

"It's like taking poison to kill poison but I have to get better": A qualitative study of beliefs about medicines in RA and SLE patients of South Asian origin

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**‘It’s like taking poison to kill poison but I have to get better’:
A qualitative study of beliefs about medicines in Rheumatoid
arthritis and Systemic lupus erythematosus patients of
South Asian origin**

K Kumar^{1,2}, C Gordon^{1,2}, R Barry², K Shaw³, R Horne⁴ and K Raza¹

reason(s) for not taking their medication has recently been highlighted.⁵ For example, patients may avoid medicines because of doubts about their personal need for treatment (despite medical evidence for the prescription) and because of concerns about potential adverse effects.^{6,7} Moreover, medication concerns are often based on potentially mistaken beliefs about the dangers of medicines, and are related to negative perceptions of pharmaceuticals as essentially harmful substances that are overused by doctors.⁸ It is therefore important that information is targeted to address the specific doubts and concerns held by the individual.⁹

Several studies have documented that there are differences between individuals from different ethnic groups in the way that medications are viewed.^{10,11} The South Asian population is the largest minority ethnic population in the UK. The high prevalence of certain rheumatic diseases such as SLE amongst patients from this ethnic background¹² makes it crucial for rheumatologists to understand the views of this group in order to improve adherence and encourage involvement in decision making about their care.

We have recently investigated beliefs about medicines in RA and SLE patients of South Asian and white British origin.¹³ There was no difference between the groups in terms of the proportions who thought that disease-modifying anti-rheumatic drugs (DMARDs) were necessary for their disease management. However, compared with patients of white British origin, those of South Asian origin had more concerns about DMARDs and viewed medicines in general as harmful and overused. Of the variables that we studied, the one that associated most strongly with a belief that medicines in general were harmful and overused and that DMARDs in particular were of concern was ethnicity.

In the present study we sought to investigate the factors that influenced beliefs about medicines in patients with RA and SLE of South Asian origin and to assess why patients from this background felt that medicines were overused and harmful. Using a qualitative, focus group based approach,¹⁴ we gathered together groups of patients of South Asian origin to explore their beliefs about medicines.

Methods

Patients were recruited from the rheumatology department of City Hospital, Sandwell and

West Birmingham Hospitals NHS Trust and the SLE clinic at the Wellcome Trust Clinical Research Facility, Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust. These Trusts serve a multicultural population. About a third of patients at City Hospital are from a South Asian, Punjabi or Urdu speaking, background. This study was approved by the South Birmingham Research Ethics Committee and all patients gave written informed consent at the beginning of each focus group.

Participant selection and recruitment

Hospital clinical databases were used to identify potentially suitable patients who fulfilled classification criteria for RA or SLE,^{15,16} had been taking a DMARD for more than 3 months prior to the study and had been diagnosed six or more months previously. Invitation letters were sent to potentially suitable patients. This was followed up by a phone call to ensure that patients had received and understood the information about the study. At this point patients were asked whether they would, in principle, like to take part in the study and to identify their ethnic background. For the purposes of this study (and consistent with our previous study)¹³ patients were classified as being of South Asian origin if they had three or more grandparents who had been born in India or Pakistan and regarded themselves as being of South Asian origin. In addition, patients were asked what language they would prefer to speak at a focus group meeting. Fifty seven patients were invited to participate. Eighteen patients declined to participate when contacted by phone and seven agreed to take part but did not turn up for a focus group session. The final study population consisted of thirty two patients.

Participants were allocated to one of two categories according to whether they preferred to speak in Punjabi/Urdu or English (no patients chose to speak in another language). Within each category patients were asked to take part in one of four separate disease-based discussion groups. The four non-English speaking groups were: Group 1 RA patients ($n=6$); Group 2 RA patients ($n=5$); Group 3 SLE patients ($n=5$); Group 4 SLE patients ($n=3$). The four English speaking groups were: Group 1 RA patients ($n=4$); Group 2 RA patients ($n=3$); Group 3 SLE patients ($n=4$); Group 4 SLE patients ($n=2$).

Data collection, analysis and validation

Face-to-face focus groups were conducted to collect data. The patients who chose to speak in either

Punjabi or Urdu participated in groups that were facilitated by KK and HT. Both these researchers spoke fluent Punjabi and Urdu. Participants who chose to speak in English joined groups that were facilitated by KK and RB. Patients with RA and patients with SLE joined different groups. All group discussions took place on the hospital site away from a clinical setting at the postgraduate centre. Each group discussion lasted between one and two hours. Open ended questions were asked to encourage patients to talk and to generate points of discussion between themselves regarding their perceptions about their medicines for RA or SLE and their views about medicines in general. All interviews were audio recorded and transcripts were typed and independently analysed by KK, HT and RB. Emergent themes were agreed by consensus. During this process the data were searched in detail for similar words, patterns and themes which were coded. For interviews conducted in Punjabi and Urdu the content of the discussion was translated by KK or HT.

Data saturation was achieved after repeating each of the groups four times as no new themes emerged in the fourth session. For simplicity, patients who chose to speak in Punjabi or Urdu are referred to as non-English speaking patients throughout the rest of this paper (we note that most of these patients were able to speak English to some extent but chose to speak in Punjabi or Urdu as they felt that they were able to communicate more effectively in these languages). Punjabi and Urdu are similar languages with many shared words and Punjabi and Urdu speaking patients thus communicated with each other very well during the relevant focus group discussions.

Results

The demographic details of all patients invited to take part in the study are shown in Table 1 which compares participants with non-participants. The majority of the participants were female;

only one male agreed to take part. There were several recurring themes across the groups that covered not only beliefs about prescribed medicines but reasons for these beliefs and the influence of these on patient behaviour. The views expressed by the RA and SLE patients were very similar and are reported together; however there were important differences between those expressed by the non-English and the English speaking patients.

Areas discussed by patients could be grouped into one of the following categories: (1) beliefs about the necessity of DMARDs; (2) concerns about DMARDs and other prescribed medicines including: (a) long-term side-effects; (b) the apparent lack of efficacy of some therapies; (c) concerns about changing from one drug to another and the large numbers of different medicines being taken; (3) contextual factors which informed the patient's view on the necessity for particular medicines and concerns about them including: (a) beliefs about the causes of disease and the influence of religious beliefs on this; (b) barriers to communication with health care professionals about the medications being prescribed in clinic; (4) consequences of beliefs on patient behaviour including the use of traditional dietary and other non-pharmacological approaches. There were important contextual factors which differed between the non-English and English speaking patients relating to the patient's understanding of the causes of disease and the influence of this on the strategies used by patients to manage their disease.

Beliefs about the necessity of DMARDs

All patients expressed the view that taking DMARDs was vital to control their symptoms but not necessarily to control their disease in the long-term. Patients recognized that by not taking DMARDs regularly their ability to undertake day-to-day activities might be restricted and that this could have a huge impact on their functional ability.

If you do not take them we will get bad, pain will increase. I get help from them quite a bit.

Table 1 Demographic characteristics of participants and non-participants

		Participants (n = 32)	Non-participants (n = 25)
Gender	Male	1	15
	Female	31	10
Age: years, median (IQR)		52 (44–55)	51 (42–55)
Disease	RA	18	16
	SLE	14	9

Yeh...when there is a lot of pain everyone wants anything that pain will become less, I mean it is a sharp pain you know. (Punjabi speaking patient, 48 years)

There was recognition by some, of the fact that their disease could not be made to 'go away' and that there was a need for long-term therapy.

When I try to stop them I cannot get on with things. It's like your body cannot do without them. I don't like that. (Punjabi speaking patient, 52 years)

For others, who accepted that DMARDs were necessary to control their symptoms, there was nevertheless a lack of understanding that their underlying condition would require life-long therapy and, as a result, several such patients had considered stopping or had actually stopped treatment prematurely. Patients with RA on anti-TNF α therapy particularly reported an improvement in quality of life but nevertheless remained unconvinced of the necessity for long-term drug treatment.

Concerns about DMARDs and other prescribed medicines

Concerns about long-term side effects

Concerns about DMARDs were expressed from a number of perspectives. A common theme that appeared across the groups was a concern about the long-term damage that DMARDs might have on their health in general and on specific organs in particular.

You know sometimes I sit there and think – I take so many and all these chemicals in our body, I will blow up like a toxic bomb one day. What are they doing inside you? (Punjabi speaking patient, 62 years)

This concern was expressed by all patients. Patients felt that the longer they took their treatment the greater the likelihood of damage and dependency.

I know that we are too used to taking these tablets now. It's not good. I want to be able to do without them but I know I was dependent on them now...It's a worry. My life is just not mine. (Punjabi speaking patient, 45 years)

Many patients thus felt that they were trapped in a vicious circle and this was a source of anxiety and frustration. For other patients, the development of resistance to treatment rather than dependency was a source of concern with long-term usage.

I do worry about the whole thing really. It's like taking poison to kill poison but I have to get better. If I don't take them how will I get better? Yes I am

worried about the lupus but...I have concerns but the long term damage...but...I think I want to get better. (English speaking patient, 52 years).

Apparent lack of efficacy of some therapies: the experience-expectation gap

Patient's judgement of the efficacy of their medicines was influenced by the degree to which symptom experiences matched expectations. Some patients expressed doubts about the efficacy of DMARDs. This view was directly related to their previous experience of DMARDs and other drugs and whether they had worked effectively to control the symptoms for which they had been used. Many held the view that despite taking a number of different drugs, their symptoms had not improved to the extent that they had anticipated or had hoped for and this left them with negative views about the treatment.

Every tablet that I have had for lupus has given me reaction. He is thinking (referring to the doctor) about this new one now...I want someone to help with my lupus. I do want to beat it. (Punjabi speaking patient, 47 years)

I have a long list to take but I feel despite this my disease is getting worse. (Urdu speaking patient, 55 years)

There was also a disappointment expressed about the time taken to see benefit after commencing most DMARDs. In contrast, patients spoke very positively about the rapid benefit seen with steroids which were widely viewed as 'magic medicines'.

The steroid injection was wonderful. It was magic. (Punjabi speaking patient, 63 years)

Concerns about changing from one drug to another and the large number of medicines being taken

Patients said that they were particularly apprehensive when they were switched from one DMARD to another or when additional DMARDs were added as they were not clear about the underlying reasons for the changes in therapy.

I feel like an animal coming to the hospital and they just trying different things all the time and there are so many...You do feel that, because they keep swapping and changing all the time. I guess it's got to be done but you know, what are they doing to you all these different. (English speaking patient, 36 years)

Then there's thoughts that God, they are trying a lot of tablets...why doesn't anything work? (Urdu speaking patient, 45 years)

Some patients expressed the view that their confidence in their treatments lessened if they were changed too often. An apparent lack of

effective communication between the patient and health professional clearly increased patient concerns.

Patients made reference to feeling trapped by the need to take their medication and disliked the large number of different medicines that they were faced with every day.

I feel as if I am trapped and I cannot get out. There is no way out. I feel like this...I would be happy if doctors reduce my tablets. (Urdu speaking patient, female, 61 years)

The thing is how much longer I have to carry on with these? We both (referring to other patient) been diagnosed a very long time and most of this past time I have been on medicines. I have never been medication free and that is a concern. (English speaking patient, 59 years)

When I look at my medicines in the morning I wish they would disappear from me. I want my list to be reduced. Why, why, I am taking so many medicines. If these are working then why my list is so big? (Urdu speaking patient, 52 years)

Some held the view that the large number of different medicines being used was a consequence of doctors, especially in secondary care, not knowing enough about alternative therapies.

When you come to the hospital there's none of that that's ever looked at. When I read books and see on the television it's now like alternative, even in some doctors' surgeries, and there are some doctors who have alternative therapy practitioners. Which we, as patients here, have no choice but to take the drug we are given. I feel that they reject that alternative medicine side of it when I think they should look at that more as well. (English speaking patient, 36 years)

Although the patients in our study did not admit to altering drug doses, they did admit to stopping some of their medication without consulting their physician.

Contextual factors

Beliefs about the causes of disease

When discussing beliefs about medicines, patients frequently talked about their beliefs about the underlying causes of their disease. There were interesting differences between the English and non-English speaking patients in this context. The non-English speaking patients held the view that the occurrence of disease was strongly related to climate, diet and stress.

You see...India is a hot country. You sweat a lot. There is fresh air and you feel better whereas here it is cold. (Punjabi speaking patient, 39 years)

In addition, they tended to view the development of their disease as part of their 'fate' or a manifestation of 'God's will'.

If you have a disease there is reason for that suffering. There is way that he is making for you. But we don't know what he is planning. (Urdu speaking patient, 59 years)

I believe in Allah and he does everything so what ever he commands will happen. I believe 70% in him and some in doctors and medicines. You see what ever pain or illness we get is due to fate so as well as counting medicines with your doctor you should ask for relief off him at the same time. (Urdu speaking patient, 63 years)

Such an attitude led many to an unquestioning acceptance of their illness. In contrast, many English speaking patients talked about biological reasons for disease which they viewed as a 'system failure'.

Communication barriers

The 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, impart and discuss information was very limited. They also highlighted that using family members to translate the consultation with their health professional was not always successful, as they felt that family members sometimes failed to relay the correct information to them and to the health professional. The English speaking patients had concerns about the way that some health professionals explained what to expect from the medicines being prescribed; in particular they felt that there was lack of explanation about potential drug side-effects.

It really depend how the doctor approaches you. I would say I have had a lot of good experiences with doctors but have had bad as well. It all depends on how they talk to you. So once reason explained why...you can understand but it's when you are not consulted about anything enough. (Punjabi speaking patient, 45 years)

Consequences of beliefs about medicines on patient behaviour

All patients viewed prescribed medicines as only one of a number of approaches by which their disease could be controlled and discussions about beliefs about medicines led, in all cases, to discussions about non-pharmacological strategies

employed by patients. The strategies used by the non-English and the English speaking patients differed and this was frequently related to differences in beliefs about the cause of disease. One view was that traditional (or 'desi') dietary and other treatments had an important role in the maintenance of health and the management of disease.

I am speaking from as Asian view point here. We weigh things up as hot and cold diet...So why do we take the hydroxychloroquine it gives me a lot heat so to prevent side effect from the heat I take diet things to stop them harming me to the other organs. (English speaking patient, 47 years)

I try and reduce mine but what can we do when the disease does not control itself. So see...In India we had desi treatment...and people used to take the herbs and they would feel a lot better. We do that at home and we do make sund (ground ginger) as well. But here it doesn't seem to take the same effect. (Punjabi speaking patient, 65 years)

Patients viewed traditional dietary treatments as less harmful than conventional drug therapy. They also expressed the view that the reason for a perceived high prevalence of disease in the UK was because of the many non-organic foods eaten by people and an inadequate intake of fresh vegetables and fruit.

The thing that has drastically gone wrong or is getting worse the fact is that not many things are grown organically and in the olden days they used to grow virtually everything organically so people are getting more and more diseases by the new processes. (Punjabi speaking patient, 63 years)

The fatalistic view held by some non-English speaking patients also influenced their behaviour. Some patients held the view that God controlled their health and disease. Often these patients did not believe that they could play an active role in managing their disease and that the outcome of their disease lay in the hands of God. In some cases, this attitude hindered their compliance with treatment recommended by their doctor.

You see...I was told that I had to have my knees injected but I refused the steroid injection. You know why...because I wanted to put all my faith into my god. That's how I get on really. (Punjabi speaking patient, 65 years)

However, many accepted that God might wish for their disease to improve and held the view that if this were to be the case then this may be mediated via the doctor and the medicine(s) prescribed.

Discussion

The decision-making processes that underlie whether patients take medicines are complex. A range of contextual factors impact on beliefs about the necessity of particular medicines and concerns about them; the balance between necessity and concern influences adherence. This study is the first to provide a detailed exploration of perceptions about DMARDs in Rheumatology patients of South Asian origin and to identify those factors influencing patients' assessments of their need for DMARDs and their concerns about them.

Overall, patients in our study recognized the necessity of prescribed medicines, and deemed DMARDs to be important, at least in the short-term. However, many patients failed to recognize that their DMARDs would be necessary in the long-term. In addition, many patients had concerns about DMARD treatments, particularly related to side-effects from long-term usage. Neame et al. have reported similar concerns.¹⁷ Particular concerns related to an apparent lack of efficacy of medicines and the fact that physicians frequently changed treatments; many patients in both the English and non-English speaking groups clearly did not understand the reasons for this or that the beneficial effects of many DMARDs were frequently not apparent for several weeks or months after drug initiation.

Our results show that patients' understanding of the disease process, and in particular of the cause of their disease, has a large impact on their perception of the value of medicines. This was apparent for both RA and SLE patients. Patients who believed that the cause of their disease was a biological one, viewed medicines less negatively than those who held the view that stress, God or fate were important causative factors. Ultimately, these beliefs appear to impact on the way in which patients participate in managing their disease and may impact on their willingness to adopt behaviours that promote self-management including regular drug treatment. Many of the South Asian patients in our study who spoke Punjabi or Urdu felt that their medicines would only work if it was part of their fate to be free from the punishment that their disease represented. Interestingly, in a recent study of lay beliefs about diabetes held by residents of Bangladeshi origin in Tower Hamlets, London, and by their Islamic religious leaders, the latter group saw religious fatalism as a misinterpretation of Islamic teaching and were keen to address this in their role as educators.¹⁸

Our findings are consistent with those of previous studies that have examined health beliefs in patients of South Asian origin. In a study of patients in Birmingham who were receiving warfarin for atrial fibrillation (AF), patients of 'Indo-Asian' origin were found to hold different views to those of other backgrounds.¹⁹ In that study most 'Indo-Asian' patients felt that the control of their health lay with God or 'fate'. In contrast, most patients of Afro-Caribbean origin felt that the control lay with them while most 'white' patients felt that it lay with them or their doctor. Furthermore, 'Indo-Asian' patients were relatively unaware of issues related to AF including the potential complications of the condition and of the reasons for taking warfarin.

Diet played an important part in disease management for many of the patients in our study. Those who believed that the disease was caused by an inadequate diet used alternative therapies in addition to, or instead of, their prescribed medication. The use of alternative therapies for other diseases by patients of South Asian origin has been highlighted in other studies.^{20,21} Furthermore, it has been observed that patients of South Asian origin frequently use traditional medicines and culinary ingredients for conditions such as colds, sore eyes, constipation and fatigue.²² Patients in our study held the view that natural herbs did not imbalance the body and believed that these herbs had fewer side-effects than western medicines. Interestingly, a recent study conducted in Jamaica reported that SLE patients often took herbal treatments to counteract side effects of prescribed medicines.²³

A lack of effective communication was a common theme in this study. The non-English speaking patients said that they were often unable to understand or felt unable to question what was advised. These patients felt less able to engage in the plans for their treatment. Poor communication between the patients and health professionals, contributing to a lack of understanding about disease and therapy, could result in patients taking greater interest in alternative therapies, traditional therapies or relying on their faith which may have an impact on adherence. Language barriers and a lack of appropriate translators is clearly an important issue. Approaches to address this include the use of helplines that operate in languages other than English. Interestingly, experience with a recently established helpline operating in Urdu, Punjabi and Hindi showed that a large proportion of calls received concerned medication²⁴ raising the possibility

that the establishment of appropriate communication channels such as this may allow issues relating to negative beliefs to be addressed.

Our study has a number of limitations. Firstly, the term 'South Asian origin', as we have used it, is a very broad descriptor within which there is great diversity, particularly at religious and regional levels. The approach that we used for patient selection and categorization did not allow us to address issues of the relationship between health beliefs and beliefs about medicines and these religious, regional and other variables. Our data should however provide a starting point for future work in this area. Secondly, the difference between the non-English and the English speaking patients' beliefs about medicines may relate to levels of acculturation but this was not specifically addressed and further work is needed in this area. Thirdly, the majority of the participants were female and it is possible that men might have different views. Fourthly, we studied only patients taking DMARDs. It thus may be that patients with RA or SLE who had the most negative views about medicines were excluded from our study because they had declined therapy; our selection strategy may have thus biased our patient population towards those with a more positive attitude towards medication. In addition, disease modifying drugs were grouped together for the purposes of this study and future work should address differences in beliefs about different classes of drugs with different modes of action (e.g. biological versus conventional disease modifying drugs) and methods of administration (e.g. oral versus injectable). Further work is also needed to address whether or not there is an association between beliefs about medicines and socioeconomic variables (including level of education) and also the presence of comorbidities in addition to the diagnosis of SLE or RA.

In conclusion, patients' beliefs about the cause of their disease influenced their beliefs about medicines recommended for the disease. Other important factors contributing to negative beliefs about medicines included an inability to effectively communicate with their health care provider. Our patients' beliefs and experiences do not promote adherence to drug therapy or full patient involvement in disease management. If health care providers are to find ways to improve adherence to treatments, these views need to be understood and taken into account when explaining the need for therapy and what to expect from it. Our findings should help to inform education programmes for patients from a South Asian background.

Whilst some of our findings may be particular to the South Asian population, others, including concerns about polypharmacy, may well be generic concerns applicable to the whole of the British population. Future work is needed to address this.

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Conflict of interest statement

None declared.

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