Patient Access to Mental Health Notes

Motivating Evidence-Informed Ethical Guidelines

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Abstract: In the last decade, many health organizations have embarked on a revolution in clinical communication. Using electronic devices, patients can now gain rapid access to their online clinical records. Legally, patients in many countries already have the right to obtain copies of their health records; however, the practice known as "open notes" is different. Via secure online health portals, patients are now able to access their test results, lists of medications, and the very words that clinicians write about them. Open notes are growing with most patients in the Nordic countries already offered access to their full electronic record. From April 2021, a new federal ruling in the United States mandates—with few exemptions—that providers offer patients access to their online notes (Office of the National Coordinator for Health Information Technology, Department of Health and Human Services, Available at: https://www.govinfo.gov/content/pkg/FR-2019-03-04/pdf/2019-02224.pdf#page=99). Against these policy changes, only limited attention has been paid to the ethical question about whether patients with mental health conditions should access their notes, as mentioned in the articles by Strudwick, Yeung, and Gratzer (*Front Psychiatry* 10:917, 2019) and Blease, O'Neill, Walker, Hägglund, and Torous (*Lancet Psychiatry* 7:924–925, 2020). In this article, our goal is to motivate further inquiry into opening mental health notes to patients, particularly among persons with serious mental illness and those accessing psychological treatments. Using biomedical ethical principles to frame our discussion, we identify key empirical questions that must be pursued to inform ethical practice guidelines.

Key Words: Electronic health records, open notes, ethics, evidence-based practice, serious mental illness

(*J Nerv Ment Dis* 2021;209: 265–269)

Patients have long lacked ready access to their clinicians' notes, even though for more than 20 years the Health Insurance Portability and Accountability Act (HIPAA) has given Americans the legal right to retrieve copies of their records (US Department of Health and Human Services, 1996). HIPAA remained unclear when defining how much of the medical record must be made available, in what form, and what providers could charge for access; in addition, providers were not obliged to share psychotherapy notes (Daw Holloway, 2003). Addressing some of these issues, from April 5, 2021 (postponed from November 2, 2020 due to COVID-19), a new federal ruling will go into effect requiring organizations to share online access to clinical notes via secure patient portals ("open notes") (Blease et al., 2021; Health and Human Services Department, USA, 2020). Notably, the ruling similarly exempts the sharing of psychotherapy notes and does permit "information blocking" if doing so "…will substantially reduce the risk of harm" to a patient or to another person (§171.201(a), p 704). Licensed health professionals can decide what constitutes a substantial risk when working "…in the context of a current or prior clinician-patient relationship" (p 702). However, the upshot for providers is that sharing clinical notes with patients will soon be mandatory.

Embracing greater moves toward shared decision-making and transparency in health care, in the last decade, open notes has grown worldwide (Essén et al., 2018). In multiple studies, the majority of surveyed patients with experience of the practice report feeling more empowered and increased understanding and engagement with their care (Moll et al., 2018; Walker et al., 2019). So far, however, many health organizations in other countries have resisted sharing mental health notes or have limited access to clinical notes from psychiatric centers.

Should open notes be extended to patients accessing specialty mental health care (Blease et al., 2020b; Strudwick et al., 2019)? Currently, only a few small scale studies have examined patients' experiences with open notes in specialized mental health settings (Cromer et al., 2017; Denneson et al., 2017; O'Neill et al., 2019; Peck et al., 2017; Strudwick et al., 2020). Although preliminary evidence from these studies is promising, sample sizes are small and missing experiences of patients with serious mental illness (SMI) including persons with bipolar disorders, cognitive disorders, psychotic disorders or personality disorders, and family and friend caregivers. Furthermore, in surveys, many mental health clinicians anticipate that patients may become confused or worried by what they read and that open notes access will lead to increased work burdens (Dobscha et al., 2016; Petersson and Erlingsdóttir, 2018a, 2018b).

With limited evidence and lack of clear guidelines, mental health clinicians may be uncertain about when it is appropriate to open notes to patients and how to embrace best practice. For example, in Norway, where all patients are offered access to open notes, a recent survey found that, among 8% psychiatry clinicians, working hospitals reported keeping a "shadow record" to prevent patients from reading their notes (Kristiansen et al., 2019). Such omissions or deviations from practice recommendations may foster inappropriate decisions regarding patient access; clinicians may decide on arbitrary or subjective grounds who can access their notes, exacerbating problematic power imbalances. Our aim is to motivate further research and guidelines on the harm or risk to patients of open notes in mental health contexts, including in psychiatry and psychotherapy. Using a framework of professional biomedical ethical principles (Beauchamp and Childress, 2001; Mehta et al., 2019), we identify key empirical questions pertaining to patient access to mental health notes that, we argue, now warrant further study (see Table 1).

DISCUSSION

Respect for Patient Autonomy

Clinicians are obliged to be open and honest with patients and to respect patient autonomy. However, mental health clinicians remain conflicted about whether access to open notes will empower patients or enhance understanding about their care. For example, in a study in

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ISSN: 0022-3018/21/20904–0265

DOI: 10.1097/NMD.0000000000001303

TABLE 1. Open Notes in Mental Health: Ethical Issues That May Be Informed by Empirical Research

Ethical Principle	Empirical Research Questions[a] Does Open Notes…
Respect for autonomy	I. Influence perceptions of empowerment among patients? II. Influence patient understanding about their diagnosis, treatment, or care plan? III. Improve recall among patients about their treatment or care plan?
Nonmaleficence	IV. Increase patient anxiety? V. Increase incidents of self-harm? VI. Influence diagnostic accuracy? VII. Influence rates of medication errors? VIII. Does denying patients access to their notes increase feelings of stigmatization?
Beneficence	IX. Increase patient adherence to psychotropic medications? X. Increase patient adherence to nonpsychotropic medications? XI. Improve the therapeutic alliance between patients and clinicians? XII. Increase subjective measures of patient wellbeing? XIII. Improve patient outcomes? XIV. Change attendance rates at visits?
Privacy and confidentiality	XV. Change patients' perceptions of privacy about their health information? XVI. Do patients favor proxy access during periods of acute mental illness or incapacity?

[a]We recommend that research investigate 1) patients' experiences in different mental health care contexts, such as outpatient psychiatry, inpatient psychiatry, and psychotherapy settings; and 2) the experiences of persons with different mental health diagnoses including individuals with SMIs.

Sweden, over half of all psychiatric professionals surveyed (53%, n = 438) believed that "a majority of patients will find the notes more confusing than helpful" and only 30% (n = 252) believed that "a majority of patients will better understand their health and medical conditions" as a result of accessing their notes (Petersson and Erlingsdóttir, 2018a).

Preliminary survey research challenges these findings. For example, a comparison of primary care patients with and without a mental health diagnosis reported no differences in patient experiences with open notes. Most patients felt more in control of their health care (92%, n = 336 of patients with a mental health diagnosis compared with 91%, n = 1789 without), and only a minority found the notes more confusing than helpful (1%, n = 5 of patients with a mental health diagnosis compared with 3%, n = 49 without) (Klein et al., 2018). Currently, over 50 million US patients have access to their primary care physician notes, which often contain very detailed personal information, and in the United States, a significant amount of mental health care is provided in primary care settings. After implementing open notes for 20 months, a study at an outpatient psychiatric clinic in Boston concluded that the majority of patients reported better understanding of their mental health condition and better remembering of their care plan (Peck et al., 2017). In Canada, a survey of patients with complex and serious mental health needs reported that patients experienced greater engagement in their health care, experienced an enhanced sense of autonomy, and experienced personal progress after portal access (Kipping et al., 2016). In a more recent focus group study, also conducted in Canada, patients reported that access to their information allowed them to better identify patterns related to their mental health which, in turn, provided a greater sense of control over their illness (Strudwick et al., 2020).

Qualitative research in psychotherapy also indicates that many patients who access their notes feel more empowered and report greater understanding about the psychotherapeutic process (Cromer et al., 2017; O'Neill et al., 2019). Confusions may be especially high in psychotherapy where, dependent on the modality, practitioners may write notes that are perceived to be esoteric or unclear from a nonspecialist standpoint (Blease et al., 2020d).

As noted, however, studies are small, most excluded persons with SMI and/or involved self-selecting practitioners. We recommend future empirical research to assess whether rapid access to clinical notes influences perceptions of empowerment or engagement, or leads to routine confusions or misunderstandings, among a wider population of mental health patients. This will be especially important to assess patients with different medical conditions and needs. In addition, we strongly advocate that researchers investigate client perceptions of patient empowerment and understanding, after accessing notes in different psychotherapy modalities.

Nonmaleficence

Patient Anxiety

Clinicians have an ethical duty to "first do no harm," and many mental health clinicians remain concerned that patients may become anxious if they read their clinical notes (Dobscha et al., 2016; Petersson and Erlingsdóttir, 2018a, 2018b). For example, 77% (n = 156) of mental health clinicians at the Department of Veterans' Affairs (Dobscha et al., 2016) and 58% (n = 488) of surveyed Swedish psychiatric professionals anticipated that patients will worry more (Petersson and Erlingsdóttir, 2018a).

Scarce data, however, have explored the question about whether patients do, in fact, experience greater anxiety because of reading their notes. In the survey at the outpatient psychiatry clinic in Boston, only 4% (n = 2) of psychiatric patients reported worrying more as a result of accessing their notes (Peck et al., 2017). Again, sample sizes are too small to draw informative inferences, and selection bias may affect results. Future research must now assess whether patient access to clinical notes increases anxiety and, furthermore, whether any such increased anxiety reaches a clinically meaningful threshold. Some patients may find notes to be helpful and clarifying, whereas others may be upset by the content of notes. It will be necessary to explore whether some patients, or medical conditions, are associated with greater levels of anxiety after access.

Risks of Self-Harm

Might sharing notes with mental health patients exacerbate or even reduce emotional or physical self-harms? It is conceivable that some patients, for example, persons with borderline personality disorder, might become so deeply upset by what they read that access worsens symptoms. We are aware of no research that has systematically explored the question of harm with greater precision; however, we argue that more extensive quantitative and qualitative survey research among patients must investigate the possible negative experiences including changes to symptoms and to progress in recovery. Again, tracking the responses among patients, and responses of individuals across different psychiatric or psychological conditions, will be imperative.

Diagnostic Accuracy

In surveys, many mental health clinicians report changing their clinical documentation with the knowledge that patients might read it (Dobscha et al., 2016; Petersson and Erlingsdóttir, 2018b). In a study conducted with mental health clinicians at the Veterans Health Administration, responding to whether they had made or will make changes to

the way they document mental health notes as a result of patient access, 69% (n = 108) of respondents reported they would write fewer details and 29% (n = 45) reported they would write less about the diagnosis (Dobscha et al., 2016).

Strategies aimed at writing patient-friendly notes are to be welcomed, but changes to documentation practices must be balanced against the risks of oversimplification in clinical records (Blease et al., 2020b). The original function of medical notes is to act as an aide-mémoire and communication tool among clinicians, and it is unknown whether patient access may devalue the utility of documentation for health professionals. Future research might thereby aim to investigate whether patient access to mental health notes interferes with diagnostic reasoning. Measuring the rate of diagnostic error, especially in mental health settings, is challenging. The use of patient surveys or retrospective case reviews may help to explore the influence, if any, of open notes on diagnostic accuracy (Graber, 2013; Zwaan and Singh, 2015). We also suggest that future research might assess how open notes influences quality of care as gauged by clinical outcome measures.

Perceiving Errors in Notes

A growing body of research in ambulatory care suggests that, after reading their clinical notes, patients can, and do, perceive inaccuracies, omissions, and errors (Bell et al., 2020; Blease and Bell, 2019). In the United States, in a recent online survey of more than 22,000 patients who read their notes (with a response rate of 22%), one in five patients reported a mistake and 40% perceived the error to be serious (Bell et al., 2020). Although we do not have research on inaccuracies in mental health notes, qualitative studies in psychotherapy do indicate that at least some patients discern inaccuracies in reporting patients' subjective or emotional states (O'Neill et al., 2019).

No large-scale surveys have specifically investigated whether mental health patients perceive errors in psychiatric or psychotherapy notes, including in the reporting of subjective emotional states. Indeed, the scope for error may be higher in circumstances where clinicians are required to write reports of patients' subjective mental states. Furthermore, owing to the interpretative nature of psychological treatments, psychotherapy notes may be particularly vulnerable to error. It is also conceivable that some disagreements about the notes may also be owed to differences in perception and some errors may be the result of poor information on the part of both the clinician and/or the patient. These considerations point to the need for both clinician and patient training and for guidance in relation to both writing and accessing clinical notes (see *Conclusions and Recommendations*).

There may also be an important role for patients acting as collaborators with mental health clinicians to identify the extent of omissions or inaccuracies in their mental health records that could affect the quality of care, including improving precision in clinicians' interpretations of patients' mental states. If patients' responses to inaccuracies or omissions were routinely solicited in psychiatry contexts, this might enhance diagnostic accuracy, reduce medication errors, and strengthen the feedback loop on care (Blease and Bell, 2019).

Information Blocking and Stigmatization

As noted, some health care systems have favored information blocking for patients in psychiatric and psychotherapy health settings. Patient safe-guarding and the prevention of harm are likely to be among the justifications behind selective provision of access to notes. However, in small qualitative studies in psychotherapy, some participants reported negative feelings as a consequence of being denied access to their notes (Cromer et al., 2017; O'Neill et al., 2019). Research should aim to investigate whether blocking patients' access to notes, including those with SMI, is associated with increased feelings of stigmatization and/or strains trust in therapists and the therapeutic alliance (see *Beneficence*).

Beneficence

Adherence to Medications

The duty of beneficence in medical ethics refers to the promotion of the wellbeing and best interests of patients (Beauchamp and Childress, 2001). In a recent major online patient survey of open notes in the United States, the majority of participants reported better understanding of the rationale for their medication and 14% reported better adhering to their medications as a result of reading their clinical notes (DesRoches et al., 2019). Supporting these findings, a small study found that 29% patients (n = 13) in outpatient psychiatric care reported doing a better job taking their medications due to reading their notes (Peck et al., 2017). Nonadherence to psychotropic medications remains a persistent problem in mental health contexts and is associated with worse outcomes for psychiatric patients including relapse, rehospitalization, and increased risk of suicide (Farooq and Naeem, 2014; García et al., 2016; Witt et al., 2013). Survey findings therefore point to potentially important implications for improving care among patients with serious mental health conditions. More extensive survey research into patients' experiences with psychotropic medication adherence will be valuable to explore whether open notes supports clinicians in this aspect of their duty of beneficence.

The Therapeutic Alliance

The strength of the therapeutic alliance is recognized as critical to recovery in mental health care (Krupnick et al., 2006). This alliance encompasses factors relating to the rapport between patients and clinicians, patient engagement, mutual trust, and perceptions of clinician empathy and competence. Preliminary research from surveys in psychiatric and psychotherapy settings also suggests that offering patients access to their notes may strengthen the therapeutic relationship (Cromer et al., 2017; O'Neill et al., 2019; Peck et al., 2017). One US survey found that 40% (n = 26) of patient respondents reported trusting their therapist more and 28% (n = 18) reported talking more openly with their therapist as a result of access to their psychotherapy notes (O'Neill et al., 2019). Comments from surveys also suggest that access to notes can promote feelings of validation among patients (Peck et al., 2017). There also appears to be scope for using notes as a treatment tool in psychotherapy, for example, to set "homework" between sessions. Some patients who read their psychotherapy notes referred to this benefit of access (O'Neill et al., 2019).

However, some patients report strained trust in mental health clinicians as a result of what they have read, and a number of surveyed participants perceived the language in their notes to be judgmental (Peck et al., 2017). Similarly, in qualitative research, some psychotherapy patients perceived their notes to be disrespectful or negative (Cromer et al., 2017; O'Neill et al., 2019). Patients also discerned incongruencies between what was talked about in sessions and what is written in the notes, and this was perceived as a source of distrust (Cromer et al., 2017; O'Neill et al., 2019; Strudwick et al., 2020).

Using validated measures, future research might usefully explore whether patient access to open notes influences perceptions about the strength of the therapeutic alliance, mental health outcomes, and subjective measures of wellbeing, for example, via quality of life scales. Again, it will be important to explore whether patient access to mental health notes influences attrition rates in therapy sessions and psychiatric visits.

PRIVACY AND CONFIDENTIALITY

Privacy is a central consideration in the fiduciary clinician-patient relationship. Clinicians must state clearly how clients' confidentiality and privacy will be protected, and outline any circumstances in which confidential or private information will be communicated to others—for example, protecting third parties from potential harm as a result of what

might be disclosed, or when clinicians are legally required to disclose information to other authorities.

Preliminary findings reveal that access to notes does prompt some mental health patients to worry about privacy and security of their information access (Cromer et al., 2017; O'Neill et al., 2019; Peck et al., 2017; Strudwick et al., 2020).

Although open notes might not raise new concerns about the security of electronic records per se, it may influence perceptions about privacy among patients. In addition, it invites ethical challenges about privacy in relation to proxy access. For example, should parents or guardians be given access to the mental health notes of children or adolescents? If an adult patient lacks cognitive capacity, during acute episodic psychiatric illness, should family or friend caregivers obtain proxy access to their notes? We suggest that future quantitative and qualitative survey research should explore, more deeply, patients' attitudes and concerns about privacy and confidentiality, including their views on proxy access among family and friend caregivers, for example, for advance directives for times of incapacity.

CONCLUSIONS AND RECOMMENDATIONS

Open notes are here to stay. Sharing mental health notes could be more complicated than in other clinical specialties. Permitting clinician discretion about when to share notes on a case-by-case basis could shift communication back to a model of problematic power imbalance (Blease, 2020). Pilot surveys of patient experiences in psychiatric and psychotherapy contexts are encouraging, but current research is limited, and it is not known how responder biases on the part of clinicians or patients might affect results. Most studies have excluded persons with SMIs or those accessing in-patient care. We urge that high-quality empirical research is relevant to the ethical evaluation of open notes in mental health settings (Table 1). Research should compare patients' experiences of accessing their notes in different mental health care contexts, such as outpatient psychiatry, inpatient psychiatry, and psychotherapy settings. In addition, the experiences of persons with different mental health diagnoses including individuals with SMIs must also be explored.

A necessary component of future research will also involve examining patients' perceptions about what clinicians' have written. In subtle ways, the character and tone of notes may influence ethical dimensions of care, along positive or negative dimensions—for example, by influencing level of engagement, understanding, or affective responses (Blease et al., 2020a, 2020c). Even if clinicians do not intend to upset patients, some patients may perceive what clinicians have written to be judgmental or react strongly to what they have read, and such responses may sometimes be unavoidable. Therefore, we suggest that research might usefully investigate how prospective patients might perceive the intention and tone of clinical notes.

Resolving ethical dilemmas, and making progress on the question of note-sharing, will require the active commitment of health providers to reconceive the purpose of clinical documentation (Blease et al., 2020b). This necessitates conversations about how to preserve standards of accuracy in clinical records while optimizing the function of notes as a communication tool with patients. Mental health clinicians will require training and advice on how to utilize clinical notes to benefit patient care (Dobscha et al., 2019). Patients will need guidance on how to read notes, including on how to raise concerns with clinicians. This advice should also extend to conveying the context in which notes are written and in which clinicians use notes to make descriptive, evaluative, and tentative formulations. Patients should also be advised that, as the therapeutic relationship evolves, they may change their personal preferences about whether they want or desire to access their clinical notes (Denneson et al., 2019).

DISCLOSURE

The authors declare no conflict of interest.

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