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Title: Impacts of clinical empathy on outcomes for Canadians with chronic illnesses: a qualitative focus group study

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Reviewer 1: Martina Kelly

Institution: Department of Family Medicine. University of Calgary

General comments (author response in bold)

I think my one hesitation is that the results reflect a binary model of empathy, which reflects the questions of the interview and I think that in the real-world setting empathy is likely not typically an all or nothing engagement but likely more nuanced, contextual and interdynamic.

We absolutely agree with the reviewer that clinical empathy is rarely “entirely present” or “entirely absent” in real-world clinical encounters. In our results, we describe the elements that patients used to characterize what they perceived as experiences that did or did not embody clinical empathy – these experiences may have comprised an entire clinical encounter, but often were merely a specific element of an encounter. Although our model of empathy portrays the characteristics of patient-perceived presence and absence of clinical empathy separately for ease of understanding, we do not intend to imply that these are mutually exclusive. Acknowledgement of this nuance has been added to the third paragraph of the Interpretation section on page 10, with discussion of how the positive and negative aspects of an encounter may have unequal impact on a patient’s perceptions and response.

The paper may benefit from some gentle toning as in some places it is, I feel, overstated.

Thank you for this valuable feedback. The passion expressed by patients in the focus groups prompted us to write strongly to mirror their communication, but perhaps we sometimes get too excited when writing about it! We have reviewed the paper and softened wording throughout by removing blanket statements and unnecessary adjectives, in particular throughout the Results (see response to comment about removing unnecessary adjectives below) and Interpretation sections.

Title: There is a slight mismatch between the title and the aim, as stated in the abstract and paper. The stated aim seemed to be more about understanding empathy, then the impacts came out during the focus groups and fed into the findings? I wonder if trying to ensure more coherence between aim, data etc might help.

Title has been modified to the following: Clinical Empathy as Perceived by Patients with Chronic Illness in Canada: A Qualitative Focus Group Study

Introduction: At the bottom of page 3, the authors state that ‘existing literature on clinical empathy comprises studies performed on patients with specific disorders....and so on. This sentence encapsulates a number of ideas and I wondered if it might benefit from a bit more clarification e.g. a reference for studies on patients with specific disorders; the gap this brings and then a new sentence on the rationale for engaging people with

chronic disorders. I also wondered if any literature existed to support the statement that data on experiences in Canada are scarce.

Thank you for this comment. In developing the background for a concurrent study on the teaching of clinical empathy in medical school, we identified that literature describing patients' experiences of clinical empathy was typically siloed by condition. For example, what empathy looks like is described in breast cancer care,(12) oncology and palliative care,(13) and emergency care.(14) Our study aimed to characterize common elements of clinical empathy across patient conditions and settings. We have broken up the sentence and added two references for the paucity of research on the topic in Canada. Tan *et al.* (15) performed a study on clinical empathy in Singapore, and in their review found that most studies on empathy in biomedicine were performed in the USA and the UK; the systematic review by Boshra *et al.* on patient involvement in empathy-promoting medical education found studies almost entirely from the USA and UK as well.(16)

The rationale for engaging people with chronic disorders is included in the "Population and Recruitment" subsection of the Methods on page 5.

Depending on space, the intro could strengthen the rationale for the study by drawing attention to the growing awareness of including patient voices e.g. in health policy, in research design and that, it is a gap in medical education.

We have added: "Patient partnerships are increasingly recognized as central to designing healthcare interventions, and features prominently in research design, health policy, and medical education in other countries."(16,17,18) Patient participation in empathy-related educational interventions has recently been described in a systematic review by Boshra *et al.* (16) which found that almost all published literature on this topic was derived from the USA and UK; we have mentioned their findings in the Future Directions section of the revised manuscript. Systematic exploration of patients' experiences of empathy in Canada and subsequent incorporation into medical school curricula has yet to be developed.

I understand the Canadian focus of the work, but as an immigrant myself, might point out that many people living in Canada are not Canadian, nor are all physicians working in Canada, Canadian. I'm not meaning to be pedantic but I think diversity and identity, particularly as intersubjective experiences, are central to understanding empathy and just wondered if the authors may consider nuancing their use of this word, even if as simple as 'living in Canada'. Perhaps one of the most wonderful things about Canada is its diversity.

Thank you for this important point! Wording has been changed from "Canadian" to "in Canada" or "receiving healthcare in Canada" in the following places: Title, Abstract (background/methods) final paragraph of introduction (page 4), Population & Recruitment paragraph (page 5), final paragraph of Data Analysis subsection (page 7), Future Direction section (page 11). We have also changed "Canadian physicians" to "physicians in Canada" in the Introduction (page 4) and Population & Recruitment subsection (page 5).

Methods: Data analysis: last paragraph: I wonder if the term constant comparison was used to compare codes, over the term 'versus' which seems to imply a dichotomous approach to data interpretation.

The reviewer is correct that constant comparison was used, and that codes were grouped into categories based on their content (as a part of focused coding) which generally, though not always, fell into larger umbrellas of quotations relating to presence or absence of clinical empathy. We have modified the wording in the data analysis section (page 6-7) to reflect this constant comparative approach.

Can the authors clarify what they mean by 'relationship between codes were 'simplified and averaged'.

Thank you for pointing out that this is unclear. We have modified the wording of this concept to be clearer and representative of our methods. It is integrated throughout the second paragraph of "Data Analysis" (page 6-7) with a detailed description of the focused and axial coding methods.

As the authors used constructivist grounded theory (Charmaz), this section would benefit from some reflexivity on behalf of the team. It would also help credibility to know more about the experience of the team in relation to qualitative approaches.

A reflexivity section has been added to the Methods of the paper on page 7. For full details regarding reflexivity and experience of the team, please see response to Editor Comment #3.

Results:

For me, while I enjoy active voice in introduction etc, data are usually reported in past tense to link to what participants stated during data collection and to avoid overgeneralising one's findings. e.g. participants processed (as opposed to 'patients process'). Will defer to editorial preference.

Results section has been modified to the past tense according to the reviewer's excellent suggestion.

Consider avoid using too many adjectives to maintain a balance presentation of the data e.g. 'Ripple effects impacted crucial elements of their personal lives, the sentence can manage well without 'crucial' (unless this word was specifically used by a participant and included as part of a quotation). Similarly, did participant report 'unnecessary referrals' or is this part of the authors' interpretation?

The word "crucial" was removed on page 8 as per the reviewer's recommendation as this was not a word specifically used within a patient quotation. We have also softened the wording of other descriptors in the results section ("that leads to a spiral of worsening physical and mental health outcomes" → "that contributed to negative physical and mental health outcomes"; "outright antagonistic" → "antagonistic"). Patients did describe that physicians were referring them to other practitioners repeatedly in a way the patient felt was not helpful and a consequence of a lack of clinical empathy. For clarity, we have changed the word "unnecessary" to "ineffective" on page 9; note that neither of these words was used directly in a quotation, but the quotations provided a longer description without the use of a single word to summarize the concept, and we feel that "ineffective" is a clearer translation of the patients' narratives.

I don't quite understand the sentence 'Through a feedback loop, these outcomes amplify the pre-existing factors inhibiting physician empathy' (how do you know?)

This was intended to be a description of the upwards, broken-line arrow depicted in Figure 1, pointing from “↓Quality of care/↓Resource use” to “Physician factors”. This represented how these outcomes of a lack of empathy were also described as contributors to the factors predisposing physicians to act with a lack of clinical empathy, such as physician burnout and patient load. This sentence was simplified for clarity by removing the term “feedback loop” and adding the specification “by increasing healthcare utilization and physician frustration”.

I wondered if a more balanced description of the data, as presented in table 2, might be helpful here (e.g. to explain in this section ‘physicians’ ways of knowing. Table 2 has rich data which is could be better anchored to the text of the results section, requiring less effort from the reader.

The sentence order of the first paragraph of the Results section was modified to reference Tables 2 & 3 first to represent the direct patient quotations and the concepts derived from the focused analysis. In Charmaz’s constructivist grounded theory methodology, it is essential for the analysis to involve not simply categorizing codes into a list of concepts but to construct an overarching theory based on what emerges from these concepts and their connections.(2) This does inevitably include elements of researcher subjectivity, and Charmaz indeed highlights the ever-present interaction between the researcher and research participants that must be recognized, and inevitably contributes to the theory that emerges. This theory is what is depicted in Figure 1, and described in the Results text on pages 8 and 9.

(also for Table 2, to explain what numbers and A, B mean.)

Individual participants are designated by a number representing the focus group they attended and a unique letter within that group. This explanation has been added to the captions for Tables 2 and 3.

Interpretation

The paragraph on interplay between physical, mental health and resources didn’t quite flow and I wasn’t sure how it was relating to the data presented and I think this is where I might have appreciated some of the material presently in the results section?

We agree that it can be difficult in qualitative research to distinguish between Results and Interpretation. However, given that constructivist GT necessitates researcher interpretation of the data in the formation of the theory, we feel that the current paragraphs in the Results section describing the constructed theory make the most sense there rather than in the Interpretation.

Although we think that the link between resource use and clinical empathy is important to contextualize the potential impacts of our findings on a population level, we agree that this is not as directly relevant to this paper as the impacts on individual patients. Therefore, this section has been reduced in length and integrated into a later part of the Interpretation (last paragraph of the interpretation prior to “Future Directions”, on page 11).

Towards the end of the paper, the authors mention that this study is part of a larger body of work, I wondered about having this earlier e.g. just a sentence or so, to set this discussion up later...as it came as a bit of a bolt from the blue.

A reference to the larger project has been added in the last paragraph of the Introduction: “as part of a larger project with the aim of promoting clinical empathy training in Canadian medical education” (page 4).

I think the limitation section could reflect more on the sampling in relation to self-selected inclusion of a group of already self-selected patients (those using support groups), primarily urban and educated. This could be turned into a suggestion for future research. **These important limitations are now acknowledged in the Limitations section of the discussion (page 12) per the reviewer’s excellent suggestion.**

The last sentence of this section refers to ‘these obstacles’ and I’m not sure what is being referenced here.

This phrase was changed to “the issues described by participants” for clarity (page 12).

Conclusion: first sentence – the study does not report patient stories but quotations. **Word “stories” has been changed to “discussions” (page 13). We have opted against using the word “quotations” as our analysis captures the larger themes and stories discussed by patient, though only isolated quotations are included in the manuscript for practicality.**

Final thoughts: I really appreciate the work that went into this study, and as mentioned there are some lovely features of study design and execution but I might push the authors to help situate their findings perhaps more in those innovations of the study (student led, patient involvement). At present, the findings seem to echo many well-worn adages in relation to empathy and patient care and directions in medical education. **We thank the reviewer for this feedback. Further details on these elements of the study have now been addressed in the Reflexivity subsection of the Methods (page 7). We have also modified the wording of the first sentence of the “Future Directions” section in the Discussion (page 11), to highlight that the project is student-led in addition to its goal of amplifying patient voices. We believe the model derived from this study adds new relationships to thinking about empathy, as well as prioritizes the important components from the patient perspective, and in particular highlights negative consequences of the absence of empathy that are less well-characterized in existing literature. Please see the response to Editor comment #4 for further details on the originality and usefulness of this particular study.**

Reviewer 2: Carolyn Canfield

Institution: Faculty of Medicine, University of British Columbia
General comments (author response in bold)

GENERAL REMARKS This interesting study examines patient experiences of poor clinical empathy and patient suggestions to raise this competence by greater patient partnership in medical training. However, as a model of patient partnership in research, this project misses many opportunities for bringing the lived experience of patients into co-design and co-production. This would have enhanced the credibility and likely the substance of the study.

1) Do the researchers provide a clear description of how they engaged patients in their research?

YES. One patient partner is identified as a collaborator. All other patients in the study are research participants.

a. Were patients engaged in various phases of the project? (e.g., Were patients involved in identification of priorities for what should be studied, in how the research should be done, in analyzing or making sense of the data or in disseminating the findings?).

UNCLEAR. In the Acknowledgements section, a single named patient partner is thanked for being involved with “study objectives and design” only. In the Methods section, it is stated that “Study conception was informed by discussion with patient, physician, and student partners.” It is unclear if this activity included more unnamed patient partners. It is also unknown how many physician and student partners were involved, how they were recruited, or what experiences they could draw upon related to clinical empathy.

b. Did patients contribute meaningfully to the research (rather than just as a participant, or as a token member of the research team)?

UNKNOWN. The authors provide no detail about the influence of single patient partner’s contribution. It appears that this one patient partner contributed neither more nor less to “study conception” than the unspecified physician and student partners.

c. Do the researchers describe how the engagement of patient partners added value (or did not add) to the results or outcomes of the study?

NO. We do not learn what added-value the patient partner contributed to the “study conception” nor how the study changed as a result.

2) Do the researchers describe any challenges with engaging patients in the study?

PARTIALLY. Patients primarily served as research participants, with only one patient partner. Challenges related to recruitment of research participants are described. There is no information about the recruitment, training, support or compensation of the single patient partner. There is also no mention of challenges in recruiting that person as particularly suited to this study. For example, no mention is made of their prior experience partnering with teams in similar research, or the alignment of their patient experiences with the selection criteria for research participants.

3) Does the article include lessons learned from using a patient-oriented approach to research, so that others can learn from their experience?

NO. There is no reflection on what may have been learned from this experience with patient partnership on the research team, beyond a statement of thanks to the patient partner.

4) In your opinion, are the outcomes of the research ones that will make a real difference to patients, their families and their providers?

YES, but a heightened benefit to patients may have been lost from such limited patient partnership.

The research question speaks directly to the quality of patient interactions with physicians. The paper speaks directly to the profound impact if recommended changes were found to be effective. What is overlooked is the value-added contribution of patient partners in co-designing the focus group guide, participating in the recruitment of

research participants, sharing in the focus group facilitation, engaging with the interpretation of transcripts for coding, joining in data synthesis processes to identify findings, and writing and reviewing the manuscript. There is some irony in a study aiming to learn from patients, that the research team misses an opportunity to trust and value the lived experience of patients sufficiently to include patient partners as co-equals on the research team.

Thank you to the patient reviewer for this detailed, thoughtful, and valuable feedback about the extent to which this study constitutes patient-oriented research. We hope that the description of patient involvement included below addresses the reviewer's questions regarding details about how patients were involved in this study.

Our study involved patients in the following ways:

- Four medical students on the research team are patients with chronic illness. Although these patients are also in the medical field, the study was designed during their first term of medical school and carried out subsequently throughout the remainder of their first year prior to clinical activities or clerkship. Thus, although medical students with chronic illness are different from the general patient population in that they share a clinician-oriented perspective, these members of the study team had no clinical experience and were newly forming identity as healthcare professionals. Please see comments on reflexivity for further information regarding how this was addressed.**
- One patient partner who was not a medical student was consulted during study design for their input on study objectives and methodology. This patient partner has extensive experience and involvement in advocacy for people with chronic illness and disability, and has worked as a patient representative helping teach medical students at the University of Toronto medical school.**
- Focus groups were adapted iteratively based on patient feedback that was regularly solicited. Each focus group was followed by a non-recorded debrief session where patients were encouraged to provide feedback on the content and facilitation of the group and the research study as a whole. In case participants did not feel comfortable communicating feedback in the Zoom call, an anonymous feedback form was distributed after each focus group. Feedback from participants was incorporated into subsequent groups.**
- Member-checking was performed by sending each participant a list of descriptions of all initial codes from the focus group they participated in, and were given an opportunity to provide feedback including if they thought we had missed an important element of their discussion or disagreed with any of the codes as written. Their feedback was incorporated into the codes that were used for subsequent focused coding. In this way, patient participants had input in the coding & analysis process.**

Although this paper is not patient-oriented research as defined by CMAJ, we attempted to make many efforts to ensure that we were representing patient perspectives accurately and respectfully. As students and researchers, we recognize that we are continually learning about ways in which we can better orient and perform our research to meet the needs of the populations that our research aims to benefit. We are grateful for this learning opportunity and hope to develop future research with more formalized involvement of patient partners throughout all steps of the research process.

Reviewer 3: Trina Fyfe

Institution: Northern Medical Program, University of Northern British Columbia
General comments (author response in bold)

It is suggested that the following word in the paragraph prior to the Methods section be reconsidered: opinions. Essentially what the authors are striving for are recommendations, so I would use that word instead.

On page 4 at the end of the Introduction, the word “opinions” has been replaced with “recommendations”.

As mentioned, virtual focus groups were conducted over Zoom with 20 participants. For clarity, it would be helpful to state how many focus groups were held, how many participants attended each group, and the duration of the focus groups.

Focus groups were 90 minutes long, this has been added to the “Data collection” paragraph of methodology (page 6).

It is stated in the “Participants” section of the results (page 8) that 20 patients participated across six focus groups – this is included in the results section rather than methodology as the number of patients/groups included was dependent on the iterative analysis and reaching theoretical saturation. It has also been clarified in the “Participants” section of the Results (page 8) that each group was scheduled with three to five participants, although one contained only two as one participant cancelled at the last minute and another participant who had confirmed attendance did not show – the group was still carried out with the two participants out of respect for the patients who did attend, and included as it yielded valuable data.

One researcher facilitated the focus group by utilizing the question guide and the second researcher focused on asking follow up questions. The third person from the team to attend the focus groups did so to ensure there was consistency across groups.

A total of four members of the study team moderated focus groups, with two moderators at each group. S.G. was a moderator for all groups and the second co-moderator varied. As the initial wording may have led to misunderstanding of this, it has been modified in the Data Collection section (page 6) to make the number of moderators clear.

In following grounded theory, the researchers utilized a constant comparative method of analysis. They achieved data saturation after coding six focus group transcripts. Again, it would be helpful to understand how many focus groups were held and how many participants were in each. This may impact the rigour of the focus group approach.

See response to previous comments.

When the authors try to quantify, it would be helpful to contextualize. For example, in this statement it would be helpful to state prevalence as a percentage or to say 66 out of XXX quotations: “Impact on mental health was the most prevalent theme with over twice as many quotations as any other code (66 quotations).”

Thank you for this important point. Our methodology did not include formal frequency counting in our analysis as some quotations may represent multiple codes & themes. Therefore, in retrospect, we feel that the numerical percentage value would not be accurate nor meaningful. As mental health was a very strong theme that patients emphasized repeatedly, we have removed the numerical value and reworded this to say that “mental health was a dominant” theme in the “Clinical empathy model” subsection of the results (page 9).

There is another example of this in the sentence: “In the current study, the impact of physician- 17 patient ... was the theme most emphasized by patients”. Perhaps add a numerical value to “most”.

Due to reworking of the Interpretation section in response to other comments, this sentence has been removed (page 10). We now highlight the importance of mental health in the second paragraph of the interpretation without quantification.

In general, this is an interesting and important paper. Providing recommendations for medical education is helpful. There is acknowledgement of a strained healthcare system, how will empathy be impacted by this strain and will other innovations that have strongly emerged from the pandemic, like telemedicine, impact empathy?

Thank you for the feedback and the excellent suggestion. There is evidence that maintaining empathetic communication over telemedicine causes increased provider fatigue.(19) As patients acknowledged that factors such as burnout and overwork may reduce their physicians’ abilities to act with clinical empathy, this could have negative impacts on overall clinical empathy. However, all of the factors comprising empathetic care as defined by patients in this study (Table 3) are able to be performed virtually, and it is also possible that the increased accessibility to care facilitated by virtual care options may help optimize care and accommodate patients in ways that enhance the physician-patient relationship. Thus, it is difficult to say if the net effect on clinical empathy will be positive or negative, and it may vary on an individual basis. More research into this in the coming years would be very interesting!

We unfortunately lacked the space to describe this in our discussion, but have included it as a relevant citation for barriers to physician empathy on page 12 (end of “Future Directions” section).

Here is a systematic review you may want to consider reading to add to your Future directions section as evidence for patient involvement in teaching.

Boshra M, Lee A, Kim I, Malek-Adamian E, Yau M, LaDonna KA. When patients teach students empathy: a systematic review of interventions for promoting medical student empathy. *Can Med Educ J.* 2022;13(6):46-56. Published 2022 Nov 15. doi:10.36834/cmej.73058

Thank you for providing this interesting article which is highly relevant to our paper. All included studies in this review demonstrated improved empathy post-intervention, and many demonstrated increased medical student knowledge and ability to retain information. Patients post-intervention also described increased confidence in their knowledge of their conditions, and found meaning in sharing their experiences. We have included a mention of these findings in our Future Directions section on page 11. We have also cited this study in the Introduction as evidence that most of this work has been done in the USA and the UK (page 3-4).

Reviewer 4: Jennifer C.H. Sebring

Institution: Community Health Sciences, University of Manitoba

General comments (author response in bold)

I have a few minor suggestions for revisions: 1. In the methodology section, page 4, line 40: Can you provide more information on how patients, physicians and student partners informed the conceptualization of the study? I wonder, given the study design and mention of "patient-oriented" in this section and again on page 9, if it might be worth

going into more detail on what you mean by patient-oriented and how this study met that definition. If you haven't already, perhaps it is worth reviewing CMAJ Open's Patient-Oriented Research collection to consider if your paper could be published accordingly. <https://www.cmajopen.ca/patient-oriented-research>

We have reviewed the definition of “patient-oriented” research according to CMAJ Open, and this study does not meet the criteria of the GRIPP2 checklist regarding patient involvement. Although we strived to involve patients in the research process in order to design and deliver a study that addressed patients’ needs, we have removed the term patient-oriented from the paper due to the fact that this has a specific definition at CMAJ Open, to avoid misleading readers. We have also removed the sentence about patient, physician, and student partners as we realize the word “partners” is vague. This has been replaced with more details in the Reflexivity section on page 7. Please see the response to Reviewer #2’s comments and the response to Editor comment #3 for full details on patient involvement.

2. It might be worth including a citation on page 5, line 3 to help justify your use of facebook for recruitment along the lines of it being "ideal for support groups." Many people with chronic illnesses rely on social media support groups for socialization due to being housebound etc., so a citation that explains this or even an additional sentence to justify may help strengthen rationale.

Wording of this sentence was modified and multiple citations were added to support the fact that patients with chronic illness commonly use Facebook as a medium for support groups and health information-sharing (page 5).(20-24) In fact almost 90% of older adults using Facebook and Twitter use these sites to find and share health information!(24)

3. Is there a citation you can include about how you approached "reflexive note-taking" in your analysis? [page 6, line 45] Linabary, Corple, and Cooky (2020) came to mind, but not sure if it represents your approach. Good that you included it was done to "correspond to patient descriptions rather than researcher-assumed phenomena" which gets at reflexivity element.

We thank the reviewer for this suggested citation. We believe this refers to a paper on feminist reflexivity which does not quite represent our approach. We have added a citation for Charmaz 2014 (2) as this most closely reflects the reflexive note-taking (i.e. memoing) used in our study, and moved this description into the Reflexivity subsection of the Methods (page 7).

4. Typo on page 7, "participates" instead of participants.

Typo has been corrected in the “Participants” subsection of the Results, now on page 8.

5. Page 12, line 29 - explain what you mean by "unique barriers" (e.g., such as...)

Thank you for this opportunity to clarify the language used in the manuscript. The sentence now reads: “As discrimination was commonly identified as a barrier to empathy, it is likely that more marginalized populations would face the issues described by participants to an even greater extent in addition to unique barriers related to race, ethnicity, gender, sexual orientation, and socioeconomic status” (Limitation subsection, bottom of page 12).

6. Appendix D: Behaviours conveying absence of clinical empathy - Box 3: What do you mean by "explanation of action/inaction defines its meaning to patient."
Elaboration/clarification needed.

Wording was modified to “The physician’s explanation of their course of action defines the meaning of the action to the patient” for clarification. This is now in the file designated Appendix E due to the addition of a new Appendix.

Box 4 of same section: re physicians "may not provide adequate explanations" - explanations of what? healthcare system as mentioned earlier in sentence or something else? clarification needed.

Wording has been modified to “Physicians often do not understand the complexities of navigating the healthcare system from the patient’s perspective and may not provide adequate explanations on how the patient should do so” to clarify that it is referring to navigating the healthcare system (now in Appendix E).

Seems to be some very interesting and probably frustrating paradoxes being experienced by patients, as described in Appendix D (e.g., being expected to do own research but then being criticized for it, same for box describing pain medication and pill-pushing) among other examples! May not be relevant for revising the paper but perhaps for developing medical education interventions. Something to consider highlighting or developing further in the rest of the project you describe.

We thank the reviewer for this excellent point! This was indeed a very frustrating phenomenon described by patients and will certainly be considered during future elements of the project.

7. Use of terms "trauma" and "gaslighting". Given the prevalence of these terms in our current cultural moment, it might be worth noting your use of the terms trauma and gaslighting and what is meant by it/how these experiences constitute trauma or gaslighting. Are these terms coming from participants verbatim or researcher interpretations of patient experiences? The Sloan reference you included is helpful for providing justification. There may be other literature that could be helpful, for instance: Tamaain et al 2017.

May also consider citing literature on medical invalidation (e.g, Bontempo 2021), disenfranchisement (e.g., Thompson et al 2022) and gaslighting (e.g., Russell et al 2022) in interpretation section regarding chronic illness and healthcare to make further connections with current scholarly discussions.

The use of the terms “trauma” and “gaslighting” are verbatim from participant quotations. Therefore, although they are used frequently and perhaps injudiciously in common discourse, we think it is appropriate to represent the patients’ experiences using their own words. In Appendix E (previously Appendix D), quotation marks were added around “gaslighting” to clarify this.

We would like to make a correction, as our citation for Sloan 2020 referenced the wrong article. This has now been replaced with the correct citation.

We thank the reviewer for the interesting and highly relevant additional references. Unfortunately, we were unable to find the paper by Tamaain et al. in our databases. However, we have integrated the findings of Bontempo,(25) Thompson,(26) and Russell (27) into the second paragraph of the interpretation.

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