# The moral experience of illness and its impact on normalisation: Examples from narratives with Punjabi women living with rheumatoid arthritis in the UK

**Abstract**

The moral component of living with illness has been neglected in analyses of long-term illness experiences. This paper attempts to fill this gap by exploring the role of the moral experience of illness in mediating the ability of those living with a long-term condition (LTC) to normalise. This is explored through an empirical study of women of Punjabi origin living with rheumatoid arthritis (RA) in the UK. Sixteen informants were recruited through three hospitals in UK cities and interviews conducted and analysed using a Grounded Theory approach. The intersection between moral experience and normalisation, within the broader context of ethnic, gender and socio-economic influences, was evident in the following: disruption of a core lived value (the centrality of family duty), beliefs about illness causation affecting informants' 'moral career', and perceived discrimination in the workplace. The data illustrate the importance of considering an ethnic community's specific values and beliefs when understanding differences in adapting to LTCs and changing identities.

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*Introduction*

The moral component of living with illness is not new, but is often overlooked in analyses of experiences of LTCs. Charmaz's (1999) hierarchy of *moral status* in living with a LTC illustrated how a sick person's ability to make moral claims can change over time (from validated to accepted to questionable) and lead to a loss of moral status. Moral status may be contested by others and individuals often risk the deterioration in their condition to lessen the impact on their identity as a competent actor, for example, functioning mother, husband, worker (Charmaz 1999). Bury (2001:274) describes the *moral narratives* that are evident in descriptions of biographical disruption as evaluating the links between the person and the social, as 'sufferers seek to account for and perhaps justify themselves in the altered relations of body, self and society brought about by illness'. Bury (2001) shows that moral narratives may be used to exonerate the individual from blame and maintain self-worth, where others may portray culpability. Both of these authors describe the role of legitimisation of illness in indicating a larger problem about how to reinstate one's morality and identity.

Early recognition of a moral component in illness and disability is found in the contributions of Goffman (1963), Erikson (1966), and Scott (1969) in their analysis of the concept of stigma and provide a tangible example of morality in the illness experience. For example, Goffman (1963) describes stigma as occurring through a "moral career"; when a stigmatized person learns society's standpoint and what it might be like to possess a particular stigma. Yang and colleagues (2007:1524) used the concept of *moral experience*, or '*what is most at stake for actors in a local social world*', to understand the stigma of mental illness in China and the United States since it allows an examination of what really matters and what is threatened. Stigma processes may occur during key times that introduce patients (and family) to stigmatized "careers", which may be culturally determined (Yang et al. 2007), such as marriage. By understanding how the individuals' and their community's core lived values

and actions are affected by and shape the lived experiences of illness, it may also be possible to explain how the moral experience affects the ill person's ability to adapt over time, and what mediates this relationship between moral experience and adaptation.

The concept of stigma has been differentiated into problems of knowledge (ignorance or misinformation), attitudes (prejudice) and behaviour (discrimination) (Thornicroft 2006). One of the ways in which an individual may hope to limit discrimination is through normalisation. Knafl and Deatrick (1986) identified four elements in this normalisation process: (1) acknowledging the impairment is present; (2) defining life as basically normal; (3) minimising social consequences of the illness; and (4) engaging in behaviour that demonstrates normalcy to others. However, this may be difficult in communities where illness is viewed as a person failing, isolates affected individuals, and where extended families living together provide little privacy (Kett et al. 2010). There is little evidence about how ethnicity and culture affect illness management strategies. Anderson and colleagues' (1989) study described how the moral discourse around normalisation differed between Chinese and white families living in Canada. Importantly, the authors emphasized that it may be the material circumstances of people's lives, rather than ethnic differences that explained differing belief systems.

Ethnicity in this paper is concerned with notions of language, culture, religion, nationality and shared heritage (Fenton 1999, Modood et al. 1994), and how these influences further complicate living with a LTC. Identity is fluid, contingent on social circumstances, economic position and individuals' choice of characteristics with which to define themselves (e.g. language or religion) (Karlsen & Nazroo 2006) and studies collecting data at one time point may provide a static snapshot of a concept that changes through time and space. Ethnicity may be defined in terms of lifestyle, rather than ancestry or skin colour (Karlsen 2004), and

therefore individuals' definition of ethnic identity may put more emphasis on shared traditions, beliefs, practices or tastes (e.g. in clothes) than in traditional classifications found in the literature. It is beyond the scope of this paper to provide an overview of the literature on health and ethnicity (see e.g. Davey Smith et al. 2000), but there is a lack of literature examining the intersectionality of ethnicity, gender, class and socio-economic factors in the meaning of (ill)health. Cooper (2002) illustrated that gender inequality remained after adjusting for socio-economic characteristics in health disparities, and therefore we consider gendered expectations in particular an important aspect to explore in relation to normalisation.

The original aim of the study was to determine important treatment outcomes for Punjabi women living with RA in the UK (Sanderson et al. 2012), but it was found that there was substantial data on the importance of normality and wanting to lead a 'normal life'. The aim of this paper is to present how the moral experience of illness and the process of normalisation intersect for Punjabi women living with RA in the UK.

*Methods*

A pragmatic decision was made to recruit UK Punjabi RA patients, given existing collaborations with rheumatology clinical consultants with access to sufficiently large numbers of a minority population to aid recruitment. Given the complexity of ethnicity and culture, this study focused on one cultural group: those self-defining as Punjabi, which was characterised by speaking Punjabi, migrating from the traditional area of the Punjab region, or having relatives that had done so, but within the context of currently living in the UK. The intention was to avoid creating a heterogeneous group of participants, which is common in

4

rheumatology research (e.g. South Asian) and it is believed through feeding back of emergent themes to subsequent informants that a shared identity of UK Punjabi is appropriate.

Face-to-face interviews were conducted since they allow in-depth understanding of the personal context of the participants and are well suited to researching complex phenomena (Ritchie & Lewis 2003). Informants with a confirmed diagnosis of RA (Aletaha et al. 2010) were recruited through three teaching hospitals in three English cities with diverse Punjabi communities (in terms of size and dominant religion). Patients were identified from medical notes available prior to clinical appointments by clinical staff and approached by professionals able to speak Punjabi when they were available. Information was available in written English and an audio Punjabi version since many individuals of Punjabi origin are unable to read the script.

Recruitment focused initially on those who were first generation migrants since these were thought to be harder to recruit.[i] Informants were purposively sampled for age, being first or second generation, English proficiency, disease duration, self-reported disease severity, functional disability, and religion. Diversity was achieved, apart from religion where most informants were Sikh and this reflects the dominant religion of the Punjabis living in the three recruitment locations.

Of the 42 women approached to participate, 19 were recruited, but three did not attend the interview due to a flare up in their condition. Feedback indicated that these Punjabi women regardless of socio-demographic background were wary of participation in research, and disinclination from their families was sometimes very strong. In total, 16 informants were interviewed (Table 1). Two informants were interviewed at work and 14 in the respective hospital premises in a private room, away from their usual place of care. Homes were often housing many family members (up to 14) and it was thought that this may be problematic for

interviewing for reasons of confidentiality, although the setting would have provided valuable context.

INSERT TABLE 1 HERE

Informants gave written informed consent and completed a pre-interview questionnaire, which included demographic and illness-related questions to describe their characteristics. Five interviews were interpreted by KS (a nurse researcher based at one of the hospitals, but who for consistency interpreted across all three sites). Interviews began with a general invitation to "Tell me about your health" to enable data to emerge spontaneously, before prompting was used to address more specific themes identified from the literature (see Figure 1). The older informants generally found the broad opening question difficult and prompting around the impact of RA on their lives was required to build their confidence about their ability to contribute to the interview. A female Punjabi patient research partner was involved throughout the study, including interpretation of the data. The interviews were recorded and transcribed verbatim.

Where interpretation was needed, KS provided the translated transcript and the translation in a sample of these were verified by a professional, independent interpretation service. This was particularly valuable in translation of concepts such as disability or social circle, and was overcome by asking informants to clarify with concrete examples. Cross-checking between interpreted and uninterpreted data for differences in expression was helpful in minimising the effect of translation on the process of analysis. The dynamics of conducting interpreted interviews with two researchers (one with a clinical background has been reflected upon in detail elsewhere (Sanderson et al. 2013).

INSERT FIGURE 1 ABOUT HERE

A Grounded Theory approach was used in order to develop theory around the moral experience of illness, grounded in data systematically gathered and analysed (Strauss & Corbin 1998). Data were initially coded to identify treatment outcomes important to the informants (Sanderson et al. 2012). The large amount of data on normality outcomes was further coded by cross-reference to the contextual explanations that informants gave for a lack of normality or challenges to self-management. In seeking to understand the similarities and differences in normalisation, it became evident that the moral experience of illness was central to their narratives, particularly in the micro-context of the daily life of informants. Last, 'normality typologies' (Sanderson et al. 2011) were applied to each informant to determine whether these categories mapped across to these data by matching their profiles to the descriptions given for each typology (see Table 1).

Data were primarily analysed by TS, and a sample of the transcripts were double coded by members of the interdisciplinary team, who were experienced in qualitative analysis. Data saturation was reached after 16 participants in relation to the intersection of their moral experience and the normality typologies. Ethics approval was granted by the local Research Ethics Committee (ref. 10/H0102/10).

*Findings*

The findings are in two parts. First, two case studies are presented, which illustrate the diverse moral and normalisation experiences of a first generation and a second generation woman. Second, the different influences on moral experience will be examined to provide an explanation for differences in normalisation. The analysis will therefore focus on the explanatory value of ethnicity, gender, and socio-economic position for understanding the interrelationship between moral experience and normalisation.

*Part one: Case studies illustrating the diversity of moral and normalisation experience of RA among UK Punjabi women*

Case study 1 provides an overview of the experience of a first generation woman.

INSERT CASE STUDY1 HERE

Case study 2 provides an overview of a second generation woman.

INSERT CASE STUDY 2 HERE

It is not the intention to imply that the experiences are diverse only due to the generation. A difference in the social position of the first and second generation informants was evident, partly due to most first generation women being older with ageing shaping their narratives, but also due to macro-contextual factors such as lack of education.   However, there were also commonalities across the generations, such as the strong cultural value of 'family duty', which will be explored next.

*Part two: The interrelationship between moral experience and normalisation*

The common cultural influences affecting the Punjabi women's moral experience of illness will now be addressed, using other informants' experiences to expand on the relationship between moral experience and normalisation in the case studies.  Attention is focused on three main influences on moral experience: disruption of a core lived value (the centrality of family duty), how beliefs about illness causation affect informants' moral career, and perceived discrimination in the work place.

*The core lived value of the 'centrality of family duty'*

This was a recurrent theme throughout the data, which focused on the women's expected

social roles within the family and how the illness affected their ability to fulfil their

"responsibilities". Although previous research showed that (predominantly) white British

women with RA were sometimes concerned about being a 'proper mother or wife'

(Sanderson et al. 2011), there was not the same explicit emphasis on duty or responsibility.

This has implications for the moral weight attached to not being able to fulfil this social role.

The influence of traditional social norms around gendered roles and expectations was

described by all age groups, from the first generation grandmother to the second generation

'acculturated' daughter.  The RA threatened to interrupt a valued social cycle of caring and

being cared for, which they implied was different from mainstream gender-appropriate

behaviour towards one's family:

> *"It is our duty to look after the children when they are small.  It is when I can't do things any more, that is when I will expect my children to do things for me.  So then it is their duty..." (Jai: first generation, None/Limited (L) English)*

> *"It's about having that responsibility for your elders. When you're a youngster they raise you.  When they're old you're there for them and that's how Punjabi culture is." (Jasnam: second, Proficient/Fluent (P/F) English)*

The timing of the onset of symptoms was crucial for the magnitude of impact that this

cultural value had on the individual's illness experience.  Those who were diagnosed in older

age were affected by personal feelings of guilt for being a "burden", dependent, and in need.

These older women still valued independence highly and wanted to contribute to looking

after the younger members of the family, despite the expectation that they would be cared for.

Although their dependence signalled a diminishment of their social worth to themselves

(because they could no longer fulfil the social roles that had previously given them social

status), the anticipation (Williams 2000) of illness in older age by the community meant that their illness was to some degree legitimised.

However, where onset of symptoms occurred earlier in life, the social impact of the illness was seen to be devastating. Abinaash's experience was shared by others of traditionally marriageable (and reproductive) age. The key times when a diagnosis could initiate a stigmatised trajectory (Yang et al. 2007) and thus cause significant 'biographical disruption' (Bury 1987) or struggle to maintain normality were when arranging a marriage, being newly married and/or having young children to care for. Being diagnosed at a young age with a LTC appeared to create 'moral questionability' (Charmaz 1999) about women because it was not biographically anticipated by others.

> "They [the older generation] feel like you must have done something. Because they just don't understand that: how can young people get ill." (Sukhnam: second, P/F)

As a result, for those with unsupportive in-laws, little or no allowances were made for the invisible symptoms of pain and fatigue, and the effect that these had on carrying out everyday activities. When living with large extended families (the largest household was 14 people), the workload at home could be substantial. The psychological burden was increased when the woman was living with her in-laws because she perceived an increased need to prove her ability to fulfil her duties and maintain her moral status.

> "I mean I don't have no support, no support whatsoever... I can't tell my mother-in-law, "Look, I've done this room, I've done that room, and now I'm going upstairs because I feel embarrassed to work in front of you."." (Keerat: second, P/F)

Abinaash, with her parents' support, decided to abandon her pursuit of a traditional marriage arrangement and the social expectations attached to traditional married life afterwards. However, Keerat could not remove herself from the social roles that aggravated her illness

because it would mean leaving her husband's family and a loss of social status that would affect her children's lives. She talked about her current pregnancy in an extreme example of her need to prove her place in her husband's family:

> *"I felt like I was forced [in]to having this baby just to prove that I'm able to (sobs) give you grandchildren or, you know, able to have kids." (Keerat: second, P/F)*

The social roles described by the informants created not only a social expectation, but also a duty that the daughter-in-law will be capable of looking after the family and will put their needs first:

> *"You see we have this concept in our community that if you have bore boys then they should look after you. Our community relies on sons and daughters-in-laws." (Birinder: first, None/L)*

In one case, the lack of support extended to disapproval of attending hospital appointments because of the impact this would have on the woman's workload at home. This could be viewed as an attack on the moral worth of this woman within the family and the legitimacy of the seriousness of her illness.

Thus, the core live value of the 'centrality of family duty' appears to have created a shared conceptualisation of what constitutes 'normal' life for a Punjabi woman, which is easily threatened by a LTC and has tangible consequences:

> *"What was once a massive sense of duty, we'll look after them in their old age, now it's a huge burden of guilt. It's going to tear my husband in half really, you know it's awful for him, but I know it's affected my health." (Jasnam: second, P/F)*

Therefore, those informants who were unable to fulfil their gendered social roles, as expected within their 'traditional' group identity, tended to present a 'struggling with normality' typology, whereas those who felt that they had already fulfilled their family duty or had

supportive families who altered their expectations illustrated 'resetting normality' as dominant and showed evidence of normalisation. For example:

> *"There is no sympathy, there is no excuse. [...] I need to be able to do things that are [pause] very normal for other people, but for us it's such a struggle just to open a jar." (Keerat: second, P/F)*

> *"I don't worry about that [housework] anymore because they [children] all grew up... If you control things yourself, to me that is normal." (Birinder: first, None/L)*

It was evident that how much agency an informant illustrated in her everyday life, whether she felt in control or that family members were, and how tied she was to a 'traditional' female Punjabi role, impacted on her ability to reconceptualise what constituted normal life. The ability to normalise the illness therefore appeared to be influenced by an informant's position in the traditional gendered social cycle, the consequences of the diagnosis, disclosure and symptoms at key social times, and how willing/ able she was to achieve social expectations in a different social space.


*Beliefs about illness causation*

Commonly, the first generation Punjabi women made sense of the development of RA as a consequence of past "bad" actions. This karmic explanation was also reported by the second generation women to be a common explanation for the onset of illness amongst the Punjabi elders.

> *"I do think that I must have done something bad in my last generation and that is why I have this arthritis." (Aman: first, None/L)*

> *"You deserve to be ill because you were a bad person or something, there is a lot of that." (Deepinder: second, P/F)*

This moral judgement, either made by the woman herself or by others, leads to a 'discreditable' status, countering moral claims that the individual is deserving of support. Gurveer (Case study 1) did not want to disclose her illness to others because of the assumptions they would make about her moral character. Goffman's (1963) 'moral career' is

made explicit through these illness narratives where the onset of an illness is perceived as the outcome of discreditable action made tangible.

The assignment of self-blame may indicate why illness is commonly hidden from others among the Punjabi community, both in the UK and "back home", in order to avoid the moral judgements and consequent stigmatisation:

> "A lot of times you won't find out if somebody is ill with anything in our people." (Chann: first, P/F)

> "I got married in Pakistan.  My husband said "Don't tell them you're ill [with RA]... they're going to know I've got an ill wife"." (Nirmail: second, P/F)

The second generation women wanted to distance themselves from the discriminatory attitudes of their elders, perhaps enabling them to attempt to maintain a more elevated moral status.

Some of the women (both first and second generation) were fatalistic, believing that being diagnosed with RA was a predetermined fate that was unalterable except by God's will:

> "The doctors do try, but they are not God.  We have to accept that we have this condition, but let's face it, that God has the ultimate control." (Aman: first, P/F)

Charmaz (1999:368) wrote that 'suffering can award an individual an elevated, even sacred, moral status'.  Although one woman described herself as a "superwoman" for coping with the illness and continuing to present a normal life, these fatalistic beliefs undermined an externally elevated status.  Due to the association of illness with immoral activities amongst the elders, the ill health experienced by the women was not publically acknowledged and RA almost always led to a diminished moral status within the community.  However, with two exceptions, these 'fatalistic' women also described their agency in how they lived with the

disease, for example, utilising self-management strategies and adhering to their prescribed treatment:

> *"If God gave me the disease he has to put it right as well and give me relief. I am taking the medication, my body functions at least." (Jai: first, None/L)*

Therefore, these beliefs about illness causation did not necessarily prevent the informants from practically managing their condition, but appeared to influence their ability to incorporate it cognitively into their sense of normal life. Lived religion is often difficult to differentiate from ethnic cultural mores and expectations (Ahmed 1992), so it was not possible for them to pinpoint where these beliefs originated and to resist discriminatory practices.

Enacted stigmatisation was commonly thought to be caused by a lack of understanding about disease in general, and RA specifically, amongst the older generation. However, it was not only older people that were described as not understanding, but also those who had recently arrived from "back home" where there was a different concept of health and illness.

> *"They [the older people] don't really understand what it is... I don't think they'd be able to actually understand the biology behind it and the physiology behind it." (Sukhnam: second, P/F)*

> *"I don't think my husband understands what it [RA] actually is. He's from Pakistan, obviously different culture, different way of thinking." (Nirmail: second, P/F, husband arrived in UK 7 years ago)*

Amongst the informants, there was an unanimous perception that other illnesses were viewed as more serious (by both the community and the informants themselves despite some high levels of self-reported disability). For example, RA was thought of as less serious because the symptoms and treatment side effects of cancer, diabetes or heart disease were worse:

> *"What can be worse than cancer? I don't think that arthritis is serious. Look, let me tell you my sister-in-law had it [cancer] and her hair fell off." (Jai: first, P/F)*

> *"At least I only have RA and not diabetes or any other disease" (Dhiaan: first, None/L)*

> *"I have seen people with way, way worse things, you know, people with heart problems.  And this [RA] is nothing." (Chann: second, P/F)*

This comparison of RA to other conditions (acute and long-term) results in a devaluing of the severity of their illness and its consequences.  The lack of understanding about the intangible symptoms of RA such as pain and fatigue, and the potential long term joint damage and disability, would explain why many of the informants were 'struggling with normality' and unable to reset or return to normality.  Even if symptoms could be alleviated by medication, it appears that the diagnosis, continuation of medication and hospital visits would maintain a stigmatised status and could prevent normalisation from occurring.

The differences between the first and second generation women may signal how able or willing they were to acculturise, that is, move away from 'traditional' beliefs about illness causation in favour of allopathic explanations that removed self-blame. This is illustrated by a younger first generation woman (Ajeet, 36 years) who identified less with her elders' views and more with her peers:

> *"The older ones are ashamed. They want to hide. They won't go out in a wheelchair. I'm not like that." (Ajeet: first, P/F)*

Although informants talked about the importance of their religious beliefs in their lives, there were not specific teachings or beliefs quoted about how to cope with illness or clear difference between the Muslim and Sikh women in how they normalised illness.

*Discrimination in the workplace and mediating factors*

Loss of self-worth was also caused by perceived discrimination in the workplace. All but one informant had worked outside the home in paid employment (including those employed in

family businesses).  There were common experiences of struggling to continue work because of RA symptoms, particularly due to joint stiffness affecting mobility in the morning, painful and weak joints impacting on physical tasks, overwhelming fatigue resulting in lack of concentration, and where relevant, standing for extended periods:

> "After six months I got really bad so I had to stop for good. It was all factory work [...] We used to stand in our job nearly all day. My legs used to give way." (Jai: first, None/L)

However, there was a difference between the first generation women and those born and educated in the UK.  The older women described how the RA led to their cessation of employment because the nature of the work and work environment was unsuitable, including long hours and manual work:

> "I started a 12 hour shift [at a factory] and I was getting worse after that. Moving the big loads." (Gurveer, B3: first, None/L)

> "We have [had] to sell the shop [...] All I wanted to do is stay in bed, so my husband couldn't do it on his own." (Narinder: first, P/F)

These informants were unable to get any job accommodations for their work disability due to communication barriers, lack of education/qualifications that limited the type of employment they were engaged in, and/or implicitly a lack of knowledge about rights or confidence in asserting them:

> "I have the problem of English, that's the only thing that has kept me behind really." (Aman: first, None/L)

> "I can speak English, but I don't know how to construct my sentences properly. Sometimes it's hard to understand." (Jai: first, None/L)

The acceptance of discrimination may indicate differing perceptions of citizenship, or cultural changes between generations, as signalled through maintenance (or not) of attitudes perceived as 'traditional' to an ethnic (minority) group (Nazroo & Karlsen 2203; Karlsen 2004), but further research is required to clarify this.  Similarly to Gurveer (Case study 1), these informants found the loss of work distressing and this discrimination led to a devaluing

of their status as citizens in their 'adopted' country and their self-identity as providers for their children's futures. As migrants, their socio-economic position is in the UK, whatever their former status 'back home' may have also contributed to illness as a barrier to continued employment (see Elstad 1996; Nazroo 1998 for fuller discussion).

In contrast, the second generation women interviewed described no work discrimination and were often offered job accommodations by understanding employers that meant that barriers to working with RA were overcome:

> "My boss is really, really good and I spoke to the Occ. [Occupational] Health here. Occ. Health said work from home two days a week." (Jasnam: second, P/F)

Similarly to Abinaash (Case study 2), these professional informants were confident in disclosing their illness because they knew that there was flexibility in time management and the ordering of tasks within their position. However, there were two exceptions. One informant had not disclosed to her employer due to fear of dismissal, but had to a trusted, supportive colleague:

> "Obviously I haven't told work [about RA], so I just carry on doing it. I had a colleague that was helping me but she sort of understood what I was going through." (Nirmail: second, P/F)

In the other case, the informant had disclosed her illness to her employer, who had attempted to make accommodations, but due to the nature of her job (as a dinner lady) was unable to continue with her work. Those informants with a university education had obtained work that was more flexible and could be adjusted to the fluctuating RA symptoms. These resources mediated the potential for a devalued status in a work setting for all but one of the second generation women (who did not have a degree) and resulted in them not being excluded from a meaningful activity. For those that had lost work, the diminishment in moral status was evident:

*"I don't work and I hate it. I really hate it... Because I don't go to work I feel guilty now." (Narinder: first, P/F)*

In relation to normalisation of their illness, the loss of employment may substantially affect their ability to 'reset normality' since a major component of their role identity has been altered. The intersection of illness and work disability requires more attention but is mentioned briefly here to illustrate some of the mediating factors that affected the moral experience of illness in these women's broader context.

**Discussion**

The moral narratives in these data, as highlighted in the case studies, focus on the difficulty of escaping culpability for the onset of the illness and its consequences. This difficulty particularly resulted from beliefs about illness causation that blame the individual for the onset of illness, and disruption to social roles and expectations underpinned by the core lived value of the 'centrality of family duty'. This illustrates how the 'lived' religious beliefs and gendered expectations linked to this ethnic group resulted in some participants losing moral worth, contributing to their struggle to normalise. Punjabis talk of who is honourable, particularly in relation to girls' reputations, has been documented previously (Bradby 2007).

The link between the person and the social that is characteristic of moral narratives (Bury 2001) was explicit amongst these Punjabi women. Blaxter (2010: 70) suggests that '*women especially having a moral duty to manage illness because they care for others, but for everyone moral character is assessed through the responses to ill-health and adversity'.* It may be that gendered roles are less fluid in Punjabi culture and men are less likely to take on caring roles, thus extenuating the women's moral experience. The Punjabi women's journeys of normalisation were clearly dominated by interaction with the values of their specific 'local social world', but varied between informants due to different degrees of acculturation. The

hierarchy of their moral status (Charmaz 1999) appeared to be determined more by their ability to fulfil their role in the social cycle, rather than by evidence of personal suffering.

The concept of moral experience has explanatory value because it focuses attention on what is most important to actors in their local social world (Yang 2007), and thus to what may impede adaptation to illness. Where a core lived value such as the 'centrality of family duty' is widely held, and fulfilled in a formulaic social cycle, disruption of this value through illness must be addressed if normalisation is to be supported. Abinaash's case study illustrated that illness may disrupt key social processes, such as arranging a marriage. The importance of key social events is evident in other studies. For example, the negative impact of disclosure on marriage prospects for young women and men with Type 1 diabetes was so prevalent in India, particularly due to the perception about the hereditary nature of diabetes, that a website was commissioned to dispel common myths and reduce stigmatisation (Patel et al. 2001). The key times of entering a stigmatised or moral career become not only difficult phases in an illness trajectory to be endured, but catalysts for the course of an individual's biography to be substantially altered and normalisation made exponentially more difficult to achieve. Thus, where there are gendered expectations in an ethnic group, interventions may need to be sensitive to differences in the impact of illness on men and women. However, because of the fluid nature of identity, the impact of changing cultural values present a more complex picture.

Minimising the social consequences of illness, one of Knafl and Deatrick's (1986) key elements in the normalisation process, was commonly important to the Punjabi women. There appeared to be a moral imperative amongst the Punjabi women to minimise the social effect of the RA, not only because of personal stigmatisation but also potentially of the

family. This has also been recognised in relation to mental illness in China where a moral "defect" is assigned to sufferers and their families (Yang et al. 2007). However, these efforts to minimise the social impact may affect the ability to self-manage illness and adapt to it in a way that is constructive for the psychological well-being of the patient. For example, a wish to hide deformity in the hands from RA may result in isolation and not engaging in the social activities that constitute a 'normal' life for many. Ahmad et al. (2002) described the complexity of negotiating identity for young Deaf Asians, including the role of religion as a symbol of identification. For these Punjabi women, RA appeared to be one additional, unwelcome, part of an already complex identity (including cultural and gendered aspects) that needed to be minimised in order to maintain status in a 'compound' ethnic identity.

Anderson (1986:1279) questioned whether the 'ideology of normalisation' that a Western health care system subscribes is relevant for different cultural groups since it *requires the patient to be normal, at the same time that it requires the patient to comply with treatments and cope with the limitations imposed upon everyday activities'*. The Punjabi informants spontaneously talked about the importance of normality and provided examples of adaptation that indicated that many were actively engaged in the process of normalising illness. However, their moral experience indicates that there may be barriers to overcome in this process, where internal and external attitudes to long term illness intersect with external attitudes toward minority groups, how to present oneself as a member of a particular ethnic group or internal and external attitudes towards cultural assimilation (Karlsen 2004). Normalisation has its own moral imperative and health professionals may wish to consider exploring and discussing cultural values about health and illness, before asking patients to adhere to normalising treatments or self-management strategies.

The work discrimination reported as being experienced by the (mainly first generation) informants, as a result of their symptoms and disabilities, was compounded by communication barriers and a lack of education (leading to limited alternative opportunities), and possible perceptions of citizenship (or entitlement) or cultural changes between generations. That is, the structural discrimination that they commonly faced was not mediated by the second generation's personal resources or attitudes perhaps gained through acculturation.

Link and Phelan (2001: 377) note that stigma '*exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them*'. It would be prudent for health professionals who are in a position of power during a consultation to consider that socioeconomic circumstances may sometimes be behind differences in treatment priorities, rather than make assumptions about ethnic or cultural differences per se. It was difficult to ascertain from the data to what degree material circumstances affected the Punjabi women's ability to normalise (for example, financial difficulties could preclude adaptations to bathrooms). However, it was evident that the loss of work and income, led to disruptions of identity and self-worth.

Although recruitment of minority groups into research is known to be difficult (Hussain-Gambles et al. 2004), a modest sample was successfully achieved for this study (38% of those approached). The original intention was to conduct a follow-up interview with each informant to collect life history data, which would provide further context for their illness narratives, such as migratory experience. However, informants were unanimously reluctant, indicating that participating at all was a big step (only one had taken part in research before). However, given the complexity of issues hinted at in this paper, future research would benefit

from a longitudinal approach through developing trust with and a presence within the community. There is evidence that men's experience of RA is different (Lack et al. 2011), and further research is required with men from this minority group, in addition to identifying the salience of the moral experience of illness in other cultural groups and LTC.

The normality typologies of struggling, resetting and disrupted normality (Sanderson et al. 2011) were evident in the Punjabi women's accounts, indicating how normalisation may in part be influenced by moral experience of illness. The absence of 'return to normality' or 'continuing normality' typologies may be indicative of wider social inequalities. For example, access to care may be more problematic for minority groups due to delays to secondary care and language barriers (Sheppard et al. 2008), which may affect their ability to have the timely access to effective medications that some of the White British informants reported (Sanderson et al. 2011). It is known that these Punjabi women have different priorities for treatment than their white British peers (Sanderson et al. 2012), but the data presented in this paper show that by identifying important ethnic cultural values (such as the gendered expectations around 'centrality of family duty') the experience of illness must be understood within the broader context of the well-being of the family and wider community, alongside the impact of socio-economic influences. Thus the emphasis on self-management interventions in NHS policies (DoH 2008) is misguided if family management, community awareness of long-term illness, and health care access issues are not addressed. If illness experiences are to be understood within the total context of the patient's life, not only the dominant ideological or moral structure needs to be analysed, but also those of the patient's local social world where different values and priorities may have currency. In conclusion, ethnicity may richly contribute to understanding different illness narratives, but because of its' interrelationship with gender and socio-economic position it is not possible to determine a

separate influence of ethnicity in the relationship between the moral experience of illness and its impact on normalisation.

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Table 1. *Informants' characteristics*

| Pseudonym | Age (years) | Illness duration (years) | Medic-ation[a] | Functional disability[b] | Global health[c] | Migrant generation | English proficiency[d] | Religion[e] | Normality typology[f] |
|---|---|---|---|---|---|---|---|---|---|
| Birinder | 55 | 35 | DMARD | 1.625 | 0.8 | First | None/L | Sikh | Reset |
| Dhiaan | 61 | 26 | DMARD | 1.750 | 4.9 | First | None/L | Sikh | Strug |
| Gurveer | 59 | 4 | Biologic | 2.250 | 5.0 | First | None/L | Sikh | Disrupt |
| Kirpal | 62 | 5 | DMARD | 0.375 | 2.9 | First | P/F | Sikh | Reset |
| Sukhnam | 30 | <1 | DMARD | 0.375 | 5.9 | Second | P/F | Not P | Strug |
| Abinaash | 43 | 29 | Biologic | 2.125 | 3.2 | Second | P/F | Not P | Reset |
| Chann | 41 | 7 | DMARD | 0.125 | 1.8 | First | P/F | Muslim | Reset |
| Ajeet | 36 | <1 | DMARD | 1.125 | 3.5 | First | P/F | Sikh | Disrupt |
| Jai | 60 | 11 | DMARD | 2.125 | 4.8 | First | None/L | Sikh | Disrupt |
| Keerat | 29 | 2 | Steroids | 1.750 | 4.0 | Second | P/F | Muslim | Strug |
| Narinder | 59 | 3 | DMARD | 1.875 | 6.1 | First | P/F | Sikh | Strug |
| Deepinder | 50 | 8 | DMARD | 1.125 | 4.6 | First | P/F | Not P | Strug |
| Guntas | 57 | 30 | Biologic | 2.000 | 6.5 | First | P/F | Sikh | Reset |
| Aman | 72 | 10 | DMARD | 2.000 | 4.8 | First | None/L | Sikh | Reset |
| Nirmal | 38 | <1 | DMARD | 1.250 | 5.1 | Second | P/F | Muslim | Strug |
| Jasnam | 39 | <1 | DMARD | 0 | 2.4 | Second | P/F | Sikh | Fluc |

[a]DMARD=Disease Modifying Anti-Rheumatic Drug (Methotrexate, Sulphasalazine or Leufledomide); Biologic= Biologic therapy (Humira, Enbrel or Rituximab); [b]Health Assessment Questionnaire (Fries et al. 1980) (0=no disability, 3=severe disability); [c] Patient global health VAS 0-10cm (0=doing very well, 10=doing very badly); [d] None/L = None/Limited (interpreter required); P/F = Proficient/Fluent; [e] Not P = Not practising; [f] Normality typologies (Sanderson et al. 2011): Disrupt=Disrupted normality; Strug=Struggling for normality; Fluc=Fluctuating normality; Reset=Resetting normality; Return=Returning to normality; Cont=Continuing normality

*Figure 1: Overview of interview schedule*

- Tell me about your health… (Tell me about your rheumatoid arthritis…)
- What is the most difficult aspect of the arthritis for you?
- Other patients have talked about wanting a normal life. What does that mean to you?
- What makes you feel well (or better)?
- How do you deal with the arthritis? (or cope / manage)
- (If appropriate): Tell me about your (or your family's) move to the UK...
- How do others react to your arthritis within your community? Outside of your community? (including religious community)

Case study 1. *Gurveer's isolation and struggle for normality*

Gurveer was diagnosed with RA four years ago, has high functional disability and is prescribed a powerful medication (anti-TNF therapy) for high disease activity. She moved from India in the 1960s, is currently in her late fifties, a widow and speaks English hesitantly. She struggles with RA daily:

> *"I get very depressed easily. I get tired very quickly. It's basically a struggle really... pain is my main problem. I used to do everything myself, but now I can't do that."*

This inability to complete everyday tasks has led to a devalued sense of self. Additionally, Gurveer feels that she can no longer groom herself properly. She has stopped attending the Sikh temple and other social gatherings for fear of what her peers may think (i.e. felt stigmatisation). Her main strategy for maintaining an outwardly normal life is to stay at home, and this has led to isolation:

> *"I can't socialise like before. I feel ashamed in front of others when I drop things. I try and can't even eat [with my hand]. I feel my dignity is not there anymore... I feel people are going to say "She can't eat properly, she can't sit properly, she's dropping things"."*

She also does not talk about her "suffering", being silenced by her perceptions of others' judgements about her illness, their lack of knowledge about the condition, and the need to justify her appearance and behaviour:

> *"I don't like going to people's houses because I don't like their attitude... I don't show people that I'm suffering, I'm in pain, I just keep quiet."*

Outside of the Punjabi community, she has experienced discrimination in her workplace: a factory. She was unable to speak more than a few words of English at that time and felt that she had no choice but to resign from her employment:

> *"If we used to go off sick, they used to tell us off. "We can't afford people off sick." They used to say "If you can't do it, then just go." [...] I still miss my work. Even when I pass the factory now I feel shocked."*

She appears to be at a loss about how to fill her days. Her main strategy for coping with the RA is distraction (visits from her daughter and grandson or watching Indian dramas on TV), rather than actively managing it:

> *"I was listening to that [arthritis] CD [that the specialist nurse gave me] and getting so depressed. I am trying to forget everything and just carry on."*

Her narrative is one of being overwhelmed and struggling to maintain normality. She repeated *"I don't want to be a burden"* throughout the interview and projected a sense of worthlessness. The felt and enacted stigmatisation has led to a diminished moral status where she is no longer a functioning worker or member of the community:

> *"Even this morning I was sitting here thinking "Can I get normal? How can I get normal?" Inside me, if I am normal I don't have pains or anything. Good health, like no pains, you can do everything, that's normal for me."*

Case study 2. *Abinaash's resetting of normality*

Abinaash was diagnosed with RA almost 30 years ago, but has similar levels of self-reported disability to Gurveer and is also receiving anti-TNF therapy. She is in her early 40s, married to a White British man with two small children, and works in an office. She was born in the UK and has moved into a semi-rural area, but has frequent contact with her extended family. She describes the *"worst period of my life"* as in the past, when she had two hip replacements:

> *"I almost feel my twenties were wiped out, instead of moving on in my career, it was literally just a lot of pain and hassle. I had it [second hip] done at 27, so I was nearly 28 when I went back to work."*

In addition to the physical impact of the illness at this time, there was social pressure to arrange a marriage for her:

> *"That wasn't happening to me. I had a physical disability, which in the Asian community isn't looked upon very well really... The moment I'd say "Oh, I have rheumatoid arthritis and I have a false hip", their faces would just "Oh God, what have we come to see"."*

This perceived enacted stigmatisation included direct questions about whether Abinaash's condition would affect her fertility and ability to raise children. Her parents agreed to discontinue with the matchmaking because the physical disability and its impact on the potential in-laws' social worth appeared to be too big a barrier to a successful outcome. Abinaash effectively removed herself from this 'social space' and others' expectations for her as a Punjabi woman at a key time, entering prescribed social roles:

> *"It depends on when the physical disability starts, if you're a woman... Say you have had your first child and you get RA, it's more acceptable because you are the mother of their grandchild. 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."*

Her independence from these social expectations is also shown through her decision to study in a different city from where her parents lived, which she described as unusual amongst her peers. She attributes her university experience to providing the confidence to assert her needs at work:

> *"I have learnt to stop. I have learnt to say "OK I need to ring work and tell then I am not working this afternoon."*

With her desk job, she is able to be flexible about when tasks are completed and work around fluctuating symptoms. She communicates openly about her illness, asking for help from strangers (e.g. to open tops on bottles) or reminding family members that tiredness is a symptom of RA. She actively manages her disease and in this way has incorporated it into a new 'normal' life:

> *"I'm conscious of what I can and can't do. I know there are different ways of doing things. [...] I have got back to what I know as normality. We have a normal family life. The difference is that my son did my sandals up for me this morning."*