

# 'It's leaflet, leaflet, leaflet then, "see you later": black Caribbean women's perceptions of perinatal mental health care

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## ABSTRACT

### Background

Despite high levels of psychosocial risks, black women of Caribbean origin rarely consult health professionals regarding symptoms of perinatal depression. Reasons for this are unclear as there has been little perinatal mental health research among this ethnic group.

### Aim

To examine stakeholder perspectives on what might account for low levels of consultation for perinatal depression among a group of women who are, theoretically, vulnerable.

### Design of study

A qualitative study using focus group interviews.

### Setting

Community settings in the northwest of England.

### Method

A purposive sample of black Caribbean women ( $n = 42$ ) was split into focus groups and interviewed. This sample was drawn from a larger study. Interviews were digitally recorded and transcribed verbatim. Framework analysis was used to generate themes.

### Results

Perceptions of practitioners' lack of compassion in delivering physical care and women's inability to develop confiding relationships with professionals during pregnancy and childbirth were significant barriers to consulting for depressive symptoms in particular, and health needs more generally. Advocating a 'stepped-care' approach, black Caribbean women suggested that new care pathways are required to address the full spectrum of perinatal mental health need. Apparently eschewing mono-ethnic, 'culturally sensitive' models, women suggested there was much to be gained from receiving care and support in mixed ethnic groups.

### Conclusion

Black Caribbean women's suggestions for more collaborative, community-based models of care are in line with policy, practice, and the views of members of other ethnic groups. Adopting such approaches might provide more sustainable mechanisms for improving access and engagement both among so-called hard-to-reach groups and more generally, thereby potentially improving maternal and child outcomes.

### Keywords

ethnic minority women; ethnicity; perinatal depression; primary care.

## INTRODUCTION

Limited evidence from primary care in the UK suggests that women of black Caribbean ethnicity are less likely than women from other ethnic groups to seek help for perinatal depression.<sup>1,2</sup> This is surprising given that known risks, such as lone parenthood, deprivation, and lack of social support, disproportionately affect black Caribbean women.<sup>3,4</sup>

Low levels of consultation among this group, which is theoretically at risk, are also concerning, given that growing international evidence shows that black women from deprived communities may be especially vulnerable to depression during pregnancy and the early postnatal period.<sup>5-7</sup> There may be a number of potential explanations for unexpectedly low levels of consultation by this group:

- negative experiences of services by black and minority ethnic (BME) communities in general, and black Caribbeans in particular, result in fear, mistrust, and reluctance to engage with mental health services;<sup>8,9</sup> and
- black Caribbean women's beliefs about mental illness, their fear of stigma, and their help-seeking approaches — central to which is a strong external locus of control and self-reliance.<sup>7</sup>

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More positively, there is emerging evidence that peer support and the ethnic density effect might buffer women against the potentially depressogenic impact of psychosocial stressors.<sup>10,11</sup> However, these hypotheses have not been formally tested within this ethnic group as there has been little research into perinatal depression among black women in the UK. Increasing evidence of the deleterious consequences of perinatal depression for women's life-long mental health as well as the physical, cognitive, emotional, and psychological development and wellbeing of their children suggests that this is a serious omission.<sup>12,13</sup> A policy focus on reducing health inequalities,<sup>14</sup> improving access to psychological therapy in primary care,<sup>15</sup> delivering race equality in mental health care,<sup>16</sup> and improving the psychosocial wellbeing of mothers and their children<sup>17</sup> suggests that research into the perinatal mental health of women in underserved communities is both necessary and timely.

## METHOD

Between September 2007 and June 2008, a purposive sample of black Caribbean women ( $n = 42$ ) and healthcare professionals ( $n = 42$ ) was interviewed to explore their views on anecdotal evidence from primary care that surprisingly few black Caribbean women are diagnosed with perinatal depression. This article reports the views of women in the study; those of healthcare professionals have been reported elsewhere.<sup>2</sup>

Black Caribbeans were selected because they are a relatively homogenous group of settled migrants (indeed, the majority of women in the study were born in the UK but self-labelled as being 'of black Caribbean origin') and because, in contrast to the large volume of research into the mental health of black Caribbean men, there has been relatively little research among women from this ethnic group. Focus groups were used, in part, to examine the apparent contradiction in previous women's accounts of black Caribbeans' unwillingness to openly discuss psychological problems while simultaneously espousing the importance of peer support.<sup>8</sup>

As this was a qualitative study, participants did not constitute a statistically representative sample; instead, women were purposefully selected to represent a range of perspectives and experiences that would facilitate insight into the issues that might contribute to low levels of diagnosed perinatal depression in this ethnic group. Inclusion criteria included self-identification as 'black Caribbean' and being aged 18 or over. No restrictions were placed on how long ago women delivered their babies, but the majority had children who were aged under 2 years old.

## How this fits in

Perinatal depression is a serious public health issue, which affects around 15% of women in the UK. Suboptimal detection and treatment can be deleterious for mothers and their children. Women from disadvantaged backgrounds may be particularly at risk. Black Caribbean women's greater exposure to psychosocial risks, such as social and material deprivation, could place them at a high risk of onset but few women from this ethnic group present for diagnosis and treatment. By exploring the reasons why this is the case and what might be done in an attempt to improve consultation levels, the findings of this study might go some way towards influencing future policy and practice in this area.

Recruiting via posters in community settings, use of local media, such as community radio and local newspapers, contacts in churches with a congregation that was mainly black, and NHS organisations maximised within-group diversity. As such, participants included women aged 18–43 years, those who lived in the inner city and the suburbs, lone parents, and women who were married or cohabiting. Recruitment via churches with a congregation that was mainly black was based on previous findings that black Caribbean women in the area in which the study was undertaken frequently sought church-based support for psychological distress during and after pregnancy, even if they were not religious or had no religious affiliation.<sup>8</sup>

After giving informed consent, an interview guide (available on request), developed from existing literature and the limited empirical evidence,<sup>3,18</sup> was used to explore women's perceptions of the factors that might explain low levels of consultation and diagnosis for perinatal depression among women in their communities. Topics included women's experiences of perinatal depression and their perceptions regarding the ability of current services to meet their needs. Women were also asked to describe key components of their 'ideal service'. The interview guide comprised open questions that allowed participants to explore issues in their own way; more direct probes and prompts facilitated deeper understanding and clarification.

There were five focus groups in total, each of which contained between 6 and 10 women. Two of the five groups comprised regular church attenders only ( $n = 14$ ), two contained only women from the wider community who did not go to church ('community women') ( $n = 18$ ), and one was a mixed group ( $n = 10$ ). Focus group sessions lasted between 60 and 90 minutes each. They were conducted by the author in various community settings including women's homes and a 'black majority' church hall. Interviews were digitally recorded and subsequently transcribed verbatim.

Data were analysed using framework analysis. A matrix-based, hierarchical method of analysing and synthesising qualitative data,<sup>19</sup> framework analysis has become increasingly popular among healthcare researchers as its rigorous processes facilitate the development of recommendations for practice and policy.<sup>20</sup> Subsequent to familiarisation with the raw data, initial coding was developed by the primary researcher. Codes were refined into key themes and concepts, and emergent categories were organised into a thematic framework. Using a comprehensive matrix to chart participants' views facilitated interpretation and explanations because individuals' views and opinions could be compared and contrasted both within, and across, focus groups.

NVivo 8 (QSR International, Cambridge, MA) was used to support data management and analysis. Data verification strategies included peer and participant review to examine and verify themes, findings, and conclusions.<sup>21</sup> As an example, preliminary findings were presented to the mixed focus group for comment and academic peers were involved in the entire process from coding to the development of conclusions. As findings are illustrated by verbatim quotes, participants' anonymity has been preserved by using numbers and an indication of whether women were recruited via church or community.

The study received ethical approval from local research and university ethics committees and research governance in participating NHS trusts.

## RESULTS

The study generated a large volume of data, which were coded to identify key emergent themes. This article focuses on themes relating to black Caribbean women's perceptions and experiences of current services and the factors that might act as barriers to accessing care and treatment. Women were also encouraged to describe key differences between their 'ideal service' model and current provision.

### **Experiences of current services and barriers to care**

Although the primary aim of the study was to examine black Caribbean women's views about perinatal mental health care and the factors that might account for apparently low levels of consultation, the discussions frequently broadened to include health care more generally. In particular, women often began addressing questions about perinatal mental health care by recounting experiences of the physical care they received during and after pregnancy, and highlighting how this was linked to their reluctance to consult for psychological difficulties.

Although some women spoke positively about

their care, they were in the minority; the remainder indicated that maternity care was less than ideal. Perceptions of positive or negative experiences and good- or poor-quality physical care appeared to depend on whether care had been received in the community or in the hospital:

*'... the [community] midwife who you visit during pregnancy and who comes after you have given birth, I found that she was very helpful but the midwives in hospital, I would never advise anyone to go and see them ... it's not one midwife, it was all of them ... They just approach you as if you are like a log being rolled over. You could be crying with pain and [they] will be treating you like a log. I didn't feel like a human being at all.'* (Church attender 4)

*'... they just shoved me on the bed. It was just terrible, a bad experience. Being a first-time mum, I would have expected something much better. Then this doctor comes, the same doctor that had seen me before and she said, "Have I seen you before?" it just makes you feel ... just so bad.'* (Church attender 5)

According to women in this study, experiences of poor physical care and apparent lack of compassion on the part of practitioners generated both disappointment and mistrust, and reduced the likelihood of engaging with mental health services in the perinatal period and, indeed, with health services more generally. Perceptions of staff as uncaring meant that women were not confident that they would receive 'sympathetic' care. Reluctance to engage with services was especially acute in relation to mental health problems, as women suggested that having positive, trusting relationships with health professionals is essential if they are to disclose psychological problems:

*'That is probably why a lot of black women don't bother going to the system ... the majority have had nightmares. So you're thinking, "What's the point in going back?" It [negative experience during pregnancy and labour] just doesn't give you any confidence to think they'll be sympathetic.'* (Community woman 17)

In this context, an important barrier to consultation and diagnosis was women's perceptions that staff (especially midwives and health visitors, from whom they expected support) were too busy to address their psychological needs. As this woman's account of a conversation with her health visitor illustrates, health professionals' apparent 'busyness' made her

feel like an irritant, rather than someone with legitimate needs:

*'... the health visitor said something like, "you know in this community we have to look after a thousand and something babies" and that instilled in me the feeling like "oh they are very busy these people and I don't have to be bothering them all the time". So sometimes when you think of just calling them for something, you don't.'* (Community woman 6)

Although some women were sympathetic to staff workloads and limited resources, more commonly, they suggested that being busy was not a justifiable explanation for failure to address their mental health needs. They also expressed resentment that, with time and other resources at a premium, practitioners appeared to focus on the health and wellbeing of their infants at their expense. Furthermore, they suggested that encounters with professionals in the perinatal period were protocol driven and formulaic, affording little scope to discuss psychological distress, identify morbidity, or deliver interventions that might restore or maintain maternal mental health:

*'I remember when she [health visitor] came to my place ... she only talked about my baby — nothing about me. So I was thinking "maybe it's nothing to do with the mothers, it's just about the baby". So, in my mind ... if your baby is not well you can ring them, but nothing about you.'* (Church attendee 5)

*'My experience has been: leaflet (baby massage); leaflet (postnatal depression); leaflet (baby immunisations). "Any questions let us know. Any problems, [see your] GP". It's leaflet, leaflet, leaflet; then "see you later".'* (Church attendee 4, mimicking a professional for whom handing out leaflets was like dealing a deck of cards.)

### Alternative models of care

Asked to describe their 'ideal service', women said that what is required is a dedicated, well-resourced service, capable of addressing the full spectrum of need — care pathways that can provide support for women with mild symptoms of emotional distress and treatment for those with clinically significant, diagnosable mental ill health:

*'If it's not serious postnatal [depression] where you feel like killing your own baby, if it's something minor, you know ... create something like this [focus group], where people get together and start talking. It does help. It does uplift you.'* (Community woman 2)

In keeping with predominantly social models of perinatal depression, some of these women suggested that their 'ideal service' model would adopt a community-based, multi-agency, women-centred approach. In this model, care and support would be holistic and non-judgemental, delivered by empathetic professionals who would focus on mothers' needs so, as church attendee 3 put it, *'... somebody [is] not just checking on the baby but actually sitting down with you asking, "how are you doing?" "What can I do to help you?'*

Most women agreed that care and support need not be delivered by professionals; they suggested that community-based support could be an effective mechanism for restoring and maintaining mental health and wellbeing, but perceived that informal care and support is largely ignored and/or undervalued by formal caregivers. To evidence their assertions, several women recounted personal experiences of psychological distress and/or those of family and friends. This extract, which describes how a group of women supported their friend, typifies many accounts. It also highlights recurrent concerns about the capacity of health services to appropriately care for women who are depressed — especially those with sub-threshold morbidity, which might not be clinically significant, but could still adversely affect psychosocial functioning:

*'How we managed to get her out of that deep cloud was by giving her a lot of support. Literally staying in the house sometimes ... because if she had gone down the tablets route, she would definitely be institutionalised by now.'* (Church attendee 10)

In light of concerns about services' ability to deliver appropriate (non-institutionalised) care, perhaps unsurprisingly, women's 'ideal service' model would deliver care and support in non-clinical, community-based settings — a kind of 'home from home' (community woman 1). In this model, psychosocial interventions would not be 'culturally specific', which, according to these women, is interpreted by some organisations as delivering care in 'ethnic' or 'cultural' groups. Instead, women said care should be delivered in multi- versus mono-ethnic groups. Participants felt that group, rather than individual approaches, were preferable as they might facilitate access and engagement; reduce stigma; and improve psycho-education among black Caribbeans, who may be more reluctant to disclose psychological distress in 'black-only' groups:

*'If you sit in a room with all black people, they will all just sit there looking at each other ... Even if they were depressed they would hide it as much*

*as possible. I think we need to integrate with other people ... to talk our way through the different experiences that we have.'* (Community woman 13)

In contrast to current provision, women's 'ideal service' would be based on 'asking women what they want' (community woman 31). Suggested interventions that were most popular were alternative therapies, such as reflexology and therapeutic massage, alongside opportunities to talk and be heard. In contrast to almost-universal agreement about talking and alternative therapies, women were much more ambivalent about the role of antidepressants. Despite a general consensus that antidepressants might worsen, rather than improve, mental health, women advocated their use — but only when symptoms were severe or did not respond to psychosocial interventions. However, their ambivalence about antidepressants and perceptions that medication was the most likely (if not the only) treatment that GPs would offer appeared to reinforce their reluctance to consult their GPs with depressive symptoms:

*'... one of my friends got really depressed ... [her] GP offered her antidepressants and she refused ... all they are interested in is giving you drugs. They don't really give you social support. It's not about, "what are your needs?" It's about "how much can I drug you? Do you need sleeping tablets? Do you need antidepressants?".'* (Community woman 20)

## DISCUSSION

### Summary of main findings

Black Caribbean women in this study suggested that there was a strong correlation between their experiences of physical care during pregnancy and labour and the likelihood of seeking help for perinatal depression. Perceptions of insensitivity in meeting their physical needs and an apparent lack of compassion by health professionals caused women to doubt that their mental health issues would be dealt with sympathetically.

Moreover, even women who reported positive experiences suggested that an apparent increase in staff workloads militated against developing confiding relationships with health professionals, which they regarded as being crucial for disclosure of psychological problems. They also suggested that current practice provides little scope for disclosure about mental health problems. They were resentful that, faced with scarce resources, health professionals appeared to focus on the health of their babies at their expense. This perception is not unique to black Caribbeans, but it further reduces the likelihood of women who are already fearful of contact with mental

health services disclosing psychological problems to primary care practitioners.

Asked how services could be improved to meet the particular needs of women of BME groups, black Caribbeans proposed a multi-ethnic, women-centred, community-based model. Despite their perceptions of current drivers to develop 'culturally sensitive' services, women in this study suggested that cultural or ethnic segregation of provision might deny women from BME populations important opportunities to learn and receive support from other ethnic and cultural groups.

In their predominantly social approach, preferred interventions included alternative and talking therapies. Although advocating antidepressant therapy in severe and non-responsive cases, there was ambivalence about medication, the general consensus being that antidepressants might actually worsen, rather than improve, mental health.

### Strengths and limitations of the study

This article derives from a study in which the views of black Caribbean women and health professionals were sought regarding the apparent under-representation of this ethnic group among those receiving perinatal mental health care. Qualitative methods provided an important means of beginning to understand why this should be so, given the high levels of psychosocial risks within this group.<sup>1,11</sup>

Use of an interview schedule based on the existing literature and academic scrutiny ensured robustness of data collection. Adopting the framework-analysis approach to data analysis,<sup>20</sup> coupled with robust data-verification strategies (including participant verification and review) increased the trustworthiness of findings and conclusions.<sup>21</sup> However, a degree of caution should be exercised when interpreting findings as, despite attempts to maximise the sociodemographic diversity of the sample, the views of a relatively homogenous group of black British women of Caribbean origin in one region of the UK cannot be extrapolated to other areas or ethnic groups.

### Comparison with existing literature

In contrast to the large volume of studies about mental illness among black Caribbean men, there is surprisingly little research about women from this ethnic group. The views of women in this study resonate not only with other service users but also with those of health professionals.<sup>2,18</sup> For example, women's views about health professionals' focus on the health of their infants resonate with health visitors' reports of the conflict they experience in trying to balance the, sometimes competing, needs of mothers and infants.<sup>22</sup>

There was also a surprising degree of convergence between women's 'ideal-service' model and the views of health professionals<sup>23</sup> and policy guidance for a

'stepped-care' approach to managing perinatal depression.<sup>24</sup> Women's accounts also cohered with practitioners' views that focusing on those with symptoms that are sufficiently severe to cross diagnostic thresholds fails to address the full spectrum of need in primary care.<sup>25</sup> Advocating care pathways that also manage sub-threshold psychological distress by developing collaborations with voluntary and community-based organisations is in line with research,<sup>2</sup> practice guidance,<sup>26</sup> and current trends in government policy.<sup>27</sup>

### **Implications for future research and clinical practice**

The importance of women's relationships with healthcare professionals for the diagnosis and treatment of perinatal depression was a recurrent theme in these women's accounts. This has been previously reported and is not exclusive to black women of Caribbean origin.<sup>18,28</sup> Indeed, suboptimal detection and treatment of depression in primary care is an ongoing concern.<sup>29</sup> However, in light of reports of fear and mistrust of mental health services among BME groups and the association between deprivation, ethnicity, and poorer mental health,<sup>30,31</sup> an inability to confide in health professionals might have added salience for black Caribbean women's ability to receive adequate care. According to health professionals, fragmentation of services and a lack of clarity about professional ownership of perinatal mental health care, coupled with an apparently 'colour-blind' approach<sup>2,18</sup> can leave black, other minority, and marginalised groups at particular risk of 'falling through the net' and failing to receive the care and support they need.<sup>2,32</sup>

In this context, it is noteworthy that there was surprisingly little reference to the role of GPs in women's accounts. Black Caribbean women did not perceive their GPs as gatekeepers to care, but rather as individuals with a limited repertoire for dealing with perinatal mental health. As women in this study advocated social models of care and were, at best, ambivalent about the role of antidepressants, their perception of GPs as being only 'interested in giving you drugs' is clearly problematic in terms of help seeking for depressive symptoms. This is worthy of further exploration. It is also important to note that these women made little distinction between different aspects of service. Perceptions of poor or unsympathetic care in any area became a barrier to disclosing psychological problems.

Black Caribbean women in this study endorsed health professionals' views that the greatest perinatal mental health need is at the mild/moderate or even sub-threshold end of the spectrum of need.<sup>2</sup> Accordingly, their 'ideal service' model mirrors the

stepped-care approach in which antidepressants and other intensive treatments are reserved for those who do not respond to lower-intensity interventions, such as guided self-help, or where practitioners can accurately predict those most likely to need more intensive intervention from the outset.<sup>33</sup> Women's preferred model of care is also in line with the National Institute for Health and Clinical Excellence and professional body recommendations for developing regional managed care networks, which transcend boundaries between statutory health and social care and voluntary sectors, and foster collaborations with community-based groups.<sup>24,26</sup> This might include establishing novel care pathways in partnership with faith-based groups from whom many minority groups already seek support in times of psychological distress.<sup>8,34</sup>

Although women's involvement in this study appears to contradict their assertions that perceived stigma would prevent black people from discussing mental health problems with others from within their own community, their suggestion that the perinatal mental health needs of women from BME groups might be better met if interventions were delivered in mixed rather than mono-ethnic groups is an important, if somewhat surprising, finding. In the context of shrinking resources and an increasingly diverse population, this has important implications for policy makers and practitioners who are attempting to deliver 'culturally sensitive' care. However, this does not imply that services should adopt a 'one-size-fits-all' approach; rather, it illustrates women's contention that commissioners and providers should 'ask women what they want'. Participants' responses suggest that, if this was done, a surprising degree of convergence between policy and practice guidance and patient preference might be found. In this context, not only are the suggestions for developing more collaborative, community-based models of care in line with new government proposals,<sup>27,34</sup> but adopting such approaches might also provide sustainable means for improving access and engagement among so-called 'hard-to-reach' groups.

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### **Ethical approval**

The study was approved by the National Research Ethics Service North Manchester Research Ethics Committee (REC: 07/Q1406/3), Greater Manchester Primary Care Trusts Research Group (RMG/07/017), Central Manchester and Manchester Children's NHS Foundation Trust (PIN: 10421), and the University of Manchester's Committee on the Ethics of Research on Human Beings (07095).

### **Competing interests**

The author has stated that there are none.

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### Discuss this article

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