Internet Interventions 2 (2015) 84-90

Contents lists available at ScienceDirect



Internet Interventions

journal homepage: www.invent-journal.com/

Women's experiences of factors affecting treatment engagement and adherence in internet delivered Behavioural Activation for Postnatal Depression



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ARTICLE INFO

Article history: Received 8 July 2014 Received in revised form 16 November 2014 Accepted 16 November 2014 Available online 12 December 2014

Keywords: Postnatal depression Internet Behavioural activation Cognitive behavioural therapy Adherence Randomized controlled trial

ABSTRACT

Introduction: Women with postnatal depression (PND) face significant barriers to treatment that may be overcome by internet based delivery of treatment. Demand for a self-help internet postnatal treatment offered via a parenting site was high, but attrition rates were also high.

Aims: To gain patient perspectives on engagement and barriers to the Netmums' "Helping with Depression" treatment.

Method: Semi-structured interviews were conducted with 17 participants selected from the Netmums trial. *Results:* Thematic analysis revealed motivators and barriers to treatment. Women reported that the flexibility and anonymity of internet interventions fit with their postnatal circumstances. They identified that the relevance of the intervention to their personal circumstances, expectations of motherhood, stigma about depression and motherhood, hopelessness about their ability to improve, previous negative experiences with treatment and treatment seeking, and a lack of practical and emotional support contributed to feelings of being overwhelmed. Women who felt more overwhelmed were more likely to discontinue treatment. Women suggested that support would reduce the impact of barriers and improve adherence.

Discussion: Open access, self-help internet interventions are acceptable to women with postnatal depression, but it is critical to provide tailoring and support to help overcome barriers and improve treatment adherence. Crown Copyright © 2014 Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license

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1. Introductuion

Postnatal depression is common, affecting up to 13% of women (Gavin et al., 2005). Postnatal depression also negatively affects mother–infant relationship and has long-term negative consequences for the child (Pawlby et al., 2008; Murray et al., 2010). Despite this, recognition of postnatal depression amongst health professionals is poor (Ericksen et al., 2005) and help-seeking amongst postnatal women remains low (17%–25%; Buist et al., 2005).

Postnatal women report preferring psychotherapy over antidepressants, particularly when they are breastfeeding (Dennis, and Chung-Lee, 2006). However, they face a number of barriers to psychotherapy. These barriers include struggles with transportation and childcare (Goodman, 2009), variable infant feeding and napping schedules that

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may interfere with regular appointment attendance, and stigma about postpartum depression (Goodman, 2009; O'Mahen and Flynn, 2008). A significant minority of women also report fears that their children will be removed from their custody if health providers discover that they suffer from depression (Dennis and Chung-Lee, 2006). Further, face-to-face and home based treatments can be costly and timeintensive for providers, reducing the capacity of reach of these treatments.

Internet delivery systems offer an alternative, promising approach that may circumvent many of the difficulties of face-to-face delivery techniques (Khan et al., 2007). Internet treatments can be economically and flexibly delivered in contexts of the woman's choosing. Their relatively anonymous delivery may also overcome women's fears of stigma (Beattie et al., 2009).

Working with women who suffered from postnatal depression, we designed and tested an online, self-help Behavioural Activation treatment for postnatal depressed mood in a preliminary trial (see O'Mahen et al., 2013 for details of the trial outcomes). We offered the

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treatment via a popular UK parenting website, Netmums.com. The treatment was marked by high initial demand; 910 women signed up to the trial. Intent-to-treat analyses demonstrated that women in the treatment condition had a greater reduction in their depressive symptoms compared to women in the Treatment-as-Usual condition, although the effect size was small. These results were qualified by attrition and adherence rates. Only 36% of women completed the outcome measures and views of the treatment sessions decreased significantly between sessions 1 and 3, although a sub-sample of women continued to view material through session 11. These rates of attrition and adherence are consistent with online, unsupported treatments. In quantitative data from the efficacy trial, a number of explanations for low rates of treatment uptake and adherence were offered. These explanations include specific characteristics of the sample of participants (e.g., perinatal-specific barriers), the organization, and the delivery of the treatment. These reasons are similar to explanations from a large primary care trial of a self-help intervention for depression, which included delivery and intervention content changes, and specific characteristics of the population (De Graaf et al., 2009a). There remains, however, little information about the direct experience and accounts of internet treatment participants in self-help internet treatments, and their perspective on factors affecting both their uptake of the treatment and treatment adherence (Waller and Gilbody, 2009). The dearth of indepth, gualitative information is especially acute in specialist populations, who may have specific content and delivery needs (Hind et al., 2009).

Following Kaltenthaler et al.'s (2008) recommendation, we included a qualitative study alongside the trial in order to determine patient acceptability of the treatment, with a specific focus on factors affecting women's adherence to the treatment. Recent qualitative studies of internet based Cognitive Behaviour Programs for depression have looked at participant's experiences (Bendelin et al., 2011; Lillevoll et al., 2013). However, we are aware of only one qualitative study that has looked explicitly at factors affecting adherence in a pure self-help internet intervention for depression in the general population (Gerhards et al., 2011). That study found that computer, social and research aspects of the intervention affected treatment adherence. Notably, individuals felt that the applicability of the course to their personal situations and the lack of support and feedback affected their continued adherence with the course.

Because the perinatal period can present specific barriers and content needs (O'Mahen et al., 2012; O'Mahen and Flynn, 2008) we were interested in this study in exploring both general and perinatal specific factors affecting the acceptability of the treatment and treatment adherence amongst perinatal women. We asked the following questions: "What were women's views of an online treatment for postnatal depression?" and "What factors affected women's uptake and adherence to the treatment?"

2. Methods

Ethical approval for this study was given by the University of Exeter's Ethics Committee. Interview participants for this study were selected from participants in a trial of a minimal support online 11-session Behavioural Activation for Postnatal Depression trial (postnatal iBA; for further details of the trial, please see O'Mahen et al., 2013). In the original consent, participants were advised that the study could involve qualitative components. We followed a two-stage sampling approach. We first purposively divided the original trial sample (n = 910) into sub-categories of theoretical interest for this study (those who completed the end of treatment assessment measures versus those who did not). We further oversampled from those who had accessed the treatment in order to ensure thematic redundancy regarding our research questions regarding the acceptability and feasibility of the treatment. Because the original trial sample was large, we then randomly sampled individuals within our relevant sub-groupings of interest. Our sampling

approach therefore enabled a representative, in-depth analysis of the data representative of our study. Potential participants were contacted via telephone and email within 12 months of completing the treatment. If willing to participate in this portion of the study, participants scheduled a telephone interview. We approached 48 participants via email; of these 22 responded. Two could not be contacted, and 2 withdrew, although they declined to give a reason. One interview was incomplete due to family interruptions. Due to the extent of the incompleteness of the data we removed this interview. We continued with our sampling procedures until we achieved thematic redundancy.

2.1. Participants

The inclusion criteria for the original trial from which women were selected were: aged 18 or older; had a baby within the previous 12 months, an Edinburgh Postnatal Depression Score greater than 12, able to read English, and living within the UK. See Table 1 for a description of the trial characteristics of the 17 interview participants for the qualitative study. Of the participants, only 1 at the point of interview (within 12 months post-treatment) had an EPDS greater than 12. The majority (83%) of women were in treatment condition, and 2 of the 3 women in the wait list control condition had since accessed the treatment at least once. Rates of treatment and trial completion were consistent with rates in the larger study (see Table 1). Eighty percent of women were in a relationship, and the majority were employed or studying. There was broad socioeconomic and educational representation (see Table 1).

Table 1

Characteristics of participants.

Baseline characteristic	Intervention
Age (years) (n, mean (sd))	31.3 (3.95)
Income (%, n) <£10,000 £40,000-£49,999 £60,000-£69,999 £70,000-£79,999 £80,000-£89,999 >/£90,000	10 (2) 30 (5) 10 (2) 10 (2) 20 (3) 20 (3)
Work status (%, n) Homemaker/maternity leave/disability leave Full or part-time employment Student or volunteer	40 (7) 40 (7) 20 (3)
<i>Relationship status (%, n)</i> In a relationship Not in a relationship now	80 (14) 20 (3)
Qualifications (%, n) None Secondary Post-16 First degree of higher degree	10 (2) 30 (5) 40 (7) 20 (3)
Number of children (%, n) 1 2	56 (10) 44 (7)
EPDS Baseline Time of qualitative interview	16.93 (7.75) 5.03 (5.26)
<i>Randomization status</i> Wait list control Treatment	17 (3) 83 (14)
Treatment completers Completed treatment Did not complete treatment	35 (6) 65 (11)
<i>Trial completers</i> Completed trial Did not complete trial	57 (10) 43 (17)

2.2. Qualitative study

A semistructured interview guide was developed by the study investigators with the goal of eliciting perceptions of desired thematic content for participants' experiences of the intervention and factors affecting adherence. This was (see Table 2) based on a review of the literature, the investigators' clinical experience, initial quantitative input from participants in the baseline interview, and from service user input. We modified the interview guide iteratively, as the interviews and concurrent data analysis proceeded, to incorporate new information and to focus progressively on emerging themes.

Interviews were conducted via telephone between August 2011 and December 2012 by female bachelor's level research assistants not involved with data collection from the main trial. The research assistants were trained in qualitative interviewing and coding by HO and JW and were provided with ongoing supervision by either HO or JW during interviewing and coding. The average duration of an interview was 60 min. Interviews were audio-recorded and then transcribed verbatim.

2.3. Data analysis

We employed a thematic analysis approach, drawing on principles of grounded theory to identify themes of individuals' views of the treatment and factors affecting treatment adherence. These principles included constant comparison of participant responses concurrent with data collection and identification of themes from the data. Study findings were developed through a group consensus process with three content experts (three psychologists). We developed codes from the raw data, based on common themes we identified as analytically relevant to addressing our research questions. We were also guided by sensitizing concepts from behavioural activation theory and the broader internet literature on the acceptability of online interventions. An iterative process was used to compare results until agreement was reached on code definitions. At least two research team members independently coded each transcript and compared coding. The agreed codes were then used in the interviews. Coder agreement, calculated using the last five interviews coded, was 81%. We used NVivo 9 software (QSR International) to produce code reports and diagrams of inter-relations between codes, which were summarized by the investigators. The analysis team met regularly to review the code summaries and discuss and interpret the data in light of the original study purpose, with a focus on

Table 2

Interview guide.

- What did you want from treatment?
- Why did you go for an online treatment?
- What were your expectations of what an online treatment might be like?
 What kind of support would you generally want from treatment? What did you expect you'd get from this treatment? What kind of support would you ideally like to get from a treatment like this? Given that, what did you think of the support you did get in the treatment? Would you change that? If so, how?
 For those in the treatment condition:
- Now that you've participated in the course, what kinds of thing would you want from a treatment?
- · What were your impressions of the Netmum's self-help course material?
- What did you like and what didn't you like?
- · What encouraged or discouraged you from continuing?
- What were your experiences of the treatment(s) you used specifically? What did you find helped? Was there anything you found unhelpful?
- How do you feel you will be able to continue using the self-help strategies you have learnt?
- Is there anything you would change about the treatment to make it better?
- Have you received treatment for postnatal depression before? If so, what kind of treatment? If so, how does the Netmum's course compare to the treatment you have previously received?

informing practical recommendations for improving online postnatal depression treatment engagement and adherence. The credibility of study analyses was enhanced by detailed data from in-depth interviews, rigorous code development, and the group consensus process.

3. Results

The main themes emerging from women's interviews were around the motivators and barriers to treatment adherence. As illustrated in Fig. 1, these factors were interlinked and collectively contributed to a sense of isolation. Feelings of isolation contributed further to feeling overwhelmed and unable to adequately proceed with the treatment. To manage these barriers and their subsequent negative effects, women predominately proposed providing support, specifically telephone based support.

3.1. Themes

3.1.1. Relevance to lifestyle

All women discussed the treatment in relation to their personal circumstances, reporting that they wanted the content of the treatment to be relevant to their needs. Treatment relevance was an important factor concerning both the mode of delivery and treatment content.

Regarding the treatment content, a number of women expressed a strong need to have content relevant to their particular circumstances. Some women reported forming a personal connection with the example mothers, as they could relate to their daily-life problems, which encouraged them to adhere to the treatment and follow their story throughout.

"... the online course, it was tailored to my needs at the time and I think that's how it helped so much."

[participant 2]

Alternatively, other women found the examples irrelevant and struggled to apply the treatment to their personal situation, which for many led to discontinuing the treatment.

"I struggled to recognise things that were useful examples from day to day life."

[participant 5]

Some women noted that they immediately noticed the relevance of the content of the treatment to their circumstances, and were reluctant to continue with the treatment when the content was not immediately relevant to them. Women particularly requested content around relationship difficulties, parenting, sleep, and managing the transition to motherhood.

Regarding the relevance of treatment delivery, a number of women reported that they initially found an online approach appealing because it was flexible and fit with the unpredictable demands of motherhood. Women commented that being able to access treatment emails conveniently from home, and having the ability to complete as little or as much treatment as they had the opportunity to do at any given moment enabled them to continue working with the treatment, when otherwise transportation or childcare needs would have interfered with their ability to continue the treatment.

"It was just there ... that you could dip into and dip out of." [participant 10]

Other women, however, found the flexibility of the treatment difficult to manage, preferring a more routine treatment schedule. This was particularly difficult for women who reported they lacked motivation. For women in areas where perinatal treatment was not readily available, or National Health Service treatments had long wait lists,

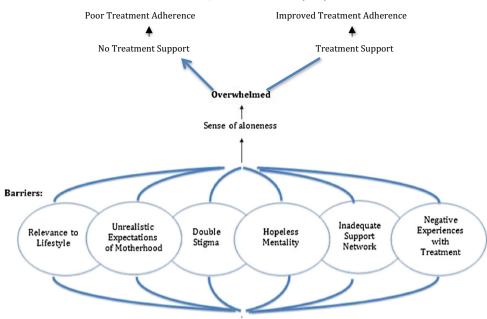


Fig. 1. Women's perceived barriers to treatment adherence.

and private treatments were costly, the women stated that they appreciated having a no-cost treatment alternative.

3.1.2. Unrealistic expectations of motherhood

Many mothers stated that their hoped-for expectations of motherhood did not match their actual experiences. Instead, a number of women's accounts of motherhood were characterised by negativity and feelings of disappointment. Their descriptions ranged from babies with a challenging temperament to difficulties with sleeping and feeding. A small number of women also reported struggles bonding with their child, feeling confused because they had anticipated feeling excited about being a parent. Some women reported that they felt deskilled as a mother, when previously they were successful or had achieved at work.

"... baby whose behaviour was such that I couldn't have imagined it would be so dreadful."

[participant 16]

By drawing comparisons with other mothers, these feelings of disappointment were compounded as women felt that they were inadequate mothers. They described feeling that an idealized form of motherhood was unattainable for them, and this contributed to feelings of being overwhelmed. Some women internalized their sense of inadequacy.

"I'm just like a complete mess and I'm obviously doing something wrong."

[participant 12]

These mothers perceived the possibility of change to be overwhelming. They stated that the demands of motherhood directly interfered with their ability to complete weekly treatment tasks, and this resulted in further feelings of hopelessness. Mothers who attributed their difficulties with motherhood to their babies perceived their depressive symptoms as modifiable, and treatment as useful. In those cases, women were more likely to have progressed further with treatment.

3.1.3. Double stigma

Many women in this study expressed an acute awareness of the stigma surrounding depression and explicitly commented on negative images of PND that are portrayed in the media. These women subsequently reported feeling shameful and secretive about their condition. "None of us have ever admitted to having post-natal depression ... there is still such a stigma it's incredible."

[participant 3]

A number of women stated that they felt they would be judged if they sought help, fearful others would belittle their struggles or would perceive them to be inadequate mothers. Some women found the privacy and anonymity of an online treatment reduced stigma and encouraged adherence. Others reported that their worries about stigma interfered with their ability to carry out treatment activities. These women, aware of stigma, had retreated from social contact. As the treatment is built around re-engaging in meaningful activities, many of which involve social contact, women with high stigma concerns struggled to complete these tasks.

3.1.4. Barrier: hopeless mentality

A number of women struggled with feelings of hopelessness regarding the efficacy of treatment.

"Think I'm going to feel like this for the rest of my life ... it's because it's like being stuck in a fog."

[participant 5]

For these women, if they were unable to complete sessions, they reported that they interpreted this as confirmation of their inability to change, and of depression's permanence.

Women's beliefs about the cause of their depression influenced their beliefs about treatment. For example, women who reported that their depression was genetic expressed hopelessness about the efficacy of a behaviourally oriented internet treatment for PND.

"If I've got a predisposition to it ... it's probably more chemical than just something that can be changed by my behaviour."

[participant 8]

Others reported that the treatment helped them to realize that other mothers also felt similar to them; these normalizing experiences helped some women to feel that there was hope for improvement.

3.1.5. Negative Experience with previous treatment

Many women reported previous negative experiences and poor quality of therapeutic treatment. Many women spent months being referred to different services with a large time lag between diagnosis and receiving treatment. Their accounts illustrated feeling disillusioned with health services, painting a picture where these women felt unimportant and had increasingly low self-worth. In some cases women became dejected and ended up begrudgingly accepting medication.

"They just seemed to tick the boxes, they don't seem to be personal enough."

[participant 11]

Consequently, these women had low expectations of this treatment and some discontinued with the treatment, as they needed regular reassurance and support that it would not replicate previous treatment experiences and have a detrimental effect. Other women reported that they preferred face-to-face treatment. However, faced with a lack of access to appropriate face-to-face treatments, they had signed up for the internet treatment out of curiosity, but with low commitment.

3.1.6. Barrier: inadequate support network

Almost all the participants expressed a lack of support from family and friends. In some cases women had virtually no access to any form of family support. Collectively, the lack of support from neither family and friends nor professionals resulted in women feeling helpless and isolated, both practically and emotionally. The majority of women described wanting support, for instance encouragement to carry out challenging parenting tasks on a day-to-day basis or overcoming emotional struggles. Ultimately without adequate support women were overwhelmed by the struggles of not only motherhood but the treatment itself.

"The feeling of isolation and aloneness and no hope is overwhelming."

[participant 9]

A number of women reported that they felt that without personalized email or telephone monitoring by professionals, it was easy to fall behind, lack motivation and drop out of treatment.

3.2. Suggestions for treatment improvement

3.2.1. Interactive

Many women proposed making the treatment more interactive. This included boxes to write answers and comments in which would enable women to use the online format as a kind of "workbook" with spaces for responses that could then be saved. These women felt that direct involvement with the treatment would help them connect with the material.

"You could write into the templates themselves ... then it becomes yours."

[participant 10]

3.2.2. Individualised

A theme that repeatedly appeared across accounts was the need for treatment to be more personalized: having treatment that was tailored to participant's individual needs. For example, some women requested having modules to choose from, following a broader range of examples relevant to their own circumstances, or having flexibility to look at the treatment when it was convenient to them.

"Almost doing a module yourself when you are ready to do it." [participant 6]

Some women also expressed wanting a modular approach as a way of immediately engaging them with content that was relevant to their needs.

3.2.3. Therapeutic support

Many women stated that they felt unable to complete the treatment without some additional support, particularly in the context of having inadequate support in their own lives. Participants described wanting help working through the treatment, encouragement and personalized guidance.

"Some way of actually talking to somebody about what was happening."

[participant 14]

Women most frequently suggested regular telephone support provided by someone who trusted and linked with the treatment (e.g., trained, supervised peer supporter), or a mental health professional experienced with postnatal depression.

"A repeated contact with one person not, not an anonymous thing." [participant 5]

A number of women stated that support was crucial to overcome their feelings of being overwhelmed and isolated.

4. Discussion

The efficacy trial was marked by both high initial interest and high levels of attrition. The results from this embedded qualitative study suggest that women sought out an online postnatal specific treatment for a number of reasons, including: curiosity, last hope, stigma, preference for anonymity, and flexible treatment delivery. Women's treatment adherence was strongly impacted by factors that contributed to them feeling overwhelmed. These reasons were both practical and psychological in nature, and were often specific to the perinatal period. Women suggested that personalizing the treatment material and providing support would reduce the impact of these factors and improve treatment adherence.

The results from this study and the efficacy study are consistent with the broader literature on pure self-help interventions, which have found high rates of access, but low treatment adherence in interventions that offer simple access (e.g., a brief demographic and mood screen) compared to treatments offered as part of research trials, which often reguire participants to complete a series of guestionnaires and a clinical interview prior to accessing the treatment (Spek et al., 2007). The former, Eysenbach (2005) argues, encourages "curiosity seekers" who are interested in exploring a treatment. However, these individuals may be ambivalent about engaging with or completing the treatment. Consistent with this idea, some of the women in this study indicated that they were either curious about the treatment itself, or preferred faceto-face treatment, but found it was not currently available in their area. Treatments that use an open-access approach may serve a psychoeducational function for some individuals, who can explore the treatment content of a given approach, and may then choose to pursue that treatment or additional treatment in another fashion. Studies that track the health care utilization patterns of online 'curiosity' treatment users over time are needed.

A number of women in this study reported that the personal relevance of the content of the treatment and the flexible delivery approach were appealing. This is consistent with qualitative and quantitative studies that have reported women in the perinatal period struggle with practical and logistical barriers to treatment that are unique to the perinatal period (e.g., changing infant feeding and sleeping schedules) (Goodman, 2009; O'Mahen et al., 2012). Although the flexible delivery approach of internet treatments may be especially useful for this group, the results from this study suggest that tailoring the level of flexibility versus routine is critical to ensuring adherence.

All women reported that the perceived relevance of the content of the treatment affected their engagement with and adherence to the treatment. Women reported that it was critical to be able to immediately access content that was relevant to them. When this happened, women stated they were more likely to continue with the treatment. Perinatal specific content was especially important to women. Women expressed a desire for information on parenting in the context of PND, managing the transition to motherhood, content on communication and eliciting support, managing maternal sleep in the postnatal period, and anxiety, particularly social anxiety as it impacted on women's ability to integrate with other new mothers. Treatments that include a wide variety of treatment examples, modular and/or adaptive content can help ensure that individuals can personalize materials (Donkin and Glozier, 2012). This will help ensure that women are able to immediately access treatment relevant content. In addition, support offered in blended treatment approaches may further assist participants in personalizing treatment content.

There was a complex relationship between women's beliefs and cognitions and their adherence to treatment. Although all women struggled with depressive symptoms, for some, the hopelessness associated with depression permeated their belief that they might improve. These women were also less likely to adhere to the treatment. Further, although most mothers described feeling overwhelmed at the mismatch between the realities of motherhood and their expectations, only those who internalized responsibility expressed struggles to adhere to the treatment. Women who believed that their depression had a genetic cause reported that they were less adherent because they didn't think that psychological approaches would help. These findings are commensurate with previous quantitative and qualitative research, which has found that both attributions for low personal control and participant beliefs about the causes of their mood were associated with poorer treatment adherence (O'Mahen et al., 2009; van Schaik et al., 2004; Weich et al., 2007). Together with previous research, this study suggests that adherence to treatment may be improved by addressing individual beliefs about treatment modalities, both at the beginning of treatment, during the engagement process, and throughout the treatment itself.

Consistent with the broader literature on internet interventions (Kelders et al., 2012; Spek et al., 2007), women in this study reported that the provision of support would have the greatest impact on their adherence to treatment. Support was not appropriate for all, as a minority worried that it would reduce the anonymity of the treatment. However, support emerged for most as an important counter to women's poor practical and emotional support, and their sense of being overwhelmed. This was important both in their broader lives and with their ability to undertake treatment. Recent reviews suggest that minimal support (e.g., email) may be sufficient to improve adherence and treatment outcomes (Farrand and Woodford, 2013). However, most of the women in this study requested telephone support. Research examining predictors of treatment support needs will help to tailor support intensity per individual need. This idea is consistent with another gualitative study of internet based treatment for depression that found that different levels of support may be appropriate for individuals at varying stages of change (e.g., action) (Bendelin et al., 2011).

4.1. Limitations

This was an in-depth study of a sample of individuals involved in a larger study of an internet intervention for postnatal depression. Consistent with qualitative methodologies, we continued to interview individuals until we reached thematic redundancy across a range of individuals with different experiences of the intervention. Although this approach helps to ensure that we achieved a level of representativeness regarding the views of participants, we note that the results cannot be necessarily generalized to all individuals who received the treatment, nor to the larger population of women suffering from postnatal depression. The qualitative sample was diverse in terms of economic status and educational level, but only had two women with more than one child, and one woman who had not recovered in terms of mood. Further, all women from our qualitative sample were White/British. We also conducted interviews with women in the year following the termination of the study. Women's varying times from completion of the treatment may have impacted their respective recollections of the study and treatment.

In this trial, women were recruited solely from Netmums.com. They were therefore at least somewhat familiar with the internet, and had used the internet to seek out advice/information about parenting. An internet based intervention may have been particularly acceptable to this group of women compared to women who seek treatments in primary care or other settings and therefore have different expectations of what treatments might be acceptable (e.g., face-to-face).

5. Conclusions

The findings from this study are consistent with the broader qualitative literature on factors affecting adherence to face-to-face treatment for postnatal depression, and specifically highlight the role of internet based treatments for women struggling with stigma, and practical barriers to treatment. Whilst also broadly consistent with the adherence and acceptability literature on internet treatments, this study emphasizes the unique needs of postnatal women regarding engagement and adherence, highlighting the importance of considering the dyadic nature of the mother and infant and its effect on maternal expectations and attributions for treatment. This study may therefore contribute to the refinement of internet and face-to-face treatment delivery designs, focusing on methods to improve engagement and adherence to treatment.

Acknowledgements

We would like to thank Netmums.com for their inspiration and continued support throughout this project. Specifically, we would like to thank Sally Russell, Liz Andrews, and Mary Duggan.

We would also like to thank the mothers who participated in the trials and those who provided support to the chat rooms. We acknowledge funding from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for the South West Peninsula. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health in England.

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