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Citation: Moore, D. & Ayers, S. (2016). Virtual voices: social support and stigma in postnatal mental illness Internet forums. *Psychology, Health and Medicine*, 22(5), pp. 546-551. doi: 10.1080/13548506.2016.1189580

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Link to published version: <https://doi.org/10.1080/13548506.2016.1189580>

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Virtual voices: social support and stigma in postnatal mental illness Internet forums

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Abstract

Many women with postnatal mental illness do not get the treatment they need and this is often because stigma prevents disclosure. The purpose of this study was to explore online social support for postnatal mental illness, how women experience stigma and potential disadvantages of using Internet forums. Interviews were conducted with fifteen participants who had suffered postnatal mental illness and had used forums. Systematic thematic analysis identified common themes in relation to social support, stigma and disadvantages of using forums. Most women felt they benefited from visiting forums by developing a shared understanding and discourse about their illness. Findings suggest future research should investigate if women benefit from using online social support provided by forums, if use challenges stigma and further explore potential concerns about using forums.

Introduction

Postnatal mental illness is a global health concern with well-documented negative effects of postnatal mental illnesses on the infant and mother (Almond, 2009; Letourneau et al., 2012). The most common disorders are depression and anxiety disorders, which affect between 10 and 20% of women (Ayers & Shakespeare, 2015). Stigma can delay help-seeking and many women feel postnatal mental illness is stigmatised and do not want to be seen as a “bad mother” and this is often cited as a barrier to care (Dennis & Chung-Lee, 2006; McLoughlin, 2013; Weiss, Ramakrishna, & Somma, 2006). Stigma can be external or internal. External stigma is the extreme disapproval of a person or a group of people due to a

characteristic that is considered abnormal or highly undesirable by society (Goffman, 1963). Internal stigma occurs if the stigmatised individual agrees with the external stigma and applies the negative appraisal to themselves thus internalising the stigma (Corrigan, Rafacz, & Rüsich, 2011).

Online social support via forums could offer an opportunity for stigma reduction through education and identification with other people with the same stigma (Crabtree, Haslam, Postmes, & Haslam, 2010). Reduced stigma correlates to increased help-seeking behaviour often through increased disclosure, normalising, and framing the problem as an illness (Clement et al., 2015; Makkarala, O'Brian & Siegel, 2016). There are hundreds of websites offering information on postnatal mental illness and some provide forums (Moore & Ayers, 2011). Some research suggests that women may benefit from the social support from forums for postnatal depression (Alang & Fomotar, 2015; Evans, Donelle, & Hume-Loveland, 2012). Furthermore, some research suggests that women may overcome stigma by posting on forums and this in turn leads to disclosure to healthcare professionals (Kantrowitz-Gordon, 2013, Moore, Ayers & Drey, in press). Sometimes forums may provide misinformation or enable social avoidance (Chung, 2013; Lawlor & Kirakowski, 2014). This study aimed to explore women's experiences of social support and stigma and possible disadvantages when utilising a forum for postnatal affective disorders.

Method

A qualitative study using semi-structured interviews to explore women's experience of using forums when they had postnatal mental illness. Women were recruited by advertising on parenting websites and inclusion criteria included; self-reported postnatal distress, they had

used forums for social support and were a UK resident. There was no inclusion criteria for number of children or time since birth to maximise the sample. The interview schedule was designed to explore forum use and experience of postnatal distress. Current symptoms were assessed using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Ethical approval was acquired from the University Research Ethics Committee. Interviews were conducted between 07/2011 and 12/2011 and lasted between 30 and 100 minutes.

Transcripts were analysed using thematic analysis to identify the main themes emerging from the interviews (Braun & Clarke, 2006). Transcripts were coded by the first researcher in collaboration with a senior researcher (SA) and themes were generated and defined in relation to the research aims. Themes were then reviewed and refined with the senior researcher to create a coding schedule. The coding schedule defined each theme, provided notes on how to identify when the theme occurred and gave examples. All interviews were then coded again using this coding schedule. The qualitative data analysis was conducted using computer software NVivo (QSR International Pty Ltd. 2010).

Results

Sample

Eleven participants reported that they were diagnosed with postnatal mental illness (depression, n=6; post-traumatic stress, n=5). Four participants stated that they were not professionally diagnosed, but believed they experienced postnatal distress. Most participants had recovered by the time of the interview, only one women reported moderate symptoms of depression. All participants were White and most were married (n=13), had a graduate or postgraduate level of education (n=10) and reported accessing forums two or more times a week (n=13). Women's ages ranged from 20-48 years of age (M=32.6, SD=6.7) and the time

since they had their child ranged from six months to 10 years ($M=28.3$ months, $SD=34.4$).

Participants are identified by their number and diagnosis.

Thematic analysis

To check reliability of coding, 10 themes and 5 quotes for each were coded by a third researcher trained in thematic analysis (YP). This found a percentage agreement between coders of 94%.

Two major themes were identified: Social support and stigma; and Disadvantages of forum use.

1. Social support and stigma

The majority of mothers described how forums provided social support and suggested an online community of sufferers and survivors actively and passively engaging in a shared voice in cyberspace. This theme comprised of two sub themes (i) anonymous and non-judgemental support and (ii) not alone.

(i) anonymous and non-judgemental support

The majority of women visited forums to reduce their feelings of inadequacy and perceived stigma from others:

“they could put it on there because of anonymity nobody really knows who you are and everyone who'd obviously on there has postnatal depression so there's no stigma because you're all suffering” (16; depression)

For some women this was the first step in enabling offline disclosure:

“I was looking for reassurance to know that somebody else is going through the same thing as you and you realise that you're not alone 'cause when I first got diagnosed I kind of felt like I shouldn't tell my friends 'cause I'm the only person in the world to have gone through this”

(10; depression)

(ii) *not alone*

As women identified with others they developed an understanding of their symptoms as an *illness*. This enabled them to challenge internal stigma that they were to blame for being ill, thus lessening feelings of guilt and promoting help seeking behaviour. Women often gained a new understanding of themselves as having a *real* condition with hope of recovery:

“I felt this huge relief that somebody else had gone through this. I guess it made me feel like I'm not just a complete failure, it was an illness”

(11; depression)

Many women felt supported even if they did not actively participate on forums. One woman who did not interact on forums described how she still felt part of the community:

'it does make you feel like part of a community and not on your own' (5; post-traumatic stress)

2. Disadvantages of forum use

There were two instances of negative experiences and three women expressed that there were times when using forums may do more harm than good. This comprised two sub themes (i) forum moderators and (ii) knowing when to use forums.

(i) forum moderators

One negative experience occurred because the forum was not moderated. Women described how they chose forums that provided an atmosphere that was trustworthy, non-judgemental and monitored. One mother describes how she was discerning in choosing a forum:

'I just felt they were judgemental, it didn't feel a safe place to go, it felt like you couldn't be sure that anybody there would be understanding, and actually if somebody did write something horrible to you that it would be stopped' (1; depression)

(ii) knowing when to use forums

A few women described how sometimes forums made them feel worse. These women described how they managed this by recognising when forums help and when to avoid them.

“it's a double edged sword really, you find that people are going through the same thing as you and having similar experiences, but sometimes that almost makes you wallow...it can add to your negative thoughts, and then it doesn't necessarily help you especially if you're having a really bad day” (2; depression)

Discussion

The majority of women suggested that their internal stigma was challenged by social support in forums that expressed an alternative discourse about postnatal mental illness. The anonymity and non-judgemental social support may have made it an acceptable way to challenge internal stigma through normalisation, validation and separating the illness from their identity as a mother. Most women reported that engaging either actively or passively with this virtual "voice" empowered them to disclose offline. A minority of women explained negative experiences.

The findings are consistent with literature suggesting that members benefit from forums and they may lessen internal stigma (Crabtree, 2010). This exploratory study points towards some ways that forums may challenge the stigma women with postnatal mental illness may experience. Findings extend previous research by providing a unique perspective of the interactions of women engaging in a collective shared "voice". Unlike previous studies, some possible risks to women have been highlighted. It may be important for women in this sample to recognise times when reading forums can be of benefit and times when it can be detrimental rather than issues with overuse (Lawlor, 2014).

There are reasons the sample may not be representative; sample size was small, self-selected, White, mostly educated and women may have been more proactive in seeking social support. However, findings prepare the way for research that explicitly examines if there is an online conceptualisation of postnatal mental illness that reduces stigma and if so, how women engage with it. There may be concerns about using forums for postnatal mental illness which should be explored further.

Acknowledgements

We would like to thank all the women who took part in the study for sharing their experiences and Ylva Parfitt for her time as an additional coder.

Conflict of interest

The authors declare that they have no conflict of interest.

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