**Patient education for diverse populations**

All governments are, at least publicly, committed to providing good-quality health-care for all members of their population. Recently, equity in health-care provision has become a major plank of the UK Government’s health-care policy [1, 2]. Similarly in the USA, there have been recent stakeholder conferences and pronouncements from the Senate on ensuring adequate levels of health-care provision for minority groups.

Patient education is a major aspect of health-care provision. This can be provided in a number of ways, including written materials and multimedia presentations.

In the UK, most current approaches depend on literacy in English. This has the potential to exclude minority groups and disadvantaged people. If such people are unable to access services that are available they cannot then profit from them. Social exclusion co-locates with learning difficulties, other disabilities, poor education, economic disadvantage and ethnic minorities, all of which are interrelated [3, 4]. Unfortunately, many people who belong to ethnic minorities are also educationally or economically disadvantaged and are least able to access the educational materials currently available.

Throughout the 1990s there has been a growing interest in the specific health needs of ethnic minority groups. Both the National Health Service and the Health Education Authority have taken a lead in researching this area and more information is now available to support providers of health-care and to encourage voluntary organizations develop good practice. There are three million people of non-European origin in Britain with cultural, religious and linguistic traditions which contribute to their lifestyles. Many can use English as well as their own first language but there are a significant number who are not comfortable with English as their second language [5]. The Health Education Authority has recommended that organizations should develop a strategic and coherent approach to the provision of resources in different languages [4]. Black and Asian people represent the largest ethnic minority groups for whom data on languages and health are available; these include the Black African and Caribbean, the Indian, the Pakistani and the Bangladeshi communities.

Access to health services is a key issue. General practice consultations are higher among black and minority ethnic populations than for the UK, and yet there is a general perception that these population groups feel disadvantaged in terms of being able to access health-care that is equitable and comparable to that available to the white British population [3–5]. This needs to be addressed.

There are a few studies reporting on the prevalence of musculoskeletal symptoms in ethnic minority groups. The majority of studies focus on differential consultation rates and/or pain experience or beliefs. As South Asians form the largest ethnic minority group, most studies of musculoskeletal symptoms have focused on them. Hameed and Gibson [6] found that non-specific musculoskeletal pain, soft tissue conditions, knee pain and low back ache were more common in Pakistanis living in England compared with those living in Pakistan. A recent study examines the problems of musculoskeletal symptoms in a multi-ethnic community [7]. The study population was a community sample of 2117 adults from the Indian, Pakistani, Bangladeshi and African Caribbean communities. This study found that back pain and knee pain were most commonly reported and that subjects from ethnic minorities reported widespread pain more commonly than white subjects.

Communication between patients and practitioners is a fundamental aspect of patient care and yet poor communication is the most common source of patients’ complaints in the health-care sector. Good communication skills and strategies are particularly important in the diagnosis, treatment and management of chronic diseases, of which rheumatic diseases are one of the most significant. It is clear that rheumatic diseases affect both genders and all age groups, and spreads across social class and ethnic groups. It has been suggested that one of the causes of reduced tolerance to drug therapies in the South Asian population of Bradford may be poor communication during patient education, as this is not specifically designed for this population [8]. Other work indicates that miscommunication often occurs because of cultural differences between the communicator and recipient. Problems of miscommunication and language may not only influence treatment but may also contribute to the reinforcement of stereotyping behaviour [9]. Miscommunication can arise from differences in the meaning of words or phrases; for example, in metaphorical expression of health problems. Stereotyping and the inadequate provision of bilingual support can undermine the quality of communication and care. Even the use of interpreters is potentially problematic as an understanding of culture, language and individuals poses a huge challenge in interpreter-mediated health-care encounters.

Recently the Arthritis Research Campaign (ARC) of the UK set up a multidisciplinary group involving the various stakeholders to discuss these and related issues and suggest recommendations.

Amongst the group’s conclusions was the view that literacy is a major problem for a significant number of patients. Consequently, it suggested that all patient education literature, regardless of target audience, should be as reader-friendly as possible. In particular, the group commended the widely used Suitability Assessment of Material system [10] whose criteria include readability, amount and organization of content, writing style, graphics, layout and typography, evidence of learning stimulation and cultural appropriateness. The ARC-supported group concluded that attendance to these details would benefit all readers from all population groups, as literacy problems are not limited to any one ethnic population.

The group felt that an additional type of written material of potential use was pictorial representations, similar to the mind maps often used to support people with dyslexia. Such picture representation has the advantage of greatly reducing the amount of reading material, although it was recognized that even pictorial representation needs to be culturally sensitive. Consequently, the ARC supported group felt that other modes of transmitting information apart from reading material are needed. In particular, the use of bilingual audio cassettes or compact discs was recommended. It was noted, however, that it is still unclear as to how much access target groups have to computers and the Internet.

These steps by the Arthritis Research Campaign are laudable but they still need to be evaluated. Areas identified for further exploration include the training needs of link workers and interpreters. Resource centres such as the Birmingham Arthritis
Resource Centre (also ARC-supported) are welcome, but still need to demonstrate their effectiveness.

The provision of literature alone is held by some to be insufficient [11]. Arthritis Care and more recently the British Government, through its Expert Patient Programme [12], have demonstrated their commitment to the principles of self-efficacy for patients with chronic health conditions by providing lay-led self-management training courses throughout England and Wales. These have received positive feedback from many of those attending, but inherent problems remain for minority groups. For although the Expert Patient document [12] reiterates the necessity for self-management programmes to reach those for whom literacy, culture, ethnicity or language might present barriers to accessing services, the course content was developed for the majority white culture. Furthermore, the development of self-efficacy is dependent upon reinforcement through reading materials both during and between sessions.

Self-efficacy is only one aspect of patient empowerment. Another issue alluded to above is that of cultural attitudes. South Asian cultures for example, often place more value on a listening relationship with a person who understands them than on written forms of communication. Different cultures have different attitudes to pain, illness and drugs as well as to their relationship with medical professionals. In a traditional English culture, health education is often seen as giving the hard medical facts and supporting independent lifestyles. However, in South Asian cultures health is not always seen as scientifically defined but is related to positive social relationships, spiritual qualities and personal worth. For example, disability may not be a problem if it does not affect a person’s ability to become a parent and if the family and community are well informed and accepting. Information about the illness is perhaps less important than what the behaviours and outcome of the illness might be.

Clearly, in order to address these issues it is important to work with a target community in developing the most effective health promotion strategy and materials. This may involve a bilingual health professional liaising with community groups that develop positive relationships and trust, to assess health information needs and to produce and trial educational materials. For example, the Expert Patient website reports a study in the East End of London in which focus groups identified barriers to the management of chronic health conditions by local Bangladeshis [13]. Researchers were able to respond by implementing and evaluating a cross-culturally adapted version of the Stanford Chronic Disease Self-Management Course, led by Bangladeshi course tutors, and targeting 300 Bengalis with a range of chronic conditions, including arthritis. This is an example of how a mixed methods approach can be instrumental in identifying and responding to the particular difficulties of minority groups.

Alongside quantitative and epidemiological studies, more qualitative work with our patients and with minority groups is required in order to understand their needs, experiences and preferences within health-care. Then and only then can we fully understand what sort of educational or other materials might be of value. We can then design such materials with the user groups and evaluate them in collaborative research involving patients.

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