The experiences of refugee and asylum seeking women of maternal healthcare in the UK

Imogen Horn, Medical Student

St George's University of London

Aim

To investigate the experiences of refugee and asylum seeking women in accessing maternal healthcare in the UK, and suggest ways to overcome the challenges to ensure a better outcome.

Background

The health of refugee and asylum seekers is a major concern for the UK public services. Evidence shows a failure to meet their complex health needs. Pregnant women are particularly vulnerable, with broad medical and psychosocial needs. Research indicates poorer outcomes in Europe compared to native mothers in a range of measures. The Confidential Enguiry into Maternal and Child Deaths (CEMACH)(1) revealed 12% of maternal deaths are among refugees and asylum seekers in the UK, despite making up only 0.3% of the UK population, and asylum seeking women are three times more likely to die in childbirth than the general population (2). These woman are much more likely to book late and miss multiple appointments compared to the general population, which correlates with increased risk during the pregnancy and poorer outcomes. Data collected on asylum seekers and refugees at a Doctors of the World London drop in clinic found that 62% of women had their first antenatal appointment late, and 50% had five or fewer antenatal appointments (3).

There is inequality of accessibility and provision of obstetric care. It is likely that exposures associated with migration may increase the risk of poor outcomes amongst refugee and asylum seekers. However maternity care in the UK is currently not providing sufficient standards of care for these women.

This project was carried out in collaboration with Community Action for Refugees and Asylum Seekers (CARAS), an organisation providing help and support for refugees and asylum seekers in London.

Methodology

A qualitative study using data from questionnaires, and a focus group, with a literature search, Ethical approval was obtained from St George's Clinical Ethics Committee (CEC). Refugee and asylum seeking women, who attend the Woman's group at CARAS or are beneficiaries of CARAS, were invited to participate in the study if they have a child of age six years or less, born in the UK, 17 women completed the questionnaire and 5 also took part in the focus group. The questionnaire comprised 27 questions , and 10 main themes were discussed in the focus group.

Participants were fully informed of the purpose and nature of the study, and assured that all data would remain anonymised and confidential. The women were assisted with the questionnaire by myself due to the complicated nature of some of the questions. The focus group, led by a CARAS team member, was recorded in notes. All recorded information was anonymised and was only available to the research team.

Limitations

The recruitment targeted a specific local group for its sample (all were users of CARAS's services) so findings are not generalizable. The sample size was also small.

The focus group and questionnaires were carried out in English, which is not the first language of the participants and thus may have limited their ability to express themselves fully and could have lead to some confusion.

Some of the women may have had their last child up to six years ago and it is therefore likely some of the information may have been forgotten or misremembered by the

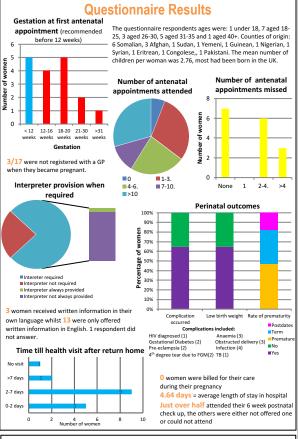
Some participants felt uneasy sharing personal information with the rest of the group.

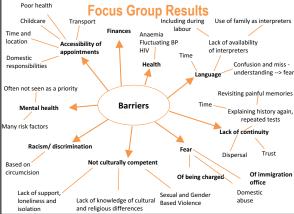
Acknowledgements

I would like to thank the women who kindly participated in this study. I would also like to thank Dr Jess Thomas, Professor Shirley Hodgson and Eleanor Brown for their help.

'There was a problem with my baby and they took him away. I didn't know where or why? They used a telephone interpreter later, but I was crying, I was so scared for him.'

'I asked for a lady doctor but they only had man. That made me ashamed for him to see all that.'





Discussion

m1400278@sgul.ac.uk

This project has revealed numerous inconsistencies and a range of barriers to treatment. Clearly lack of English is a major obstacle. It is the responsibility of the NHS to arrange free interpretation; however the questionnaire results show overwhelmingly that this is not achieved. Lack of interpretation leads to confusion and misunderstanding. One focus group attendee said she didn't understand what was happening during her C-section, no one explained properly. Family members including husbands are simply not a suitable alternative. Women cannot speak openly and their husbands may not always be present to interpret for them. Also using the husband as the sole interpreter can potentiate abuse as the women are denied an opportunity to talk alone, and the husband may 'selectively' interpret.

Not receiving care from the same midwife prohibits the continuing development of trusting relationships and necessitates women repeating their history multiple times, not only time consuming but also forcing women to revisit painful memories . Disruption of care continuum is often due to dispersal: asylum seekers are moved between accomodation centres while their claim is considered. A pregnant woman can be moved any time until their 36th week of gestation or 4 weeks postnatally (4). Dispersal 'inevitably disrupts maternity care which is a continuous and cumulative process.... woman's distress is noticeably increased, creating higher risks of postnatal depression and concomitant problems for their relationship with their babies.' (5) Two focus group participants did not attend appointments due to fear of the home office, 'I thought maybe they will ask if I am legal in the UK.' An additional questionnaire respondent gave birth at home with no care for these reasons. Clinicians have a duty of confidence to their patients clearly outlined in GMC guidance (6) which extends to their immigration status. It is important this is emphasized to the patient and they must be assured confidentiality will be maintained. No participants were charged for their care, however fear of being billed still deterred some. The introduction of charges was the UK government's attempt to combat 'health tourism'. Refugees, asylum seekers, those awarded humanitarian protection and discretionary leave are fully entitled to free NHS primary, secondary and A&E care, including maternity services. Failed asylum seekers are not eligible for free hospital care, including maternal care (7) and a normal vaginal delivery can range from £1500 to £3000 (8). Many in this position are particularly vulnerable as they often have no rights to work or to the benefits system. These women are not health tourists as they did not come to the UK to use the NHS. Although maternity care is 'immediately necessary' and cannot be denied on the grounds the woman cannot pay, this does not always appear to be applied and The Reaching Out Project has found instances of women being refused care after arriving at hospital in labour (8).

Societies vary widely in cultural norms . Areas of controversy and difference include: involvement of the father in pregnancy and child birth, FGM, caesarean section, pain relief, male doctors. The focus group emphasised the importance that staff appreciate and, if appropriate, respect these differences, particularly FGM. One woman said 'when the midwife found I'd been circumcised she treated me different... like I would harm the baby'. FGM has been shown to increase the risk of perineal tears, obstructed labour and postpartum haemorrhage amongst other complications, thus its identification is important whilst maintaining cultural sensitivity.

Often these women have suffered multiple bereavements, endured traumatic experiences such as rape, cutting, and their journey here, and been physically attacked or imprisoned. They may also be lonely and isolated or suffering domestic abuse. These are strong risk factors for mental health problems in pregnancy and postnatally. Regardless, it seems appointments cannot accommodate the breadth of social and psychological issues and thus mental health support may not be adequately implemented. One focus group attendee said 'they asked me do you feel depressed, are you suicidal? It's just routine. They don't care about the answer or what you've been through'.

These findings should be implemented to improve future experiences of refugee and asylum seeking women. The focus group attendants and I have formed a short list of recommendations: longer appointments, continuation of midwife care, improved access to and provision of interpreters and written information in the correct language, more training for health care professionals to allow better understanding for example on FGM, entitlement, and to encourage cultural sensitivity, support groups, mentoring from women who understand the maternal care pathways, more flexible appointment schedules and more accessible clinics for example at childcare centres or community

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