14

Race, ethnicity, culture and later life: Problematic categorizations and unsatisfactory definitions

Moïse Roche, Claudia Cooper and Paul Higgs

In 2020, the differential impact of Covid-19 mortality and morbidity accentuated the need to interrogate the role of race and ethnicity in the field of health and ageing (Bhala et al. 2020), and to understand the interconnections between race and ethnicity, and history and inequality (Taylor 2020). The growth of older populations in the UK, as in other high income countries, has also added renewed urgency to academic and professional interest in 'ethnogerontology' (Crewe 2005). Making sense of the language that is used to describe populations and to frame how racial and ethnic disparities are experienced whilst considering how race and ethnicity as identification grounds contribute to inequalities is an important discussion to be had, if we are to advance the gerontological imagination on race, ethnicity and ageing well.

This chapter provides a critical commentary on the nature of the plurality of terminology and meanings of racial and ethnic categories used in gerontological research. It argues that the collective categorization and labelling of minoritized[1] ethnicities (ME), as the groups bearing the brunt of this homogenization, offers little clarity and perpetuates a culture of racial binary of 'Whiteness versus Otherness'. Attention is drawn to the problematic history and unscientific basis

[1] The use of 'minoritized' underlines that people are actively minoritized by others, as a consequence of socio-political construction processes shaped by power dynamics, rather than existing naturally as a minority, as conferred in widely used terms, such as Minority Ethnic or Ethnic Minority (ME). Minoritization is a socially created process that places individuals into minority status based on circumstances rather than their own characteristics. This approach allows description of any 'specific' group of people who, by virtue of numerical size and place of residence, in relation to current understanding of ethnicity, is in a minority, and, while heterogeneous, may have, to some extent, overlapping experiences of inequalities and marginalization.

of the key concepts – of race and ethnicity – on which the formulation of these categories and collective terminologies are predicated. The chapter also queries their value and appropriateness to modern research and practice. It concludes that their use should be limited to rare and specific circumstances instead of becoming ubiquitously routine. Advice and recommendations are made on information that should be included in ethnicity-focused research that might better meet the needs of a diverse and racialized society.

Introduction

Historically, there has been a proliferation of terminologies to categorize minoritized ethnicities because of ongoing debates that resemble an absolute 'battle of the name' (Banton 1987). Terms and labels such as Black and Minority Ethnic (BME), Black, Asians and Minority Ethnic (BAME), People of Colour (POC), Black and Indigenous People of Colour (BIPOC), non-White, and many more, have been used in the UK and other countries. These continue to evolve and alter, giving rise to a range of nebulous, problematic and unwieldy terms, creating an *ersatz* 'homogeneous' group as the obverse of an equally flawed notion of a 'White group'. These terms create a general sense of confusion and lack of clarity, even among policymakers and political officials who are responsible for the population's health and managing disparities within it. On 7 June 2020, the then-UK Secretary of State for Health and Social Care, Matthew Hancock, was asked in a televised interview: 'How many Black people are in the current Cabinet?', to which he replied with hesitation: 'Well, there's a whole series of people from a Black and Ethnic Minority background'. But he then proceeded to name the Chancellor of the Exchequer (Rishi Sunak) and the Secretary of State for the Home Office (Priti Patel), neither of whom identifies with a Black ethnicity. This occurred even after Priti Patel had already warned Conservative colleagues not to 'label [her] as BME', calling it 'insulting' and 'patronising' (BBC 2018). Whether this homogenization was intended to express the shared experiences of those who do not identify with the White population, or to demarcate population groups, the fashioning of categorical descriptors for minoritized ethnicities remains a powerful preoccupation of British society.

The scholarly controversy concerning the political and social debates that continue to plague the formulation of collective terminologies for minoritized ethnicities has largely bypassed the terms 'White' and 'Caucasian', which in public discourse are unjustifiably accepted as normative and treated as self-explanatory

(Bhopal and Donaldson 1998). They have also tended to be exempted from indices or definition in censuses, statistical records and research. Despite the apparent normalization of 'White' as the standard category of reference, all these terms are open to equal levels of obscurity and imprecision. They all aggregate groups of disparate people based on socially constructed and poorly understood concepts such as race and ethnicity, and a flawed and imagined 'cultural essence' that connect *all* members. Ironically, these concepts that in their very nature imply and share an idea of commonality in ancestry, heritage and characteristics have essentially created a dichotomy between White skin people and people of all other skin colours (Allen 2014). For example, the acronym and initialism BAME and BME were arguably introduced in the UK to address the complexities of a multicultural society under the guise of political good intentions; however, they have in effect created a superordinate divide between the White majority British population and all others by conflating racial and ethnic characteristics. Although BME and BAME officially include certain White minorized groups such as Irish and Gypsy, the assessment of racial and ethnic affiliation of these terms, which draws on commonplace assumption, general narrative, popular usage and the social zeitgeist, has gravitated towards minoritized people with black, brown and other skin colour – except those whose skins are white. The exclusion of 'national minoritized ethnicities', such as Cornish, Welsh and Scottish, reinforces the preponderance of skin tone, a racial attribute, in the formation of these terminologies.

Despite undergoing surface evolution through socio-political advances, these terms are unhelpful, misleading and conflict with the rigour of modern research. They continue to perpetuate a culture of racial dichotomy of 'Whiteness vs Otherness' that was invented under the flawed and biased 'science' of race (Malik 1996). Why do researchers still use racial and ethnic administrative categories that are acknowledged as having no scientific or anthropological validity? Why has the quest for the appropriate classification and terminology for race and ethnicity solely focused on minoritized ethnicities when they are recognized to be conceptually, sociologically and politically problematic across the board? There is an argument to be made against their use and in favour of a more reliable and objective approach that would uphold the unbiased and systematic values of science.

This conversation about the conceptual and moral implications of the language that is used to talk about race, ethnicity and the disparities that relate to these concepts has particular importance in ageing research, as older people are, by the shared experience of the consequences of older age and

ageing, often disempowered from participation in research and society, in the same way that ageism excludes older people from the formulation of policies. Researchers in health, social gerontology and any fields that involve human subjects should reflect on how the use of catch-all terminologies might escape the realm of academic research and negatively impact popular views of older peoples' experiences, needs and sense of identity and agency. There is a risk these terminologies might compound the sense of disempowerment among minoritized older people to whom researchers set out to give voice. Moreover, given racial and ethnic divide is pervasive and entrenched in society, this conversation about the categorization of race and ethnicity extends beyond any specific field and discipline.

The use of collective terms

The racial and ethnic classifications and naming conventions in countries such as the UK are largely grounded in civil and political rights and were devised initially as part of a broader strategy to foster equity and reduce inequalities, driven by political responses to social movements, public opinion and pressure from race equality organizations, advocates and equality debates. The emergence of the initialism BME in the late 1980s followed the Scarman Report, commissioned by the British Government after the 1981 Brixton riots (Scarman 1986; Saeed et al. 2020). At the time, the rationale was to retain the word *Black* in the descriptor, not for its racial, ethnic or cultural significance but for its political overtone, which had begun to drift from a historically derogatory connotation to a sense of shared experience of racial discrimination faced by all people who did not fit the 'White group' descriptor. This initiative, which clearly had no scientific objective, forged an *ersatz* group with a flawed politically racialized meta-identity that inappropriately dichotomized the growing multicultural UK population into White vs everyone-else-who-is-not-White, often labelled as 'non-white', a term now also considered derogatory.

New debates ensued among sociologists, activists and politicians within their respective fields mostly around superficial concerns regarding political correctness and issues of the ambiguity, usefulness and practicality of these terms. This led to the proliferation and continual iteration of terms both in their full form and as acronyms and initialisms such as, Black, Asians, BAME, ABME, WOC, BIPOC, ME, etc., elongating an already lengthy and confusing list of terminologies (Bhopal 2004). For example, some argued for reframing

these descriptors to reflect the importance of South Asians who had become the largest minoritized ethnicity, and to make clear that Black groups were also a minoritized population, by adding 'other' to the terms (e.g. Black, Asians and *Other* Minority Ethnic) (Cole 1993). Sociologists have pointed out multiple problems with these collective terminologies, starting from their failure to distinguish race from ethnicity (Torres 2020). The two concepts, which are discussed in more detail later, are often confused, combined or treated as synonymous.

This disposition to conflate and confuse race and ethnicity is apparent not only in the use of ordinary language and official nomenclature of collective terms that utilize racialized ethnic categories to group people, but also in census questions (ONS 2011). The US census, where the concept of race appears to be more accepted and acceptable, does make this distinction (U.S. Census Bureau 2020). Sociologist Peter Aspinall (2002) has highlighted what he regarded as 'persistent problems' with existing terms. He underlined their ambiguity and acceptability with respect to the populations they purport to describe, questioning whether the collectivities they embody have any substantive meaning and representativeness (Aspinall 2020), concealing as they do some minoritized groups, notably White minoritized groups. The incoherence in the pattern of inclusion of certain White minoritized groups and the exclusion of others, the masking of the *true* reality of the experience of some groups whose marginalization and exclusion are exacerbated, diminished or elided, and the exposure of others to false realities through a process of assimilation, render these collective terms impractical and inappropriate for research and practice. Unless categories are clearly defined and the individuals included in studies described accurately, it becomes impossible to understand to whom study findings refer and apply. In most studies, it would be feasible to use descriptors with greater specificity in the place of BME/BAME and avoid perpetuating a culture of racial dichotomy of 'Whiteness vs Otherness'.

This is not to say that there is no rationale or circumstance when these collective terms can be used. In accordance with their monitoring purpose, they have value in revealing broad disparities based on skin colour or phenotype. Lin and Kelsey (2000: 187) list a number of epidemiological purposes in categorizing populations by race and ethnicity, ranging from 'elucidating disease aetiology, to applications in clinical settings, to [identifying and] targeting specific groups for prevention and intervention on a public health scale'. However, as they noted, 'race and ethnicity are less objective and more difficult to conceptualize and measure than other factors such as age and sex' (187). They also lack scientific basis and

are more prejudicial as they are too often and too promptly transformed into risk factors for ill health (but not good health), poor socioeconomic conditions and other areas of attainment. Despite lacking objectivity, validity and reliability, they have been operationalized and are used routinely as default analytic tools to make evaluations and judgements in research and practice, and to inform policies.

Unlike in the UK and US, in France, in line with 'laïcité' that seeks to foster greater integration of all citizens and give equal treatment to everyone, the French government prohibits collection of data based on race, ethnicity or religion (Romain 2008; Lenoir 1983). Despite laudable aims, this model has not eliminated discrimination and may have created new systemic forms of it, by rendering minoritized populations and the difficulties they face almost invisible (Ndiaye 2020). Absence of questions about race or ethnicity from the French national census precludes any form of targeted measures for specific groups that might experience unequal treatment (Chevalier 2020).

Beyond the labels: Conceptual difficulties

Regardless of how these terms are formulated and presented, their nexus in demarcating population groups is race. Even when ethnicity or culture or national identity is introduced in the process, racial considerations remain the commanding factors that lead population grouping and classification, feeding into an underlying context to serve political, economic or social purposes. Both race and ethnicity are concepts laden with problematic historical, political and social contents.

Although related, race and ethnicity are distinct concepts that are often mistakenly used interchangeably. The appropriate assessment of race and ethnicity is crucial to research and practice, as researchers and government officials employ them routinely in their analysis and to make judgements. For example, studies have associated South Asians with stigma of mental illness and dementia, attributing their apparent reluctance to engage with services for these conditions to ethnocultural characteristics (Seabrooke and Milne 2004; Giebel et al. 2015; Mukadam et al. 2015; Werner et al. 2012). Following a similar line of reasoning, the Social Care Institute for Excellence (SCIE) advice for professionals working with minoritized ethnic people affected by dementia, utilizes racial and ethnic characteristics as a frame of reference for their guidelines (SCIE 2020). Race and ethnicity are complex, multidimensional, overlapping and highly

controversial constructs. They denote belonging to a constructed social group in which members allegedly share presumed and/or apparent similarities that distinguish them from other groups.

Race

The idea and classification of race originate from eighteenth-century naturalists and philosophers (Smedley, Takezawa and Wade 2017), who used observation of geographical location and phenotypic traits such as skin colour to categorize people into racial groups. This flawed, Eurocentric and pseudoscientific idea of racial types gained wider currency throughout the eighteenth and nineteenth centuries, particularly as it served the needs of colonialist and imperialist expansion and domination. Writings from people with vested interests in maintaining racial distinction such as Edward Long, a former British plantation owner and jurist in Jamaica, and Charles White, an English physician, were given great weight as 'scientific' vehicles to confirm the delineation of races and deepen the rift between groups of people on the basis of skin colour (Smedley et al. 2017). Not long after, Arthur de Gobineau's essay on *The Inequality of the Human Races* further helped to legitimize racism using scientific racist theory and racial demography (de Gobineau 1855). He argued that intellectual differences existed between races and the mixing of races between those he considered superior with others led to the decline of civilization.

The biological positioning of race as an indicator of distinct, genetically different population groups has not stood the test of time and is now widely considered to be 'non-existent' in scientific terms (Beutler et al. 1996; Bradby 1995; Chaturvedi and McKeigue 1994; McKenney and Bennett 1994; Senior and Bhopal 1994; Williams, Lavizzo-Mourey and Warren 1994). There are no genetic variants that occur in members of one socially constructed racial group that cannot be found in another. Research has shown that genetic differences between humans are 'inconsistent and typically insignificant' (Cornell and Hartmann 2006; Cashmore 2004). In fact, there are greater intraracial genetic variations than interracial ones (Senior and Bhopal 1994; Williams et al. 1994).

Ethnicity and culture

Whilst race tends to be ascribed to individuals, ethnicity is more likely to be a matter of choice, with individuals able to subscribe to more than one ethnic group. This makes ethnicity an even more elusive construct from an observer

perspective, and it can remain difficult for the individual to self-assign ethnic identity. It is a multifaceted construct that conflates multiple characteristics, some of which are assumed to be inherited, and others taught, learned and/or passed on across multiple generations. Ethnicity has also a sense of peoplehood as it refers to closeness in physical characteristics and commonality in historical, ancestral, cultural, culinary, linguistic, national, social, behavioural and religious heritage. Although less controversial than race, ethnicity too evolves in the context of social and political phenomena and movements and brings into the mix a cultural dimension that relates to shared and learned values, behaviours, beliefs and attitudes that make people behave in a certain way. According to Corin (1995), culture is 'a system of meanings and symbols that shape every area of life', which binds individuals together into communities. Like ethnicity, culture is not static, varies largely within groups, and certainly cannot apply to every individual within a specific subculture.

Identity

Although race and ethnicity have no genetic or scientific basis, the concepts of race and ethnicity are important and consequential to identity, as much in the ways people see themselves as in how they are perceived by others. Jenkins's (2008, 2014) work on social identity points to the notion of ethnicity as being intimately connected to identity. In a similar vein, it refers to identity in terms of a process rather than a 'thing' that people have. Jenkins's social-constructionist perspective rejects the essentialist notion that race and ethnicity somehow condition – or shape – people to be who they are. For Jenkins, ethnicity is 'rooted in, and the outcome of, social interaction' (Jenkins 1997), and is about cultural differentiation, just like identity is invariably concerned with difference and similarity. In this regard, ethnic identity is both internally imposed in personal self-identification and externally constructed in social interaction; hence, both collective and individual. As identification grounds, race and ethnicity cannot be separated from the social context within which they occur because without social interaction there is no ethnicity.

The importance of social context and social interaction in the determination of ethnicity is evident in how society uses concepts of race and ethnicity. They are designed to divide and categorize people into groups ranked by assumed similarities and differences, which are applied to people to establish whether they belong or do not belong to a social group. Still, for reasons that are clearly not rooted in science, when racial and ethnic disparities become apparent

in any context, no attempt is made to peek behind the surface of race and ethnicity, to gaze into the social antecedents and the social determinants of these inequalities. Instead, enquiries about racial and ethnic disparities remain focused on highlighting differences between groups. By not peeking beyond the surface of racial and ethnic disparities into what lurks behind, research that draws attention to race and ethnicity risks buttressing beliefs and ideologies that perpetuate the social divisions and social injustices they seek to address.

It is noteworthy that despite ethnicity's close connection to identity, the ethnic group responsible for constructing the *concept* is less likely to associate with it. Even though everyone is in some sense 'ethnic', the term tends to be erroneously applied only when dealing with minoritized groups. Surveys conducted in the US over a number of years reported that Black adults are more likely than other groups to say that race or ethnicity is central to their identity and to feel connected to a broader Black community (Barroso 2020). Nearly three-quarters of Black adults surveyed said that being Black is extremely (52 per cent) or very important (22 per cent) to how they think about themselves, whereas only 15 per cent of White adults say that race is central to their identity (Barroso 2020). The surveys did not mention how important members of racial groups felt race or ethnicity was for them in the identification of groups that are different to theirs. However, it is very telling that the group historically culpable of racial segregation is less likely to say that race or ethnicity is central to their identity.

Racial and ethnic categorization in dementia research

The problem of categorization in gerontology generally reflects and amplifies the taxonomic problems described above. Minoritized ethnic populations have become the focus of increased attention in dementia research as the issue rises up the global health agenda. In the UK, using conventional terminology, researchers continue to demonstrate racial and ethnic inequalities in dementia outcomes, with minoritized ethnic populations documented to be at pronounced disadvantage on most facets of dementia treatment and care (Knapp et al. 2007; Prince et al. 2014; Mehta and Yeo 2017). Quantitative empirical research repeatedly flags the higher risk of dementia for Black and other minoritized populations in comparison to 'the White population'. It also reports higher prevalence and incidence of the condition, earlier onset, lower diagnosis rates, poor engagement with services, lower participation in research and reduced

treatment uptake for these groups (Adelman et al. 2011; Mayeda et al. 2015, 2016; Pham et al. 2018; Tuerk and Sauer 2015).

While monitoring disparities in dementia is well intentioned, there is a risk that minoritized ethnic populations can be presented in these reports as problematized collectivities based upon their racial, ethnic and cultural affiliation. This message is amplified in qualitative research that describes minoritized ethnic groups as holding misconceptions, poor knowledge and inappropriate beliefs about dementia (Adamson 2001; Ayalon and Arean 2004; Werner et al. 2014; Mukadam et al. 2011). Generally, inequalities in dementia are correlated with 'preformed' ethnic categories, which are often combined with cultural components that determine both outcomes and risk factors proposed as mediators. Researchers tend to use existing administrative categories created by national and local government out of convenience, uncertainty or lack of better options, often omitting to include clear definitions or important characteristics of the individuals under investigation. There is an irony that studies with the explicit purpose of highlighting unfairness for individuals in receipt of care, treatment and services, may themselves perpetuate inequalities.

In a review of qualitative research looking at experiences of dementia among people from Black, African and Caribbean backgrounds, only four out of the twenty-eight papers provided a definition for the ethnicity of the participants involved, and only two papers reported participants' background information, such as sociodemographic characteristics, migration history, and more. What was also apparent was that there was little attention given to the specific differences between those of African American descent and those from Black backgrounds in countries such as the UK or the Netherlands (Roche et al. 2020). In the UK, the origins and cultures of Black African and Black Caribbean as well as other minoritized ethnic populations vary greatly. Added to this is the linking together of different populations such as those from South Asia as part of a composite BAME category in dementia research (Johl, Patterson and Pearson 2016; Lawrence et al. 2008). Acknowledging the greater variety of cultural backgrounds warrants greater attention if researchers are to make meaningful contributions to our knowledge of diverse populations and development of culturally informed, effective, inclusive care and policy.

Categorization of human characteristics and experiences is an essential component of research, certainly of quantitative analyses; but categories need to be meaningful, experienced as legitimate and not disempowering to those who are being researched. This principle that research should be in partnership with, rather than 'done to' communities is widely accepted (Burton, Ogden and

Cooper 2019), and yet ethnic categories are rarely challenged or opened to this scrutiny. The framing of dementia research, and indeed other conditions or phenomena experienced by ageing populations, must acknowledge the layered plurality of subgroups that exist within these predefined ethnic categories. It would be amiss to presume that all the individuals confined under the umbrella term Black ethnicity/Black British/Black Caribbean constitute a uniform entity with a unified cultural element that can be measured. This will be even less likely possible for terms that include multiple groups such as BME or BAME, yet much research and government information are reported using these terms.

Conclusion

There is much controversy around using race, ethnicity and ill-defined collective terminologies such as 'BME' and 'BAME' as classification and/or identification devices. This continues to be done in much thinking about health and ageing, as we have shown in the case of dementia research. Continuing to use these forms of classification risks overemphasizing a flawed unscientific sense of '*nature*' over nurture or vice versa, or falling into damaging stereotypical generalization. In many countries such as the UK, the development of collective terms to describe minoritized populations has exacerbated historical divides and caused confusion, ambiguity and discord. By attempting to combine large heterogeneous groups of people with little objectively in common, these labels often cloud interpretation of research relating to the very cultural and ethnic considerations that studies seek to elucidate (Aspinall 2002; Bhopal and Donaldson 1998; Cole 1993; Polenberg 1980). These terms, ones that are generally devised by members of the majority population with little or indirect contribution from minoritized ethnicity representatives, can underestimate the impact they can have on groups' and individuals' sense of identity.

The use of race, ethnicity and culture as identifiers and indeed their lexicon of terms should be limited to rare and specific circumstances, such as monitoring broad disparity based on skin colour and numerical size, and cautious elucidation of health (good and bad) aetiology. Even in these circumstances, additional information such as background, demographics and socioeconomic details should be provided and inform our analysis, instead of allowing racial and ethnic characteristics to be the determining factors when they may distract from the real causes of an effect. Using the most appropriate and specific ethnicity label is

also essential, not only at the stage of selecting the study population but also at the design and reporting stages of any study. Where granularity is not possible, the use of terms such as 'minoritized ethnicity', as used in this chapter, is advisable (Khunti et al. 2020), provided researchers reflect on the use of ethnicity in the context of their research and report on the extent they think it has played a role in their findings. Additionally, researchers should justify *why* they identify race or ethnicity in studies: often it is unclear why ethnicity or race features in many health and medical studies other than to provide a source of contrast between groups. This can ultimately detract from finding important information about minoritized groups, or more egregiously lead groups to be understood in terms of 'artefactual' problems linked to perceived cultural differences.

Given the ambiguity and difficulty around the categories and terms of classification systems and their underlying concepts, as well as their problematic historical development and political resonances in racism, it is troubling that they continue to be used in research, practice and policy about and for groups of people who have little to no direct involvement or say in their development or validation. It is something that current researchers reframing ageing need to be both cognizant of, and critical about.

Bibliography

Adamson, J. (2001), 'Awareness and Understanding of Dementia in African/Caribbean and South Asian Families', *Health & Social Care in the Community*, 9: 391–6.

Adelman, S., M. Blanchard, G. Rait, G. Leavey and G. Livingston (2011), 'Prevalence of Dementia in African-Caribbean Compared with UK-born White Older People: Two-stage Cross-sectional Study', *The British Journal of Psychiatry*, 199(2): 119–25.

Allen, T. W. (2014), *The Invention of the White Race, Volume 2: The Origin of Racial Oppression in Anglo-America*, London: Verso.

Aspinall, P. J. (2002), 'Collective Terminology to Describe the Minority Ethnic Population: The Persistence of Confusion and Ambiguity in Usage', *Sociology*, 36(4): 803–16.

Aspinall, P. J. (2020), 'Ethnic/Racial Terminology as a Form of Representation: A Critical Review of the Lexicon of Collective and Specific Terms in Use in Britain', *Genealogy*, 4(3): 1–15. Available at: https://doi.org/10.3390/genealogy4030087 (accessed 26 January 2023).

Ayalon, L. and P. A. Arean (2004), 'Knowledge of Alzheimer's Disease in Four Ethnic Groups of Older Adults', *International Journal of Geriatric Psychiatry*, 19(1): 51–7.

Banton, M. (1987), 'What We Now Know about Race', *New Community*, 13: 349–58.

Barroso, A. (2020), 'Most Black Adults Say Race is Central to Their Identity and Feel Connected to a Broader Black Community'. Available at: https://www.pewresearch.org/fact-tank/2020/02/05/most-black-adults-say-race-is-central-to-their-identity-and-feel-connected-to-a-broader-black-community/ (accessed 24 November 2022).

BBC (2018), 'BME Label Insulting, Says Ex-Minister Priti Patel'. Available at: https://www.bbc.co.uk/news/uk-politics-43350527 (accessed 24 November 2020).

Beutler, L. E., M. T. Brown, L. Crothers, K. Booker and M. K. Seabrook (1996), 'The Dilemma of Factitious Demographic Distinctions in Psychological Research', *Journal of Consulting and Clinical Psychology*, 64: 892–902.

Bhala, N., G. Curry, A. R. Martineau, C. Agyemang and R. Bhopal (2020), 'Sharpening the Global Focus on Ethnicity and Race in the Time of COVID-19', *The Lancet*, 395: 1673–676.

Bhopal, R. (2004), 'Glossary of Terms Relating to Ethnicity and Race: For Reflection and Debate', *Journal of Epidemiology & Community Health*, 58: 441–45.

Bhopal, R. and L. Donaldson (1998), 'White, European, Western, Caucasian, or What? Inappropriate Labeling in Research on Race, Ethnicity, and Health', *American Journal of Public Health*, 88: 1303–307.

Bradby, H. (1995), 'Ethnicity: Not a Black and White Issue. A Research Note', *Sociology of Health & Illness*, 17: 405–17.

Burton, A., M. Ogden and C. Cooper (2019), 'Planning and Enabling Meaningful Patient and Public Involvement in Dementia Research', *Current Opinion in Psychiatry*, 32(6): 557–62.

Cashmore, E. (2004), *Encyclopedia of Race and Ethnic Studies*, London: Routledge.

Chaturvedi, N. and P. M. McKeigue (1994), 'Methods for Epidemiological Surveys of Ethnic Minority Groups', *Journal of Epidemiology & Community Health*, 48: 107–11.

Chevalier, J. (2020), 'TOUT COMPRENDRE - Pourquoi les Statistiques Ethniques font Débat en France'. Available at: https://www.bfmtv.com/societe/tout-comprendre-pourquoi-les-statistiques-ethniques-font-debat-en-france_AN-202006150240.html (accessed 24 November 2020).

Cole, M. (1993), '"Black and Ethnic Minority" or "Asian, Black and Other Minority Ethnic": A Further Note on Nomenclature', *Sociology*, 27: 671–73.

Corin, E. (1995), 'The Cultural Frame: Context and Meaning in the Construction of Health', in B. C. Amick, S. Levine, A. R. Tarlov and D. Chapman Walsh (eds), *Society and Health*, 272–304, New York: Oxford University Press.

Cornell, S. and D. Hartmann (2006), *Ethnicity and Race: Making Identities in a Changing World*, London: Sage.

Crewe, S. E. (2005), 'Ethnogerontology: Preparing Culturally Competent Social Workers for the Diverse Facing of Aging', *Journal of Gerontological Social Work*, 43: 45–58.

Giebel, C. M., M. Zubair, D. Jolley, K. S. Bhui, N. Purandare, A. Worden and D. Challis (2015), 'South Asian Older Adults with Memory Impairment: Improving

Assessment and Access to Dementia Care', *International Journal of Geriatric Psychiatry*, 30(4): 345–56.

de Gobineau, A. (1855), *Essai sur L'inegalité des Races Humaines*, vol. 1 Paris: Librairie de Firmin Didot Freres.

Jenkins, R. (1997), *Rethinking Ethnicity: Arguments and Explorations*, London: Sage.

Jenkins, R. (2008), *Rethinking Ethnicity*: *Arguments and Explorations*, 2nd edn, London: Sage.

Jenkins, R. (2014), *Social Identity*, London: Routledge.

Johl, N., T. Patterson and L. Pearson (2016), 'What Do We Know about the Attitudes, Experiences and Needs of Black and Minority Ethnic Carers of People with Dementia in the United Kingdom? A Systematic Review of Empirical Research Findings', *Dementia*, 15(4): 721–42.

Khunti, K., A. Routen, M. Pareek, S. Treweek and L. Platt (2020), 'The Language of Ethnicity', *British Medical Journal*, 371. Available at: https://doi.org/10.1136/bmj.m4493 (accessed 26 January 2023).

Knapp, M., M. Prince, E. Albanese, S. Banerjee, S. Dhanasiri and J. L. Fernandez (2007), *Dementia UK: The Full Report*, London: Alzheimer's Society. Available at: https://www.alzheimers.org.uk/sites/default/files/2018-10/Dementia_UK_Full_Report_2007.pdf?fileID=2 (accessed 26 January 2023).

Lawrence, V., J. Murray, K. Samsi and S. Banerjee (2008), 'Attitudes and Support Needs of Black Caribbean, South Asian and White British Carers of People with Dementia in the UK', *The British Journal of Psychiatry*, 193(3): 240–6.

Lenoir, N. (1983), 'La Loi 78-17 du 6 Janvier 1978 et la Commission Nationale de L'informatique et des Libertés: Elements Pour un Premier Bilan de Cinq Années D'activités', *La Revue Administrative*, 36(215): 451–66.

Lin, S. S. and J. L. Kelsey (2000), 'Use of Race and Ethnicity in Epidemiologic Research: Concepts, Methodological Issues, and Suggestions for Research', *Epidemiologic Reviews*, 22(2): 187–202.

Malik, K. (1996), *The Meaning of Race: Race, History and Culture in Western Society*, London: Bloomsbury.

Mayeda, E. R., M. M. Glymour, C. P. Quesenberry Jr, J. Y. Liu, J. Johnson and R. A. Whitmer (2015), 'Racial/Ethnic Differences in Dementia Survival in a Cohort of 59,494 Dementia Patients from a Healthcare Delivery System', *Alzheimer's & Dementia*, 11(7S_Part_6): 294–5.

Mayeda, E. R., M. M. Glymour, C. P. Quesenberry and R. A. Whitmer (2016), 'Inequalities in Dementia Incidence Between Six Racial and Ethnic Groups over 14 Years', *Alzheimer's & Dementia*, 12(3): 216–24.

McKenney, N. R. and C. E. Bennett (1994), 'Issues Regarding Data on Race and Ethnicity: The Census Bureau Experience', *Public Health Reports*, 109(1): 16–25.

Mehta, K. M. and G. W. Yeo (2017), 'Systematic Review of Dementia Prevalence and Incidence in United States Race/Ethnic Populations', *Alzheimer's & Dementia*, 13(1): 72–83.

Mukadam, N., C. Cooper, B. Basit and G. Livingston (2011), 'Why Do Ethnic Elders Present Later to UK Dementia Services? A Qualitative Study', *International Psychogeriatrics*, 23(7): 1070–7.

Mukadam, N., A. Waugh, C. Cooper and G. Livingston (2015), 'What Would Encourage Help-Seeking for Memory Problems among UK-Based South Asians? A Qualitative Study', *BMJ Open*, 5(9): e007990. Available at: doi: 10.1136/bmjopen-2015-007990.

Ndiaye, S. (2020), 'Sibeth Ndiaye: "Nous Payons Aujourd'hui L'effacement de L'universalisme Républicain"'. Available at: https://www.lemonde.fr/idees/article/2020/06/13/sibeth-ndiaye-nous-payons-aujourd-hui-l-effacement-de-l-universalisme-republicain_6042708_3232.html (accessed 24 November 2021).

ONS (2011), 'Household Questionnaire'. Available at: https://census.ukdataservice.ac.uk/media/50966/2011_england_household.pdf (accessed 26 January 2023).

Pham, T. M., I. Petersen, K. Walters, R. Raine, J. Manthorpe, N. Mukadam and C. Cooper (2018), 'Trends in Dementia Diagnosis Rates in UK Ethnic Groups: Analysis of UK Primary Care Data', *Clinical Epidemiology*, 10: 949–60.

Polenberg, R. (1980), *One Nation Divisible: Class, Race, and Ethnicity in the United States since 1938*, New York and London: Penguin.

Prince, M., M. Knapp, M. Guerchet, P. McCrone, M. Prina, A. Comas-Herrera, R. Wittenberg, B. Adelaja, B. Hu and D. King (2014), *Dementia UK: Update, London: Alzheimer's Society*. Available at: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf (accessed 26 January 2023).

Roche, M., P. Higgs, J. Aworinde and C. Cooper (2020), 'A Review of Qualitative Research of Perception and Experiences of Dementia among Adults from Black, African, and Caribbean Background: What and Whom are We Researching?', *The Gerontologist*, 61(5): e195–e208.

Romain, G. (2008), 'La Décision n 557 DC du 15 Novembre 2007 du Conseil Constitutionnel sur la Loi Relative à La Maîtrise de L'immigration, à L'intégration et à L'asile', *Publications Doc Du Juriste*. Available at: https://www.conseil-constitutionnel.fr/decision/2007/2007557DC.htm (accessed 26 January 2023).

Saeed, A., E. Rae, R. Neil, V. Connell-Hall and F. Munro (2020), 'To BAME or Not To BAME: The Problem with Racial Terminology in the Civil Service', *Civil Service World*, 4 October. Available at: https://www.civilserviceworld.com/news/article/to-bame-or-not-to-bame-the-problem-with-racial-terminology-in-the-civil-service

Scarman, L. G. (1986), *The Scarman Report*: *The Brixton Disorders 10–12 April 1981*: *Report of an Inquiry*, London: Puffin.

SCIE (2020), 'Black and Minority Ethnic (BME) Communities and Dementia', *Social Care Institute for Excellence*. Available at: https://www.scie.org.uk/dementia/living-with-dementia/bme/ (accessed 13 April 2021).

Seabrooke, V. and A. Milne (2004), *Culture and Care in Dementia*: *A Study of the Asian Community in North West Kent*, Northfleet: Alzheimer's and Dementia Support Services.

Senior, P. A. and R. Bhopal (1994), 'Ethnicity as a Variable in Epidemiological Research', *British Medical Journal*, 309(6950): 327–30.

Smedley, A., Y. I. Takezawa and P. Wade (2017), 'Race: Human', *Encyclopædia Britannica*. Available at: https://www.britannica.com/topic/race-human/Hereditarian-ideology-and-European-constructions-of-race (accessed 26 January 2023).

Taylor, K. Y. (2020), 'Of Course There Are Protests: The State is Failing Black People', *The New York Times*, 29 May.

Torres, S. (2020), 'Racialization without Racism in Scholarship on Old Age', *Swiss Journal of Sociology*, 46(2): 331–49.

Tuerk, R. and J. Sauer (2015), 'Dementia in a Black and Minority Ethnic Populations: Characteristics of Presentation to an Inner London Memory Service', *The British Journal of Psychiatry Bulletin*, 39(4): 162–66.

U.S. Bureau Census (2020), 'Questions Asked on the Form'. Available at: https://2020census.gov/en/about-questions.html.

Werner, P., D. Goldstein, D. S. Karpas, L. Chan and C. Lai (2014), 'Help-Seeking for Dementia: A Systematic Review of the Literature', *Alzheimer Disease & Associated Disorders*, 28(4): 299–310.

Werner, P., M. S. Mittelman, D. Goldstein and J. Heinik (2012), 'Family Stigma and Caregiver Burden in Alzheimer's Disease', *The Gerontologist*, 52(1): 89–97.

Williams, D. R., R. Lavizzo-Mourey and R. C. Warren (1994), 'The Concept of Race and Health Status in America', *Public Health Reports*, 109(1): 26–41.