Knowledgeshare

Reviews

The Politics of Sickle Cell and Thalassaemia

EN Anionwu and K Atkin

This book is underpinned by two themes of special relevance to this new journal on diversity, namely disability discrimination and racism in health and social care. Sickle cell disorders and the thalassaemias are serious inherited blood disorders that primarily, but not exclusively, affect communities in the UK who have been racialised. The book is written by authors from nursing science and social science backgrounds respectively, and seeks not only to document the clinical and social experience of living with these chronic illnesses, but also to advocate for change. This is made possible by the authors' own extensive experiences of, and contributions to, community development and struggles for change.

The book addresses issues as diverse as laboratory diagnosis, clinical treatment and management, screening and genetic counselling, formal services for health and social service provision and the community activism that helped to create them. It also includes the experiences of young people living with haemoglobinopathies, as they negotiate as normal a life as possible with regard to relations with family, neighbours, friends, relatives and service providers. Underpinning the thoroughly referenced analysis is the knowledge of how various form of racism have helped to shape the experience of sickle cell and thalassaemia in the UK.

Thus we learn that the geographical origins of sickle cell, in areas of the world formerly malarial, was a connection missed by early scientific enquiry because of the racist discourse of the early 20th century that framed the black body as one inherently diseased. Those who conducted early screening programmes for sickle cell in the US confused the carrier states with the conditions. Systematic community education or culturally competent counselling were not available. The later development of services in the UK has at least been able to learn from these mistakes. Nevertheless, the treatment of sickle cell disorders and of beta-thalassaemia has been accompanied by racist myths of low pain thresholds and accusations of drug-seeking behaviour that have led to the denial of pain relief medication by health service staff for severe pain. Service development has been slow and inconsistent across different parts of the country, and was not, until recently, part of mainstream service budgets. Sickle cell and thalassaemia, as issues, have received far fewer resources for screening, counselling and research, than less common conditions including cystic fibrosis, haemophilia, and phenylketonuria that primarily affect white communities. This lack of resources has been compounded by the absence of health worker knowledge when dealing with clients with haemoglobinopathies. Consequently, sufferers have received poor quality care and either been misinformed or uninformed by professionals. In addition, the wider issues of racism as wider racisms in housing, education and employment impinge on the strategies available to young people living with sickle cell or thalassaemia, and further complicate their construction of robust identities, identities that acknowledge, but are not determined by, their sickle cell anaemia or thalassaemia.

The book ends with a recognition that developments in services for those with sickle cell and thalassaemia have been hard won by community activism, and that future developments too may have to be progressed through the advocacy of voluntary organisations, for whom contact and website information are provided, and key professional advocates, but most of all by the experts living with sickle cell anaemia or thalassaemia themselves.

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Review of the Occupational Health and Safety of Britain's Ethnic Minorities

A Szczepura, A Gumber, D Clay et al

The Race Relations Amendment Act 2000 places a statutory responsibility on all public services, including the NHS, to 'have due regard to the need to eliminate unlawful discrimination'. This report, commissioned by the Health and Safety Executive (HSE), aimed to provide an evidence based overview of

whether or not 'ethnic minority groups in Britain are disproportionately affected by work-related health and safety, outcomes, issues or activities' and, in so doing, provide the HSE with the necessary background evidence to help ensure that it is complying with this new legislation.

The experienced and multidisciplinary research team relied on two main sources of evidence: a review of the published and grey literature on workplace injuries, accidents and work-related ill-health; and existing national datasets such as the Labour Force Survey and Health Survey for England. Although systematic review purists may have some methodological concerns about ways in which certain aspects of the review process were handled, the authors have, on the whole, conducted a reasonably broad sweep of the literature and it is unlikely that there is much of major relevance that has been missed. The team has supplemented the review with secondary analyses of data from nationally representative datasets, a factor that further strengthens the epidemiological rigour of the report.

The main drawback of this primarily quantitative approach is in the report's somewhat predictable conclusion: 'the main finding from our project is a lack of UK research evidence on ethnic minority populations and work-related health and safety issues ...' Such a conclusion should, it could be argued, have been apparent from the preliminary work involved in drawing up the commissioning brief, and had the paucity of such data been recognised early on, might have led to alternative methodological approaches being considered. More in-depth qualitative work would, for example, have allowed a working appreciation of the main health and safety concerns of employees and employers in the context of increasingly multi-ethnic workforces and, furthermore, through drawing on examples of best practice, could also have offered the insights needed to successfully help overcome such issues.

Readers may struggle with some of the language in places, and an apparent lack of proofreading. However, this issue aside, those with an interest in ethnicity and health should welcome this well-structured one-volume report summarising the current state of evidence in relation to ethnicity considerations in occupational health and safety. Particularly useful are the comparisons with US findings, the carefully considered recommendations for further research and the extensive bibliography.

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Conference reports

Social Aspects of Ethnicity and Health: Research and Service Provision, 16 June 2004, The Institute of Health, The University of Warwick

This one-day colloquium attracted over 100 registrations including representatives from the worlds of policy making, funding, service provision, service use, academic research and the voluntary sector. The fraught issue of the role that research should play in redressing the well-documented inequities along lines of class, ethnicity and sex was the main focus of discussion and the politics of inequality were never far from the top of the agenda.

Professor James Nazroo (University College London) opened the day with a paper on health inequalities, using familiar census ethnic group categories and empirical data as a springboard to thinking more deeply about the complex interrelations of sex, generation, racism and class that make up ethnicity, and the circumstances that influence it when it comes into play as an identity. This was followed by the launch of the National Centre for Research into Ethnicity and Mental Health with presentations from Professors Sashi Sashidharan and Scott Weich of the University of Warwick and Professor Clair Chilvers of the Department of Health, each followed by general discussion.

After lunch, presentations on current research were given by Dr Tarani Chandola of University College London, on researching health inequalities, Dr Lorraine Culley of De Montfort University, on infertility services and ethnicity, and Dr Hannah Bradby of the University of Warwick, on mental health services and institutional racism. Using different approaches and methodologies, these papers analysed and evaluated the contribution to differential and poorer outcomes for minority ethnic groups of pathways through and perceptions of care. The day closed with Dr Maria Stuttaford of the University of Warwick reminding the conference of the significance of 16 June as Soweto Day, and giving timely consideration to the possibilities of emancipatory research. She urged researchers to ask who will be emancipated by the next piece of work undertaken, and to consider how this might be measured.

All papers shared one theme: differential treatment or experience as a result of minority ethnic status/identity. While some speakers highlighted the unwitting nature of this differential treatment, others raised questions over institutional racism and direct individual racism. Inevitably the pathways via which these impact on health are multiple and need careful attention.

In discussions of service provision, there was an appeal for more and better communication and information provided in the appropriate language or dialect. Other solutions were presented in the shape of counteracting harmful stereotypes using theoretically based classifications that avoid conflating heterogeneous ethnic groups. A desire for greater representation of black and minority individuals in clinical trials was expressed.

The central role of reflexivity was emphasised in service provision, an awareness of which is equally applicable in social research. Ultimately, the attainment of recognition, acceptance and embracing of different cultural values and attitudes within the health services, rather than the often predominant assimilationist approach, was a common objective.

In summary, the colloquium provided a forum whereby those representatives from multidisciplinary backgrounds conducted a discourse that was inclusive of both theoretical and practical dimensions/considerations. Sharing a common agenda, they focused on the ways in which black and ethnic minority groups experience disadvantaged health status, and the means by which these could be feasibly addressed. For further details and powerpoint presentations see: www2. warwick.ac.uk/fac/cross_fac/healthatwarwick/past_ events/ethnicity_and_health_/

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Irish Health Summit: Challenging the Health Deficit of the Irish in Britain 5–6 July 2004, Manchester Conference Centre

This was first ever summit on the health of the Irish in Britain. It was organised by the Federation of Irish Societies and supported by the Department of Health, the Health Development Agency, Manchester City Council, Manchester Joint Health Unit, Manchester North, Central and South Primary Care Trusts and Cara Irish Housing Association. The aims were to:

- promote awareness, among health and social care professionals, policy makers and service providers, of the serious and persistent physical and mental ill-health needs that exist among Irish people in Britain
- begin a process of dialogue with policy makers and statutory providers to address health inequalities that are comparable to, and in some cases worse than, those experienced by other minority ethnic groups.

In addressing these aims, several recurrent themes became apparent. First, was the invisibility of the Irish in discussions about minority ethnic health, an invisibility attributed to a combination of assumptions based on skin colour and the legacy of racism. Second, was the presentation of a considerable body of research based evidence that demonstrated the continuing poor health of the Irish community and the historical failure to address their needs.

Many of the delegates were shocked to learn that the Irish in Britain experience some of the highest rates of mental illness across all ethnic groups (Bracken *et al*, 1998), including high rates of suicide at all ages (Leavey, 1999). In addition they experience the highest rates of cancer mortality in the whole population (Harding, 1998), have among the highest death rates from heart disease and stroke (Harding and Balarajan, 1996), and levels of limiting long-term illness are broadly comparable to those of the Bangladeshi community (Erens *et al*, 2001). This picture of poor health persists into the second and third generations following migration (Harding and Balarajan, 1996, 2001). Research evidence suggests that no single factor is responsible for the poor health of the Irish in Britain. Structural, socio-economic, cultural and lifestyle factors all appear to interact with each other to construct health disadvantage (Tilki, 2003). As experienced professionals, delegates questioned why they had not been aware of these issues when the evidence had been available for years. The recently completed National Health Impact Assessment demonstrated the failure of primary care trusts to take account of Irish health issues (Glackin, 2004). The lack of statutory provision had prompted Irish voluntary organisations, funded predominantly by the Irish government, to develop culturally appropriate services. Despite this bleak picture, a range of key speakers, workshops and networking sessions offered much scope for examining cultural competence in relation to Irish people and providing creation of good practice. These generated a lot of enthusiasm and plans include links with the National Institute for Mental Health in England (NIMHE), the establishment of an online network and various local initiatives.

There was concern about the lack of statutory representation at the summit despite extensive lobbying and advertising when other events about minority ethnic health were normally well supported. Many of those who did attend were Irish or of Irish origin, who were either motivated by their own Irishness or encouraged to attend by their (non-Irish) seniors who believed the summit was of relevance because they were Irish and, by implication, of less importance to those who were not. On a positive note, it was reassuring to find that a significant number of delegates were from other minority ethnic communities or groups and were committed to tackling Irish health issues within the broader minority ethnic health agenda.

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Resources

Diversity and emergency care

A search undertaken by Meher Grigorian, Information Officer, Diversity Health Institute Clearinghouse, Parramatta, Australia (email: Meher_Grigorian@wsahs.nsw.gov.au) has revealed a range of references and other resources relating to diversity and emergency care. These include:

Do you need a hospital emergency department – or can your local doctor help?

This is an information sheet, produced by the New South Wales Multicultural Health Communication Service, available in Arabic, Bosnian, Chinese, Croatian, English, Farsi, Greek, Indonesian, Italian, Japanese, Khmer, Korean, Lao, Macedonian, Portuguese, Russian, Serbian, Spanish, Turkish and Vietnamese. It can be downloaded for free at the following address: mhcs.health.nsw.gov.au/health-public-affairs/mhcs/publications/5975.html

Effective Communication and Cultural Competence in Emergency Care of the Adolescent Training Curriculum (manual, slides)

This is a comprehensive training curriculum designed to improve and/or enhance the cognitive skills and interpersonal capabilities of emergency medical services providers in communicating with and understanding adolescents. It can be ordered from: www.emsc.org/products/frameproducts.htm (Product ID: 000851).

Emergency Multilingual Phrasebook

The Emergency Multilingual Phrasebook, produced and updated by the British Red Cross Society with advice and funding from the Department of Health and endorsed by the British Association for Emergency Medicine (BAEM) is translated into 36 languages. It covers the most common medical questions and terms to help first contact staff to communicate with patients who do not speak English and make an initial assessment while an interpreter is contacted. All emergency departments in England have been sent free copies of the phrasebook. Other organisations can purchase copies directly from the British Red Cross by contacting +44 (0)800 73 11 663.

The phrasebook can be downloaded in Portable Document Format (PDF). For ease of access, the PDF version of this document has been loaded as separate chapters – one for each language. *The Emergency Multilingual Phrasebook* is available in the following languages: Albanian, Amharic, Arabic, Bengali, Bosnian-Bosanski, Chinese, Czech, English, Farsi, French, German, Greek, Gujarati, Hindi, Hungarian, Italian, Japanese, Korean, Kurdish, Lingala, Macedonian, Pashto, Polish, Portuguese, Punjabi, Romanian, Russian, Slovak, Somali, Spanish, Swahili, Tamil, Turkish, Ukrainian, Urdu, Vietnamese, Welsh.

It is available at: www.dh.gov.uk/Publications AndStatistics/Publications/PublicationsPolicyAnd Guidance /PublicationsPolicyAndGuidanceArticle/ fs/en? CONTENT _ID=4073230&chk=8XboAN

Diversity webwatch

The Office of Minority Health (OMH): www.omhrc.gov

The US Department of Health and Human Services (HSS) established the Office of Minority Health (OMH) to 'improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities'. The website contains

information about a number of public health initiatives, campaigns and conferences, and includes a resource centre which serves as an information and referral service on minority health issues for professionals, community groups, consumers, and students.

The Centre for Research in Ethnic Relations at the University of Warwick (CRER): www.warwick.ac.uk/CRER

The Centre for Research in Ethnic Relations (CRER) based at the University of Warwick is a major academic body in the UK for the research and teaching of aspects of race, migration and ethnic relations. Its research agenda includes a focus on the processes of racial discrimination, issues of citizenship, political participation, cultural identity, refugees, ethnic mobilisation and nationalism. It also has materials of value in relation to the study and practice of health and social care. The Resources Centre houses a unique collection of primarily British non-book materials covering a wide range of issues in ethnic relations. Especially useful is the wealth of grey literature on the subject of ethnic relations, including pamphlets and reports,

periodicals such as *New Community and Ethnic Minorities Health*, newspaper titles such as *The Voice*, *Caribbean Times* and *Q-News* and press cuttings. It is open to the public for reference use.

Healthweb: http://healthweb. blink.org.uk

Healthweb is the health site of the 1990 Trust, a voluntary sector organisation set up to protect and pioneer the interests people of African, Asian, and Caribbean descent.

Healthweb aims to enable black and minority ethnic communities, regional and local organisations, the general public and health professionals to gain access to health information via the internet. It contains health advice and information on common conditions in seven languages, and a newly available resource on infertility and its treatment available in English, Gujarati, Punjabi, Bengali and Urdu. The general Blink website (www.blink.org.uk) contains lots of additional information and comment relevant to those interested in diversity and equality issues, plus links to other useful sites.

Knowledgeshare welcomes the following contributions

- short accounts/evaluations of specific initiatives to improve practice or education in health and social care
- reviews of books, websites, games or other resources that can inform practice or education
- information about assessment tools and their applications
- conference reports
- other information that may inform the development of health and social care practice.

All contributions for this section should be sent to Lorraine Culley, Email lac@dmu.ac.uk