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Development of a Targeted Patient Portal Intervention to Improve Depression

Treatment Adherence, Satisfaction, and Outcomes

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Structured Abstract

Purpose: The aim of this study is to develop ConnectCare, an intervention to engage and activate patients treated for depression with their electronic health record patient portal.

Scope: This R21 entailed the development and pilot testing of an intervention promoting patient portal use in patients currently treated for depression.

Methods: There were three phases to this project: 1) online survey and direct interview of mental health patients and providers about their experiences with patient portals; 2) ConnectCare was developed based on results of this survey and direct stakeholder interviews; 3) A pilot randomized controlled trial tested the acceptability and effectiveness of this new intervention.

Results: In online surveys, providers endorsed that their patients became more activated when they accessed visit notes, such as requesting the provider change his or her note (72% endorsed) and asking more questions (69% endorsed). Patients endorsed gaining a better understanding of what was discussed during the appointment (86%) and trusting their provider more (84%). Information from the surveys informed the pilot intervention trial and redesign of the Epic © MyChart interface. In the randomized controlled trial, 16 patients were randomized to ConnectCare while 14 were randomized to an Attention Control condition. Patients in ConnectCare experienced an average decline of 3.55 points (SE=1.68) on the 9-Item Patient Health Questionnaire as compared with a 1.08 (SE=1.77) point decline in the Usual Care group. As this was a pilot study with a small sample size, these differences did not achieve statistical significance.

Key Words: Patient Portal, Mental Health, Depression

PURPOSE:

One in five people in the United States experience depression at some point in their lifetime, and it is the fourth leading cause of morbidity and mortality worldwide[1-3]. There are a range of effective treatments for depression, but identifying the most effective strategies that minimize side effects can require multiple trials of medications[4, 5]. In addition, Bultman and Svarstad[6] found that 82% of patients new to antidepressants missed doses or discontinued early and this was associated with how the provider communicated about the treatment.

Patient portals are secure online websites that give patients electronic access to portions of their medical record. Portals provide patients a tool in understanding and managing their health care. They can view visit notes, review their medication list, send their provider a secure message, and access laboratory results. One of the primary purposes of patient portals is to educate patients about their health and engage them in becoming active partners in their care. Such engagement is critical in depression treatment where identification of effective treatments may entail trial and error. Treatment response is not always easy to determine and systematic monitoring is essential to identify which treatments are working. Moreover, active patient participation is needed to counter low adherence. However, mental health providers have specific concerns that patients accessing their mental health information online may cause unnecessary distress and may damage the therapeutic alliance – a critical component in mental health care[7, 8]. Providers also fear inappropriate use of secure messaging[8].

The goal of this project is to develop ConnectCare, a new depression intervention that combines depression-specific patient portal features with provider communication strategies. ConnectCare aims to increase patient activation, promote collaborative decision making, encourage treatment adherence, and reduce depressive symptoms. Patient portals are secure online websites that give patients access to their health information, most often provided by their health care organization. The proposed intervention aims to 1) provide patients training and guidance on effective use of secure messaging and the ability to read visit notes online to improve self-management of their mood disorder; 2) conduct patient reported outcome assessments using treatment targets identified by patients as most salient; 3) give patients access to the results of these assessments in graph format. The provider communication strategies to be developed include: 1) promoting shared and collaborative decision making over multiple visits using patient reported outcomes to evaluate treatment effectiveness; and 2) expanding assessment of patient reported outcomes to include domains identified by the patient as most important.

SCOPE: The aim of this study was to explore mental health patient and provider experience of patient portals in the context of treatment for mental disorders. The results of this initial exploration would inform an intervention designed to engage patients treated for depression in using their portal to better understand and manage their depression. There were primarily three phases to this study, the first being an online survey and direct interviews of portal users, both patients and providers to inform

the intervention. Intervention development, in this instance, the intervention entitled ConnectCare which included education, training, and redesign of the patient portal to allow patients to view graphs of their depression symptoms graphed over time. Finally, we conducted a small pilot study where patients currently treated for depression were randomized to receive either ConnectCare or an attention control condition.

Specific Aim #1: Identify desired portal features and functions through stakeholder interviews with a nationwide sample of mood disorder specialists and their patients.

Specific Aim #1 METHODS
This study consisted of Qualtrics online surveys of patients and providers in mental health treatment settings fielded between November 2018 and September 2019. Procedures followed have been assessed and approved by the University of Iowa Institutional Review Board.

Providers
The Principal Investigator circulated a link to the provider survey through multiple venues: The University of Iowa Department of Psychiatry; clinicians practicing within the Mental Health Service Lines of the Department of Veterans Affairs (VHA) in Iowa City, Iowa, Portland, Oregon, and Denver, Colorado and member providers of the National Network of Depression Centers. The National Network of Depression Centers (NNDC), is a nationwide non-profit consortium of 27 leading clinical and academic member centers in the United States who specialize in the treatment of mood disorders.

Patients
Patient surveys were circulated via Research Match, a national health volunteer registry created by several academic institutions and supported by the U.S. National Institutes of Health as part of the Clinical Translational Science Award (CTSA) program. Patients who indicated they were receiving treatment for mental health conditions were eligible.

Survey Design, Content, and Analysis
Two surveys related to user experience of portals were designed to address parallel domains, each tailored to either patient or provider perspectives. Providers were asked if they worked at an institution that supported a patient portal and/or secure electronic messaging between patients and providers and whether these features were available in the context of treatment for mental health conditions. Providers were then asked about their related experiences. Note secure messaging may be available in mental health treatment, without providing access to mental health clinical notes.
Similarly, patients were asked if they had electronic access to patient portals, secure messaging, and mental health clinical notes, and about their related experiences. The response choices for patients differed from that of providers. Providers endorsed if specific outcomes occurred in ANY of their patients, whereas patients were asked to indicate they experienced an outcome "Never," "Rarely," "Sometimes," or, "Often."

Patients and providers had the opportunity to provide open text responses, most often by endorsing "Other, please specify" at the end of a list of possible experiences. In this QUANT dominant mixed methods design, the open-text responses were reviewed by

the PI and the qualitative lead for the project, and representative texts were identified to illustrate key findings from the survey data.

A summary of Results highlights are presented below. The full methods and results are available in two publications resulting from this award.[9, 10]

Specific Aim #1 RESULTS

Patient and Provider Demographic Characteristics
The initial sample included 80 providers. Of these 76 (95%), indicated their organizations provide patients portals, with 51 (64%) endorsing patient access to general medical notes, and 29 (36%) endorsing patient access to mental health notes. Organizations may provide secure messaging to patients via their portals even if they do not provide access to narrative notes, and 68 (85%) of the 80 providers endorsed they use secure messaging with their patients.   The initial sample size for patients was 168, and 152 (90%) endorsed access to patient portals, with 37 (22%) endorsing access to mental health notes and 140 (83%) endorsing use of secure messaging.

Provider Experience of Patient Portals and Patient Access to Mental Health Information
Providers working at institutions that provided access to mental health notes (N=29) endorsed their experience of patient portals. The most highly endorsed item was patients requesting a change in the content of a provider note (72%), followed by a patient asking more questions about his or her treatment (69%), and a patient experiencing significant distress after reading mental health information (55%). Twenty-nine percent of these providers endorsed that they experienced a patient terminating treatment after accessing mental health notes, while 21% endorsed that a patient reported engaging in negative and/or self-destructive behavior towards themselves or others. Providers also endorsed positive experiences with access to mental health notes with 17% reporting patients feeling comforted after reading notes, and 14% reporting patients following their provider recommendations more closely.

Open text responses allowed providers to describe their views about patient portals.
> "While I have not omitted important clinical information in a note, I have changed the description of the content in a way to not anger/upset the patient. More specifically, a psychotic patient who did not believe he was psychotic and would become very upset when seeing the word "psychosis" in the chart."

> "As a former outreach social worker going to visit homeless people, I have omitted words that I felt client would find offensive such as "delusion" for my own safety in subsequent visits, did not omit the fact of the matter, just my assessment of their thought content. …. I think providers who are outside the safety of a medical facility should have special consideration for notes as they are frequently alone with people with significant mental health problems who may be emotionally disregulated [*sic*]."

Other providers addressed concerns about patient negative responses differently. One provider described how patients disagreeing with note content can lead to a discussion about the provider's choices and enhanced collaboration between the provider and patients.

> "I am and have always been extremely careful when writing case notes, knowing that not only can other providers, insurance carriers, etc. read these notes, but so can my patients. I try to be as objective as possible and back up diagnoses and other statements with actual symptoms, narratives provided by the patient, and examples that illustrate my points. On rare occasions when patients question or disagree with material in my notes, I spend time discussing the reasons I documented as I did and collaborate with the patient on the best way to resolve any differences of opinion."

<u>Patient Experience of Patient Portals and Access to Mental Health Treatment Information</u>

Patients with access to their mental health narrative notes (N=37) were presented possible impacts. The most common items endorsed (i.e., "Sometimes," o "Often" occurring) were the patient's better understanding of what occurred during the appointment (86%), trusting their healthcare provider more (84%), feeling better prepared for appointments (84%), gaining a better understanding of their treatment plan (81%), and feeling comforted or relieved after reading their health information in the portal (77%). Patients also endorsed negative consequences. For example, 14% of patients reported requesting a provider change the content of their note, 11% reported experiencing significant distress after reading notes, 1 patient reported engaging in negative or self-destructive behavior, and 1 patient reported terminating treatment after reading a visit note.

In the open text responses, many patients provided brief endorsements such as, *"I love my patient portal!," "I find the portal very convenient and I use it often,"* and, *"I Love the patient portals. It helps me keep on top of my medical information."*

One patient who elaborated further wrote:
> "…When it comes to medical records having immediate access to them has helped me in so many ways on so many occasions.   I look forward to the future and how they will expand. I currently use my chart and am in [town] so every provider in my area that I go to utilizes it and again it's just phenomenal."

Importantly, one patient highlighted the negative impact that occurs when access to mental health notes is denied relative to other general medical notes.
> "With psychiatry progress notes are hidden as is the ability to schedule and re-schedule mental health appointments. This is not the case with the rest of the healthcare network at the hospital, only in psychiatry. I find this bothersome and would like to see it changed since it furthers the feelings of stigma."

<u>Secure Messaging: Provider Perspectives</u>
Of total participating providers, 68 work in organizations that support secure messaging. When asked about experiences with messaging occurring, "Never," "Rarely," "Sometimes," or "Often," those most commonly reported (e.g. "Sometimes" or "Often") were, patients requesting a prescription refill (68%), and reporting side effects (65%). Patients sending messages that were too long or too frequent were also common (41%), as well as raising health issues that were too complex to be addressed via secure messaging (57%).

Provider open text responses illustrated an overall positive view of secure messaging, with some providers preferring secure messaging to telephone calls because of its ease and efficiency:
> "I actively encourage patients to use this functionality instead of phoning me – works much better" "…is much more efficient than phoning and an unintended consequence is a more efficient workflow and a happier doctor!!"

Providers appreciated the use of secure messaging as a tool for monitoring patient status between visits.
> "As a therapist, I have enjoyed using the secure messaging. It is easier for many of my patients to send a message than call our call center and then be routed to my phone, where I often have to take a voice mail because I am with other patients…"
> "There are several things I am not comfortable *managing* via the portal, but I much prefer getting initially notified about them via the portal so that I can follow up via phone or in person as appropriate."

Several respondents had experiences with patients using secure messaging for urgent or complex concerns and reiterated the need to provide guidance about appropriate use.
> "…I have had very rare instances where a patient sent something inappropriate or too long for secure messaging. I have found it helpful to have a conversation about the portal and stating that it is not for emergencies."

Some providers did report experiencing threats or violent language via secure messaging from their patients, with one writing, "refill requests are most common. Vitriol is second most common." Such experiences may lead to providers or organizations restricting access to this feature on a case-by-case basis: "We have had to deny numerous patients continued access to secure messaging given their use of it--threats of violence toward providers are common."

Despite its ease of use, providers expressed fatigue regarding the additional workload associated with secure messaging. Providers identified institutional and workflow barriers – uncompensated work and poor work design – that made secure messaging a drain, and in one case, a source of burnout.
> "This has ridiculously increased our non-compensated time. We have to watch the wording so carefully because there is no nuance in written language. I think

the time and anxiety around the endless e-messaging will ultimately be the major driver of when I decide to retire- right now I'm tending to think I'll do it as soon as I can."

Secure Messaging: Patient Perspectives
Patients with access to secure messaging (N=140) reported a range of benefits. Of this sample, 66% endorsed (occurred "Sometimes" or "Often) that secure messaging replaced calling their provider by phone, 51% endorsed that they avoided an in-person visit, and 57% endorsed that they and their provider were able to address a medical concern effectively via secure messaging. Nineteen percent endorsed that their providers asked them to send messages on a regular basis to provide updates about medical concerns. Five percent endorsed that they sent a message indicating they have and/or might harm themselves or others and 4% endorsed that their provider told them their messages were too long or too frequent.

Patients' open text responses highlighted both their knowledge of appropriate use as well as the benefit of the asynchronous communication:
> "I usually only use the portal to check test results and other routine issues (requesting a medication refill). Anything more serious and I save it for an appointment."
> "I've sent messages when I was having a particularly hard week to ask if we could have a longer visit because of various things in my life that were triggering. Basically, just letting her know that I had a lot to unpack on the next visit"

Patients appreciated being able to contact their provider with questions or concerns between appointments, particularly when a response could offer resolution or calm anxiety. The accessibility afforded by secure messaging was linked to strengthening the therapeutic alliance by one patient:
> "Being able to connect with my provider through the portal and skip a lot of the hurdles including waiting on hold sometimes for up to 45 minutes is really a different way of life and I appreciate it more and more every day. It also helps that my providers are fantastic people who are aware that sometimes just one simple question answered via a message can make a world of difference."

Another patient perspective notes the importance of helping providers to see patient portals and secure messaging as tools for collaboration.
> "Some providers are exemplary: they answer within a few hours, they release test results as soon as they're available. Others do not respond at all or respond five or eight days later. And they're annoyed when you calmly request a more timely response. In my experience, everything depends on the provider's willingness to use the portal as a valuable mode of communication. I wish all of my providers could see it that way."

Specific Aim #1: Discussion
Provider acceptance of patient access to mental health notes requires an evolution from the view of electronic health records as a tool available exclusively for doctors to

manage patient health, towards the view of the electronic health record as a tool shared between doctors and patients. Some providers in our study have made this transition and use the patient portal to collaborate with patients to better achieve treatment goals. As organizations implement OpenNotes for mental health, this transition can be facilitated through a combination of education and professional guidance. To date, many portal promotional materials target patients only, and have a narrow emphasis on efficiency, comparable to marketing used for online banking. Healthcare organizations should adopt a broader campaign which promotes the value to both patients and providers in promoting overall health and well-being. Organizations could also disseminate patient testimonials about positive impact providing detail about specific use cases of how patients and providers can use visit notes to help manage specific medical conditions.

Specific Aim #2: Integrate interview results to develop both portal features and a clinical protocol for ConnectCare.

Development of ConnectCare based on results from Specific Aim #1 occurred just as the COVID19 pandemic began. In response to COVID19, all in-person visits were postponed or conducted via telephone or videoconferencing to the patient's home. The Health Care Information Systems program at the University of Iowa Carver College of Medicine dedicated itself entirely to supporting pandemic-related services and telehealth. Therefore, we had to modify significantly our original design in this program. ConnectCare intervention development integrated recommendations from both patients and providers.

We developed Connectcare as a 6-month telehealth intervention where the principal investigator met once a month with patients currently in treatment for depression. The initial visit was educational and through screen sharing, study staff taught patients 1) to use their patient portal, 2) access and read their mental health visit notes, 3) use secure messaging appropriately in communicating with their mental health provider, and 4) view their measurement-based-care assessments of depressive symptom severity using the 9-Item Patient Health Questionnaire. Consistent with results from Specific Aim #1, the portal was presented as a collaborative tool to engage patients in their treatment and self-management of their depression.

The intervention entailed educating patients about the use of the patient portal including collection of patient reported outcomes, in this case measures of depression, side effects, and functioning. Patients were then followed on a monthly basis and any questions they had about portals were addressed. Then their scores on the depression and functional measures were reviewed via zoom and the graphs were also shared with the treating providers. The graphs contained patients' monthly scores for depression as well as scores on the Work and Social Adjustment Scale. This allowed review of both symptoms and functioning and supported discussing the relation between the two.

We also developed within MyChart a graph function for PHQ-9 scores so that mental health patients can view their trajectory over time, comparable to how patients with

diabetes may observe graphs of their hemoglobin A1c, or patients with hypertension may review graphs of their blood pressure (Figure 1 in Products section). This trajectory will allow patients to evaluate the effectiveness of their treatments as well as any progress they have made in recovery. This is a new feature within Epic ©, and represents a step towards equity in the management of mental health conditions with other chronic conditions.

Specific Aim #3: Test the usability, acceptability and effectiveness of ConnectCare in a pilot randomized controlled trial of 30 patients. The primary hypothesis is that the patients receiving Connect Care will have improved scores on depression and functional outcomes as compared with those randomized to an Attention Control condition.

As with Specific Aim #2, the implementation of this aim was shaped by the changes in care delivery in response to COVID19.

Sample: English speaking, cognitively intact patients, aged 18 or older, receiving medication treatment with or without psychotherapy for major depression at the University of Iowa Outpatient Psychiatry Clinic were approached for participation. To be eligible, the patient must be willing to sign up for MyChart.

Eligibility was originally assessed via medical record. We assessed 1,024 medical records, excluding 994, with 641 not meeting the inclusion criteria, 72 declining to participate, 15 not showing for the initial screening visit, and 266 not responsive to efforts to contact. A total of 30 were randomized to either ConnectCare (N=16) or an Attention Control Condition (N=14). The ConnectCare intervention is described under Specific Aim #2. The Attention Control condition entailed an initial educational visit about My Chart, but did not include specific training and guidance about how to use it and no sharing of graphs. One patient dropped out after randomization in both arms leaving the analytic sample size of 15 for ConnectCare and 13 in the Attention Control Condition.

We conducted a series of linear mixed effects (LME) models with initial models including treatment group and time period with a random effect that accounts for repeated measures over the same subject. As this is a pilot study, exploration of associations between study arm, time period, and primary outcomes will provide a general understanding of the effect size to inform a future RCT. Table 1 presents the least squares means derived from these models on each of the three main outcomes explored in this study, the 9-Item Patient Health Questionnaire Measure of Depression. The 8-Item NIH Promis Social Functioning Scale, and the Work and Social Adjustment Scale.

Table 1: Least Squares Means from Mixed Regression Mode on Depression and Functioning Outcomes for Patients in the Connect Care and Attention Control Conditions.

	Intervention Arm	Range and Direction of Improvement	Baseline Mean (SE)	3-Months Mean (SE)	6-Months Mean (SE)	Mean Difference Baseline to Follow-up
9-Item Patient Health Questionnaire	Connect Care	0-27 higher score = higher impairment	15.93 (1.32)	10.87 (1.49)	12.38 (1.60)	-3.55 (1.68)
9-Item Patient Health Questionnaire	Attention Control		14.28 (1.41)	12.52 (1.50)	13.20 (1.69)	-1.08 (1.77)
PROMIS Social Functioning Scale	Connect Care	8-40 lower score=higher impairment	23.43 (1.74)	25.00 (2.00)	25.13 (2.07)	1.69 (2.06)
PROMIS Social Functioning Scale	Attention Control		19.14 (1.86)	21.07 (1.97)	19.37 (2.19)	0.23 (2.18)
Work and Social Adjustment Scale	Connect Care	0-40 higher score = higher impairment	22.25 (2.29)	18.37 (2.57)	19.88 (2.64)	-2.36 (2.38)
Work and Social Adjustment Scale	Attention Control		23.71 (2.45)	23.41 (2.57)	21.71 (2.79)	-1.99 (2.50)

For each outcome, there appeared a trend towards patients in the ConnectCare arm to demonstrate better improvement in symptomatic and functional measures. In addition, adoption of secure messaging was higher in the Connect care group -(54%) as compared with the Attention Control (38%). However, the limited sample size prevents firm conclusions until a larger trial is conducted.

We also requested patient comments on their experience of the intervention. Patients reflected in open ended questions about their experience of reviewing the graphs and accessing their provider notes. Some characteristic quotes about the graph feedback were:

"At least I was aware of the trends and had this information to take back to therapy and other health professionals."

"I liked checking in with Dr. Turvey or her representative and the questionnaires helped me think about my depression. Instead of one looming and overwhelming cloud, breaking it into individual characteristics is helpful."

"It made me think more about all of the things that can be and are affected by my depression and anxiety. It made it more "real" and can be an incentive for change, or at least more effort."

"Just by answering the questionnaires I found areas I really needed to work on."

In response to reading provider notes, patients stated:

"It's helpful to see if I am on the same page as my provider as well as being able to review afterwards."

"I like that it is easy to see exactly what I am taking for medication."

"I like being able to see my medication list and current notes to tell me where I am at mentally."

Specific Aim #3: Discussion

Patient acceptance and experience of ConnectCare seemed largely positive and there appears to be a modest impact on outcomes which would need to be tested in a larger trial. The discrepancy between providers and patients in positive views of portals is consistent with prior work and must continue to be addressed directly[11]. Limitations due to COVID19 required modifications to the final intervention that may have limited its impact. A revised intervention that better engages providers could increase impact and better promote adoption portals and a collaborative tool that further empowers patients.

Overall, the benefits of patient access to their mental health notes via patient portals as well as their trajectories on key patient-reported outcomes will likely enhance recovery of this debilitating illness[12]. Interventions that address provider hesitancy could include direct quotes as well as statistics demonstrating how powerful this tool is in helping patients manage their depression[13]. ConnectCare lays the groundwork for such interventions, but needs further development to improve overall impact and better integration into day-to-day mental health treatment.

PRODUCTS:

1. Turvey CL, Lindsay JA, Chasco EE, Klein DM, Fuhrmeister LA, Dindo LN. Current Practices in Electronic Capture of Patient-Reported Outcomes for Measurement-Based Care and the Use of Patient Portals to Support Behavioral Health. Psychiatr Clin North Am. 2019;42(4):635-47. doi: 10.1016/j.psc.2019.08.006. PMCID: 7778878

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Figure 1: MyChart Patient Portal feature providing patients a graph of their depressive symptom severity on the PHQ-9 over time.
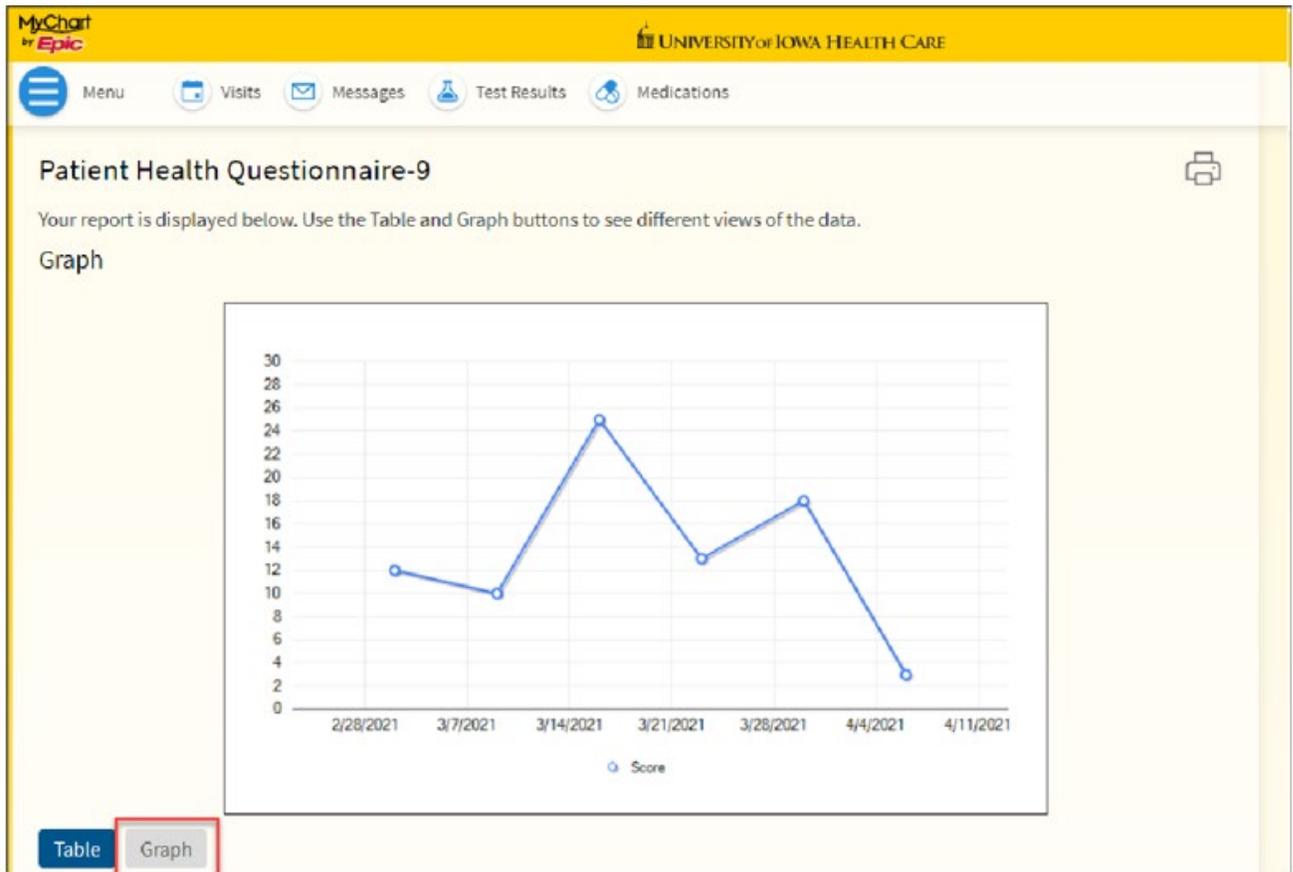
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