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Online Access to Clinical Notes Affects Patients' Trust of Mental Health Clinicians

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Abstract

Objective—This study explored patient perspectives of how online access to Veterans Affairs (VA) clinical notes (OpenNotes) may affect relationships with their mental health clinicians.

Methods—Semi-structured qualitative interviews were conducted with 28 patients receiving VA mental health care who had used OpenNotes. Transcripts were coded and analyzed using a constant comparative approach.

Results—Respondents consistently reported that clinician-patient relationships—feelings of trust in particular—are critical to the therapeutic process, and that reading clinical notes strengthens or strains trust in mental health clinicians. Perceptions of transparency and respect as conveyed in notes were central to maintaining trust.

Conclusions—Findings suggest that ensuring consistency between what occurs during appointments and what appears in clinical notes, as well as highlighting patient individuality and strengths in notes, may help engender patient trust and avoid negative consequences of OpenNotes in mental health care.

Introduction

The collaborative relationship that develops between therapist and patient, referred to as the *therapeutic alliance*, is a key component of mental health care(1-4), regardless of the therapist's technique or training. Researchers propose that the therapeutic alliance bolsters patient confidence as therapy begins and as patient and therapist collaborate to develop

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treatment goals(4). Therapeutic alliance also supports patients through challenging therapeutic work; the formation of a bond with a therapist can be therapeutic itself.

Recent research has found that providing patients access to their electronic health record information may help strengthen patient-clinician relationships by enhancing trust, transparency, communication, and shared decision-making(5, 6). Several healthcare systems across the U.S. now offer patients *OpenNotes*: online access to their clinical notes (also sometimes referred to as progress notes). However, some individuals have expressed concern that ready access to mental health clinical notes could harm the patient-clinician relationship(7, 8). Mental health progress notes typically contain sensitive information, andfrank documentation about mental illness has potential to upset, confuse, or worry some patients, and could lead to reduced trust in clinicians(7, 9).

Accordingly, many healthcare systems that have introduced OpenNotes give clinicians the option to block patient access to selected notes. In contrast, the Department of Veterans Affairs (VA) has offered patients access to all of their clinical notes, including notes related to mental health treatment, since January 1, 2013 through VA's online patient portal. To investigate the effects OpenNotes has on patient-clinician relationships, we conducted qualitative interviews with patients who receive VA mental health treatment and have used OpenNotes.

Methods

All participants completed an informed consent process and all study procedures were approved by the local VA Institutional Review Board.

Setting and Sample

This study took place at a single VA Medical Center (VAMC) providing comprehensive care to 85,000 unique veterans each year, with 18,000 veterans receiving mental health services across a main hospital complex and 11 primary care clinics. Beginning in 2013, clinical notes and all laboratory and imaging results became available through the Blue Button function in MyHealth*e*Vet – VA's online patient portal. Veterans must complete a user verification process called "authentication" to access all functions in MyHealth*e*Vet. When our sample was drawn in May 2014, 51% of patients receiving mental health services at the VAMC were authenticated MyHealth*e*Vet users. In the prior year, 13% of them had downloaded VA clinical notes.

We used VA databases and a purposive sampling strategy to identify a heterogeneous sample of patients with diverse demographic characteristics and who had utilized a range of mental health services at the VAMC. After obtaining clinicians' permission to contact patients, 402 potential subjects were mailed recruitment letters; follow-up screening was conducted by phone. We enrolled eligible patients in the order in which they contacted us. We excluded 64 patients who reported not reading their notes at least once. Recruitment was halted when the study team agreed that no new themes were arising in interviews. Twenty eight patients were enrolled and completed interviews between July and December 2014 (26 in-person, two by phone). The average age of participants was 47, ranging from 30 and 69. Fifty-seven percent

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were women (n=16) and 86% were white, non-Hispanic (n=24). We enrolled participants with varying mental health diagnoses: major depressive disorder (n=19; 68%), post-traumatic stress disorder (n=19; 68%), bipolar disorder (n=5; 17%), and schizophrenia (n=2; 7%). Our sample was highly educated, as 18% had graduate degrees and 29% had college degrees.

Data Collection

We developed a semi-structured interview guide informed by our main research questions, current literature on patient experiences with full health record access(5, 10, 11), and input from mental health clinicians. The interview guide (Online Appendix 1) focused on elucidating patients' ideas across five domains: note reading *practices*, including reasons for reading; *impressions* about what they liked, disliked, and learned from reading notes; *experiences* discussing notes with clinicians and others; beneficial or concerning *impacts* of reading notes on their lives and healthcare; and *resources* to assist them or other patients with OpenNotes, including *advice* for mental health clinicians who write notes. Each interview lasted approximately 60 minutes. Participants were reimbursed \$25.

Analysis

All interviews were audio recorded and transcribed. Transcripts were double-coded by two authors using ATLAS.ti software(12) and verified by a third author to ensure consistency. We used a constant comparative approach for our analysis(13), consistent with Grounded Theory. This approach allows for comparing discrete narratives within common themes in order to develop a theory of how themes are related to each other and to potentially identify hypotheses for future testing. To define codes, three authors reviewed transcripts separately and identified initial themes that emerged from the data, using an iterative process. Analysts reached consensus on a codebook of 43 codes that were applied to all transcripts. All authors reviewed code reports for theoretical interpretations until agreement was reached on main findings.

Results

Overall, analyses showed that patients receiving mental health care consider strong patientclinician relationships—and feelings of mutual trust in particular—to be critical to the therapeutic process. Reading clinical notes can strengthen or strain trust in clinicians. Patients' perceptions of the level of *transparency* and *respect* in notes contributed to feelings of trust for their clinicians.. We elaborate on these themes in the paragraphs that follow (Online Appendix 2 provides a full set of relevant patient quotes).

Patients in our sample strongly believed that the patient-clinician relationship is important to their care, and that OpenNotes can help foster this relationship: "OpenNotes is a move in the right direction. Like anything when you first start it, it has fits and starts, and people are reluctant and people don't like change, and psychiatrists like to keep their secrets. You know, and not hurt somebody's feelings or whatever. It kind of misses the point. The point is to develop this relationship." Patients felt the patient-clinician relationship develops by establishing good rapport, talking openly, and feeling comfortable with their clinicians. In

particular, many respondents considered *mutual trust* with their clinicians foundational to this relationship. "If you don't trust your clinician, what value is your conversation?" Patients sometimes worried that clinicians who did not believe them ultimately did not want to help them. Those who had difficulty establishing mutual trust or who had experienced a breach of trust with their mental health clinicians described it as a barrier to therapy, with some patients responding by being more careful with what they say in session, reviewing their notes carefully, asking their clinicians questions about their notes, or seeking care from a different clinician within or beyond VA.

Patients reported greater trust when their mental health clinicians listened in session, focused on patient strengths, and approached the therapeutic process as an equal. Specifically, trust in clinicians – and thus the therapeutic relationship – was strengthened or strained largely based on patient evaluations of the levels of *transparency* and *respect* conveyed in notes.

Transparency

Transparency was evident to patients when notes accurately reflected what happened during clinical sessions. Many appreciated thorough notes such that nothing seemed left out or misrepresented. Notes also clarified for patients whether a clinician was forthcoming in session about his or her interpretations and assessments. Patients were more trusting when clinicians reviewed mental health diagnoses with them before documenting in their records: "It made that relationship stronger, the trust was there, because they were open to talking to me about [the diagnosis]...instead of stuffing it under the carpet." Although most patients had not spoken with their clinicians about reading notes, clinicians who initiated conversations with patients about what they document garnered trust.

In contrast, patients reported strained trust when they perceived low transparency; when they noticed incongruences between sessions and notes, including the absence of information discussed in session, outdated copied and pasted sections, mistakes (e.g., incorrect age or gender), and details that misaligned with a patient's recollection about a session. Patients described these discoveries as surprising, odd, and upsetting. Many were especially surprised to discover diagnoses in their mental health records that had not been discussed with them. Some worried that inaccuracies in their records could negatively affect their treatment, for example, other clinicians perceiving or treating them differently. One patient was concerned about how perceived errors in her health record might affect a pending court case. Others who were surprised by their notes wondered if mental health care was worth their time: "I'm...giving up a lot of time...I would like you to take it seriously too, not just spit something out on paper and not proof read it."

Respect

Patients felt respected and reported greater trust in clinicians when their notes contained evidence of being heard. Most felt that clinicians truly listened when everyday details about their lives, such as grieving the loss of a pet or a patient's volunteer work, were documented in their clinical notes. Respectful notes also showed evidence of clinician thoughtfulness and consideration; they helped patients feel, as one described"Not just a repeat from the last PTSD person he talked to, but an individual with PTSD." When reading their notes, patients

evaluated whether their clinicians regarded them as whole persons. Patients felt seen holistically when clinicians documented their strengths and efforts, not just diagnoses or symptoms. One patient reported"It's nice to know when I read the notes that the doctor noticed I was staying on task, because I was really trying to." Patients appreciated when they

Conversely, patients' trust in clinicians was strained when they did not feel respected. "Did they actually listen to me? ...It seems like a very different person written in the notes at times," expressed one patient, echoing a common complaint. Notes comprised primarily of surface level observations indicated to some that clinicians did not understand them as individuals. Also, the tone of notes contributed to some patients feeling disrespected; they described such notes as unfriendly, negative, badgering, or angry. While some accepted that feeling disrespected could simply reflect their personal perceptions, such impressions negatively affected some patients' trust in certain clinicians.

perceived that clinicians wrote notes with the patient in mind as a reader.

Discussion

Like mental health clinicians, patients consider the patient-clinician relationship a powerful tool important to the therapeutic process. Patients in this study echoed research identifying trust as key to developing or maintaining strong patient-clinician relationships(14). Our findings add to the growing literature demonstrating that sharing clinical notes can facilitate enhanced patient-clinician relationships in general; in a recent study of OpenNotes in primary care, 70% of clinicians reported strengthened relationships with their patients(5). The current study also reveals that trust within patient-clinician relationships can be strained by OpenNotes, especially when patients perceive that the clinician is not being transparent or not respecting the patient.

Based on our findings, we offer some specific recommendations for mental health clinicians to help strengthen therapeutic alliance in the context of OpenNotes. First, we suggest that clinicians consider proactive communication with patients about the content of notes and the documentation process. Communicating openly and transparently about observations, interpretations, and diagnoses may help mitigate surprises when patients read their notes. Second, we encourage clinicians to use documentation that highlights the individuality of the patient and that includes patient strengths. Our findings suggest that including unique details from each session could help patients feel heard and understood by their clinicians; also, documentation highlighting patient progress could be therapeutically motivating. However, future research should examine whether – and the extent to which – such strategies could help strengthen the therapeutic relationship in the context of OpenNotes. Further research on mental health clinician perspectives of the therapeutic alliance in the context of OpenNotes may elucidate additional strategies for minimizing opportunities for unintended consequences. Though challenging to conduct, additional research designed to quantify actual impacts and outcomes related to OpenNotes may also prove beneficial for health systems considering offering full patient access to mental health records.

These findings and recommendations should be considered in light of several limitations. This was a small qualitative study. However, we utilized purposive sampling to recruit a

sample with a range of mental health diagnoses, and rigorous qualitative methods were used to collect and analyze the data. This study was conducted at only one VAMC; findings may be subject to regional or facility norms. Additionally, as veterans may be unique in their experiences accessing and participating in mental health care, there should be some caution in generalizing our findings to other health care systems.

Conclusion

In this study, we explored patient perspectives of the therapeutic alliance and how OpenNotes may affect patients' relationships with their mental health clinicians. We found that reading mental health notes may strengthen as well as strain patient-clinician relationships via trust. Patients glean information from reading mental health notes about clinician transparency and respect, via assessments of how attentively clinicians listen to and understand them, how accurately a clinician documents what happened in session, and whether or not clinicians discuss diagnoses openly. Proactive clinician communication with patients about the content of notes and the note-writing process, as well as documenting strengths and highlighting the individuality of patients, may improve the likelihood of maintaining or developing stronger therapeutic alliances between patients and clinicians in the context of OpenNotes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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