Conference Abstract

How social media is influencing relationships between people using and providing mental health services

Nikoo Atraki, Leeds and York Partnership NHS Foundation Trust, United Kingdom

Victoria Christine Naomi Betton, Leeds and York Partnership NHS Foundation Trust, United Kingdom

Correspondence to: Nikoo Atraki, Leeds and York Partnership NHS Foundation Trust, United Kingdom, E-mail: victoria.betton@nhs.net

Abstract

This abstract is for a presentation of early findings from PhD research co-supervised by the University of Leeds Institute of Communications and the King’s College London Institute of Psychiatry. The researcher is in the third year of part-time study and is ready to share preliminary research findings.

The research aims to understand the extent to which relationships between users and providers of mental health services, and institutions, are being disrupted in the online mental health sphere, sometimes known as the ‘madosphere’.

The research objectives are to explain:

• Who is participating, how do they experience their engagement, what meanings does it carry for them?
• What are the behaviours, practices and social norms?
• How do participants engage with and resist mainstream media reporting of mental health issues?
• How do participants engage in discourses relating to themes identity, power, stigma and discrimination?
• How are participants engaging with and resisting institutional paradigms and discourses relating to mental health?

The research method is an online collaborative ethnography comprising fieldnotes, interviews and sustained researcher participation in the field.

Early findings comprise themes of identity, power, hierarchies and peer support which are elucidated through case studies:

Identity, power and hierarchies – participants in the madosphere are largely educated, with liberal sensibilities and are in their twenties through to middle age. Whilst a mental health diagnosis can be a deficit in day to day life, it can be an asset in the madosphere and lead to a sense of
empowerment and even ‘star status’. Social media platforms afford a potential flattening of formal hierarchies with greater possibility for people to interact without professional or institutional boundaries. This has an empowering effect for some people accessing mental health services and professionals whilst presenting challenges to institutions. However, informal cliques and hierarchies can emerge and manifest themselves in more subtle ways.

**Peer support:** the role of peer support in the madosphere is a consistent theme, with many using platforms such as Twitter to share experiences and source support. The anonymity and ability to self-edit identity afforded by the Internet is a positive factor for many participants. Some people are using social media to engage in support outside of mental health service provision.

**Stigma and empathy:** stigma literature points to three methods for challenging stigma – education, protest and direct contact. A blend of these three methods and are being used by some participants to reduce prejudice. People accessing services are able to see the ‘real person’ behind the name badge and practitioners are able to see beyond the diagnosis, thus sharpening empathy.

**Conclusions:** I conclude that the madosphere affords a reshaping and problematising of relationships between people living with mental health problems, professionals and institutions. Citizens are increasingly able to produce as well as consume information, share experiences and challenge institutions. Institutions are only beginning to appreciate the challenge this poses to professional identities and organisations used to having control of both information and relationships. This is increasingly being eroded with new expectations, and opportunities, for increased transparency, accountability and collaboration.

**Keywords**

social media; mental health; professionals; institutions; service users