

Racism and health

Kwame McKenzie says racism may be aetiologically important in the development of an illness

Discussion of racial discrimination in medicine has concerned mainly recruitment and career development.^{1,2} This has overshadowed a growing literature showing an association between racism and morbidity and mortality.³⁻⁷ Racism may be important in causing the development of illness.

Racism stems from the belief that people should be treated differently because of a few phenotypic features. Racism can manifest itself as individual or group acts and attitudes or institutionalised processes that lead to disparities. Racism is common: in one national survey in the United Kingdom, 25-40% of participants said they would discriminate against ethnic minorities; an estimated 282 000 UK crimes were racially motivated in 1999; and a third of people from ethnic minorities constrain their lives through fear of racism.^{8,9} Disparities between ethnic minority and majority groups in housing, education, arrests, and court sentencing are believed to be due to racism, not simply to economic forces.^{8,9}

Cross sectional studies in the United States found associations between perceived racial discrimination and hypertension, birth weight, self related health, and days off sick.^{3,4} In a recent study from the United Kingdom, victims of discrimination were more likely to have respiratory illness, hypertension, a long term limiting illness, anxiety, depression, and psychosis. People who believed that most companies were discriminatory were also at increased risk of mental illness.⁵

Racism may be associated with illness at an ecological level.⁶ Kennedy et al found that a 1% increase in racial disrespect in a US state was associated with an increase of 350.8 per 100 000 in "black" all cause mortality.⁷ Most of the studies have, however, been secondary analyses, and racism has often been poorly measured and the ability to allow for confounders limited.

One prospective study in the literature adds support to the hypothesis that discrimination affects psychological health. In a study of over 4800 residents of Maastricht who screened negative for mental illness and paranoid traits at baseline, those who said that they had experienced discrimination were twice as likely to develop psychotic symptoms in the three years after.¹⁰

Stress mediated responses in the neuro-endocrine and immune systems have been considered possible mechanisms for the effects of racism on health.¹¹ Racist acts may be acute stressors and the perception of society as racist and the effects of racism on self perception may be chronic stressors.¹¹ But the literature is sparse. To date the effects of racism at a community level—such as the

production of alternative economies (for example, gang culture) or the creation and maintenance of socioeconomic disparities—have rarely been modelled as part of its effects. The effects of racism on future generations—for example, on the long term impact of having a parent with an illness—have not been addressed either.¹¹ The effects of racism are modified by individual coping styles and expectations,⁴ community structure and response to racism, and historical and macropolitical factors.¹¹

Considering racism as causative is an important step in developing the research agenda and response from health services. It moves the discussion away from recruitment and access and towards prevention and the impact of societal structures on rates of illness. The investigation of specific risk factors for illness in ethnic minority groups may be vital if we are to develop equity in efficacy of treatment. For example, is the poorer response to antihypertensive treatment in African-Caribbean people due to biology or is it a reflection of the role of perceived racism in its development and persistence? Investigation of racism's pathophysiological, cognitive, or psychophysiological correlates may offer new avenues for treatment and more efficacious management. Developing a deeper understanding of possible links between racism and health is a prerequisite for initiatives to decrease impact at a community and individual level.

Despite general agreement that racism is wrong, no concerted political effort has tried to decrease its prevalence. Granted, if the Race Relations Amendment Act were enforced it could decrease institutional racism in public bodies, but it is an isolated bill that should be seen in the context of other bills and government rhetoric considered to harm race relations—for example, the current discourse on asylum—and the widespread nature of racism.¹²

Public health is the art and science of preventing disease, prolonging life, and promoting health through the organised efforts of society. One of the chief responsibilities of public health medicine is fostering policies that promote health. I argue that countering racism should be considered a public health issue. The lack of a concerted research and public health effort mean that in the United Kingdom the science of investigating the effects of racism on health and the development of preventive strategies are in their infancy. It is tempting to argue that it is not for doctors to be involved in areas that are so political. The real question, however, is best laid at the doors of those who would prefer not to take on this challenge. How can we have equity in health if one of the major

possible causes of illness in minority ethnic groups in the United Kingdom does not have a dedicated research effort or prevention strategy?

Kwame McKenzie *senior lecturer in transcultural psychiatry*

Department of Psychiatry and Behavioural Sciences, Royal Free and University College Medical School, London NW3 2PF
kmckenzie@rfc.ucl.ac.uk

- 1 Bhopal R. Racism in medicine. *BMJ* 2001;322:1503-4.
- 2 McKenzie K. Something borrowed from the blues. *BMJ* 1999;318:616-7.

- 3 Collins JW, David RJ, Symons R, Handler A, Wall SN, Dwyer L. Low-income African-American mother's perception of exposure to racial discrimination and infant birth weight. *Epidemiology* 2000;11:337-9.
- 4 Krieger N. Discrimination and Health. In: Berkman L, Kawachi I, eds. *Social epidemiology*. Oxford: Oxford University Press, 2000:36-75.
- 5 Karlens S, Nazroo J. Relation between racial discrimination, social class, and health among ethnic minority groups. *Am J Public Health* 2002;92:624-31.
- 6 Gee GC. A multilevel analysis of the relationship between institutional and individual racial discrimination and health status. *Am J Public Health* 2002;92:615-23.
- 7 Kennedy B, Kawachi I, Lochner K, Jones C, Prothrow-Stith D. (Dis)respect and black mortality. *Ethn Dis* 1997;7:207-14.

- 8 Chahal K, Julienne L. "We can't all be white!": *Racist victimisation in the UK*. London: YPS, 1999.
- 9 Virdee S. *Racial violence and harassment*. London: Policy Studies Institute; 1995.
- 10 Janssen I, Hanssen M, Bak M, Bijl R, Vollebergh W, McKenzie K, et al. Evidence that ethnic group effects on psychosis risk are confounded by experience of discrimination. *Br J Psychiatry* (in press).
- 11 King G, Williams DR. Race and health: a multi-dimensional approach to African American health. In: Levine S, Walsh DC, Amick BC, Tarlov AR, eds. *Society and health: foundation for a nation*. Cambridge, MA: Oxford University Press, 1995.
- 12 Race Relations (Amendment) Act 2000. Chapter 34. London: Stationery Office, 2000. www.hmso.gov.uk/acts/acts2000/20000034.htm (accessed 8 Jan 2003).

The challenge of myalgic encephalomyelitis

Samantha Radford looks at the controversy surrounding myalgic encephalomyelitis

A collective sigh of relief was heard across the United Kingdom in January 2002 when the chief medical officer, Professor Liam Donaldson, published his working group report describing myalgic encephalomyelitis (ME) as a "real, debilitating, and distressing illness."¹ The estimated 240 000 people in the United Kingdom who have ME—also known as chronic fatigue syndrome—have been holding their breath, waiting for the moment the illness would come out of the cold.

Prevalence

The UK government estimate of 240 000 people being affected by the condition is based on a survey done in Chicago, which suggests 4.22 cases per 1000 population. Estimates vary greatly, although the condition seems to be found mostly in advanced industrialised countries. The real extent of the problem worldwide is unknown. Underrepresentation of developing countries could be explained by poor health care and monitoring, as most chronically ill people are cared for in the community setting without proper medical care. Further epidemiological research is needed to clarify exactly how many people are affected and to what extent, to form a basis for health service planning.

What is ME?

ME is not a new illness; the first officially recorded outbreaks go back to 1934. But even now, little is known about the condition.³ It has characteristic features but is highly variable in severity and duration. ME affects all age groups and typically more women



Tilt tests are used to reproduce symptoms of dizziness or loss of consciousness which can help with diagnosis and treatment

than men. About a quarter of patients are either housebound or bedbound.

Symptoms include overwhelming fatigue, which differs from normal tiredness and is made worse by increased activity with a delayed impact. Patients also experience cognitive problems such as poor concentration, difficulty finding words, and problems with their short term memory. Patients often have muscle and joint pain, along with recurrent headaches or migraines. Sleep disturbance and digestive problems, with features of irritable bowel syndrome, are typical. Other symptoms include sensitivity to light and sound and alcohol intolerance.

The exact cause of ME is unknown, though infections such as glandular fever and viral meningitis are identified as possible

triggers in 10% of cases. Many of the symptoms suggest dysfunction of the central nervous system. Immune, endocrine, and musculoskeletal abnormalities are also implicated, though much more research is needed to identify the disease process and ultimately find a cure.

Practical steps can be taken to ensure the patient has maximum support on the road to recovery. The report underlines the importance of prompt diagnosis as with early diagnosis and advice, most patients can be expected to make a recovery. A management plan which is mutually agreed with the patient is crucial in treating a chronic illness such as ME, as doing too much can make the condition worse while too much rest can also be unhelpful.

The current lack of medical understanding of the condition and existing controversy are not an “excuse for inaction,” as the chief medical officer’s report stated. A cure may not exist at present, but the basic principles of listening and working with the patient are vital if a recovery programme is to have any chance of success.

Why the controversy?

Dispute over the condition and to what extent it is physical or psychological has caused huge divisions between health professionals and patients over the past two decades. Few disorders have ever been surrounded by similar amounts of disbelief and prejudice.

The controversy emerged partly because of the lack of certainties about the illness. In addition to little serious research being available on either cause or effective treatments, an important contributory factor has been the lack of a reliable diagnostic test. Current diagnosis of ME relies on the exclusion of other conditions and identifying the characteristic pattern of symptoms that distinguishes the condition. It is an unsatisfactory process for both doctor and patient and can lead, in the worst instances, to a breakdown in the relationship. Many patients have been disbelieved by doctors who are, in turn, unable to find any explanation through routine tests for the bizarre symptoms described by their patients. This can lead to problems for those affected by the condition in dealing with employers, benefits agencies, and occasion-

ally even family and friends. In a survey in 2001, almost two thirds of patients with ME reported not having received any advice on managing the condition from their doctor and 33% had to wait more than 18 months to receive a diagnosis.²

Medical training and ME

With an estimated prevalence of 0.2-0.4% (240 000 cases in the United Kingdom alone), most general practitioners can expect to come across patients with ME, yet it is still not consistently included in medical training. Set this against the fact that the chief medical officer’s report states that most patients can be dealt with in the primary care sector and the strain begins to show. This is compounded by the lack of specialist treatment, which means both the doctor and patient often feel they have nowhere to turn to.

The General Medical Council, which is responsible for undergraduate curriculums in the United Kingdom, explained that the decision to include specific subjects lies with medical schools, which to a large extent develop their own detailed curriculums. As a result, although some lecturers choose to touch on ME, it is not included as a matter of course. This is the unmapped territory on which charities such as Action for ME continue to build their campaigning for the development of better services and research and bridging some of the wide chasms that have developed over the years.

The future of ME

The chief medical officer’s report identified an urgent need for more research and resulted in a government referral to the UK Medical Research Council to develop a strategy for advancing biomedical and health services research on ME.

The Medical Research Council set up a research advisory group early last year and published a draft research strategy in December 2002. The draft strategy builds on the chief medical officer’s report and gives guidance on how research into ME should be developed, while highlighting priority areas such as finding more effective treatments. Following final publication later this spring the major concern is whether the government will allocate research funds to ensure the research strategy is put into practice.

Samantha Radford *Action for ME*

Competing interests: SR is employed by Action for ME.

Please contact Action for ME (tel 01749 670799) for a general practitioner’s quick reference guide to ME based on the chief medical officer’s report.

Further information on the Medical Research Council and the draft ME research strategy can be found at www.mrc.ac.uk

- 1 Department of Health. *The chief medical officer’s working group report on CFS/ME*. London: DoH, January 2002.
- 2 Action for ME. *Severely neglected: ME in the UK*. London: Action for ME, March 2001.
- 3 MacIntyre A. *ME*. London: Thorsons, 1992.

Commentary

Former nursing student **Laura Shave** has ME; she shares her views

Myalgic encephalomyelitis is an illness that cuts against the grain of how doctors are trained and challenges them to the core. If you can’t give a patient medication what can you do? Doctors choose to be doctors because they want to help people, and, if they can’t, then they despair. Despite amazing technological and medical advances, patients with ME present the same symptoms year after year, sometimes deteriorating and often not tolerating medication, which is extremely frustrating.

Doctors could learn a lot by listening to patients’ experiences. Many patients are well read, especially those who have been ill for a long time, and have ideas on what might help or what they’d like to try next. Self help measures have helped me. Using and understanding medical terms have made doctors shy away even more; one doctor suggested I have multiple sclerosis and then on a follow up visit dismissed his diagnosis as mine by saying, “Many medical students think they have that.”

Doctors get suspicious when someone has ME—media coverage is partly to blame. Every time ME is mentioned, the focus is on the controversy. ME is frustrating for doctors as it doesn’t respond to conventional treatments and nothing seems to make the patient better. Doctors are also limited to controlling the symptoms and rarely have any specialists to refer people to; it’s difficult to understand why there are not more of them in the field.

Doctors would benefit from visiting severely affected people who are confined to their house or bed to see the physical effects and focus less on psychology. Not taking a patient seriously is mentally damaging and can lead to depression. No one would make up this illness and put themselves in this position. Getting help is difficult, and, as a patient, it is hard not to take what the doctor says too personally as it can have serious consequences—for example, loss of benefits. The most important thing a doctor can do is to listen to and believe in the patient even when things sound unusual.

Diet and lifestyle changes help many patients and should be looked at. Complementary approaches often reduce symptoms and many patients with ME have chemical sensitivities, allergies, and intolerances, which when identified and eliminated improve the condition.

Although money is now going into research in the United Kingdom, the emphasis is still on psychological aspects. More research into causes, symptoms, and treatments would help and so would more specialists in the field. Reading outside of British journals, lots of interesting research is being done (for example, in the United States). I don’t think one specific cure or diagnostic test will ever be found; a multifactorial cause needs multifactorial approaches. ME shows signs of being an umbrella illness which eventually will be split into several categories like multiple sclerosis has been. In addition to viral causes, bacterial and environmental effects may also play their part.

Laura Shave

Glasgow