Knowledge is Power

By Dr Cara Bell, Specialty Doctor.

The culture within psychiatry has changed alongside seismic shifts in our society. Power structures, hierarchy and experts are challenged and scrutinised on a much greater level. The historical attitude of paternalism in medicine has been replaced with an acceptance that relationships need to be based on collaboration, mutuality and greater honesty and transparency. These changes have been made to try and empower patients, since empowerment refers to the level of choice, influence and control that user of mental health services can exercise over events in their lives.[1]

In the spirit of such empowerment clinicians within psychiatry have been copying outpatient clinic letters to patients and the Royal Collage of Psychiatrists have provided Guidance on the practicalities involved.[2] However, this practice is far from universal and outpatient clinics form only a part of the overall care and treatment provided to patients.
In England, patients have had the legal right to access their health records since 1998, but access to paper-based health records is mediated by health professionals and data controllers, through a cumbersome procedural process.[3]

This sense that there is information 'held' by mental health professionals and not shared easily seems to be in direct conflict with patient autonomy and empowerment and does nothing to help with candour, transparency, and the eradication of unnecessary power relationships.

To address these issues there has been a quiet revolution over the past 10 years where health organizations in over ten countries have begun to provide patients with access to their clinical records via a secure online portal. This movement is called 'OpenNotes' and studies demonstrate that reading clinicians' notes helps patients and their caregivers remember important information, improve health literacy, and increases patients' and carers engagement and trust in their care. Engaged patients are more motivated to follow their care plan, and they have higher rates of medication adherence.[4]

There have been concerns and a reluctance by psychiatrists in the 10 countries to join this movement. This is based upon the fear that some patients could become confused, anxious, upset, and harmed by reading their notes. However, preliminary research suggests that sharing notes might well benefit patients in mental health settings. A study[5] performed at a psychiatric outpatient clinic found that, after 20 months, most patients reported increased understanding of their mental health, better remembered their care plan, and had better awareness about the potential side-effects of medications. Qualitative research also shows that, because of reading their notes, many mental health patients describe feelings of validation, greater engagement, and enhanced trust in clinicians. In preliminary research there was no evidence of harm to patients.[5,6] Further research is of course necessary.

The entire premise that harm could occur suggests that clinicians are powerless to prevent such harm, which of course is false. It is possible for all mental health clinicians to adapt to this change and learn to be skilful in the content and tone of documentation without resorting to the ethically dubious practice of "note sanitization'. There is little doubt that opening notes will be more challenging in Psychiatry than in other specialties but there does seem to be a need to improve the documentation in psychiatry per se. We need to be mindful to remove jargon, pejorative, and more judgmental terminology. We need to make our notes more understandable, clear, accurate and as objective as is possible. In this way clinical notes will be written with sensitivity, respect, and with positive regard.

To prevent harm, we can provide guidance to our patients on the risks and benefits of reading their notes, when or where to read and get the most out of them and how to get support or raise concerns. Rather than cause harm, patients who are exhausted from telling their story time and time again can share the most appropriate note with other clinicians and mental health practitioners. The fact that patients can also share their notes will allow a more streamlined engagement with other departments in the hospital, their employer, other organizations such as the DVLA or government organizations involved in organizing benefits or local housing.

Within the appointment, clinicians can discuss what will be included in the notes, in doing so they can correct misunderstandings, ensure patients are fully aware of the working diagnosis and treatment plan. This may well ward off most problems. The refreshing perspective is that clinical notes will become an increasingly important communication, therapeutic and dynamic tool, one that "strengthens and extends" the visit.

The challenge will be reaching out to the patients who are difficult to engage, the older patient with cognitive impairment and the acutely unwell. We will need to breach the digital divide and provide access to the internet for more marginalized communities. However, in America, studies have shown that more marginalized communities are more likely than more affluent communities to develop greater trust in clinicians when they can read their notes.[6]

Historically, people with mental health problems have lacked a voice. The simple ability to read their own notes should be empowering and this can give a voice to the voiceless and more importantly; making the unseen – seen may be just what patients want, need but more importantly deserve.

References:

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