

The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK

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ABSTRACT

This article is based upon qualitative research carried out with members of the Sikh community caring for a person with dementia. Previous research with South Asian carers of people with dementia has reported problems with both access to, and use of, health and social care services namely due to cultural and language barriers within existing services. The research reported in this article sought for an in-depth understanding of the experiences of Sikhs caring for their family member with dementia. The aim of the research was to explore how migration experiences and life histories impact on perceptions and experiences of caring for a family member with dementia for Sikhs living in Wolverhampton in the West Midlands, United Kingdom. The research, undertaken by the author, applied a biographical approach using narrative interviews. Twelve Sikh carers of a family member with dementia were interviewed. Findings highlighted that migration experiences and migration identities are important for understanding participants' experiences of services and experiences of caring for a family member with dementia. Person-centred dementia care as a model for practice highlights the importance of understanding life histories to support people to live well with dementia, including their family carers. This paper reinforces this message, demonstrating the impact of specific migration experiences on the experiences of caring for a family member with dementia.

KEY WORDS—dementia, care-giving, migration, Sikhs, South Asians, minority ethnic communities, person-centred care, services.

Introduction

The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which 'there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication

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skills and the ability to carry out daily activities' (Department of Health 2009: 15). The increasing demand for care and support for people with dementia is a global issue. The total estimated number of people living with dementia in the United Kingdom (UK) is thought to range from 684,000 to 822,000 (Luengo-Fernandez, Leal and Gray 2010), with approximately 25,000 from Black and Asian Minority Ethnic (BAME) communities (All Party Parliamentary Group on Dementia (APPG) 2013). This figure is likely to rise to 50,000 by 2026 and 172,000 by 2051 in correlation with the growing and ageing UK BAME population living in England and Wales (APPG 2013). In 2001, approximately 532,000 people from BAME groups were aged 65 years and over. By 2051, it is estimated that this figure will increase to approximately 3.8 million (Lievesley 2010), with significant proportions being those from Black Caribbean and Asian Indian communities (Wohland *et al.* 2011). Though the UK is striving to meet the needs of people with dementia and their families, made evident by the release of the National Dementia Strategy (Department of Health 2009) and the Prime Minister's Challenge on Dementia Care (Department of Health 2012), dementia care in BAME communities living in the UK is seldom understood (Botsford, Clarke and Gibb 2011; Jutlla 2013; Moriarty, Sharif and Robinson 2011).

Existing research on caring for a person with dementia in South Asian communities in the UK has reported their poor access to health and social care services (APPG 2013; Jutlla and Moreland 2007; Moriarty, Sharif and Robinson 2011; Seabrooke and Milne 2004). Though there is in general a low service uptake, those that have used services have frequently experienced cultural and language barriers (Jolley *et al.* 2009; Jutlla and Moreland 2007; Moriarty, Sharif and Robinson 2011). The stigma attached to mental health in such communities often means that carers are reluctant to ask for, or accept, support from services (Jutlla and Moreland 2007; Mackenzie 2006; Moriarty, Sharif and Robinson 2011; Seabrooke and Milne 2004; Turner and Benbow 2002). Consequently, dementia remains a hidden problem with families presenting themselves in crisis situations, emphasising the need for early intervention (APPG 2013; Jolley *et al.* 2009; Jutlla and Moreland 2007; Mackenzie 2007; Seabrooke and Milne 2004). Assumptions about community norms such as 'they look after their own' can also lead to negative experiences for those from such groups when using services (APPG 2013; Department of Health 1998; Moriarty, Sharif and Robinson 2011). The APPG (2013) feels that the risk of this stereotyping is a failure by services to reach out to ethnic communities and ensure support is in place. Whilst the service deficits for South Asian communities are clear, policy and practice initiatives in the UK are still striving to meet the needs of such communities and a model of practice for improving their access and experiences of

services is yet to be explored (Milne and Chryssanthopoulou 2005; Shah, Oommen and Wuntakal 2005).

Current drivers for change were highlighted in the National Dementia Strategy (Department of Health 2009)¹ which set out a five-year plan with priorities in order to achieve its vision of enabling people to live well with dementia. This need to understand people as individuals is becoming ever more evident in dementia care (Brooker 2007; Kitwood 1997; May, Edwards and Brooker 2009), a point reiterated in the Prime Minister's Challenge on Dementia (Department of Health 2012)² and more recently the APPG (2013)³ enquiry on the experiences of dementia in BAME communities. Echoing Beach and Inui (2006), Brooker (2007: 13) suggests that the person-centred approach to dementia care, first introduced by Kitwood (1997), comprises four essential elements which she terms the VIPS framework: a *value* base that asserts the absolute value of all human lives regardless of age or cognitive ability; an *individualised* approach, recognising the uniqueness; understanding the world from the *perspective* of the service user; and providing a *social environment* that supports psychological needs. Applying the VIPS framework seeks to maintain personhood for those who find themselves in a state of dependence and vulnerability which, Brooker (2007) suggests, not only applies to those with dementia but also their carers. A personalised approach recognises uniqueness and individual identity which, as noted by Brooker (2007), is about having a sense of continuity with the past: a life history. Important to the life histories and experiences of many Sikhs in the UK are their experiences of migration.

Part of the difficulty of developing a model of practice has been because previous research in this area has tended to focus on carers' access to, and experiences of, health and social care services as opposed to their actual experiences of caring which will have important implications for service use (e.g. Jutlla and Moreland 2007; Moreland 2001, 2003; Seabrooke and Milne 2004). Moreover, little research has applied qualitative methodologies to gather detailed information about the similarities and differences in their life histories, which are both likely to exist irrespective of their actual shared ethnic origins, and how such varied histories are pertinent to their particular experiences of caring for a person with dementia. As the requirement to understand people as individuals is becoming more prominent, it is important to also note that many members from South Asian communities were not born in the UK.

To deepen our understanding of both migration experiences and the impact of such experiences upon caring for a person with dementia, a qualitative study was carried out with Sikh carers of a family member with dementia in Wolverhampton – a city in the West Midlands region of the UK. The overall findings of the research support the work of

Mackenzie (2007: 76), who suggests that in order to achieve ‘mutually satisfying user/provider relationships’ such people should be regarded as individuals alongside knowledge of the social and political influences on their lives rather than regarding them as members of ‘other’ groups with collective norms. For many of the Sikh older people in the UK and their carers, the political influences on their lives are those associated with their migration experiences as well as migrant and minority identities. The research reported in this article highlights the internal heterogeneity within the Sikh community based on their different migration experiences and thus supports person-centred dementia care as a model for practice as it is one which recognises the importance for understanding life histories (Brooker 2007; Kitwood 1997), including such life experiences and identities which will be unique to each individual.

Methods

Narrative interviews as research tools

The research utilised narrative interviews as the basic data collection tool. At its most simple, a narrative interview ‘envisages a setting which encourages and stimulates interviewees to tell a story about some significant event in the informant’s life’ (Bauer 1996: 2). The importance of narratives for the individual is that ‘they foster an unfolding of the self and help us to centre and integrate ourselves by gaining a clearer understanding of our experiences, our feelings about them, and their meaning for us’ (Atkinson 2002: 122). Narrative interviews allow respondents to create plausible and persuasive accounts of personal experiences, including their experiences of migration and cultural difference. Consequently, they offer powerful expository insights ‘indicating the diverse elements that constitute identity, and the ways in which identities shift and are contested within the same individual’ (Gardner 2002: 29). As suggested by Gardner (2002), migrants need to give coherence and meaning to their experiences which can be encouraged through the process of telling stories. Two in-depth narrative interviews were carried out with 12 participants. The first interview focused on their experiences of caring and the second focused on their personal histories including their experiences of migration.

Constructivist Grounded Theory

Grounded theories in research are particular constructions of reality that sit within the interpretive tradition of theorising. Interpretive traditions of theorising arise from ‘social constructionist assumptions that inform

symbolic interaction, ethnomethodology, cultural studies and phenomenological discourse, and narrative analysis' (Charmaz 2006: 129). Constructivist Grounded Theory, developed by Charmaz (2006), acknowledges that the derived theory is an interpretation that depends on the researcher's view and epistemology. Taking into account the theoretical and methodological developments of grounded theory, Charmaz offers flexible guidelines to produce a grounded theory method that does not imply 'methodological rules, recipes and requirements' (Charmaz 2006: 9). Her approach to grounded theory assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it.

Guided by Charmaz, the process of analysis for the research reported in this article was by no means a simple one but broadly involved various processes of: open coding, making comparisons, diagramming and writing memos which led to a conceptual framework for understanding the experiences of Sikhs as migrants, carers of a person with dementia, and as their relational role to the cared-for person. Due to the unique and detailed nature of qualitative research, many researchers have developed their own concept of validity and ways of measuring for the 'quality' (Corbin and Strauss 2008) or 'usefulness' of their research findings (Charmaz 2006). To ensure validity, several peer researchers were invited to interpret the data at various points of the analysis – a particularly useful method where qualitative research has adopted constructivist notions concerned with revealing social realities (Golafshani 2003). Central to Constructivist Grounded Theory is that it 'places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants' (Charmaz 2006: 13).

The research sample

Whilst South Asian communities are found across the UK, the research site – the city of Wolverhampton in the West Midlands region of the UK – has received a significant South Asian population as a result of migration from the Indian sub-continent in the 1960s, and the numbers have continued to grow since (Phillipson *et al.* 2001). In 2001, South Asians comprised 14.3 per cent (33,870) of the total population (236,582) in Wolverhampton. Sikhs, who are part of the South Asian community, comprised 7.6 per cent (17,944) of the Wolverhampton population, representing the second largest religious group after Christians (Wolverhampton City Council 2003). According to the 2011 census, South Asians comprised 18 per cent (44,904) of the total population of Wolverhampton, whilst the proportion of Sikhs in Wolverhampton has increased to 9.1 per cent (22,701) of the

TABLE 1. Participant information

Participant name	Age	Gender	Migration route	Cares for
Amar Kaur	77	Female	Migrated from Punjab (via East Africa)	Husband
Boota Singh	83	Male	Migrated from Punjab (with a short stay in Singapore)	Wife
Dal Singh	70	Male	Migrated directly from Punjab	Wife
Darshan Kaur	46	Female	British born	Mother
Harbans Kaur	Over 70 ¹	Female	Migrated directly from Punjab	Husband
Kareena	50	Female	Migrated from Punjab (at seven years old)	Father
Mr Silvers	46	Male	British born	Father
Ram Piari	44	Female	British born	Father-in-law
Rani	44	Female	Migrated from Punjab (via East Africa)	Father-in-law
Sarah Kaur	53	Female	Migrated from Punjab (at nine years old)	Father-in-law
Simarjeet Kaur	49	Female	Migrated directly from Punjab	Mother
Swaran Kaur	80	Female	Migrated directly from Punjab	Husband

Note: 1. Precise age not known.

total population. Wolverhampton now has the second highest percentage of Sikh residents in England (Wolverhampton City Council 2012).

As mentioned, 12 Sikhs caring for a family member with dementia took part in the research. Whilst this number is relatively low, the research did not seek to make generalisations, but rather gather an in-depth understanding of participants' experiences. Of the 12 participants, nine were women and three were men. Participants were either spousal carers (five) or inter-generational carers (seven), and had various migration histories including British-born carers to migrant parents. Seven participants migrated to the UK in their adult years (between the ages of 20 and 25 years); five of whom were born in rural Punjab in India, and two who migrated from East Africa. A further two participants migrated from rural Punjab at the ages of eight and nine years. The remaining three were born in the UK. Table 1 provides key attributes for each participant.

Of the 12 participants, four were not known to services at the time of their interviews in 2008. All participants chose their own pseudonyms as a way of maintaining authenticity and eliminating the possibility of their identity becoming revealed.

Findings

Analysis revealed that experiences of migration and migration identities are important for understanding participant's experiences of services and

caring for their family member with dementia. Their experiences of services are strongly connected to their experiences of social inequalities and exclusion, and possible institutionalised racism within the context of their perceived and actual social positioning as migrants in the UK. Also evident from the data were how their self-efficacy and resiliency skills developed as a result of their migration experiences were transferrable to their caring situations. To further emphasise this, these findings were compared with the experiences of caring for those Sikhs who had not either experienced migration (British born) or experienced migration at a young age (below ten years of age). These participants reported higher levels of carer stress and health-related problems when compared with their migrant peers.

Migration identities and experiences of services

As mentioned earlier, the Sikh community living in Wolverhampton have a strong migration history to the city. Like many other migrant communities living in the UK, the Sikh community in Wolverhampton became well established over time and for the majority of migrants this was not an easy process as they were faced with hostility and racism upon their arrival. Their experiences post-migration to the UK has important implications for how participants experience and perceive their relationship with the state. Three case examples have been selected here to illustrate how experiences post-migration to the UK can impact on the way in which services are both experienced and perceived when caring for a family member with dementia.

Boota Singh: 'They don't give it to people like us'

Boota Singh is a man aged 83 years. He was born in a village in Punjab in India. At the age of 22, Boota Singh migrated to Singapore for an employment opportunity where he lived for five years working as a chef. Boota Singh then returned to Punjab to get married and, shortly after, migrated directly to Wolverhampton, again for an employment opportunity. Four years later he sent for his wife to join him in Wolverhampton. Boota Singh is thus a twice migrant. He has lived in Wolverhampton for 51 years where he has always worked in foundries, on the production line. He is now retired.

Boota Singh cares for his wife who has been physically unwell for 15 years, and has had dementia for the last five years. At the time of his interviews, he was receiving formal support from services to assist with the care for his wife. The formal support services he was receiving for his wife included carers paid to help with his wife's personal hygiene, the use of day care three days a week for his wife and regular visits from the Community Psychiatric Nurse (CPN).⁴

Whilst he reported the CPN to be ‘incredibly useful’, he experienced home care as not so useful stating that: ‘the carers come but they don’t do anything. I have to tell them, then they will do it. They come and she does most of it herself . . . she combs her own hair . . . puts her clothes on herself . . . they come at half eight in the morning . . . by the time they get here she’s already ready’. For Boota Singh, day care three days a week for his wife was also not useful, and he stated: ‘I tell them that I need a break in the evenings . . . I need at least one, two hours . . . they said you have to pay for the service . . . we can’t do it otherwise’. Consequently, Boota Singh stated that he has ‘no choice’ but to manage on his own.

Though such issues are common for family carers regardless of their ethnicity, Boota Singh’s experiences of these services are strongly connected to his migrant identity of being ‘uneducated village people from Punjab’:

They don’t give it to people like us because we are not educated. The ones who are educated, they get it. They read the book [picks up a leaflet] and put it in front of them . . . so they have to give it to them. What can I do? I can’t read or write anything . . . we are uneducated village people from Punjab.

Although for Boota Singh his poor access to services is about not being able to read and write in English, being a migrant from Punjab, his narrative also employs at the same time a wider discourse about social inequalities – the working classes being underprivileged compared to those who are middle class and educated. Even though Boota has lived (and grown old) in Wolverhampton – an urban area in the UK – for 51 years, he identifies himself in terms of his migrant identity as an uneducated, rural villager from Punjab, thus unlocking the perceived (and experienced) dichotomies between poor *versus* rich, educated *versus* uneducated, rural *versus* urban and migrant *versus* native. His statement ‘they don’t give it to people like us’ suggests a form of institutionalised White racism – a familiar experience for Boota Singh who adds that ‘this is nothing new’. He explains that in the 15 years of caring for his wife ‘the Government have never really helped. You just have to accept what you are given and be happy with that’. Hence despite 51 years of living in Wolverhampton, Boota Singh still feels that his needs are ‘second to the White people’ – partly influenced by his experiences of hostility and racism upon arrival to the UK: ‘It was a horrible time when I first came. The White people used to trouble us a lot so we [Indians] had to live like a family and look out for each other.’ Whilst he acknowledged that such experiences were more prominent in the 1960s, he still felt that ‘you can bring together as many people as you want . . . this will never be home. We are too different’. His migrant identity in the UK and consequent experiences have caused Boota Singh to feel that the state do not give support to ‘people like him’.

Simarjeet Kaur: 'Is it them or is it us?'

Simarjeet Kaur is a woman aged 49 years and born in a village in Punjab. She is from a middle-class background as her father was the principal of the local village school. Being someone who valued education, her father encouraged her to study. Simarjeet Kaur successfully completed a BA and MA in India, though these qualifications are not accredited in the UK. She applied to do a PhD at Amritsar University in India but then agreed to get married instead. Aged 24 years, Simarjeet Kaur migrated to Wolverhampton to be married into a working-class family. For the first few years after migration, she sewed traditional Indian clothes at home as a form of self-employment, but then went on to become a bilingual assistant at a local school. She also developed and managed a community support group for Asian women in a city in the West Midlands. Simarjeet Kaur took early retirement as a result of ill health.

At the time of her interviews, Simarjeet Kaur had been caring for her own mother who had had dementia for approximately eight years. She had a daughter and a son who provided help with the care of their grandmother although at the time of the interviews her son had been living away at university while her daughter had just recently returned from university. Simarjeet Kaur's husband worked long day shifts and thus spent little time at home. The formal support services Simarjeet Kaur received in relation to her mother's condition and her own carer role included attendance at the carer support group and regular visits from the CPN. The monthly carer support group meetings were Simarjeet Kaur's only break from caring as her mother refused to attend day care or to receive support from formal carers to assist her with her personal hygiene.

Despite the challenges associated with her mother's dementia, much of Simarjeet Kaur's narrative too reveals how her migrant identity in the UK impacts upon her experiences and perceptions of service use. In her view, Asians are a marginalised group and consequently do not get fair access to services:

Sometimes I feel like the Government does differences when it comes to our people. I don't know like . . . it is them or it is us? Perhaps we don't know how to ask for help . . . honestly. But then, if you don't know what's available, how are you going to ask? The CPN told me and I said, no-one told us about that. It's supposed to be the doctor's duty isn't it, to tell you? So many things that would help to make it easier to care for mom. I've applied for a shower to be fitted downstairs for her but I don't know why us Asians never get it straight away. Maybe they [the Government] just like to give it to the White people first.

In this narrative, Simarjeet Kaur reveals the complexity and challenges of being Asian in the UK. Although Asians are commonly perceived as creating

their own barriers by not asking for formal support, there are significant external barriers – in the form of institutionalised White racism, which reinforce the current dispositions of the latter in terms of their help-seeking behaviours and access to (and use of) formal services. In this narrative, Simarjeet Kaur actually challenges the widespread assumption that Asians do not ask for formal support from services by focusing on the complexity of the actual issue in question: ‘if you don’t know what’s available, how are you going to ask [for support]?’ She then suggests ‘it’s supposed to be the doctor’s duty’ and by doing so further challenges the dominant view taken within policy, practice and academic circles, and wider public discourses too, that members of the South Asian community in the UK prefer not to receive help from services. She further adds how she has actually applied for one of the services/facilities once she came to know about what was available, but even so it was perceived and experienced as not being readily available to Asians, causing her to raise the question: ‘it is them or it is us?’.

Her narrative clearly employs a discourse of social exclusion faced by ethnic minority and migrant groups in the UK. Like Boota Singh, her perceptions of this are also connected to her experiences of racism in the UK post-migration – experiences which, like those of many of the other migrants, have continued rather than changed over time. Hence, connecting her present predicament as an ethnic minority and immigrant person in the UK with her particular experiences of White racism and exclusion which she recalls from the past, Simarjeet Kaur explains:

at work I made many White friends who were good to me, but I will never forget how I was treated when I first came. People would look at you funny and call you names. It’s not so much like that now but I learnt very quickly that I can’t trust White people. We are in their country and people always look after their own don’t they?

Some ambivalence other than that linked directly with her own migrant identity and ethnic minority status undoubtedly remains, nevertheless, in relation to negotiating formal care and support from services. For example, when informed of her financial entitlements, Simarjeet Kaur describes herself as first going through some process of self-reflection and contemplation with respect to her own personal situation as a carer living within a closely knit community of Sikhs in Wolverhampton:

I’ve never asked because they’ll [*i.e.* acquaintances from the local community of Sikhs] start saying . . . she’s taking money for her mom? It’s very expensive, they don’t realise . . . it’s hard to get by. I used to say why should me and my mom apply to the Government for money? You know like . . . inside . . . and the CPN said it’s your right, you’ve paid your taxes.

In contrast to the often over-generalised, and stereotypical, picture drawn of South Asian minority carers as being homogeneously afflicted by oppressive

cultural norms and community expectations, acting as a barrier in terms of their receiving the much-needed support available for them, in the case of Simarjeet Kaur her own personal situation and needs as a carer have taken precedence over the perceived expectations of the Sikh community. This is because, despite the potential criticism and disapproval from the community, Simarjeet Kaur is still able to justify receipt of the financial support and simultaneously maintain a positive self-identity through reasoning that such support is her right as a tax-payer. However, in a similar way to Boota Singh, the perceived lack of adequate support from the state itself makes Simarjeet Kaur contend too that 'you just have to accept what you are given'. It is important to note, however, that whilst the participants shared similar experiences, their specific migration routes appeared to have an impact on the way in which such experiences were managed. This is revealed through the case of Rani which is presented next.

Rani: 'Always trying to better our circumstances'

Rani is a 44-year-old woman. She was born in Punjab in India and migrated with her family at ten years of age to East Africa to join her father who had previously migrated there. At 20 years of age, Rani had an arranged marriage in East Africa. After her two daughters were born, Rani and her husband agreed to migrate to the UK so that their children could acquire British citizenship as the law in East Africa, at that time, declared them stateless. They migrated directly to Wolverhampton and have resided there ever since. Rani has never had paid employment. At the time of her interviews, she attended computer classes at college.

Rani cares for her father-in-law who is in the later stages of his dementia. He moved to the UK 16 years ago to live with Rani and her family. Rani's father-in-law has never been in good health since his arrival and was diagnosed with dementia five years ago. Rani lives with her husband, her two daughters, her son (who is British born) and her father-in-law. At the time of her interviews, the formal support she received from services in relation to her father-in-law's condition included paid carers to assist with the personal hygiene of her father-in-law, and regular visits from both the CPN and a social worker.

Although her caring role was largely considered an extension of her role as a daughter-in-law, Rani had been aware that additional support was required in order for her to deliver her role as his carer effectively – especially as he was in his later stages of dementia. Rani had been able to negotiate the resources available for her father-in-law to ensure that he was getting the best possible care, whilst ensuring that such support was also appropriate for

herself as his carer. Despite being a full-time housewife for most of her life, Rani had achieved several diplomas in both East Africa and in the UK. It was, however, not just her educational qualifications and English-language ability that enabled her to raise any concerns with health professionals and demand support when necessary, but also her refusal to easily accept what was given or denied to her and her persistence in demanding appropriate care for her father-in-law which for her was about 'always trying to better your circumstances'. Though Rani narrated a very positive experience of caring for her father-in-law, she made it very clear that 'you have to be persistent in everything you ask for . . . else you won't get it'. Indeed, her education equipped her with the necessary skills to negotiate support, Rani, nevertheless, identified this ability with her identity as an East African Sikh who, for her, is a community that always 'strive to do better'.

According to Rani, her double migration route (*i.e.* from India to East Africa and then to the UK) was important as it resulted in a more 'forward' way of thinking leading towards a lifestyle with a higher standard of living. Revealing the social and cultural heterogeneity within the Sikh community in Wolverhampton and their respective migrant identities and experiences, including those relating to the use of formal support services, Rani made a clear distinction between herself and the wider Sikh community in Wolverhampton which consisted largely of migrants from rural Punjab. According to Rani:

Coming from East Africa . . . we're different you know. Education there is different. The living standard is different. Even the way you speak Punjabi is different . . . we don't use slang – that's something that they use in the Punjab . . . so Punjabis here [in Wolverhampton] . . . they are different because they are mainly from India. Also . . . my husband says it too . . . There's something about being from East Africa . . . it's like you know . . . we always want to better our circumstances . . . the way we live, the things we have and all that.

As Rani distances herself and her own situation as a migrant from that of the wider Sikh community in Wolverhampton with origins in Indian rural Punjab, her narrative does bring to our attention the diversity of experience and social inequalities existing within the same ethnic minority community such as the Sikhs in the UK who are not a homogeneous group. More importantly, her narrative also demonstrates in addition, how specific migration routes and experiences (rather than the so-called 'ethnic cultures' or affiliations) are significant to immigrant ethnic minority people's sense of their own social identities, their situations and resources, and both their perceived and actual experiences of (including access to) formal services and institutions within the host countries. Hence, in relative terms, there are clear advantages of being an East African Sikh as recounted by Rani. This part of the Sikh community, however, still operates within the externally

perceived homogeneous Sikh and South Asian community, often positioned as the culturally different *Other* within dominant policy discourses and practice circles, therefore facing similar challenges with respect to the use of formal services.

Similar to Boota Singh and Simarjeet Kaur, Rani suggested that ‘services here [in the UK] are just not tailored to meet the needs of our people. But that’s what you get in a different country. India was one thing, East Africa was something else and here . . . well . . . it’s this’. Similarly, her experiences and perception of services are strongly linked to her experiences of migration: ‘Even though we have a better standard of living in the UK, we are always going to be different here. It has been like that since we arrived you know . . . so you have to be persistent with everything.’ Experiences of institutionalised White racism and marginalisation have meant that these participants, similar to the other Sikh migrants in this study, have called upon other resources to help them manage the responsibilities associated with caring for their family member with dementia. Experiences of migration and the ability to adapt in different environments have resulted in levels of self-efficacy and resiliency transferable to their caring situations.

Caring for a person with dementia: self-efficacy and transferrable resiliency skills

To make evident how self-efficacy and resiliency skills developed as a result of migration have been transferrable to caring situations, this section focuses on the same three case examples as discussed above, followed by a comparison of those Sikhs who have not experienced migration or migrated before ten years of age.

Boota Singh’s experiences of health and social care services to help support his wife to live well with her dementia revealed wider discourses about social inequalities for migrant communities living in the UK. Consequently, his migrant identity as a villager from rural Punjab has imbedded in him a level of self-efficacy as he described ‘we are very hard workers’. Through a process of self-reflection, Boota Singh stated during his time in Punjab:

The rich people had servants to make their food, they didn’t have to do much work but, small, uneducated people like us . . . we didn’t have that . . . we had to work really hard. We had farms but, we didn’t have enough to live like them. People would eat ghee to keep their energy going. If there’s one thing about us village people . . . we are very hard workers.

Here, Boota Singh is explaining that it is his determination to ‘work hard’ that has motivated him to provide the best possible care for his wife despite the lack of appropriate support from the state. Such self-efficacy has resulted

in his ability to adapt to stressful situations and quickly attain the skills required in order to survive. As for most carers, he explained that coping with his wife's dementia 'means that I am always in a state of worry' and that 'when life throws challenges at you, you have to learn to cope'. Such resilience for Boota Singh have been the result of his experiences of migration as he explained that it is due to these experiences that he and his wife are 'still alive':

I worked there [in Singapore] for five years. I got a job as head cook. Because of that we are still alive. If I didn't know how to do all these things we would have died of starvation by now. I learnt over there. I've got full knowledge about food and cooking. Even when I first came here to Wolverhampton I was on my own. She [wife] came afterwards. We [the men] had to cook for each other, do our own cleaning and washing. So it's nothing new. I did it then, I do it now. It's just that now my health is not as good. All my life I've got by like this.

Though he cannot read or write any language (*i.e.* English or Punjabi) and has little English-language speaking ability, his determination to survive meant that he very quickly learnt skills to assist with daily activities, so much so that he stated:

I'm just thankful that I can get about. If I have to take her to the hospital or the doctors, I have a car. If there's an emergency, I can go. I learnt how to drive when I first got here . . . and I can cook . . . and I can clean . . . I get things written if I need to . . . I get by like this . . . this is how I have coped.

For Simarjeet Kaur, resilience is accrued as a result of her educational qualifications, English-language ability, work experience and coming from a middle-class background, as she stated 'many people didn't have things like cars, scooters and motorcycles, television and radio . . . but we had it all'. Consequently, her education was helpful in meeting the challenges of marriage and migration, as she explained:

After I got married a lot of hurdles fell at my feet. Because I had my education, I knew English so I was able to carry on with things . . . if I was uneducated, then I don't think I'd be around today . . . I would have come to an end.

In support of Boota Singh's statement about 'hard work' and middle-class people, Simarjeet Kaur acknowledged that 'coming from a middle-class background though . . . I guess I was a bit spoilt. Everything was done for me. So when I came here [to the UK] I didn't know what hard work was . . . but I soon learnt . . . even if my health has paid the price now'. Whilst her reasons for migration were different to Boota Singh's, she similarly had to 'work hard' to adjust to her new circumstances and her role as a daughter-in-law. So much so that her developed resiliency skills support her role as her mother's carer, for 'those experiences made me strong. I had no choice but to carry on and do my duty . . . just like I have to now'. Her migrant identity

and experiences of marriage are reworked in the context of caring for her mother:

when you have been brought up well and given everything, and then you marry into a family and country where everything is different . . . you get used to that feeling. I have been struggling for so long now that I don't know any different. I cope with mom just like I had to cope with getting married and coming here . . . you have no choice.

Similar to Boota Singh, migration for Simarjeet Kaur meant that she had to adapt very quickly in order to cope with her new circumstances. Just like she had 'no choice' in her migration to the UK for her arranged marriage, she has 'no choice' but to cope with her mother's dementia. Consequently, Simarjeet Kaur's experiences of migration to the UK have imbued in her levels of self-efficacy and resilience that have helped her to cope with caring for her mother.

Rani and her family migrated for political reasons, being essentially forced to leave East Africa. Similar to Boota Singh and Simarjeet Kaur, Rani had to be resourceful in order to overcome the challenges of migration to the UK. In contrast to Boota Singh and Simarjeet Kaur, however, Rani had socio-cultural advantages as she migrated with her family into a supportive family network already living in Wolverhampton. As most East African Sikhs were forced to migrate, arriving in the UK as a family, with the advantage of having family networks already in the country, is common for migrants like Rani. These experiences can be contrasted with Simarjeet Kaur who, like Rani, is educated and from a middle-class background, but had quite different experiences having migrated directly from rural Punjab for her arranged marriage. Just as Boota Singh's experiences in Singapore were significant to his experiences of living in Wolverhampton, so were Rani's experiences of living in East Africa as it resulted in a 'more forward way of thinking' to better your circumstances as opposed to just accepting them. Rani's experiences as an East African Sikh, and as a migrant in the UK, are thus important to the ways in which she has managed caring for her father-in-law with dementia. Her education and consequent English-language ability, in addition to her belief to always 'strive to do better' has encouraged Rani to be persistent in getting support from the state to help support her father-in-law to live well with his dementia.

The self-efficacy demonstrated by Boota Singh, Simarjeet Kaur and Rani is evident from their ability to persist and overcome challenges in stressful situations. Their various experiences of migration have given them the ability to adapt to stress and adversity. Because such resilience has been a process developed as a result of their experiences of migration and their position as migrants in the UK, those Sikhs who had not experienced migration, or experienced it at a young age, were unable to cope with the

challenges of caring for their family member with dementia to the same level as those Sikh carers who were also migrants.

British-born Sikhs and young migrants

Three participants in the research were British born, and two migrated to the UK at the ages of seven and nine years from rural Punjab. All of these participants, with the exception of one who migrated to Germany in her adult years from Wolverhampton, reported higher levels of carer stress because of their different life histories and experiences to the Sikh carers who have experienced migration. Like many carers of a family member with dementia (*i.e.* regardless of their ethnicity), these participants expressed similar notions of having ‘no choice’ but to cope with their carer role which, for them, was due to the expectation to cope with situations of stress and adversity from older members within the Sikh community.

Ram Piari is a 44-year-old woman and cares for her father-in-law with dementia. Born in London in the UK she moved to Wolverhampton for her arranged marriage when she was 24 years old. She has been caring for her father-in-law for ten years and stated:

I don't know what it is about our community... especially the elders... they just expect you to just get up and get on – you know, just brush it off... like they do. All my life I've struggled with that – just being expected to cope... like looking after dad [father-in-law with dementia]... it's the hardest thing ever and I'm just expected to cope.

Here, Ram Piari is referring to the expectation from the older people in the Sikh community that she has the same level of self-efficacy and resiliency ‘like they do’. This ‘expectation to cope’ has resulted in a lack of support and understanding from extended family members and local acquaintances of the Sikh community regarding the pressure of her role as a carer of a person living with dementia. Ram Piari's high levels of carer stress and isolation impacted greatly on her mental wellbeing – so much so that she even considered committing suicide:

I had depression and things got so bad that I got up... I went to the chemist... and I got 32 paracetamol and I went to... the other shop... and I got another 32 paracetamol... and then I went to the wine shop... and got a bottle of gin. I've never drank gin in my life but I know you always have pills and gin... and that night... I can't... I can now... but at that point I couldn't swallow tablets so I had to crush them and I sat there with a chopping board and a spoon... and I crushed all the [tablets]... I must have crushed about 20 tablets I suppose... a nice pile. I poured myself some gin in this glass... and the house was deadly quiet... (*her eyes fill up with tears*) and I just sat there and I thought... you know... what the hell am I doing? I've got three lovely children.

Whilst personality factors will impact on the way that carers react to stress and adversity, other participants similarly reported health-related problems due to high levels of carer stress stemming from an expectation to cope.

Kareena is a 50-year-old woman who cares for her father who has dementia. She was born in Punjab in India and migrated to a city in the West Midlands region of the UK with her family to join her father when she was seven years old. She moved to Wolverhampton for her arranged marriage at 18 years of age. Prior to her father's dementia, Kareena unfortunately developed cancer which she stated was due to 'a lifetime of stress that caught up with me':

So many problems I had in life ... like getting married and being bullied ... I was treated so badly but everyone ... like the family ... just expected me to cope. It didn't matter what the situation was, it was never going to be as stressful as what they had been through in their lives ... So I just put up with it ... and then I got cancer ... a lifetime of stress that caught up with me.

In this narrative, Kareena explains that those events considered as stressful for her were not considered so by her family members because of 'what they had been through in their lives', including their experiences of migration. Echoing the experiences of the other Sikh migrants in this research, Kareena explained that 'it was a hard time' for her parents who 'came from a poor background and had to work really hard here [in the UK]'. Similar to Ram Piari, Kareena has been expected to cope with situations of stress and adversity throughout her life which for her resulted in her cancer. Consequently, Kareena made it very clear that in caring for her father with dementia: 'I try not to get stressed about it ... I really don't want the cancer to come back.'

Sarah Kaur is a 53-year-old woman who cares for her father-in-law. She was born in a village in Punjab and migrated with her family to a city in the East Midlands region of the UK to join her father when she was nine years old. She moved to Wolverhampton for her arranged marriage when she was 19 years of age. Though Sarah Kaur reported high levels of carer stress and physical health-related problems as a result of caring for her father-in-law, she stated:

I daren't complain about my stress when you think about the older couples that live alone and have to do this for their partner. I remember when I was a child in India watching how hard the women used to work out there ... they are made of something we are not.

Here, Sarah Kaur is in fact referring to the self-efficacy and resiliency that these women are 'made of', which for her is a trait that her generation of younger migrants do not possess, as she stated: 'we are just not built that way ... at least I'm not ... and my children are definitely not'. To further

emphasise the impact of migration experiences on the ability to cope with stress and adversity, she implied that her children ‘definitely’ do not have such skills because they are British born.

Darshan Kaur is a 46-year-old woman who cares for her mother who has dementia. Born in Wolverhampton, she migrated to Germany for her arranged marriage in her early twenties where her mother frequently stayed to help Darshan Kaur with domestic chores and child care during the school holidays. Darshan Kaur lived in Germany for 20 years before deciding to move back to Wolverhampton so she could care for her mother full time who, by this time, had moved into a nursing home. Darshan Kaur removed her mother from the nursing home and set up home for them both in Wolverhampton.

Though British born, Darshan Kaur’s migration to Germany meant that she had to be self-efficient and resilient in order to set up a business and adapt to her host country successfully. Interestingly, she did not experience hostility and racism upon her arrival but instead suggested that such a phenomenon was no different to her experiences growing up as a Sikh in the UK. Having left her two sons and husband in Germany, she stated ‘it’s very difficult trying to care for mom alone. I don’t have any support from any family members but I didn’t have that in Germany either . . . apart from mom during the holidays . . . so you very quickly learn to cope alone’. She consequently did not report the same levels of carer stress as Ram Piari, Kareena and Sarah Kaur but, similar to Rani, suggested that ‘you have to go and find out what’s out there and keep calling people – just like I had to in Germany when I was setting up my business and trying to build a home’. Similar to the other Sikh migrants, Darshan Kaur’s self-efficacy and resilience developed as a result of migrating to Germany has supported her role as her mother’s carer – emphasising the impact of migration experiences on experiences of caring.

Conclusions

Previous research on dementia care in South Asian communities in the UK has reported a number of challenges, including: their poor access to health and social care services; low service uptake; cultural and language barriers within services; the stigma of mental health; and a reluctance to ask for, and accept, formal support from services. Consequently, dementia has remained a hidden problem with such community members presenting themselves to services in crisis situations. An enquiry into the life experiences of Sikhs caring for a family member with dementia has in fact challenged such culture-based explanations presented in the earlier literature.

Such challenges to service access are shared somewhat with the White population too, rather than being distinctive to South Asian populations. Also, the reported barriers to service use are assumed to be associated with community and cultural norms resulting in an externally perceived homogeneous Sikh community (and South Asian communities in general) becoming positioned as the culturally different *Other* within dominant policy discourses and practice circles, therefore facing similar challenges with respect to the use of formal services. Research with Sikh carers presented in this article has emphasised that the differences in service use actually arise from the minorities' experiences of migration and migration identities and specific positions and locations within the White host country as migrants and minorities as opposed to arising from their cultural difference.

Experiences of health and social care services for Sikh carers revealed wider discourses of the social inequalities and exclusion faced by ethnic minorities when attempting to access services. Experiences of hostility and White racism upon arrival to the UK have continued rather than changed over time, causing the migrant Sikh carers to connect their present predicament as ethnic minorities and immigrants in the UK with their particular experiences of White racism and exclusion recalled from their past. Whilst participants shared similar experiences regarding their access to (and use of) health and social care services, the self-efficacy and resiliency skills employed to cope and manage with their caring situations have been accrued based on their own individual experiences of migration. Specific migration routes and life experiences (rather than the so-called 'ethnic cultures' or affiliations) are thus significant to immigrant ethnic minority people's sense of their own social identities, their situations and resources, and both their perceived and actual experiences of (including access to) formal services and institutions within the host countries.

Recognising the diversity and internal heterogeneity of the Sikh community is important – further evidenced by the Sikh carers who had not experienced migration or migrated before ten years of age. The higher level of carer stress and health-related problems reported by these participants were the result of a synergy between an expectation to cope with stressful situations by the older (migrant) members of the Sikh community and their inability to cope with stress and adversity in the same way that the Sikh migrants have been able to. Another aspect of diversity and internal heterogeneity in such communities is thus linked with whether members have experienced migration or not.

Building on Brooker's (2007) definition of person-centred dementia care, health and social care services should reach out to ethnic minorities asserting a value base that is non-discriminatory of their ethnicity, age or cognitive ability; recognise the uniqueness of individuals and avoid

community and culture-based stereotypes; understand the perspective of the service user (*i.e.* as migrants living in the UK); and provide a social environment that is inclusive and supportive of their psychological needs as carers of a person with dementia. This is further emphasised by Mackenzie (2007: 76), who suggests that in order to achieve ‘mutually satisfying user/provider relationships’ such people should be regarded as individuals alongside knowledge of the social and political influences on their lives rather than regarding them as members of ‘other’ groups with collective norms. Assumptions about oppressive cultural and community norms such as ‘they look after their own’ (Department of Health 1998) can reinforce the social inequalities and exclusion faced by such groups, highlighting the need for services to reach out to ethnic communities and ensure support is in place.

Acknowledgements

I would like to express my gratitude to all the men and women that took part in this research and for their assistance in the realisation of this study. I would also like to thank Keele University for funding this research. This study was guided by the British Sociological Association’s 2002 ethical guidelines for researchers conducting sociological research and gained consent from Keele University. This research was funded by Keele University. There are no conflicts of interest.

NOTES

- 1 In 2009, the Government identified dementia as a national priority in the UK. A five-year plan was developed with the core aim of developing services that meet the needs of everyone, regardless of their age, ethnic group or social status. The strategy identified three key outcomes to improve the quality of life for people with dementia and their carers: (a) better knowledge about dementia and remove the stigma; (b) early diagnosis, support and treatment for people with dementia and their family and carers; and (c) develop services to meet changing needs better. The strategy lists 17 key objectives in order to meet these three outcomes. For more information, the National Dementia Strategy is available online at <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>.
- 2 In March 2012, the Prime Minister set a challenge to deliver major improvements in dementia care and research by 2015. Three champion groups were set up to focus on the main areas for action: driving improvements in health and care, creating dementia-friendly communities and improving dementia research. For more information about the challenge and progress, the annual report of progress is available online at <https://www.gov.uk/government/publications/the-prime-ministers-challenge-on-dementia-annual-report-of-progress>.
- 3 The All Party Parliamentary Group on Dementia (APPG) is a cross-party group made up of Members of Parliament and peers with an interest in dementia. Its aim is to raise awareness of dementia amongst parliamentarians and to influence legislation and policy making in order to improve the lives of people

with dementia and their carers. The APPG meets several times a year and uses each meeting to focus on specific issues affecting people with dementia. It also conducts an annual inquiry on a specific topic. In spring 2013, the APPG brought together evidence and understanding about the experience of people with dementia from Black and Asian Minority Ethnic (BAME) communities living in the UK. It looked at good practice examples where services have been tailored to people with dementia from BAME communities, so that these examples can be shared across the country. The report highlighted seven recommendations to support BAME people with dementia and their families and carers to live well. The report is available online at http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1857.

- 4 Due to the large South Asian population living in Wolverhampton, the Community Psychiatric Nurse (CPN) developed a service specifically aimed at South Asians with mental health problems, including dementia, aged over 65 years. All of the participants in the research reported positive experiences of the CPN who is also a Sikh woman living in Wolverhampton. Her shared ethnicity and drive to support such families to live well with their circumstances were important for participants who have perceived and actual experiences of institutionalised White racism within services; she is passing on information to them which they have felt that nobody else did before. For more information about this service and the role of the CPN, see Kaur *et al.* (2010).

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Accepted 2 June 2014; first published online 18 July 2014

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