# Exploring the cultural validity of rheumatology outcomes

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## Abstract

In rheumatoid arthritis (RA), the use of a 'core' set of treatment outcomes was pioneered to ensure that the same outcomes are measured across all clinical trials to enable comparison of trial results. However, studies have not investigated the influence of patients' ethnic and cultural background on which treatment outcomes are important from a patient perspective. This pilot study identified 74 treatment outcomes from the female Punjabi RA patients, including 21 new ones that were not identified in previous research with White British RA patients. The social impact of RA created significant additional burden for these Punjabi women, with 'less stigmatisation' and 'improved ability to carry out family duties' generated as important new outcomes. This study illustrates a need to address cultural validity in outcome elicitation and prioritisation, to ensure interventions are evaluated using criteria that have meaning for people with that condition.

## Key phrases

UK Punjabi women with RA may describe symptoms such as pain and fatigue differently from White British patients

They describe a broader range of symptoms, functional restrictions, psychological effects and social impact from RA than White British patients

Stigmatisation and discrimination, and social norms regarding family duties, are important areas of social health that affect UK Punjabi women with RA

The RA patient and professional ‘core’ sets of outcomes may not include outcomes important to minority groups

Instruments measuring ‘core’ outcomes would benefit from evaluation of cultural salience

## Key words

Rheumatology, Treatment outcomes, Patient Perspective, Qualitative research, Culture

## Introduction

Careful selection of outcomes is essential in the design of randomised controlled trials (RCTs). The development of standardised ‘core’ sets of outcomes was pioneered by the Outcome Measures in Rheumatology Clinical Trials (OMERACT) collaboration in rheumatology and the core set for rheumatoid arthritis (RA), developed by professionals, has been successfully implemented (Tugwell et al., 2007). The importance of including patients’ priorities in this process has since been recognised and researched (Gossec et al., 2009; Sanderson et al., 2010a). However, these patient perspective studies did not sample for cultural diversity within countries and this may result in core outcomes and outcome measures that are not meaningful for a large proportion of patients. Despite the rapid pace of development around patient reported outcomes in general, there is a lack of evidence for relevant and important outcomes for the diverse clinical patient population, including ethnic minority groups.

There is evidence that the experience and meaning of outcomes, such as pain, varies across cultural groups (Lasch, 2002). While a number of studies have been conducted in the UK and the USA illustrating differences in outcomes such as disability and depression among different ethnic groups (Jordan, 1999; Escalante, del Rincorn, Mulrow, 2001; Neville, Hassan 2003), there has only been one previous qualitative study, with systemic lupus erythematosus

(SLE) patients, examining cultural differences in patient perspectives of important treatment outcomes. Focus groups with these Asian English-speaking SLE patients in Singapore found that there were domains not covered by the International Classification for Functioning, Disability and Health (ICF) core set for SLE (Ow, 2011). Therefore, there is no evidence of whether RA patient priorities vary between different cultural groups, but the broader literature indicates that this is possible.

Guidelines stipulate that it is best practice to use qualitative data collection (or literature review of such studies) to inform the elicitation of outcomes and content of outcome measures (FDA, 2006), and in providing a conceptual framework for patient-reported outcomes (PRO) (Kirwan, Tugwell 2011), and this has effectively been done with mainstream patient populations (Gossec et al., 2009; Sanderson et al., 2010a). If patient samples are not culturally diverse, there is potential for core sets to not have global validity. In this situation, the application of mandatory core sets could be disadvantageous (HTA, 2011). The objective of this exploratory qualitative study was to use RA as an exemplar to determine whether important treatment outcomes in one minority cultural group in the UK, those of Punjabi origin, differed to those of White British RA patients, and thus explore the cultural validity of existing patient and professional sets of outcomes.

## Patients and Methods

Given the complexity of ethnicity and culture, this study focused on one cultural group, defined by language and region of (family) origin; and comprised 16 interviews with female Punjabi-speaking RA patients. Purposive sampling was used to obtain a diversity of characteristics: disease duration, age, generation of participant, work status, English fluency, and religion. In this study, first generation is used to mean a woman who was born abroad and moved to the UK and second generation to mean a woman who was born in the UK. These participants all identified themselves as being of Punjabi origin.

South Asians are the largest minority ethnic group in the UK (50% of the UK's minority population) (ONS, 2001). This study took place in three cities in England: two in the Midlands have large Asian/ Asian British populations (19.7% and 12.3%) compared to one (5.1%) in the Southwest of the UK (ONS, 2001). Potential participants were recruited through rheumatology departments at the three hospitals (in quotations: A, B, C). Ten participants were recruited from hospital B, 4 from C and 2 from A. The numbers partly reflect the differently sized Punjabi communities, but also the lack of availability of Punjabi speaking health professionals or researchers in city A (these 2 respondents both spoke fluent English). Information was available in written English and an audio Punjabi version (few individuals are able to read the Punjabi script (Kumar et al., 2009)).

A pre-interview questionnaire was completed, capturing data on illness duration, medication, disability (as measured by the Health Assessment Questionnaire) (Fries et al. 1980), patient global numerical rating scale (NRS), educational attainment and household composition. TS conducted the interviews using a topic guide to elicit outcomes and explore the complex outcomes of well-being and normality, derived from a review of the literature, including our previous work with White British RA patients Sanderson et al., 2010b; Sanderson et al., 2010c; Sanderson et al., 2011). A nurse researcher (KK) provided interpretation across all three sites where participants did not have adequate proficiency in English to participate in an interview. The data protection policy of the University of the West of England was implemented. Ethics approval was granted by the local Research Ethics Committee (ref. 10/H0102/10) and participants gave written consent.

Interviews were digitally recorded and transcribed verbatim. Where participants responded in Punjabi, KK provided translation. A sample of these translated transcripts was verified independently by professional interpreters to reach a consensus on nuances in meaning. All English transcriptions were independently checked for accuracy and anonymised. An analytical tool (Framework) was employed for managing the data (Ritchie, Lewis, 2003). Analysis involved indexing (labelling) data relevant to each of the questions, then grouping similar indexes to form themes, and last, entering indexed data into Framework with themes (in columns) against participants' stories (in rows) providing context. Constant comparison was employed to look for similarities and differences between indexes and then themes. Double-coding of data was undertaken by the team, including the patient research partner (female Punjabi) to ensure rigour. Careful comparison was made between these Punjabi data and the interview data from the 17 White British female RA patients interviewed in a previous study in Bristol (Sanderson et al., 2010b).

## Results

Table 1 shows the demographic details of the interviewees, with a range of disease and cultural characteristics. 74 treatment outcomes were elicited during the interviews, 53 of which had been identified in the previous research with White British females with RA (Sanderson et al., 2010b) and 21 were new outcomes. Six outcomes elicited from the White British females were not identified in the Punjabi data. Convergent outcomes are listed in Table 2 and divergent outcomes in Table 3, grouped by theme (physical, mental and social health). Sample quotations illustrating new outcomes are provided in Table 4.

### Physical health

Eight new outcomes were identified in this theme. ‘Greater bodily strength’, ‘stand more easily’ and ‘easier to lift objects’ were reported in relation to work activities, mostly by the first generation women who generally had more physically demanding employment than the second generation women. Concern with carrying out activities slowly was common across different home contexts. The desired outcome to be ‘able to do things more quickly’ appeared to be connected to the cultural value of women being industrious at home. ‘Body feels less heavy’ was an outcome linked to the reported effect of RA making the body feel heavy, linked to symptoms of tiredness. Interviewees reported lying down to rest when the pain or fatigue was overwhelming. Pain was a symptom experienced by all interviewees, but with more descriptions of widespread pain than in the White British data:

> “My whole body was feeling like somebody had an accident. The whole body was aching. I was feeling like someone put two rods through my body.” (B4: First generation (1G), proficient English).

Although fatigue was a commonly reported symptom of RA, ‘tiredness’ and ‘exhausted’ were generally used instead of the term ‘fatigue’. Two participants used the term ‘joint damage’ explicitly, but more commonly it was reported using descriptive language (e.g. “My fingers had changed shape” (B1)). No interviewees spontaneously identified ‘having a physical relationship’ as an issue and those that were asked if this was a problem, following descriptions of how their relationship with their husbands had changed, were shy to speak about it.

### Mental health

Among the first generation and a couple of the second generation women, a reluctance to share the psychological impact of RA with others was described (“You get depressed and... it got very, very bad. I didn’t show anybody my emotions” (A1: 2G, fluent English)).

However, during the interviews many mental health outcomes were elicited. Five new outcomes were identified. ‘Feel less angry’ was a new emotion identified with a minority of the Punjabi-speaking RA patients. ‘Regain sense of freedom’ was another new outcome, which linked to the previously identified outcome ‘new lease on life’. ‘Feel less isolated’ was elicited from two diverse groups of interviewees. Participants diagnosed at a younger age felt that they were different from their peers and thus isolated from normal teenage/ young adult life. Three first generation women described how there are few places for Asian women to go, particularly when you feel uncomfortable about your illness. ‘Avoid hospital’ was placed in the psychological theme because the main reason these women wanted to avoid hospital was because they felt isolated from their families and home life.

Outcomes affecting the individual were often framed within the context of the family such as being less anxious about how their illness would affect their children’s future. This may indicate a different perspective with more concern for familial than individualistic impact. In the Punjabi data, outcomes such as ‘more confidence’, ‘more motivation’ and ‘more possibilities / choices’ were not identified. Overall, Punjabi women seemed to find it more difficult to describe what they meant by ‘feeling well’ compared to the White British RA patients, but it was evident that the support, harmony and security of the family were what distinguished well-being from health. This emphasised the psychological importance of the immediate and extended family.

> “They will say we are your support don’t use a stick. So when I get that love and affection, then I don’t need anything else in life.” (B1: 1G, minimal English)

The women described a range of household networks from large extended families living together or nearby, to living alone. The extended family was generally a source of substantial support, which depended on harmony between the family members. However, some women wanted to convey how living with their in-laws could be very stressful and adversely affect their health. This was described as resulting from different beliefs about how to raise the (grand)children and the burden of housework in larger families.

> "When you have a child you want things to be the way you want things to be [...] It's going to tear my husband in half really, he's stuck between his wife and his daughter, or his mum and his dad. It's awful for him, but I know it's affected my health." (A2: 2G, fluent English)

**Social health**

Eight new outcomes were identified in this theme, all indicating how illness is experienced in a social context. These outcomes range from the broad outcomes 'avoid stigma and discrimination' and 'less embarrassed by actions/disability', to specific ones such as 'groom oneself properly'. The latter related to attending social events at the temple and the desire to appear and act according to the social norms for Punjabi women. The effects of discrimination were most apparent for young women diagnosed with RA prior to or in the early years of a marriage:

> "Mid twenties is when a lot of the young ladies get married... but that wasn't happening to me, you know. I had a physical disability, which in the Asian community isn't looked upon very well really..." (B6: 1G, fluent English)

Women's responsibility to their family was an important theme throughout the data. The influence of traditional cultural values was described by all age groups, from first generation grandmothers to second generation 'acculturated' daughters. For those diagnosed in older age, support from their children was part of a natural social cycle:

> "It is our duty to look after the children when they are small... It is when I can't do things any more... So then it is their duty... it will be their responsibility eventually to look after us." (B9: 1G, moderate English)

However, it was recognised that a cultural shift was occurring where their children "have their own life" (B2: 1G, minimal English) and are living more independently than before, and are thus potentially less present to provide support. For the younger women, the disability caused by RA could be devastating because they were not able to fulfil their expected roles of caring for children and the household.

> "When an Asian girl gets married, she not only accepts the husband's family, she takes over everything they do, then she has her children, she's got to look after those." (C2: 2G, fluent English)

The guilt felt about not being able to carry out one's family duties was widespread and was a prominent new outcome. The ability to do paid work was another common important outcome for the Punjabi women. First generation women valued working because it contributed to their children's futures (e.g. paying for marriage, education) and enabled them to socialise outside the home. Second generation women valued the satisfaction that work gave to them personally and was "part of my identity" (A1: 2G, fluent English).

Some women described enjoying activities at home to keep them occupied (e.g. sewing, watching Bollywood films) and activities that they missed doing because of disability (e.g. camping). However, descriptions of valued activities did not commonly extend beyond the household activities that they wanted (and felt obliged) to do for their families. That is, their identities were strongly tied up with an informal, caring role. This contrasts strongly with the White British data that showed that leisure activities were often impacted by RA and that women experienced a sense of loss for leisure activities that defined who they were as individuals.

## Prioritisation of outcomes

The outcomes described spontaneously by eight or more of the female Punjabi patients (of 16) are indicated in Tables 2 and 3 to provide an approximation of commonality of importance, but this should not be taken as representative in a quantitative sense. These 'Top 8' outcomes were pain, stiffness, ability to exercise, activities of daily living, independence, ability to work, easier to lift objects/children, and ability to function quickly. The eight priority outcomes from a UK survey of male and female White British patients (Sanderson et al., 2010a) are provided in Table 3 for comparison with the outcomes elicited from the Punjabi women across Tables 2 and 3. Punjabi participants were specifically asked at the end of the interview which outcomes were most important to change. In the interviews, pain was clearly the most common priority, followed by fatigue/tiredness. In addition, joint damage (1 person: B8), activities of daily living, mobility, independence and valued activities (as a second priority) were selected (see Table 5 for sample quotations). Life enjoyment or associated outcomes were not selected as most important, but this may be due to a belief that psychological well-being could not be affected by clinical care and were thus not relevant to the question about priority treatment outcomes:

> "Well-being is your happiness and I don't think health services have anything to do with your well-being." (A2: 2G, fluent English)

# Discussion

## Results in context

Seventy-four important treatment outcomes were reported by the UK Punjabi women with RA in this study, 21 of which were new when compared to the White British data (Sanderson et al., 2010b). In addition, the experience and cultural meaning of some outcomes, such as pain, fatigue and disability, were different. For example, the burden of disability linked to the cultural value of one's duty towards family. In other research, South Asians with musculoskeletal disorders are reported as being more likely to describe pain as radiating through the body, as paralyzing and precarious, and being linked to domestic social burdens compared to African-Caribbean participants (Rogers, Allison, 2004). It is possible that different cultures express or interpret symptoms, as well as experience them, differently. For example, the outcome 'body feels heavy' in these data may indicate a different interpretation of fatigue, but refer to the same symptom. Therefore, it is paramount to focus on the patient perspective, and include those who speak English fluently (as well as their 'mother' tongue) and are acculturated to the newer culture in order to be able to discuss potential issues of language and cultural translation. It is also important for health professionals to be open to new expressions of symptoms and the impact arising from specific cultural contexts.

Among the older women in particular, there was a reluctance to describe the psychological impact of RA. This may be linked to religious teachings. For example in Sikhism, to worry or be troubled by one's fate is not only bad for one's health, but is also morally wrong because it demonstrates self-centredness ('*haumai*') or I-ness (*mai)* (McLeod 1984). Overall, the Punjabi women appeared to find it more difficult to describe what they meant by 'feeling well', compared to the White British RA patients who readily described its multidimensionality (Sanderson et al., 2010c). However, it was evident that well-being focused on the support, harmony and security of the family, rather than on individual satisfaction with life. Where well-being is assessed in a global question, such as emotional well-being in the Rheumatoid Arthritis Impact of Disease scale (RAID) (Gossec et al. 2009), participants from different cultural groups may be unsure what is being asked or answer according to different experiences and conceptualisations of well-being.

Focus groups with English-speaking Asian systematic lupus erythematosus (SLE) patients in Singapore also found that domains of family, relationships, and stigma and discrimination were important to patients and were not addressed by existing SLE-measures (Ow et al. 2011). In the current study, the common importance of the outcome ‘able to carry our duties to family’ indicates that it is not simply a question of whether a patient is physically able to undertake activities of daily living, but of the societal consequences of functional restriction. Differences in cultural values and expectations can thus affect the outcomes that are clinically meaningful to patients and their caregivers (Chiu, Lam 2007). The social theme indicates a broader impact of chronic illness than is usually addressed by core sets, but is increasingly recognised as relevant (Sanderson, Kirwan 2009). However, these social outcomes may not be easy to measure, or to change through clinical interventions. For example, issues related to family or cultural dynamics may need to be supported through public health interventions instead.

The American College of Rheumatology (ACR) core set for RA includes tender and swollen joint count, patient’s assessment of pain, physical function and fatigue, physician’s and patient’s global assessment of disease activity, and an inflammatory marker (Felson et al., 1993; Kirwan et al., 2007). Some treatment outcomes described as important by these participants, such as stiffness and ability to work, are not included in this core set developed with professionals. Although function is assessed, the recommended measure is the HAQ (Fries et al., 1980), and this may contain inappropriate items. For example, “Are you able to cut your meat?” is not appropriate for patients who are vegetarian, and may lead to missing data. Patients’ priority outcomes, selected by 98.0% White British RA patients in a national survey, included pain, fatigue, joint damage, activities of daily living, mobility, independence, valued activities and life enjoyment (Sanderson et al., 2010a). In the Punjabi data, although there is evidence that the first six of these priorities are relevant to these patients, valued activities and life enjoyment obtained less support. This exploratory study indicates that the current professional and complementary patient core sets in RA may not capture all of the outcomes that are important to female Punjabi RA patients; this may have relevance for other cultural groups.

## Strengths and weaknesses of the study

This was an exploratory qualitative study to determine whether treatment priorities were different for one minority group (female Punjabi patients), in comparison to previous research with White British patients (Sanderson et al., 2010b). It is known that male experience of RA is different from females' (Lack, Noddings, Hewlett 2011). Only women were approached for this study, and Punjabi men's experience may be different and provide additional outcomes. In common with other qualitative studies it cannot be assumed that our sample is representative, but we aimed to describe a diverse range of experiences and views within this specific cultural group.

## Implications for clinical practice and research

In relation to core set methodology and cultural salience, there are several issues to consider. First, the core outcomes as well as the outcome measures must be appropriate to all cultural groups of patients. That is, issues of face, content, construct and criterion validity should be addressed. For example, when symptoms may differ experientially among cultural groups it is important to measure what it is intended to measure. Second, cultural factors may affect the interpretation of a clinically meaningful outcome (Chiu, Lam 2007) and thus issues of reliability and sensitivity to change need to be addressed. For example, where extended families are supportive, a change in functional ability may have less of an obvious impact on functional assessments, and not discriminate between situations of interest. Third, the pragmatic reality of developing a culturally salient core set should be considered. How many cultural groups should be consulted? Should qualitative research with different cultural groups of patients be conducted routinely to underpin subsequent cultural adaptation and translation of instruments? At what stage is cultural appropriateness of core sets considered?

Cross-cultural adaptation of outcome measures usually occurs after an instrument has been constructed and validated in a source language, following published guidelines (Beaton et al., 2000). Misfitting items (e.g. due to differences/ ambiguity in meaning or irrelevance) are problematic (Woodburn et al., 2012), but may be avoided if cultural validity was addressed at the stage of identifying outcomes or items. Research into the cultural salience of mental health outcomes is more established and may provide guidance in considering these complex issues for core set methodology (Verhey et al. 2004). Ultimately, we should ensure that interventions are evaluated using criteria that are meaningful to patients.

## Unanswered questions and future research

This study provides evidence that further qualitative research is required to explore what outcomes are important to RA patients (women and men) in other cultural groups. The sociological implications of the data on stigmatisation and on the inability to carry out family duties according to social norms will be discussed indepth elsewhere. Consensus techniques with multicultural representatives could be used to determine culturally salient patient priority outcomes for RA. This could provide a model for core set methodology that is culturally appropriate.

## Conclusion

Seventy-four treatment outcomes were elicited from female UK Punjabi RA patients, including 21 new outcomes that were not previously identified. The new outcomes included additional symptoms, functional restrictions, psychological effects and social impact, some of which were culturally specific. This study provides evidence that further research is required to understand whether the RA core sets are appropriate across different cultural groups. It also illustrates a need to address cultural salience in core set methodology across all health conditions.

## Acknowledgements

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## Conflicts of interest

TS received a grant for conducting the submitted research from the MRC/ESRC (G0802695); SH has been paid by PharmaQuest and UCB for consultancy work; KR has received grant funding from UCB, honoraria from Pfizer and UCB, and conference expenses from UCB and Roche; KK was supported by the European Community 6th Framework Programme, AutoCure Project; there were no other relationships or activities that could appear to have influenced the submitted work.

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## Figure legends

Table 1: Participant characteristics

Table 2: Outcomes identified as important by both female Punjabi and White British RA patients in interviews

Table 3: Outcomes identified as important divergently by female Punjabi and White British RA patients in interviews

Table 4: Sample quotations of outcomes related to RA experience from interviews

Table 5:  Sample quotations of prioritisation of outcomes from interviews

**Table 1: Participant characteristics**

| **Characteristics** | | **Mean (S.D.)** | **n** |
|---|---|---|---|
| Age (years) | | 49.4 (12.9) | |
| Disease duration (years) | | 10.7 (12.1) | |
| Functional disability[a] | | 1.37 (0.77) | |
| Patient global[b] | | 4.13 (1.60) | |
| English proficiency: | None or limited | | 5 |
| | Proficient or fluent | | 11 |
| Education: | Did not finish primary school | | 1 |
| | Primary school | | 7 |
| | Secondary school | | 2 |
| | University | | 6 |
| Religion: | Sikh | | 10 |
| | Muslim | | 3 |
| | Non-practising | | 3 |
| Generation: | First (migrated to UK) | | 11 |
| | Second (UK born) | | 5 |

[a] Health Assessment Questionnaire: range 0-3, 3=severe disability [b] "Considering all the ways your arthritis affects you, how well are you doing?" range 0-10, 10='very well'

**Table 2: Outcomes identified as important by both female Punjabi and White British RA patients in interviews**

| Theme | 53 Outcomes identified by both groups of patients (*=elicited from >8 Punjabi patients) |
|---|---|
| Physical health | Less pain* |
| | Less stiffness* |
| | Less swelling |
| | Less fatigue (tired/exhausted),* Tiredness is earned; More energy |
| | Sleeping better |
| | Feet better |
| | Less weakness in joints |
| | Less (i.e. fewer) bad flares; More good days; More predictable disease |
| | Feeling better |
| | Visible signs less; No more joint damage; Avoid surgery |
| | Reduce effect on fertility |
| | Less side effects from medication; Reduce medication |
| | Able to drive |
| | Able to exercise* |
| | Doing everyday things* |
| Mental health | Better mood (e.g. less irritable/ anxious/ upset); |
| | Less depressed; Less stressed; Less frustrated |
| | Confident in planning |
| | Feel useful |
| | Feel (more) normal; Feel well; Return to/maintain a normal life |
| | Feel mentally stronger e.g. empowered |
| | New interest in things/people/life |
| | Feel younger/ equivalent to peers |
| | Brings you out of yourself e.g. feel ‘lighter’ |
| | Forget have RA/ focus not on RA |
| | New lease on life; Life back on track |
| | Enjoy life |
| | Qualify of life improved |
| | Life more manageable |
| | Cope (better) with emotional aspects |
| | Cope (better) with physical aspects |
| | Cope with external pressures |
| Social health | More mobility (i.e. getting around) |
| | More independent* |
| | Able to work* |
| | Do things you want to do |
| | New relationships/ socialise more |
| | Others close to you happier |
| | Others aware of improvement |
| | Maintain/ regain sense of own identity |
| | Less embarrassed by appearance (including clothes and shoes) |

**Table 3: Outcomes identified as important divergently by female Punjabi and White British RA patients in interviews**

| **Theme** | **New outcomes identified by Punjabi patients** (*=elicited from >8 Punjabi patients) | **Outcomes identified by White British patients, but not by Punjabi patients**[15] | **Top 8 priorities as ranked by White British patients in survey**[3] |
|---|---|---|---|
| Physical health | Greater bodily strength<br>Stand more easily<br>Easier to lift objects/children*<br>Able to do things more quickly*<br>Body feels less heavy<br>Less time lying down<br>Sit cross-legged<br>Grip more easily | Quicker recovery<br>Having a physical relationship | Pain<br>Fatigue<br>Joint damage<br>Activities of daily living |
| Mental health | Feel less angry<br>Regain sense of freedom<br>Feel less isolated<br>Avoid hospital (because of isolation)<br>Less worried about children's future | Feel more settled<br>More confident<br>More possibilities/choices<br>More motivation | Life enjoyment |
| Social health | Avoid stigma and discrimination<br>Less embarrassed by actions/disability<br>Groom oneself properly<br>Eat with hand confidently<br>Feel less ashamed<br>Maintain dignity (self-respect)<br>Able to carry out duties to family<br>Feel less guilty | | Independence<br>Mobility (getting around)<br>Valued activities |

**Table 4: Sample quotations of outcomes related to RA experience from interviews**

| New outcomes by theme | Sample quotation of experience |
|---|---|
| **Physical health** | |
| Greater bodily strength | "I didn't have that much strength in my arm. I couldn't reach and push them in (light bulb), so I had to get people around to do things like that." (B8: 2G*, fluent English) |
| Stand more easily | "We used to stand in our job nearly all day. I couldn't stand for long time, I used to do eight or nine hours." (B9: 1G, minimal English) |
| Easier to lift objects/ children | "I was getting worse there [work], lifting my shoulders as well. You have to move big loads and everything there. They used to say "You have to carry on, if you can't do it, then just go."" (B3: 1G, no English) |
| Able to do things more quickly | "I used to work so fast.... I get tired, I can't do things quickly anymore." (C4: 1G, no English) |
| Body feels less heavy | "I feel my body is heavy." (B9: 1G, minimal English)<br>"I was just aching all over my body, and it was like this tiredness and this heaviness that I hadn't being having before." (A2: 2G, fluent English) |
| Less time lying down | "I've been feeling so tired all the time, I feel I have to lie down all the time." (C3: 1G, proficient English) |
| Sit cross-legged | "I haven't been to the temple because you have to sit cross-legged on the floor and I can't do it, I can't go." (B7: 1G, fluent English) |
| Grip more easily | "I find it difficult to do some jobs like clean up, like grip the vacuum." (B5: 2G, fluent English) |
| **Mental health** | |
| Less angry | "I don't feel sorry for myself, I feel angry. I feel angry because, I think probably because I feel tired all the time." (C1: 1G, fluent English) |
| Regain sense of freedom | "I couldn't do things myself. I do like to do my chores myself. I feel my freedom has gone." (B3: 1G, no English) |
| Feel less isolated | "With Asians, if they develop arthritis, they become secluded. [...] They'd rather hideaway than allow the world to see that they're not well." (C2: 2G, fluent English) |
| Avoid hospital | "I don't like to come in hospital, I miss my house... I was felt down all the time you know but, you know, say you got no like proper life." (C3: 1G, proficient English) |
| Less worried about children's future | "I used to think that my children are young. Who will look after them? I mean the fact that I was so ill and in bed." (B1: 1G, minimal English) |
| **Social health** | |
| Avoid stigma and discrimination | "If you've got an illness which many people don't know about... Especially in the Asian community, because they're really good at being, "Oh what's wrong with her?" (A2: 2G, fluent English) |
| Feel less embarrassed by actions / disability | "I had two sticks but I used to avoid them. I used to hold on to the walls." (B1: 1G, minimal English) |
| Groom oneself properly | "Even when I go out I feel I haven't dressed myself properly... I don't feel that I look right. I haven't done my hair." (B3: 1G, no English) |
| Able to eat with your hand confidently<br>Less ashamed<br>Maintain dignity | "I can't socialise like before. I feel ashamed in front of others when I drop things, but I try and can't even eat. I feel my dignity is not there anymore." (B3: 1G, no English) |
| Able to carry out duties to family | "It should be mother look after children, you know, not children look after the mother." (C3: 1G, proficient English) |
| Feel less guilty | "I've felt quite guilty not being able to do what I was supposed to be doing" (C2: 2G, fluent English) |

*1G= First generation, 2G=Second generation

**Table 5: Sample quotations of prioritisation of outcomes from interviews**

| **Priority outcome as selected from survey**[3] | **Sample quotations from Punjabi interviews** |
|---|---|
| Pain | "The pain is more of an issue... it's more pain than anything else." (B5: 2G, fluent English) |
| Fatigue | "Fatigue is quite important to me now... I could sleep for England." (A1: 2G, fluent English) |
| Joint damage | "I am determined now to make sure that nothing happens to my joints, my fingers getting bent or anything." (B7: 1G, fluent English) |
| Activities of daily living | "Do everything that's normal for me." (B3: 1G, no English) |
| Life enjoyment | *Was not described explicitly as a priority* |
| Mobility | "I'm up and mobile and that's what is important" (B2: 1G, minimal English) |
| Independence | "I just want to do all my things for myself." (B1: 1G, minimal English) |
| Valued activities | *As a second priority*: "What it has affected is my choice of leisure activities. I would be much more active if it wasn't for the RA." (B6: 1G, fluent English) |