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Black Women's Activism and Organisation in Public Health - Struggles and Strategies for Better Health and Wellbeing

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Abstract: Using Avtar Brah's concept of 'diaspora space', this paper argues that black women in the UK have organised in diaspora space to challenge inequities in health and develop strategies to improve health outcomes for black communities. The paper explores the post-war contribution of black women nurses in the UK to public health, both as activists for change and as organisers of change. The paper concludes by exploring the confluences and synergies between the concept of 'diaspora space' and that of '(post) diaspora' as espoused by Scafe (2018). The paper argues that both concepts are useful for understanding the ways in which Black women have used their agency to challenge health inequities.

Keywords: Black women, Caribbean, health, activism, intersectionality

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Introduction: Diaspora space as a site for Black women's health activism

Avtar Brah contends that:

diaspora space is the point at which boundaries of inclusion and exclusion, of belonging and otherness, of 'us' and 'them', are contested. My argument is that diaspora space as a conceptual category is 'inhabited', not only by those who have migrated and their descendants, but equally by those who are constructed and represented as indigenous. In other words the concept of *diaspora space* (as opposed to that of diaspora) includes the entanglement, the intertwining of genealogies of dispersion with those of 'staying put'. The diaspora space is the site where *the native is as much a diasporian as the diasporian is the native.*

Brah, 1996:208-209

Notwithstanding the complexities and ambiguities contained in this definition, the concept of diaspora space is a useful lens for exploring the ways in which black women in Britain have organised around health issues. While the majority of women in the black women's groups I discuss were women who had migrated from the Caribbean, these groups also included indigenous women, black British women, women from Asia, Africa and women of mixed heritage. Black women health professionals as well as black community workers, black women from other professions, and black women who had experienced health inequities, came together to challenge professional boundaries and to explore health issues by listening and giving voice to the experiences of women and parents concerned about particular health issues. These groups provided spaces for women who were providers and consumers of health care to come together to develop strategies for social change.

Migration from the Caribbean

Following the Second World War, Caribbean women migrated to the UK, USA and Canada to work. However, the McCarran-Walter Act of 1952 substantially reduced migration from the Caribbean to the USA between 1952 and 1965, and

diverted migration from the English-speaking Caribbean to the UK. The British government actively recruited workers from English-speaking British colonies in the Caribbean to rebuild Britain (Goulbourne, 1998, 2002). The National Health Service was established in 1948 and people from across the Caribbean were recruited to work in the NHS. Many women migrated independently to work in the NHS. They were employed in public health work as nurses, health visitors, midwives, community health workers and allied health professionals as well as auxiliaries and cleaners. However, academic literature on these health workers has focused on their experiences of discrimination (Doyal 1995) as the majority of these women experienced racism and discrimination which impacted on their ability to progress into senior management roles in the NHS (Beishon et al. 1995). The substantial contribution that these women made to public health development has not been acknowledged or documented. This paper looks at organisations and action developed by black women to advance the public's health, in areas such as mental health, reproductive health, sickle cell and thalassaemia disorders. It also explores the development of black women's groups to challenge racism and ethnocentrism in health in these areas.

While some women who migrated from the Caribbean were already trained nurses, others came to Britain to train as nurses. Here they faced discrimination within the NHS as many black women were directed towards training as State Enrolled Nurses (SENs) rather than State Registered Nurses (SRNs) (Beishon et al. 1995; Olwig 2012) which restricted their career development and progression. Despite the undermining and negative experiences of day-to-day racism and the lack of career progression that these women experienced whilst working and enabling change with the NHS in the UK, they were active in their local communities and churches. They established and actively contributed to a range of voluntary and community organisations. Some of the early voluntary organisations were established through their national geographic networks such as the Nurses Association of Jamaica, UK, founded in 1978 and the Barbados Overseas Nurses Association founded in 1994. These associations still exist but both organisations involve individuals from across the Atlantic diaspora. Later organisations such as the Confederation of Black and Ethnic Nurses, Midwives

and Health Visitors; the Sickle Cell and Thalassaemia Association of Counsellors; the Sickle Cell Society; Cancer Black Care were developed around specific health issues to name a few in the UK (Douglas 2018)). These organisations served as diaspora space and sites of activism. From the 1970s black women in the UK were involved in campaigning for change, setting up black women's groups to challenge inappropriate, racist and ethnocentric practices within the NHS – for example Birmingham Black Health Workers, Brixton Black Women's Collective and the Organisation of Women of African and Asian Descent (OWAAD).

However, there is limited research and scholarship on both black women's activism and on black women's health activism specifically. Sudbury (1998, 5) comments:

While the seeds of black women's political activism in Britain can be identified as far back as the black women who attended the Somerset case of 1772 and the societies of escaped enslaved and indentured servants which enraged white Londoners in the late eighteenth century, it was not until the early 1970s that black women began to organise autonomously

Sudbury 1998:5

From the 1970s there was a rise of black women's organisations so that by the 1990s there was a range of black women's organisations across the UK, some funded and some not funded, in cities, towns and rural areas with significant black populations (Sudbury 1998). However, these black women's organisations and black women's health activism in particular, remained an area of erasure that was ignored by historians, sociologists and white feminist scholars. It remained undocumented by white feminists or researchers undertaking research on the rise of black political action. Research on feminist agency was focused on that of white women and the work on black political action was focused on black men.

One notable early publication was *The Heart of the Race: Black Women's Lives in Britain* (Bryan et al. 1985). This publication documented the impact of employment, unemployment, poor housing and deprivation on the lives and health of black communities in the 1980s and concluded that while black women were expected to be cleaners, nurses and auxiliaries in the NHS, the health needs of black communities were not acknowledged or indeed addressed. *The Heart of the Race* acknowledged the agency and activism of black Caribbean women and was one of few publications to do so.

Sudbury also aimed to 'redress the erasure of black women's collective agency in contemporary thinking about social change' (1998, 3). Sudbury (1998) in *Other Kinds of Dreams*, demonstrated how black women's organisations were extremely heterogeneous; they changed and were reborn during the 1990s. She argues that the rise in black women's organisations was in response to the harsh, social, economic and political environment in the early 1970s in education, social justice, housing and social services. She contended that:

In the field of health, racist practices led to disproportionate numbers of black people being diagnosed as mentally unstable (Bryan et al. 1985). Black women in particular suffered from unsafe and irreparable birth control methods

Sudbury 1998, 3

Furthermore Sudbury argued that black women's autonomous spaces 'offer fertile ground for the examination of the intersection of economic, ideological and political structures, forces and counter-forces in Britain'. Despite the lack of recognition of black women's agency by white feminist scholars and sociologists exploring black political agency, black women in the UK were actively involved in campaigns for public health and health care (Douglas 1998). Black women's groups grew out of a need to take action on the inequities in health experienced by black women and their families. The issues I will focus on in this paper are reproductive health, mental health (Wilson 1994) and the paucity of adequate and appropriate services for sickle cell disorders (SCD) and

thalassaemia (Douglas 1992). This paper aims to redress this gap and now outlines three case studies that show black women as service users and providers of health care have actively campaigned for better public health policies and services during the twenty first century.

Depo-Provera.

In relation to reproductive health, black and minority ethnic women appeared to be more likely than their white contemporaries to be offered hysterectomies (Bryan, Dadzie and Scafe 1986), and they were subjected to discriminatory practices in the use of the injectable contraceptive Depo-Provera (Brent Community Health Council 1981). Black women reported the misuse of the injectable contraceptive Depo-Provera. Depo-Provera (DP) was a long term injectable contraceptive lasting three months; it was manufactured by UpJohn. It was trialled in Jamaica in 1963 before its more widespread use in Britain and the Third World. The Food and Drug Administration did not recommend its use in the USA and it was only approved by the Committee on Safety of Medicines in the UK for very limited and specific use: for women whose partners had recently had a vasectomy and for those women who had recently been vaccinated against German measles (rubella). Never the less, it appeared that DP was being prescribed to large numbers of black women without their knowledge or consent in London hospitals and in hospitals serving populations of white working class and black and minority women across the UK. It was certainly being administered to black and minority ethnic women in hospitals in Birmingham. Black and white women launched a campaign against Depo-Provera in the late 1970s, aiming to have its use banned. One of the Black women's groups that collectively campaigned against the use of D.P. was Brixton Black Women's Group. Brixton Black Women's Group was formed in 1973 to discuss Black women's experience of racist and sexist oppression (Bryan, Dadzie and Scafe 1985). They campaigned by going on demonstrations and writing about the impact of DP in their newsletter 'Speak Out' (Speak Out, Numbers 1 and 3), aiming to raise awareness of the effects of DP amongst local black women. The

campaign against Depo-Provera, although focused on the inappropriate and racist use of DP, also served as a forum for discussion and action about reproductive justice for black women more widely. While white feminists were calling for abortion on demand, black women were campaigning against the disproportionate way in which black women were given terminations more readily than white women and were being encouraged to have terminations when they had not requested them. Black women and white working class women were targeted for abortions and long-term contraceptives by health professionals and policy makers who had a view that they should not reproduce.

The use of Depo-Provera comes out of a very different approach to health care. An approach which accepts uncritically ruling assumptions- in this instance the desirability of reducing the black birth rate and the assumed ignorance and unreliability of black women – and seeks to change people’s behaviour accordingly, whatever the suffering this may cause.

p.24, Brent Community Health Council 1981

Despite the view of black women as fertile, fecund and feckless, black women organised to challenge this notion and to campaign against the unwarranted use of Depo-Provera amongst black women. In April 1982, the Minister of Health declined to grant Upjohn Ltd a license for long-term use. This decision was in part due to the sustained attack by the Campaign against Depo-Provera (Timmins 1982). Despite the Committee on Safety of Medicines being prepared to approve Depo-Provera based on scientific evidence, the Minister of Health (Kenneth Clarke) did not accept the advice and was swayed by the arguments that vulnerable women may be given Depo-Provera without their informed consent (Timmins 1982). Upjohn appealed the decision and a public hearing under the 1968 Medicines Act took place in April 1983 to discuss the licencing of Depo-Provera for long term use. After the public hearing, the decision remained that Depo-Provera should only be licensed for short-term contraceptive use

following a vasectomy or rubella vaccination. (Dening 1983). This action demonstrates the effectiveness of black women to organise, challenge and change health service provision that was seen as detrimental to black and working class communities.

Sickle Cell Disorders.

Sickle cell disorders, including sickle cell anaemia and thalassaemia, are inherited blood disorders which are more prevalent in black and minority ethnic communities. Cases of sickle cell anaemia were documented following post war migration in the UK; however health services failed to recognise this as an important health issue, although the number of individuals affected was similar to those affected by haemophilia and cystic fibrosis (Anionwu 1985). Black families complained about the lack of information about sickle cell disorders, poor treatment in hospitals and a lack of sensitivity from health workers. One of the key campaigners for improvements in sickle cell disorders was Professor Elizabeth Anionwu. Elizabeth Anionwu highlighted that during her training as a nurse, midwife and health visitor, she received very little information about sickle cell anaemia. She realised her own lack of knowledge when she attended a community meeting and was asked about it. When she failed to provide information the community members retorted: "if you don't know, how are we supposed to know?"

Douglas (2016)

Professor Elizabeth Anionwu became active in campaigning for sickle cell services and became employed as one of the first sickle cell counsellors at the Brent Sickle Cell and Thalassaemia Centre in 1979. In this post, Professor Elizabeth Anionwu continued to be an active member of the Sickle Cell Society which provided information on sickle cell disorders and also campaigned for improved health services and awareness training for health and social care workers, teachers and social security officers. Campaigning for improved services for sickle cell disorders became an important political issue in the UK in the 1970s

and 1980s when community groups, with the combined efforts of OSCAR (Organisation of Sickle Cell Anaemia), Sickle Cell Society, Community Health Councils organised public meetings to raise awareness and fund-raising events. In response to complaints from families, patients, support groups and health workers, the government established a working party of the Standing Medical Advisory Committee in 1992. The aim of the working party, which included people with sickle cell anaemia, specialist and non-specialist doctors, and Professor Elizabeth Anionwu as a sickle cell counsellor, was to develop guidelines for health services for improved services for sickle cell disorders.

The development of appropriate services was very slow and several authors argued that the reason for this was institutional racism as sickle cell disorders affected predominantly minority ethnic families (Ahmad and Atkin 1996; Anionwu and Atkin 2001). A number of haemoglobinopathy counselling centres, employing specialist haemoglobinopathy workers were established based upon the model of the first centre in Brent in 1979 and by 1995 there were 37 district health authorities employing 57 sickle cell and thalassaemia counsellors (Anionwu 1996). The sickle cell and thalassaemia counsellors were minority ethnic nurses and midwives. Although it was encouraging that some district health authorities recognised and attempted to meet these needs, the centres were often inadequately resourced (Anionwu 1993; Potrykus 1993; Gould et al. 2000). After a number of years of campaigning, all pregnant women in England are now offered screening for sickle cell disease in pregnancy and all babies are offered screening as part of the new-born blood spot test (NHS choices).

Mental Health Services

In relation to mental health, the early research emphasis was on black Caribbean men with high rates of serious mental illness, while black women were seemingly ignored (Edge 2013). The emphasis on research on black men and severe mental illness was reinforced by the stereotype of black men as 'dangerous' and feckless. Thus research on black women's mental health and

wellbeing has been sparse. There are limited studies that have pointed to inequities in health in relation to African-Caribbean women and mental health. Edge (2013) argues that one of the issues relating to anxiety and depression is that often black women do not wish to talk about anxiety and depression and that they do not want to discuss their personal issues with white health professionals who do not understand the social and cultural context of their lives. The National Service Framework for Mental Health in 2001 (NSF 2001) stated that the rate of depression in African Caribbean women was believed to be about 60% higher than in the white population, but black women were least likely to receive treatment. Although black women may experience anxiety and depression, they do not appear to be seeking or receiving treatment.

As well as projects in London such as the London Black Women's Health Action Project which aimed to promote the general well-being of black women in London and offered advice and counselling (Wilson 1996) and the Shanti project which was set up in 1989 in South London by West Lambeth Health Authority to provide a mental health service for women in a community setting (Stephens 1996), black women's groups across the UK campaigned for appropriate mental health services.

In Liverpool, the black women's group, Liverpool Black Sisters, identified mental ill health and the lack of appropriate mental health services as a grave concern in the early 1980s. Liverpool Black Sisters and the Granby Community Mental Health Group campaigned vigorously for appropriate provision which materialised in 1989 as the Granby Community Health Drop-In Centre – Mary Seacole House. Torkington (1991) discusses the difficulties, disappointments, obstacles and tensions with seeking funding from the Health Authority and the City Council:

Unfortunately, many large institutions see their relations with non statutory groups in a conflictual mode, rather than seeking to develop a co-operative relationship with them

Torkington (1991, 180)

A black women's support group for African-Caribbean women in Sheffield started in the early 1980s. This group campaigned on health inequities including mental health support for black women. It was founded by the late Dorothy Dixon Barrow, a midwife, feminist and political activist, who had been a member of the West Indian Association formed in 1955-56. This group became the Sheffield and District Afro Caribbean Community Association (SADACCA).

Watt and Jones (2015), in documenting black women's activism in the Abasindi Black Women's Cooperative in Manchester, discuss how the late Louise Da-Cocodia, a state registered nurse, was involved in a range of community development organisations in Manchester in the 1980s and 1990s, in addition to her work in the NHS. Health and wellbeing, health issues and health inequalities run through the narratives of the women involved in the Abasindi Co-operative in Manchester, although health activism has not been highlighted specifically and this is an area that needs documenting more fully.

Achieving success: improved services for sickle cell disorders; mental health advocacy and reproductive health

The black women's groups in all of these case studies provided 'diaspora spaces', where black women could come together to discuss health issues that were concerning them and explore creative ways to develop strategies and create solutions. In the case of sickle cell this was to collate the experiences of people who had experienced sickle cell disorders and sickle cell crises, particularly the experiences of young children through their parents. Then they developed strategies to change health services through service managers and also change local, regional and national policies through politicians and policy makers. Educating the community and health professionals about SCD was a very important part of the strategy as myths and misunderstandings existed in black communities about sickle cell disorders. In the case of reproductive health, different strategies were used involving community demonstrations, marches and lobbying politicians as well as working with other feminist

organisations and building alliances. In challenging the omission of appropriate mental health services for black women it was important to create those spaces for black women who were experiencing anxiety and depression to be supported as well as to influence research funders and research agendas to focus research on the mental health and wellbeing of black women as well as black men. Mental health and black women came onto the agenda in the National Service Framework (2001) policy report which reported that black women were more likely to experience depression but less likely to report it (NSF 2001).

These case studies demonstrate that more recently research and activism on black health issues in the UK has been led by black women who have worked in the health services as nurses, physiotherapists, health promotion specialists and other health practitioners and have become health researchers because they were outraged by the racist, ethnocentric practices that they observed and so developed a research focus on black health issues and concerns as black women practitioner/activist/scholars. An example of this is the Black Women's Health and Wellbeing Research Network at the Open University (www.open.ac.uk/black-womens-health-and-wellbeing).

The Black women's health groups reported in this paper have used a variety of strategies to achieve change and improve health outcomes for black communities. This has involved learning from each other and learning together (Etienne, 2016); building alliances with white feminists while keeping the health issues of Black women at the fore; working with and challenging white politicians and policy makers; learning from other international struggles at the time - in the US and South Africa.

In addition, black women's health groups were instrumental in challenging myths and stigmas in black communities. In all of these health issues black women have taken an intersectional approach, knowing that race, gender, class, sexuality, culture and religion all intersect in a range of ways to affect the

health and wellbeing of black women. Black women worked across professional and disciplinary boundaries and were able to apply learning from one context to another. Bryan et al. argued in relation to Brixton Black Women's group 'As the first autonomous black women's group of its kind, certainly in London, there were no models for us to follow, no paths laid out. We just had to work it out as we went along.' (Bryan et al. 1985, 150) Black women brought their knowledge that had been developed through their histories and geographies and the migratory processes that some had experienced to bear on public health issues and to organise for better health and wellbeing for black communities and for black women. Other people organising in different communities to achieve social change can learn from these struggles and strategies.

These case studies have demonstrated the importance of the concept of (post) diaspora advocated by Scafe (2018). Although the women were active in specific local campaigns for improvements in health and wellbeing, they drew upon experiences, knowledge and examples for action from the Caribbean, the USA and Africa.

Future Action

This paper has argued that while black women's health activism has been largely ignored by white feminist scholars, it needs to be acknowledged and documented. Although black women's health activism in the USA has been documented, black women's activism in general and health activism in particular has received scant attention in the academic literature in the UK (Sudbury 1998; Watt and Jones 2015). In a review of black women's health activism in the United States, Susan Smith (1995) argued that black health activism emerged in the 1890's at a time when the American welfare state was expanding, but black rightere was decreasing. The book documents black health activism through to 1950. The National Black Women's Health Project was established in Atlanta, Georgia in 1983 following the first national conference on Black women's health issues at Spelman College - thus marking a shift from

black women organizing for their communities, to black women organizing for themselves. The contemporary black women's health movement in the US asserts that poverty and racism, as well as sexism and homophobia, continue to contribute to the poor health status of African- Americans.

Although we do not have such a long history of health activism In the UK, in the 1980s and 1990s, black women's groups were active in public health, promoting the health and wellbeing of black communities and for many black people access to medical health care remained an important and over-riding concern (Bryan, Dadzie and Scafe 1995). More recently black scholars have attempted to address the erasure of black women and document and acknowledge their activism. While this has happened in relation to education, employment and social justice, there has been limited recognition of black women's health activism in the UK, which has remained a lacuna except for the work of Bryan et al. (1995), Sudbury (1998), Wilson (1994) and Watt and Jones (2015). The lack of attention that black feminists in the UK have paid to health activism remains an area that warrants further exploration. Often references to health in black feminist scholarship in the UK are implicit rather than explicit. This is inexplicable, given the number of black women who worked in the newly established NHS in different roles.

The concept of 'Diaspora space' in the context of black women organising and agitating for change, provided a creative, reflective space for critical discussion and analysis to challenge inequities, accepted norms and to develop alternative policies and practices. These spaces transcended the professional backgrounds of the public health practitioners, policy makers, community workers and activists within them.

Scafe (2018) espoused the concept of (post) diaspora:

What I'm proposing here with this specific example of "political blackness", as practised by late twentieth-century black feminist activists, is a theoretical space that is multiple diasporic, but is also

specific and local, rather than abstract or instrumental. As such, it offers multiple and overlapping possibilities for belonging through affiliation and difference, and it can be mobilised to develop new meanings in contemporary Caribbean and black British cultural production. By claiming this space as “post-diasporic”, it is possible to project beyond the loss and longing, the fragmentation and dislocation to which all theories of diaspora, old and new, are attached.

An examination of the three case studies I have presented, demonstrates that by Scafe's definition, they could be described as examples of (post) diaspora. They were specific and local, and offered multiple and overlapping possibilities for belonging through affiliation and difference. Hence I see synergies and commonalities between the concept of 'diaspora space' and that of (post) diaspora. Future health concerns may be more focused on a wider African diaspora and the connections and discontinuities between African and Caribbean health. Whether we call it diaspora space or (post) diaspora, The AHRC network created a space where intergenerational, international and interdisciplinary black women scholars from the Atlantic diaspora came together to discuss a range of intellectual concerns including health which recognised intersectional approaches to health and the intersections between gender, class, 'race', ethnicity, culture, sexuality and health.

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