

Communicating with patients of South Asian origin: problems and solutions in the context of rheumatoid arthritis

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Abstract

Rheumatoid arthritis is a common chronic disease associated with significant morbidity and mortality. As with all chronic conditions, active participation by the patient, in areas ranging from accepting the diagnosis and its treatment to the implementation of coping strategies, is essential for effective management. Involving any patients in these process can be difficult; however patients of South Asian origin can present particular challenges. Many patients of South Asian origin have beliefs about disease causation and the utility of pharmacological and non-pharmacological treatments that differ from those held by other patients. Communication difficulties can make it difficult for health care professionals to address these issues. We discuss strategies to support patients and encourage their involvement including linguistically appropriate educational material, peer support and telephone helplines.

Key words

Rheumatoid arthritis; ethnicity; therapies; communication; patient education.

Introduction

Rheumatoid arthritis (RA) is a chronic disease that affects one per cent of the population

(Symmons *et al*, 2002). It is an important cause of morbidity and mortality, as a consequence

of accelerated arthrosclerosis (Bacon *et al*, 2002) and is associated with significant cost for the individual, the NHS and society (The King's Fund, 2009). Highly effective therapies are now available for RA both in the form of orally administered disease modifying anti-rheumatic drugs (DMARDs) and the newer biological agents. These agents control inflammation, slow the rate of joint destruction and are associated with improved functional ability and quality of life (Emery, 2002; Emery & Salmon, 1995; Raza *et al*, 2006). However, as current treatments are not curative, drugs need to be taken long term. Furthermore, current treatment regimens are frequently complex with multiple agents being used simultaneously.

Patients are faced with huge challenges when they develop a chronic disease. These include the need to accept the diagnosis and its treatment. Knowledge, on the part of the patient, is central to the patient's ability to meet these challenges. For example, an adequate understanding of the disease and the role of pharmacological therapies is important to facilitate adherence (Horne & Weinman, 1999; National Institute for Health and Clinical Excellence, 2009). Imparting this knowledge, in a manner that the patient can understand, is a key role of the health care professional.

The management of RA in patients of South Asian origin is associated with its own particular challenges (Samanta *et al*, 2005). Important among these are language barriers and issues related to literacy (Kumar *et al*, 2009a). In addition, a patient's cultural background may influence their own beliefs, relating to issues such as the causation of disease and utility of pharmacological therapies (Horne *et al*, 2004), as well as their family and community's beliefs about illness in general and their disease in particular (Kishore *et al*, 2008). Health care professionals need to be aware of and sensitive to these issues to allow an effective interaction with patients.

There is an extensive literature on health needs of black and minority ethnic groups in the UK (Bhopal, 2009; 2006; Bhopal & Donaldson, 1988). This highlights the need for a tailored approach to interventions that enhances behavioural changes in the context of disease prevention, management and medication adherence. Self-management and empowerment are core concepts in the management of long-term conditions (Lorig *et al*, 1993; Protheroe *et*

al, 2008). The ability to effectively communicate with patients is central to the implementation of these tailored approaches and the engagement of patients in self-management programmes. Using RA as an example, we discuss some of the particular issues that relate to patients of South Asian origin, and, drawing on our own experiences, suggest potential solutions.

Examples of problems: beliefs about medicines and the causes of disease

Personal beliefs about medicines are important, as they significantly influence adherence (Phatak & Thomas, 2006). Using a validated questionnaire, we have studied beliefs about medicines (Horne *et al*, 1998) in patients with RA of South Asian origin and a control group of RA patients of white British origin (Kumar *et al*, 2008). We showed that patients of South Asian origin had more concerns about disease modifying anti-rheumatic drugs than white British patients did, and believed that medicines in general were more harmful and overused. A follow-up study, conducted using qualitative methodologies, sheds considerable light on the reasons underlying these negative beliefs in patients of South Asian origin (Kumar *et al*, 2009a). Important explanatory factors included the following.

- The patients' beliefs about the causes of their disease, and the influence of their religious beliefs on this.
- The patients' frequently strongly held beliefs about the benefits of traditional dietary and other non-medical treatments.
- Difficulties in effectively communicating with health care professionals about their disease and its treatment.

Interestingly, patients in this study who chose to speak in English had different views from those who chose to speak Punjabi or Urdu, which may reflect their degree of acculturation. Patients' perceptions about the cause of their disease had an important impact on the way that they viewed drug therapies and managed their disease. For example, patients who believed that their disease has been caused by fate, God or Karma (as opposed to offering a biological explanation for their disease) viewed prescribed medicines particularly negatively; this perspective was held more frequently by patients who preferred to communicate in a South Asian language.

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Many such patients felt that their medicines would only work if it were part of their fate to be free from the punishment that their disease represented. In contrast, patients of South Asian origin who, when given the choice, preferred to speak in English frequently offered a biological explanation for their disease; such patients had a better understanding of the rationale underlying the use of their medicines and were more accepting of them. The fatalistic perspective held by a proportion of patients can have a profound effect on adherence to treatments and future disease management. This is a common factor in rheumatology practice in India (Mahendranath – personal communication). In the UK it has been found in patients of South Asian origin with cardiac diseases (Lip *et al*, 1996; 2002). These studies suggest that patients' low internal locus of control hampered their involvement in care. In addition, our study showed that, negative views about prescribed medicines frequently went hand in hand with positive views about traditional approaches to management, including dietary and ayurvedic (traditional Indian) treatments. Many patients held the view that these alternative approaches would offer a better chance of cure than conventional Western medicines.

Difficulties in communication can make it difficult to address these issues. Certainly in our study, non-English speaking patients felt that language barriers between them and health professionals who were unable to communicate in their preferred language were a fundamental hindrance to the exchange of information. These patients felt that their ability to receive and discuss information was very limited. A focus group study of what patients with arthritis from ethnic minorities wanted from the NHS in Birmingham similarly emphasised the strong feeling that they were not being listened to by their doctors (Adab *et al*, 2004). Interestingly, many patients in our study said that using family members to translate the consultation with their health professional was not always successful, as they felt that family members failed to relay all the correct information to them and to the health professional. A recent study from Scotland addressing the experiences of Sikh and Muslim patients with cancer, revealed similar findings (Worth *et al*, 2009). In particular, that study highlighted that relatives of some patients controlled the information during the interpretation especially with regard to poor prognosis. Difficulties in communication have

been highlighted in other studies. In a study from Bradford, which revealed that patients of South Asian origin with rheumatic disease terminated their medicines sooner than other patients (Helliwell & Ibranhim, 2003), poor communication with health care professionals was highlighted as a likely causative factor. In a study by Lip *et al* (2002) of patients with atrial fibrillation, a lack of appropriate explanation about drug therapy was suggested as an important factor in non-adherence in patients of South Asian origin. A recognition of the difficulties with verbal communication have, in some cases, led to the development of written informational material in South Asian languages. However, low literacy rates in patients of South Asian origin who find it difficult to communicate in English casts some doubt over the utility of this approach. For example, we have reported that 75% of patients of South Asian origin attending our rheumatology unit, who said that they needed an interpreter to effectively communicate with an English speaking health care professional, were unable to read the script of the language that they could speak (Kumar *et al*, 2009b).

Examples of solutions: the Birmingham experience

We have developed four resources to support communication with, and education of, patients of South Asian origin who find it difficult to communicate in English. The rheumatology team at Sandwell and West Birmingham Hospitals NHS Trust have developed an Asian language helpline for the use of patients in secondary care (Kumar *et al*, 2009b). This helpline operates in parallel with our standard English language helpline and is run by health care professionals fluent in Urdu, Punjabi and Hindi (the three languages most relevant to our local population). This allows patients to communicate directly with health care professionals, rather than having to rely on an intermediary, and facilitates their active engagement with their disease and its management.

Second, the Birmingham Arthritis Resource Centre (BARC) has developed a series of bilingual audio CDs that provide patients with information about arthritis in general and RA in particular. Ongoing evaluation of these audio CDs highlights the benefit that patients derive from listening to material in a language that they can understand (Sharif *et al*, 2008).

Third, BARC has developed a network of bilingual trained volunteers covering a large selection of languages, who can provide support to patients with RA who find it difficult to communicate in English. Again patients derive significant benefit from having the opportunity to talk to trained patient volunteers (Gordhan, 2003).

Finally, it is essential that the patient's perspective underpins any development in service delivery either in primary care, secondary care or in community settings. At Sandwell and West Birmingham Hospitals NHS Trust, we have established patient user groups for patients who can communicate in English and also for patients who cannot, but who can effectively communicate in a South Asian language (reflecting the large South Asian population that we serve). This group has highlighted the need for additional resources, such as a patient support group to allow fellow patients to meet, socialise and overcome their frequently profound feeling of isolation.

Conclusion

Effective communication is central to the delivery of high quality health care. Dealing with patients from a different cultural and linguistic background from that of the host country poses specific challenges. Without addressing these, the quality of care and outcome for the individual is likely to be diminished and the cost to society enhanced. The solutions we have suggested may be of benefit in other units and in other diseases. Further evaluation is both needed and encouraged.

Implications for practice

- There are many barriers to patient involvement in South Asian populations.
- Patients' perceptions about their disease and its management have a significant effect on their beliefs about medicines and is likely to impact on their adherence with treatment.
- It is relevant for health care professionals to be aware of the low literacy status of some of their patients, especially non-English speaking patients of South Asian origin.
- A range of information about the disease and its treatment should be provided to patients, as well as telephone helplines staffed by health care professionals who can speak to the patients in their own language.

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