Acceptability of Health Information Exchange and Patient Portal Use in Depression Care Among Underrepresented Patients

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BACKGROUND: Depression is often untreated or undertreated, particularly among underrepresented groups, such as racial and ethnic minorities, and individuals of lower socioeconomic status. Electronic health information exchange (HIE) is a recommended practice to improve care coordination and encourage patient engagement in services, but it remains underutilized in depression care. Understanding factors affecting acceptance and adoption of this technology among underrepresented patient populations is needed to increase dissemination of HIE within mental health treatment.

OBJECTIVE: The present study aims to identify patient barriers and facilitators towards the acceptance of HIE within the context of depression treatment and to examine how HIE impacts depression-related care coordination and patient activation.

DESIGN: Semi-structured qualitative interviews were conducted with 27 patients.

PARTICIPANTS: Respondents were English-speaking adults (> 18) receiving depression treatment within a large, safety-net primary care clinic.

APPROACH: A grounded theory approach was used to code and analyze data for emergent themes. Thematic analysis was guided by the Unified Theory of Acceptance and Use of Technology, a leading informatics theory used to predict end-user adoption of technology.

KEY RESULTS: Respondents reported that HIE made depression care more convenient, transparent, and trustworthy. Though respondents desired greater access to their health records, stigma surrounding depression inhibited acceptance of electronic communication and information sharing. Confusing electronic interface also diminished perceived benefits of HIE.

CONCLUSION(S): Respondents desire greater transparency in their depression care. While HIE was perceived to improve the overall quality of depression care, stigma associated with mental illness undermined more robust adoption of this technology among underserved populations.

KEY WORDS: Health information exchange; Patient portals; Unified Theory of Acceptance and Use of Technology; Depression; Health disparities.

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BACKGROUND AND RATIONALE

Depression is a leading cause of disability but is often untreated or undertreated, especially among medically underserved patients, such as those from racial and ethnic minorities or in lower socioeconomic brackets. Currently, as few as 35.7% of individuals with newly diagnosed depression initiate treatment. Among those engaged in care, less than 25% receive care that met recommended standards and many leave treatment earlier than recommended. In response to these challenges, efforts have largely focused on improving initial service linkages through systematic coordination within and across health and mental health care systems and encouraging sustained engagement in services by keeping individuals actively involved in their depression care.

Care coordination and patient activation efforts rely on provider’s ability to effectively communicate and exchange information with both patients and other professionals. This capacity is largely dependent on successful utilization of health information exchange (HIE), where patient health information is stored, retrieved, and updated via transmitted electronic health records (EHRs). HIE refers to electronic functionality that “allows doctors, nurses, pharmacists, other health care providers and patients to appropriately access and securely share a patient’s vital medical information electronically, improving the speed, quality, safety and cost of patient care.” HIE can be provider-facing (i.e., directed- or query-based exchange) or patient-facing (i.e., patient-mediated exchange). Providers use HIE to better coordinate care, facilitate service linkages, and exchange relevant health information so that decisions about health care can be made using the most accurate and complete information. Patient-facing HIE primarily occurs using patient portals and personal health records, which allow individuals to communicate directly with...
METHODS

Setting and Participants

The study took place within a large safety-net hospital system serving one of the poorest catchment areas of Philadelphia, PA (North and Lower North City Planning Districts). The patient population reflects traditionally medically underrepresented groups, with the majority being predominantly Black or African American, and more than 70% receiving Medicare or Medicaid. Recent reports show that this area has the highest rates of all causes of medical mortality and is characterized by disproportionately low socioeconomic status.

The hospitals and affiliated ambulatory clinics use Epic, a large commercial EHR system, and the MyChart patient portal, which is available to all individuals receiving care within the system.

Eligible patients were identified using EHR chart data and included English-speaking adults (> 18 years) with a diagnosis of depressive disorder as defined by ICD-10-CM diagnostic codes F22 and F33. Recruitment was limited to patients receiving care within the system’s two primary care practices, Internal Medicine and Family & Community Medicine, with at least one primary care visit within the previous 12 months. Using a complete list of eligible participants, recruitment was conducted by three research assistants using a consecutive sampling approach. Because the study was conducted during the COVID-19 pandemic, individuals agreeing to enroll in the study were interviewed over the phone or via video. Interviews with participants were recorded and lasted an average of 45 min (Table 1).

Following established frameworks for qualitative interview guides, a semi-structured interview guide was developed by the first and last authors using UTAUT constructs and the extant literature on adoption and acceptance of patient and provider HIE (see Appendix I). To best capture the nuances of the participants’ experience, the interview was organized around main questions and follow-up prompts, which are probing questions or responses designed to guide deeper understanding of phenomena of interest. To ensure rigor, the interview guide was piloted internally for comprehensiveness and flow. Three trained research assistants conducted interviews. Respondents received a $20 gift card for their participation. Study protocols were reviewed and approved by a university institutional review board.

Analysis

All interviews were transcribed verbatim and uploaded into Dedoose, a qualitative analysis platform. Coding and analysis were guided by contemporary applications of a grounded theory approach. This inductive method requires a multi-stage, iterative approach to analysis, beginning with open coding, or a line-by-line examination of interview transcripts designed to identify broad concepts derived from the data. The process of open coding was guided by preestablished...
organizing framework for making sense of the data. 40 Often informed by the investigators’ basic research questions, sensitizing concepts guiding this study’s initial coding included patients’ communication preferences, their experience using HIE, and their attitudes towards technology.

Following this initial stage of open coding, a codebook is further refined using a constant comparative method, which refers to an iterative process where similarities and differences between and within codes are systematically examined.39 To accomplish this, the first author and a research assistant first independently coded a sub-sample of interviews, then compared codes in order to identify and refine key emergent themes, and resolve any discrepancies through consensus building. To enhance objectivity and triangulate data, the last

Table 1 Sample Interview Guide and Summary of Key Themes

| Question | UTAUT domain | Summary of key theme(s) | Sample quotations |
|----------|--------------|-------------------------|------------------|
| Keeping information private is an important part of providing good care. How confident are you that computers and electronic health records can keep your information private? | Performance Expectancy | Respondents were overall confident in the ability of portals and HIE to keep information secure from breaches, though some risk was acknowledged | I’m comfortable with it as long as they have the proper security of course, is secure as anything else to be honest. |
| Sometimes, doctors’ offices have websites or portals that let you access your health information online. Have you ever accessed your health information online? | Performance Expectancy | Patient portals were used to manage care and remain informed about their treatment | If there is a study done um you know and once he releases the test I can see the results….It’s very useful because since my memory it’s kind of you know confusing and cloudy. If I need to tell another doctor I can go back in there refresh and talk a little bit about it you know, so I don’t miss any details. |
| Sometimes, providers use the computer during visits. Often, this is to pull up information about your care, send messages to other providers, send prescriptions and referrals, or print out information about your treatment. How does your provider use the computer to help deliver your treatment? | Performance Expectancy | Respondents consistently articulated the value of coordinating care, and the desire for their providers to communicate | I think that the sharing within [hospital system] and those doctors, I think it is crucial for each one of them to have a way to openly understand what is going on with me. |
| Can you tell me about a time you first learned how to use a new piece of technology? | Effort | Levels of general technological literacy varied | [family member] will pull up information from my chart it’s better than me because I don’t use the computer |

sensitizing concepts, or “interpretive devices” that provide an organizing framework for making sense of the data.40 Often informed by the investigators’ basic research questions, sensitizing concepts guiding this study’s initial coding included patients’ communication preferences, their experience using HIE, and their attitudes towards technology.

Following this initial stage of open coding, a codebook is further refined using a constant comparative method, which refers to an iterative process where similarities and differences between and within codes are systematically examined.39 To accomplish this, the first author and a research assistant first independently coded a sub-sample of interviews, then compared codes in order to identify and refine key emergent themes, and resolve any discrepancies through consensus building. To enhance objectivity and triangulate data, the last author, who was not involved in the coding process, was involved in the process of adapting, refining, and distilling codes into more precise constructs. A total of 20% of transcripts (n = 6) were co-coded and reviewed in this manner to establish reliability in coding. This process was repeated until no new themes emerged, and remaining transcripts were coded using the finalized codebook. An audit trail of all team meetings and codebook revisions was kept to further promote rigor.

Inductive thematic analysis41 was used to understand key questions about how patient and provider HIE was used within the context of depression care, and the ways in which HIE helped or harmed patients’ experience in treatment. To examine any sources of discrepancy, cross-case analysis45 was also used to examine differences among the diverse sample.
Additional strategies to increase the trustworthiness of the themes identified in this data included routine peer debriefing, data triangulation, an audit trail, and negative case analysis.

**RESULTS**

Study recruitment continued until the research team achieved a consensus that thematic saturation was reached, meaning that no new codes or themes were evident from interviews. A total of 314 individuals were contacted for enrollment. Of this, 226 declined, 59 were lost to follow-up after an initial contact, and 29 individuals were successfully enrolled. Technical issues compromised the quality of two participants' responses, for a total sample of 27 patient respondents. Sample demographics are summarized in Table 2.

Respondents described a wide range of ways to electronically share information, including electronic scheduling, exchanging messages with providers, and sending and receiving mental health records between treating providers. While some of these activities extend beyond traditional definitions of HIE, they were included in the study results because of their particular impact on respondents' experience in care.

### Performance Expectancy of Patient Portals

The UTAUT framework asserts that a primary predictor in end-user acceptance of technology is performance expectancy, or the degree to which technology will make tasks easier or more effective. A third ($n = 17, 36\%$) of respondents described ways in which patient portals improved their depression care:

**Efficient Access to Depression Care.** Respondents described elements of portal use that made their access to depression care easier and more efficient. Messaging and scheduling features of the patient portal facilitated quick access to respondents' providers, creating opportunities to overcome accessibility barriers associated with reaching providers by phone:

> When I send an email through the system I know someone is going to see it, so um, like, I always get an answer whether it is from a nurse or from the doctor um always get a phone call back like it is definitely calling the office is a nightmare um but using the online like portal has been tremendously helpful.

> [Portal] was convenient in some ways and in a way of scheduling through a computer. And for appointment I guess it's convenient in some way because you don't have to wait for the person to answer your call or anybody to write it down. You just see which slots are available

A critical component of this theme was respondents' emphasis on the value of convenience and efficiency. Messaging and scheduling features allowed patients to manage their depression care on their own time, rather than on the schedule of their provider or doctor's office.

**Information Transparency Is Empowering.** Another facilitating factor related to HIE's performance expectancy was the role of information access and transparency. Respondents expressed a strong desire to have access to lab tests, medications, and diagnoses:

> [Portals] keep me in the loop about the medications. What you taking this for each medication they talk to me to make sure that I am still using it and how many times I am taking it.

> You can go home and read about things, so they trigger um different printouts on your medicine, your diagnosis, your treatment plan whatever. Uh, so there is a lot of information right at your fingertips.

Respondents described that patient HIE helped them stay engaged in their treatment by allowing them to track their own care and remember information that could be important for ongoing health maintenance and symptom reduction, such as the names of medications or one's diagnosis.

### Performance Expectancy of Provider HIE

Almost half ($n = 12, 45\%$) described a strong preference for coordinated care and viewed HIE as an effective tool to accomplish this. Respondents expressed that the quality of their care was enhanced when providers shared information with one another. By enabling providers to obtain complete and comprehensive information about their current and historical physical and mental health, provider HIE made respondents feel more confident in their providers' recommendations for treatment. This was particularly true, as illustrated below,
when patients had co-occurring depression and chronic medical conditions.

Just saying if my therapist and my primary care doctor know what is going on with me within medications. And then I’m a diabetic, so I, you know ... yeah I like it ... It’s like a tree...every branch functions well because of the other branch... And that makes me comfortable that you can pull me up from a computer and get my doctor’s notes from that doctor that’s pertaining to this issue.

I think it [portals] actually makes the interaction better. Because before they would have to keep writing things down... and sometimes papers are missing or whatever. Now they look that they look back and say ‘oh in 1988 your hemoglobin was 15’. So, I actually think that it in enhances my care.

They will open my record and they can look at things right away... And what’s nice is you don’t have to physically saying it out loud. ... if they are going to change medication dosage or something. I know that they did it right then and there. So, that’s very helpful to me.

Facilitating Factors Inhibiting Acceptance of Provider HIE

Within the UTAUT framework, acceptance and adoption are also shaped by the availability of perceived resources and support that promote a particular behavior (i.e., facilitating conditions). In our sample, facilitating conditions emerged as barriers to the acceptance of provide HIE.

Stigma Inhibits HIE Acceptance. Perceived stigma was associated with ambivalence regarding HIE acceptance, as half of respondents (n = 12, 45%) described concerns about who had access to their information:

Everything that is going on with me, is not always physical, but I am very aware of the effect how my mental, mentality effects my physical body. With pain and nausea, it has even affected my eyesight. That um, I that is fine going through that system. But I don’t think anyone else should have access to that, unless they ask me for permissions to have it

This ambivalence offered critical insight into the unique function of provider HIE within the context of depression care. Respondents did not endorse strong concerns about the confidentiality or security of their health information generally. Most participants (n = 21, 78%) either felt completely confident in the system’s security or equated the level of security risks with any other online task, such as electronic banking or online shopping:

I’m confident I always find out, I mean yeah, there probably hacker in there. ... I feel really comfortable there is not much you can do about it.

I’m comfortable with it as long as they have the proper security of course, is secure as anything else to be honest.

Instead, concerns about exchanging information related to depression appeared closely linked to the stigma associated with mental illness, and how this information would be used or perceived by other parties with access to their health information:

You know, it’s certain things you just don’t want people to know about you. You know I remember a long time ago, I went through a phase where I was very depress. And I want to seek help, but I was embarrassed, and I was afraid that somebody would find out that I had some mental issues. And somehow that would give people a negative imprint in me. You know, that they would judge me because I needed help.

Yeah, I think there is things on there that shouldn’t be share with other entities. You know uh, like, okay, my workplace doesn’t need to know. That of course I’m out on mental stress leave. But, they don’t need the details of that. I don’t want people looking at me differently, because, and they will.

Effort Expectancy Reduces Patient Portal Acceptability

A third of the respondents (n = 10, 37%) identified usability and digital literacy as a barrier to accepting patient portals. Usability concerns related to the design of patient portals specifically:

It’s really hard to navigate uhh the portal. Uhh I just find it confusing.

There is a lot of links and a lot of things that I don’t understand it’s kind of overwhelming.
As well as with technology more generally:

*I don’t know how to do that [use of the portal]. I’m not good with all this, the computers and stuff.*

**DISCUSSION**

The present study, guided by constructs from UTAUT, adds to our limited understanding about factors affecting patients’ acceptance of HIE in primary care–based depression treatment. The study also provides insight into the potential of HIE to improve care coordination and patient involvement in their own care, key components of the quality and continuity of depression care. Across both provider and patient-facing HIE, patients described high HIE *performance expectancy* that facilitated accessible, high-quality care. However, concerns about depression-related stigma were perceived as a barrier undermining respondents’ willingness to consent to provider HIE. Negative appraisals of patient portal use were primarily driven by high *effort expectancy* associated with cumbersome or confusing portal interfaces.

**Performance Expectancy Facilitates Acceptability of Patient-Facing and Provider-Facing HIE**

Respondents described positive appraisals of performance expectancy related to both patient-facing HIE and provider HIE. A desire to improve access to mental health information was a common theme when discussing both patient- and provider-facing HIE. In addition to making care more accessible through messaging and scheduling functions, patient portals can empower patients by giving them greater control of their own health information. Similar work suggests that providing access to medications, lab results, and other information is increasingly viewed as a core patient-centered care strategy to support health literacy and illness management.

Respondents were clear about their desire for regular communication and coordination, and endorsed provider HIE as an acceptable and efficient mechanism to accomplish this. Provider HIE was associated with several benefits: improving visit efficiency by centralizing information and reducing the patient’s need to frequently repeat the same psychiatric history. In contrast with the management of physical health, recounting one’s full psychiatric history often places patients into a position of unwanted or uncomfortable vulnerability, particularly when such information requires recalling traumatic or distressing life events, highlighting a particular benefit to HIE within the context of behavioral health treatment.

**Stigma as a Condition Inhibiting Acceptability of Provider HIE.**

Although provider HIE was associated with improved care quality, respondents also expressed concerns about with whom their sensitive information would be shared. Interestingly, though security concerns are frequently cited as a major obstacle to provider HIE,44,47,48 fears of or general information breaches were not the most salient force driving respondents’ hesitation around HIE. Because technology changes develop rapidly, this may reflect an attitudinal shift as much more information is now stored electronically.

When confidentiality concerns did arise, they focused specifically on the disclosure of sensitive psychiatric history and depressive symptoms, suggesting that the stigma associated with mental illness can inhibit patients’ acceptance of mental health–related HIE. This pattern aligns with prior work indicating that patients are less willing to share health information that is perceived to be sensitive or complex.49 These attitudes may be particularly relevant within this study’s racially and ethnically diverse sample, as stigma around mental illness remains pervasive within Black and African American communities,50,51 and longstanding mistrust of the health system52 may amplify concerns about disclosing depressive symptoms. Together, these findings highlight that negative labels and stereotypes associated with depression make HIE within mental health treatment differ from acceptability of HIE for managing physical health conditions. Efforts to modify attitudes towards provider HIE must therefore attend to the particular intersection between depression, confidentiality, and culture that is reflective of the patient population being served.

The tension between expanding access to health information while safeguarding patients against stigma has implications for future policies guiding both patient and provider HIE. In an effort to prioritize the protection of individuals’ privacy, current policies allow providers to limit what mental health information is shared with patients,53,54 and many states require patients to explicitly opt in, or actively consent, to provider HIE before it can occur. While developed as intended safeguards, these restrictive policies may be misaligned with patients’ preferences for greater access to their information, and have the unintended consequence of reducing the exchange of health information. For example, Apathy and colleagues55 found that the administrative and legal burdens of opt-in regulations decreased health organizations’ capacity to engage in provider HIE. Similarly, in their study of patient portal use within a safety-net ambulatory clinic, Ancker and colleagues56 found significant racial and socioeconomic disparities existed when patients had to opt in to receive a portal account; however, racial differences in portal use disappeared when universal (i.e., opt-out) policies were installed. This study’s and other recent findings21,57 reporting that patients desire greater access to and control of their health records, suggest the need to reconsider how policies can better prioritize transparency and information exchange in health care, and particularly mental health care.
Effort Expectancy Inhibited Portal Use

Respondents expressed concerns with the usability of the patient portal, which inhibited acceptability and adoption of this function. Consistent failures to develop more user-friendly and patient-centered interfaces are a well-documented barrier to end-user adoption across numerous forms of health information technology, including mHealth apps, electronic health record systems, and personal health records. As evidenced by this sample of patients from a safety-net setting, portals with complex or confusing digital platforms are likely to discourage use and may disproportionately disincentivize use among underrepresented populations. Indeed, over 100 studies have documented disproportionately lower portal use among racial and ethnic minorities, and individuals with lower educational attainment and lower socioeconomic status, yet few interventions have been developed to explicitly reduce these disparities. Patients’ desire to access their records, and the benefits derived from doing so, present a clear motivation for addressing this gap.

Our findings should be considered in light of the following limitations. First, the findings may not be generalizable to individuals with depression who live in other geographic areas. Also, this research utilized a purposeful sample of patients. Patients who had particularly strong or negative opinions about HIE experiences may have been more likely to join the study. In addition, we had a relatively low response rate, and though the final sample reflected the racial and ethnic diversity of the clinics’ patient population, our sample was also highly educated (52% college educated). This is likely the result of conducting the study during the first wave of the COVID-19 pandemic, as restrictions required virtual recruitment and interviews. This may have biased our sample against those with inconsistent internet or access to technology or those with competing demands, such as childcare. As demographic information was not collected from individuals who declined to participate, we cannot draw conclusions about the representativeness of the study sample or how they compared to those who declined to participate. Finally, our study did not evaluate what type of technology was used to access the portal (e.g., computers versus tablets or mobile devices). Some evidence suggests that members of vulnerable groups, including racial and ethnic minorities and those with lower educational attainment, are more likely to access patient portals through mobile devices rather than computers. Mobile access has also been associated with overall lower rates of portal use, perhaps due to unmeasured differences in functionality and usability. Future work in this area should focus on gaining a deeper understanding of patterns of access and how this impacts the user experience.

To conclude, this study highlights several ways in which HIE and portal use can enhance depression care for underserved patients, yet barriers to more robust acceptance of these technologies persist. Results underscore the need for a more user-friendly design, while also adding novel insight into how the unique stigma accompanying mental health may inhibit adoption of information-sharing practices that could ultimately support ongoing efforts to better coordinate depression care and activate patients to remain engaged in services.

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**Supplementary Information**

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