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ORIGINAL PAPER

Barriers to Seeking and Accepting Treatment for Perinatal Depression: A Qualitative Study in Rio de Janeiro, Brazil

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Abstract

Few studies have investigated the reasons why pregnant and puerperal women fail to seek or accept treatment for perinatal depression in low- and middle-income countries, where there is a high prevalence of this disorder. To help fill this gap, this study investigated the factors influencing the decision not to seek or to refuse treatment for perinatal depression in a low-income community in Rio de Janeiro, Brazil. Qualitative research was conducted in two primary health care units in Rio de Janeiro, Brazil in 2017–2018. Five focus groups were held with 26 women. Convenience sampling was used, and the sample size was determined by data saturation. A content analysis methodology was used to identify theme categories to objectively describe the group's manifest contents. Ten categories were obtained: stigma and misconception, self-image as a mother, socioeconomic stigma, lack of knowledge, lack of a health service approach to mental health, difficulty recognising depression symptoms, fear of children being removed, negative reaction to patient referral, denial of the problem and previous experience with the care unit. Perinatal depression is permeated with stigma and prejudice, and there is a belief that women with depression are unable to be good mothers. It is important to conduct programmes disseminating information about perinatal depression and implementing an approach that includes routine consultations so that women can access perinatal mental health services.

Keywords Help-seeking behaviour · Perinatal mental health · Perinatal depression · Screening · Perceptions

Introduction

Pregnancy, childbirth and the postpartum period are events of great complexity in a woman's life, since they require psychological, social and physiological adaptations (Brockington 2004). These changes may lead to the onset or aggravation of psychological problems, with perinatal depression being one of the most common mental disorders during the pregnancy–puerperal cycle (Gavin et al. 2005). Perinatal depression is defined as a major depressive episode (MDD) that occurs during the pregnancy–puerperal period, i.e. symptom onset during pregnancy or in the 4 weeks following delivery (American Psychiatric Association 2013). Prevalence estimates for perinatal depression vary greatly and are relative to location. A systematic review and meta-analysis of 99 papers from low-, middle- and high-income countries reported an overall pooled prevalence of 11.9%. This prevalence was significantly higher in low- and middle-income countries compared with high-income countries in both the prenatal (19.2% vs. 9.2%, respectively) and postnatal (18.7 vs. 9.5, respectively) periods (Woody et al. 2017). In Brazil, a nationally representative study showed that 26.3% of women presented symptoms of postpartum depression (Theme et al. 2016).

Perinatal depression has negative effects on the physical and mental health of both the mother and baby (Dubber et al. 2014; Stein et al. 2014; Fuhr et al. 2014), it can also have direct and indirect economic impacts on society and the public health system (Bauer et al. 2014). Roughly 28% of this impact relates to adverse effects on the mother [health and social care use, productivity losses and losses of quality-adjusted life-years (QALYs)] and 72% on the child (preterm birth resulting in cognitive impairments, infant death, special educational needs, school qualifications, depression and anxiety, and conduct problems). Despite these negative

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repercussions, this disorder remains under-reported and untreated (Brady et al. 2018; Noonan et al. 2017).

There are several reasons why perinatal depression remains undiagnosed and untreated including that pregnant and postpartum women fail to seek or refuse specialised treatment (Darling and Viveiros 2018; Fonseca et al. 2015). Several studies that have explored the barriers to seeking and accepting treatment for perinatal mental health have reported that these barriers include stigma (Bilszta et al. 2010; McCarthy and McMahon 2008), lack of knowledge about perinatal depression (Hadfield and Wittkowski 2017; Kopelman et al. 2008), difficulty differentiating between normal gestation and postpartum states and depressive symptoms, the demands of childcare, negative experiences seeking help from mental health professionals in the past (McCarthy and McMahon 2008), feelings of shame, fear of being seen as a bad mother, fear of children being removed, distant service location and the cost of treatment (Darling and Viveiros 2018).

Nevertheless, the majority of these studies have been conducted in developed countries, with insufficient data from low- and middle-income countries (Hadfield and Wittkowski 2017; Clement et al. 2015), where there is a greater estimated prevalence of perinatal depression (Fisher et al. 2012). To aid in diminishing this knowledge gap, the present research investigates factors that influence the decision to seek and accept treatment for perinatal depression in a low-income community in Rio de Janeiro, Brazil.

Materials and Methods

This qualitative research was conducted in two primary care units located in the Manguinhos neighbourhood, in Rio de Janeiro, Brazil, from October 2017 to March 2018. The Manguinhos neighbourhood is a region described as a complex of slums located in the north of Rio de Janeiro. The neighbourhood comprises about 40,000 people living in 13 communities, some of whom live in situations of extreme precariousness and social exclusion. A lack of urban infrastructure and public services in the areas of education, health, culture, leisure and public safety are the main characteristics of this area, whose Human Development Index (HDI: 0.726) ranks 122nd among the city's 126 districts. The HDI of Manguinhos is below the average of the city of Rio de Janeiro (HDI = 0.84). Among the districts, 69 (54.76%) also have the HDI below average (SIURB 2010).

For data collection, a focus group technique was used. Pregnant and postpartum women over 18 years of age who attended both study units were invited to attend the meetings at a previously defined location, date and time. For this, the researchers explained to the participants that it was a study on motherhood and that the meetings were to exchange experiences about being a mother. Convenience sampling was used, and the sample size was determined by data saturation (Denzin and Lincoln 1994). Focus groups were repeated until the emergence of a new thematic category. To monitor the sample saturation process, the protocol suggested by Fontanella et al. (2011) was used. This protocol aims to systematize the treatment and analysis of the collected data to assist in the verification of the sample theoretical saturation.

To ensure privacy and confidentiality, the focus groups were held in a reserved place and were coordinated by an experienced psychologist with the assistance of two observers who recorded observation scripts. None of the groups contained professionals from the health units. Before each activity, participants completed a structured questionnaire with questions related to socioeconomic characteristics (name, age, marital status, self-reported skin colour, paid work and education) and obstetrics (parity, number of children, current gestational age and intentionality of gestation). Unintended pregnancy was defined as a pregnancy that is not desired at that particular time (mistimed) or not wanted at all (unwanted). In addition, puerperal individuals were questioned about their baby's name, age and date of birth.

The dynamics of the group conversations were led to investigate factors that influence the decision to seek and accept treatment for perinatal depression. Several approaches were used: structured and open questions, case examples and videos with reports of other women with perinatal depression. Audio from all groups was recorded then later transcribed. The transcripts were created by the researchers and supervised and reviewed by the research coordinator.

To describe the sociodemographic and obstetric profile of participants and their infants, descriptive analyses were used, and frequencies, proportions and means were calculated for each group and for the total sample. For these analyses, the software R version 3.5.1 was used. To analyse the manifest content of the focus groups, audio transcriptions were used following the content analysis methodology suggested by Bardin (2011). This is an analysis technique that systematically categorizes message content to understand the characteristics, meanings, beliefs, and social and personal motivations for message construction. A clipping of the women's quotes was made in order to seek the meaning of the sentences and words. These semantic units were grouped into thematic categories according to the similarity of meaning to allow an objective and systematic description of the group contents. To achieve this, the women's discourse was cut out into sentences and words, generating the nuclei of the analysis that were later grouped into themes. This process of constructing the thematic categories was carried out for several meetings with all the researchers present.

Results

The five focus groups were attended by 26 participants, with a mean age of 24.9 years. Among these women, 18 (69.2%) were pregnant and 8 (30.8%) in the puerperium. A majority of the women reported living with a partner (76.9%), having black or brown skin colour (84.6%), being primiparous or multiparous (53.8%), not having paid work (65.4%) and having 9 to 11 years of schooling (42.3%). Regarding the intentionality of gestation, 61.5% stated they unintended to conceive at that time (mistimed or unwanted) (Table 1).

As a result of the content analysis, ten theme categories were obtained: stigma and misconceptions, self-image as a mother, socioeconomic stigma, lack of knowledge, lack of health service approach to mental health, difficulty recognising depression symptoms, fear of children being removed, negative reaction to patient referral, denial of the problem and previous experience with the care unit. The theoretical sample saturation was reached in the third focus group, since no new content appeared from that point onwards (Table 2).

The theme category 'stigma and misconceptions' contain beliefs and judgments that characterise a stigmatised, stereotyped and distorted view of perinatal depression and patients with the disorder. This category was present in all groups (Table 2). Some of the phrases expressed in the groups were 'depression is bullshit/rubbish/fussiness', and 'it's lazy people's stuff' (Table 3). The second category, 'self-image as a mother' refers to how women self-assess and evaluate other women with depression and how participants believe society will judge them as mothers if they have perinatal depression. The predominant idea was that perinatal depression is strongly associated with the image of a bad mother who is unable to provide adequate care for her child. They also emphasised the fear of being accused of violence against their child and a feeling of great insecurity in exercising motherhood in the presence of the symptoms of perinatal depression.

The third category, 'socioeconomic stigma' expresses the belief that depression is not a disease suffered by poor people, only the wealthy. Many participants believed and reported that they had already heard from others the following phrase: 'Depression isn't the stuff of the poor, only the rich have it' (Table 3). The fourth category, 'lack of knowledge' reveals a lack of knowledge about the meaning

Table 1 Sociodemographic and obstetric characteristics of focus group participants and their infants

	Group 1 n (%)	Group 2 n (%)	Group 3 n (%)	Group 4 n (%)	Group 5 n (%)	Total n (%)
Number of participants	9	4	5	3	5	26
Pregnant women	8 (88.9)	3 (75.0)	1 (20.0)	2 (66.7)	4 (80.0)	18 (69.2)
Post-partum women	1 (11.1)	1 (25.0)	4 (80.0)	1 (33.3)	1 (20.0)	8 (30.8)
Mean age of mother (years)	28.4	18.8	22.2	24.7	26.4	24.9
Mean age of baby (months)	2.0	4.0	9.8	6.0	3.0	6.7
Marital status						
Live with partner	7 (77.8)	3 (75.0)	3 (60.0)	3 (100)	4 (80.0)	20 (76.9)
Do not live with or have a partner	2 (22.2)	1 (25.0)	2 (40.0)	0 (0.0)	1 (20.0)	6 (23.1)
Skin colour						
White	2 (22.2)	0 (0.0)	1 (20.0)	1 (33.3)	0 (0.0)	4 (15.4)
Black/Brown	7 (77.8)	4 (100)	4 (80.0)	2 (66.7)	5 (100)	22 (84.6)
Parity						
Nulliparous	5 (55.6)	3 (75.0)	0 (0.0)	1 (33.3)	3 (60.0)	12 (46.2)
Primiparous/multiparous	4 (44.4)	1 (25.0)	5 (100)	2 (66.7)	2 (40.0)	14 (53.8)
Paid work						
Yes	4 (44.4)	0 (0.0)	1 (20.0)	0 (0.0)	4 (80.0)	9 (34.6)
No	5 (55.6)	4 (100)	4 (80.0)	3 (100)	1 (20.0)	17 (65.4)
Years of education						
0–8	3 (33.3)	1 (25.0)	3 (20.0)	0 (0.0)	2 (0.0)	9 (34.6)
9–11	3 (33.3)	3 (75.0)	2 (20.0)	3 (33.3)	0 (0.0)	11 (42.3)
> 11	3 (33.3)	0 (0.0)	0 (0.0)	0 (0.0)	3 (60.0)	6 (23.1)
Intentionality of pregnancy						
Intended	6 (66.7)	0 (0.0)	1 (20.0)	0 (0.0)	3 (60.0)	10 (38.5)
Unintended	3 (33.3)	4 (100)	4 (80.0)	3 (100)	2 (40.0)	16 (61.5)

Table 2 Theme categories obtained from content analysis and the sample saturation process

	Category	Group 1	Group 2	Group 3[a]	Group 4	Group 5	Total
1	Stigma and misconceptions	**X**	X	X	X	X	(5) 100%
2	Self-image as a mother	**X**	X	X	X	X	(5) 100%
3	Socioeconomic stigma	**X**	X	X	X		(4) 80%
4	Lack of knowledge	**X**	X	X	X		(4) 80%
5	Lack of health service approach to mental health	**X**		X	X	X	(4) 80%
6	Difficulty recognising depression symptoms		**X**		X	X	(3) 60%
7	Fear of children being removed		**X**			X	(2) 40%
8	Negative reaction to patient referral		**X**	X	X	X	(4) 80%
9	Denial of the problem		**X**	X	X	X	(4) 80%
10	Previous experience with care unit			**X**	X	X	(3) 60%
Total of new categories		5	4	1	0	0	10

Bold indicates new theme category

[a]Point of sample saturation

of the term 'perinatal depression', which may relate to a failure of the health unit to approach the women. A lack of clarification by the health services about the signs and symptoms of depression in prenatal and postpartum visits was the fifth category, 'lack of health service approach to mental health'. The vast majority of women affirmed that during perinatal care (prenatal and postpartum), mental health issues were not addressed.

The sixth category, 'difficulty recognising depression symptoms' includes statements that demonstrate the women's difficulty recognising the symptoms of depression and differentiating those from the 'normal' emotional swings they dealt with during gestation or in the postpartum period. This theme is expressed in this speech: 'There are days when we are more introverted, sadder… but if this is depression, I do not know' (Table 3). Faced with a suspicion or confirmation of a depression diagnosis, women also reported a significant fear of losing the custody of their children. These statements constitute the seventh category analysed, called 'fear of children being removed'.

The eighth category, 'negative reaction to patient referral' concerns participants' responses when asked if they would accept a referral to mental health services if they were diagnosed with depression during pregnancy or postpartum. The most frequent response was that they would not accept a referral. The ninth category, 'problem denial', includes reports of situations in which participants denied or evaded a possible diagnosis of depression. Even at times when they suspected they might be depressed, participants reported denying the problem to themselves and others. Some participants reported that they did not know and did not want to know what depression was, so they would not recognise themselves in the symptoms: 'I thought it was happening to me (depression), but I did not want to accept it, I denied it' and 'I did not know what depression was and I did not want to know' (Table 3).

The tenth category 'previous experience with the health unit' contains reports of how experiences with care in the unit influenced seeking and accepting referral to mental health services. Some participants commented that the way they were treated at the unit was critical to their acceptance of a referral to mental health services. If they had a negative experience and/or lack of confidence in the team, they tended to refuse a referral.

Discussion and Conclusions

This study identified ten barriers to accessing treatment for perinatal depression from women's perspectives. In women living in a low socioeconomic status context in the city of Rio de Janeiro, with the exception of the third category (socioeconomic stigma), the reasons why pregnant and postpartum women do not seek or even refuse a referral to perinatal mental health services are similar to those found in developed countries (Button et al. 2017; Kingston et al. 2015; Bilszta et al. 2010; McCarthy and McMahon 2008).

In all focus groups, stigma was identified as a factor preventing women from seeking and accepting help. Stigma is a barrier that is consistently and frequently identified in the literature (Corrigan 2004; Thornicroft 2006; Dennis and Chung-Lee 2006; Bilszta et al. 2010; Clement et al. 2015). According to Goffman (1963), stigma is the relationship between a singular characteristic of the subject (attribute) and the preconceived classification about the person or a group (stereotype). Constructions of stigma are generated socially, whereby prejudice and discrimination devalue

Table 3 Theme categories and women's quotes

	Theme category	Women's quotes
1	Stigma and misconceptions	'Depression is bullshit/rubbish/fussiness' 'It's lack of will,' 'Depression doesn't exist' 'Depression is fussiness, is lazy people's stuff' 'Depression is a lack of work'. 'A person with depression is cracked and mad' 'People can't understand you, label you mad' 'Depression isn't nice' 'You can't hold yourself' 'Maybe she is on drugs' 'Maybe she is a cuckold' 'She is depressed because her husband feels cheated'. 'You are out… people don't take you as normal' 'To be labelled as depressed shakes you; I would feel shaken' 'That's because she's got no job, get her a job and depression will fly away' 'The common idea is that you go to a shrink because you are nuts'
2	Self-image as a mother	'A woman with depression can't be a good mother' 'The mother with depression feels unable to take care of her baby' 'The mother (with depression) rejects her baby… she denies him' 'She feels unable to take care of him' 'She feels like throwing the baby down the stairs; in this case, she has postpartum depression' 'I came up to my mom and said: "Mom, I don't think I love my baby, am I depressed?"' 'I nearly thought I was depressed because I didn't love the baby' 'You can't be like that (depressed); if you are like that you pass it on to the baby' 'She has postpartum depression and I saw it; she was unable to take care of her baby' 'I thought she was unable to take care of her baby because she was depressed' 'If I get depressed, I can't handle it, I can't take care of my (baby)'. 'The mother with depression is afraid of being judged as a bad mother' 'I would feel lower than those who are pregnant without depression'
3	Socioeconomic stigma	'Depression isn't the kind of thing poor people have; only the rich have it' 'The poor have no time to have depression' 'The poor can have no frailties… even dogs are depressed nowadays' 'If you are poor and depressed, go get a job'
4	Lack of knowledge	'I hardly ever hear it (depression)' 'This depression stuff, I can't make sense of it' 'Never heard of it (depression); nobody ever told me' 'People don't know much about what depression is' 'I myself say, I don't know… I found out I had it, I don't know exactly what it is' 'Sometimes people say it… but deep inside, I don't know what it is' 'I had no idea what it was about'
5	Lack of health service approach to mental health	'No one talked about this (perinatal mental health) with me during the prenatal consultations' 'Her (doctor) never touched it… How do you feel?' 'We came to the health care unit, but I guess nobody talks about it'
6	Difficulty recognising depression symptoms	'There are days when we are more introverted, sadder… but if this is depression, I don't know….' 'I cried a lot, I didn't eat… I don't know if this is depression'
7	Fear of children being removed	'Going to parental court, I don't know… it may happen, and you lose the baby' The neighbour said to a depressed women: 'If you treat your daughter bad, I will take her away'
8	Negative reaction to patient referral	'It's hard… like… the impression you have they say we are cracked' 'I will refer you to a psychologist and I replied: "No dad, for God's sake!"' 'The first thing that comes to you when people say you need a psychologist… they think you are going mad' 'It's hard to visit a psychologist' 'If someone came up and said I was depressed and offered help, I would never accept it' 'I told him (doctor) he was mad' 'If people came to me and said you are depressed, I would cry'

Table 3 (continued)

	Theme category	Women's quotes
9	Denial of the problem	'I didn't know what depression was and I didn't want to know' 'We get no explanation right away' 'I thought I was depressed but I denied it' 'When she (friend) asked me what was going on with me, I said nothing' 'I thought something was going wrong with me, but I did not want to point out that it was depression' 'I didn't want to accept I was depressed' 'I found an excuse on the day, so I didn't have to see the psychiatrist' 'I denied it all; I thought I could bear it alone, that I could get rid of it' 'I didn't give a damn about it when I thought I was depressed' 'If I read the symptoms of depression and I knew I had it I would feel very bad'
10	Previous experience with the care unit	'I came often times and they said they were on strike' 'It is hard to have a psychologist on duty in the care unit as far as I know' 'I made a decision then I went to a psychologist, but he was not there, then you give up and don't seek for it again' 'I came to the doctor knowing it was crowded; I have many questions, but I can't say anything because he has no time' 'The nurse only cares about my baby' 'There is a big turnover here; when you trust people, they leave, it's hard to trust anyone' 'I do not trust the professionals here, so I do not go to the shrink'

subjects with properties that are considered undesirable, in this case, perinatal depression.

In addition to stigma, there is a belief that mothers with depression are unable to exercise motherhood. Thus, many women who are afraid of being judged and seen as bad mothers decide not to seek or accept psychiatric treatment. This barrier has also been reported in other studies (Bell et al. 2016; Hadfield and Wittkowski 2017), demonstrating that in several societies, women faced with a diagnosis of perinatal depression end up self-questioning or having their self-image as a mother questioned. This makes the occurrence of depression in the perinatal period laden with greater stigma and prejudice than other periods in a woman's life, which in turn makes it even more difficult to identify and refer pregnant and puerperal women to mental health services.

The belief that depression is not a disease for poor people and is only experienced by the wealthy was another access barrier found in this study. This theme calls attention to the impossibility of this population to recognise themselves as people who experience psychological suffering. Self-classification as a poor person does not authorise the subject to think of themselves as having depression, making it impossible for them to seek psychological or psychiatric treatment. This belief recalls the exclusion and prejudice of social class to which this population is subjected daily, as can be seen in the following excerpt: 'the poor can never have any frailties… even dogs today have depression'. This statement indicates that they consider that even a dog has more right to psychological suffering than a human being.

Additionally, most of the study participants were unenlightened regarding the meaning of 'depression'. This lack of knowledge has also been reported among women in developed countries (McCarthy and McMahon 2008; Hadfield and Wittkowski 2017), thus impacting their ability to recognise the symptoms and consequently seek treatment. To make matters worse and reinforce this situation, the health unit does not address this lack of knowledge during the perinatal consultations. When health services do not address the issue in routine prenatal and childcare consultations, a great opportunity for further clarification and screening of these women is missed. Although there are no guidelines regarding the screening and treatment of mental health during the perinatal period in Brazil, it is recommended that the psychological state of pregnant, parturient and puerperal women should be monitored (MS 2001).

The present study also demonstrates the important role that health professionals play in accepting referrals to mental health services. It is important to ensure that the health unit and health professionals are welcoming and attentive to encourage the seeking and acceptance of referrals to mental health services (Kopelman et al. 2008; Hadfield and Wittkowski 2017). For this reason, the approach used and relationship between the health professional and pregnant and postpartum women should be one of the focuses of the work process, requiring continuous improvement and/or training for health teams.

In many situations in which women fail to seek or refuse care, they do so due to a combination of the theme categories identified herein. For example, a lack of knowledge to perinatal mental health and a failure of the health unit to approach the women makes it difficult for women to recognise the symptoms and reinforces the stigma and prejudice. This situation only serves to help women deny or cover up

their psychological problems, thus creating a vicious cycle: barriers lead to and reinforce a subsequent barrier, thus delaying the onset of psychological and psychiatric treatment, and potentially incapacitating treatment effectiveness.

To reverse this troubling situation, it is necessary to adopt several actions. First, an approach to mental health issues in routine prenatal and childcare consultations should be implemented. For this, it is important to educate health professionals regarding these issues, so that they can not only inform but also identify perinatal psychological problems. In this way, health services can take advantage of several opportunities to work on the identified themes with women attending at the health unit or at home.

Second, programmes must be implemented to address the identified barriers at the population level through campaigns aimed at disseminating information about perinatal depression (the concept and symptoms) and reducing stigma and prejudice. For this, electronic media such as websites, social networks, YouTube, online platforms and traditional means of communication such as radio and television can be used. Changing the mentality and beliefs of a population is a difficult task that often requires hard and continuous work by policymakers, health professionals and civil society. However, such a change must be made to reverse the state of disinformation, stigma and prejudice against perinatal depression and to deconstruct the image that women with depression are incapable of being good mothers.

This study provides important insights regarding the barriers to women seeking and accepting treatment for perinatal depression in the context of a low- and middle-income country. Yet, the study has some weaknesses. Owing to the difficulties faced by women in accessing health units, adherence to the focus groups was low, and some meetings were attended by only a few women. Additionally, due to urban violence, only women who attended health facilities during the survey period were invited. Despite these limitations, the majority of the research findings are corroborated by other studies with different populations and sample sizes which found similar results.

Finally, this research identified several barriers faced by women in Rio de Janeiro that make it difficult for women to seek and accept psychological and psychiatric treatment during the perinatal period. Health professionals should monitor the emotional well-being of women at each prenatal and postnatal consultation, clarifying and providing support when needed. Uncovering perinatal depression as a public health problem and reducing the stigma of mental disorders are major challenges to address to help women feel at ease to seek and accept help. Strategies must be adopted to break this vicious cycle that often leads to them suffering hidden and alone, thus allowing women and their families to enjoy the benefits of good mental health.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval This study was conducted according to Resolution n. 196/1996 of the Brazilian National Health Council, which sets the standards for research involving human subjects, issued by the Research Ethics Committee of the Sergio Arouca National School of Public Health, Oswaldo Cruz Foundation, under CAAE 21982613.6.0000.5240. All the participants assigned a free and informed consent.

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