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# Impact of a mental health patient portal on patients' views of compassion: a mixed-methods study

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## Abstract

**Background** Compassion is central to achieving positive clinical outcomes, commonly studied as a concept that enhances therapeutic alliance between patients and clinicians. Within mental health care, compassion may be enhanced by a patient portal, a digital platform where information is exchanged between clinicians and patients. The portal is viewed as a compassion-oriented technology, as it may positively influence safety, disease management, and patient engagement. As portals have limited implementation in mental health care, it is imperative to research the impact of portal use on patient's perspectives of compassion expressed by clinicians.

**Methods** We conducted a convergent mixed methods study to assess and understand the impact of portal use on patients' experience of compassion in mental health care settings. The quantitative strand encompassed a self-administered survey consisting of a validated compassion scale at the time of enrolment in the portal and after both three and 6 months of portal use. The qualitative strand consisted of semi-structured interviews with patients after the three-month mark of portal use. Data collection and analysis of both strands happened independently, then these two complementary findings were merged narratively.

**Results** A total of 113 patient surveys and ten interviews were included in analysis. The univariate model with time as the only independent variable did not show significant differences in the total compassion scores across the three time points,  $F(2, 135) = 0.36, p = 0.7$ . The model was then adjusted for sex, age, and diagnosis and did not show significant changes in the total compassion scores,  $F(2, 135) = 0.42, p = 0.66$ . Interview findings identified both positive and negative influences of portal use in patients' perception of compassion. Some participants described compassion as something personal, not associated with the portal use. However, some participants reported that portals facilitated treatment experiences, being reflective of compassionate care.

**Conclusions** Patient portals in mental health care may allow for timely exchange of information and create a space outside appointments to strengthen relationships between clinicians and patients, improving compassionate delivery of care. Further research can help better understand how portals can contribute to digital compassion as technological advancements continue to be integrated into mental health care contexts.

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**Keywords** Mental health, Patient portal, Mixed methods, Compassion

## Background

Compassion is at the centre of clinical practice across health care disciplines including, but are not limited, to nursing [1] and medicine [2]. Despite its significance in quality of care, there is no one agreed-upon definition for compassion but rather, it is described in various ways [3, 4]. One of the common defining qualities of compassion includes “awareness of/noticing/sensing suffering in another; participation in the suffering; empathising or suffering with another; being moved to alleviate the suffering of another; and taking appropriate action to relieve the suffering of another through appropriate response” ([3], p. 1383). Specifically, an empirically derived patient definition of compassion is “a virtuous response [from the health care provider] that seeks to address the suffering and needs of a person through relational understanding and action” ([5], pp.195). As such, compassion within a health-care context can be understood as collectively related to clinicians’ actions and responses to relieve patients’ suffering.

Health care, including mental health, has been traditionally delivered in the context of unequal power relationships between physicians and patients [6, 7]. Nevertheless, since the movement towards patient-centred care, there have been collective efforts to shift the power back to patients [8, 9], even in involuntary mental health care settings to minimize coercive practice without compromising safety [10]. One particular strategy to practice patient-centered care is to develop and implement a common platform to exchange health information between clinicians and patients [11]. This platform is often called a patient portal, which gives patients secure access to their own health information and allows for secure means of communication and information sharing. By sharing health information and records between clinicians and patients, power may be redistributed, promoting patient autonomy and empowering patients to make informed decisions about their care [12, 13]. In other words, a patient portal can act to minimize unequal power relationships and promote therapeutic alliance between patients and clinicians.

Patient portals have been identified as one of the possible compassion-oriented technologies [14]. This means that it has numerous potential benefits of improving care and patient outcomes as shown in diabetes management [15], heart failure management [16], and primary health care settings [17]. Specifically,

the patient portal has improved patient safety [17], patients’ self-engagement in their disease management [16], shared decision making with clinicians [18], and clinical outcomes including improved glycemic control [15]. Furthermore, patients have reported positive experiences using the portal [19–21]. For example, patients reported feelings of validation and improved therapeutic alliance when reading the open mental health therapy notes [21, 22]. Despite these positive benefits, patient portals are not yet widely used internationally, especially in mental health care settings. There has been resistance against implementing patient portals in mental health organizations [23]. For example, one major concern clinicians may encounter when sharing notes is providing transparent information while preventing potential patient harm from reading notes that may be upsetting or confusing [24].

As of 2022 in Canada, there are limited examples of comprehensive patient portal use in mental health settings. The lack of implementation (or lack of implementation of functionalities reported in other care settings) and justification for the use of mental health patient portals can be attributed to the limited evidence on its use and benefits amongst mental health populations. More research is needed in this area to further investigate patients’ experiences and advocate for patient portal implementation in mental health settings. In particular, emphasis has been placed on the need for empirical research on the value of patient portals related to provider-patient interaction and therapeutic alliance [25]. In response, this current study investigated mental health patients’ experience using the patient portal. Digital tools can shape patients’ experience of compassion [14, 26]. In recognition of compassion being central to care delivery and therapeutic alliance, this mixed-methods research aimed to assess and understand the impact of patient portal use on patients’ perspectives of compassion expressed by their clinicians. Specifically, the quantitative strand assessed the impact of patient portal use on compassion over time, and the qualitative strand provided in-depth description of patients’ experience of compassion shaped by the portal use.

## Methods

To achieve the overall mixed methods aim stated above, this study addressed the following objectives:

## Research objectives

1. Quantitative strand: Determine if patient portal use is associated with improved compassion scores over time (baseline, 3-month, 6-month)
2. Qualitative strand: Describe how patient portal use shapes patients' experiences of clinician compassion.

## Study setting

The study was conducted at Canada's largest mental health and addictions teaching hospital called 'The Centre for Addiction and Mental Health (CAMH)'. CAMH is located in Toronto, Ontario, and has a large patient population; specifically, care was provided to approximately 37,065 patients during 2018-2019 [27]. CAMH provides care to patients of all ages, ranging from children to older adults with varying mental health diagnoses (e.g., depression, schizophrenia, schizoaffective disorder, etc.). Mental health services are offered through inpatient, outpatient, and hospital programmes.

## Theoretical frameworks

The Strategy for Patient Oriented Research (SPOR) Patient Engagement Framework [28] was augmented to inform the methodological approach for this study. A Patient and Family Advisory Committee at CAMH was engaged during each stage of the research process (planning, execution, and dissemination) to ensure the relevance, meaningfulness, and feasibility of the study. Health professionals (e.g., nurses, psychiatrists, peer support workers, and an occupational therapist) were consulted in the design of this study to ensure its feasibility. Lastly, Sinclair and colleagues' Key Elements of Compassion [5] was used to guide qualitative data analysis. This is a clinically informed, empirical model of compassion generated from the perspective of patients [5]. The Key Elements of Compassion are organized in six categories: 1) Virtues, Relational Space, 2) Virtuous Response, 3) Seeking to Understand, 4) Relational Communicating, 5) Attending to Needs, and 6) Patient-Reported Outcomes [5]. The authors of the current study chose to use this empirical model of compassion because of the value in patients' perspectives in understanding compassion.

## Design

This was a convergent mixed-methods study [29] where quantitative and qualitative data collection and analysis happened independently, consisting of a series of surveys and semi-structured interviews with patients and their family members. After collecting and analyzing both quantitative and qualitative data, merging of both strands occurred in the end during a reporting and interpretation

phases to provide a more complete and contextualized understanding of the phenomenon being investigated [30]. A convergent design was purposefully selected because outcome measures have been informed a priori, and quantitative and qualitative strands had equal weight in this study. The study was completed in a two-year period, 2019-2021. This was a part of a larger study [31] and a protocol was previously published, which can be referred for further detail on the methods [31]. The current research specifically focused on the impact and the patients' experiences of using the portal related to compassion. Since this was a part of a larger study, we conducted a secondary analysis of interview transcripts with a compassion specific lens. Qualitative results relevant to this secondary analysis are provided herein. At the time of writing, publication of the main study was underway. The Good Reporting of A Mixed Methods Study (GRAMMS) [32] and the National Institutes of Health's Best Practices for Mixed Methods Research in the Health Sciences [33] were used to prepare this manuscript.

## Mental health patient portal

In 2018, CAMH implemented a patient portal called MyCare in mental health settings, which provided patients with access to documentation, such as notes on admission, assessment, and discharge, written by their clinicians. The portal also consisted of various functions such as self-assessments and provided secure means to send messages between patients and clinicians. The portal allows patients to send messages to clinicians and request for a prescription refill. Lastly, the portal facilitates patients to book appointments and sends reminders about upcoming appointments. There is no app for the portal, but since it is a web responsive design, the portal can be accessed via an online website, either using a computer or a mobile device. Patients are encouraged to access the portal as much as they would like to.

## Recruitment and procedures

At CAMH, there were four ways to recruit patients for this study. First, participants were provided with a pamphlet describing how to enroll in the patient portal, and recruitment flyers were also utilized. Second, patients were emailed a link during the registration process for the patient portal. At the bottom of email, recruitment information was presented to patients. Third, when patient portal users signed on to their portal, the homepage contained recruitment information for the study. Fourth, a member of the research team was available on-site during peak intake periods to answer any questions regarding the study. After enrollment into the CAMH Patient Portal with front-desk staff, interested patients or patients with study-related questions were invited

to speak to the research team in a private room. The research team member answered any questions that the patients had.

## Sampling

### *Quantitative strand*

Patients at CAMH, over the age of 16, were eligible to participate in the quantitative strand of this study if they: 1) had enrolled in the patient portal (i.e., MyCare), and 2) had access to the portal for <2 weeks. All patients initially enrolled in the study were from outpatient clinics. Since the portal content is in English, authors assumed that all participants could read English. The minimum sample size was estimated to be 100 participants based on the power calculation detailed in the protocol [31]. All participants provided written informed consent via REDCap.

### *Qualitative strand*

A self-selected convenient sample of participants from the quantitative strand participated in the interviews. Interview participants, either patients or family members, must have used the patient portal for a minimum of 3 months. Participants were eligible to participate in the interview if they completed surveys at both baseline and the 3-month mark. Family member participants were also eligible if their family member was registered in a CAMH patient portal. All interview participants provided written informed consent via REDCap [34].

## Data collection

### *Quantitative strand*

Patients enrolled in this study completed a survey that measured patients' perspective of compassion expressed by their healthcare providers with the Compassion Scale developed by Fogarty et al. [35]. There were three time point measurements, including: 1) Baseline/ T0; 2) 3-Month/T1; 3) 6-Month/T2. Baseline/T0 represented time of initial enrollment in the patient portal. 3-Month/T1 represented 3 months of portal use and 6-month/T2 presented 6 months of portal use. These time points were selected based on previous researchers' implementation benchmarks [36, 37]. The compassion scale included five pairs of clinicians' characteristics items: 1) warm/cold 2) pleasant/ unpleasant, 3) compassionate/distant, 4) sensitive/insensitive, and 5) caring/ uncaring [35]. Patients scored clinician's characteristics using this measurement tool, and each item was scored out of 100%. At the time of implementing the current study, Fogarty's compassion scale was one of the validated tools that has been implemented in previous studies [38–42]. The sum of the five items indicates the degree to which study participants perceived the physician as compassionate [35]. A overall

score can range from 0 to 500; 0 is the worst score and 500 is the best score with higher scores indicating a greater level of compassion [35]. The scale was internally consistent (Cronbach's alpha coefficient, .92), reflecting that measured a single, cohesive construct [35]. Demographic information (e.g., age, ethnicity, sex) was also collected during the baseline survey (T0). The surveys were self-administered online through REDCap and all data was securely stored on a server at CAMH.

### *Qualitative strand*

Research assistants conducted semi-structured interviews and asked patient and family members about their experiences using a patient portal. All interviews were conducted via a secure videoconference tool (Cisco WebEx). We developed a semi-structured interview guide based on the objective of the larger study [31]. Please see Supplementary File 2 for the final interview guide. All interviews were conducted between March 2021 – May 2022 and lasted 30-60 minutes. There were no repeat interviews, and all interviews were audio-recorded, transcribed verbatim, deidentified and anonymized.

## Data analysis

### *Quantitative strand*

All quantitative data captured by REDCap were managed and analysed using SAS Enterprise Guide V7.15 (SAS Institute, Cary, North Carolina, USA). Two-sided *p*-values <0.05 were considered statistically significant. Participant characteristics were summarized using descriptive statistics. Linear mixed effects models with random intercepts were used to model the trajectory of the compassion outcomes across the three timepoints. The main analysis was unadjusted. Independent variables were three time points, and dependent variables were compassion scores. As an exploratory analysis, the models were adjusted for age, sex, and primary psychiatric diagnosis. These covariates were selected a priori based on previous literature on their relationship with the primary outcome of the larger study (i.e., Mental Health Recovery and Function) [31]. Backward variable selection was employed to create a parsimonious model. To account for missing data, regression analyses were performed both in participants with complete data and the data set after multiple imputations. Missing item-level responses were imputed simultaneously across all three-time points in multiple imputations, assuming all the variables in the imputation model have a joint multivariate normal distribution.

### *Qualitative strand*

HDS and KD first read all transcripts to get a complete understanding of them. Both HDS and KD are nurses

and research trainees with qualitative research experience. They conducted directed content analysis [43] using an empirical model of compassion called the Key Elements of Compassion framework [5] to describe how use of patient portal has shaped patients' experiences and interpretations of compassion. First, the authors pilot tested the coding strategy with two transcripts. Once the coding strategy was finalized, the rest of the transcripts were read through several times then coded using NVivo software [44]. The text segments from the transcripts were mapped on to the most relevant categories of the compassion framework. All transcripts were coded by two authors, and they discussed to resolve any discrepancies in the coded data. The authors collaboratively analyzed the data for emergent themes within each category of compassion. Through iterative discussion between authors and constant comparison within and between transcripts, consensus on final themes was achieved.

### Integration

The findings from both quantitative and qualitative strands of the study were integrated to gain a more complete understanding of patients' experience of compassion as it relates to their portal use. Once quantitative and qualitative findings were analysed independently, authors merged these two complementary results narratively [45]. Integration allowed for expanding our understanding of compassion scores by contextualizing them with patients' experience, highlighted areas of convergence and divergence, and generated meta-inferences.

## Results

### Quantitative strand

A total of 113 participants were recruited, of which 77 (68.1%) identified as female, 33 (29.2%) as male and three (2.7%) preferred not to answer (Table 1). Participants most commonly identified as between the ages of 25 and 64 years (62.0%), never married (54.9%), Caucasian or European (67.3%), and have a mood disorder (38.1%).

A total of 113 compassion scores were recorded at T0, 84 compassion scores were recorded at T1, and 78 scores were recorded at T2. We were unable to follow-up with participants who dropped out before the final survey. However, the demographics of the participants throughout T0 ( $n = 114$ ), T1 ( $n = 84$ ), and T2 ( $n = 78$ ) remained fairly consistent. See Supplementary File 1 for the full demographic characteristics of participants at T1 and T2. The unadjusted mean total scores across the three time points are as follows: T0: 384.9 (IQR 331–475), T1: 382.7 (IQR 325–480), T2: 375.8 (IQR 291–488). The univariate linear mixed model did not show significant differences in the total compassion scores across the three time points ( $F_{2,135} = 0.36$ ;  $p = 0.7$ ). Note that only 237

**Table 1** Demographic characteristics of  $N = 113$  participants

| Characteristic | Category                                    | Frequency (%) |
|----------------|---|---------------|
| Sex            | Female                                      | 77 (68.1)     |
|                | Male  | 33 (29.2)     |
|                | Prefer not to say                           | 3 (2.7)       |
| Age            | 25–64 years                                 | 70 (62.0)     |
|                | < 25 years                                  | 39 (34.5)     |
|                | ≥ 65 years                                  | 4 (3.5)       |
| Marital status | Never married                               | 62 (54.9)     |
|                | Married / domestic partnership / common law | 35 (31.0)     |
|                | Widowed                                     | 3 (2.7)       |
|                | Divorced / Separated                        | 11 (9.7)      |
|                | Prefer not to answer                        | 2 (1.8)       |
|                |   |               |
| Ethnicity      | Caucasian or European                       | 76 (67.3)     |
|                | Hispanic or Latino                          | 3 (2.7)       |
|                | Black or African American                   | 8 (7.1)       |
|                | Indigenous / First Nations                  | 2 (1.8)       |
|                | East Asian                                  | 10 (8.9)      |
|                | South Asian                                 | 6 (5.3)       |
|                | Mixed Heritage                              | 4 (3.5)       |
|                | Other                                       | 4 (3.5)       |
|                |   |               |
| Diagnosis      | Anxiety                                     | 21 (18.6)     |
|                | Mood disorders                              | 43 (38.1)     |
|                | Other <sup>a</sup>                          | 35 (31.0)     |
|                | Prefer not to answer                        | 9 (8.0)       |
|                | Schizophrenia                               | 5 (4.4)       |

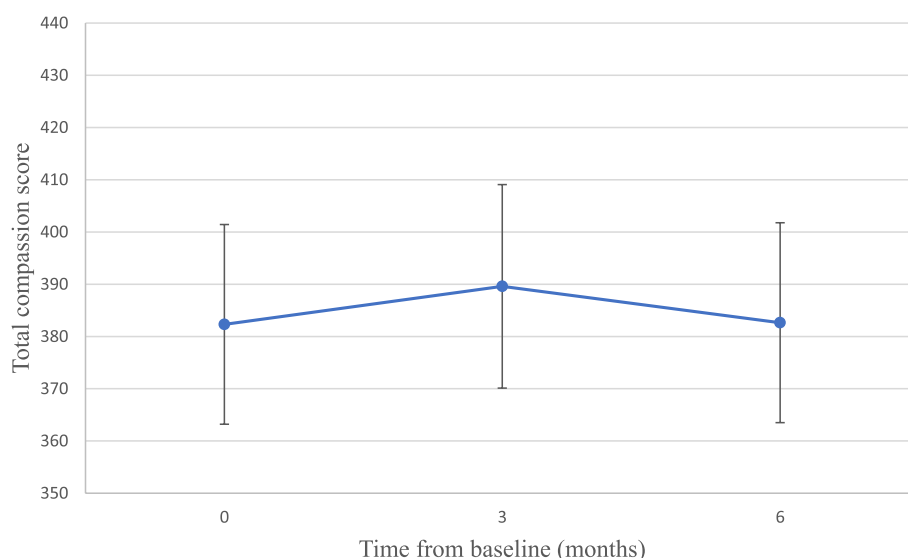
Other<sup>a</sup>: Please note 35 participants selected "other" but did not specify their diagnosis in the comment box on REDCap

records with complete data were analyzed. The estimated marginal means for compassion scores were 382.3 (95% CI: 359.0 – 405.7) for T0, 389.6 (95% CI: 365.3 – 413.9) for T1, and 382.6 (95% CI: 358.0 – 407.3) for T2 (Fig. 1). Our model shows that patients tended to have similar compassion scores throughout 6 months of using the portal. The multivariable model adjusting for age, sex, and diagnosis also did not show significant differences in the total compassion scores across the three-time points ( $F_{2,135} = 0.42$ ;  $p = 0.66$ ). The univariate and multivariable models after multiple imputation also showed similar non-significant results.

### Qualitative Strand

A total of 11 patients participated in the interviews, one interview was dropped during our analysis as it did not have any findings related to compassion. Adapted from the empirical model, Key Elements of Compassion [5], the following themes were identified: Virtues/virtuous responses, relational space, seeking to understand, relational communicating, attending to needs, and patient reported outcomes. Narrative summaries and exemplar





**Fig. 1** Estimated marginal means of compassion score over time based on the unadjusted linear mixed model. Legend: Error bars denote 95% confidence intervals

quotes of each theme are displayed below that correspond with each component of clinician compassion as it relates to the use of patient portals during mental health care delivery.

#### **Virtues and virtuous responses**

Patients feel that compassion arises from virtues of openness, understanding, and genuineness, and virtuous responses of clinicians are actions that convince virtue toward patients [5]. When patients review their clinical notes in the portal and the notes reflect the encounter with their clinician, this can enhance patient's perceptions of their clinicians being honest and understanding. Prioritizing care discussions, such as about patient's treatment, is one way that clinicians can demonstrate a virtuous response.

*"Because for this specific medication it was very detailed of how it needed to be taken, the dosage. There was a lot of information for it. And both my doctor and I actually talked about how it was so important to get that information to know exactly what to do." (T9)*

Alternatively, if patients feel that their care is not being prioritized when reviewing the portal, it can hinder their perception of the clinician's virtuous character.

*But I also felt a little frustrated, just in the sense that I kind of wished that that sort of communication had been given a little more so in the appointment. Again, I understand it's a lot easier, as we've said, after the fact, to digest everything and collect*

*yourself and write it out a little more cohesively. But I still did feel a little bit frustrated in that regard, that maybe it would have been nice to hear some of that stuff in the appointment itself. (T9)*

#### **Relational space**

Relational space encompasses compassionate encounters between a patient and their clinician, and during these encounters, patients become aware of clinicians' capacity for compassion and can experience engaged caregiving as they build relationship through their treatment journey [5]. Although some participants described compassion as something personal, others exclaimed how having control over their note access, such as reading the notes at their own discretion, allowed for engagement and empowerment in their care pathways.

*"I think, especially when you get into a medical setting, a lot of people get really freaked out. A lot of people have the white-coat syndrome, so they may not ask as much as they should be asking. Or don't know to. I saw with my friend who many, many years ago had cancer and then the cancer centre allowed her to go in and get her own results. And for her it was like an empowering thing because she was part of it. That's how she explained it, just being part of it is empowering and I think that it's important for everyone to have that. To be able to speak up. To be able to know what's going on with them and ask questions." (T6)*

Additionally, using a patient portal may not change patients' perceptions about their clinician's personal compassionate attributes. However, it can change patients' perceptions about their own care, with opportunities to include pertinent information within the notes through the portal and send messages to clinicians. As such, the patient portal created a relational space for clinicians to recognize and become aware of patients' concerns in a timely manner.

*"I think compassion, I don't know if I would use the word compassion for something you access on the internet because it's not really personal. To me compassion is a personal thing but, I think [the portal is] efficient and like most of the internet it's a great way of exchanging information in an efficient manner." (T3)*

*"I think the reason that having a space to write it would be important as because like I know for myself and a lot of other people that I know with mental illness we have a hard time speaking up." (T10)*

*"So, I think, in the sense of for people who go to [the hospital] more frequently and see medical professionals more often, I think it would be a little more beneficial just because you build up that relationship, you build up that profile there. And then there is more information to be added into the portal with the various interactions. Because there's only so much these providers could put in for this person that they met one time for an hour or so." (T9)*

### Seeking to understand

All clinicians should recognize that patients have individual needs related to their health care experiences [5]. To enhance compassionate care, exploring these needs is imperative which can be supplemented using a patient portal. For example, providing access to important health information can assist patients with recalling or clarifying important health information that may have been forgotten or not covered during an in-person appointment.

*"It would have been nice to see the notes of the doctors. Because I know they're so busy there so I don't feel like I always get my questions answered. I would be nice to have that to look back and say, oh, okay, so that's what he was thinking about." (T6)*

However, clinicians must thoroughly explain all relevant health information when patients are seeking to understand their care delivery plans. The patient portal can facilitate compassion as a supplementary tool, but it should not replace these personal discussions.

*"I feel like we're not always provided with very direct answers, like, this is what's happening. There's a lot of alluding to or kind of touching on. But there were things that I read with my first of the two appointments within the doctor's notes that I didn't even fully realize was being said in the appointment. So, that's the main function I used [the portal] for, and I found that incredibly helpful." (T9)*

### Relational communicating

Compassionate encounters between clinicians and patients include both verbal and non-verbal communication techniques, which can convey the clinician's "demeanor, affect, behavior, and engagement" ([5], p. 7). Having access to a patient portal can assist with the verification of both types of communication during clinician/patient encounters and can enhance patients' trust through self-verification and relational communicating.

*"If you give someone access to the same information as a healthcare professional has access to then it, theoretically, would ... It theoretically should increase the trust level there because I can ... If I don't think ... I could look up that lab value. If he says, oh, I don't know, everything looks good, and I'm questioning, are my lab values really good? I can log in and check those against." (T1)*

Additionally, to deliver compassionate care, clinicians must be prudent in clarifying written information that could be misinterpreted, such as medical jargon. If this information is reviewed via the portal by patients without clarification, it may enhance their levels of distress. The following participant spoke about their perceptions of the importance of clear written communication from their experience as a healthcare provider, and as a patient using the portal.

*"Some people it may not be such a great idea. I mean, just in terms of, I remember having so many patients come to me and being very upset because they had read something in their notes that they didn't understand what it meant. So, they were taking it one way when it meant something completely different and then came in just furious and then you have to sit down and explain it to them." (T8)*

### Attending to needs

The ability of a clinician to attend to a patient's needs is an integral component of compassionate care, which can include health-specific needs, timely access to care, and the need for actionable health responses [5]. Timely and efficient access to care information can be facilitated by

the patient portal, where the patient's need for accessing health care information does not always have to be in the form of a physical appointment.

*"It was helping with my medication; it was helping with reminding me to go pick up medication. And I was getting shots at the time, so it was good for that. I also was pleased to see all the notes that I could read about, going all the way back. And then meetings with the doctor, appointments, and stuff, that was very useful. And just to know that it was all on the same page, that the doctors and I were on the same platform." (T2)*

One participant also reported increased feelings of control related to their treatment plan, as this can be met in a timely manner through accessing a patient portal. These access options can improve coherence in compassionate care delivery.

*"It felt like I was kind of in control if that makes sense. And again, it was nice just not having to dwell on something and think about it like, oh, is he trying to write some crazy thing about me and say I'm completely mental. It was nice to have that come so quickly because I'm so used to talking with a doctor and it takes like six weeks to hear back from my doctor. It kind of got rid of the anxiety of having to wait. There really was no wait and it was making me feel in control of everything." (T7)*

#### **Patient reported outcomes**

Compassionate care delivery can impact patients in a variety of ways, including facilitating their sense of well-being and perception of the healthcare experience [5]. In this study, participants had varying perceptions of how viewing clinical notes via the patient portal can impact the clinician-patient relationship. For some, it was positive and for some it was negative. For example, one participant reported how this may cause an internal conflict due to anxiety about what is written in the notes.

*"If I was able to see notes after every interaction, like, what they wrote about me, I do think that would affect compassionate care. I think that it would make me ... I think knowing what they're charting afterwards would make me leery about speaking to them, do you know what I mean?" (T1)*

Others reported how timely access of the patient portal after clinical encounters increases their feelings of control, which directly enhanced the clinician-patient relationship and healthcare experience.

*"It gave me the chance to talk to them about some of*

*the diagnoses. If they said, how do you feel about this diagnosis of bipolar rather than this other diagnosis of schizoaffective, or whatever? It was good to know where that was coming from, and it was also good to know the reasoning behind it without having to waste time during a meeting with the psychiatrist or the doctor." (T2)*

*"Improved efficiency can improve the client care interaction because speedy information is always, the faster the better... .. It can improve the relationship by kind of allowing the interaction to happen in a quicker manner." (T3)*

#### **Integration of quantitative and qualitative findings**

There were areas of both agreement and disagreement between the quantitative and qualitative data related to patients' experiences of compassion. All of the statistical models, including unadjusted and adjusted, showed non-significant changes in the compassion scores over time. This aligns with some of the qualitative findings that patients often perceived compassion as something personal. Although patient portal use can be conceptualized as an extension of in-person clinical interactions, some of the patients described that their perceptions of clinicians' compassion did not change after using the portal to read clinical notes and/or lab results. However, some patients reported that their perceptions of clinicians changed after reading clinical notes when the notes were difficult to understand (e.g., due to use of medical jargon) or when the notes were not reflective of their in-person encounters. These mixed experiences reported in the qualitative strand may explain non-significant changes of compassion scores between the three time points shown in the statistical analysis. Furthermore, most qualitative findings highlighted patients' experience of compassion beyond clinicians' attributes. Some described that the portals facilitated their treatment journey, allowing timely access to prescriptions and reviewing notes before and after appointments. By enhancing patients' treatment experience aided by the patient portal, participants reported positive outcomes of meeting their needs and expectations, and being heard by clinicians, all of which are reflective of compassionate care that Fogarty's scale did not capture in the quantitative strand.

#### **Discussion**

The aim of this mixed methods study was to assess and understand the impact of portal use on patients' experiences of compassion. The quantitative strand found no changes in the compassion scores that mainly assessed clinicians' attributes, but the qualitative strand found



mixtures of both positive and negative impact of the portal use on compassion that extends beyond clinicians' attributes. Recently, Sinclair and colleagues showed strong psychometric evidence for the Sinclair Compassion Questionnaire (SCQ) as a valid and reliable patient-reported compassion measure [46]. This is currently the "gold standard" for measuring compassion, which is the most valid and reliable tool that exists in the current literature [47]. The SCQ builds on the compassion framework [5], and it not only encompasses clinicians' attributes of being compassionate, such as being attentive, but it also includes measures of patients' experiences of care including understanding their needs by their clinicians [47]. As such, Fogarty's compassion scale [35] may have been limited to capture all aspects of compassion in the quantitative strand of the current study. Nevertheless, the integrated findings from the current study confirms that compassion is a broader concept than clinicians' attributes.

There is a lack of literature that explores the role of patient portal in facilitating compassionate care, and at the time of writing, the current study is one of the first study to assess and understand the impact of portal use on patients' experience of compassion in mental health care settings. A large body of literature currently describes favourable view of portal use in facilitating health care and positively influencing patients' experience. Specifically in mental healthcare settings, although the size of empirical evidence is relatively smaller compared to primary care settings, evidence suggest potential role of portal use without negatively influencing clinical outcomes nor patients' care experiences [48]. Portal use can be conceptualized as an extension of in-person patient-provider interactions, involving exchange of information and timely communication to meet patients' needs without having to book an appointment [49–51]. Technology cannot replace essential in-person encounters, but our study findings showed that portals can facilitate compassionate care delivery in multiple aspects including recognizing and mediating patients' sufferings.

In the midst of increased technology use in health care and recognition of the digital divide [52, 53], we must put compassion at the centre of care. Compassion has been commonly studied as a critical concept that is foundational to clinical practice, but the current literature remains a growing area for understanding what contributes to compassionate care in the digital health space [14, 50]. Compassion encompasses both clinicians' attributes and the quality of patients' experiences that are shaped by provider-patient interactions [4, 5, 47], which can also include interactions in digital space as seen in this current study. Portal use in mental health setting does not appear to diminish compassionate care, and findings from the

current research can be a catalyst for future efforts to advance our understanding of digital compassion. Future research can consider using the SCQ [46] in the digital space, which is becoming more commonplace in clinical practice along with technological advancement.

There are several clinical and policy as well as future research implications related to portal use and compassionate care delivery. When clinicians are integrating patient portals into regular practice, information accessed through the portal must be consistent with what is delivered during appointments. Failure to do so can negatively influence the delivery of compassionate care as perceived by patients, leading to increased levels of mistrust and distress. Similar findings have been reported elsewhere [21, 54, 55], which may explain resistance against portal implementation in mental health care settings from the perspectives of clinicians. Nevertheless, these concerns around documentation (e.g., avoid use of medical jargons, professional and respectful language) are modifiable, and appropriate training and policy for clinicians may be necessary to facilitate the benefits of portals [24]. Further to this, the possibility of unintended consequences is not a valid justification for hiding clinical notes from patients because patients value transparency in mental health care [22, 56, 57]. For example, veterans with severe depressive symptoms tended to access the patient portal to download their medical records compared to those with milder symptoms, highlighting significant interest from the users [58]. Another study showed patients' preference towards greater transparency in their depression care [57]. Patients from the current study also reported greater sense of control in terms of owning their health data via accessing the portal, and the findings do not suggest that patient portal diminished compassionate experience.

There exists effort to ensure transparency of patients' health data while maintaining therapeutic relationship between patients and clinicians, and some evidence to date suggest that patients who view their mental health notes have positive outcomes including trusting their health care provider [22, 59]. Aligned with shifting the power back to patients [8, 9], competent patients should be able to decide whether to view their notes rather than clinicians hiding selective notes. However, the current state of literature remains limited in fully understanding portal users' experience in mental health care setting [54]. The current study report will contribute to the current scholarly discussion, and more research needs to explore how transparency of information via portal usage affects patients' experience of compassionate mental health care.

In addition to understanding patients' experience of portals and putting compassion at the centre of care in

the current digital era, we need to recognize the existing adoption divide of portals is influenced by sociodemographic factors such as ethnicity, race, gender, and income [60–64]. Despite the accumulated evidence for the positive impact of patient portals [21, 65], unequal distribution of portal user and usage may hinder achieving the values of patient portals to their fullest potential, contributing to the outcomes divide. This is an important area for future research that the current study could not explore. Policymakers and administrators of hospital organizations need to pay attention to equity considerations [66] to achieve equal distribution of compassionate mental health care when implementing portals into clinical practice.

### Strengths and limitations

One major strength of this study is the integration of quantitative and qualitative data. While quantitative data showed non-significant changes in the compassion score, which mainly assessed clinicians' attributes impacted by the portal use, qualitative data enhanced our understanding of compassion and shed light on understanding compassion that extends beyond clinicians' attributes. The integration enriched the explanation of the non-significant statistical results and uncovered aspects of compassion beyond the scale, such as patients' experiences of care, including being heard by their clinicians and meeting their needs to mediate from suffering. However, several limitations in this study may affect the interpretation and use of our study findings. First, the study was conducted in one single hospital setting in Canada, and the majority of the participants were Caucasian. Therefore, the findings have limited generalizability. In addition, there exists no available data on the demographics of patients who visit CAMH that we could compare to assess the current study sample's representativeness. Second, participants who selected "Other" for their mental health diagnosis, did not report their diagnosis when completing the survey. This may be because participants may have more than one diagnosis, may not clearly understand their current condition, or are in the process of getting diagnosed. Third, as the qualitative strand of this work is a secondary analysis as part of a larger study, the interview guide included a range of topics related to the patient portal and was not exclusive to the compassionate care delivery nor the five items included in the compassionate scale. Because of this limitation, participants were not specifically asked about different compassionate attributes of their clinicians. Furthermore, interview participants may not have fully understood the elements of compassionate care delivery and/or what defines compassion in a clinical context. However, the descriptions participants provided about their clinicians

during care delivery processes validated the empirical model of compassionate care [5]. Additionally, there was no demographic data gathered prior to conducting the interviews, and therefore, variations in responses based on contextual factors could not be analyzed in the qualitative strand.

### Conclusion

Across health disciplines and contexts, compassion has been commonly viewed as a critical concept in patient care that can enhance the therapeutic alliance between patients and clinicians. In mental health care, the integration of patient portals is one method to enhance compassionate care and reduce hierarchical relationships between patients and clinicians. The current study findings on patients' perceptions of clinician compassion in conjunction with a patient portal demonstrate potential values, and portal use in mental health setting does not appear to diminish compassionate experience. More work is needed to better understand what contributes to compassion within mental health care in digital space, and a larger experimental scale to assess the impact of patient portal in mental health setting using the most valid and reliable measurement tool will be beneficial. As digital innovations continue to evolve in health care delivery, it is imperative to research their impact on patients' perceptions of care and continue our efforts to enhance compassionate care delivery.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s44247-022-00002-z>.

**Additional file 1: Table S1.** Demographic characteristics of  $N = 84$  participants at T1. **Table S2.** Demographic characteristics of  $N = 78$  participants at T2.

**Additional file 2:** Interview Guide.

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### Authors' contributions

GS conceived the study design, secured funding, and supervised all phases of the study. HDS and KD participated in data analysis and drafted the manuscript. SC and CM participated in data analysis. BL participated in data collection. HDS, KD, BL, SC, CM, DW, and GS participated in revising the manuscript. All authors read and approved the final version of the manuscript.

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## Availability of data and materials

The raw data (both quantitative and qualitative) supporting the findings of the manuscript can be requested to the corresponding author. The anonymity of the participants must be secured; in the raw data, it is possible to identify the participants, and therefore restrictions will be applied to the availability of these data. Reasonable requests concerning the data can be sent to the corresponding author.

## Declarations

### Ethics approval and consent to participate

The research complies with all the relevant national regulations and institutional policies. Ethics approval for the study was obtained from the Research Ethics Board at the Centre for Addiction and Mental Health (REB 044/2018) and the University of Toronto (REB #40342). All participants signed an informed consent form after having received written information to enable them to make an informed choice regarding participation.

### Consent for publication

Participants consented to have the findings shared through publications and presentations.

### Competing interests

Authors have no competing interests to declare with this submission.

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