

Under-representation of Black women in UK research

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ORIGINAL

A recent UK report, *Black Maternal Health* (House of Commons 2023), stated that Black women are under-represented in research and therefore in policymaking. This is concerning, as maternal mortality reports highlight that Black women in the UK have been at increased risk of dying in childbirth compared to white women since 2000 (Knight 2022). Racial health disparities for Black mothers have been stated for decades and research is vital in identifying the possible causes. Strategies to improve Black women's participation in research are needed to discover and address the issues that contribute to maternal mortality.

Importance of inclusivity in research for Black women

Black women's under-representation in research may lead to continuance of poorer pregnancy outcomes. Black women in the UK are almost four times more likely to die in childbirth than White women (Knight 2022). Reducing maternal mortality in Black women is affected by an inability to extricate and pinpoint the pertinent issues that lead to poor pregnancy outcomes. Therefore, research into these disparities should be a priority.

There are also ethical implications for not including all groups in research (Caplan & Friesen 2017). Research studies that have limited involvement of Black ethnic groups or have no representation limit validity and generalisability (Oakley et al 2003). Social justice is also affected, regarding fair allocation of resources for services and research (Redwood & Gill 2013). Under-representation of Black women in research means that services are tailored towards the researched, further increasing health disparities.

Public involvement in clinical research should be diverse and inclusive, so that research reaches those who may benefit (Clark et al 2019, Islam et al 2021). Ensuring that health policies cater for diverse groups requires the participation of all ethnic and cultural groups in health research (Redwood & Gill 2013, Darko 2021). Involving different ethnicities in research is vital because of differences in response to medical therapies (Conforti et al 2018, Clark et al 2019). Also, recommendations for changes in care provision should include the voices of different categories of people.

Racial disparities can be addressed more effectively by researching those groups that have poorer health outcomes. Understanding the issues that underpin under-representation will lead to the development of research studies that are appropriate for Black women.

History of Black women in research

Historically, there is a lack of research involving Black women in the UK; this absence dates back to 1918, despite there being a presence of Black communities (Douglas 2023). However, the past exposes the exploitation of Black women who have been abused and mistreated in the name of research. Black enslaved women in America in the 1840s were experimented on without consent or use of anaesthesia to advance gynaecological procedures: the Sims speculum was created from these experiments and is still used in current health care practice (Campbell 2021).

In the 1800s, Saartjie Baartman, a South African woman, was taken to Europe where she was exhibited due to her unusual physique. She was examined by numerous scientists in England and France without her full consent and, after her death at 26, her body parts were displayed in a museum in Paris; campaigning resulted in her remains being returned to South Africa for a proper burial in 2002 (Henderson 2014).

In the 1950s, tissue samples were taken from an African American called Henrietta Lacks during treatment for cervical cancer, without her consent. These eponymous HeLa cells have been used in laboratories around the world and have underpinned biomedical research until the present day, owing to their capability to survive and divide indefinitely (Beskow 2016).

Current research practice should be guided by ethical principles, ensuring that participation is voluntary, with informed consent, protection of anonymity and confidentiality, prevention of harm and the right to withdraw from studies (Bryman 2016). However, these historical studies, which are known by Black communities, provide some insight into the issues that may be a concern to Black women contemplating current health care research.

Barriers to inclusion of Black women in research

The limited participation of Black women in research studies cannot solely be attributed to events in history. Several studies have provided other reasons for why Black women may be under-represented in research, ranging from lack of effective strategies to promote inclusion, and lack of culturally sensitive research methods and data collection (Burlew et al 2011, Brown et al 2014, Farooqi et al 2022).

Racial inequalities are present in academia: the next generation of researchers will be responsible for implementing research in the future but negative experiences are becoming the norm, impacting on their contribution (Powell et al 2019). Black researchers are under-represented in research careers, comprising only eight per cent of UK science undergraduates and 0.6 per cent of science professors (Gibney 2022). Therefore, there is a potential loss of experience, and diversity in ideas and innovations that could guide research projects that cater for ethnic minority groups.

Racial inequalities also ascend to the level of commissioning research, demonstrated by UK Research and Innovation (UKRI), which allocated £4.3 million Covid funds to investigate Black and other ethnic minorities but gave zero funds to projects led by Black researchers, academics or organisations. Failure to collect ethnic data from applicants was stated by the UKRI to be an oversight that would not occur in future calls for funding, to improve equity (Inge 2020). Although the barriers to involvement in research for Black women are recognised, overcoming them have proved to be difficult (Clark et al 2019).

Mistrust and fear

Trust is a crucial component in any research study: without it, individuals will not engage in research activities. There should be a priority on building trust in the research process, thereby increasing respect, collaboration and cooperation (Keikelame & Swartz 2019). Lack of trust and fear have been reported as being a major barrier to Black people participating in research (Salman et al 2016, Clark et al 2019). This mistrust has been fuelled by structural racism in health care services and ethnic exclusion, leading to negative health care experiences (Etti et al 2021).

Historical research studies have also contributed to this mistrust. Researchers should bear the responsibility for building trust with communities and also for ensuring that recruitment is equitable (Henderson et al 2022). The emphasis should be on creating an open dialogue with Black women to alleviate any fears, which may increase willingness to participate in research studies. This may be assisted by utilisation of Black researchers to engage

with Black women. Participation of Black women in research may increase with positive interaction, familiarity with health care staff and trusted health care institutions or campaigners (Tamlyn et al 2023). This is evidenced by the Five X More campaign led by Black researchers, which conducted a survey in April 2021 on Black women's maternity experiences, receiving over 1,300 responses (Five X More 2022).

Cultural considerations

It is suggested that the cultural barriers that prevent access to research are similar to those that lead to poor access to health care services (Hussain-Gambles et al 2004, Farooqi al 2022). Research with Black women should be relevant, seen to improve their quality of life, and driven by cultural values and a language that is suitable (Khupe & Keane 2017). It has been stated that communication with community groups and faith leaders is required, using an approach that is transparent and culturally appropriate (Clark et al 2019). Including family and friends in discussions about research will also aid participation, particularly in some cultures where shared decision making is practised (Esegbona-Adeigbe 2022). Smith (2021) highlights that cultural beliefs, values and practice should be an integral part of the research methodology with diverse groups, and should be explicitly built into the methodology and reflected on in a transparent way. Understanding of cultural norms can lead to creation of experimental protocols and interview questions that are culturally salient (Broesch et al 2020).

Conclusion

The importance of increasing the participation of Black women in research is already known. However, the historical impact that has led to mistrust and fear can only be limited by ensuring that research studies use methodologies that are tailored to Black women. The racial inequalities in academia and commissioning of research should also be addressed. More importantly, it should be accepted that racial disparities in pregnancy will continue for Black women and other marginalised women, unless their voices and experiences are researched. While Black women continue to have increased maternal mortality, rigorous research into the possible issues is required to stop this trend.

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For more information on this topic see MIC database search packs: P182 Racial disparities in maternal health and pregnancy outcome; M61 Research: ethical issues.

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