Online peer support for perinatal mental health

Donna Moore discusses how visiting online forums may help women deal with the stigma of perinatal mental illness and disclose to health professionals

This article considers some of the ways many women with perinatal mental illness use internet resources for peer support. It provides an overview of internet resources available for perinatal mental illness support and examines in more depth online peer support, particularly the role of online forums, which has important implications for recovery. I explore the potential of online forums for challenging stigma and encouraging disclosure to healthcare professionals in the context of my PhD research.

The internet and perinatal mental health

Mental illness during pregnancy and after childbirth (perinatal) is a global health concern. Perinatal mental illness includes affective disorders such as depression, anxiety, post-traumatic stress, obsessive compulsive disorder and postpartum psychosis. Approximately 10-15% of pregnant women and new mothers are diagnosed with perinatal mental illness, which has well-documented negative consequences if left untreated. While this article focuses on women, perinatal mental illness can also occur in new fathers, and can be detrimental to the whole family. Unfortunately, many women with
this illness do not get the help they need despite its availability, one reason being stigma. The internet could be a useful tool in helping women to access the help they need anonymously, thus circumventing any possible negative outcomes associated with stigma. Indeed, it might be the first place some women look for information and support when experiencing distress.

A Google search on ‘postnatal depression’ will yield over 2 million results.

There has been a rapid growth in online forums for peer support in recent years, allowing individuals to receive, as well as offer, support from others who are in, or have been in, a similar situation. I initially reviewed 114 websites on postnatal mental illness for quality and content, after searching via the four main search engines. I included websites that were exclusively dedicated to postnatal mental illness or had substantial information on postnatal mental illness. Rating scales were developed with a senior researcher, forum users and using high quality information including DSM-IV-TR. Scales measured information (symptoms, risk factors and impact on the family), resources for women (self-help tools and online support) and website quality (for example, presentation and navigation). My results led to identification of the five high-scoring websites providing information for healthcare professionals, and five top sites healthcare professionals could recommend to women looking for online resources.

When I started my PhD in 2009, websites for antenatal mental illness were largely absent, but now there is a multitude of antenatal resources available. Internet resources are also beginning to emerge for men with perinatal mental illness, as well as for men supporting women with the illness. My second project was an interview-based study with women who used the internet to assist their recovery from postnatal mental illness, including for peer support, which led to my interest in online forums.

What is online peer support for perinatal mental illness?

Online peer support is like face-to-face peer support except that women contact others through computers, or other electronic devices, and can interact virtually. As they do not have to leave their home in order to get support, there are obvious advantages for pregnant women and new mothers. Online peer support for parents has similar benefits to face-to-face support, and is available through forums (also known as message boards or online support groups), online chat rooms, personal messaging, email and various social media sites, such as Facebook and Twitter. These online communities allow people with similar health concerns to connect with each other. They can be quite general, for example ‘antenatal and postnatal mental illness’, or more specific, for example ‘birth trauma’.

How does online peer support work?

Women can read forum posts and start and/or contribute to existing conversations, or threads. Visitors sometimes have to sign up to become a member, but this rarely involves more than creating a password, supplying an email account (normally not visible to others) and agreeing to the forum
terms and conditions. Twitter supports online communities such as one run by Rosey, a survivor of perinatal mental illness. Women can access each other’s posts, or ‘tweets’ by creating a Twitter account and either including the tag #PNDChat in their posts or by replying to others’ posts. Contributors vary from current sufferers to recovered women, and healthcare professionals often participate. There is a weekly topic regarding perinatal mental illness every Wednesday between 8pm and 9pm. This can be found by searching #PNDHour, #PNDChat or following @PNDandMe.

‘The Birth Trauma Association is a closed group, posts are not visible to non-members, and it is a safe space for women to express feelings and fears they may feel they cannot share with friends and family. Women can find our closed group simply by searching Facebook for Birth Trauma Association and requesting permission to join the group.’

Gwyneth Eanor — group administrator

What makes this online peer support popular?

Forums offer support day and night and are easy to access through a wide range of technology, such as computers, mobile phones and tablets. Some women find it valuable to have access exactly when they need to, for example, while out, or in the middle of the night when other forms of peer support may not be available. This is particularly important if there are no available resources in the local community or if they are waiting for professional help.

‘Often women are left waiting for formal support/therapy such as counselling etc so having access to online peer support can really help bridge that gap and offer hope for recovery.’

Rosey @PNDandMe

My interview study revealed that women felt supported even if they did not post online. In fact, several women said they benefited from just knowing others were there should they wish to ask for support. One of the most commonly cited advantages was that they could access information and support from others without being identified. Unfortunately, many women with mental illness feel stigmatised, so anonymity was valued as a way to overcome this barrier to seeking peer support.

‘Peer support and advice are just a few clicks away. I can honestly say that peer support via #PNDChat has been such a huge factor during my recovery.’

Anonymous #PNDChat

The stigma of mental illness

Mental illness has long been associated with negative beliefs, such as an affected person being dangerous. Although many campaigns exist to reduce stigma (some with exceptional online coverage, for example Time to Change) many people feel that the general public still hold stigmatised
attitudes towards individuals with a mental illness. This is often termed external stigma. Conversely, internal stigma occurs when an individual takes on this stigmatised belief and applies it to themselves. This can happen even if they do not necessarily agree with the external stigma. Both types of stigma can have negative consequences for an individual such as social exclusion, lowered self-esteem and avoidance of disclosure.\textsuperscript{10,11}

The stigma of perinatal mental illness

For women and families the issue can be more complicated, as women not only have the stigma of mental illness, but also of being a mother with a mental illness. This can lead to debilitating feelings of inadequacy as a mother, and guilt about failing their child. It can exacerbate symptoms and lead them to conceal their illness because they do not want to be seen as, or feel like, a ‘bad mother’.\textsuperscript{12} This ‘bad mother’ idea is common in the literature that explores women’s feelings of perinatal mental illness stigma.\textsuperscript{13}

With this in mind, my colleagues and I conducted a deductive systematic thematic analysis of posts on an online forum for antenatal/postnatal depression on Mumsnet.\textsuperscript{14,15} We found that many women posted in order to get advice from others about their symptoms, and asked if they should tell a healthcare professional. Many women struggled with stigma and described feeling like a ‘bad’ or ‘failed’ mother and had concerns about being stigmatised should they disclose to a healthcare professional. The vast majority of replies encouraged women to disclose, seek help and take treatment. Many replied that they had overcome the stigma and taken this advice. The forum discourse presented an alternative ideology of perinatal mental illness as compatible with being a mother, especially if the woman sought professional help and adhered to treatment.

‘It gave me the courage to speak out and realise that suffering in silence wasn’t good for me, speaking to these like-minded people saved me.’

Anonymous \#PNDHour

Whilst there are scales that measure stigma associated with mental illness in general and specific illnesses (e.g. depression), research suggests that perinatal mental illness stigma is distinct from stigma attached to solely depression or anxiety.\textsuperscript{12} However, there is no known scale that measures perinatal mental illness-related stigma. I developed a 30-item draft scale from a literature review to measure this unique form of stigma and tested it with 279 women with perinatal mental illness.\textsuperscript{16} The final 15-item City Mental Illness Stigma Scale (City MISS) had a three-factor structure: perceived external stigma, internal stigma and disclosure stigma. The scale appeared to be a valid measure that could serve as a useful tool for clinical practice and research. I have used this scale to investigate the role that online forums may play in reducing stigma and, in turn, increasing disclosure to healthcare professionals.\textsuperscript{17} It is vital to continue research on interventions to reduce stigma and promote disclosure to healthcare professionals, which is often the first step in women’s recovery.
Forums may promote the idea that you can be a good mother and have perinatal mental illness. This way of thinking may challenge stigma and enable help-seeking behaviour in some women.

Disclosure to healthcare professionals

My research suggests that online forums have the potential to increase disclosure by helping women to recognise stigma and challenge it.\textsuperscript{14,17} Within forums, women may describe positive experiences with healthcare professionals; they can test out disclosing their illness on the forum; they can learn how to describe their symptoms to others; and can be encouraged by other members to talk to their healthcare providers. Nonetheless, there are some concerns about using forums. Moderators can promote members welfare and ensure members’ safety by viewing posts and removing any harmful or inaccurate messages. They can also caution and remove members who do not adhere to the forum policy, and lock conversations if they become hostile. Policies and moderators vary from site to site and may not always be reliable. Some forums are un-moderated, meaning that potentially harmful posts and/or members are not controlled, which could have serious consequences for already vulnerable adults.\textsuperscript{18} However, healthcare professionals may recommend quality and moderated forums and social media groups to interested clients.

The above research projects have worked towards testing theories of perinatal mental illness stigma, generated from qualitative investigations, and finish with a quantitative online survey to measure the role this has in mediating between forum use and disclosure to healthcare professionals.\textsuperscript{17} My final results (unpublished) suggest that women can explore their feelings by using forums and therefore become more aware of their internal stigma and become empowered to express these feelings to healthcare professionals. Further work needs to be done to consider different forums and test how easily these findings can be generalised to other populations. Future studies could consider the direction of causality: it may be that the women who disclosed were more likely to visit forums rather than forum use itself increasing disclosure behaviour. Overall, these findings have the potential to inform online peer support interventions and I hope to see these theories developed in future in order to help women and their families get the help they need.

Key points

- An increasing number of women are using the internet for peer support.
- Some women may find online forums to be a valuable source of peer support, providing similar benefits to traditional peer support.
- Perinatal mental illness stigma is complex and presents a prominent barrier to disclosure for many women.
- My research shows potential positive outcomes when women engage in an empowering online dialogue that challenges perinatal mental illness stigma.
• Peer support through online forums may encourage disclosure to healthcare professionals by promoting the idea that women with perinatal mental illness can still be a good mother, and increase their recognition of internal stigma.

• Forums differ in safeguarding practices, so it is worthwhile checking if a group has safeguarding policies and an active and reliable moderator/s.

• Healthcare professionals could recommend quality and moderated forums and social media groups to interested clients.

References


7. Moore D, Ayers S. Virtual voices: social support and stigma in postnatal mental illness Internet forums. Submitted for publication.


16. Moore D, Ayers S, Drey N. (under review). The City MISS: development of a scale to measure stigma of perinatal mental illness. Submitted for publication


Online peer support links

**Action on Postpartum Psychosis (APP)**
https://healthunlocked.com/app-network
A network of people who have experienced puerperal psychosis and professionals with an interest in the illness, offering a forum for those affected by puerperal psychosis.

**Birth Trauma Association (BTA) Facebook group**
www.facebook.com/groups/TheBTA/?ref=br_tf
A closed Facebook group to support people traumatised by childbirth.

**Mumsnet**
www.mumsnet.com/Talk/antenatal_postnatal_depression
A forum for antenatal and postnatal mental illness support hosted by Mumsnet.

**PANDAS Facebook group**
www.facebook.com/PANDASFoundation/?fref=ts&ref=br_tf
A well-established and popular closed Facebook group offering peer support.

**Post Natal Illness (PNI.org)**
www.pniorguk.proboards.com
A long-running and popular forum offering peer support for all types of perinatal mental illness with sections for issues such as symptoms, recovery and parenting advice. It enables members to create an online diary on which others can comment. There is also a chat room where members can send private instant messages to each other.

**Twitter @PNDandMe**
Follow Rosey on Twitter to get updates and encouragement. Search #PNDhour and #PNDChat to access peer support and see conversations regarding many aspects of perinatal mental illness.

Donna Moore is a PhD student at City University, London. She has been researching perinatal mental illness and internet forum use for the last seven years and has presented her findings at several international conferences. Donna’s background is in counselling and she looks forward to finishing her doctorate this summer.