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## Ethnicity and mental health encounters in primary care: help-seeking and help-giving for perinatal depression among Black Caribbean women in the UK

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**Mental Health Encounters in Primary Care:  
Black Caribbean women and help-seeking for perinatal depression**

**Abstract**

Perinatal depression among Black Caribbean women in the UK remains an intriguingly under-researched topic. Despite high levels of known psychosocial risks, Black Caribbeans remain relatively invisible among those seeking/receiving help for depression during and after pregnancy.

In-depth interviews were undertaken with a purposive sample of twelve Black Caribbean women selected from a larger sample (n=101) to examine prevalence and psychosocial risks for perinatal depression among this ethnic group. The study also sought to explore women's models of help-seeking. During analysis, the context in which help-seeking/giving is mediated emerged as a key issue. We explore the nature of these encounters thereby opening up the possibility of finding common ground between service users and providers for enabling women to receive the care and support they need.

Whether or not women configure depressive feelings as 'symptoms' requiring external validation and intervention is a reflection both of the social embeddedness of those individuals and of how '*help-givers*' perceive them and their particular needs. We suggest that the ways in which help-seeking/giving are commonly conceptualised might offer at least a partial explanation for apparently low levels of diagnosed perinatal depression among Black Caribbean women. Popular approaches to health seeking behaviours within health promotion and practice focus on individuals as the fulcrum for change, tending to overlook their embeddedness within 'reflexive communities'. This might serve to reinforce the invisibility of Black Caribbean women both in mainstream mental health services and associated research. Alternative approaches may be required to achieve government targets to reduce inequalities in access, care, and treatment and to deliver more responsive and culturally-appropriate mental health services.

**Key Words:** Black Caribbean women, perinatal depression, help-seeking, primary care, reflexive communities

## **Mental Health Encounters in Primary Care: Black Caribbean women and help-seeking for perinatal depression**

### **Introduction: Black Caribbean women and perinatal depression**

Despite initiatives to 'Defeat Depression' (Paykel *et al.* 1998) and a decade-old National Service Framework for Mental Health (DH, 1999) detection and treatment of depression in primary care remains sub-optimal (Gilbody *et al.* 2003, Oates 2003). Although this affects all ethnic groups, the confluence of social, structural, and personal barriers might render Black Caribbean women in the United Kingdom (UK) at particular risk of not receiving the care and treatment they need (Edge 2006, 2007a). Whilst treatment statistics indicate that they are less likely to receive formal diagnoses and treatment (Lloyd 1993); evidence from population-based studies suggests significantly higher levels of undiagnosed depression among Black Caribbeans than their White British counterparts – especially among women (Berthoud and Nazroo 1997, Nazroo 1997, Shaw *et al.* 1999). The mismatch between population and diagnosed levels of depression raises the possibility of currently unexamined factors militating against Black Caribbeans' ability to receive care and treatment for depression (Williams and Healey, 2000).

Although depression (Busfield 1996, Stoppard 2000) and perinatal depression (Brockington 1998, Nicolson 1998) remain contested concepts; biomedical and social research appear to provide compelling evidence for strong and consistent links between ethnicity, gender, deprivation, and poor mental health (Baker *et al.* 2002, Bhopal *et al.* 2001, Lloyd 1998, Modood *et al.* 1997, Nazroo 1997, Murali and Oyeboode, 2004). However, despite the presence of

putative risk factors such as lone parenthood, poor partner support, and significant levels of deprivation and disadvantage (Baker *et al.* 2002, Baker and North 1999, Smith *et al.* 2000), clinical and emerging research evidence from primary care (Edge *et al.* 2004) suggests that Black Caribbean women in the UK are less likely than their White British counterparts to seek help for perinatal depression (depression during pregnancy and in the early postnatal period).

There are a number of possible explanations. Firstly, despite government initiatives to deliver race equality in mental health (DH 2005), Black Caribbeans in the UK continue to report poorer access to and experiences of mental health services (CHAI 2007). Institutional racism and the use of racial stereotyping have been shown to negatively influence clinical encounters and outcomes and to contribute to the over-representation of Black Caribbeans in secondary and tertiary care (Ahmad 1999, Hickling and Hutchinson 1999, Littlewood *et al.* 2001, Spector 2001). As illustrations, commentators highlight the emergence of 'racialized' psychiatric categories such as 'cannabis psychosis' and 'rastaphrenia' in the last decades of the twentieth century (Sashidharan 1993, Hickling and Hutchinson 1999, Takei *et al.* 1998).

The 'circle of fear' which results from Black Caribbeans' perceptions and experience of unfair and unequal treatment in mental health services has generated deeply-entrenched mistrust within these communities – even among those with no firsthand experience of services – and acts as a powerful barrier to accessing care and treatment (Keating *et al.* 2002, Edge

and Rogers 2005, Keating 2007). In consequence, Black Caribbeans experiencing mild/moderate mental illnesses (common mental disorders (CMD) such as anxiety and depression) are less likely than other ethnic groups to engage with primary care services. Instead, they are more likely to enter the coercive end of the mental health system much later via so-called 'adverse pathways' with more serious and often chronic mental illness (DH 2005).

Assumptions of significant levels of undetected and untreated perinatal depression among Black Caribbean women may, of course, be spurious. In the absence of sound evidence, it may be that such hypotheses are merely extrapolated from the large volume of data about Black Caribbean men at the forensic end of psychiatry (Bhui 2001, Bhui *et al.* 1998, Bhui *et al.* 2002, Hutchinson *et al.* 1997, Littlewood and Lipsedge 1997, Lloyd 1993, Sashidharan 1993). More positively, it may be that Black Caribbean women's absence from clinical practice and associated research reflects highly evolved and effective coping strategies which serve to militate against the potentially deleterious impact of psychosocial risk factors compounded by additional stressors related to pregnancy and early motherhood (Edge and Rogers 2005, Thorogood 1989).

The paucity of research among Black Caribbean women in the UK means that these theories have not yet been formally tested. Research was therefore undertaken to explore Black Caribbean women's beliefs about mental illness in general and perinatal depression in particular and to examine whether and to what extent women's health beliefs influenced their help-seeking

behaviours. This paper examines these women's perceptions of help-seeking in the perinatal period with particular focus on the inter-relationship between individuals, their social context, and the dynamics at play within help-seeking encounters. Examination of these issues leads us to conclude that current clinical and academic approaches to help-seeking place an unhelpful emphasis on the (dislocated) actions of individuals which might increase the likelihood of excluding certain social groups from receiving appropriate care and treatment.

### **Individuals and the health encounter**

Researchers and practitioners have long been interested in the factors that influence health behaviours and the use (or not) of health services. This has resulted in a large body of literature around health beliefs and health seeking behaviours (see MacKian *et al.* 2003 for a useful review). Although many of the resulting models of help-seeking behaviour are theoretically interesting; in practice, applications fail to fully account for the complexity of contemporary experiences (see for example Sheeran and Abraham 1996). This is largely a reflection of their emphasis on the individual as a rational decision maker who, once in possession of health information, is empowered and adjusts behaviour accordingly.

The more recently emerged concept of the 'informed patient' has helpfully opened up links with the sociological literature around reflexivity (Lupton 1997). The concept of the 'informed patient' and its sociological equivalent, the 'reflexive patient' or 'reflexive consumer' (Henwood *et al.* 2003 p. 589), with its strong emphasis on the patient as customer and partnership between

healthcare providers and consumers, is central to ongoing reforms in health and social care provision in the UK. Reflected in the strong 'personalisation' of care agenda, these profound philosophical shifts have exposed the 'doctor-patient relationship' and notions of empowering patients through health information to more critical sociological examination. Accordingly some have challenged the concept of empowerment in healthcare by exposing the difficulties of applying a 'partnership model' to what are inherently unequal relationships (see for example Henwood *et al.* 2003, Groopman 2007).

However, these discussions remain largely focused on the moment of encounter between help-seeker and help-giver and the use of 'information' within that encounter. Such a focus continues to locate help-seeking in the individual, thereby tending to ignore the wider context in which information is digested and actions negotiated. As countless failed health promotion campaigns bear testimony (for example the Defeat Depression Campaign (Paykel *et al.* 1998)) being 'informed' is only one part of the story. Having information does not necessarily influence health behaviours.

It is our belief that it would be helpful to reframe the debate by shifting the focus from individual patients in help-seeking encounters to recognising the interplay between these encounters and the wider social worlds in which they are embedded. This is something which has been recognised in broader sociological discussions which critique the notion of the self-determining reflexive individual (see for example Kilminster, 2008; Berking, 1996). As Adams says, reflexivity 'is embedded and socialized in ways which are all too easily overlooked' if we focus exclusively on an individual level (2003: 224). If the 'informed patient' equates to the 'reflexive self' (Henwood *et al.* 2003, Lupton

1997), we argue that other literatures on the sociology of reflexive modernity might also be useful in teasing out the changing landscape within which health encounters take place.

Using Black Caribbean women's response to depressive feelings in the perinatal period, we draw on the literature around 'reflexive communities' (MacKian *et al.* 2004) to explore the embeddedness of help-seeking health encounters within social structures. This we believe moves beyond the rather isolated notion of the individual to acknowledging that each individual, however informed and reflexive, is also part of a wider social setting. Focussing on embeddedness highlights how encounters between women and healthcare professionals may recursively reinforce responses thereby unwittingly reinscribing health inequalities. It has been suggested that, 'reflexive thinking is always bounded, if not exhausted, by the culture and society we are a part of...which historically have come to structure our sense of self and the world beyond' (Adams, 2003. 231). We contend, therefore, that if we are to understand these and other women's responses to depressive feelings and the subsequent health encounters and outcomes, we cannot focus solely on their 'knowledge' as informed patients. We must also examine the interrelationships between individuals, their social contexts, and the wider structural/societal forces which shape their lives – with particular focus on those that influence their ability to seek and receive help.

To develop this idea, we explore women's embeddedness in what we call 'reflexive communities' and how their location influences both the messages they receive and how they respond to them. Reframing the debate within the



concept of reflexive communities allows us to access and focus upon the ways in which individuals come together; seek and receive confirmation of their feelings or 'symptom's; and how this, in turn, reinforces their own worldview. We thus move from a simplistic understanding of isolated individuals (reflexive selves) to a more nuanced perspective on 'help-seekers' and 'help-givers' as entities embedded in complex and powerful contexts (reflexive communities), which inevitably influence their behavioural responses. Whilst we do not maintain that women and their healthcare providers occupy the same standpoint, we contend that, in health encounters, they come together in particular ways which reflect something more than a simple exchange of information. As illustrated by women in this study, the manner in which these encounters are constructed and negotiated (prior to, during, and following such episodes) and whether or not individuals seeking help receive it, might have profound implications not only for current but also for future help-seeking.

### **Outline of the Study**

A purposive sample of twelve Black Caribbean women was drawn from a larger mixed-method study into depression during and after pregnancy among Black Caribbean (n=101) and White British (n=200) women who were recruited at community clinics and a large teaching hospital in the north of England, UK. Theoretical sampling was used to develop a sampling matrix (available on request) from which women were selected to reflect the full range of depression scores during and after pregnancy (as measured using the Edinburgh Postnatal Depression Scale (EPDS) (Cox *et al.* 1987)). In this

context, women's depression scores were used to assign them to one of four categories:

- (i) **Antenatally depressed** - women who recorded high depression scores (EPDS  $\geq 12$ ) during pregnancy and low scores postnatally
- (ii) **Postnatally depressed** - women who recorded high EPDS scores in the postnatal period having recorded low scores during pregnancy
- (iii) **Always depressed** - women who recorded high EPDS scores both during and after pregnancy
- (iv) **Never depressed** - women who record low (below-threshold) EPDS scores both antenatally or postnatally

Similarly, the sample included women with both high and low levels of adverse life events and difficulties (Brown and Harris, 1978, Brown and Heller, 1996) and other psychosocial factors that are linked with onset of perinatal depression such as deprivation, social isolation, and lone parenthood (O'Hara and Swain 1996). In addition, women were selected to reflect socio-demographic differences in the original sample such as age (range 18 – 43), marital status, and employment. For example, of the twelve women: four were married; four described themselves as 'single' but had partners; one as 'separated'. The remainder were single women who stated that they had no partners. In terms of employment, the sample included women with professional qualifications, students, unemployed women (both recently unemployed and women who had 'never worked') as well as women taking career breaks or long-term maternity leave. Accordingly, although the sample was recruited at clinics with predominantly inner-city populations; it

also included women from more affluent backgrounds, which is a reflection of the wider catchment area covered by the teaching hospital.

Using a topic guide derived from issues probed in the larger study and the existing literature (see for example Buist *et al.* 1999), women were interviewed in-depth approximately six months following childbirth. Interviews, lasting between 45 minutes and 2 hours were audio-taped with women's consent. They were subsequently transcribed verbatim by the researcher (DE) and analysed for emergent themes. Themes were subject to constant comparison (Glaser 1978) and examined for goodness of fit (Miles and Huberman 1994) until a final set of key themes were identified. Data verification strategies to ensure the reliability or 'trustworthiness' of the data and consequent findings included participant verification, peer review, and the use of independent researchers to examine themes, findings, and conclusions (May 1997). QSR NUD\*IST4 (Qualitative Solutions and Research 1997) was used to facilitate data management. The study received ethical approval from the relevant research ethics committees and National Health Service (NHS) bodies.

Whilst the wider study covered a range of issues, which have been explored elsewhere (see for example Edge 2007a), this paper focuses on two key points of interest: firstly, Black Caribbean women's approaches to help-seeking and secondly, their experiences of receiving help from professional 'help-givers'. Help-giving and help-seeking were not a priori concepts. Rather, they emerged during data analysis as potentially key factors for explaining apparent non-engagement of Black Caribbean women with primary mental health services in relation to perinatal depression. We suggest Black

Caribbean women's accounts of help-seeking present evidence of 'reflexive communities' at work rather than merely individuals negotiating health encounters as discrete events. We then explore practice and policy implications of the findings. As women's verbatim comments are used, they have been anonymised to protect participant's identities. Women's quotes are presented with the research ID assigned during the study.

### **1. Approaches to help-seeking**

As might be expected, Black Caribbean women's pathway to help-seeking for perinatal depression suggests that decision-making processes and subsequent behaviours are complex and multi-layered. Their approaches to help-seeking were predicated on three key factors – a social model of depression, hierarchies of help-seeking, and resistance to psychiatric labelling.

#### ***A social model of depression***

Black Caribbean women suggested that, in order to seek help, they must firstly (re)construct depressive feelings as 'symptoms' or at least something requiring attention and external validation. This inherently social process depends on verification and legitimation of depressive feelings from external sources (Helman 1994). Figure 1 shows that this might be particularly problematic for Black Caribbean women.

Figure 1 about here

Firstly, in this construction of mental health and illness, it is important to note that 'depression' is symbolised by a 'black box'. This reflects the difficulty women expressed in trying to conceptualise depression in general and perinatal depression in particular. In this context, they suggested that Black Caribbeans' unwillingness/inability to acknowledge psychological distress is compounded by lack of social discourse about what constitutes mental illness (or not) within their social networks (Edge & Rogers 2005). Hence, as Black Caribbean women, they were unable to access appropriate discursive resources that would enable them to reframe depressive feelings as legitimate 'symptoms' for which they might need care and/or support. According to these women's accounts, this leaves them at a disadvantage in terms of help-seeking and receiving appropriate care and treatment:

"I'm not saying it's [depression] totally a White person's thing. I think it is amongst Black people but it's just that it's unheard of...Therefore they're not going out there to seek help, are they? ... if they haven't recognised that there is a problem [they're] not going to seek help." (Participant 9)

Secondly, the conceptual map shows that women regarded depression as being on a continuum between mental 'health' and psychological 'wellbeing' at one end and (via 'normal unhappiness' and a 'transition zone') more 'serious mental illnesses' such as schizophrenia at the other. According to women in the study, whether or not 'depressive symptoms' become reclassified as 'depressive illness' depends on interactions within the 'transition zone'. The model shows that there are a number of potential triggers or 'push'

factors which might lead women to develop the symptoms of depression. Running counter to these, are protective or 'pull' factors that move women away from depression. It is interesting to note that the same (largely) social factors that push women towards depression (such as faith, looking after children, and utilising personal coping strategies) can also provide the means of regaining their psychological well-being. It is in this 'transition zone' that depressive feelings are mediated by factors like personal autonomy and psychosocial forces – including women's socio-cultural and spiritual beliefs and the responses they receive from potential 'help-givers'. In other words, the presence of adversity, distress, or experiencing depressive symptoms are neither necessary nor sufficient conditions for (self)diagnosis with perinatal depression. Rather, the individual's response is conditioned by issues such as previously unresolved psychological or emotional distress, inherent psychological vulnerability, and social embeddedness - a key component of which is ethnicity and the women's social identity as 'Strong Black Women'.

“...you get depressed [depressive feelings], everybody does but, like I said, I think Black women don't allow themselves to get depressed [depressive illness]. They keep themselves on top of it.... .” (Participant 4)

### ***Hierarchy of help-seeking***

In line with their social model of depression, women in this study used a lay hierarchy of help-seeking (Figure 2). In so doing, they endorsed previous reports of help-seeking for health problems among other ethnic groups by

privileging personal agency, autonomy, and self-reliance over seeking help from others (Rogers and Pilgrim 1997, Telles and Pollack 1981).

"I try and find a way of helping myself if I can. If I need help then, you know, obviously I'll look for it and I know I can get it but you have to help yourself." (Participant 6)

When self-help failed, women preferentially turned to other lay sources of support such as family members and friends. Only when self-reliance and social networks failed to meet their needs did they seek help from formal healthcare providers. In this sample, just two of the twelve women eventually sought help from mainstream services.

"It's about where you get the strength from to cope, within your structure before you actually go to the GP. It's in the home... It's from your mates and your family circle and stuff like that."  
(Participant 12)

Figure 2 about here

An important finding in this regard is that women's reluctance to engage with services was often based on previously negative interactions with healthcare providers. Of the twelve women interviewed, ten spontaneously expressed dissatisfaction with aspects of their previous interactions with healthcare professionals and spoke about the negative impact of such encounters on their willingness to seek help from professionals thereafter. In common with

other lay groups (Henderson *et al.* 1998), the consequence of these negative interactions also extended beyond the context in which they occurred. This is epitomised by one of the women's account of a poor consultation with her General Practitioner (GP) about her infant's illness, which thereafter disinclined her from seeking help or support for herself (though not for her infant) from health agencies.

"He [GP] tried to tell me I needed a counsellor and I was getting distressed. And I said, 'I'm getting distressed because you're not listening to me ... You're telling me he's alright but I'm telling you he's not. He's **my** child and **I know**'. And from then on, I just don't go ... I just don't go. If I'm ill, I really **do not** go to the doctors. I'd rather sit here in pain." (Participant 2) [Emphasis in the original]

These women's accounts also suggested that, in common with other women of African descent (Nadeem *et al.* 2007), their own emphasis on self-efficacy combined with powerful social imperatives to be 'Strong Black Women' and fear of stigmatisation were powerful barriers to help-seeking.

"... it's quite a matriarchal society and therefore you've **got** to cope. **You've** got to sort your family out, and so therefore you are not allowed to be depressed." [Emphasis in the original] (Participant 7)

Women's views about the appropriateness of help-seeking also cohered with those of the general population (Telles and Pollack 1981). Black Caribbean



women suggested that whilst it might be acceptable to seek help for physical conditions this was not the case for illnesses with less obvious (visible) signs.

"... if it's physical, if it's there and you can see.... Like if you've hurt yourself. If it's there, then they'll go and get treatment but if it's like, no-one can see it, then they feel that they don't need treatment.... " (Participant 11)

In this context, women's accounts also suggested that they may regard depression as the natural sequelae of dealing with adversity in their everyday lives rather than a legitimate illness. They were therefore disinclined to seek help from mental health providers. However, there was evidence that they were more willing to accept help from other sources. Most prominently, there was evidence of seeking and receiving help from spiritual and religious sources and from their peers. Drawing on earlier (predominantly childhood) experiences, some women sought solace in private prayer and meditation.

"I was a Sunday school girl all the way up to the age of fifteen ... even though I don't go [to church], I'd be sat here thinking 'Oh, I've got no money or I need to do this.' And I'm like, 'Oh, please, God. Look after me today.'" (Participant 11)

However, a recurrent theme was women's accounts of the acceptance, practical, emotional, and spiritual support that they received from faith communities – even if they were not 'church goers':

"One of the ladies from church came. She said, 'I've come with my gloves and bathroom cleaning stuff and I'm doing your bathroom'. She cleaned my bathroom, which was lovely!"

(Participant 7)

According to these women, the care and support received from faith communities was very affirming. This finding is endorsed by reports of an increasing awareness by policy-makers and practitioners of the importance of spirituality and religious affiliation both for maintaining and restoring mental health and well-being and embedding individuals within communities (Boyd-Franklin and Lockwood 1999, Schnittker *et al.* 2000, Swinton 2001, NIHME/Mental Health Foundation, 2003, Cornah 2006, Mental Health Foundation 2007, Koenig 2008).

### ***Resistance to psychiatric labelling***

Among Black Caribbean women, the issue which had the greatest influence on their engagement with primary care mental health services was their perception that their experiences would inevitably be negative. As Figure 2 illustrates, women believed that if they consulted their General Practitioners (GPs) prescription of antidepressants would be not just the first but the only treatment option. Women believed this to be both an ineffective and inappropriate response to managing psychological distress. Moreover, they believed that pharmacological treatment would invariably draw them into a downward spiral of increasing doses and potency of medication, escalation of symptoms, and eventual re-diagnosis with more serious mental illnesses such as schizophrenia. These women's accounts resonate with research from

the Sainsbury Centre for Mental Health, which reported that a 'circle of fear' (based on perceptions and experiences of unfair, unequal, and inappropriate care and treatment) has a profoundly negative impact on Black people's willingness to seek help for psychological distress (Keating *et al.* 2002). Black Caribbean women suggested that there are deleterious socio-cultural, personal, and psychological consequences of being diagnosed with a mental illness. Not surprisingly, therefore, they were reluctant 'to be labelled'.

"... it's just that you don't want to be labelled....I certainly haven't told other people... because I don't want them to label me. They treat you differently and I think that makes you worse".  
(Participant 7)

"I think there's a stigma as well...about failure and not being able to cope. The whole word 'depression' ...it's got such negative connotations. So perhaps that actually keeps us from actually going to ask for help." (Participant 12)

In consequence, women struggled to reconcile their need for psychological support with their resistance to being labelled with 'postnatal depression' as this account illustrates.

"It was a shock though when she [Health Visitor] said I had postnatal depression. Because I said, 'I haven't got it'. But she said, 'you **have** got it'. When I look back on it, I think she's

probably right. Although now I'll say, 'I haven't got postnatal depression'. But there'll be days that I think, 'oh yeah I have' [laughs] ... so that's why I think, 'well, she's probably right'. But I have to admit, nine times out of ten I think, 'I don't think I've got it'. I think I'm **down** at times and I call it '**down**' but I don't think I've got postnatal depression." (Participant 7) [Emphasis in the original]

## **2. Structural and professional barriers to receiving help**

Despite socio-cultural imperatives to normalise psychological distress, personal resistance to psychiatric labelling, and the fear of stigmatisation; under certain circumstances, women reportedly sought help from statutory healthcare providers (Figure 2). They usually did so as a last resort and only when they believed that their behaviour/loss of social functioning might adversely affect their children.

"So my emotional well-being is very important 'cos I didn't want to give any of my vibes off to my child. I didn't want to give any of my anger to my other two children". (Participant 2)

However, when they sought help they encountered a challenging and surprising set of barriers from current National Health Service (NHS) primary care mental health provision and practice. Firstly, even women who were willing to seek help from 'counsellors' reported being hampered by structural factors such as long waiting times and inadequate childcare – factors that are common to women from all ethnic groups. However, an issue that raised

particular challenges for women from this ethnic group was their inability to access care from (preferred) Black psychological therapists whom they believed would be more likely to understand and empathise with their lived experiences.

"I wouldn't wanna particularly unburden myself to some white woman [therapist], if I'm honest about it. It's [effective counselling] about having someone who you can chat to who understands what you're doing, where you're going, where you're coming from and all that kind of stuff." (Participant 12)

Both in terms of structural issues (such as unavailability of culturally-competent therapists) and other factors (such as staff attitudes), NHS primary mental healthcare of itself proved to be an insurmountable barrier to receiving care and treatment when these women were at their most vulnerable. This is reflected in this woman's account of her consultation with her GP, which suggests both an implicit resistance to medical intervention and dismissal of psychological therapy ('counselling') as mere 'talk' on the part of the healthcare professional (Edge 2007b). This apparent dissonance between professional guidelines clinicians say they follow and how they actually practice in real-life clinical encounters has been reported elsewhere (Callahan 1996, Higgins 1994).

"He [GP] says 'you're **not** depressed.... ' He said 'you're doing too much, you're doing **far** too much'.... He said, 'you're **not** depressed' He said, '**will you stop thinking you're depressed?**' He

said, 'I will send you for counselling'. He said, 'if you want to go counselling so you can talk, but you are **not** depressed'. He was saying I wasn't depressed, I was doing too much and running myself down." (Participant 1) [Emphasis in the original].

The inference that perinatal depression is not amenable to treatment is likely to resonate with women who are already highly resistant to psychiatric labelling thereby further reducing their engagement with and uptake of services. In common with this GP, women reported that other healthcare professionals also endorsed their social theories about the genesis of depression (most especially the concept of 'overload') to a surprising degree. In doing so, they unwittingly reinforced Black Caribbean women's personal and social imperatives to be seen as 'copers' ('Strong Black Women' in their own discourse) (Edge and Rogers 2005) and their resistance to being labelled with depression as this extract illustrates.

Q: So has she [Health Visitor] recommended any treatment?

A: No, no... she said I'm likely to get depressed. She says, 'don't get like that'. She says I have to think positive. (Participant 6)

These findings demonstrate a strongly recursive element between women's resistance to being labelled with depressive illness and the responses they received from healthcare professionals - findings which have been previously reported among White working-class women (Cornwell 1984).

"She [Health Visitor] said, 'go and see your doctor'. I saw my doctor and she said, 'oh, I think you're ok'. Well, my doctor is a bit like that anyway (laughs). I thought, 'great!' cos I didn't want tablets or anything." (Participant 1)

Finally, almost three decades after Dalton (1980) labelled postnatal depression 'the smiling depression', there was evidence from these women's accounts that some healthcare professionals lacked awareness of the lengths to which women go in order to deny or disguise depression for fear of being labelled 'bad mothers' and running the risk of having their children 'taken into care' by the state.

"I went to see the consultant a couple of weeks ago...and when I told him [about being diagnosed with postnatal depression] he said, 'you haven't got postnatal depression. You're too cheerful and bright and laughing'." (Participant 7)

## **Discussion**

Given the relative invisibility of women from this ethnic group in both clinical practice and related research, this study represents an important step in understanding minoritised women's help-seeking practices, which might facilitate development of more culturally-appropriate and responsive mental health services in a multi-cultural context. Limited sample size, use of a single ethnic group, and the fact that the women were drawn from a predominantly inner-city population means that these findings must be

interpreted with caution. In addition, the accounts are taken from the standpoint of a group of women who were sufficiently motivated to remain in the study for more than a year. These accounts may therefore not accurately reflect the voices of women who were unwilling/unable to participate fully. Neither did the study take into consideration the views of healthcare professionals. Triangulating women's views with those of a range of healthcare professionals to further unpick the issues which influence the non-engagement of so called 'hard to reach' ethnic groups is an interesting area of research and is the subject of a follow-up study (Edge, In Press). However, the study provides an opportunity to gain greater understanding of the inter-relationship between 'help-seekers' and 'help-givers' and allows us to suggest ways of working which might improve access, care, and treatment for a currently under-served group of minority women.

These findings suggest that help-seeking is related not only to social and cultural settings, but also to prior and on-going relationships with key 'gate keepers' to services. Despite practitioners' and policy makers' awareness of these issues, we argue that help-seeking behaviour is still rarely conceptualized as a socio-structural phenomenon contingent either upon the embeddedness of individuals within their social contexts or their relationships with gate keepers. Rather, it is usually understood and reported as something which resides within the individual who therefore comes to be regarded as the 'pressure point for change' (see for example Conner and Norman 1996). This has been reinforced by somewhat simplistic conceptualisations of the patient as 'informed' and 'self-reflexive'. Whilst apparently acknowledging that social context profoundly impacts health



behaviours, the overall assumption appears to be that the patient is a rational decision-maker who sits at the heart of the medical encounter independently processing and acting upon health information. Such assumptions fail to address the complexity of real life contemporary health problems or the social dynamics involved in help-seeking encounters. This is of course a criticism that has been levelled at the whole 'reflexive individual' debate, portraying as it does the seemingly autonomous, self-regulating individual who is 'oddly disembodied' and 'knows no setbacks or disappointments' (Kilminster 2008 p.134).

We believe that it may be helpful to move beyond current notions of the 'informed patient' which add little to traditional models of help-seeking behaviour based on individually-grounded KABP (knowledge-attitude-belief-practice) approaches (MacKian, 2003). We suggest instead that refocusing on the potentially far-reaching consequences of individuals' experiences of seeking and receiving help for future help-seeking decisions might heighten health professionals' awareness of the importance of the interaction between themselves as '*help-giver*' and '*help-seekers*' in the moment of encounter.

Embedding the 'informed patient' in a wider social context also acknowledges that help-seeking and giving are underscored not only by the processing of information and subsequent action by individuals but also by the mutual constitution of 'implicit assumptions' within help seeking/giving encounters (Adam *et al.* 2000). This places the emphasis not on the individual patient, but on the way in which groups of individuals in particular social contexts come together to create and reinforce distinct ways of behaving

and the health implications that ensue. Exploring the underlying, socio-cultural assumptions which underpin decision-making processes in relation to help-seeking including the collusive role of some help-givers therefore becomes an imperative for improving care.

### ***Implications for policy and practice***

The relationship between Black Caribbeans and mental health services in the UK has traditionally been problematic, generating fear and distrust among service users and wider Black communities. Reducing fear of mental health services among Black and minority ethnic (BME) communities and delivering more responsive services by culturally-competent practitioners are among the key tenets of the UK government's commitment to Delivering Race Equality (DRE) by eliminating race-based disparities in mental healthcare by 2010 (DH 2005). The UK's National Service Framework (NSF) for Mental Health (DH, 1999) and other health policies highlight the need to improve access for women – particularly in primary care and strategies have been developed to bring women's mental health 'into the mainstream' (DH, 2002, 2003). In this context, recognition of and attempts to understand the help-seeking behaviours of Black Caribbean women, coupled with exploration of the role of healthcare professionals as potential '*help-givers*' is important as this might facilitate development of new strategies for managing mental health and illness among women from this ethnic group with potentially important implications for other marginalized communities.

It has been suggested that “[r]eflexive communities reflect socially-constructed ways of behaving, thinking, and decision-making at both the

individual and group level based on individuals' positions in wider society at a particular place and time" (MacKian *et al.* 2004 p.141). As we have seen, in the case of Black Caribbean women, initiatives aimed at promoting mental health (such as the antenatal 'parentcraft' classes that these women attended) failed to demystify perinatal depression for them. In fact, although these women were familiar with the term 'postnatal depression', the condition remained a closed, 'black box' in terms of conceptualising their feelings as depressive illness as opposed to 'feeling down'. The study also suggests that implicit assumptions by healthcare professionals about these women's perinatal mental health needs might serve to direct their 'patient journeys' in ways that result in their depression neither being recognised nor validated by mainstream services. We suggest that what is required is a more overtly collaborative approach such as the 'mini clinic' approach advocated by Kendrick (2000). More collaborative ways of working might enable women seeking help and the professionals giving it the time and space to explore, understand, and negotiate the nature of the 'black box' in order to shed light on the unknowns it represents - not only in terms of 'symptoms' but also the kinds of help-giving and receiving which women from this ethnic group would find acceptable.

Removing the over-riding emphasis on the individual help-seeker creates the possibility for a more situated understanding of women's response to depressive feelings both in their everyday lives and their relationships with (potential) 'help-givers'. In doing so, we begin to move from viewing help-seeking as a one-way process, to exploring the role of healthcare providers as 'help-givers' on the other side of the partnership. Introducing the concept of

reflexive communities as a bridge between help-seeking and help-giving thus provides an opportunity for deeper understanding of the factors which influence whether or not - and from whom, when, where, and how – individuals seek, are offered, and accept help. We therefore suggest that shifting our focus from 'informed patients' to the role of how professional attitudes and engagements with the concerns of Black Caribbean communities might shape their help-seeking encounters could enable healthcare providers to develop more culturally-appropriate and responsive services, which might improve engagement and outcome – particularly for minoritized groups.

The understanding provided by this study suggests that healthcare workers might benefit from increased awareness of the complex inter-relationship between individual and collective knowledge and experiences which influence whether or not individuals seek help for common mental disorders. Our model further suggests that healthcare workers might benefit from improved understanding of the social construction of mental illness among different communities (and their role in shaping or reinforcing this).

Acknowledging that what comes to be regarded as legitimate mental illness (or not) and the most appropriate responses are subject to interpretation within socio-cultural contexts and therefore negotiable, might significantly improve help-seeking/giving encounters and subsequent compliance among so called 'hard to reach' groups.

## **Conclusions**

Despite a large volume of research into perinatal depression in other ethnic groups and serious mental illness among Black men; common mental disorders such as perinatal depression remains intriguingly under-researched among Black Caribbean women in the UK. Responding to this gap in knowledge, this paper has attempted to unpick the relationship between individuals and the influences of socio-cultural and structural frameworks (such as service provision by the NHS and the gate keepers within it) on the help-seeking behaviours.

We have presented the idea of developing relationships between health providers and consumers premised on the notion of 'reflexive communities' rather than individual patients as one way to explore this. The model developed from this study helps to visualise areas that might require especial focus in order to improve the quality and effectiveness of health encounters. We suggest the 'black box' and 'transition zone' in these women's schema of depression as two fruitful starting points. Groopman's (2007) recent exploration of what remains unsaid and unheard in the average health encounter suggests there may be wider applicability of this idea.

Our ideas have been developed from a small sample of only twelve women, but these twelve were chosen because of their 'typicality' in relation to the broader sample of 101, and can thus be said to be representative within a fixed and finite set of cases (Hammersley and Atkinson, 2007). However the parameters of qualitative protocols of analysis are to seek specific and detailed in-depth cases rather than comprehensive and generalizable findings, and that is what this paper has aimed to do. Clearly to fill the

knowledge gap more completely would require further larger scale studies, nonetheless the data generated begins to address the need for more sensitive understanding of the local and specific nature of Black women's mental health.

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