Current Sociology papers on ethnicity and health

Introduction: key themes in a developing field

Waqar Ahmad and Hannah Bradby

Abstract

Ethnicity is a social division that is increasingly difficult to ignore. Ethnicity has to be considered alongside other social divisions and socioeconomic status is clearly crucial to explaining poor health outcomes and poor health services associated with minority ethnic group status. Identity is a key dimension of ethnicity, which encompasses self-ascribed and externally-imposed elements. The stigma associated with particular conditions, combined with the effects of racism and economic marginalisation can be central for some minority groups' ability to discuss disease and seek treatment. In world where human rights are taken seriously, minority ethnic groups' presence in research has to become a routine consideration, rather than an optional extra. In research, as in service provision, planning for linguistic and cultural diversity represents additional work and will require extra resources.

Social divisions and inequalities are observable features of advanced societies and their study has been one of sociology's main preoccupations. One dimension of inequality between populations defined by social class, gender, age, and increasingly ethnicity, is the experience of ill health and access to health services. We know for example, that the provision of health services is closely related to the social class of the user, with those most in need being least likely to have access to good quality health care and more likely to receive poor quality care – what Julian Tudor Hart called the 'inverse care law' (Tudor Hart, 1971). There is incontrovertible evidence that social status, variously defined, is a strong predictor of individual and group health status (Marmot, 2004). We know that concepts of health and illness vary through time and across cultures (Kleinman, 1981) such that the experience of illness varies between cultural groups. We also know that access to health care is related to the ethnic status of those seeking the service (e.g. Smaje, 1995).

'Ethnicity' and 'race' are familiar variables in the analysis of health and health care in both Britain and the USA. 'Race' as an analytical concept has lost credibility, although its vernacular use remains widespread. 'Ethnicity', a concept which rests less on innate and immutable features of 'racial stocks', and more on shared identities built on common cultures, histories, languages, religions and regional affiliations, has strong saliency. However, as an analytic concept, ethnicity suffers from some of the same problems as 'race': it is extremely malleable and flexible to the extent that its

meaning has been highly variable between individuals, between cultures and across time (Ahmad, 1999; Bradby, 2003). 'Ethnicity' refers to the self-definition by individuals and groups, but can also encompass ascribed identities, which may contradict self-assigned identity, leading to contested identity claims. Perversely, definitions of ethnicity in some discourses are taking on the same features of permanency, immutability and essentialism which were central tenets of what has been criticised in ideas around 'race'. 'Ethnicity' is now used in such a 'racialised' fashion that some argue that 'cultural racism' has replaced 'biological' or 'colour racism' as defining and oppressing certain groups (Ahmad and Bradby, 2007; Barker, 1981). While not without merit, 'ethnicity' is a concept which requires precision and care in its use both generally and in studies of health and illness.

Ethnic divisions do not exist in isolation from other social divisions. Many minority ethnic groups are subject to forms of social exclusion and marginalisation. All too often, minorities' predicament (poor housing, poor health, unemployment) is explained, not in terms of unequal access to resources and opportunities or discriminatory state and market institutions, but as a result of innate features of the groups themselves. Thus the minority's disadvantage becomes racialised, that is, seen predominantly as something located in their problematic culture or biology. Such analyses often ignore the relationship between minority ethnic status and socioeconomic position. The evidence of an association between socioeconomic status and ethnic or racialised group is overwhelming, from the marginalised position of African Americans, to that of the 'First Nations' in Canada, aboriginal people in Australia and ethnic and religious minorities in Europe. None of these white, majority cultures is flattered by either their historical or present day treatment of ethnic minorities in their population.

While the sociology of 'race' or ethnicity was well developed by the 1970s in Britain, and earlier in the USA, sociological interest in ethnic health inequalities has a more recent history. Work by Krieger (2000) and Williams et al (1997) in the USA, and Nazroo (1997), Smaje (1997) and Ahmad (1993) in Britain, sheds light on debates around questions of socioeconomic status, discrimination, ethnicity and health. The four articles which follow, build on some of the key themes which run through the sociology of ethnicity and health which has become established over the last 20 years or so.

Chronic illness, impairment and ethnicity

Chronic illness and physical and intellectual impairments are common features of industrialised societies, increasingly so because of ageing populations and our ability to prolong life among those suffering from conditions which only a few decades ago would have been fatal. The provision of care for those in need has been conceptualised in terms of 'caring about' (concern about and provision of moral or financial support) and 'caring for' (undertaking the daily physical labour of care which might include washing, cleaning, feeding, dressing on behalf of the 'cared for' person). While this field is now well developed (Daley, 1988; Parker and Lawton, 1992; Twigg and Atkin, 1994;), the experiences of those from minority ethnic communities have, until recently, been neglected. Recently, the field has attracted sociological attention with Chamba et al's (1999) major survey reporting that, compared to white parents with severely disabled children, minority ethnic parents faced even greater hardships and isolation, had fewer informal resources to aid coping, lived in greater poverty and found communication with services highly challenging. Atkin et al (2002), Atkin and Ahmad (2000) and Chattoo and Ahmad (2004) explore the impact of chronic illness on the individual's sense of selfhood, strategies employed to maintain a semblance of normalcy and the importance of personal, family and professional resources available to cope with chronic illness. Despite this welcome addition to the sociology of chronic illness, Britain's Bangladeshi origin population has been hitherto neglected. Bangladeshis arrived in Britain much later than those from the Caribbean, India and Pakistan, at a time of relative industrial decline. Economic recession coupled with the limited skills of the migrants and their concentration in a small number of relatively deprived areas, has resulted in this community remaining more deprived than more established minorities in Britain. This is the context for Nilufar Ahmed and Ian Rees Jones' paper in this volume[or section], in which they present their findings in terms of the amplification or articulation of suffering, locating caring responsibilities within the moral economy of duty and religious obligations, and entitlements as citizens. The experiences of these Bangladeshi carers in London have many commonalities with those of other South Asian as well as white carers. For example, isolation, limited information, poverty, problems of access to resources and services and the carrying of the burden of care by a limited number of individuals within the family are all well recognised features of caring for chronic conditions. Ahmed and Rees Jones note that carers may perceive their conspicuous ability to cope as important for their moral standing in the community. Similarly, Katbamna et al (2004) note the sometimes perverse role of extended family and broader community in policing and criticising people's caring performance without providing practical support. Ahmed and Rees Jones also note that the feminization of caring results in male carers sometimes perceiving their masculinity to be under threat – a finding consistent with Katbamna et al's work on Indian and Pakistani carers (2004).

For people of South Asian and Caribbean as well as African American origin, genetically inherited haemoglobinopathies (disorders of haemoglobin, or red blood cells) such as thalassaemia and sickle cell disease have received both sociological and policy attention (Anionwu and Atkin 2001; Hill 1994; Modell et al, 1997). In relation to sickle cell disorder, Hill's (1994) work identified the role of female family networks as essential coping resources in poor African American families. Atkin and Ahmad (2000) explored the inextricable relationship between identity struggles and thalassaemia treatment, demonstrating that non-adherence with medication (a common and often lethal phase in the lives of adolescents and young adults), had little to do with lack of knowledge and much more to do with the development of autonomy and selfhood. The literature on chronic illness highlights the 'biographically disruptive' (Bury, 1984) aspects of the experience whereby the ability to plan and control one's life, to 'maintain calendars' (Schou and Hewison, 1999), is lost. Atkin, Ahmed, Hewison and Green's contribution in this volume[or section], adds to this literature through its focus on the role of religion and faith in influencing decisions over antenatal screening and termination of affected foetuses. As the authors acknowledge, their study is based on hypothetical and contextual questions; none of the participants were actively making such decisions. Nonetheless, their findings are of interest in emphasising the contextual, lived nature of religious belief, where a number of other imperatives become significant and the 'religious' becomes difficult to disentangle from the 'social' and 'cultural'. The participants noted the relative nature of decision making wherein for many, personal ethics were as (or more) important as religious imperatives. As noted by others (e.g. Anionwu and Atkin, 2001), this study confirms the importance of offering early diagnosis and shows that decisions over antenatal diagnosis and terminations are contingent on contextual, experiential and personal factors, which underlie diversity within as well as commonality between ethnic groups.

Identity and health

Health and illness has often been associated with notions of identity and morality. Many conditions have been or remain stigmatic. Mental illness, cancers, tuberculosis and genetically inherited conditions among a host of other conditions have carried social, genetic or moral stigma, often with significant consequences for sufferers and their families. At various times, the state has intervened to safeguard the physical and moral health of the broader population from those carrying stigmatic conditions, by incarcerating the sufferers in asylums and sanatoria. At other times the non-statutory power of social opprobrium has confined people to individual or family isolation. The strong alignment of sexually transmitted diseases with ideas around sexual immorality and social waywardness makes them uniquely stigmatic, particularly for women. Regarded as a major threat to

the moral fabric of society and assumed to be restricted to permissive societies, many societies still fail to recognise HIV and AIDS as current conditions which need to be considered for social and economic planning. Even in societies which acknowledge the significance of these conditions, the assumption that sexual permissiveness is associated with people of a certain age, class or ethnicity may make others (say older people) feel personally impervious to the threat of these conditions and unsympathetic towards sufferers. Bronwen Lichtenstein's paper in this volume[or section] addresses how the stigmatic nature of sexually transmitted disease (STD) leads African American elders, respected in the community for their moral and social standing, to fail to engage with such conditions. She notes that African American elders are heavily involved as advisors for managing major conditions afflicting their communities – diabetes, hypertension, cancers – but not for STDs, in spite of the higher prevalence of STDs among African Americans, compared with other groups. Lichtenstein notes that the troubled history of the public health services and African Americans - notably the Tuskegee syphilis studies of 1932-72 where 399 black sharecroppers were observed without treatment, often till their death (Jones, 1993) – results in distrust of public health messages aimed at Black populations. A cocktail of social and moral stigma, coupled with a distrust of public services, and the persistence of poor services in deprived areas, results in enhanced suffering of Black populations, due to poor screening, identification and treatment of STDs.

Planning for diversity

The final paper in this volume[or section], by Hanna, Bhopal and Hunt addresses important methodological issues of relevance to both research and policy. Ethnic diversity is a given in most industrialised societies and is set only to increase. Often it is accompanied by linguistic diversity, posing challenges for both research and policy. Britain has had an assimilationist attitude, assuming that immigrants would adopt all aspects of British life, including speaking English as a first language. The NHS has now recognised the need to offer non-English speakers interpretation services as a matter of routine. However the monoglot tradition of the UK means that the process of working across and between languages is poorly understood. Crude multicultural approaches have sometimes reduced problems of access to health care to differences in language and focused on providing interpreters as a simple solution. Greenhalgh et al (2007) examine the 'bureaucratisation' of interpreting services and the consequences for users and providers of health care, showing how far from simple such provision is in a multi-ethnic society where service providers and users speak languages other than English.

'Cross-cultural' research poses its own challenges, which have tended to be over-looked in a sociological tradition which overlooks and oversimplifies the processes involved in cultural and linguistic translation (Bradby, 2002). Languages and idioms used to describe conditions and feelings are located in particular linguistic, social, religious and personal contexts which themselves have an effect on the development of the language. Exploring health and variation in the experience of illness or care between cultures therefore requires careful consideration of issues, such as how questions are constructed and articulated, and whether or not the terms used in different versions of an instrument have conceptual equivalence. The adaptation of research instruments to different cultural contexts (Hunt et al, 1991) and the importance of developing research instruments simultaneously in different languages (Mumford et al, 1991) has been described. The article by Hanna et al reports their experiences of cross cultural research using bilingual workers as research assistants. This documentation of the processes involved in working systematically in more than one language is a welcome addition to the literature, exploding, as it does any assumption that translation is a mechanical process which could be straightforwardly standardised. The implications of the complexities are considered in a way that will prove useful for those planning multi-lingual research in the future.

Divided by a common language

Anglophone countries use the terms 'ethnicity', 'race' and 'culture' in various contexts. The difficulty of course, is that the historical and material circumstances of the establishment of minorities and the deployment of the terms varies and has specific resonance. In the UK the term 'race' tends to be used very tentatively by sociologists, with the inverted commas acknowledging the socially constructed nature of the categorisation. By contrast in the US race refers to a social division that is recognised by a wide range of the population and encompasses a dimension of what the British would call class or socioeconomic position. With the rise of the Black middle class in the US, perhaps racialised divisions will be problematised anew. The careful tracing of ethnic inequalities in health for US and UK Black Caribbean groups to the differences in patterns and contexts of migration (Nazroo et al 2007) suggests that there is much to be gained by comparative international work that examines socioeconomic status, discrimination and the cultural components of ethnicity in tandem.

Three out of four of the papers in this volume[section] focus on migrants and the descendants of migrants to Britain, as does our own research. Needless to say, this does not represent the totality of research into ethnicity, racism and health in Europe. While research into health inequalities has

attended to migrants and minority groups to some extent, pan-European sociological discussion of health and ethnicity remains under-developed. The evident difficulty of establishing a consensus on the terms of discussion within a single society, or academic discipline, has undoubtedly hindered the development of international dialogue. Furthermore the historical parallel development of sociology and anthropology in which anthropology has attended to culture while class and other structural issues has been sociology's remit (Bradby, 2002), has allowed ethnicity to be over-looked by sociologists of health and illness.

Wider social changes mean that consideration of the significance of divisions of ethnicity has to become as routine as attending to class, age and gender in the social world. In the light of Europe-wide human-rights legislation, we anticipate challenges to ethno-centric provision of health and social care from a number of quarters. The discourse of the 'special needs' of minority ethnic group patients or clients has to be replaced with a goal of equitable care based on need as a priority, in order to establish a health service that is not only culturally competent, but also humane and socially just. The British NHS has relied upon foreign-trained medical staff throughout its history. Terrorist attacks on Glasgow airport in July 2007, in which doctors employed in the NHS seem to have been involved, raises ethnicity as a crucial division for providers as well as recipients of health care.

References

Ahmad WIU (Ed) (1993) *'Race' and Health in Contemporary Britain*, Buckingham: Open University Press

Ahmad WIU (1999) Ethnicity and statistics: better than nothing or worse than nothing?, in Dorling D and Simpson S (Eds) *Statistics in Society,* London: Edward Arnold

Ahmad WIU (Ed) (2000) *Ethnicity, Disability and Chronic Illness,* Milton Keynes: Open University Press

Ahmad WIU and Bradby H (Eds) (2007 – forthcoming), *Ethnicity, Health and Health care: Understanding Diversity, Tackling Disadvantage*, Oxford: Blackwell (*Sociology of Health and Illness Monograph 13*).

Anionwu EN and Atkin K (2001) *The Politics of Sickle Cell and Thalassaemia*, Buckingham: Open University Press

Atkin K and Ahmad WIU (2000) Pumping iron: compliance with chelation therapy among young people who have thalassaemia major, *Sociology of Health and Illness* 22(4): 500-24.

Atkin K, Ahmad WIU and Jones L (2002) Young Asian deaf people and their families: negotiating relationships and identities, *Sociology of Health and Illness*, 24(1): 21-45

Barker M, (1981) *The New Racism: Conservatives and the Ideology of the Tribe*, London: Junction Books

Bradby H (2002) 'Translating culture and language: a research note on multilingual settings'.

Sociology of Health and Illness, 24(6): 842-855.

Bradby H (2003) Describing ethnicity in health research, *Ethnicity and Health* 8(1): 5-13.

Bury M (1991) The sociology of chronic illness, *Sociology of Health and Illness* 13(4): 451-68.

Chamba, R, Ahmad, WIU, Hirst M, Lawton D and Beresford B (1999) *On the Edge: Experiences of Minority Ethnic Parents of Severely Disabled Children,* Bristol: Policy Press

Chattoo S and Ahmad, WIU (2004) The meaning of cancer: illness, biography and social identity, in David Kelleher and Gerard Leavey (ed) *Identity and Health*, Routledge (p19-36)

Daley G (1988) *Ideologies of Caring: Rethinking Community and collectivism*, Basingstoke: Macmillan

Greenhalgh T, Voisey C and Robb N (2007) Interpreted consultations as 'business as usual'? An analysis of organisational routines in GP practices, Ahmad WIU and Bradby H (Eds) *Ethnicity, Health and Health care: Understanding Diversity, Tackling Disadvantage*, Oxford: Blackwell (*Sociology of Health and Illness Monograph 13*).

Hill SA (1994) *Managing Sickle Cell Disease in Low Income Families*, Philadelphia, PA: Temple University Press

Hunt S, Alonso J, Bucquet D, Niero M, Wiklund I, McKenna S (1991) Cross-cultural adaptation of health measures: European Group for Health Management and Quality of Life Assessment, *Health Policy* 19 (1): 33-44

Jones, JH (1993) *Bad Blood: The Tuskegee Syphilis Experiment,* New York: The Free Press

Katbamna S, Ahmad WIU, Bhakta P, Baker R and Parker G (2004) 'Do they look after their own?' Informal support for South Asian carers, *Health and Social Care in the Community*, 12(5): 398-406

Kleinman A (1981) *Patients and healers in the context of culture,* Berkeley, CA: University of California Press

Krieger N (2000) Refiguring 'race': epidemiology, racialised biology and biological expressions of race relations, *International Journal of Health Services* 30(1): 211-216.

Marmot M (2004) *Status Syndrome*, London: Bloomsbury

Modell B, Petrou M, Layton M, Varnavides L, Slater C, Ward RHT, Rodeck C, Nicolaides K, Gibbons S, Fitches A and Old J (1997) Audit of prenatal diagnosis for haemoglobin disorders in the United Kingdom: the first 20 years, *British Medical Journal* 315: 779-784.

Mumford DB, Bavington JT, Bhatnagar KS et al (1991) The Bradford Somatic Inventory: A multi-ethnic inventory of somatic symptoms reported by anxious and depressed patients in Britain and the Indo-Pakistan subcontinent, *British Journal of Psychiatry* 158: 379-86.

Nazroo J (1997) *The Health of Britain's Ethnic Minorities: Findings from a National Survey*, London: Policy Studies Institute

Nazroo J, Jackson J, Karlsen S and Torres M (2007) The black diaspora and health inequalities in the US and England: does where you go and how you get there make a difference? , Ahmad WIU and Bradby H (Eds) *Ethnicity, Health and Health care: Understanding Diversity, Tackling Disadvantage*, Oxford: Blackwell (*Sociology of Health and Illness Monograph 13*).

Parker G and Lawton D (1992) *Different Types of Care, Different Types of Carers*, London: HMSO

Schou KC, Hewison J (1999) *Experiencing Cancer: Quality of Life in Treatment*, Buckingham: Open University Press

Smaje C (1995) Health," race" and Ethnicity: Making Sense of the Evidence, London: Kings Fund Institute

Smaje C (1997) Not just a social construct: Theorising race and ethnicity. *Sociology*, 31 (2), 307-327.

Tudor Hart J (1971) The inverse care law, *Lancet* i: 405-12

Twigg J and Atkin K (1994) *Carers Perceived*, Buckingham: Open University Press

Williams DR, Yu Y, Jackson JS, Anderson NB (1997) Racial differences in physical and mental health: socioeconomic status, stress and discrimination, *Journal of Health Psychology* 2(3):335-351