Medical invalidation in the clinical encounter: A qualitative study of the healthcare experiences of women and non-binary people living with chronic illnesses

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Abstract:

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

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

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

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

Introduction

People living with chronic illnesses frequently interact with physicians to monitor their conditions and manage their health. In this article, we define chronic illnesses as health conditions with no known cure that "last a year or more and require ongoing medical attention and/or limit activities of daily living."[1] We use the term chronic illness instead of chronic health condition, chronic disease, or long-term health condition, as it is preferred and more commonly used by people living with these conditions.[2]

A good working relationship between patients and their physicians is a foundational aspect of care quality.[3,4] The move toward person-centered models of care emphasizes the importance of health care interactions between physicians and patients.[5,6] Yet, people living with chronic illnesses, particularly those from groups who face societal marginalization, often report being dissatisfied with their health care encounters.[7–9]

Patient expressions of dissatisfaction and negative health care encounters – especially for those living with chronic illnesses – can have far-reaching implications. Sloan et al 2020 found that negative health care encounters can lead to diminished self-confidence, distrust in the medical profession, and may deter people with chronic illnesses from seeking care when they need it.[10] Tamain et al 2017 find the increased reliance on health care mean that patients with chronic illnesses may be more likely to experience negative health care encounters, and for the same reason, the ramifications of these experiences may be amplified.[11] Björkman et al 2016 refer to this as the 'duality of suffering' where "health care encounters risk adding to rather than alleviating the burden of illness."[8]

There are numerous explanations for negative health care encounters and patient dissatisfaction. Most frequently, such encounters are attributed to communication breakdowns, in that patients and physicians' hold discordant views and priorities;[12–14] physicians may use overly technical language;[15] and patients feel as though they aren't being "heard" or taken seriously.[16,17] The latter issue is termed "medical invalidation."[18] We take up medical invalidation in this study, broadly defined as the act of dismissing, minimizing, or otherwise not taking patient concerns seriously. Medical invalidation is of particular concern to the general chronically ill population, for reasons mentioned above, and also for those from groups that have been marginalized and may face unintended prejudice in the clinical encounter.[19]

Given the increased attention to patient-physician dynamics in the context of chronic illness,[4,20–22] our study sought to answer the following question: How is medical invalidation experienced and what is its impact on patients living with chronic illnesses? To that end, we present illustrative examples of medical invalidation as expressed by participants in our qualitative study, the consequences of experiencing medical invalidation, and recommendations for avoiding medical invalidation in the clinical setting.

Methods

We used a qualitative, arts-informed participatory approach[23,24] informed by feminist disability theory, meaning that patient perspectives are foregrounded in the study design and analysis.[25,26] Qualitative methods are helpful for illustrating how a phenomenon is experienced,[27] while arts-informed methods elicit rich discussion that may not be accessible with talk-based methods alone.[28] Due to the COVID-19 pandemic, this study took place virtually over Microsoft Teams, although all participants were residents of Manitoba, Canada and received health care in Manitoba.

Participant eligibility included self-identifying as having a chronic illness; self-identifying as a woman or non-binary person receiving health care in Manitoba; and being between the ages of 20 and 35. Participants were recruited via posts on the lead author's professional social media accounts (Instagram, Facebook, Twitter), the provincial patient-oriented research unit, and the email lists and social media of relevant community organizations (e.g., disease-specific advocacy groups). Participants were then invited to fill out a demographic questionnaire to ensure our sample represented a diversity of experiences (maximum variation sampling).[29]

Participants participated in one of three virtual workshops with two to three other participants, where they were asked to create a visual collage representing their experiences of patienthood.[30] Three patient partners assisted in designing the workshop. Participants were given an informational booklet ahead of the workshop that framed the study and provided a prompt (*What does being a patient mean to you? What is your experience of patienthood*?) and list of questions to structure their artistic process (e.g., what are some of the pivotal experiences you've had as a patient?). The full list of questions are available in Appendix A. Each participant used their art as the starting point for a broader group discussion. Due to the participatory nature of the research, the discussion was largely unstructured, and the author interjected only to ask for clarification, ensure everyone had a chance to contribute, and to keep the conversation on topic.

The discussion was audio-recorded and subsequently transcribed using a third-party professional transcription company. Data analysis was completed by [redacted for peer review] in consultation with [redacted for peer review] using Dedoose qualitative analysis software. Braun and Clarke's reflexive thematic analysis was used to code the data, involving a combination of inductive and deductive coding[31,32] informed by the concept of medical invalidation.

The study received ethical approval from the [redacted for peer review].

Results

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

Table 1: Participant Demographics

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

Theme 1: Experiences of Medical Invalidation

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

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

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

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

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

Theme 2: Consequences of Medical Invalidation

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

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

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

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

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

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

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

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

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

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

Theme 1: Examples of Medical Invalidation	
Dismissal of patient concerns based on their social demographics, such as being young in age, having a rare or poorly understood condition, or co-occurring diagnoses of mental health conditions or their appearance	1. “I’m only 20, so I’m very young. And I have the clear brain scan and so a lot of the times it’s, “You’re so young.” And I was an athlete at time, so it’s, “You’re young. You’re athletic. Go have some Advil. You’re being a teenager.” And now – even now – I’m, “Look. I’m 20 years old and I’m living every single day of my life in pain. And instead of you helping me because I have this long future, I’ve just learned to get over it in a sense and find my own ways to cope, because the medicine you’re giving me isn’t helping.” And it’s very much that, “Well, you’re young and healthy.” And it’s like, “I’m really not.” And with me being so young, it’s hard to see the healthcare system. And they refer me to new doctors and you wait so long to see this doctor. And then you get told you’re young, and healthy.” P3

	2. “In my experience, if it’s anything mental health wise – if you have some kind of mental health issue, most notably anxiety or depression, or even mood disorders – especially if it’s a mood disorder actually – everything you say is filtered through this lens – through the doctor that you probably don’t know what you’re really talking about, at least if your health is concerned. Me, it’s hard for doctors to listen, because I have general – I have health anxiety – for good reason.” P11 3. “I don't really tell my doctors much because when I do then he just tells me that I'm just lying to get attention, that it's too much for him, he's totally told me just stop talking […] Because the first time I saw him he told me, I won't help you until you lose weight. And that was very difficult as I also had struggled with an eating disorder.” P4 4. “I’ll never forget walking into a doctor’s office and I had my aid with me – I was using my cane. And I had someone with me, my daughter. And I was going in because I needed antibiotics for bronchitis. I knew I had bronchitis. Anyways, I walked in with my mobility aid. This doctor had never seen me before. Before she even said, “Hi,” before she said, “Hi, I’m Dr. – anything, anything – she looked at me up and down and she went, “I hope you know we don’t – we don’t do opiate prescriptions here.” P11 5. “I have scoliosis and I’ve been diagnosed with chronic pain too and my doctor said, “Well it’s really not that bad because chronic pain is just all in your head.” And yeah, I was just like kind of flabbergasted because she doesn’t understand what it’s like to be in my body and feel pain every second.” P7
Disregard for well-being	6. “The first time I ever approached a doctor about my depression – it was a walk-in clinic so to be fair that's really not a walk-in doctor is

	meant to do, I went in and finally talked myself up to admitting out loud I think I'm depressed and also I'm suicidal, like I feel like I want to not be here anymore kind of thing. And I remember the doctor – audibly laughed and said, that's not something we deal with at walk-in. Like you'll have to – if you want to be a patient of mine you'll have to go through the same process everyone else does. I'll send you a form and you can come back for an interview and we can go from there. But she never sent me a form, she never called me to make sure I was alive. She never gave me crisis resources. She never did anything – she literally – yeah, literally out loud, I'll always remember, like she laughed at me and was like, that's not what we deal with in walk-in, which might be true. Like maybe there's not enough time or the resources to deal with depression, all that kind of stuff in a walk-in clinic but to her knowledge, like, I never went back to her since, for all she knows I could be not around anymore. And I never got so much as a phone call, a single resource, like that kind of thing. It's like, that was a wild experience." P6
Theme 2: Consequences of Medical Invalidation	
Downplaying symptoms and pushing themselves past their limits	7. "I'm constantly testing myself like, "Am I really that sore? Does my back hurt really that much? Like am I making this, could I go back to work?"And I'm constantly like well I'll just try this and then see, and then the next day I'm suffering and I'm like, "OK yeah, no still sick." But I've got to that point because so many people have doubted me in the past, had they not my experience would be different." P9 8. "I think that perhaps for some people – and especially marginalized people – that just like there's still the stigma that we don't experience as much pain and so we don't need as many pain killers…I still like downplay how much in pain I am a lot. I like check with people around me to see like, 'Oh, is it OK if sit down instead of stand for this conversation?'" P8

	9. “I have also imposter syndrome. When you start to feel like – I know that sometimes on my better days I’ll start to be, “Are you really even that sick? What are you doing? No. You could be doing this and that. And then sometimes I’ll get really excited and I’m, “Oh yes. Maybe I’ll be better forever.” And then the next day hits and a flare happens and you’re just – you can barely get out of bed. And you’re, ‘Why did I even think that?’” P11 10. “They use this term, invisible illness, because it doesn’t show up on the scans. It doesn’t show up on the blood tests. So it's invisible. And I think them telling me that, almost made me feel that I needed to act that way. I needed to act like it was invisible – because I look fine – so they criticize you for being tired and worn out. It’s almost like you have to hide that to keep up this persona – that you are fine and you are OK – and that when you are alone and behind closed doors, I think that’s why I put the window on my collage. It’s when you’re alone you have the curtains drawn, that’s when it’s OK to kind of let it out. But as soon as you’re out in the world, it’s presenting this persona and it’s keeping that face – that no-one can see it. And it’s almost like that no-one can see it, so it must not really be there, type of idea.” P3 11. “I’m always super hyper independent. And even when I know I am pushing way too hard and I’m probably not going to make it much longer, I still do it instead of reaching out and asking for help. And I’m getting better at that.” P11
Avoiding care	12. “I feel like since like kind of getting shot down by doctors for the majority of my life, it’s kind of damaging and disheartening to me because sometimes like what’s the point, they won’t even believe me or, you know, it’s different from what they write down in my file than what I say to them and stuff. So it seems like everything gets lost in translation so why

	would I try, sometimes I'm in that headspace." P7 13. "Oftentimes people will suggest, "Oh, you should go to the doctor" and stuff and I'm like I can see exactly how this goes, so pass. And like sometimes I'll wait till it gets either really bad or like it goes away or I'll self-diagnose […] I've done that quite a bit and found like not a cure, but like the answer I'm looking for and then just feel like OK, well this is what I need." P9 14. "When I have in the past and when I was young and impressionable sought out care, I just didn't get it. So now I have some more like self-diagnosis, but I just haven't got an official diagnosis yet. I'm sure at some point I'll have to but I'm just super hesitant to go to the doctor ever." P8
Worsening health (& wellbeing)	15. "I have been asking my doctor for probably the last three and a half, four years, to check my thyroid out and not just the basic tests, but like the full panel and go see somebody that's a specialist. And she just told me for four years, "There's nothing wrong with your thyroid. Nothing wrong with your thyroid." Flash forward to last – just this past May – I get an MRI on my thyroid. The thyroid is destroyed. Destroyed. And I get to go see this endocrinologist – the hormone doctor – and she tells me, "This has been going on for so long. Why didn't your doctor investigate this before?" And I'm, "I've been literally asking my doctor for four years to investigate my thyroid." P11 16. "I've had doctors before who just assumed because they have the title of doctor I know more about your own body than you do, and it's an incredibly invalidating experience. And it's also very scary – like that's another thing that maybe doctors don't realize, like, it's pretty horrifying when you don't have the backing of

	a doctor or the validation of a doctor because without that medical validation unfortunately you might not have that diagnosis on paper, and without that diagnosis on paper you might not have coverage, you might not have access to social supports, to medical supports. Like, that can be really, really scary. So yeah, it's pretty scary. It's not just like a one moment interaction, like oh maybe I wasn't as validating as I needed to be and that's the end of it. Like no, it can really – for me at least it can turn into kind of like a spiraling sort of situation where the person might feel hopeless and like [other participants] have said a very common experience with chronic illness in general is mental health [concerns].“ P6 17. (Referring to the art they made…) “I chose to put it on that background of the coding stuff because I feel like it represents my anxiety dealing with all of it and that’s what my head feels like when I walk into an office. Even though I’ve rehearsed it a thousand times, they throw a bunch of words at me and that’s all I feel and see and I can’t even collect my thoughts and sometimes I don’t say anything because they’ve thrown all this stuff at me. And they ask me if I have questions but, of course, I have none because I don’t know what I’m thinking… I would think of myself as a pretty strong individual outside the clinic and when I walk in, I crumble. I’m always standing up for people in my life and my friends I’m the helper, but when I’m in there I feel completely helpless… I have extreme anxiety walking into any medical building ever now. And even when I book a new doctor, like my heart is pounding out of my chest and I pretty much just assume the worst going in because like I can’t be hopeful anymore [laughs].

	Because yeah, if I assume that they're going to be absolutely terrible and give me no time of day, then if they give me a little bit then I'm better off." P9

Theme 3: Recommendations to Avoid Medical Invalidation

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

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

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

Table 3: Participant Quotes to Support Findings from Theme 3

Theme 3: Recommendations to Avoid Medical Invalidation	
Seeing the patient as expert of their own experience	18. "Believe your patient, we're coming to you for help…You're the one that studied for this, yes. We've spent our lives in a way studying it ourselves because we live with it." P4
Recognizing that the patient's experience is *real* and impactful to them	19. "I felt that's something that we would all appreciate if healthcare workers took that idea and respect peoples' – even if it's – let's say you have schizophrenia and you have – you're explaining something that isn't happening in real life, but to you it truly is happening – give people the respect of understanding that truly is an experience they have. And even if you can't do anything for it, just saying, "OK. It's here. There's nothing I can do for it, but I understand

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

	I just want you to understand that this is hard." P9
Help them help you by finding common ground	25. "Maybe just some education around how like a lay person who's not trained in the medical field might describe an illness or a symptom. Because if it's not – if we don't use the exact medical jargon that they're looking for then they completely write us off. And that can be really, really harmful." P6 26. "P6: I think it would also be helpful if doctors told patients how to collect data to help them help themselves. Because I come from a family with a lot of STEM people and so if they would help me get in the brain of a doctor, or someone who looks – needs to look at all this data to give a diagnosis, that's how I got my diagnosis, because I tracked literally everything and I presented them…I was like this is what I'm experiencing. So doctors could tell their patients how to collect that data that would be super helpful, because I only knew how to do it because my mom figured it out through research. P4: Yeah, instead of doctors just saying, just track what's going on. It's like, but how? Tell me the information you want."
Seeing the whole person	27. "I think the thing that I want people to take – or the doctors to get – is just that they need to take the time and they need to listen. That's it's kind of like each person is more than just a patient. Because we all could describe – each person's experience as a patient are just – we're all individuals – it's all different. And it's all of – I hate the labeling and I hate the box – we don't all fit in the box. There's so much more. And it's – they really need to take that time and listen, instead of just putting you in the box and giving you that diagnosis and this is you now. They forget – how there's so much more to you." P3

	28. "I've seen a lot of improvement with doctors lately when I've seen, like, this new allergist and I've seen some other new doctors, and [they're asking] do you have any treatment plans? Do you see a therapist? Which I think is very good that they're asking that because it's all interconnected, like the body is one system, like your physical health feeds your mental health and your mental health feeds your physical health…like, and you're dealing with – if you have chronic pain or chronic [illness] when you're in the thick of it you literally, like, can't see out of the tunnel, and then it – you start getting more depressed and then when you start getting more depressed you can't do the things that make you feel good. And it's just a spiral." P4

Interpretation

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

Medical invalidation is not a new phenomenon, and the examples described echo that of other studies where patients with chronic illnesses report dismissal of their concerns or having their experiences disbelieved by physicians.[7,18,33,34] The long-term consequences of medical invalidation have been explored to a lesser extent, though our findings are confirmed by Sloan et al 2020, who interviewed 21 people living with lupus and found that negative health care encounters had lasting behavioural consequences, including "self-treating" to avoid care and increased self-doubt.[10]

Bê 2016 conceptualizes the effects of medical invalidation as “externally imposed impairment effects” where “pain, fatigue, tiredness or soreness [are] actually created or exacerbated by the painful interactions disabled people are required to have with the state, doctors or other institutions,”[2(p14)] echoing the aforementioned term “duality of suffering” provoked by health care encounters.[8] These findings reflect Tamaian et al 2017, who found that “negative health care experiences are common” for people living with chronic illnesses, and have implications for patient well-being.[11] Considering the close ties between stress, anxiety, and symptom severity with many chronic illnesses, it is crucial that the impact of medical invalidation be recognized and steps taken to prevent this experience. We suggest, based on our findings, that the impact of medical invalidation has the potential to exacerbate some symptoms, as participants alluded to.

The recommendations provided by participants reflect recent developments in medical education named the “humanist turn.”[35,36] Infusions of the arts and humanities in medical education aim to produce physicians who have greater appreciation for the patient experience. While certainly empathy, good listening skills and other person-centered attributes are necessary to providing good care, some argue it is not enough to create change – and we would agree.[35] We would argue that, as others have, based on participant’s experiences, there is a significant need for critical reflection in the clinic.[37,38] Critical reflection would unearth the assumptions undergirding medical practice – assumptions that discount the embodied experience of patients and do not support those with chronic or hard-to-diagnose illnesses, or those from groups that experience marginalization.[39]

Limitations

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

Future directions

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

Conclusion

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

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Appendix A – Art Activity & Guiding Questions

Portraits of Patienthood - Mixed Media Collage Self-Portrait

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

Prompt: *What does being a patient mean to you? What is your experience of patienthood?*

Questions to consider while making your art:

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