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Patient and Family Member Readiness, Needs, and Perceptions of a Mental Health Patient Portal: A Mixed Methods Study

Kevin LEUNG[a,b,1], Carrie CLARK[a], Moshe SAKAL[a], Madison FRIESEN[c] and Gillian STRUDWICK[a,b]
[a] *Centre for Addiction and Mental Health, Toronto, Canada*
[b] *Institute of Health Policy, Management and Evaluation, University of Toronto*
[c] *University of British Columbia*

Abstract. Patient portals are a form of technology that supports patients in accessing their health information, and other functions like scheduling appointments. The presence and utilization of patient portals in mental health contexts is relatively new. Despite research existing in the mental health literature that indicates that there may be benefits when patients have access to their mental health notes, there is limited information as to how best to implement portals, and support adoption among patients and their family members. Given this gap in literature, this study aimed to identify patient and family readiness, needs, and perceptions of a mental health patient portal. Surveys were administered to patients (n = 103) and family members (n = 7) either in-person or over the phone by a Peer Support Worker. The sample of participants consisted of patients and family members affiliated with Canada's largest mental health hospital located in Toronto, Ontario. Study results indicated that patients had the highest interest in the following portal functions: scheduling appointments, checking appointment times, and accessing their health record. Both patients and family members expressed their concerns about cybersecurity and potential privacy breaches. The results of this study, as well as the approach, can inform future patient portal planning and implementation activities at other healthcare organizations.

Keywords. Patient portal, mental health, psychiatry, electronic health records, health information technology, informatics

1. Introduction

Patient portals ("portals") provide patients with access to their health information with the goal that patients will feel empowered to take more control over their health. This technology allows for patients and their family members to have electronic access to their health records and additional functions such as scheduling appointments and health professional-patient communication. Portals have been adopted for many years in acute settings, but portal adoption in mental health settings is relatively new [1]. Research on portals suggests that there may be benefits when patients have access to their mental health notes specifically. A study conducted at a Canadian mental health hospital

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[1] Corresponding Author, Kevin Leung, Centre for Addiction and Mental Health, 1001 Queen St W, Toronto, Ontario, M6J 1H4 ; E-mail: kevin.leung@mail.utoronto.ca.

revealed that patients who enrolled in the portal improved their scores on the Mental Health Recovery Scale [2].

2. Purpose

Currently, information is lacking on how best to implement and support the adoption of mental health patient portals among patients and their family members. There is limited information as to why patients may be interested in accessing a portal, what functions are of most interest, and what concerns patients and their family members may have about using the technology. Therefore, the purpose of this study was to identify patient and family readiness, needs, and perceptions of a mental health portal.

3. Methods

3.1. Study sample and setting

The study sample consisted of patients and family member participants affiliated with the Centre for Addiction and Mental Health (CAMH), a mental health teaching hospital located in Toronto, Canada. Patient data was collected from eight inpatient units, and six outpatient clinics. These units were representative of the age (youth to the elderly) and diagnoses (e.g. mood disorders, psychotic disorders, concurrent disorders, addictions etc.). A total of 103 patients and 7 family members participated in the study.

3.2. Study design and recruitment

The study consisted of a cross-sectional survey (with both closed and open-ended questions) administered either in-person or over the phone by a Peer Support Worker. Previous research has indicated that patients may feel more comfortable answering question questions when asked by a peer, and may provide more honest responses to questions [3]. Recruitment of patients took place in-person by the Peer Support Worker at the various inpatient and outpatient locations. This strategy was an effective way of eliciting patient feedback in a previously conducted study at the study site [4]. Family members affiliated with the Office of Family Engagement at CAMH were recruited through email and phone calls. A brief notice asking family representatives to participate in the survey was also included in a family member newsletter.

3.3. Data collection

A unique survey version was developed for each type of participant (one for patient participants, and one for family members). The patient survey was administered by a Peer Support Worker to participants in-person. The family member survey was administered to family members via a Peer Support Worker over the phone. Patients and family members were asked questions regarding access to technology, access to the internet and connectivity, access to the portal via current technology used in their everyday lives, and level of interest in portal functions. Participants were also asked open-ended questions to identify any concerns regarding portal access, or concerns with family members having access to the portal. Following these questions, demographic information was collected.

3.4. Data analysis

Quantitative survey data was analyzed using SPSS®. Descriptive statistics were generated such as means, percentages and frequencies. A thematic analysis was performed for the qualitative survey data using a thematic approach developed by Braun and Clarke [5]. Two members of the research team coded the data independently and compared codes to improve the rigour and trustworthiness of the findings [6, 7].

3.5. Ethical considerations

This study received ethical approval. Patient and family member identifiers were not collected by the Peer Support Worker when administering the surveys.

4. Results

4.1. Demographic characteristics

The survey was completed by 103 patients (n=54 participants from inpatient units, and n=49 from outpatient clinics), and seven (n=7) family members of mental health patients. Of all patients, forty (n=40) identified as female, fifty-three (n=53) identified as male, one (n=1) identified as both, and one (n=1) identified as cis. Eight (n=8) patients preferred not to say. Of the seven family members, five (n=5) participants identified as female and two (n=2) identified as male. Thirteen (n=13) patients did not have access to a computer with internet. All seven family members had computer access. The distribution of patients among the units and clinics can be found in Table 1.

Table 1. Number of patients who completed the survey in each unit and clinic at CAMH.

Unit	Absolute Frequency	Relative Frequency (%)
Inpatient Unit 1	6	5.8
Inpatient Unit 2	11	10.7
Inpatient Unit 3	1	1.0
Inpatient Unit 4	2	1.9
Inpatient Unit 5	6	5.8
Inpatient Unit 6	16	15.5
Inpatient Unit 7	4	3.9
Inpatient Unit 8	8	7.8
Outpatient Clinic 1	2	1.9
Outpatient Clinic 2	10	9.7
Outpatient Clinic 3	19	18.4
Outpatient Clinic 4	7	6.8
Outpatient Clinic 5	10	9.7
Outpatient Clinic 6	1	1.0
Total	103	100.0

4.2. Patient’s readiness and needs

Findings of this study revealed that half (50%) of the patient participants were aware that they had the right to access their health record. One participant revealed that it was “a little surprising to hear" indicating that they were unaware that they had the right. Patient participants were interested in accessing the portal for reasons related to convenience, availability, and to check the accuracy of information in their record. One participant stated, "when you come to [the hospital], there's a lot to take in and it can be overwhelming, so the portal can help". Two other participants agreed that the portal could provide "easier ways to view programs and appointments" and keep patients aware of "[their] diagnosis, [their] treatment, how [they're] doing, what's going on" etc. A participant had a similar opinion that the portal can be used "to make sure I'm on the same page as my doctor; it's more self-supporting, self-sustaining", and another participant mentioned "[the portal] seems like a good idea especially with medication renewal and appointments. Medication renewal can be a life safer".

The portal functions that were of highest interest to patients were: accessing health records (78% positive, 12% negative), checking appointment times (78% positive, 14% negative), and scheduling appointments (75% positive, 13% negative). Functions of the lowest interest for patients were renewing medication (70% positive, 22% negative), messaging health care providers (64% positive interest, 23% negative), and completing self-assessments (59% positive, 19% negative). Participants in outpatient settings had a higher level of interest in portal functions than inpatient participants (see Table 2). Participants from inpatient settings had a similar level of interest in medication renewals, and a higher level of interest in educational materials.

Table 2. Level of interest in portal functions by inpatient and outpatient settings.

Type of setting	**Interest**	**Portal Functions**						
		Messages to Provider	Health Record Access	Appointment Schedules	Appointment Times	Medication Renewals	Educational Materials	Self-Assessments
Outpatient	Negative	19%	9%	12%	13%	21%	17%	16%
	Neutral	10%	13%	10%	6%	9%	17%	20%
	Positive	71%	79%	78%	81%	70%	67%	63%
Inpatient	Negative	27%	14%	16%	16%	22%	10%	21%
	Neutral	16%	8%	12%	8%	8%	17%	25%
	Positive	57%	78%	71%	76%	70%	73%	54%

4.3. Family member's readiness and needs

Family members stated that the portal would be helpful and convenient to facilitate their support of a family member with mental illness. All seven family members (n=7) expressed interest in accessing health records, messaging providers, and receiving educational materials via a portal. Six (n=6) family members reported an interest in appointment times and self-assessments, and five (n=5) were interested in scheduling appointments and renewing medications.

4.4. Patient perceptions of the portal

There were mixed responses from patients about providing portal access to a family member. Less than half (44%) were interested in giving portal access to a family member. One participant said: "I'd prefer to keep my affairs private, but if absolutely necessary I would consent to family access". Another stated: "I like to keep my mom informed because she's a very good support". When asked about concerns with accessing the portal, one participant mentioned their fear of finding "negative comments written about me by healthcare professionals". Thirty-four (n=34) participants expressed concerns with cybersecurity, and privacy breaches.

4.5. Family member perceptions of the portal

Family members were concerned about cybersecurity and commented on the importance of privacy. One participant mentioned that there should be limited access for family members as the patient's "privacy is important; [I] only want to know about risks, treatment plan, and diagnosis". Family members mentioned that patients should be able to schedule their own appointments, and that family members may just need to know the time. Family representatives reported that they did not want to take on the responsibility of medication renewals and stated that it should be done at appointments.

5. Discussion

Patients and family members shared that a portal is a convenient way of accessing information, and that staying informed may translate into improved mental health. Overall, patients and family members have shown interest in the technology and certain functions such as accessing health records and receiving educational materials. The implementation of these portal functions may improve the adoption and usage of the technology by all user groups. In addition, issues of privacy and cybersecurity need to be considered when implementing a portal in a mental health setting. Limitations of this study include an unbalanced sample size. A balanced sample of patient and family members was anticipated. Due to the variation in recruitment strategies, a balanced sample was not achieved. Alternative recruitment methods can be considered to obtain a balanced study sample.

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