Community Participatory Research Project (CPAR Project)

Topic: Barriers to accessing maternal healthcare services faced by ethnic minority communities as a result of Covid-19 and digitisation.

By Evangeline Karanja

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A. INTRODUCTION

The (MBRRACE-UK) report showed a stark disparity in the racial variations of maternal mortality rates. Black women are four times more likely to die, while Asian women were two times more likely to die than White women during pregnancy, delivery or postpartum.

Apart from a slight drop in the maternal mortality rate for Black women, this bleak picture has not changed in over a decade[1].

Public Health England's report, *Covid-19: understanding the impact on BAME communities*, demonstrates the widening of existing health inequalities and as a result, Health Education England SE is implementing a programme of work to support community participatory research, in which researchers and community stakeholders engage as equal partners[2].

Why?

A key component in establishing equality in maternal healthcare provision is the examination of women's experiences of accessing these services.

My involvement in voluntary community work in the past two years has allowed me to engage in community talks and hear what problems women are facing.

The topic of maternal health is one that sparked my interest in listening to many women's pregnancy journeys, the highs and the lows. I was especially interested in hearing the experiences of women who could speak English fluently. As previous research has shown, language has been a big contributing factor in the barrier to accessing maternal health care.

However, what is the experience of ethnic minorities who can speak and understand the English language in accessing maternal healthcare services?

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[1] Fenton K, Pawson E, de Souza-Thomas L. *Beyond the data: Understanding the impact of COVID-19 on BAME groups*. Public Health England, 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf [Accessed 24 February 2021].

[2] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

B. RESEARCH FOCUS

Health care services must consistently and competently strive to meet the needs of the whole population. However, past research has shown that patients from ethnic minority backgrounds have faced inequality when accessing healthcare services.

Hence there is still a great deal of work to ensure that all patients, regardless of their background have equal access to healthcare services.

This study aims to explore the experiences of pregnancy, childbirth, antenatal and postnatal access, in women and healthcare professionals in the Black ethnic minority and highlight the effect of the Covid-19 pandemic and digitalisation.

1) **What are the barriers to accessing maternal services?**
2) **What was the impact of covid-19 on maternal services?**
3) **What is the effect of digitalisation on maternal services?**

C. RESEARCH METHODS

This research was qualitative, using individual interviews with open-ended interview questions so that in-depth information could be collected. This allowed me to better explain the research questions to participants, and to better understand their answers. It also enabled me to observe people's behaviour as we spoke, as this can provide extra information about how someone is feeling about an issue.

The advantage of an in-depth interview method is the rich data collected. However, the disadvantage is that it is time-intensive which limits the number of participants.

I interviewed 9 respondents: 6 mothers and 3 midwives all within the Black ethnic minority with a good understanding and knowledge of the English language.

Consent was given, confidentiality was agreed upon with respondents and all sessions were recorded.

Data collection occurred between November 2021 and January 2022.

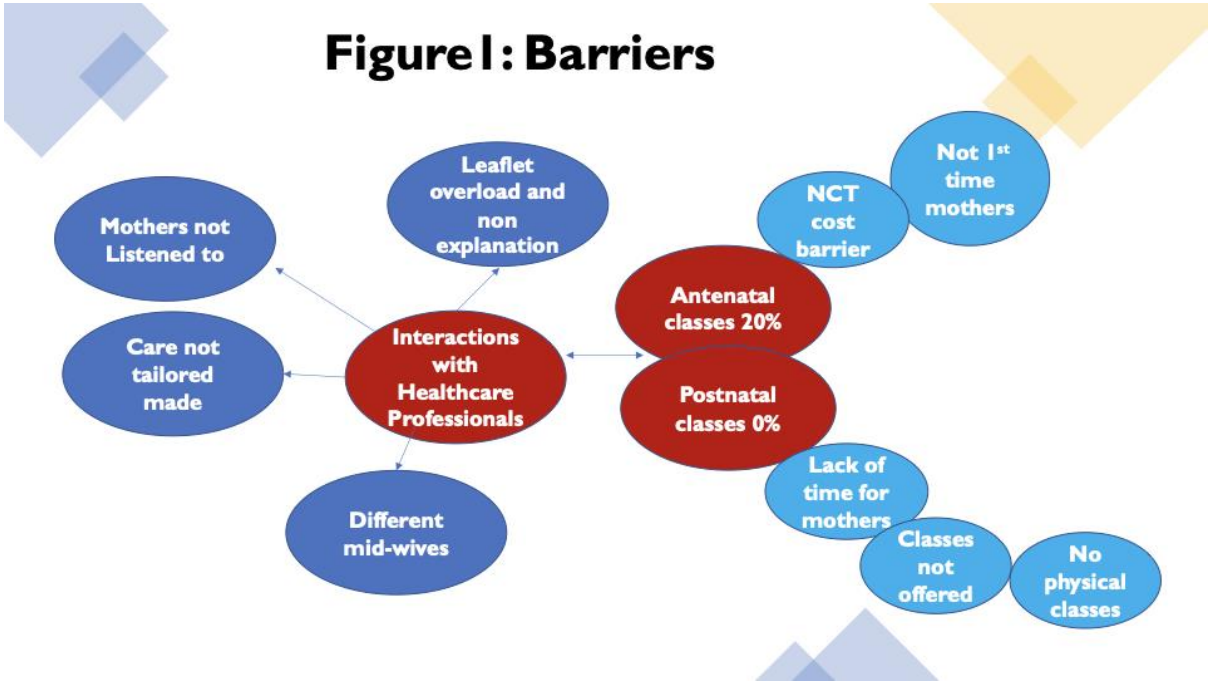
The analysis of data involved transcribing the recordings, reviewing the data, and taking notes of the findings that were emerging.

D. RESEARCH FINDINGS

1) What are the barriers to accessing maternal services

This study focused on the lived experiences of English-speaking ethnic minority women, who were pregnant or delivered within 6 months of the Covid19 pandemic. During the pandemic, maternal services became increasingly digitalised, and most of the women who were interviewed had to engage with online and digital services during their pregnancy and first few months after delivery.

Figure 1 below shows several barriers to accessing maternal services as expressed by the participants.



1.1 Interaction with Healthcare professionals

1.1.1 Different midwives every time.

All participants mentioned that they saw different midwives at all their antenatal appointments. They all felt that they had to re-explain their history and situation every time they met a new midwife. A common sentiment that arose in women requiring regular input from secondary care during the antenatal period was ineffective communication between their community midwives and hospital midwives or obstetricians and vice versa, sometimes resulting in the omission of crucial clinical information.

The participants were not allowed to bring their partners to these appointments.

“One of the things that I didn't like is the fact that I didn't have the same midwife throughout my pregnancy, I was always changing, so you know for one appointment I would see this midwife, next one I would see another one and she wouldn't know the history. And so yeah, I didn't like that.” Participant 4

“I think it was at least three different midwives. I didn't have a consistent midwife. It wasn't good, because there was no consistency. You know, having a child when you're being faced with all of this pandemic and stuff, it's so unnerving to have so many changes as well.” Participant 2

Two participants did mention that when they had a consistent midwife who followed up with them, it created a very good bond and person to rely on. They also mentioned that midwives from the same ethnic background did provide them more care and attention in hospitals.

“Midwife was a good advocate. Proactive and very good in signposting where to find help.” Participant 6

1.1.2 Leaflets

The participants all reported some level of provision from the health care professional and almost everyone agreed they would have preferred more thorough discussions. Most participants received information about their pregnancy in the form of signposting to books or websites, but they expressed that their individual information needs would have been better met by one-to-one discussions

"To give someone a leaflet and information and say, 'Read up about this and this and this, and these are… these are kind of the options'. Rather than take the time to educate the person. To say, look, we're just going to break it down to you in two sessions. This is what we want to talk about and cover here." Participant 2

"… they just sent me leaflets for exercise." Participant 6

1.1.3. Not involved in decision making

Most of the participants reported feeling like they were not involved in the shared decision making with the healthcare professionals.

The participants all reported some level of provision from the health care professional and almost everyone agreed they would have preferred more thorough discussions.

"You were not given enough information to justify why they wanted to go the route they wanted to go." Participant 4

"It was so traumatic. It was absolutely disgusting that they could have avoided a lot of things, in terms of when I was dilated, going to the hospital once. People to see where the baby's positioning was. That could have been noted down, and it could have been avoided the second time when I came in and them saying they have to do a C-section." Participant 2

1.1.4. Mothers not listened to by healthcare professionals

In this study, most participants spoke English fluently. Despite the high standard of English spoken, most participants felt that they were not listened to by the healthcare professionals.

According to past research, the findings reflect how pregnant women are being put at greater risk due to clinicians focusing on their pregnancy, rather than the woman's own health.[3]

"So, if you're birthing a human being, the best position to be in has always been on all fours. But there's never been that sort of an option for me.

[3]https://www.npeu.ox.ac.uk/news/2188-new-report-highlights-persistent-inequalities-and-continued-inequitable-care-for-pregnant-women

And I wonder, right, is it because of the age? Is it because of the colour?' You know, all these things pop up." Participant 2

So, again, it just made me feel like this is just them saying this is just the easiest way for us to make sure we're just doing our rounds, we're meeting our checks and able to tick things off. That's how it felt." Participant 2

"… they were not allowing me to have the time to be pregnant, to have the time to go into the full experience of having a natural birth." Participant 2

"The doctors were fixated on complexities; they did not listen or give enough satisfactory explanation for what and why it would be done. The care and explanation of why I couldn't have the option that I wanted, was just so blasé and tick-box and just making sure that you know, they're doing what they have to do." Participant 6

1.2. Antenatal Classes

Antenatal care is the care you get from health professionals during your pregnancy. Antenatal classes help you prepare for your baby's birth and give you confidence and information. They're usually informative and fun, and they're free on the NHS. You can learn how to: look after and feed your baby.

Only 20% of the participants attended the antenatal classes. The participants listed several reasons why they did not attend these classes.

1.2.1 Cost of classes

The participants were offered the National Childbirth Trust (NCT) classes. The NHS only offers free antenatal classes to first-time mothers, for other follow-up pregnancies the mothers are referred to NCT classes that they have to pay for. National Childbirth Trust (NCT) classes are expensive for many people, and this is a major barrier to accessing services, as illustrated by the following quotes.

"Based on affordability you have to pay for it." Participant 2

"We were asked if we wanted to attend antenatal classes, we should go on the NCT Facebook page and book. The NCT Facebook page

increased the pricing for the virtual antenatal classes. Yeah, they increased their pricing. So NCT antenatal classes are already expensive. They're over, I think, £100. Yeah. So, in the light of everything that was happening last year a lot of people were being made redundant, people were on furlough. Yes, you have to pay for those out of your own pocket. So, I think the pricing, when I checked, was about £180 and I decided, no, I wasn't going to spend £180." Participant 6

1.2.2 Not 1st-time mothers

The participants who had children already did not see any benefit in attending any prenatal classes. They felt like they already knew how to take care of new-born babies.

"It wasn't my first time." Participant 3

"I just thought that being online wouldn't be as beneficial as if they were in person, and because I already have two children, I thought that I would just pass." Participant 4

The midwives interviewed expressed their concern and the outcome of this low antenatal class attendance.

"The low attendance has had a very negative impact, especially on the care of the babies. The mothers, they come to the ward, and they look clueless." Participant 9

"I think that one has cut across babies/mothers coming back to the hospital with babies who have not been properly fed, who have lost a lot of weight." Participant 9

1.3. Postnatal Classes

This is the care given to the mother and her new-born baby immediately after the birth and for the first six weeks of life. The main purpose of providing optimal postnatal care is to avert both maternal and neonatal death, as well as long-term complications[4].

None of the participants attended the postnatal classes. The participants listed several reasons why they did not attend these classes.

[4] https://www.open.edu/openlearncreate/mod/oucontent/view.php?id=335&printable=1

1.3.1 Lack of time for mothers

Some of the participants cited the lack of time as a major barrier to attending postnatal classes. They felt that once they were home, they had to take care of the home, older children as well as the new-born baby, leaving very little time to attend to anything else.

"No, no classes. There was no time. They offered me but I didn't go." Participant 3

"...so you're dealing with the mental load of having an older child at home, trying to work, ordering a prescription online and then you have leaflets. It's more stuff, more mental load for you." Participant 6

1.3.2 Online classes were a deterrent.

Several participants reported that they would have much preferred physical classes over online classes. They felt that the physical classes would be more impactful than being online.

"I was told they would be online. I did not attend." Participant 4

"COVID had just started, we didn't even have online things set up by then." Participant 1

"Was online. Did not attend." Participant 2

1.3.3 Postnatal classes not offered

One participant was never offered postnatal classes and even enquired if it was something she was supposed to do. Two participants required postnatal physiotherapy but were told there were no classes to just use the leaflets provided for exercise.

"No, I haven't heard anything about that, no." Participant 5

"Physio was not available. They sent leaflets for exercise." Participant 3

"No, there were no antenatal classes offered." Participant 6

The midwives interviewed expressed their concern and the outcome of this low antenatal class attendance.

“Major gap after mothers have given birth and that is after they have given birth successfully and everything works well and there are no complications, but I feel at that point in time, because of the shortage of staff they don’t get one to one support. And many of them go home with lots of emotions and lots of baggage, breastfeeding ashamed that their nipples are getting cracked or they don’t want to breastfeed in front of their partner. And so complex information.” Participant 7

2) Research Findings: Effect of digitalisation

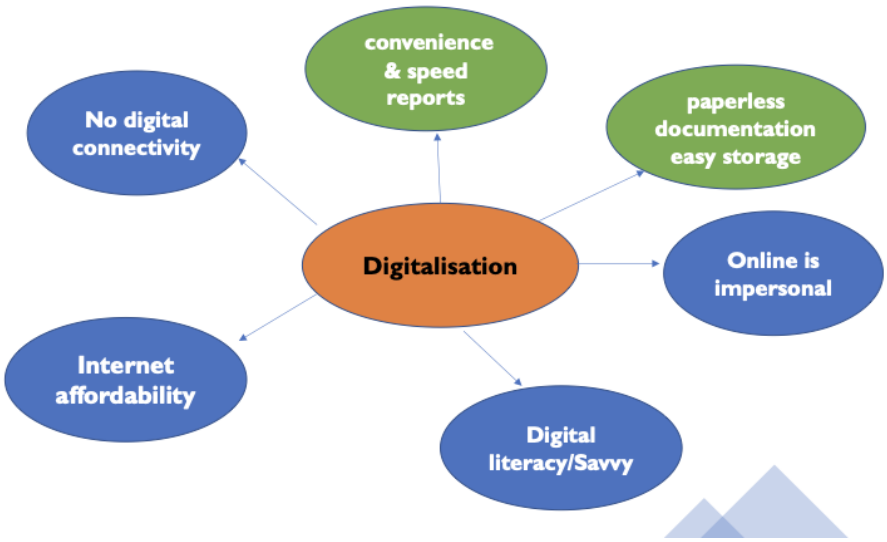
With the Covid-19 pandemic, there was quick adoption of digital technology in the NHS and significant changes in the delivery of services. The way that patients now access primary care has fundamentally changed. We witnessed the near-overnight restructuring of the initial method of patient contact, moving from the majority of appointments being face to face to the majority now being remote consultations. This was needed to free up space in hospitals, enable remote working and reduce the risk of infection transmission.

The maternal health care services saw a huge increase in remote appointments, especially antenatal and postnatal classes.

It was important to explore the effect digitalisation had on maternal services, and there were a range of barriers that women faced as a result of these service changes, as described below.

Figure 2 below shows the advantages and disadvantages of digitalisation in accessing maternal services.

Figure 2 : Effect of digitalisation



Digitalisation did provide some advantages.

2.1 Provides convenience/ease and speed to report results

All participants used apps to track their pregnancy not recommended by the NHS.

One of the participants had an app to report blood test results.

"via Bluetooth monitor. You have to periodically test your blood before a meal and after a meal and it syncs to your phone, to the app on your phone and it automatically uploads the readings to your phone. I guess if you had to go in to be monitored, you had to go into hospital every time." Participant 6

2.2 Paperless documentation and ease of data storage.

The digitalisation of hospital records means that midwives have to directly input data into computers as they see their patients. Midwives reported that this had reduced the amount of paper filling and resulted in ease of data storage.

From the midwife's perspective "...advantages of digitalisation, of course, it is good to go paperless, but it is easy to keep the notes as well." Participant 7

The digitalisation of maternal services also had some disadvantages.

2.3 No digital connectivity

To be able to participate in the online classes you would need to have a digital connection at home, a mobile device with video ability. There is an assumption that everyone is connected digitally. One participant had no internet at home and her device had no video capabilities.

"Covid-19 had just started; we didn't even have online things set up by then." Participant 1

2.4 Internet affordability

Some women mentioned how the pandemic brought the loss of jobs and as a consequence, some people cannot afford to have an internet

connection. Although this did not affect the participants directly, they did mention that they knew people who had been affected by this.

2.5 Digital literacy

Digital literacy refers to an individual's ability to find, evaluate, and communicate information through typing and other media on various digital platforms[5]. Being digitally literate increases your productivity and efficiency since you can achieve more in less time

"Yeah, and also you have to be digitally savvy, know what you're doing because you might also have the gadget, but just know how to maybe call people using it. The Echo app, would just be the Lloyds Pharmacy, but I think now it's called the Echo app. On the Echo app and you order your prescriptions, you order the medicine, so the pre-surgery medicine, physically search for the medicines, so…is relying on your ability to read and to type." Participant 6

2.6 Online is impersonal

Most participants felt that the online classes would be impersonal and not intuitive. They would not have the same feel as you would on face-to-face classes.

"Was online. Did not attend." Participant 2

"I was told they would be online. I did not attend." Participant 4

The midwives concurred that digitalisation during Covid-19 was the safest way to provide some of the services. However, this created other problems as the participants could hide their identity with the camera off and you would not be able to tell if they were fully engaged**.**

"How many can log in, people from BAME, how many can pull on their screen, comfortably say their problem? Seriously, unfortunately, the online has not helped because they can even hide their identity and not participate." Participant 7

[5] https://en.wikipedia.org/wiki/Digital_literacy

Midwives' views

"The mothers are no longer engaging physically, antenatally, like before they deliver, so they are not...Go to antenatal classes where they will interact, which has really... has had a very negative impact, especially on the care of the babies. The mothers, come to the ward and they look clueless. You know when they meet together, all physically, everybody says their experiences, the midwife demonstrates physically, they can participate. As opposed to watching online." Participant 9

3) Research Findings: Effect/Impact of Covid-19

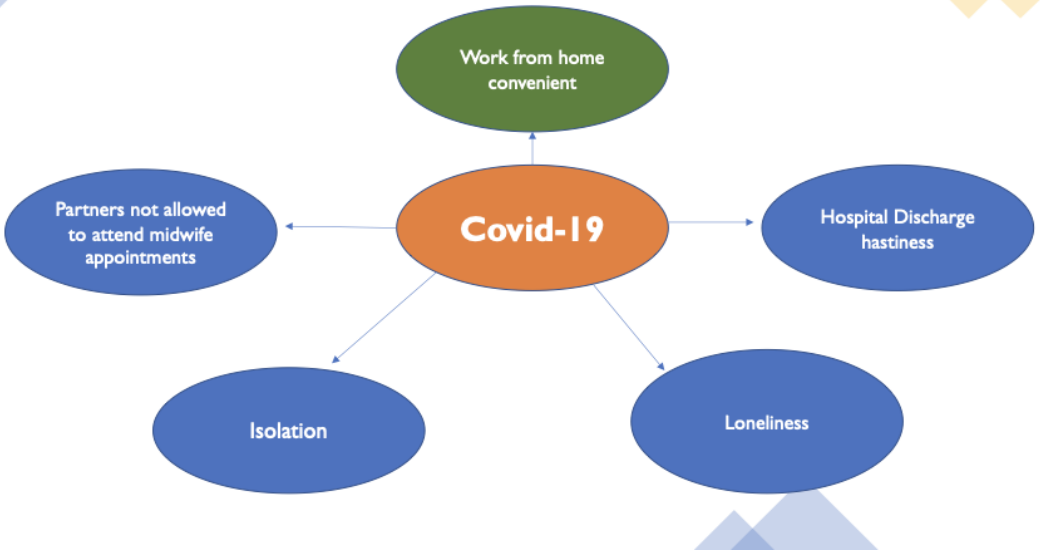
The Covid-19 pandemic has had a profound impact on healthcare systems and potentially on pregnancy outcomes.

The modern world has rarely been so isolated and restricted. Multiple restrictions had been imposed on public movements to contain the spread of the virus. People were forced to stay at home and social interactions were at a bare minimum.

The covid-19 pandemic has magnified the health inequalities and affected the members of Black, Asian and minority ethnic communities. The Public Health England report, *Beyond the data: Understanding the impact of Covid-19 on BAME Groups* demonstrates the widening of existing health inequalities. [6]

Figure 3 below shows the findings on the effect of Covid-19.

Figure 3: Effect of Covid-19



[6] Google Scholar

3.1 Work from home

Three participants were able to work from home during the pandemic. This gave them plenty of time to rest and meant they did not have to commute to work.

3.2 Isolation and loneliness

During the pandemic, social interactions were at a bare minimum. Most participants found that they could not interact with others freely, making the participants isolated and leading to loneliness. One participant said that there were no baby group classes or other opportunities to meet up, and she felt that this affected the child as she had no interactions with other children.

"No participation from mothers stayed home for 6 months" Participant 1

"It was difficult in the beginning because of the sudden change of you know not being able to see friends… missed seeing me pregnant" Participant 2.

3.3 Partners not allowed to attend midwife appointments

Most women reported feeling isolated during their pregnancy due to the pandemic. During Covid-19 the partners were not allowed to accompany mothers to midwife appointments. This was particularly a problem for those who felt that they would have benefitted from the presence of a companion when important information relating to their pregnancy was being relayed to them.

"You couldn't attend them with your partner." Participant 6

There is a need for paternity classes for men. Most ethnic minority men tend not to attend any antenatal or postnatal classes with their partners. This becomes difficult for the mother who has to do it all on her own. During labour, the partners are not able to be helpful as they have not attended antenatal classes. This causes a lot of stress on the mother as she is alone.

3.4 Hospital discharge time

The hospitals were under pressure during the pandemic to discharge patients quickly because they needed more bed spaces and to minimise the spread of the virus. The participants reported feeling rushed after they gave birth.

"But they're not really explaining to you the aftermath, the after-care, what it's going to mean for you when you have a C-section." Participant 2

Midwives' quotes

"Too quick discharge from hospital, pressure for beds and lead to many re-admissions." Participant 9

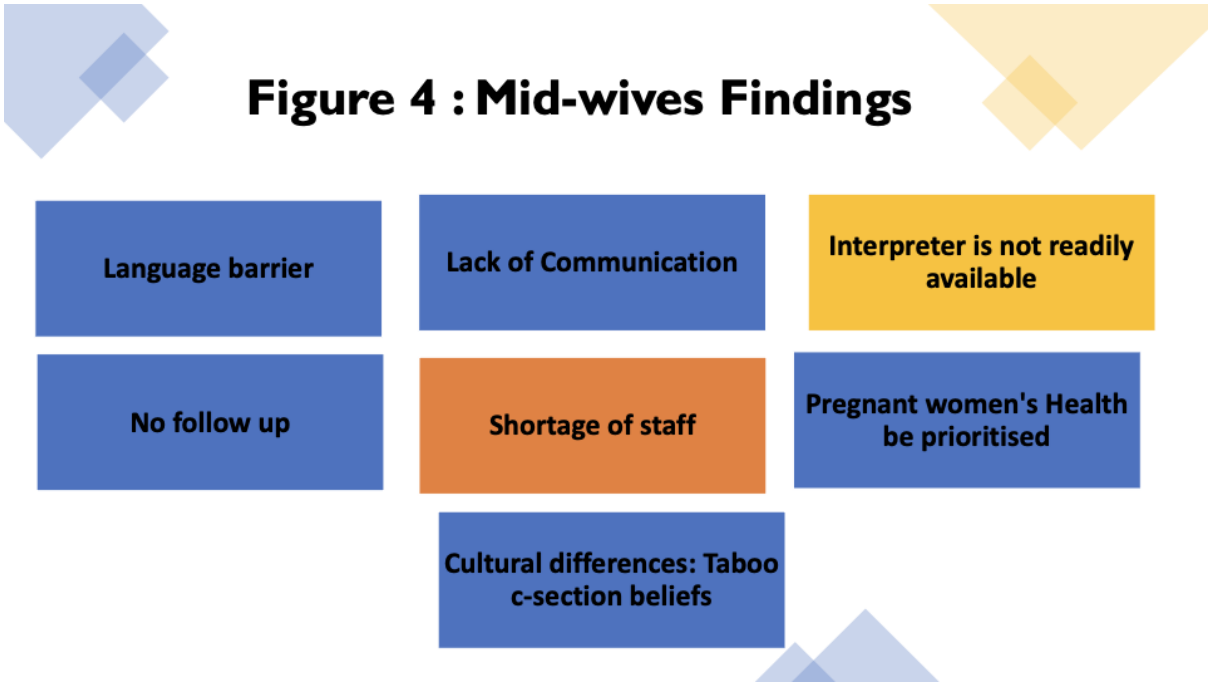
3.5 Disregard for mother's previous history

Participants felt that the health professionals did not consider previous similar occurrences in their previous pregnancies. There was a lack of consideration of women's previous conditions/situations in occurrences in previous pregnancies. The participants reported that they felt not cared for.

"I was rated high risk for pre-eclampsia and I had gestational diabetes in my first and second pregnancy. Surprisingly discharged after 24 hours after c-section surgery. It was too premature because in my first pregnancy I had preeclampsia that resulted in me spending 10 days in the hospital. Second pregnancy I had the same conditions throughout the pregnancy but was discharged 24hours after the C-section. Within 3 hours after being discharged, I'd come back home and had to call an ambulance to go back into the hospital as I was experiencing pre-eclampsia." Participant 6

4. Additional Finding - Midwives

I interviewed midwives and they had additional barriers/ challenges when caring for ethnic minority women as shown in Figure 4 below.



4.1 Language barrier

Midwives described this as a prime feature in barriers to effective communication. Understanding the English language allows one to ask questions, understand what the mother requires and give consent. If one has limited English, the care given might not be comprehensive enough until they're able to find an interpreter.

4.2 Lack of communication

The midwives' participants reported a lack of communication resulting from the language barrier among the ethnic minority women. The information being provided by the professionals to the people, they are not understanding it and they are not accessing it.

"You can imagine it's a lot because actually in maternity it's more of communication like the 90% of the care." Participant 9

4.3 An interpreter is not readily available

With language barriers, an interpreter is required. However, on occasions, interpreters are not readily available at that moment,

4.4 No follow up with mothers

No follow up from midwives of mothers who gave birth.
Mothers do still need support after they give birth. There needs to be a follow-up, especially with postnatal classes.

4.5 Shortage of staff

The shortage of staff has put a lot of pressure on healthcare professionals therefore mothers do not get one-to-one support after they give birth. Often being given many complex leaflets to take home and read.

"The pressure on the maternity department is high, so few staff and the birth rate has increased." Participant 9

4.6 Pregnant women's Health is important and should be prioritised

Ethnic minority women need to prioritise their health when pregnant. This is usually not the case because they look after everyone else in the household and not themselves**.**

4.7 The cultural differences

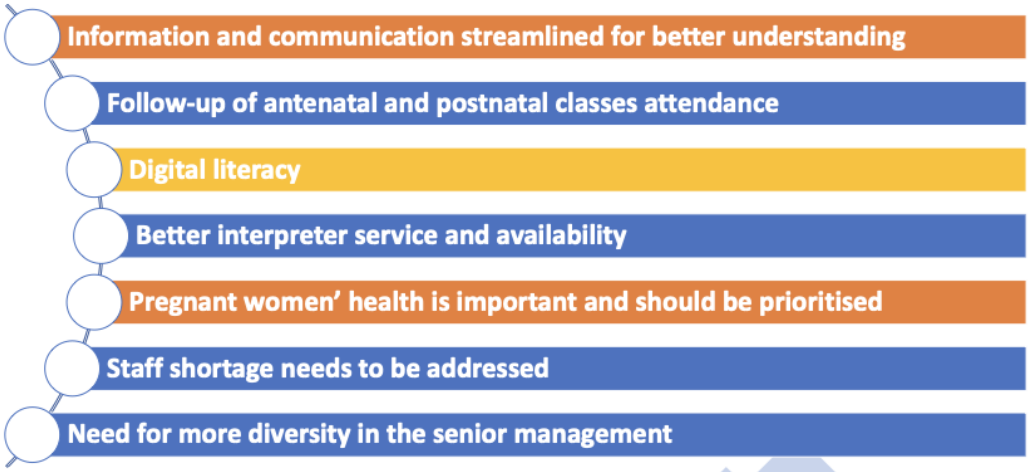
Family members can be a major barrier. Some cultures deem it taboo to have a c-section. This becomes very challenging as the mother can refuse to sign the paperwork, not turn up to appointments and make it very hard to provide her with the care necessary. This puts the life of the mother and baby at risk.

Partners can also be a barrier. In some cultures, the man is the spokesperson, and the woman is not allowed to speak. This makes it very hard to assess and diagnose the woman properly.

E. RECOMMENDATIONS

These are some recommendations from the research shown in figure 5 below.

Figure 5: Recommendations



i) Information and communication

Good communication forms the foundation of good clinical care, and therefore, it is unsurprising that issues surrounding different aspects of communication were identified.

Streamlined communication means you are not only giving infinite ways to interact but also building an effective relationship with each of them.

All parties are better able to understand the information.

- More time needs to be allocated for 1-to-1 interactions.
- Information and communication are streamlined for better understanding.
- Consistency with the same midwife or better management/understanding of patient records.

ii) Antenatal and postnatal classes

This could be implemented in a range of ways, including the following:

- This could be arranged similar/in close timings with during midwife appointments.
- Midwives explain clearly the need for these classes.
- The cost of NCT classes needs to be addressed so that it is not a barrier.
- Paternity classes for the men and the need for partners to attend these classes.
- Follow-up of antenatal and postnatal classes attendance.

iii) Digital literacy

Not all mothers who took part had internet access or the skills to use online services. Online services can be impersonal and mothers can benefit from face-to-face provision. In order to improve this situation:

- Classes should be provided on using online services and wider digital literacy.
- Face-to-face services should be offered where appropriate and where possible.

iv) Better interpreter service and availability

The mothers who were interviewed spoke good English. Many ethnic minority women do not speak such good English, and midwives identified language as a barrier.

- Better resources for translation should be provided, including readily available interpreters.
- Mothers' language needs are captured right at the beginning of the pregnancy and interpretation should be provided wherever needed.

v) Pregnant women’s health is important and should be prioritised

- Before the woman gets pregnant, she needs to understand her anatomy, her physiology, how her body functions and how hormones will affect her when she is pregnant, how to live well, eat well and deliver safely.

- People need support to be able to prioritise and understand their own health. This will help them to present their pregnancy issues to the professional. This will help them know their body, their health issues, problems they are likely to face, and they can make an

action plan, or a birth plan that is more individualised and tailor-made to the successful outcome of their pregnancy.

vi) Staff shortage needs to be addressed

Midwives identified staff shortages as a key issue which had direct effects on the quality of care for pregnant women and mothers.

- More maternity health professionals are to be trained and employed to ease the burden on existing staff.

vii) Need for more diversity in senior management.

This recommendation reflects the fact that change needs to be led from the top. Diversity in management sends out an important message to the rest of an organisation. However, this is about more than symbolism, and greater diversity at the top will help to drive change at other levels.

- The working culture needs to change in the maternal healthcare profession.
- Cultural awareness training should be provided to all NHS staff working in maternal services, so that services are culturally sensitive.

We must all play a part in the solution – whether through advocacy, recognising the impacts of our own bias, validating a mother's experiences and concerns, or simply being the one person to listen and act. I chose to seek out the mothers in my community and hear what their experiences had been. I chose to get their voices heard through this research so that we can improve our maternal services, reduce the inequalities gap and save lives.

F. ACKNOWLEDGEMENTS

The CPAR programme was initiated and funded by Health Education England South-East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHE England and Improvement.

Thank you to the mothers and midwives who gave such invaluable contributions to this research.

I would like to express my gratitude to my facilitator Esther, the research trainer Andrew, who guided me throughout this project and helped me finalize my project. Dr. Sally Lloyd-Evans of University of Reading for the support on recorders and transcribing of the interviews.

Thank you to ACRE for giving me the opportunity to participate in this research.

Thank you to the partners RBC, RVA, RCLC, UOR and ACRE.

I would also like to thank my friends and family who supported me during my study.

G. REFLECTIONS

This is my first time doing research using qualitative techniques. I received great training on how to conduct community participatory research.

I feel that more time and resources need to be allocated to capture more experiences of ethnic minority women and barriers to accessing maternal health. The interviews questions sessions were 45 minutes for each participant however most interviews lasted 1 hour and 30 mins. They were all very in-depth questions, and the participants were very descriptive of the service they received and how they felt.

I hope the recommendations in the report can be used and adopted to make a change to maternal healthcare and access.

I feel confident and empowered to carry out more community research in the future.