnesses, may have meant they were taken more seriously, interacted with the invisibility of their illnesses and their mental health diagnoses to make them more vulnerable to invalidation.

Theme 2: A vicious circle: invalidation, internalization and intensification

Notably, medical invalidation was not characterized as a one-off experience that could be easily ignored. Instead, participants described an ongoing pattern of invalidation across their

health care encounters that had vast repercussions for their well-being. As we will explain, this pattern took shape across participants' experiences as a "vicious circle." Experiencing invalidation often led to internalizing that experience. Internalization then meant either overcompensating for their illness or avoiding care, but ultimately ended up with the intensification of the symptoms that led them to seek care in the first place. Given the limited supports available for people with chronic illnesses beyond medical care (at least in the context of this study), participants experienced extreme difficulty managing their concerns without the assistance of a supportive care provider.

On experiencing dismissal of their concerns from a health care provider, participants would often inadvertently internalize the idea that they were not "that sick" (P10), as one participant demonstrates:

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

The internalization of medical invalidation often led to 1 of 2 outcomes: overcompensating for their illness as alluded to above or avoiding care. Broader societal stigma around chronic illness led participants to feel guilty or like a burden because of their illness, and so overcompensation often looked like embodying a hyperindependent persona. Participants felt pressure to act as though they were not sick at all, to not ask for support from family or friends, and to push past their physical limits: "I'm always super hyper-independent. And even when I know I am pushing way too hard and I'm probably not going to make it much longer, I still do it instead of reaching out and asking for help" (P10).

Alternatively, participants reported avoiding medical care as a response to internalizing invalidation, even when they really needed it. Many expressed a kind of hopelessness ("sometimes, like, what's the point, they won't even believe me" [P7]) that even if they did seek care, it was unlikely they would get the care they needed, and so, they avoided it altogether:

When I have in the past and when I was young and impressionable sought out care, I just didn't get it. So now I have some more, like, self-diagnosis, but I just haven't got an official diagnosis yet. I'm sure at some point I'll have to, but I'm just super hesitant to go to the doctor ever (P8).

As a result of this barrier to care, participants opted to self-manage their symptoms via online research or discussions with family and friends who live with chronic illnesses, and sometimes used self-diagnosis. Through these strategies they managed to "get what [they] need" (P9) and cope until they worked up the nerve to seek care again. Of course, overcompensating or avoiding care came with increased stress and anxiety, which, in turn, could exacerbate symptoms: "it can turn into kind of like a spiraling sort of situation where the

person might feel hopeless and like [other participants] have said a very common experience with chronic illness in general is mental health [concerns]" (P6). Medical invalidation also at times meant that participants did not receive the care they needed, leading to physical health consequences. For example, participant 11 described asking for their physician to look into their thyroid, for 4 years — to no avail. They described their thyroid as "destroyed" as a result.

Medical invalidation inevitably led to an intensification of symptoms, whether because of the emotional and behavioural consequences of internalizing negative health care experiences, or because important health issues went missed. Thus, experiencing medical invalidation in the first place triggered a vicious circle in which participants ultimately ended up seeking health care, but with worse symptoms than their original clinical presentation. At times, this experience was accompanied by intense anxiety ("Even though I've rehearsed it a thousand times, they throw a bunch of words at me and that's all I feel and see and I can't even collect my thoughts ... I crumble" [P9]), which made it difficult for participants to clearly articulate their concerns to their health care providers and potentially increased their vulnerability to experiencing medical invalidation yet again.

Medical invalidation had consequences for participants' emotional and psychological health. They emphasized the need for choice and feeling in control of their health as a means of supporting their overall well-being. Participants stressed the clinical encounter as a pivotal moment in their illness journeys — driving home the damaging consequences of experiencing medical invalidation.

Theme 3: Recommendations to avoid medical invalidation

The participants in our study were eager to promote change in health care practice and provided a variety of recommendations for physicians working with people with chronic illnesses, informed by their experiences of medical invalidation. Overall, participants recommended seeing the patient as the expert of their own experience; recognizing that even amid diagnostic uncertainty, the patient's experience is real and impactful to them; practising humility, "radical" empathy (P9) and compassion; helping them help you by finding common ground; and seeing the whole person (Table 2).

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

Interpretation

All participants in this study experienced medical invalidation to some extent, paradoxically owing to the invisible nature of their illnesses and the visibility of their social positioning, whether related to their young age, mental health status, perceived race, disability status or body size. Medical invalidation took different forms but ultimately had lasting implications for participants. Implications included behavioural consequences such as downplaying symptoms (in the clinic and outside of it), pushing themselves beyond their capacity and

Table 2: Participant quotations to support findings from Theme 3

Theme 3: Recommendations to avoid medical invalidation	
Seeing the patient as expert of their own experience	“Believe your patient, we’re coming to you for help ... You’re the one that studied for this, yes. We’ve spent our lives in a way studying it ourselves because we live with it.” (P4)
Recognizing that the patient’s experience is real and impactful to them	<p>“I felt that’s something that we would all appreciate if health care workers took that idea and respect people’s — even if it’s — let’s say you have schizophrenia and you have — you’re explaining something that isn’t happening in real life, but to you it truly is happening — give people the respect of understanding that truly is an experience they have. And even if you can’t do anything for it, just saying, “OK. It’s here. There’s nothing I can do for it, but I understand it and I’ll listen,” is going to help. (P14)</p> <p>“Recognizing that perhaps they don’t think that it’s real but recognizing that it is real to us and that it should at the very least be taken into consideration.” (P8)</p>
Practising humility, empathy and compassion	<p>“And what [other participant] was saying about the, like, “You’re not in that much pain,” yeah, it’s like, how dare you get to say that. Like, unless you literally have been dealing with the same — but even then, every person is different so you can’t and that’s where the empathy thing comes back into play ... I would say radical empathy, yeah. I mean everything else kind of falls into place once the empathy part is there.” (P9)</p> <p>“I think for me it’s just, like, be humble. Like, there’s nothing wrong with acknowledging that you’re a human being and there’s no way you know something unless you’ve experienced it or unless you’ve learned from someone who has experienced it, or unless you’ve learned from someone who has studied it, like, that kind of thing.” (P6)</p> <p>“And, yeah, it just seems like we’re always looking for that like-mind where it’s, like, maybe you don’t know but let’s figure it out and let’s do something ... ” (P8)</p> <p>“I totally agree. That’s more reassuring to have someone to try to figure out what’s going on instead of just say like, “Yeah, I don’t know. I’m not going to help you figure it out” kind of thing.” (P7)</p> <p>“I think empathy is something that a lot lack and whether they have the resources or time or whatever to put in, if someone just honestly told me, like, ‘You know what, that sucks. I can’t do this for you but, like, I can do this or this or this,’ or just being there. Like, I had a doctor recently and he gave me an honest, like, ‘I don’t know what’s going on but, like, why don’t we try this,’ but it’s like, that’s all I wanted. I don’t need you to give me the world, I just want you to understand that this is hard.” (P9)</p>
Helping them help you by finding common ground	<p>“Maybe just some education around how, like, a lay person who’s not trained in the medical field might describe an illness or a symptom. Because if it’s not — if we don’t use the exact medical jargon that they’re looking for then they completely write us off. And that can be really, really harmful.” (P6)</p> <p>“I think it would also be helpful if doctors told patients how to collect data to help them help themselves. Because I come from a family with a lot of STEM people and so if they would help me get in the brain of a doctor, or someone who looks — needs to look at all this data to give a diagnosis, that’s how I got my diagnosis, because I tracked literally everything and I presented them ... I was, like, this is what I’m experiencing. So doctors could tell their patients how to collect that data that would be super helpful, because I only knew how to do it because my mom figured it out through research.” (P6)</p> <p>“Yeah, instead of doctors just saying, just track what’s going on. It’s like, but how? Tell me the information you want.” (P4)</p>
Seeing the whole person	<p>“I think the thing that I want people to take — or the doctors to get — is just that they need to take the time and they need to listen. That’s it’s kind of like each person is more than just a patient. Because we all could describe — each person’s experience as a patient are just — we’re all individuals — it’s all different. And it’s all of — I hate the labelling and I hate the box — we don’t all fit in the box. There’s so much more. And it’s — they really need to take that time and listen, instead of just putting you in the box and giving you that diagnosis and this is you now. They forget — how there’s so much more to you.” (P3)</p> <p>“I’ve seen a lot of improvement with doctors lately when I’ve seen, like, this new allergist and I’ve seen some other new doctors, and [they’re asking] do you have any treatment plans? Do you see a therapist? Which I think is very good that they’re asking that because it’s all interconnected, like the body is one system, like your physical health feeds your mental health and your mental health feeds your physical health ... like, and you’re dealing with — if you have chronic pain or chronic [illness] when you’re in the thick of it you literally, like, can’t see out of the tunnel, and then it — you start getting more depressed and then when you start getting more depressed you can’t do the things that make you feel good. And it’s just a spiral.” (P4)</p>
Note: STEM = science, technology, engineering and mathematics.	

avoiding care even when needed, instead relying on self-diagnosis and management. In some cases, medical invalidation meant arising health issues were missed completely, resulting in worsening health and complications from undiagnosed and untreated issues. Further, the participants emphasized the psychological toll of experiencing medical invalidation repeatedly and how it affected their confidence in the clinical encounter.

Medical invalidation is not a new phenomenon, and the examples described echo other studies where patients with chronic illnesses report dismissal of their concerns or having their experiences disbelieved by physicians.^{25–29} Our findings emphasize the importance of connecting invalidation experiences to the social contexts and positionality of patients and suggest that young women and nonbinary adults living with chronic mental and physical illnesses represent a unique intersection for further consideration, both in terms of conceptualizing invalidation experiences and the consequences of invalidation. Long-term consequences of medical invalidation have been explored to a lesser extent, though our findings are confirmed by Sloan and colleagues, who interviewed 21 people living with lupus and found that negative health care encounters had lasting behavioural consequences, including “self-treating” to avoid care and increased self-doubt.²

Bê conceptualizes the effects of medical invalidation as “externally imposed impairment effects” where “pain, fatigue, tiredness or soreness [are] actually created or exacerbated by the painful interactions disabled people are required to have with the state, doctors or other institutions,”³⁰ echoing the aforementioned term “duality of suffering” provoked by health care encounters.³¹ These findings reflect those of Tamaian and colleagues, who found that “negative health care experiences are common” for people living with chronic illnesses and have implications for patient well-being.³² Considering the close ties between stress, anxiety and symptom severity with many chronic illnesses, it is crucial that the impact of medical invalidation be recognized and steps taken to prevent this experience. We suggest, based on our findings, that the impact of medical invalidation has the potential to exacerbate some symptoms, as participants alluded to.

Our specific conceptualization of medical invalidation as a problem of in/visibility together with participant recommendations for practising “radical empathy” suggest that medical invalidation is not an issue that can be ameliorated with person-centred care alone. We would argue that, as others have, based on participants’ experiences, there is a considerable need for critical reflexivity in the clinic.³³ Critical reflexivity involves a continuous interrogation and unearthing of the assumptions undergirding medical practice — assumptions that discount the embodied experience of patients and do not support those with chronic or hard-to-diagnose illnesses, or those from groups that experience marginalization.^{34–36}

Further studies on the subject would benefit from larger samples with diverse participants to understand how these experiences differ for different populations. Considering the important role of anxiety and stress in chronic illness, more studies could help identify the relation between medical

invalidation and stress and symptom intensity — this is something that was alluded to in our study, but the data were not definitive enough to make a direct conclusion. Whereas the study focused on interpersonal interactions, it is important to further contextualize medical invalidation, paying attention to the system-level factors that may play a role. Finally, participant experiences reflect a need for engagement in reflexivity in clinical practice.

Limitations

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

Conclusion

This study provides insight into the phenomenon of medical invalidation, understood as the act of dismissing, minimizing or otherwise not taking patient concerns seriously. In our study, 10 young women and nonbinary adults living with multiple physical and mental health conditions experienced medical invalidation to some extent in their illness journey, and some experienced it repeatedly. Medical invalidation had several consequences for patients’ overall well-being and their willingness to access care, and sometimes resulted in important health issues going undiagnosed. Given participants’ experiences, we argue for the imperative of clinical reflexivity in the clinic, and the need to honour patients as experts of their embodied experience, so that people living with chronic illnesses may be taken seriously and the substantial health implications of medical invalidation are minimized.

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