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3 **Impacts of Clinical Empathy on Outcomes for Canadians with Chronic**
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6 **Illnesses: A Qualitative Focus Group Study**
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10 Shira Gertsman BSc¹, Ioana Cezara Ene BHSc¹, Sasha Palmert¹ BSc, Amy Liu¹ BHSc, Mallika
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12 Makkar¹ BSc, Ian Shao¹ BHSc, Johanna Shapiro PhD², Connie Williams MD PhD^{3,4}
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15
16

17 **Affiliations:**
18

19
20 ¹Michael G. DeGroot School of Medicine, McMaster University, Hamilton, Ontario, Canada
21

22 ²Department of Family Medicine, UC Irvine School of Medicine, University of California Irvine,
23
24 Irvine, California, USA
25

26
27 ³Department of Pediatrics, Faculty of Health Sciences, McMaster University, Hamilton, Ontario,
28
29 Canada
30

31 ⁴Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada
32
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34
35

36 **Corresponding author:**
37

38 Shira Gertsman
39

40 Email: shira.gertsman@medportal.ca
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ABSTRACT

Background: Clinical empathy is the ability of a physician to understand a patient's illness experience, communicate this understanding, and act collaboratively to create a treatment plan.

Although clinical empathy provides substantial benefits to both physicians and patients, medical students typically experience a decline in empathy during training. The primary objective of this study was to generate a model of clinical empathy grounded in the perspectives of Canadians with chronic illnesses, to be used as a basis for empathy-focused curricular development in Canadian medical education.

Methods: Adults with chronic illness who recently saw a Canadian physician were recruited from virtual support groups. Each participant took part in a semi-structured virtual focus group. Focus group transcripts were coded using the constant comparative method and a theory was generated using constructivist grounded theory analysis.

Results: Twenty patients from across Canada participated in six focus groups. A two-sided theory of the presence and absence of clinical empathy was developed from patients' responses. Perceived presence of physician empathy engendered positive internal processing by patients leading to increased efficacy of healthcare delivery and enhanced mental health outcomes. Negative patient internal processing in response to perceived absence of empathy led to reduced quality and increased utilization of healthcare, disruptions in patients' personal lives, and negative physical and mental health outcomes.

Interpretation: Clinical empathy can have life-altering impacts on patients and its absence may increase resource utilization. As empathy involves understanding patients' lived experiences, any valid intervention to improve clinical empathy must be informed by patient perspectives.

INTRODUCTION

The physician-patient relationship is a key contributor to the quality of healthcare, with physician empathy benefiting patients and physicians alike.¹ The construct of empathy has multiple components, namely affective (experiencing others' emotions), cognitive (understanding others' feelings), and behavioral (communicating understanding), with the latter two being of most importance in clinical scenarios.²⁻³ Clinical empathy can thus be defined as the physician's ability to understand the patient's illness experience, communicate this understanding, and act on it to create a collaborative treatment plan with the patient.³⁻⁷

Empathetic care can improve patient mental health outcomes and coping,^{5,8-9} as well as physical health outcomes such as improved HbA1c in patients with diabetes and faster recovery from the common cold.^{6,10} Furthermore, empathetic care may promote patient understanding and confidence in their care plans, increasing adherence and reducing the perceived need for additional referrals and interventions.^{7,9} From the physician perspective, higher patient-rated physician empathy scores are associated with reduced burnout,^{3,11-13} lower risk of litigation,¹⁴ and improved resource stewardship.¹⁵

Despite the clear benefits to both physicians and their patients, medical students experience a decline in empathy throughout training.¹ Various interventions have been attempted to mitigate this, including written reflections, dramatizations of clinical scenarios, and interpersonal skills training.¹⁶ However, there is no consensus on their efficacy, and their development has lacked systematic input from patients with lived experiences. Existing literature on clinical empathy comprises studies performed on patients with specific disorders; as patients with complex and/or chronic illnesses typically interact with many different physicians, we hypothesize that patients' experiences of clinical empathy are not unique to particular diagnoses or physician specialties. It

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3 is these overarching factors that are the most useful to inform undergraduate medical education
4 since they are relevant to *all* future clinicians. Furthermore, data on patient experiences within
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6 Canada are specifically scarce.
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10 The primary objective of this study was to generate a novel theoretical model of clinical
11 empathy grounded in the perspectives of Canadian patients with a variety of chronic illnesses, in
12 order to establish an evidence-base for empathy training in Canadian medical education. This
13 involved elucidating how patients with chronic illnesses describe clinical empathy, their
14 experiences of empathy from Canadian physicians, and subsequent impacts to their health and
15 quality of life. The secondary objective was to collect patient opinions on how medical education
16 could be improved to address deficits in empathy.
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28 **METHODS**

29 **Study Design**

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31 This was a patient-oriented, virtual, focus group-based qualitative study employing
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33 constructivist grounded theory methodology.¹⁷⁻¹⁸ This open-ended methodology was selected to
34 generate a theory grounded in participants' lived experiences. Study conception was informed by
35 discussion with patient, physician, and student partners.
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45 **Population & Recruitment**

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47 Participants were recruited from virtual support groups targeting Canadian patients with
48 chronic illnesses [**Appendix A**]. This population was selected because patients with chronic
49 illness are major utilizers of the healthcare system and typically have experiences with multiple
50 physicians.¹⁹⁻²⁰ Facebook was selected as the primary recruitment platform due to its large and
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3 diverse user base, accessibility, and interface that is ideal for support groups. Groups were
4 selected that targeted Canadians with general chronic illness/disability or any of the ten most
5 prevalent chronic diseases according to the Public Health Agency of Canada.²¹ Due to a paucity
6 of male participants, promotion was expanded to the Prostate Cancer Support Canada e-
7 newsletter. Participants were included if they met the following eligibility criteria: at least 18
8 years old, comfortable speaking English, self-identified as having a chronic illness (mental or
9 physical) for at least 24 months, using the Canadian healthcare system as their primary source of
10 medical care, and had an appointment with a Canadian physician in the previous 12 months.
11 Endpoint for recruitment corresponded to the point of theoretical saturation, i.e., the point at
12 which no new themes that contributed meaningfully to the theory being constructed were
13 identified from newly collected data.²²
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31 **Ethical Approval and Consent**

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33 This study was approved by the Hamilton Integrated Research Ethics Board #12912.
34 Study procedures were explained to interested participants over the phone and consent was
35 obtained verbally and by electronic signature before enrollment.
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42 **Data Collection**

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44 All participants completed an anonymous demographics survey. Semi-structured virtual
45 focus group interviews were conducted on Zoom by two members of the study team: one
46 followed the moderator guide [**Appendix B**] while allowing for participants to guide the
47 discussion as appropriate; the other asked follow-up questions and took live notes for
48 triangulation purposes. The definition of clinical empathy was provided without use of the word
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3 “empathy” to reduce the influence of participants’ variable definitions of this construct. S.G. was
4 present at every focus group to ensure consistency across groups. Focus groups were recorded
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6 with participant consent and transcribed verbatim.
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10 11 12 **Data Analysis** 13

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15 Iterative coding using the constant comparative method was performed concurrently with
16 data collection.²³ Transcripts were coded independently by M.M. and S.P. who subsequently
17 conferred to reach consensus on common themes. As new categories were identified, they were
18 compared to previously identified categories to allow for combination and further delineation.
19 We reached theoretical saturation following the coding of six focus group transcripts. Codes
20 were verified with the live interview notes. At this point, member-checking was performed by
21 sending descriptions of the codes derived from each transcript to the participants of the
22 corresponding focus group for feedback [**Appendix C**], which was subsequently incorporated
23 into the data.
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35 Individual quotations that corresponded to each code were reviewed by S.G. to determine
36 sub-themes within codes (deductive analysis) and intercompared to determine multi-directional
37 linkages between codes (inductive analysis), which were then visualized using idea-mapping
38 software.²⁴ Quotations describing the presence versus absence of clinical empathy were distinct
39 and plotted on separate mind maps. Several new codes were elicited in this process. Reflexive
40 notetaking was performed and discussed with team members to ensure that mapped linkages
41 corresponded to patient descriptions rather than researcher-assumed phenomena. The
42 relationships between codes were simplified and averaged, with preservation of grouping and
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3 directionality as much as possible, to construct an overarching model of the impacts of clinical
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5 empathy on Canadian patients with chronic illnesses.
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8 9 10 **RESULTS**

11 **Participants**

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15 Twenty patients participated across six focus groups. Participant demographics are
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17 summarized in **Table 1**. Diagnosis was not formally elicited, but diagnoses that patients
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19 volunteered included rheumatoid arthritis, asthma, cancer, and fibromyalgia. Participates rated
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21 their overall satisfaction with the Canadian Healthcare System as a mean of 5.4/10 (median = 5).
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24 25 26 **Clinical empathy model**

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28 The patient-derived model of clinical empathy is depicted in **Figure 1**. Components of
29
30 each item in the model and representative participant quotations are included in **Tables 2 and 3**.
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32 Further details of the patient-perceived phenomena can be found in **Appendix D**.
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35 36 37 *Perceived absence or deficiency of clinical empathy*

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40 Patients postulated that internal factors (burnout, biases) and external factors (setting,
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42 specialty, patient load, ableist culture of medicine) predispose physicians to interact with them
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44 with a lack of trust and understanding. This may manifest in a failure to display supportive
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46 behaviours, or even in outright antagonistic behaviours such as name-calling and patient-
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48 blaming. Patients process these experiences in ways that reduce their trust in physicians and the
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50 healthcare system and compromise their self-image. Ripple effects impact crucial elements of
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52 their personal lives, including work and family relationships. These processes are also
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3 interrelated with a decreased quality of healthcare delivery despite increasing resource utilization
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5 (e.g. unnecessary referrals and more appointments); for instance, non-empathetic care makes
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7 patients more likely to delay seeking care until severely ill due to fears of re-traumatization, and
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9 promotes non-adherence to prescribed treatment regimens. Through a feedback loop, these
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11 outcomes amplify the pre-existing factors inhibiting physician empathy. Impacts on patient
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13 cognition, personal life, and healthcare form a vicious cycle that leads to a spiral of worsening
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15 physical and mental health outcomes. Impact on mental health was the most prevalent theme
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17 with over twice as many quotations as any other code (66 quotations). Patients described
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19 exhaustion, hopelessness, helplessness, anxiety, depression, and suicidal ideation occurring as
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21 downstream effects of clinical empathy deficiency.
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28 *Perceived presence of clinical empathy*

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31 Patients believe that factors such as having had a patient-centred medical education and
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33 adequate support and resources allow physicians to engage with patients' experiences and exhibit
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35 clinical empathy. Empathetic behaviours include listening, honest and supportive
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37 communication, and collaborative care plan formulation. This engenders a positive internal
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39 response from the patient characterized by feelings of hope, empowerment, and trust in their
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41 physician and treatment plan, which promotes a cycle of improved treatment adherence and more
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43 effective resource utilizations. Participants said that the hope provided by physician validation is
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45 the most crucial thing for patients living with chronic illness – with this, patients feel motivated
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47 to self-manage their health via lifestyle improvements, treatment adherence, attending
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49 appointments appropriately, and educating themselves about their medical condition. Overall, the
50
51 downstream effects of clinical empathy enhance patients' health and well-being by improving
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3 their self-image and self-efficacy, their mood and mental health, and even how they perceive
4 their symptoms and pain.
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7 *Patient recommendations for medical education*

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10 Patients shared changes to medical school admissions and training that they believed
11 could improve clinical empathy (**Table 4**). They also acknowledged that supporting physicians'
12 mental health and mitigating burnout is an essential for any intervention to have sustainable
13 impact.
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21 **INTERPRETATION**

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24 To our knowledge, this is the first patient-oriented study on the impacts of clinical
25 empathy on the health and quality of life of Canadians with chronic illnesses. Patients perceive
26 clinical empathy, or its absence, as initiators of self-perpetuating cycles of positive or negative
27 health outcomes, respectively. Some outcomes are mediated by the impact of empathy on
28 therapy and disease course, but empathy also triggers direct, independent impacts.
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36 The interplay among physical illness, mental illness, and resource utilization is
37 inextricable. Patients with chronic illnesses utilize significant healthcare resources: in Canada,
38 over 50% of the adult population has at least one chronic disease,¹⁹ costing the Canadian
39 economy an estimated \$190 billion annually in direct and indirect costs.²⁰ In this study,
40 participants with any chronic illness were eligible, though all participants identified as having a
41 physical (35%) or mixed physical and mental (65%) illness. It is well-established that having a
42 diagnosis of a chronic physical illness significantly increases the risk of psychiatric
43 comorbidities and vice versa.²⁵⁻²⁹ A cohort study of nearly 100,000 adults in Alberta, Canada
44 demonstrated that among patients with a chronic physical illness, those with a comorbid mental
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3 health disorder had 70% higher total three-year adjusted costs, and higher resource use including
4 hospitalization and emergency department visits;³⁰ another prospective cohort study
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6 demonstrated that depressive symptoms are associated with higher health resource utilization
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8 after acute myocardial infarction independent of cardiovascular risk.²⁷
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12 In the current study, the impact of physician-patient interactions on patients' mental
13 health trajectories was the theme most emphasized by patients. Congruent with previous
14 evidence,³¹⁻³² being disbelieved and dismissed appears to have profound negative impacts on
15 patients' self-worth, identities, and mental health. Sloan et al. (2020) demonstrated that elevated
16 patient anxiety during medical encounters may in some cases be attributable to medical post-
17 traumatic stress following negative medical experience rather than trauma from the illness
18 itself.³¹ Many positive experiences may be required to rebuild medical trust, while a single
19 negative experience can cause significant regression.³¹ Our findings further demonstrate that
20 anxiety born from negative experience is often generalized to systems and other physicians,
21 while positive experiences build trust in the specific enacting physician and are less likely to be
22 generalized. Moreover, these infractions need not be major – the relative position of authority of
23 physicians makes patients' confidence in self-assessment particularly vulnerable to damage from
24 even small expressions of physician doubt and increases the likelihood of resultant depression.³²⁻
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44 It is important to emphasize that in most cases, physicians whom patients perceive to be
45 acting without clinical empathy are doing their best to serve their patients within the limitations
46 of their institutions, training, and experiences.¹ The call to address the clinical empathy crisis is
47 not an attack on physicians, but a recognition of the systems that disempower physicians from
48 interacting with patients in ways that promote better outcomes for everyone. Our healthcare
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3 system, already strained before the COVID-19 pandemic, has been pushed to the brink.³⁴ It is
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5 essential that we prevent non-empathetic care from further straining the healthcare system
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7 through direct and downstream harm. Enhancing clinical empathy has no financial cost, need not
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9 require significantly more time per visit,³⁵ and may even save time by minimizing
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11 miscommunication. Providing care with clinical empathy is imperative not only for the health
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13 and wellbeing of the patients in front of us, but for the durability of the healthcare system.
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19 **Future directions**

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21 This patient-perspective study is part of the Empathy in Medical Professionals:
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23 Augmenting Curriculum and Training (EMPACT) project, which seeks to amplify the voices of
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25 Canadian patients and inform innovation in medical education. Patients agreed that clinical
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27 empathy should be an essential part of physician training and offered a variety of suggestions.
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29 Acknowledging that understanding patients' experiences can be challenging for those without
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31 firsthand experience of chronic illness, they suggested that increased patient involvement in
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33 medical training (e.g. through sharing stories with students) and admission of more students with
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35 personal illness experiences may foster more understanding.³⁶⁻³⁷ Currently, medical students with
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37 chronic illnesses and disabilities are significantly underrepresented and under-supported,³⁸ and
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39 this exclusion of patients from the medical profession perpetuates the “othering of the sick
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41 person” and an ableist culture that hinders clinical empathy.¹ We can begin by including patients
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43 in the development and implementation of medical school curricula and increasing the
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45 accessibility of the medical field to students with medical conditions.^{36,39} Future phases of the
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47 EMPACT project will collect data from Canadian medical schools and medical students to
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3 characterize the current state of clinical empathy training in Canada and inform development of
4 educational interventions that meet the needs of both patients and students.
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10 **Limitations**

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12 Despite researcher attempts to increase sample diversity through recruitment expansion
13 and specific calls for diverse populations on follow-up advertisement posts, the study sample
14 consisted of mostly women, only 20% of participants self-identified as being a member of a
15 visible minority, and none identified as Indigenous. Furthermore, all participants required access
16 to a device with internet, possibly excluding individuals of lower socioeconomic status. As
17 discrimination was commonly identified as a barrier to empathy, it is likely that more
18 marginalized populations would face these obstacles to an even greater extent in addition to
19 unique barriers.
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33 **Conclusion**

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35 Although it has been known that empathy augments patient care, these patient stories
36 indicate that acting with clinical empathy is not a luxury, but a necessity – its absence is not
37 neutral, it causes harm. The knowledge that clinical interactions can impact a patient's health,
38 self-concept, and quality of life should be treated with the same responsibility as any other
39 medical intervention. In the words of one participant: "Being a doctor doesn't just mean curing
40 or giving medicine or diagnoses. [...] Like, I wouldn't want to be a doctor for the totally honest
41 truth. The responsibility, to me, is just so great. So, I give my hat off to anyone who wants to be
42 in medicine, I'm very grateful [...], because we really do need them. But we really need them to
43 help us, too."
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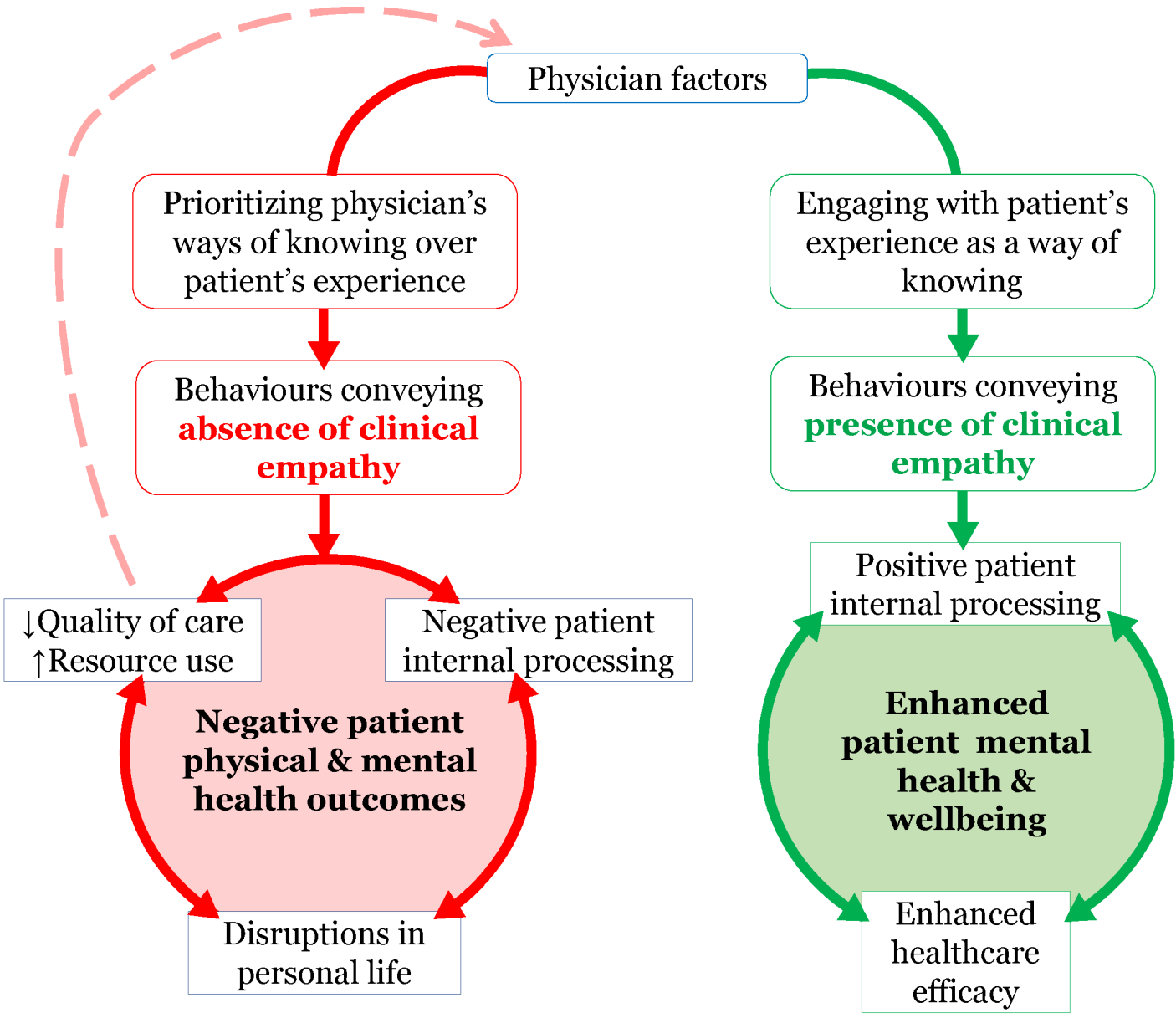


Table 1. Participant characteristics according to responses on the Demographic Survey.

Characteristics	Number of participants, <i>n</i> (%)
Gender identity	
Woman	17 (85%)
Man	3 (15%)
Age (years)	
18-35	4 (20%)
36-55	8 (40%)
56-75	7 (35%)
75+	1 (5%)
Education	
High school graduate	2 (10%)
Some post-secondary studies, no degree	4 (20%)
College or vocational degree	5 (25%)
Undergraduate degree	6 (30%)
Post-graduate degree	3 (15%)
Identification as visible minority	
Yes	4 (20%) ^a
No	16 (80%)
Province/territory in which patient primarily receives healthcare^b	
Alberta	1 (5%)
British Columbia	4 (20%)
Manitoba	1 (5%)
Newfoundland & Labrador	1 (5%)
Nova Scotia	1 (5%)
Ontario	12 (60%)
Saskatchewan	1 (5%)
Region of residence	
Rural	4 (20%)
Urban/Population centre	16 (80%)
Pop. 30,000-99,999	4 (20%)
Pop. 100,000-499,999	7 (35%)
Pop. 500,000+	5 (25%)
Classification of chronic illness	
Primarily physical	7 (35%)
Primarily mental	0 (0%)
Both	13 (65%)

^aParticipant self-descriptors included “Asian”, “Half-Iranian”, and “Eurasian”. No participants self-identified as Indigenous.

^bTotal percentage exceeds 100% because one participant received healthcare in multiple provinces. Recruitment was open to residents of all provinces and territories – those not included in table had zero participants.

Table 2. Components of the patient-derived clinical empathy model (Figure 1) corresponding to the absence or deficiency of clinical empathy, and corresponding participant quotations

Item on Model	Patient-perceived phenomena	Select quotations*
Physician factors (inhibitory)	Physician specialty Burnout, patient load, setting, time/resources	"I think the doctors have started to become mechanical in their work because they're so busy and the true compassion of what they're supposed to be doing, has started to dissipate because they know that there's X number of people right behind you that they've got to deal with." – 5A
	Physician frustration with lack of patient improvement	"I think [...] some physicians, they don't respond to people with chronic conditions anymore because they can't deal with the fact that there's nothing they can do to help them.[...]It's burning them out and they don't have a way to deal with that." – 1C
	Ableism/hierarchy in medicine Implicit/explicit biases	"There's a little less room for empathy, or a little less room for understanding the patient's perspective because it's really hard to do that and be God at the same time." – 5A "[What happens] to a lot of us women [...] is the assumption that when we talk about pains is that [...] 'Oh it's just period pain, that's normal. Oh, it's just some anxiety. Oh, it's just some depression.' [...] Unless you would say it to yourself, then it's not appropriate." – 1C
Prioritizing physician's ways of knowing	Not listening to patient	"I just felt like giving up because I was so frustrated, and the frustration had to do with that doctor because he just wasn't listening to me." – 6C
	Anchoring on assumptions, stereotypes, schemas Not trusting the patient's experience and knowledge of their own body	"The patient knows their body best. They're the one who are the one who lives in it 24/7. Just because the doctor has been to medical school and knows how everything works does not mean that they're the expert on the patient's body." – 1C
	Seeing the patient as their disease rather than a whole person	"I think that my biggest problem right now is that [...] he's looking at me as a disease, not as the person that has the disease, and all the issues I'm having with the meds they're putting me on." – 6C
Behaviours conveying absence of clinical empathy	Lack of support/validation Lack of effort, "giving up", dismissiveness	"It's anywhere from being dismissed to belittling. And I think because of the label of my chronic illness, [...] so many things are brushed under the rug of that diagnosis, which actually shouldn't be under that diagnosis." – 2A
	Insults, discrimination, "gaslighting"	"I've been called crazy, I've been laughed at." – 2B
	Inadequate explanations Failure to collaborate with patient	"When things don't go well, I relate that more to my doctor not providing an explanation why we can't do A, B and C.[...] I find that is lacking as well, the communication and the education of my physician's decision making, and that leaves me in the dark where I feel like my needs aren't being addressed and I'm not being heard." – 5B
	"Pill-pushing" Patient-blaming/labelling	"When they saw my pain medications they said, 'Oh you know what? You're an addict, you need to go to the pain clinic.'" – 1C "I got off of them and my pain didn't change, so now whenever I go to the doctor, they're like, 'Well, you're not on any medications, so you don't really have a problem.'" – 3A
Negative processing	Loss of trust in physicians and healthcare system	"I lost a lot of trust in the medical profession, and I was planning to just stop going to the doctor altogether and just kind of give up. My doctor was giving me no options, no help at all and I just felt like she didn't understand me, she wasn't trying anymore, she just [...] seemed frustrated that nothing she was doing was working to help me." – 1A "I think the part that kind of hits the deepest is that... like I'm losing trust in the entire system. And that's really scary." – 2A
	Questioning own feelings and reality	"Mentally, in my daily life, like the first participant was saying, it makes you feel crazy, it makes you feel like what you're feeling isn't real." – 1A
	Healthcare trauma & avoidance of future encounters	"I usually end up leaving and I'm in tears." – 2B "[A negative appointment] can trigger things like depression and anxiety and can make you feel down for several days, if not more, [...] and then it can give you sort of like PTSD-type symptoms. You get nervous about going to the doctor or specialist to sort of like you go, 'Oh my God, I got

		the appointment again, oh my God.” [...] That hypervigilance sort of stuff – and you can’t sleep the night before because you’re so nervous about ‘How is this doctor going to treat you?’” – 1C
	Feelings of guilt, burdensomeness, shame for not getting better	“I find myself being a lot more critical of myself for having the condition as if it’s my own personal failure for having it, which I know is wrong, but I just can’t seem to stop myself from doing that.” – 3B “When my doctor is having a good day, and he’s very receptive and listening, I leave that appointment much better than when he’s having a dismissive type day – the whole thing just starts on a downward spiral and I feel worse about myself and guiltier about needing him and everything.” – 3C
	Loss of hope	“I think it does strip that that hope away bit by bit and it’s hard to care about yourself when no one else like seems to care, you know?” – 5C
Disrupted personal life	Impacts ability to work & relationships with partner/family	“They want you to lose weight but [...] I have to get some exercise in order to lose weight and in order to exercise I have to be relatively pain free because if I exercise I’m going to be in even more pain and then I can’t go to work.” – 1B “I feel very hopeless because I’m trying to live my life, I have a child and a full-time job and when you told me ‘This is just your life now’ and I’m barely getting by, that’s not very hopeful. Just give me some hope.” – 1A
Healthcare: reduced quality & increased utilization	More appointments & referrals	“Well, we don’t have time to address all of this today,’ whereas I feel like if I could just have that one chunk of time, I wouldn’t have to come back as often.” – 3C You feel some anger towards the system but at the same time you feel guilt because you keep going back, hoping for a different result.” – 3B
	Inaccessible treatments & non-adherence	“I waited on a waiting list for almost five years, and they gave me one [...] 30 miles away. [...] When you’re sick, you can’t do that on a taxi.” – 4B “I can’t pay for a lot of things that my doctor says I need.” – 2A
	Patients avoid seeking healthcare	“Shortness of breath, chest pain in the middle and on the left, like really classic symptoms that you should go to the hospital, and I just didn’t want to. Like, I was so exhausted from doctors, that I didn’t want to.” – 2A “My eyes went yellow before I would go to the doctor because I was like, ‘They’re not going to believe me anyway.’” – 4C
	Patients withholding health information	“I don’t tell doctors everything anymore either because I feel like [...] if I tell them past experiences then it just nullifies everything I’m about to tell them, and they won’t even look into it because ‘Oh, it’s just part of this.’” – 1A
Negative health outcomes	Negative physical health outcomes: mediated by stress, unhealthy lifestyle choices, delayed pursuit of care by patient, leaving against medical advice, non-adherence, or delayed/refused treatment	“My emotional health which unfortunately affects my physical health given the condition that I’m dealing with, [...] I go home cranky or I grab a chocolate bar because I am an emotional eater.” – 5B “And the doctor at the hospital didn’t want to do tests because he was like ‘Oh, you have this chronic pain condition, that’s probably what it is.’ [...] And I had fucking pneumonia.” – 2A “I know that stress makes pain worse. [...] basically anytime I have to deal with doctor, I know I’m going to flare.” – 2A “And when they finally did diagnose it, it was so aggressive that they’ve had a hell of a time getting it brought back down. And I think if someone had just really sat and listened in the first place, a lot of steps could probably have been skipped and she wouldn’t have suffered as much either.” – 3C
	Negative mental health outcomes: reduced self-esteem, emotional exhaustion, anxiety, depression, and suicidal ideation	“It becomes difficult to live day-to-day, and it’s difficult when the person who’s supposed to understand you, doesn’t. [...] It feels like I’m just screaming into the void sometimes.” – 5C “I really think doctors need to know that... their decisions, their diagnosis, the way that they treat their patients can really, really make a huge impact. I’ve been to the point where I just don’t want to be here . I have two kids, and that’s what’s kept me here.” – 2B “If I’m not listened to or feel like my medical professional is partnering with me then, to a certain extent, it’s almost ‘ What’s the point of being alive? ’” – 1B

*Filler words such as “um” and “like” may be omitted from quotations

Table 3. Components of the patient-derived clinical empathy model (Figure 1) corresponding to the presence of clinical empathy, and corresponding participant quotations

Item on model	Patient-perceived phenomena	Select quotations*
Physician factors (facilitative)	Adequate time & resources Being treated kindly by patients Personal experience with chronic illness	“I think there may be some room here for training patients to try to recognize that doctors are people too.” -6A “Having cancer made him a better doctor because, all of the sudden, he realized what it was like being helpless, and in that bed, and waiting for somebody who knew something to do something, and having no control.” -5A
Engaging with patient’s experience	Listening mindfully to the patient to learn about their experience, while acknowledging the physician cannot fully understand it Seeing the patient as a whole person rather than just their disease Believing and trusting the patient as an expert on their own body	“There’s only one that’s been able to communicate to me [...] not that they understand, but they’re truthful in the fact that they say that they <i>can’t</i> understand.” – 2A “She heard me and she knew my whole story as a human being, not just my illness.” – 4A “You know, if a doctor believes, and I go home, I’m happy, I’m very happy.” – 6D
Behaviours demonstrating presence of clinical empathy	Communication that is honest, supportive, validating, and normalizing Willingness to put in effort, even if the physician does not know exactly what to do Trauma-informed care Collaborating with the patient to develop a care plan, valuing their perspective/research	“The doctor taking the time and acknowledging feelings, validating feelings, and providing that [...] reassurance or encouragement, or just saying ‘Yes, it sucks, but this is what we’re going to do.’” – 5B “I’ve had some times with doctors who’ve been really, really great. Like, I’ve been able to come with them to research about medications that I thought, ‘Hey, can we try this?’ and we’ve talked about, and we’ve come up with a collaborative plan, and that’s been awesome.” – 1C
Positive processing	Feelings hope, empowerment, and increased trust in the physician and healthcare system	“I guess just to listen to you and make you feel [...] validated and that it’s not all in your head, and just give you some hope to just get through to your next appointment, something to try. [...] My mood definitely gets better, like I feel less hopeless, less depressed, just not as scared or [...] nervous to go to the doctor the next time because of, you know, how is this appointment gonna go.” – 1A
Enhanced healthcare	Patients more likely to self-educate, try new treatments, adhere to treatments, and make healthier lifestyle changes	“I’ve been a smoker for 43 years, on and off, and this time was the easiest time for me to quit, [...] I think because my physician was supporting me and all of the aspects.” - 1B
Enhanced mental health & wellbeing	Improvement of mood and energy levels Increased patient confidence, self-image, and resilience	“‘If you can’t see the light at the end of the tunnel, there’s no point in being alive’ is the way I talked to myself in my head. [...] I think I have renewed hope because I have a medical professional on my side. [...] I don’t even think you can quantify or put a value to having somebody that works with you and listens to you and it makes you feel valid.” – 1B “You feel more hopeful. Not necessarily that your pain will go away or your disease will go away. It’s just that I’ll have as normal life as I possible can given my current condition. And you feel validated, so it gives you the courage to try new things, it improves your actual physical and mental energy, and, trust me, when you suffer from chronic pain, that is depleted before you even get out of bed.” – 1B

*Filler words such as “um” and “like” may be omitted from quotations

Table 4. Patient recommendations for medical education to improve clinical empathy in future physicians.

Category	Suggestions for Improvement
Admission to medical school	<ul style="list-style-type: none"> • Factor diversity and emotional intelligence into selection • Consider personal experience as a patient to be an asset in applicants
Curriculum content	<ul style="list-style-type: none"> • The interplay between mental and physical health • Cultural humility and anti-oppression training • Non-medical factors impacting health, such as socioeconomic status and healthcare accessibility • Alternative treatments that patients may be receiving (for physician awareness/understanding, not practice)
Practical training	<ul style="list-style-type: none"> • Formal training on interviewing and therapy techniques • Evaluation of students' interpersonal and communication skills
Knowledge of patient experience	<ul style="list-style-type: none"> • Incorporate patient stories, especially those told by patients themselves • Teaching about medical trauma and medical gaslighting, and the emotional implications for patients
Physician mental health	<ul style="list-style-type: none"> • Teaching on strategies to identify and mitigate burnout

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3 **APPENDIX A: Virtual groups used for participant recruitment**
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6 The Facebook groups that permitted advertisement of the study were:

- 7 • Surviving Chronic Pain in Canada (1.7K members)
- 8 • Mental Health Support in Canada (1.3K members)
- 9 • Canadian Cancer Support Group (550 members)
- 10 • Rheumatoid Arthritis Canada (2.5K members)
- 11 • Asthma Support for Canadians (279 members)
- 12 • Canadian Disability Alliance (1.5K members)
- 13 • Disability/Special Needs Benefits in Canada (1.5K members)
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18 Due to a paucity of male participants, recruitment was expanded off Facebook through the
19 Prostate Cancer Support Canada e-newsletter.
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APPENDIX B: Semi-structured focus group guide

[Note: general prompting phrases such as “Would you like to elaborate on that?” will be used throughout at the moderator’s discretion. Questions may be modified, reordered, or reworded depending on participants’ responses]

We would like to talk about your physician’s **ability to understand your illness experience, their ability to communicate that understanding to you, AND their ability to act on that understanding when providing care** *[type this into Zoom chat in case participants wish to reference it]*. We encourage you to use personal experiences and examples wherever you feel comfortable, and elaborate on the thoughts behind your answers as much as you like.

1. Can you describe a time when your physician* acted this way towards you?
 - a. What did that look like? What did they say or do, for example?
 - b. How did that make you feel?
 - c. Do you think that this affected the care that they provided you?
2. Can you describe a time when your physician has NOT acted this way towards you?
 - a. What did that look like? What did they say or do, for example?
 - b. How did that make you feel?
 - c. Do you think that this affected the care that they provided you?
3. How have those experiences (both positive and negative) impacted your life or overall wellbeing?
4. How important to you is it that your physician is able to...
 - a. Understand your illness experience?
 - b. Communicate that understanding to you?
 - c. Act on their understanding of your experience to provide you care?
5. In general, do you think physicians should improve with respect to these skills – and if so, how?
 - a. For example, do you think these skills should be a part of a physician’s training? What could that look like?

*Patients may talk about experiences with different physicians for different examples, including both specialists and primary care physicians

APPENDIX C: Initial code descriptions sent for member-checking

Codes are bolded within the descriptions. Each participant was sent only codes that applied to the focus group they participated in and was given the opportunity to provide anonymous feedback.

1. Patients benefit from knowing their physician **listens to**, **understands**, and **believes** them
2. **Prescriptions** and **referrals** are a prominent aspect of the physician-patient relationship
3. Deficits in the physician-patient relationship can contribute to **delayed treatment**
4. Patients often fear being perceived as “**drug seekers**”
5. The experience of chronic illness also spills over into a person’s ability to cope with/sustain **work or employment** and manage **family dynamics**
6. The patient is an **expert on their own body** and should be consulted/treated as such
7. The relationship with a physician may have significant negative **mental health impacts** on patients such as feelings of frustration, depression, guilt, and anxiety
8. It is helpful when the physician is **supportive** towards their patients
9. It is helpful when the physician **normalizes** and **validates** a patient’s experience and is **supportive** towards them
10. Patients can sense when their physicians are **frustrated** with them
11. The relationship with a physician may contribute to feelings of either **hope or hopelessness**
12. One factor that contributes to overall quality of care is when the physician **takes time** during each appointment and **focuses** on the patient
13. Patients value the opportunity to **collaborate** with their physicians when planning next steps or treatments
14. Patients want to know and see their **physician’s effort** towards developing a diagnosis and treatment plan
15. Patients have often had to deal with **unprofessional behaviour** including insensitive comments from physicians as well as outright **refusal of care**
16. Patients want to have a comprehensive **care plan** and want their physicians to explain/teach them about their treatment to gain **knowledge**
17. The **physician’s competence** and **ability to communicate** directly affect the quality of care
18. Patients are often left feeling like they are **losing trust in the healthcare system** and are **reluctant to engage in care**
19. Patients want **honest physicians**
20. It is helpful when the physician **validates** a patient’s experience
21. Patients have experienced serious **physical health impacts** from delayed or poor treatment by physicians
22. Poor quality of care can be **exhausting** for patients
23. Patients are often told from physicians that **nothing is wrong**
24. **Accessibility of care** is paramount and often overlooked when physicians suggest treatments
25. Physicians should **delegate** tasks to other professionals to improve clinical workflow
26. Medical school curricula should **teach medical students communication skills and patients’ experiences of illness**

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- 3 27. Patients want to be looked at as a **whole person** by their physician, not just their specific
- 4 disease
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- 6 28. Patients are often cognizant of the challenges physicians face with **burnout** and how this
- 7 affects their ability to provide care
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- 9 29. Patients appreciate when physicians are able to **provide collaborative care** in
- 10 conjunction with many types of healthcare practitioners
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- 12 30. Patients value receiving **trauma-informed care**
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- 14 31. Patients often feel like they are **automatically dismissed** by and are a **burden to**
- 15 physicians
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- 17 32. Patients struggle when physicians **make assumptions** about why they are having a
- 18 particular experience
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- 20 33. Patients struggle when physicians do not **remain current** on the most current medical
- 21 knowledge
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- 23 34. Patients who identify as women sometimes perceive their physicians to be
- 24 **discriminatory** towards them on the basis of gender
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APPENDIX D: Detailed descriptions of patient-perceived phenomena in clinical empathy model (Figure 1)

Absence/Deficiency of Empathy:

Item on model	Patient-perceived phenomena
Physician factors (inhibitory)	Ableism and hierarchy are embedded in the culture of medicine, and intersect with other implicit/explicit biases leading to preconceived ideas about patients.
	Physician specialty may impact level of empathy; emergency department was frequently identified as an empathy-deficient setting.
	Many physicians are very busy, overworked, stressed, and burned out in the system, which leads to a loss of compassion, mechanical care, and lack of mindfulness in interactions with patients. When patients have a chronic illness, physician frustration that the patient is not getting better may lead to withdrawal of empathy.
Prioritizing physician's ways of knowing	Physicians often fail to take time to focus and listen; subsequently, care is decided based on preconceived ideas rather than through an understanding of the patient's experience.
	Doctors make assumptions based on stereotypes/schemas and may be dismissive of things that stray outside that picture, and do often not trust the patient's knowledge of their own body.
	Physical illnesses are inadequately addressed when issues are siloed and patients are not seen as a whole person, including their mental health.
Behaviours conveying absence of clinical empathy	Non-empathetic communication ranges from that which lacks support/validation to that which is directly insulting/discriminatory.
	Physician dismissal and assertions that nothing is wrong despite patients' experiences of symptoms leads patients to doubt themselves and feel "crazy" (gaslighting).
	Patients become frustrated when they do not understand why their physician chooses to do (or not do) things in their care. The explanation of the action/inaction defines its meaning to the patient, and therefore its impact.
	Physicians often do not understand the complexities of navigating the healthcare system from the patient's perspective and may not provide adequate explanations, leading patients to fall through the cracks.
	Physicians are perceived as unmotivated to put effort into chronic illness and they "give up" when it does not improve. Patients must be extremely ill for doctors to act or else everything is chalked up to the chronic condition or mental health.
	Patients often feel that they are responsible for managing their own care and doing their own research, but then are criticized for doing their own research.
Negative processing	Patients feel both that pills are "pushed" on them and that they are blamed for taking "too much" medication at the same time. Their pain is not considered serious if they do not take pain medication, and their issues are all chalked up to drug-seeking if they do.
	Patients lose trust that empathy-deficient physicians will treat them appropriately, and also doubt their clinical competence. This mistrust can generalize to the healthcare system as a whole, resulting in a feeling that no one is there to help if they are sick.
	Physician disbelief can lead patients to question their own feelings and sanity.
	Patients develop a trauma response to interactions with physicians, and avoid future encounters as much as possible.
Disrupted personal life	Patients feel guilt for burdening their doctors, shame for not getting better.
	Hope is essential for resilience in people living with chronic illnesses, and appointments without clinical empathy strip it away. What happens in the patient's medical care directly impacts their ability to work, and their work impacts their ability to adhere to treatments. Negative emotional/psychological states evoked by physician interactions can be projected onto partner/family, leading to further shame, guilt, and hopelessness.

Healthcare: reduced quality & increased utilization	When the physician is distracted or not truly listening, patients end up need more appointments and issues take longer to solve.
	Lack of effort/listening leads to inappropriate referrals.
	Many treatments that physicians prescribe do not reflect an understanding of the patient’s location and financial situation, leading to inaccessible recommendations that the patient cannot adhere to.
	Patients avoid seeking healthcare until they are seriously ill.
	Patients refuse medications when they need them to avoid being labelled as a drug-seeker in future.
Negative health outcomes	Patients are more likely to hide information or lie to physicians for fear of information being used against them.
	The cycle of self-advocacy and being dismissed leads to profound exhaustion.
	Gaslighting leads to self-doubt and reduced self-esteem in patients.
	Patients often experience a “spiraling” of hopelessness after appointments, leading to depression, anxiety, and suicidal ideation attributed to the physician interaction (not the illness).
	Poor physical health outcomes may occur secondary to mental health impacts, as well as due to delayed pursuit of care by patient, leaving against medical advice, non-adherence to treatment, or delayed/refused administration of treatment.

Presence of Empathy:

Item on model	Patient-perceived phenomena
Physician factors (facilitative)	Physicians who have adequate time and resources often display more empathy.
	Patients treating physicians with kindness and empathy helps evoke reciprocity.
	Physicians who have experienced chronic illness are often the most empathetic.
Engaging with patient’s experience	Clinical empathy involves taking time to truly listen mindfully to the patient to learn about their experience with their illness and the medical system, while acknowledging that they cannot fully understand it. This involves seeing them as a whole person rather than just their disease.
	Patients need their physician to believe them and trust them as an expert on their own body.
Behaviours demonstrating presence of clinical empathy	Patients value communication that is honest, supportive, validating, and normalizing.
	Patients need to feel like their physician is willing to put in effort, even if they do not know exactly what to do
	A trauma-informed approach shows empathy for many patients who have experienced healthcare (or other) trauma.
Positive processing	Patients want to be an active member in developing a collaborative care plan, with their perspective and research valued.
	Clinical empathy fosters feelings of hope and empowerment in patients, as well as increased trust in the physician and healthcare system.
Enhanced healthcare	When patients have hope regarding their healthcare, they are more empowered to educate themselves, try new treatments, adhere to treatments, and make healthier lifestyle changes.
Enhanced mental health & wellbeing	Clinical empathy itself has direct positive effects on mood and energy levels, is protective of patient self-image, and increases patient confidence and resilience.