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Research papers

Rheumatoid arthritis in minority ethnic groups: patterns of disease, clinical and sociocultural features among British South Asians

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ABSTRACT

Rheumatoid arthritis (RA) is a chronic inflammatory condition that may lead to long-term disability. An understanding of the disease by health professionals in conjunction with early intervention improves clinical outcomes. Attention to ethnic variation adds an important dimension to this understanding.

International research has demonstrated considerable variability in prevalence and clinical features of RA amongst different ethnic groups. The 2001 census reveals that over 12% of the British population are classified as ethnic minorities, of which South Asians form a large group. In some areas, they form a very significant fraction of the population. In major metropolitan urban agglomerations they may form nearly a majority of the population in selected areas, as is also the case in some major provincial cities such as Leicester (where 25.7% population was said to be of South Asian Indian origin in the 2001 census). Genomic and pharmacological research in other clinical areas has revealed interesting differences between ethnic groups in the natural history of disease and the efficacy of drugs. An understanding of disease patterns in diverse ethnic groups, as well as sociocultural aspects that might impact upon health, is essential for the adequate provision of local healthcare.

Published medical literature about RA pays scant attention to South Asians or other minority ethnic groups in Britain. Much of the current literature on RA in South Asians is either limited or inconsistent. The prevalence of the disease appears to be nearly as high as in the white population with similar clinical features, but we found no good studies regarding clinical outcomes. There appears to be a higher usage of complementary and alternative medication, and sociocultural perceptions of a chronic disease such as RA may limit the use or acceptance of traditional pathways that access healthcare. These factors are of fundamental importance for healthcare providers in a multicultural society such as Britain, in order to ensure an equitable service for patients with RA in the South Asian ethnic minority group.

There is a need for well-designed studies to establish how best the healthcare needs of South Asians with RA may be met. Such studies would need to include not only the more traditional clinically based approach of data collection, but would also need to incorporate psychosocial research in order to be able to understand and provide for ethnic-specific healthcare requirements. Healthcare providers in Britain must acknowledge the multiracial character of the population that they serve, and should be prepared to address the needs of these populations proactively.

Keywords: disease patterns, rheumatoid arthritis, South Asians, systematic review

Introduction

Two of the authors (AS, JS), who are in clinical practice in the City of Leicester, have been struck by their informal clinical observations, which suggest distinctive features associated with rheumatoid arthritis (RA) in South Asians (Samanta and Roy, 1988; Samanta *et al*, 1991, 1992). The present paper presents a critical systematic review of the literature to determine whether there are differences in the prevalence, clinical features and clinical outcomes of South Asian patients with RA. This inclusive review adopts a biopsychosocial approach to disease and incorporates pathways to healthcare, the use of complementary and alternative medicine, and sociocultural aspects relevant to South Asian patients with RA.

The search strategy used for the review followed the pattern developed by the Economic and Social Research Council (ESRC)-funded UK Centre for Evidence in Ethnicity Health and Diversity at De Montfort University Leicester, and Warwick University (Szczepura *et al*, 2004). This mixes traditional techniques and criteria for inclusion in systematic reviews derived from York Centre for Reviews and Dissemination (CRD) and Cochrane approaches with handsearching of 'grey literature' from official reports and community-based research, and the imposition of quality criteria relating to the description of minority ethnic groups, to avoid drawing misleading conclusions from studies using poorly defined categories of ethnicity (see Appendix Table 1). Reports relating to minority groups not represented in significant numbers in the UK population were excluded from the final study, as were papers which did not relate to rheumatoid arthritis but were primarily focused on other 'rheumatic' or 'arthritic' conditions. We have also excluded a very large number of papers from North America which have focused on the differences between groups of Native Americans (formerly referred to as American Indians), since their findings did not appear to be transferable to European or UK practice (see Appendix for search strategy and criteria).

England is now recognised to be a multiethnic, 'multiracial' society, with nearly one in ten of the population giving their ethnic origin as one of the 'black and minority ethnic groups' recorded in the 2001 decennial census of population (www.statistics.gov.uk/census2001/profiles/commentaries/ethnicity.asp). Following the report of the Stephen Lawrence enquiry (Macpherson, 1999) and the passing of the Race Relations (Amendment) Act 2000 (and other European legislation also bearing on human rights and equalities or discrimination), increasing attention has been focused on the health and social care needs of these groups. Research has consistently described inequalities in health (Johnson, 2003), in terms of both outcomes and access to care; and it is also established that for certain conditions and diseases there are distinctive patterns of prevalence, treatment needs, and prognosis (Gill *et al*, 2002).

Rheumatic diseases are extremely common conditions and may affect one in ten of the population, thereby representing a high demand for healthcare (Gamez-Nava *et al*, 1998; Brooks and Hochberg, 2001). A study from Manchester (Allison *et al*, 2002) showed a raised prevalence of reported musculoskeletal pain in people over the age of 45 years in ethnic minority groups, as well as a higher level of reported disability relative to what might be expected on the basis of demographic patterns derived from the 1991 and 2001 censuses. There are very limited data on musculoskeletal problems among UK minority groups, but some suggestion that early industrial employment of migrant populations may have led to adverse patterns (Szczepura *et al*, 2004). These findings were not linked to either treatment or outcomes.

However, it is recognised that musculoskeletal pain is more generalised among people from ethnic minorities (Emery *et al*, 2002). Any inferences drawn from this would, however, need to be interpreted with caution. There is a need to look more closely at the relationship between symptoms and objective measures of morbidity relating to musculoskeletal symptoms within ethnic minority communities. It is recognised that whilst there is higher usage of NHS services by ethnic minority groups, this can be closely related to sociological inequalities such as housing, employment and income (Johnson *et al*, 1983). We would also urge some caution over making such generalisations in a city such as Leicester, where the former largely refugee ex-East African and South Asian population has become relatively affluent, although it may still demonstrate such 'learned' patterns of use. Other differences related to ethnic or 'racial' variation, including appropriateness of service provision, quality of care, and support for service users (such as provision of interpreter support, training in cultural sensitivity and diversity awareness), may still remain. It is, however, as yet unclear as to whether such disadvantages lead to poorer outcomes in RA in South Asians.

Within the broad spectrum of rheumatic disorders, RA is common and may account for an annual consultation rate of nearly 6 per 1000 patients in general practice (Stevens and Raftery, 1994). It has proved very difficult to obtain any estimates of rates among UK minority populations, but a study from Manchester (MacGregor *et al*, 1994) reported lower rates of RA in an African-Caribbean population, and a study from Norfolk (Symmonds *et al*, 2002) suggests that the level of RA appears to be falling in the UK. However, the Manchester study did not survey a South Asian population and the Norfolk study used data based primarily in a rural area with no specific reference to ethnic

diversity. It is difficult therefore to assess with any reliability the health needs of South Asians with RA due to their inadequate representation in such studies. This would appear to be a wider problem in many other conditions, as a recent analysis of trials data also indicates that people of South Asian origin may not be adequately represented within clinical trials, thus introducing a substantial bias in terms of extrapolating the findings and results to ethnic minority groups (Mason *et al*, 2003). There are good clinical reasons to pay specific attention to the ethnic profile of the population in medical studies, and the lack of such data may result in an ineffective health policy for ethnic minority groups (Johnson and Szczepura, 2003).

Leicester is one of the most ethnically diverse cities in the UK. Only 63.9% of the total population in Leicester gave their ethnic group as white British, compared to 87.5% of the national population, according to the 2001 census. Over a quarter (25.7%) of the population in Leicester is of South Asian origin, which is the highest proportion of any urban area in Britain. It is not surprising therefore that much health research has been conducted in the South Asian population, as this has considerable significance for health service provision locally (Samanta *et al*, 1986, 1987; Samanta and Burden, 1989; Rashid and Jagger, 1992; Johnson and Scase, 2000; Conroy and Mayberry, 2001). There is a large proportion of referrals from primary to secondary care rheumatology services in Leicester, and approximately one-quarter of such referrals are for joint or muscle disease (Samanta and Roy, 1988). The overall prevalence of some rheumatic diseases is noted to be higher in South Asians (Samanta *et al*, 1992). Systemic lupus erythematosus, for example, was noted to be three times more common in South Asians compared to white individuals (Samanta *et al*, 1992). Furthermore, patients of South Asian origin with lupus had higher systemic disease and mortality (Samanta *et al*, 1991). These findings may have a high clinical relevance for other rheumatic conditions as well.

Prevalence

Studies conducted over the last several decades confirm that RA is a disease found throughout the world. Abdel-Nasser and colleagues (1997) have attempted to review the world literature relating to RA, and conclude that the evidence suggests that RA has existed in the Americas ('New World') since prehistoric times, but that it is a 20th-century phenomenon in Africa and a post-17th century one in Europe – the temporal origins in Asia are not stated, but rates there and in Africa are found to be lower than in the European setting (1% prevalence, 0.03% incidence). Other differences including sex-linked variations in prevalence and expression are also frequently reported, although Abdel-Nasser and colleagues are critical of the confounding effects of poor methodology in many comparative studies. That said, they also suggest that 'age of onset' does seem to vary between populations.

There are national variations in the prevalence of RA which do not seem to be fully explained by genetic patterns of human leucocyte-associated antigen (HLA) (DR4) as summarised by Mijiyawa (1995). While there is clearly some genetic link, there is no uniform link to HLA (DR4) in 'Asian' (Chinese and Indian) populations. A survey of 44 551 adults living in a rural area in India and applying the revised American Rheumatism Association (ARA) criteria suggested a prevalence rate of 0.75 (Chandrasekaran *et al*, 1995). This was similar to prevalence rates in Europe and North America but significantly lower than those in China, Indonesia or the Philippines, where rates of <0.4% were ascertained (Lau *et al*, 1996). Prevalence rates are also higher in Jamaica and Latin America, but some studies suggest that the disease may be less severe in these areas (Mijiyawa, 1995).

Recent data from Nahaqi Hospital, Pakistan, suggests a self-reported rate of arthritis as being 3.7% (Dr Mukhtiar, personal communication). This may be higher than the rate reported by clinical examination, and is closer to the relatively high rate of 1.5% found by Farooqi and Gibson (1998) among a similar northern Pakistani population, compared to the very low rates suggested by other authors (Malaviya *et al*, 1993; Lau *et al*, 1996).

Data on the Pakistani population living in England indicate that the prevalence of RA is higher (possibly double) than in a similar population in Pakistan, but has not reached the observed prevalence among the ethnic English population (Hameed and Gibson, 1997). The differences are attributed to a higher level of RA in Pakistani families in England. Part of this difference may be attributed to better reporting amongst Pakistanis in the UK, although lifestyle changes and environmental factors may also be implicated – as too would differential mortality from other intervening causes among Pakistanis in Pakistan. Their earlier work in Pakistan (Hameed *et al*, 1995), for example, showed differences in lifestyle and prevalence of specific complaints such as knee pain (as opposed to RA) between affluent and poor populations, some of which may be associated with obesity among the more affluent in either country. Because of variation in definitions and sample bases, it is however not possible to present reliable comparative estimates of prevalence across populations.

Clinical features

Consideration of the world literature, when ethnic or 'racial' differences have been discussed, suggests that there are important differences in the expression and presentation of the disease between ethnic groups, although the significance of this is not always clear (Jordan, 1999). It is, however, important to examine this question since it may affect initial diagnosis and management and, among the lay population at risk, may affect self-referral and pathways to care. There is also considerable evidence pointing to the role of referring physicians, and differences between primary care gateway doctors, in the recognition of disease, 'ascertainment bias' and the pathways followed by patients (Graham and Glass, 1997; Gamez-Nava *et al*, 1998), although this does not (yet) seem to show differences between ethnic, as opposed to national, groups.

Chandrasekaran and Radhakrishna (1995) suggest that the disease appears to be less severe in Indian populations, but this may reflect higher mortality in 'less developed' settings. At the same time, it is suggested that in genetic terms, the South Asian (Indian/Pakistani/Bangladeshi) population is closer to the white ('Caucasian') group than to Africans, Chinese and Filipinos (Malaviya *et al*, 1993) and might be expected to resemble that population more closely when living in a Western lifestyle and setting.

An American comparison between white and non-white (African–American black) young people presenting with juvenile arthritis suggests that African–Americans are more likely to present with poly-arthritis (i.e. arthritis in many places), while there are fewer joints involved among the white patients (Graham and Glass, 1997; Schwartz *et al*, 1997). The majority of USA research has focused on describing striking variations between 'native American' or 'American Indian' groups (Mauldin *et al*, 2004; Ferucci *et al*, 2005), but these are ethnic groups far removed from the 'Asian' groups found in Europe. A study from Canada found differences between those of Canadian Aboriginal origin and three white European groups (Jacono *et al*, 1996). All three European groups had a later onset of disease compared to the Canadian Aboriginal patient population. Serological parameters were frequently different, and Europeans were much less likely to show a higher rate of family history of the disease.

There are few well-conducted clinical studies to identify clinical patterns of disease amongst South Asians of Indian origin. One study suggests that the general clinical course of the disease is similar to that in Western populations. However, compared with whites, the disease amongst Indian patients is said to be mainly articular and mild with systemic manifestations being rare. The incidence of subcutaneous nodules and rheumatoid factor is also lower (Chopra *et al*, 1988). Griffiths and coworkers (Griffiths *et al*, 2000) compared 107 South Asian patients with RA to 107 similar white patients. South Asian patients had significantly fewer bony erosions, but had similar levels of inflammation and more pain and disability. An increased level of disability was also recognised in the Manchester study (Allison *et al*, 2002). Higher levels of pain were reported by the majority of older South Asian and African–Caribbean people, although the study was not confined only to RA.

Our own observations (unpublished) on auditing a series of 100 consecutive South Asian and white patients attending secondary care rheumatology services at Leicester, and reviewed retrospectively, indicate that South Asian patients tend to have mainly oligo-articular (few sites) or poly-articular large joint disease rather than the more traditional distal symmetrical peripheral arthritis. Our clinical impression is that South Asian patients also tended to present at a later stage of their disease, with clinically more apparent joint deformities and lower inflammatory markers, with a low, or absent, rheumatoid factor. Subcutaneous nodules were also rare and the overall clinical features of active inflammation around the joints were less. While our observations are in many respects similar to those described by Griffiths *et al* (2000), the principal difference would appear to be in the degree of joint damage. That study and one by Chopra *et al* (1988) both describe relatively mild articular involvement. Our observations suggest that joint disease is more severe in South Asian patients with RA, which appears to be in contrast to previously reported findings by different authors. It has been postulated that one possible reason for the observed high bone and joint destruction might be an increased frequency of polymorphism of the vitamin D receptor gene, which has been described as having a significant influence in bone turnover. The higher expression of this gene in South Asian patients studied in Leicester may have a pathogenic role in joint destruction (Ghelani *et al*, 2003). A higher degree of depression has also been noted in people of South Asian origin with RA from Leicester (Neville and Hassan, 2003a).

Pathways

There is some evidence in the general research literature relating to ethnicity and healthcare that minority ethnic groups, and Asian patients in particular, may follow distinctive routes to access treatment, at least in relation to other disease conditions. There is no concern that minority ethnic groups in the UK are not registered with general practitioners (GPs), or that they are unfamiliar with the service; however, a high rate of consultation does not always

lead to resolution of healthcare needs, or earlier referral for investigation and specialist treatment (Johnson *et al*, 1983; Gillam *et al*, 1989). Early studies such as that of Clarke and Clayton (considering maternity care) (Clark and Clayton 1983; Clark *et al*, 1988) showed that late presentation leading to poorer access to treatment, and hence more adverse outcomes, was sometimes associated with the quality of general practice care received, although other studies have suggested that late presentation and self-referral may have similar effects. Even when South Asian patients are more likely to visit the GP, there remain discrepancies and delays in access to hospital care, in some cases for no apparent reason (Chaturvedi *et al*, 1997).

There is a similar literature relating to outcomes in rheumatic disorders, with findings by Gran and Nordvag (2000) that there is considerable variation between practitioners in the quality of their referrals and their propensity to refer to specialist care. A high threshold for referral, combined with long waiting lists among specialists 'may delay correct diagnosis and the initiation of appropriate therapy' (Gran and Nordvag, 2000). It appears from these papers that better awareness of the clinical picture and natural history of the disease might assist in bringing about improvements in treatment and outcome. If ethnic minority patients tend to present with fewer typical clinical pictures, greater awareness of this fact, and of their needs, will also be required. On the other hand, it may be important to avoid jumping to conclusions if symptoms mimic those of diseases such as tuberculosis (TB), said to be more common in Asian populations (Chandrasekaran and Radhakrishna, 1995). Similarly, it may be that members of the minority communities may require education in the recognition of significant diagnostic signs, to assist self-referral at an appropriate time. Lay diagnosis and the 'lay referral' system play a key role in ensuring that help is sought when needed (Shaukat *et al*, 1997).

There are no UK studies on healthcare service delivery to South Asian patients with RA. However, certain factors may be elicited from the general research relating to the access of these groups to healthcare (Rashid and Jagger, 1992; Johnson, 2003). Specific barriers to healthcare for South Asian groups may include waiting times and obtaining referrals to secondary care. There is a reluctance among South Asian patients to use telephone consultation or helplines, and most prefer visits at home or personal intervention by their GPs (Chanchal *et al*, 1985). As Irvine *et al* (1999) have shown, earlier referrals lead to better outcomes in RA, and this applies irrespective of ethnicity. Early institution of disease-modifying drugs leads to better long-term outcomes (Irvine *et al*, 1999). Facilitating access of South Asian patients with RA to secondary care for such treatment is of high clinical importance.

Treatment

A number of disease-modifying agents have been used to treat RA. According to Chandrasekaran and Radhakrishna (1995), most disease-modifying anti-rheumatic (DMARD) drugs used in the 'West' are also available and used in the subcontinent, and there is little evidence of ethnic difference in effectiveness. There are also limited studies on non-traditional DMARDs such as ayurvedic drugs. To our knowledge, as far as conventional medicine is concerned, the same agents are used in South Asian patients, both in India (personal communications) and in patients of South Asian origin in the UK. A number of studies have shown that examination of racial and ethnic differences may influence outcome from arthritis (Jordan, 1999). These studies have suggested that a more detailed examination of social and cultural environments of subgroups may mediate or interact with ethnicity and outcome.

One of relatively few papers identified that discusses differences in side-effects or responses to treatment was that by Jacono *et al* (1996), which noted that white European, and particularly Italian-origin, patients were more likely to show cutaneous reactions to the administration of gold salts, compared to Canadian Aboriginal groups (there were no South Asian or black members of their sample). Many drugs used in the treatment of RA have adverse effects and may (for example) increase the risk of malignancies (Hawker, 1997) but we found no evidence of differences between minority ethnic groups present in Europe having been examined.

Clinical outcomes

A poor outcome might be related to early joint destruction, seropositive disease and early systemic involvement (Hawker, 1997). There are few studies to suggest that South Asians with RA have a poorer outcome compared to the indigenous white (so-called 'Caucasian') population, but this may be an effect of the lack of studies examining this possibility.

Jordan's study (1999) (largely based on American sources) makes it clear that there is a need to document differences in disability and other outcomes between specific ethnic groups, in order both to improve care and to better understand the nature of rheumatoid diseases. Some of the differences observed, however, may be due to characteristics of the rating scales in use (Arthritis Impact Measurement Scale, Health Assessment Questionnaire, etc.), since she reports that in at least one study, 'limited educational ability was associated

with (reported) difficulty in walking'. The expression (and possibly, salience) of pain differs between cultural groups, and lifestyles and occupational profiles may also vary between ethnic groups, making cross-cultural comparisons difficult. In one parallel paper, Jordan and colleagues (1998) note that while there were no 'ethnic effects' in pain level or affect between their two samples, African-Americans (48) were more likely to rely on 'diversion' or prayer, and were less physically active, while white 'Caucasians' (52) 'ignored' pain: they recommend that clinicians take differences in coping strategy into account.

Complementary or alternative therapies (CAM)

A further factor that needs to be considered is the usage of complementary or alternative therapies (CAM). Rheumatologists tend to follow a traditional medical view and discount popular lay notions of climate and diet as a cause of RA (Grelsamer and Leech, 1996). Complementary or alternative medicine tends to present a different perspective for patients. Widely considered to be natural and holistic, these therapies seek to connect illness and disease to people's, diet, bodily constitution and environment. As RA is a chronic disease, patients may turn to CAM as an alternative to conventional treatment regimes that offer limited efficacy and are frequently toxic. One study suggests that between 60% and 90% of RA patients are likely to use CAM at some stage of their illness (Grenfell *et al*, 1998). However, in westernised societies their use tends to be as an adjunct to conventional care, rather than as replacement therapy. Types of CAM used by persons with RA include herbal medicine, acupuncture, homeopathy, the behavioural or cognitive therapies, photopheresis and apheresis.

In India and South Asia, persons suffering from arthritis seek treatment from a range of healthcare specialists including physicians trained in conventional medicine, traditional healers, homeopaths and faith healers (Helman, 2000). However, in India the traditional medical disciplines of Ayurveda/Unani often represent first-line care and may be accessed in preference to conventional therapy. (The traditional medicine practices of Ayurveda and Unani represent significant components of the South Asian healthcare system. The term Ayurveda describes the traditional Hindu Sanskritic system, whereas Unani represents the Graeco-Arabic and now largely Muslim healing tradition.)

Both of these tend to favour a humoral interpretation of arthritis and joint disease, and link the pathogenesis of arthritis to the gut (Zysk, 1991). According to Ayurvedic teachings the rheumatic diseases are categorised as types of 'wind disease', and more particularly with arthritis being classified as 'wind in the joints' (Pugh, 2003). The rheumatic disorders are collectively considered to be 'cold' disorders, although with RA, 'hot' humors or *dosha* are also involved which combine with 'wind' to produce the characteristic inflamed and painful joints. Unani and Ayurvedic practitioners regard wind as a natural and essential component of bodily health. It is thought to be pathogenic when it becomes disturbed or excesses settle in the various joints or organs. Food is also viewed as a major contributor to rheumatic disease; for example, cold, windy foods such as rice and lentils are seen as a primary cause of arthritis. Practitioners of Unani and Ayurveda (Hakims and Vaids) will typically recommend dietary adjustments and topical or oral medications. Dietary regimes will typically exclude foods thought to be causative of symptoms. Massage with medicated oils to warm the affected joints and disperse trapped wind to relieve tension is often advised. Oral medications include plants with anti-inflammatory properties, hot spices, digestives, carminatives and laxatives.

We found little published work in respect of the uptake of CAM for arthritis and rheumatoid diseases by South Asians living in the UK, although there are a considerable number of publications suggesting the importance of CAM therapies among these populations in general. Preliminary work suggests that South Asians use and claim more benefit from herbal treatments, glucosamine and acupuncture (Neville and Hassan, 2003b). South Asians were less satisfied with conventional therapy compared to the indigenous white population.

Social and cultural aspects

We were unable to find reliable studies of perceptions by patients with RA amongst ethnic minority groups in the UK. However, certain culture-specific issues may have relevance in South Asians, such as the manner in which the disease is explained, the social stigma associated with RA, sex relations and the possible effects upon an arranged marriage, living within the extended family context and diet and religious observance. Clearly, stigma, sex relations, family patterns and similar cultural issues are experienced (possibly but not invariably differently) in all populations. Here, however, we are concerned primarily with the ways in which those may be expressed or experienced within societies organised around South Asian cultural heritages.

We found very little research even in the social science literature relating to the disease or its implications for minority ethnic groups, despite the current

focus in many social care fields on the 'social model' of disease (Oliver, 1996) and similar ways of viewing impairment and activity-limiting disease. There were some indications in the clinical papers reviewed that there may be different implications for lifestyle, and that obesity (or enhanced nutritional status) may be significant in affecting the reported prevalence and impact of the disease, especially in the subcontinental setting and most notably in Pakistan (Farooqi and Gibson, 1998; Hameed *et al*, 1995). Nevertheless, Farooqi and Gibson suggest that their earlier study in Pakistan did not support the idea that squatting and knee flexion at prayer made a significant difference, compared to the impact of obesity on knee pain (Gibson *et al*, 1996).

Hussain *et al* (2002) present the voices of a number of young people with disabilities, including (presumptive juvenile) arthritis. The disease is not highlighted in their report, but the interesting point is made that ethnocultural differences in disability may occur, since at least one informant complained that their impairment affected their ability to perform their regular religious (prayer) duties in the manner they wished. Clearly, joint problems due to arthritis would be one such handicap.

Conclusion

RA is a chronic inflammatory condition that mainly affects the joints, and can lead to long-term disability. Whilst there is an extensive published medical literature regarding RA in white populations, there is relatively little published data pertaining to RA in ethnic minority groups in the UK. In view of the large, growing, and increasingly elderly ethnic minority population in Britain, of which a very high proportion is of South Asian origin, understanding of the clinical features and patterns of RA in this group, as well as sensitivity to its specific sociocultural needs, is essential if their health needs are to be adequately met.

Data on the prevalence of RA among South Asians are limited. There is some evidence that the prevalence of RA in the Pakistani population living in England is higher than in a similar population in Pakistan, although not as high as in the indigenous white population (Hameed and Gibson, 1997). Symmons *et al* (2002) suggest that the prevalence of RA in the UK is falling. However, this does not specifically address any issues of prevalence in South Asians. Likewise, there are limited data on the clinical features of RA. Griffiths *et al* (2000) suggest that South Asian patients have fewer bony erosions but express more pain and disability. Our own clinical experience (see Samanta and Roy, 1988; Samanta *et al*, 1991, 1992 and unpublished) would suggest that South Asians may have a greater degree of joint destruction while showing less inflammation in the way of a rise in the traditional inflammatory markers. We have found no good studies that provided an indication of long-term clinical outcomes or actual disability in South Asians with RA.

There is anecdotal evidence in the literature of a higher use of complementary and alternative medicine amongst South Asians. There is no definite indication that South Asians use clear pathways to access healthcare, and there is some evidence that sociocultural aspects may lead to a degree of reluctance among South Asians to accept their disease, or even access healthcare. If this is true, then this could lead to long-term disability and adverse outcomes in this group, as it is now well recognised that early intervention in RA improves clinical outcomes and prognosis.

Given the significance of this disease in both clinical workloads and quality of life, and the need to meet the needs of minority ethnic groups, reinforced by the requirements of the Race Relations Amendment Act and the NHS Chief Executive's challenge to all trusts (Crisp, 2004), there is an urgent need to improve the evidence base for practice in rheumatology. This will require attention to the prevalence, expression, pathways to care, attitudes and beliefs of minority ethnic groups, and the impact of RA on their specific lifestyles. This should lead on to discussions between clinicians and the community on how best to meet their needs, and a programme of education and training for all stakeholders. This paper has been presented as a first step in that process.

We have identified some key actions that are required to address the needs of people of South Asian descent with RA. Firstly, it is clear that there needs to be a significant increase in the degree to which research recognises the multicultural diversity of the population. This may mean specific studies of minority (South Asian and other) communities or it may mean that 'booster samples' of people from these communities should be sought in studies about RA and clinical trials, rather than their being excluded from the analysis. Secondly, there is a need to raise awareness and knowledge about the rheumatic diseases in minority populations, to increase the likelihood of people recognising the symptoms and seeking treatment (and being aware that there is help available) at an early stage in the progression of the disease. Thirdly, it is essential that practitioners, both referral agents (such as GPs) and specialists, should be more familiar with the patterns, presentation, prognosis and social factors (such as stigma, 'fatalism', or impact on prayer) associated with the disease in their minority patients, to ensure that cases are not missed or misadvised. It is also desirable that standard measures such as 'quality of life' score systems should be assessed for their cross-cultural validity. In the process of our review it became obvious that many such scoring systems (such as the Western Ontario and McMaster Index (WOMAC)

and Childhood Health Assessment Questionnaire) have been translated into most European languages, Arabic and Chinese, but very rarely into South Asian languages. It may also be necessary for explicit, targeted outreach activities to take these messages to the communities at risk (in which we would include the community of practice).

Postscript

We have, since the start of this review, become aware of a number of initiatives which may provide ways forward, or possible answers to some of the issues arising from this review. In particular, the Birmingham Arthritis Resource Centre has been set up in the main city library (Adab *et al*, 2004) to offer information, including leaflets and audio-cassettes, to members of the public. Reaching people from minority ethnic groups has been seen as a priority, and information on RA and osteoarthritis has been made available in Gujurati, Punjabi, Urdu, Bengali, Cantonese and Arabic, although these are not yet available over the internet (http://webrheum.bham.ac.uk/barc/central. htm). Similarly, and also supported by the Arthritis Research Campaign, leaflets about osteomalacia have been translated into five South Asian languages, and also made available in spoken form on CD-ROM (www.arc.org.uk/orders/langres.asp). An evaluation of this latter initiative is in progress. There have also been developments in the education of medical practitioners regarding 'ethnic diversity', and the Department of Health has released new guidance on ethnic monitoring which should lead to improved research and audit data (http://www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights/fs/en). None of these facts affect our fundamental conclusions and recommendations.

Note: The Minimum Dataset Grid and bibliography for the systematic review which underpinned this study is available on the website of the Mary Seacole Research Centre, De Montfort University (www.dmu.ac.uk/msrc) and the website of the UK Centre for Evidence in Ethnicity Health and Diversity (www.ethnic-health.org.uk).

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CONFLICTS OF INTEREST

The authors are part of a team evaluating the Arthritis Research Campaign materials on osteomalacia. This paper was written before that initiative was released for public use.

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Appendix

Table 1 Ethnic rheumatoid arthritis – review search strategy

Ovid MEDLINE(R) in-process, other non-indexed citations, Ovid MEDLINE(R)

#	Search history	Results
1	ethnic$.mp. [mp = ti, ot, ab, nm, hw]	51 903
2	minorit$.mp. [mp = ti, ot, ab, nm, hw]	23 080
3	(multicultural or multi-cultural).mp. [mp = ti, ot, ab, nm, hw]	974
4	(crosscultural or cross-cultural).mp. [mp = ti, ot, ab, nm, hw]	14 313
5	(transcultural or trans-cultural).mp. [mp = ti, ot, ab, nm, hw]	2847
6	(multiethnic or multi-ethnic).mp. [mp = ti, ot, ab, nm, hw]	1120
7	(multiracial or multi-racial).mp. [mp = ti, ot, ab, nm, hw]	277
8	(migrant$ or immigrant$).mp. [mp = ti, ot, ab, nm, hw]	14 525
9	refugee$.mp. [mp = ti, ot, ab, nm, hw]	4856
10	cultural diversity.mp. [mp = ti, ot, ab, nm, hw]	5169
11	(multilingual or multi-lingual).mp. [mp = ti, ot, ab, nm, hw]	269
12	(roman$ or gyps$).mp. [mp = ti, ot, ab, nm, hw]	12 210
13	asylum seeker$.mp. [mp = ti, ot, ab, nm, hw]	289
14	(arab$ or somali$ or yemini$ or vietnamese or chinese or caribbean or pakistani$ or indian$ or bangladeshi$).mp. [mp = ti, ot, ab, nm, hw]	144 369
15	(Islam or Hindu$ or Sikh$ or buddhism).mp. [mp = ti, ot, ab, nm, hw]	3120
16	mixed race.mp.	189
17	or/1–16	251 104
18	exp Arthritis, Rheumatoid/	71 778
19	Rheumatoid arthritis.mp. [mp = ti, ot, ab, nm, hw]	45 807
20	(Rheumatology or rheumatism or rheumatics).mp. [mp = ti, ot, ab, nm, hw]	10 679
21	(RA and rheumatism).mp. [mp = ti, ot, ab, nm, hw]	256
22	or/18–21	87 966
23	17 and 22	1333

Note additional material was identified by handsearching and following up references as well as using the Mary Seacole Research Centre (MSRC) in-house collection of research materials relevant to minority ethnic group health: all materials were subjected to the inclusion and exclusion and quality criteria adopted for the review (see Table 4).

Many items were excluded from the search results because of their lack of applicability to UK populations and settings or because they did not refer to RA, the condition of prime interest to this review. We also excluded papers which focused on laboratory studies of HLA allele frequencies. No useful papers were found after the first 1000 (dated from 1991), mostly because of a lack of abstracts in earlier papers.

Table 2 Methodology algorithm for systematic review

Reference ID	Type of rheumatic disorder and body part	Type of study*	Country of study	Issue		Population(s) studied						Quality rating***	Study design and status (CRD)****	Key findings
				Focus**	Intervention – drug/other	Age range (years)	Sex	Ethnic group(s)	Other ethnic data: language/ religion	Size of sample	Comment			
Example	RA – knee	Control trial	UK/NL	Treat-ment	Physio	50+	M/F	White/ non-white	NESB*****	230	Mixed methods	C	3b but weak ethnic split	

* e.g. Randomised controlled trial (RCT)/control trial/descriptive/epidemiology/case study/good practice/other ...
** Focus (as in the paper: Prevalence/treatment/ pathways/outcomes
*** Rating of study quality (see Table 3) (Alpha to Epsilon)
**** CRD: Assessment of robustness of study, if good description of design given (else 0) (see numbers in Table 4)
***** NESB: non-English-speaking background

Table 3 Ratings of study quality

Quality	Criteria	Comment	Label
Alpha	RCT or high-quality structured research base with well-described, detailed ethnic or religious categories	'Gold standard'	A
Beta	Comparative studies with authoritative findings or recommendations based on sound references and accurate, detailed categories	Often descriptive 'best practice'	B
Gamma	Descriptive but evidence-based studies, may be less detailed in categorisation of groups	Potential sources of good practice	C
Delta	Descriptive or demotic advice and argument, weak research design, loose use of ethno-religious descriptors	Seldom add to the overall sum of knowledge	D
Epsilon	Potentially misleading descriptions or research combining groups of dissimilar characteristics without justification	Worst practice	E

This compares with the normal (York CRD) status rating (which was used for the other quality column) as shown in Table 4.

Table 4 Hierarchies of study design and evidence quality

CRD	CRD description	UK-CEEHD review grade	Comment
1	Experimental studies, e.g. RCT	Alpha (A)	Few in number; have to meet other quality criteria
2	Quasi-experimental study	Alpha (A)	Few in number; have to meet other quality criteria
3a	Controlled design: cohort studies	Alpha/beta (A/B)	Ranking depends on strength and design quality
3b	Controlled design: case–control studies	Alpha/beta (A/B)	Ranking depends on strength and design quality
4	Observational studies (no controls)	Gamma (C)	Ranking depends on strength and design quality
5	Expert opinion based on research or consensus	Delta (D)	May be upgraded if philosophically well founded
–		Delta (D)	Seldom adds to overall knowledge
–		Epsilon (E)	Needs to be exposed or noted if contributes to bad practice

UK Centre for Evidence in Ethnicity, Health and Diversity (UK-CEEHD) review grading was developed at the ESRC Centre for Evidence in Ethnicity Health and Diversity
Critical difference is the degree of qualitative information, e.g. on process, ethnicity, etc.

Table 5 Summary data extracted from all articles meeting the primary inclusion criteria for the literature review

Reference ID	Type of rheumatic disorder and body part	Type of study*	Country of study	Issue		Population(s) studied					Comment	Quality rating***	Study design and status (CRD)	Key findings
				Focus**	Intervention – drug/other	Age range (years)	Sex	Ethnic group(s)	Other ethnic data: language/ religion	Size of sample				
Abdel–Nasser *et al*, 1997	RA	Epidemi-ological review	World	Prevalence	–	–	–	–	'Region****	–	Major review of literature-over continent and time	B	Systematic review ?1	RA believed to originate in New World; late in Africa – decreasing in USA/Europe; high rates in Native Americans, low in Asian and Africans, with different patterns. Very critical of quality of most studies' methodology
Allison *et al*, 2002	Musculo-skeletal pain	Epidemi-ological survey	UK Manchester	Prevalence	– (body mass index (BMI) and Townsend score)	Adult	M/F	Indian Pakistani Bangla-deshi African-Caribbean	–	2117	Rare good postal survey of 3 GP lists: GP letter, ethnic group as stated by participant, follow-up	B	3b	Younger Bangladeshi women had less musculoskeletal pain (MSP) than whites, African-Caribbean more, but older black and minority ethnics (BME) all had more MSP than whites; smaller but similar differences for disability in Asian groups and for multi-joint pain
Anaya *et al*, 2001	RA	Epidemiology	Colombia	Prevalence	–	>18		African and Mestizo		3044	Record review and follow-up survey and investigations	C	3b	Hospital incidence and population prevalence estimated: lower erosion in black groups but no relation to serology – RA 'rare' in this group
Chandra-sekaran and Radha-krishna, 1995	RA, systemic lupus erythematosus (SLE), Systemic Scleroderma Sjogrens Syndrome, etc.	Epidemiology ? descriptive review	India/Pak/ Bang/SE Asia	Prevalence and treatment	–	–	–	–	Nationality	–	Large-scale review of literature	B/C	4	Brings together many studies: many similarities arguing is the same disease, but some differences in early stages: Data are poor: RA prevalence is lower and milder than in the 'West' and not linked to HLA;

													SLE is possibly also less but prevalence mortality may be higher. India polyarticular, mild at start but still 'crippling' at end: methotrexate widely used, also CAM drugs. Few studies on conditions other than RA & SLE
Chikanza *et al*, 1994	RA	Case–control descriptive epidemiology	UK Zimbabwe	Prevalence	–	Adult	M/F	'Caucasian' white or black (Bantu) Zimbab-wean	?Urban/ rural	168 matched (84 pairs)	Clinical case review	A/B	3b	Black African patients had less severe disease – fewer extra-articular signs including nodules and Raynaud's and fewer joints or early morning stiffness – less toxic effects from DMARDS
Chopra *et al*, 1988	RA	Descriptive	India	Prevalence		Adult		Indian		110	Prospective descriptive review of patients attending clinic	C	4	Compares civilians and young servicemen and notes that disease is typically mild and lacking in systemic features but the general pattern and course of the disease resembles European literature: diagnostic criteria hard to apply
Chopra *et al*, 2001	All	Epidemiology	India	Prevalence	–	Adult		Indian		4092	Cross-sectional village survey of all population with clinical follow-up	B	3a	Prevalence of RA (0.5%) was the highest yet reported from Asian rural population
Farooqi and Gibson, 1998	RA, osteoarthritis (OA), low back pain (LBP) (All)	Epidemiology	Pakistan	Prevalence	–	Adult	–	Pakistani	–	1997	COPCORD Survey of three areas of Pakistan Urban/Rural/ Affluent	B	3a	North Pakistani patterns higher than Southern and closer to UK Pakistani population. Rural-urban differences noted – urban poor may die first; rich get OA knee more often
Gibson *et al*, 1996	Knee pain	Epidemiology	Pakistan	Prevalence	–	Adult	–		Poor/ affluent	~2000	Basically similar to Farooqi and Gibson (1998)	B	3a	See Farooqi and Gibson (1998) – which gives more detail (not related here to UK)

Reference ID	Type of rheumatic disorder and body part	Type of study*	Country of study	Issue		Population(s) studied						Quality rating***	Study design and status (CRD)	Key findings
				Focus**	Intervention – drug/other	Age range (years)	Sex	Ethnic group(s)	Other ethnic data: language/ religion	Size of sample	Comment			
Graham and Glass, 1997	Juvenile RA	Epidemiology	–	Prevalence		Child		All			Editorial review	C	5	Discusses differences and ponders the impact of genetic differences and patterns of HLA type
Griffiths *et al*, 2000	RA	Epidemiology	UK	Disease expression (prevalence)	–	?	M/F	European and Asian	–	107 matched pairs	Immuno-genetic and presentation type	B	3b	Asian RA patients had less bony erosion, tender joints, worse 'health assessment questionnaire' scores – other factors no difference: pain and disability worse in Asian patients
Hameed and Gibson, 1997	RA, all	Epidemiological survey	UK and Pakistan (London)	Prevalence	–	All	M/F	Pakistani	–	2056 UK 4232 Pakistani	Consistent use of questionnaire method	B	3 – large sample, not strictly random. Hypothesis based	SMR***** higher in UK females – some impact of affluence (report bias) – cold climate blamed but also lifestyle/obesity? Knee pain major symptom
Hawker, 1997	LBP, OA, osteoporosis, RA	Literature review	–	Prevalence: epidemiology	–	–	–	–	–	–	Ethnic group not specified	D	3 – no detail on search strategy or quality; non-systematic review	Does discuss problems of standardisation of criteria
Hirsch *et al*, 1998	RA	Epidemiology	USA	Prevalence	–	>20	–	Pima (Native American)		88 cases	Record review	C	3a	Some pattern of family association: no comparison data available
Hoaglund and Steinbach, 2001	OA of the hip	Descriptive	USA	Prevalence	–	?	M/F	Caucasian (white) Asian black East Asian Hispanic	–	?	Discussion of various sources	C	4	Hip OA range is 3–6% in white; stable rates – very low rates in Asian black and East Indian/Hispanic. Suggests genetic component

Hussain *et al*, 2002	X (disability)	Qualitative	UK	Other	–	17–30	M/F	South Asian	Religion	29	Muslim (Urdu) and Sikh only	C	4	Descriptive, allows the voices of younger people to explain impact of disability on life – no obvious reference to RA
Jacono *et al*, 1996	RA	Record-based epidemiology	Canada	Prevalence	–	<30–>50	M/F	White (142)/ Finnish (34)/ Italian (16)/ Aboriginal (43)	–	235	SPSS tests of record data – including lab records; small *n*	C	4 – well described and careful	Differences in haemoglobin and platelet: Italian/white had most reaction to gold; First Nation (Aboriginals) had earlier onset and family history. Nothing on culture
Jordan, 1999	RA lupus Fibromyalgia	Literature review	USA	Outcomes	–	–	–	Black, Hispanic, Chinese, white	–	–	Focus on outcomes and quality of life	B	3 – no detail on search strategy or quality – non-systematic review but critical	Stresses that the outcome of disability varies between ethnic groups and that details are needed: ethnic differences help understanding of diseases
Jordan *et al*, 1998	RA	Case–control	USA	Treat-ment/ outcome	–	Adult	F	African-American/ white Caucasian	–	48 African-American, 52 white	Psychosocial study: control for socio-economic factors and disease level	A/B	3b	Ethnic groups have different patterns of coping strategies (which vary in efficacy) – whites say they ignore pain: blacks 'divert', pray or hope it will improve
Kurahara *et al*, 2002	Juvenile RA, SLE	Descriptive epidemiology	Hawaii	Prevalence	–	<21	M/F	Caucasian (white)/ Polynesian/ Samoan/ Filipino/ Japanese	–	922	Retrospective study. No South Asians cited	B	4 – records based	Polynesians more advanced rheumatoid features; Samoans, Filipinos and Japanese more SLE but less juvenile RA compared with whites
Lau *et al*, 1996	RA OA of the hip	Epidemiology	Far East	Prevalence	–	–	–	–	–	–	Literature review	C	4	Low prevalence of OA of the hip in Chinese, Japanese and 'other Asian' populations: RA associated with HLA (DR) gene but this does not explain the low prevalence

Reference ID	Type of rheumatic disorder and body part	Type of study*	Country of study	Issue		Population(s) studied						Quality rating***	Study design and status (CRD)	Key findings
				Focus**	Intervention – drug/other	Age range (years)	Sex	Ethnic group(s)	Other ethnic data: language/ religion	Size of sample	Comment			
MacGregor *et al*, 1994	RA	Epidemiology	UK Manchester	Prevalence	–	Adult	M/F	Black (Caribbean)/ white	–	3680	Postal survey of primary care plus follow-up	B	3b	Screening survey found similar rate of swelling/ 'arthritis' (20–30%) but lower confirmed RA disease in blacks (2.9/8.0) but sample not easy to predict from
Malaviya *et al*, 1993	RA	Epidemiology	India	Prevalence	–	>16	–	–	–	44 551	Rural survey	C	4	House-to-house survey located 299 'cases' – prevalence of 0.75 established
Mijiyawa, 1995	RA	Epidemiology	'Third World'	Prevalence	–	–	–	–	–	–	Literature review	C	3/4	Summarises various national and regional studies: India (0.75%) similar to 'The West'; China/Indonesia/ Philippines (<0.4%), but Jamaica over 2% adults; also high in Latin America; no uniform link to HLA
Molokhia and McKeigue, 2000	SLE RA	Literature review	–	Prevalence	–	–	–	West African, European, Native American	–	–	Discussion	C	4	SLE higher risk in West Africans; RA high in Native Americans, compared to Europeans; reasons not established, not due to HLA genetic make-up
Peschken and Esdaile, 1999	All	Prevalence	USA/Canada	Prevalence	–	–	–	Native Americans	(Eskimo)	–	Literature review search and summary of 'world literature'	B	4	Many Native American groups have high prevalence of RA which is severe, early onset, and linked to genetic type (HLA), but may be atypical in presentation

Roussou *et al*, 1988	Ankylosing spondylitis	Descriptive	Pakistan	Prevalence/ treatment					Pakistani/ British	53 matched pairs	Letter describing series of patients	C	3b	Pakistani patients more likely to be on methotrexate, sulfasalazine or penicillamine, and had worse outcomes
Samanta *et al*, 1991	SLE	Prevalence	UK Leicester	Prevalence, outcome	–	Adult	M/F	Asian/white	–	87 cases	Case reviews	C	4	Earlier age of onset among Asian patients; more systemic disease and higher mortality
Samanta *et al*, 1992	SLE	Prevalence	UK Leicester	Prevalence	–	Adult	M/F	Asian/white	(mostly Gujarati)	50	Case reviews	C	4	Case identification by systematic trawling of records: confirms higher age-adjusted prevalence estimate (×3): 20/100 k in white, 64/100 k Asian
Seth *et al*, 1996	Juvenile RA	Epidemiology	India	Prevalence	–	Young	M/F	–	–	361	Retrospective record study	C	4	Some sex differences in types of juvenile RA but overall demographic patterns resemble 'Caucasian' reports
Veerapen *et al*, 1993	RA	Epidemiology	Malaysia, UK	Prevalence/ disease	–	–	–	Malaysian, British	? state	70 matched pairs	Consecutive index patients	C	3b	No differences in serology, functional status, etc.; British had more severe foot disease, nodules, vasculitis and fibrosis: Malays had lower erosion, more spinal and wrist, but milder radiography
Wang *et al*, 2000	All	Epidemiology	Canada	Prevalence	–	>20	M/F	Place of birth – Asia, Europe, North America	Place of birth	39 240	National population health survey data	C	4+	Age–sex-adjusted rates for Asian country of birth half (6.9%) that for Europe/ Australia or N America (14.2–14.4%)
Zhang and Verhoef, 2002	All	Descriptive	Canada	Therapy/ pathways/ lay				Chinese		19	Qualitative interviews	C	4	After self-care was tried, views about traditional Chinese medicine did not lead to preference for Chinese healers over Western medicine

* e.g. Randomised controlled trial (RCT)/control trial/descriptive/epidemiology/case study/good practice/other ...
** Focus (as in the paper: Prevalence/treatment/ pathways/outcomes
*** Rating of study quality (see Table 3) (Alpha to Epsilon)
**** Region: location of study
***** SMR: Standardised Mortality Ratio

The following articles are included in the reference grid but not reviewed in the text. The reasons are given for each one:

Anaya *et al*, 2001: no relevance to UK groups.
Chikanza *et al*, 1994: no relevance to UK groups.
Hirsch, 1998: no relevance to UK groups.
Hoagland and Steinbach, 2001: no relevance to UK groups.
Kurahara *et al*, 2002: no relevance to UK groups.
Peschken and Esdaile, 1999: no relevance to UK groups.
Roussou *et al*, 1988: not RA.
Seth *et al*, 1996: juvenile cases.
Veerapen *et al*, 1993: no relevance to UK groups.
Wang *et al*, 2000: no relevance to UK groups.
Zhang and Verhoef, 2002: no relevance to UK groups.