

Patients' Positive and Negative Responses to Reading Mental Health Clinical Notes Online

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Objective: This study describes responses to OpenNotes, clinical notes available online, among patients receiving mental health care and explores whether responses vary by patient demographic or clinical characteristics.

Methods: Survey data from 178 veterans receiving mental health treatment at a large Veterans Affairs medical center included patient-reported health self-efficacy, health knowledge, alliance with clinicians, and negative emotional responses after reading OpenNotes. Health care data were extracted from the patient care database.

Results: Reading OpenNotes helped many participants feel in control of their health care (49%) and have more trust in clinicians (45%), although a few (8%) frequently felt upset after reading their notes. In multivariate models, posttraumatic stress disorder was associated with increased patient-clinician alliance ($p=.046$) but also with negative emotional responses ($p<.01$).

Conclusions: Patients receiving mental health care frequently reported benefits from reading OpenNotes, yet some experienced negative responses.

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The OpenNotes initiative encourages health care systems to provide patients online access to their clinical notes. Clinical notes contain clinicians' and other health care personnel's documentation of health care contacts. The Veterans Health Administration (VHA) is one of many health care systems across the United States providing patients access to their notes through an online patient portal. VHA, unlike most other health care systems, does not allow clinicians to decide which notes become available online. As such, VHA patients have online access to all notes written in their medical records since VHA's implementation of OpenNotes in 2013. As of July 2017, data from the VHA Office of Connected Care show that more than four million users had registered for VHA's online patient portal (1), approximately half of whom have read their notes (2).

Although prior research has suggested that enhanced access to clinical notes benefits patients by increasing health-related knowledge and engagement in care (3,4), concerns have been raised in the mental health community regarding potential harms of OpenNotes (5,6). In a recent survey of mental health clinicians about OpenNotes, respondents reported writing fewer details and writing less about diagnoses in response to OpenNotes (5). In a qualitative study, mental health clinicians were concerned that OpenNotes may cause a rift in rapport and that patients may experience negative emotional responses from reading notes (6). Stronger concerns were expressed regarding patients with certain conditions (such as psychotic disorders and personality

disorders), with whom establishing trust may be especially challenging.

Little information exists regarding patients' responses to reading mental health notes online. Qualitative findings suggest that reading these notes can strengthen or strain relationships with clinicians, depending on whether patients felt the notes reflected conversations with their clinicians and conveyed respect (7). In this study, we used survey methods to examine the effects of OpenNotes among veterans receiving VHA mental health care. Specifically, we investigated whether reading OpenNotes improves mental health patients' ratings of health efficacy (for example, self-care) or health knowledge (for example, understanding of the treatment plan), changes their relationships with clinicians (such as changes in the amount of trust), or causes patients to experience negative emotional responses (such as worry). We also explored whether these effects vary by patients' demographic or clinical characteristics (for example, age or diagnosis).

METHODS

This study was reviewed and approved by the institutional review board of the participating Veterans Affairs Medical Center (VAMC). All participants provided informed consent prior to study activities.

In 2003, VHA launched an online patient portal called My HealtheVet. To access clinical notes, veterans must complete an identity-verification process to become authenticated.

This study was conducted at a large VAMC in the Pacific Northwest, where more than 200 mental health clinicians provide services to approximately 20,000 veterans at 11 urban and rural facilities. These veterans are predominantly white, non-Hispanic (82%) and male (88%); the average age is 53 years. Common diagnoses are posttraumatic stress disorder (PTSD) (28%), depression (26%), substance use disorder (12%), schizophrenia/bipolar spectrum disorders (9%), and personality disorders (3%). Approximately one-half of these veterans are authenticated My HealtheVet users.

Data used in this study were from the baseline survey of a longitudinal study examining a Web-based course designed to educate VHA patients on the use of OpenNotes. We recruited participants between February and July 2016. Eligible patients completed at least one in-person VHA mental health appointment during the six previous months, had logged into My HealtheVet at least twice during that period, and were authenticated My HealtheVet users. We excluded patients with dementia or cognitive disorder diagnoses. We used the VHA patient care database to purposively identify eligible patients from mental health programs representing a range of psychiatric conditions. All participants received instructions for using My HealtheVet to access their clinical notes and received a \$5 gift card. For the larger longitudinal study, we administered the survey to 393 participants in August 2016 and received responses from 352 participants (90%).

The current study included only participants who indicated that they had read mental health OpenNotes at least once ($N=178$; 51%). Data on health care utilization and mental health diagnoses (depression, PTSD, substance use disorder, anxiety, schizophrenia, bipolar disorder, delusional disorder, and personality disorder) during the year prior to the survey were extracted from VHA's patient care database. Schizophrenia, bipolar disorder, and delusional disorders were combined into one category labeled psychotic or bipolar spectrum disorders.

In addition to demographic items (age, race, ethnicity, gender, education, employment status, and marital status), the survey comprised several self-report items assessing experiences with mental health OpenNotes. Many survey items were adapted with permission from a 2012 study by Delbanco and colleagues (3). Prior to survey administration, items were tested and revised by using cognitive interviews with four veterans receiving VHA mental health care.

Two items assessed participants' ability to take ownership of their health care (health self-efficacy): "How much does reading your mental health notes help you take better care of yourself?" and "How much does reading your mental health notes help you feel in control of your mental health care?" Response options range from 1, not at all, to 5, extremely.

Two items assessed participants' sense of knowledge about their health and health care (health knowledge): "After reading your mental health notes, how much has your understanding of your mental health treatment improved?" and "How much does reading your mental health notes help you to follow your mental health clinician's treatment

recommendations?" Response options range from 1, not at all, to 5, extremely.

Two items asked participants about how their relationship with their clinician had changed since reading their notes (patient-clinician alliance). The first item asked, "After reading your mental health notes, how much trust do you have in your mental health clinician?" Response options range from 1, a lot less trust, to 5, a lot more trust. The second item asked, "How has reading your mental health notes affected your relationship with your mental health clinician?" Response options range from 1, a much worse relationship, to 5, a much better relationship.

Two survey items asked participants about negative emotional responses to reading their notes (negative emotions): "How often does reading your mental health notes cause you stress or worry?" and "How often do you feel upset by your mental health notes?" Response options range from 1, never, to 5, always. An additional survey item asked respondents to indicate what they found upsetting about their notes, inviting participants to select all that apply from a list of response options derived from previous qualitative work (7). This item was used for descriptive purposes only.

Race and ethnicity data were collapsed to create a dichotomous variable indicating minority status. We examined the psychometric properties for each two-item scale describing the four possible responses to OpenNotes (health self-efficacy, health knowledge, patient-clinician alliance, and negative emotions) and determined that internal consistencies (Cronbach's alpha ranging from .75 to .85) and interitem correlations (Pearson's r ranging from .60 to .71) for each scale were strong enough to support their use as dependent variables in subsequent analyses. Scale scores were all normally distributed. We selected model variables a priori based on theoretical associations with online patient portal use or with findings from previous research on clinicians' concerns about OpenNotes. The model variables were age, education, number of mental health visits, depression, PTSD, substance use disorder, anxiety, psychotic or bipolar spectrum disorders, and personality disorder. We examined collinearity diagnostics as well as bivariate correlations of the selected variables. We used Pearson's r for all correlation estimates, because there were no discernible differences between r and point-biserial correlations for categorical variables. We then constructed a multivariate regression model for each of the four responses to OpenNotes. Analyses were conducted with IBM SPSS Statistics, version 22.

RESULTS

Most participants were male ($N=141$, 79%) and white, non-Hispanic ($N=154$, 87%) with an average age of 55 years. [Details are available in the online supplement to this article.] They were highly educated, with 30% ($N=54$) having completed more than a four-year college degree. Most participants ($N=149$, 84%) had service-connected disabilities resulting in the receipt of VHA health care benefits or

compensation. Participants had a range of mental health diagnoses.

Overall, responses to the survey items reflected a variety of experiences, with most respondents reporting moderately to extremely positive experiences. [Details are available in the online supplement to this article.] Participants reported that reading OpenNotes helped them feel in control of their health care ($N=87$, 49%, very to extremely in control) and have a little ($N=30$, 17%) to a lot ($N=49$, 28%) more trust in clinicians. Fewer participants experienced stress or worry ($N=47$, 26%, sometimes experienced stress or worry; $N=15$, 8%, often or always) or reported feeling upset after reading their notes ($N=32$, 18%, sometimes felt upset; $N=15$, 8%, often or always). Those who “rarely” to “always” felt upset ($N=101$, 57%) were asked what they found upsetting about their mental health notes. The most frequently endorsed response option ($N=38$, 38%) was “the notes make my problems seem smaller than they are.” Finally, negative emotional responses were negatively associated with health self-efficacy ($r=-.27$, $p<.001$), health knowledge ($r=-.18$, $p<.05$), and patient-clinician alliance ($r=-.27$, $p<.001$).

In multivariate models, education was associated with decreased patient-clinician alliance ($B=-.15$, 95% confidence interval [CI] $=-.29$ to $-.02$, $p=.03$), and PTSD was associated with increased patient-clinician alliance ($B=.30$, CI $=.01$ to $.59$, $p=.046$). A diagnosis of PTSD was also positively associated with experiencing negative emotional responses to reading notes ($B=.45$, CI $=.14$ to $.73$, $p<.01$). A diagnosis of personality disorder diagnosis was marginally associated with having a negative emotional response ($B=.41$, CI $=.00$ to $.82$, $p=.05$) but was not associated with other outcomes. No demographic or clinical differences were observed for health self-efficacy or health knowledge. The results of bivariate correlations of study variables and multivariate models are presented in the online supplement to this article.

DISCUSSION

In this study of responses to mental health OpenNotes, many patients reported that reading their notes improved their health self-efficacy and knowledge, with no demographic or clinical differences observed regarding who might experience these benefits. In addition, many patients reported that OpenNotes strengthened the patient-clinician relationship. These findings are consistent with previous work showing that most primary care patients benefit from OpenNotes by feeling more in control of their care and better equipped to take care of themselves (3,8). We also found that 35% of patients reported “sometimes” or more frequent occurrences of stress or worry, and one-quarter reported at least “sometimes” being upset in response to reading their notes; many of these patients were upset by notes that they perceived minimized their problems. In prior work, approximately one-quarter of primary care patients said that visit notes make them worry more (8). Although our sample is

derived from one VAMC, our findings suggest that patients receiving mental health care may benefit from OpenNotes as much as other patients, yet clinicians may need additional training in writing notes that reduce negative responses.

Patients with PTSD reported, on average, experiencing greater levels of negative emotional responses to OpenNotes. Patients with PTSD may be more prone to distress when reading their notes because of higher levels of baseline arousal associated with PTSD (9). Also, patients with PTSD may respond negatively to reading about previous trauma that may be documented in notes. Service connection status (that is, receipt of disability compensation) may also play a role in these negative responses. Patients with high levels of PTSD symptoms often receive service connected disability compensation for PTSD (10), and patients reading their clinical notes online often have active claims for service connection status (7). These patients may be especially upset by notes documenting symptom severity levels discrepant from their own perceptions. Previous work has shown that veterans want to see consistency between the note content and in-clinic discussions and that they want clinicians to initiate conversations about OpenNotes (7). Therefore, clinicians might consider discussing clinical notes with patients who have PTSD to address concerns about how their symptoms or prior trauma experiences are documented. However, more work is needed to understand how such conversations might affect patients’ responses to OpenNotes.

Patients with PTSD also reported stronger positive alliances with their clinicians after reading their notes. This finding corroborates past literature showing that although individuals with PTSD have higher levels of negative emotions such as anger or hostility (11), these emotions are generally not associated with clinician- or patient-rated alliance (12). In our study, negative emotional responses were statistically, but not strongly, indicative of worse patient-clinician alliance ($r=-.27$). As such, although patients with PTSD may be more likely to have negative emotional responses to notes, these responses may not have substantial effects on the patient-clinician relationship.

In findings that were unexpected, neither a diagnosis of a psychotic or bipolar spectrum disorder nor a diagnosis of personality disorder was associated with negative emotional responses to notes, although the association with personality disorder approached significance. It is possible that the potential negative effect of such disorders was mitigated by a higher level of functioning, because the study participants were already authenticated in My HealtheVet and presumably were comfortable using the patient portal. Other work has found that Internet and patient health portal use is less common among veterans with serious mental illness than among other veterans (13), suggesting that those who use these resources are higher functioning or otherwise better prepared.

Several limitations should be considered in this study. All measures were self-report. In addition, the survey was cross-sectional, precluding inference of causality. We did not

measure all possible responses to OpenNotes, so there could be additional responses not captured in this study. However, survey items were selected to reflect qualitative interviews with veterans about their experiences reading mental health notes (7). Our findings show small-to-null effects regarding associations with positive and negative responses to OpenNotes; the effects of these associations may not be clinically noticeable. Although our sample was highly educated, the level of education observed in our sample is congruent with past literature showing a positive association between education and OpenNotes use (14). We also lacked some demographic diversity to examine race-ethnicity and gender in analyses, but our sample was representative of the general veteran population on these variables (15). This study examined a relatively small sample from clinics of one VAMC, so generalizability may be limited. Finally, the VHA system differs from other large health care systems in ways that might affect generalizability.

CONCLUSIONS

Contrary to previous reports of mental health clinician concerns about patients' negative responses to OpenNotes, our results show that such responses may be relatively infrequent and that many patients benefit from reading their mental health notes. Although most clinicians may be able to expect that their patients will rarely experience negative responses to their clinical notes, clinicians should be mindful of the potential for clinical notes to cause upset or worry. In particular, patients with PTSD may be more likely to experience negative responses from reading clinical notes. Overall, more research is needed to determine additional effects of OpenNotes on patients and effective strategies to reduce negative responses.

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