#### Effectiveness of a peer support intervention for Antenatal Depression: <u>A feasibility study.</u>

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## Abstract

### **Objective**

A feasibility study for a randomised controlled trial to assess the acceptability, recruitment, feasibility and effectiveness of a peer support intervention for women with antenatal depression. The key premise of peer support is based upon the trust and empathetic understanding engendered by common experiences.

## <u>Method</u>

Twenty pregnant women were recruited by their community midwife using the Whooley questionnaire (Howard et al 2018) at between 28-30 weeks' gestation to ascertain their level of mood and general mental health.

Women identified as having potential antenatal depression were randomly assigned into a control group (routine care alone which includes contact with a midwife and in some case an obstetric Doctor with access to a GP if required) or intervention group (6-weekly visits from a peer support worker in addition to routine care). Participants from both the control and intervention group, and the Peer Support Workers (PSWs) were then interviewed at the end of the sixweek period. All participants, and the PSW's, were also asked to keep log books during the trial to record their feelings and experiences. The results were then analysed using thematic analysis.

# <u>Results</u>

The analysis of qualitative data from the PSWs, and the participants in the intervention group, suggest the peer support intervention is acceptable, helpful and supportive to both pregnant women and, indeed, the PSWs. The women within the intervention group valued the peer support highly, reporting that being able to speak openly to a PSW meant that feelings of alienation, abnormality, isolation and stigma were replaced with social support, confidence, self-esteem and hope for recovery. The PSWs reported a positive impact upon their own wellbeing and a realisation that they had, indeed, moved forward with their lives. A proportion of the women randomised to the control group described feelings of disappointment and frustration with the lack of support currently available to them.

# **Conclusion**

This feasibility study suggests a full randomised controlled trial (RCT) is warranted given the high recruitment, adherence, and acceptability of the intervention to participants.

# **Introduction**

# **Background and Justification for study**

Perinatal mental health is a major public health concern due to the effect on mother and baby and carries a significant UK economic cost of approximately £8.1 billion per year, equivalent to approximately £10,000 for each UK birth (Bauer et al., 2014). Perinatal mental health research has traditionally focused on maternal postnatal depression (PND). However, antenatal depression has a similarly high incidence of 10-20% in developed countries (Biaggi et al., 2016), and is associated with psychological and physical morbidity, including poor birth outcomes, increased risk of maternal suicide (Royal College of Midwives (RCM), 2015), and emotional, behavioral and cognitive difficulties in offspring (O'Connor et al., 2003). It has been suggested that screening and support for perinatal mental health should begin in the antenatal period (National Institute of Clinical Excellence (NICE), 2014; Howard et al 2015). NICE perinatal mental health guidelines (2014) recommended that all pregnant women should be asked about their mental health, using the Whooley guestionnaire, at their initial appointment with their midwife and then at every contact following- thus enabling the recognition of potential problems early and signposting to relevant agencies (NICE 2014). Affected women have previously highlighted the lack of tailored support for perinatal mental health and service provision, with the quality and availability of these services often depending on where you live, with inequality in provision existing (Cust, 2016a,b; Odette et al 2015).

Previous qualitative studies suggest that women with mental health issues value peer support as an effective intervention (MacLellan et al 2015, Cust 2016). Such studies have explored some of the mechanisms of peer support that have benefitted woman (Pfeiffer et al, 2016). These include being able to speak openly to a peer who has experienced similar feelings of

alienation, of feeling abnormal, isolated and experiencing stigma. Findings from these studies have included feelings of increased social support, confidence, selfesteem and hope for recovery (Dennis, 2010; Jones et al, 2014; Letourneau et al, 2007; Mauthner, 1995; McLeish and Redshaw, 2017a, Cust 2016).

Pfeiffer and colleagues (2011) state that additional studies are needed to determine the effectiveness of PSWs in primary care and other settings with limited mental health resources.

# The proposed intervention

The role of PSW is based on the premise that people with similar experiences can authentically support others with similar issues (Davidson et al 2006). Peer support may be mutual (between people who are currently unwell, in a group, or an online forum) or unidirectional (between a trained peer supporter who has recovered and a recipient who is unwell). As a form of social support, it is often conceptualised as comprising emotional, appraisal (affirmational), and informational support (Dennis 2003). Different forms of organised peer support have previously been found to be effective in preventing and/or reducing PND among high-risk women and assisting recovery in women who have PND (McLeish and Redshaw, 2017a,b; Cust 2016a; Carter et al., 2018), for example, group peer support (Jones et al., 2014); telephone support (Dennis et al., 2009; Letourneau and Secco, 2015); and individual peer support (Cust, 2016a). This study uses a model of individualised peer support. The aim of this feasibility study (a randomised controlled trial) was to assess the

recruitment, acceptability and effectiveness of six weekly, one-hour peer support visits for women with antenatal depression in comparison to a control group of women receiving standard care alone (midwifery support and GP). <u>Ethics</u>

This research was a feasibility study using a randomised controlled trial (RCT). University Ethical approval was obtained in addition to ethical approval from the NHS health research authority- IRAS project ID 226165 and REC reference 17/WM/0202.

## PSW's

The PSW's were mothers who had suffered previously from antenatal depression but had recovered and were not receiving any form of psychotherapy or taking antidepressant medication.

The PSW's were recruited via an advertisement that was placed in two local health centres, and within the information point at the University campus where the research team are based. The aim was to recruit five PSW's. Eight applications were received and reviewed, and six applicants were invited for interview. Five PSW's were recruited and four provided peer support. The fifth PSW being unavailable due to workload and family demands.

An NHS site organised, and funded, both the references and the disclosure and debarring service (DBS) for the PSW's. The DBS information is legally required for any volunteer or employee who will be working with either children or portentially vulnerable adults.

A two-day training session was delivered to the five PSW's in which they were provided with a full explanation of the study both verbally and in written format, the aims and objectives of the research study, safeguarding/child protection, the importance of maintaining confidentiality, and the role of the PSW. Two members of the research team led the training sessions (both hold teaching qualifications and are registered practitioners). There was no formal training in terms of counselling methods - the aim of the study being to ascertain what effect, if any, receiving support from a peer who had experienced depression in the antenatal period would have. The PSW's simply wanted to provide support to the women as a fellow 'mother to mother'. They wanted to listen, guide, and support in ways that may have helped them when they were experiencing similar emotions. They were all unanimous in the decision not to receive any formal style of therapeutic training. The PSWs were also asked to sign a consent form to say that they had received information about the study and understood that they could withdraw from the role at any time.

#### Participants

Twenty pregnant women were recruited. The inclusion criteria being that all participants were English speaking, approximately 28-30 weeks' gestation, and first-time mothers with no previous history of mental health issues, miscarriage or still birth. The ten women who were randomised to receive peer support received all six sessions of peer support. The participants randomised to the control group did express their disappointment at not being allocated a PSW but continued and completed the study. The participants were recruited by their community midwife between 28-30 weeks' gestation using the Whooley questionnaire. The midwife gave an information sheet and, briefly, discussed the study with the potential participant. If the participant was interested in taking part, their details, with their consent to share these, were forwarded to a member of the research team. A member of the research team contacted the pregnant woman and discussed, over the telephone, the finer details of the study. If she was keen to take part the researcher visited the woman in her own home to gain consent and to ascertain full comprehension of the study.

All participants were randomised by a computer-generated package and assigned a number which placed them either into the intervention or the control group. The intervention continued for a six-week period with a one-hour visit scheduled by a PSW each week. The visit was arranged in a venue agreeable to both the PSW, and the woman, to ensure that both parties felt as comfortable as possible.

#### **Method**

Ten women were randomised into the intervention group (peer support in addition to routine care), and ten women randomised into the control group (routine care alone). The PSWs and the women participating, both in the control and intervention group, were asked to keep a log book recording and reflecting upon their meetings. They were asked to maintain this for the six-week intervention period. Following completion of the six-week period the research team contacted all participants and a semi structured telephone interview was arranged within a two week period. The interviews were, with consent, audio recorded and subsequently transcribed.

Semi structured interviews were chosen because the interviewer still required the option of a clear list of issues to be addressed and questions to be answered (Cust 2014). The questions had been devised in collaboration with local stakeholders including midwives, health visitors and mothers who had recovered from previous perinatal mental health issues. The interviews took place over the telephone at a time to suit the interviewee The interviewer had a quiet and private room to conduct the telephone calls, and the interviews lasted approximately 30 minutes. Nine women from the intervention group were interviewed and six from the control group. The same researcher carried out all of the interviews to ensure that the process was standardised as much as possible.

OutcomeThis study created a large amount of rich qualitative data, which was analysed by the researchers using a thematic analytical approach (Denscombe 2014). The data from both the log books and the telephone interviews was scrutinised and initial themes emerged, these themes were then reviewed, and subsequently defined and categorised. Following the defining of the themes the participants were contacted again, by telephone, to ensure that a correct comprehension of their data had been interpreted by the researcher.

# <u>Analysis</u>

Nine participants from the intervention group and six from the control group were interviewed. Four participants from the control group did not consent to interview. One participant from the intervention group was unable to consent to interview due to unrelated health issues. Four PSW's were interviewed. All participants from the intervention group completed the six-week intervention.

Data was also gathered from the logbooks of PSWs and participants, and the semi structured telephone interviews with participants in both the control and intervention group. A thematic analysing of data was utilised to attempt to identify common themes within both the logbook recordings and the data from the

telephone interviews. The information was read and re-read, and recurring comments were highlighted. This enabled the research team to explore and provide clarification of the themes that emerged.

For ease of reporting, these themes are divided into sections related to which group the participant belonged to.

# **Results**

#### **Intervention Group**

#### Six themes arose from the interviews, and also reflected the findings from the data taken from the log books. These are discussed as follows,

#### 'Time to spend'

As demonstrated in an earlier study (Cust 2016a,b), several participants within the intervention group reported that they really appreciated having time to spend with their peer support worker. This theme assisted in the demonstration that the intervention was acceptable to the participant.

They felt that time was being provided to focus on this aspect of their health, concentrating on issues concerning their mental health. This was in comparison to their previous contact with health professionals, in particular midwives, where there was a lot of time spent *'form filling and providing routine information about themselves'*, within a relatively short appointment time. *`It was nice to be able to talk to the PSW without feeling that they were in a rush, disinterested, or that they had a tick box checklist that they had to get through.' (Millie)* 

#### 'Empathy' 'lived experience of the PSWs',

The theme of PSWs providing empathy and sharing lived experience became very apparent in the data collected. This theme also demonstrated that the intervention was acceptable to the participants and was effective in terms of enabling participants to `*open completely and connect with their PSW'*.

*`I felt that the PSW had been exactly where I am now. She really understood me and I felt that she could genuinely feel the absolute turmoil that I was living every day.' (Claire)* 

## 'Non-judgemental',

The participants often perceived, unfortunately, that they were being negatively judged by the health care professionals that they had previously had contact with. This was not the case with the PSWs, and several participants stated that they felt that they could say anything to their PSW without the fear of `*being judged*.' Quotes such as the following were typical,

*`She put me at ease. I don't always feel I can say what I am thinking to the midwife, I always feel as if I'm being judged, but this was a whole different situation. I could finally talk openly about how I really felt.' (Kirsty)* 

#### 'Gap in services',

While the postcode lottery of services for perinatal mental health has been highlighted, all participants stated that there was a lack of services for those women who were not '*suicidal*' or '*psychotic*', but still desperately needed support.

*`I was pleased to experience help from a PSW, there doesn't appear to be a lot around unless you are actually feeling completely suicidal, in fact there doesn't seem to be anything at all' (Sophie).* 

#### 'Fear of intervention ending.'

As again demonstrated within earlier research, Cust (2016), four of the intervention group participants expressed feelings of concern and anxiety leading up to the completion of the support visits.

*`I wondered how I was going to cope without my support from my worker, particularly before my last visit.' (Carly)* 

'I dreaded my visits ending, I was really going to miss this support.' (Emma) 'I really can't think about the visits ending, they have helped so much.' (Catherine)

#### 'Making a difference'

A resounding theme that emerged frequently within the data by all women within the intervention group was that their PSW '*really made a 'difference'*. The participants felt that the peer support made a positive impact upon their mental wellbeing, and how they now felt about their pregnancy. Further comments included,

'I feel much stronger now and I am actually looking forward to meeting my baby. I don't just see my baby as an 'it' but actually feel it is 'my baby'.' (Rebecca)

#### Control Group

The two themes that emerged from the control group participants were also categorised and are as follows,

## 'No help available'

The control group described their feelings of '*despair and frustration'* at the lack of appropriate help available.

They all expressed feelings of '*disappointment' and 'despair'* that they were not allocated into the intervention group.

- `I was delighted when I heard about this intervention as I was aware that I really wasn't feeling great. I felt so very disappointed not to be receiving visits from a peer support worker. I guess it's good though to know that mental health is not being ignored.' (Fay)

# 'Stigmatised'

The participants in the control group also described feeling of being '*judged'* and '*stigmatised'*.

All were very aware that professionals have limited time to spend with them and this often made them feel that they were an `*imposition.'* 

Women within this group felt that professionals had `*little understanding*' and demonstrated '*text book empathy.*'

*`Often the midwife starts off by asking, are you feeling any happier today, it's the way she says it - as if I really should be feeling great and if not, why on earth not?' (Amy)* 

The research team feels that the above exerts help to demonstrate that there was a perceived need for this proposed intervention and that the intervention was acceptable.

#### Peer Support Workers

# The five themes that arose from the interviews with the PSWs are as follows,

#### 'Felt useful and purposeful`

A number of the PSWs commented that being involved in providing this intervention had made them feel '*useful'*. They all commented that it had felt '*uplifting*' to be able to use what had been such '*a negative experience in such a positive way'*. Three of the PSWs commented that they felt that it would have been very difficult for them to have delivered the intervention if they did not now feel mentally strong having received some form of help themselves.

*I felt as if this was my purpose, that I had been given the opportunity to give something back, that something positive had to come out of the terrible time that I had had. (Kay)* 

# 'Recognition of progress made in their own mental health journey`

Two of the PSWs reflected that during the intervention they had a `*light bulb*' moment when they realised how far they had come in their `*own personal recovery'*. They described it *'as a huge feeling of relief.'* 

'Providing the support to my lady made me recognise my own strength, how ill I had actually been but how hugely different I now felt. It was therapy for me too!' (Sharon)

## 'Need for Supervision'

One of the PSW's commented how distressing she had found a visit in which the woman had shared her previous traumatic history. Following the visit, she realised she needed to contact the research study supervisor and received appropriate support.

*`It just bought memories flooding back, it was, at that moment, just too close to home, I recognised that I needed to gain some support from the supervision team – which I did and it really helped.'*(*Laura*)

#### 'Guilt`

Two of the PSWs felt that there should not have been a time limit on the intervention. They felt a natural conclusion to the visits would have been more acceptable. They described feelings of guilt at providing all the support and then '*withdrawing their help'*. And simply '*abandoning their mother'*. '*I wish that I could have visited for longer, that I could offer support until it was felt that my job had been completed. I felt guilty when the visits came to an end.'(Sharon)* 

#### 'Help not Hindrance'

Three of the PSWs described their feelings of anxiety as to whether they were really making a difference. One of them expressed concern that by encouraging the participant to `*concentrate on her feelings she was perhaps having a negative impact'*.

'I worry that I am asking her to focus upon her negative thoughts too much, should I just try to get her to think positively? But then I don't feel that that is what I would have wanted. I wanted to talk about how dreadful I actually felt.' (Molly)

#### **Discussion**

The aim of this feasibility study was to review the recruitment of participants and PSW's, and to establish whether the support provided by a PSW with previous experience of antenatal depression was feasible, and if the intervention was acceptable to a woman with existing antenatal depression. The researchers also wanted to assess whether such an intervention was robust and advantageous, in comparison to existing services.

The recruitment process of the participants by the community midwives took longer than the research team anticipated. This may have been due to inadequate preparation of the community midwives by the research team or a confusion as to whom the midwives should directly liaise with within the research team. Recruitment of the twenty participants was achieved over a 4 week period. However, it is recognised that not all community midwives participated in recruitment and there were 2-3 'champions'. Without their support recruitment would have taken a lot longer or may not have been achieved at all. This does demonstrate how important the communication and time spent discussing the outline of the study with the community midwives was in terms of gaining their support.

The Whooley questionnaire was used for this study as this was the existing method of screening used by the participating Trust. However, the simple yes/no response to only a few questions made it difficult to grade/score the level of antenatal depression that participants entered the study with.

The research team felt that participants in both the control and intervention groups should be made aware, from the beginning of the study, that they could contact a member of the research team (both professionals within the field) should they have any issues concerning their PSW. Each participant was provided with the relevant contact details. One participant did contact a member of the research team during the study. This highlighted the importance of this communication channel as if this support had not been available a participant may have discontinued her involvement in the study and, indeed, left with negative connotations – missing the potentially valuable opportunity of support from a PSW. Feeding this back to the PSW in question was rather sensitive, but necessary, and the PSW was reassured that this was not a personal sleight. Further supervision and support was provided to the PSW.

As already discussed, all ten women in the intervention group reported the intervention as being acceptable, highly supportive and useful. The women appreciated the feeling that the PSW's had time to spend, focusing solely upon them, and the issues concerning their mental health. They felt that the PSWs demonstrated empathy and understanding. Four of the ten women did comment that they had experienced some feelings of concern and anxiety leading up to the completion of the support visits. It could be argued that this demonstrated dependency on the PSW. Whilst this may appear concerning, the research team reflected that these women did receive enhanced support in comparison with their peer group (other pregnant women with antenatal depression in this area), and routine care from maternity services was still provided. In terms of the benefits of the intervention it was agreed by all four women that these far outweighed any negatives. Sadly, both the PSW's and all of the participants that took part in this study commented on the lack of services available in the area for women suffering from depression in the perinatal period. The team are aware of the deficiency in traditional perinatal mental health services (counselling, listening visits from health professionals and anti-depressant medication), and it could be questioned whether the need is not for this intervention, but for more effort to be put into finding funding for traditional therapies in this area. However, this study has added to the growing body of evidence that 'lived experience' is invaluable - and that is what the PSW's did indeed provide.

The PSWs commented that they felt participation in this research had been positive in terms of reflecting upon their own mental health, and how far they had progressed in their own personal journey. This is an interesting reflection, and an unexpected outcome of the intervention. Whilst we had hoped that the intervention would make a difference to the participants, we did not envisage that it would have such a positive impact upon the PSW's too. On one occasion, a PSW became concerned as to how traumatic she had found it when a woman confided openly to her - including events that had occurred in her childhood. The PSW realised she needed to contact the research study supervisor and she received support. This highlights the requirement for robust, protected supervision, which has been recognised and encompassed into the grant for a larger, future study.

It may be considered that the 'hoped for' targets of the intervention have been met in relation to how the participants found the support from their allocated PSW, and surpassed, in relation to how the PSW's felt about the support they offered and their own position of recovery.

#### **Recommendations**

A finding echoed in a previous study (Cust 2016) is that prior to the participation of PSWs in providing support to women it is vital that they are sufficiently recovered from their own antenatal/postnatal depression. This is to ensure they are not vulnerable, and that they are well enough to be able to provide effective support to their participant in a meaningful way. It is recommended that this finding is recognised and addressed in the design of a larger scale study.

As highlighted within the discussion section, recruitment of participants by the community midwives was slower than anticipated. Effective communication between the research team and the clinicians (midwives involved in the recruitment of participants and providing routine antenatal care for women) is imperative – and regular face to face meetings must be arranged to ensure that all parties are fully aware of up to date data and progress within the study. It

is therefore recommended that there is a single, named researcher for the midwives to connect with.

It is important that the PSW's receive relevant training prior to commencing their role and that there is ongoing, robust supervision provided to the PSWs. This should include consideration of the finding of 'feelings of guilt' at the completion of the study that some of the PSW's reported. The PSW's need to be fully aware of what their role may involve, and the commitment required to carry out this role.

The research team also recognise the importance of women being able to change their PSW if necessary, and to have the direct contact details of a member of the research team if any queries/ concerns arise.

The researchers felt that meeting with and having an informal interview with potential PSW's was crucial to enable information to be provided about the study. Based upon this, an applicant may decide that the role, actually, is not right for them, or the commitment is not achievable within their lives.

The interview process also enables a level of assessment to be made as to whether the candidate is at an appropriate stage in their own personal recovery to be able to participate in this role effectively, and safely. An alternative screening tool such as

the Edinburgh Postnatal Depression Scale (EPDS) alongside a clinical, diagnostic interview may be better suited to enable a scoring process and subsequently allow results to be compared longitudinally. This will assist in enabling the research team to quantitatively assess the impact of the intervention in terms of recovery.

# **Conclusion**

The recruitment and retention of participants to both the intervention and control group was positive. The research team have recognised the importance of assessing the suitability of the PSW - in particular ascertaining whether they are mentally strong enough within their own recovery to be able to fulfil the role. The importance of PSWs being fully informed and that a mechanism exists for both the PSWs and the participants to enable them to contact a member of the research team with any concerns has also been highlighted. These concerns require prompt action and indeed, may include the need to communicate with the community midwife, for example if there are any safeguarding concerns.

The research team were able to gather rich data from both the interviews, and the log books recordings from all participants and the PSWs. The randomised controlled trial (RCT) method was advantageous in enabling comparisons to be made, particularly in relation to whether the routine care women receive with

depression, in the antenatal period, can be improved upon.

Thematic analysis enabled a thorough exploration of the themes embedded within the data. The data showed that this intervention – the provision of one to one peer support for one hour a week, for six weeks, was acceptable and had a positive impact upon women with antenatal depression. The peer support role was also, somewhat unexpectedly, beneficial to the PSWs.

Further, larger randomised controlled trials, within the field of peer support for perinatal mental health are required, and subsequently planned, for the following year. It is hoped that, following on from this small-scale study, funding will be sourced in the future for a much larger exploration into the effectiveness of peer support for women in the antenatal period, identified as having antenatal depression by their midwife.

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