AIMS For a better birth...

Diverse, not defective

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The latest MBRRACE report[1] was released in November 2018. I found it very difficult to read as I couldn't help but think about the women and babies behind the numbers. One of the women who died was my friend. I almost became one of them myself after suffering severe post-traumatic stress disorder (PTSD) as a result of the abusive treatment I received during my second birth. I thought of the trauma, the grief, the children and families left behind, some may still be in search of explanations and answers, trying to come to terms with what happened.

The report highlighted that black women were five times and Asian women twice as likely as white women to die in pregnancy and childbirth. The startling differences in mortality rates by race sparked heated debate in the popular Matexp Facebook Group[2] (a forum for maternity services users and health care providers to share experiences) and on other social media platforms. There was a lot of debate on the existence of racism in the healthcare system. It was obviously a topic that people have been wanting to discuss and one that should not be dismissed. I am concerned about how the maternal mortality data can be misused to support the arguments that if Black, Asian, Minorities and Ethnic (BAME) women are at a higher risk as their birth outcomes are statistically worse than white British women, they should be subjected to more interventions. This is a self-fulfilling prophecy.

How many (BAME) people are there?

Hundreds? Thousands? Millions? Billions? Yes, there are BILLIONS of BAME people in the world. They in

fact make up most of our planet's population, with hundreds of ethnic groups. Amongst BAME people there is vast diversity and mixes, different body and pelvic shapes[3] and sizes in the various regions (consider different climate/geography, diet, bone density and body fat composition) and, of course, variation even within the same family. According to the 2011 census, there were over 8 million BAME people living in the UK. That is 13% of the total British population, or at least 1 in 8 people! For a country so diverse, why is there such substantial disparity in maternal mortality?

The Curse of Stereotypes

When discussing the poorer maternity outcomes for BAME women, I notice people often fall back on the stereotypical narratives of vulnerability due to lack of language skills and low socioeconomic status. However, these assumptions are outdated. Most British-born BAME women speak English as a first language and many who are immigrants to the UK speak English even in their countries of origin. The MBRRACE report table 2.9[1] outlined that out of all the women who died, 96% spoke English and 63% were actually born in the UK. Just look around your workplace, commuter trains, hospitals, cafes and restaurants, there are BAME women working everywhere in a range of professions and are of various socioeconomic status. What is going on?

I've spoken with a number of birth workers. The general observation has been that well educated and articulate BAME women are actually treated the worst when accessing maternity services because they challenge institutional protocols and do not fit the submissive stereotypes. Perhaps we are seen as unwelcome rivals to their authority, in a similar way to how Brexit has fed hatred for difference. In-groups versus out-groups. Insiders versus outsiders. Perhaps there are also remnants of colonialism. These women's birth choices – mine included - are thus limited; they are not listened to, nor treated with respect. This resonates with the birth stories from my circle of friends of Southeast Asian origin, all of whom speak perfect English, have university degrees and work in professional jobs.

What is racism?

Racism isn't just about name-calling, though that still happens. Racism is the inability to see a person of a different race or ethnic origin to one's own in a position of power; believing they are less able, less intelligent, or to treat them as human beings less deserving of equal rights, dignity and respect. Experience and outcomes are worst for BAMEs across different socioeconomic statuses[4]. In other words, race/ethnicity itself is a risk factor for higher maternal mortality rates and worse maternity services experiences.

How does racism infiltrate the healthcare system?

One huge issue that BAME women often come across is the comparison of their bodies to the apparent "norm" i.e. the bodies of white Caucasian women. A recent comment seen on social media was, "Asian women are more prone to 3rd and 4th degree tears because their perineums are shorter". The assumption in this statement is that Asian women are being compared to white, western women. "More prone THAN white, western women" and "shorter perineums IN COMPARISON TO white, western

women" was simply missing from the statement – it was just assumed to be understood in this way. The statement itself puts the "fault" for any increased number of tears in BAME women on their "imperfect" body compared to white women – rather than any outside influences such as, for instance, BAME women being classified as "high risk" due to their body types not falling within the Western norm, and their subsequent obstetric led interventions leading to more severe birth injuries. I will also note that no evidence was submitted to support this "shorter perineum" claim and in fact it appears to simply be a repeated assumption or a myth not based on reality[5,6].

There is something dangerous and psychologically damaging about measuring every woman to a theoretical statistical average white woman that rarely exists in real life. The shaming narratives of NHS maternity services are built on women failing to measure up to this peculiar mannequin, rather than acknowledging its own systematic failure in understanding and caring for human variation. Many women and babies inevitably become casualties. Although this affects women of all ethnic backgrounds and skin colour, BAME women are affected disproportionately more than white, British born women as their bodies differ from what the western medical narratives perceive as the norm.

How many women know that BMI is not evidence-based? It's an arbitrary ratio of body fat, muscles and bone density to height ratio that really doesn't tell you anything about a person's health, body shape nor their ability to birth. Yet, it is often used to limit women's birth options. For instance, women who are themselves, or whose ancestors are from certain parts of Asia, where people have a smaller build compared to the average white British woman, are disproportionately affected. Their birth place options are often limited and they are more frequently subjected to close monitoring and interventions because of the fear of a "small baby" or "small pelvis". I noticed that gestational diabetes interventions (many of which are not based on strong evidence either, with inconsistencies between different trusts' guidelines on diagnostic criteria[7]) are also used to limit options for them.

The narratives that feed cultural bias and the perceived supremacy of the white body are difficult to dispute when the medical/institutional protocols support it. We all go into pregnancy and birth with risk factors regardless of the colour of our skin. How physiological birth progresses and how women feel depend very much on how they are treated by birth attendants, how respectful their care is and the environment in which they give birth. When BAME women are seen as "high risk" solely due to their natural body type, treated differently and without kindness, risks and complications can be introduced by biases, interventions and healthcare providers' actions. Racism can go on undetected and unchallenged in the disguise of perceived body deficiency.

How can racism happen in practice in the maternity system?

My own experience of this issue was in my first pregnancy in 2014. I was assigned obstetrician-led "care" at a hospital in a diverse area of West London because my BMI was one point below the NHS cut-off. However, after some research I discovered that my BMI was considered a normal range when adjusted for people of Southeast Asian origin like me. My body is the average size in my hometown. I raised this with every obstetrician I met. I was asked to attend appointments with at least 5 different ones, who each

asked me more or less the same questions in an appointment lasting just 5 to 10 minutes (after I had waited for at least an hour), without any further understanding or value added. I requested repeatedly to be transferred back to community midwife care, as I felt healthy and baby was growing, with strong kicks. I was also gaining weight.

It became very stressful because I was not listened to and had to take time off work to attend these extra appointments which had been scheduled at the start of my pregnancy. Rather than feeling productive or supportive, these appointments caused me a great deal of anxiety. Every time I tried to decline them I was referred to a more senior obstetrician instead of being respected for my informed decision. The way they coerced me into these interventions made me feel that I was not in control of what happened to me during my pregnancy. These medical staff exercising authority over me made me feel angry and undermined.

With a maths degree under my belt and the research I had done, I tried to reason with the obstetrician about the need to adjust my BMI score because of my ethnic origin. He needed to consider me as an individual, my ethnicity, my husband's and the size of our bodies. He did not like to be challenged at all, so shouted at me with fury and threatened that if my baby failed to grow then he would cut it out from me. He also told me that I would not be allowed to use the birth centre.

Some health care providers are very determined in deciding what kind of birth women should have; it was exercising dominance. This obstetrician was black South African which highlights that not all racism is carried out by white people towards BAME people but frequently stems from cultural bias. I was 31 weeks pregnant. It became clear to me that what he wanted to do to me had nothing to do with what I was saying. It was a case of a power struggle which he was determined to win. My voice, knowledge and rights were not considered. I was not listened to nor respected. Institutional standardisation and protocols were used as a way to undermine my decision making, intellect and autonomy.

Out of panic, I went up to the front desk to request to see the obstetricianI had seen in my previous appointment, as he seemed more receptive to my reasoning for using the birth centre. Luckily he was available and made a note in my records to say it was okay. However, when I went into labour just before my due date, the hospital midwives at triage not only denied every request in my well thought out birth plan, including access to the birth centre, they also refused to listen to me and abused me intensely, psychologically and physically. They had no understanding of me as a person and were unwilling to provide care. They coerced me into unwanted vaginal examinations (VEs) and continuous monitoring (CTG), saying they were routine protocols that had to be carried out otherwise I would not be allowed to use the birth centre. Their violent actions, holding me hostage tied up by CTG belts under intense bright light in a shoebox size assessment room for 4 hours, not allowed to move sabotaged the physiological progression of my birth. I was treated equally cruelly at my second birth, in an NHS hospital in Berkshire, with access to the birth centre denied, coercion for VEs and pain relief withdrawn.

Did I think, if my skin was white, that I would have a better chance of being listened to and being respected? Absolutely. The constants in my two pregnancies and births were me and the NHS system. I

have lived outside of my native country for so long and integrated so well in the UK that I had forgotten the colour of my skin and my body shape/size are different to Caucasians and that I had heard the medical establishment treats people differently because of their ethnic origin. Sadly, now I know this from experience. It happens. Too often in fact.

BAME women can be subjected to more interventions because of the institutional criteria and protocols limiting their choice of place of birth. They are often subjected to birthing in the obstetric units, interventions and cascading effects because their bodies are different to the Western "norm" and so considered to be less able and defective. If more interventions actually lead to improved safety, you would expect mortality rates to be lower for BAMEs as they are more subjected to protocol interventions and yet the MBBRACE report shows that this is not the case. Something is not adding up. When women of colour are not being treated with kindness, staff being less patient and respectful with our bodies, for example by denying access to pain relief, not listening to us, complaining about us, rough handling us, ignoring our birthing decisions, not explaining procedures and not seeking informed consent, not accepting refusal, they make us feel unsupported. This could affect not just the physical outcome but how we feel. The trauma can have lasting effects. When healthcare providers fail to make us feel safe during our pregnancy and birth, even if we escape severe physical damage, our mental health may be badly affected for a long time afterwards.

I have seen various articles in the media labelling black and Asian women as loud and hysterical in labour[8]. The midwives I had made similar degrading comments. Complaints from these women and requests for pain relief are often dismissed because they are not being listened to or considered equally. Women should not need to be silent when having the most powerful experience of giving birth. The problem with such racial or racist myths is they reinforce racism. Racial stereotypes, particularly about women's bodies and ability to tolerant pain (their pain threshold) or prejudice can cause clinical bias and harm.

What can improve outcomes for BAME women?

The fragmented care model that most of us still experience, together with the lack of accountability for the actions of individual care providers, leaves women wide open to abuse. Racism and tribalism go on undetected. Poor working conditions, low pay and dismal job satisfaction mean that many maternity staff that remain in the system either do not or cannot offer good care. Violence and violation are far too common. Under pressure, with an absence of relationship and client knowledge, they have little to go on but to follow protocols. A few minutes of flicking through a woman's notes is not enough. No wonder lots of mistakes are made within the maternity services. These mistakes often equate to injuries and even loss of lives for mums and babies.

Legal risks are often raised as concerns in discussions on improving maternity services. Continuity of Carer, a relationship-based model, will help to mitigate them because client knowledge and a relationship with the pregnant woman will minimise mistakes and improve birth experience. It will also give BAME women a better chance of being listened to, treated with respect and provided with individualised care. Safer for everyone involved. No brainer really.

A woman's chance of survival, how she is treated in pregnancy and childbirth and her autonomy should not be determined by the colour of the skin she was born with or the ethnic community she came from. It's time for healthcare providers to see past the colour of someone's skin and acknowledge the effects of structural inequality in the healthcare system, their attitude and practices.[9] We are unique individuals deserving of personalised, respectful and safe heath care.

Breaking the habit of decision-making based on cultural bias requires education and conscious effort but it is essential for the provision of ethical and respectful care to improve safety and outcomes. Most importantly, we need to stop racist narratives about women's bodies; stop presenting "white, British women" as the default to which we should all be compared to, the average to which we are considered to deviate and start talking about diversity. After all, diversity is what helps humanity survive and thrive.

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Further reading:

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