ETHICS CASE

When and How Should Clinicians Share Details from a Health Record with Patients with Mental Illness?

Commentary by Robyn P. Thom, MD, and Helen M. Farrell, MD

Abstract

Stigma associated with mental illness—a public health crisis—is perpetuated by the language used to describe and document it. Psychiatric pathology and how it can be perceived among clinicians contribute to the marginalization of patients, which exacerbates their vulnerability. Clinical documentation of mental illness has long been mired in pejorative language that perpetuates negative assumptions about those with mental illness. Although patients have the legal right to view their health record, sharing mental health notes with patients remains a sensitive issue, largely due to clinicians' fears that review of this content might cause harm, specifically psychiatric destabilization. However, the ethical principles of justice, beneficence, and autonomy as well as nonmaleficence must be considered by clinicians in determining when and how to share psychiatric details from a health record with their patients.

Case

Dr. Kelly, a psychiatrist, has been seeing Maya, a 36-year-old woman, for management of a personality disorder for several years. Based on her symptom profile, Dr. Kelly has diagnosed her with borderline personality disorder. He has noted her fragile self-image, volatility, and frequent displays of anger, intense paranoia, unstable relationships, substance abuse, and serious threats of self-injury as well as suicidal ideation. Despite the difficulties in caring for a patient with a personality disorder, Dr. Kelly has managed to develop a working relationship with Maya using psychodynamic psychotherapy.

One day after a session that was a bit awkward, Maya—who had recently met with a friend who had suffered a medical error in an emergency department—became suspicious of Dr. Kelly and requested access to her health record in order to see what had been written about her.

Dr. Kelly worries that if Maya sees her record, it will disrupt all the progress she has made so far in identifying perceptual distortions and developing healthier modes of perception and response. In the past, he has written in his notes about how Maya can be

"manipulative," is an "addict," and has several "failed relationships." He worries that Maya's already fragile self-image could be further damaged after reviewing her record and wonders what to do.

Commentary

Language used to describe mental illness has long been mired in what can be viewed as pejorative terminology. Historically, mental illness was described as "madness," "insanity," and "lunacy" [1]. The term "borderline personality disorder," a more contemporary example, suggests someone who is marginal in quality of character or altogether lacking character. Stigmatizing language in a health record can have far-reaching effects that clinicians should consider from ethical and clinical standpoints. A patient's mental health record is not only used as a reference by clinicians but also available to health professionals from multiple disciplines for the purposes of coordinating care. Furthermore, the emergence of electronic health records offers opportunities to provide patients with real-time access to their records. In this commentary, we describe how mental illness can be documented with neutral language and offer suggestions to patients requesting access to their record.

An Increasing Number of Patients Are Accessing Electronic Health Records

Although patients have had the right to review their medical records since the Health Insurance Portability and Accountability Act (HIPAA) was passed in 1996 [2], the practical challenges of accessing paper records limited access. As of 2014, however, 76 percent of US hospitals had adopted electronic health record systems [3]. With this change, health care systems and clinicians are revisiting the issue of how best to share the content of health records with patients.

In 2010, OpenNotes, a pilot study of shared primary care notes, was rolled out across multiple institutions in the United States [4]. Over 100 primary care physicians and about 25,000 patients were enrolled in an observational study in which patients had real-time access to their record through a secure internet portal. Overall, both patients and primary care physicians were pleased with the initiative: 99 percent of patients wanted OpenNotes to continue and no physicians wanted it to stop. Advantages included patients feeling more in control of their care and increased medication adherence. Only 1-8 percent of patients reported that viewing their online health record caused confusion, worry, or offense [5]. Although results from this pilot study within the primary care population were quite positive, the extent to which it is generalizable to a psychiatric population is unclear.

Research on Increasing the Transparency of Mental Health Notes

In the case, Maya is not being offered routine access to her record; rather, she is requesting access to her health record after a specific incident that caused suspicion.

Furthermore, her record contains stigmatizing language such as "addict," "manipulative," and "failed relationships." How might Maya be affected by reading her record?

Although the OpenNotes pilot study showed that transparent primary care notes was relatively successful, it did not address increasing the transparency of or patient access to mental health notes, in particular. A different pilot study is ongoing at Beth Israel Deaconess Medical Center in Boston, which allows mental health clinicians to "opt-in" to allow high-functioning patients access to their record through a secure internet portal [6]. Although it is unclear how the team defined "high functioning," it is probable that some patients, particularly those who are not severely impaired by their mental illnesses and who have achieved clinical stability or a good therapeutic alliance with their clinicians, would be less likely to be adversely affected by reading their record. We know little about Maya's level of functioning related to important social and health determinants—for example, her employment status, housing status, and social support are not discussed. These would be factors for Dr. Kelly to consider when deciding how to proceed.

Initially, at least, Beth Israel clinicians participating in this pilot felt that bringing transparency into the mental health field was not without risk [6]. Specific concerns included whether patients would be upset by reading aspects of their record—say, a diagnosis of a personality disorder, or, for patients with schizophrenia, that their firm convictions are seen as delusional—and how standard psychiatric terminology could be perceived as judgmental, dismissive, or reductionist. Dr. Kelly's concern that sharing the record with Maya could cause harm and destabilize her is certainly a valid one.

Retrospective studies that have reviewed mental health records for stigmatizing language reveal that such language is common. Crichton et al. [7] had both study staff and patients review 50 sets of psychiatric case notes for offensive content. "Offensive" was defined as "annoying" or "insulting" and reviewers were deliberately instructed to interpret "offensive" broadly. They found that more than 80 percent of case notes contained content that was either moderately or extremely offensive when rated by two professionals. In comparison, only 24 percent of medical case notes from a matched sample contained offensive content when rated by two professionals.

An Ethical Argument for Increasing the Transparency of Mental Health Notes
Reticence concerning increasing the transparency of the psychiatric record likely stems from the ethical principle of nonmaleficence, which means "do no harm." As discussed previously, note contents can evoke feelings of confusion, anxiety, worry, or offense in patients [5, 7], which in turn can cause psychiatric decompensation. Furthermore, if clinicians knew that patients would read their notes, they might exercise censorship in documentation, such as not including a diagnosis of borderline personality disorder, not clearly conveying that the patient's thought content might be delusional, or not

documenting a patient's pattern of suspected lying. From a clinical perspective, withholding this kind of diagnostic or clinical detail from a record could negatively affect a patient's care if that patient seeks care in the emergency department or from another clinician.

There are other ethical justifications for increasing transparency. With the trend of mental health professionals sharing notes with primary care professionals, it could be argued from the standpoint of justice that mental health patients should also be able to read their notes. Furthermore, allowing a mental health patient to view or perhaps even collaborate in creating his or her health record by reviewing it in real-time and discussing inaccuracies or need for amendments with the clinician suggests that such an approach might enhance that patient's autonomy during a clinical encounter. Finally, a transparent health record might actually be therapeutic and therefore motivate beneficence and the therapeutic capacity of the patient-clinician relationship. For example, patients can feel mystified about what their clinician is thinking about them; allowing them to read their clinical notes takes away this mystery [8] and perhaps some anxiety associated with it. Furthermore, if patients help their therapists accurately formulate and represent what they experience, it might help them feel better understood by their therapists. For example, in our experience, patients might be relieved to receive a diagnosis of borderline personality disorder, particularly if they take comfort in knowing that the chaos and unhappiness they experience stems from a known, treatable clinical entity rather than being due to a fault in themselves [9]. In the case, Dr. Kelly can do two important things: (1) use descriptive, nonjudgmental language in Maya's health record that can illustrate how Maya meets diagnostic criteria for borderline personality disorder and (2) discuss with her the formulation of this diagnosis, which might lead to a deepening of their therapeutic alliance.

How to Move Towards Transparency
As an increasing number of health care systems adopt electronic health records, mental health documentation will likely also move towards more transparency. What are practical considerations for transitioning to more transparent electronic record maintenance that have important clinical and ethical relevance in the context of mental health care?

First, as in much of clinical medicine, clinicians should carefully consider how a transparent record might impact each individual patient. We would suggest a "why, when, where, and how much?" approach. Clinicians should explore with their patients why they are interested in reviewing their health record, including what they are hoping to learn and what they might fear reading. Timing is also important when determining how to disclose records' content. For example, it would be inappropriate for acutely psychotic patients to review their records, and it would be prudent to achieve clinical stability before sharing the record. Patients and clinicians should also collaboratively

determine whether it would be more therapeutic for the patient to review the record in private or with the clinician present. Finally, there are aspects of health records that should not be shared with patients. These include sensitive information, such as information about violent behavior or substance use, obtained by a third party.

Second, as health records become more transparent, we believe that clinicians will need to become more cognizant of the language they use to describe patients. Accurate, precise, fact-based descriptions of behavior rather than subjective or opinion- or assumption-based labeling should be used. For example, rather than writing "Mr. A is a known addict," one could write "Mr. A continues to drink two pints of vodka daily." This type of writing might lead to less clinical prejudice on the part of a clinician and decrease diagnostic anchoring that can lead clinicians to jump to a diagnosis based on a clinical buzzword rather than considering a patient's complete clinical presentation. For example, while "paranoia" may be considered a buzzword for schizophrenia, the full clinical presentation should be taken into consideration when making this diagnosis. That said, descriptive language should not replace a clear diagnosis. Although one could argue that many diagnostic terms in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) remain offensive or stigmatizing, for the present, this volume contains the contemporary shared language among health professionals on mental health diagnostics. Descriptive terminology should be used to nonjudgmentally substantiate a diagnosis, which should be clearly documented in the record using the currently recognized and accepted *DSM* terminology. Finally, the National Alliance on Mental Illness [10] and individual psychiatrists [11] have begun analyzing and cataloging specific words that should be avoided when writing about persons with mental illness. For example, "schizophrenic" should be replaced with "person with schizophrenia," and rather than writing a patient "suffers" from mental illness it is preferable to replace this word with a value-neutral word that does not express assumptions about a patient's feelings.

Conclusion
From what we know, Dr. Kelly has been acting in good faith as Maya's clinician, has therapeutically aligned with her, made a diagnosis, and recommended a treatment plan of psychotherapy. The case illustrates areas for improved sensitivity and objectivity when documenting delicate details about a patient's pathology. While Maya has expressed interest in seeing her record, Dr. Kelly would do well to adopt the "why, when, where, and how much?" approach that we recommend to explore her interest in reviewing her record. If Maya remains interested in reading the record, they could then formulate a plan together for when and where it should be shared. They could consider sharing the notes during an office session so that there is a built-in context for immediate discussion and clarification. As we've argued, she might find this helpful in terms of rebuilding trust with her psychiatrist who has expressed intent to act in her best interest and cause no harm. Finally, depending on Maya's goals for reviewing the record,

Dr. Kelly should determine how much of her record should be shared. For example, if she is simply looking to better understand his formulation of her diagnosis, a case summary might be sufficient.

The bottom line for mental health care professionals and other clinicians to keep in mind is that this is a time of opportunity. Electronic health records are more accessible to patients and health professionals alike. Although both the language traditionally used in psychiatric documentation to describe clinical observations and the use of diagnostic terms themselves can be stigmatizing, this shift in accessibility affords us an opportunity to modify the ways we write and think about patients. As an initial step, we should take care to use as much nonjudgmental and factually descriptive language as possible while continuing to use accurate diagnostic terminology. And though diagnostic terms will likely be slower to change, they eventually will need to be replaced with less stigmatizing language, too.

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