

Perspectives on ageing in South Asian families

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Chanan and Joginder

This generation have been born and brought up in a different country – the awareness isn't there or acknowledgement of the cultural needs, especially for those who have dementia. It's about honouring the person.

(Kal, family carer)

This paper explores the experiences and views of South Asian elders and their families living in Wolverhampton, highlighting cultural expectations and the challenges this community faces in terms of ageing and support needs.

Introduction

This paper draws on the experiences and views of people within the South Asian elder community living in Wolverhampton. Through their stories, I am going to explore the issues and challenges this community faces in terms of growing old and developing high support needs, and what quality of life means for these people and their families.

I am going to highlight what facilities are already available, and what this group of older South Asian people think needs to be done or thought about for future services. This includes funding, resources, training and the understanding needed to implement them. Finally, I will explain how this community feels that they can be involved in the decision-making process, and how their voices can be heard more clearly.

About the author

I'm Manjit Kaur Nijjar. I was born and raised in Wolverhampton, then lived abroad for a while, but came back when I was 25 years old to become a carer for both my parents. My mum had been diagnosed with terminal cancer and my dad had vascular dementia and Alzheimer's.

I spent the next nine and a half years working and caring for my parents. We underwent many trials and tribulations associated with living with life-limiting illnesses, including accessing appropriate services, understanding the processes required by statutory services, and coping with the cultural expectations, biases and prejudices of being part of a South Asian community. This was made more difficult as my brother had moved abroad, and my thoughts and opinions did not carry the gravitas needed with either the statutory services or the South Asian community to support my parents in the way I would have wished. For example, it was not until my brother came to visit us that a doctor revealed that our dad had a dual diagnosis of vascular dementia and Alzheimer's.

As a working carer I had to juggle constantly between my parents and my job. This caused tensions between the needs and expectations of my parents, my employer and the wider community.

It was as a direct result of my experiences that I began working for the charity Wolverhampton Elder Asians and Disabled Group (WEAD), helping Asian families living with dementia. I am also part of Uniting Carers, Dementia UK, which has given me the opportunity to raise issues facing Asian families living with dementia.

Participants

I have spoken in depth to six older people with high support needs and one carer in her 40s. The group is made up of one couple, whilst the rest are all widowed. Of those who are widowed,

all except one are living with their families. Five of the older people have physically limiting illnesses, whilst the sixth person has advanced dementia, so was unable to verbally express her experiences. In this case, her daughter, who is also her full-time carer, provided an insight into their lives.

All of the people in this study group came to the UK from the Indian subcontinent over a 20-year period from the early 1950s to the 1970s. Whilst living here they have maintained links with their culture, faiths and languages. It is these links that form a fundamental part of their approach to the illnesses they live with and their subsequent expectations regarding the quality of their lives. Below is a little information about each person – I have used pseudonyms in all cases.

Daljit is now a widow. She came to the UK in the late 1960s with her two children to join her husband. She worked full-time and cared for her husband who had severe health problems. She has had a number of conditions including heart disease, diabetes, arthritis and an under-active thyroid. Daljit lives with her son, daughter-in-law and two grown-up grandchildren.

Sarbjit followed her husband to the UK in the late 1950s, having grown up in Pakistan, but then moved to India. All of her five children were born in England. She was diagnosed with dementia in 1998 and her daughter, Kal, is her sole carer. She also has a number of physical illnesses, including rheumatoid arthritis.

Kal, Sarbjit's daughter, was born and raised in Wolverhampton in the late 1960s and early 1970s. She lived in Germany for a number of years, where she raised her family. Her mother stayed with her in Germany and they both then moved back to Wolverhampton. Kal has kept a journal chronicling her experiences as a carer and her mother's behaviour.

Balraj came to the UK in the early 1950s. He worked full-time in a local factory until his retirement. He met and married his wife here and they raised their family in Wolverhampton. Since retiring, Balraj has suffered from several heart attacks and had a stroke, which has limited his mobility. He is now a widower living with his son, daughter-in-law and three grandchildren.

Chanan came to the UK in the late 1960s. When he came here he had no intention of staying on a permanent basis. He has been involved in politics from an early age and been an active member of a number of unions. His illnesses cut his working life short; he had his first heart attack in 1978. He now has a number of illnesses and cannot walk unaided. He lives with his wife, Joginder, son, daughter-in-law and two young grandchildren.

Joginder came to the UK with her daughter in the early 1970s. She joined her husband, Chanan, who was already living here. She is the full-time carer for her husband, despite having her own health issues. She lives with her husband, son, daughter-in-law and two young grandchildren.

Pal came to the UK in the late 1960s. He had no intention of remaining here on a permanent basis. His wife and children joined him in the early 1970s. He has been a widower for 28 years and lives on his own. He receives regular visits from his son and grandson, who live nearby.

Expectations of health and illness

One of the key issues facing this generation is that they never expected to be ill. They were never prepared for illness or the impact it would have on their lives. It has dramatically altered their ability to lead their lives in the way they would have wished and their expectations of what they thought they would be doing in their old age. Most of them had already been living in the UK when their own parents became unwell and subsequently passed away. The medical interventions available to them would not have been available to their parents or grandparents. So this generation had very little awareness that

their disabilities would impact on their lives so greatly. They had expected to continue their lives as they had before.

Growing up in their indigenous countries, there was little or no awareness of the illnesses that have now befallen this group. There may have been people who had cancer, diabetes, dementia and heart disease etc. when this generation were growing up in the Indian subcontinent, but whether those people would have received a diagnosis would have been another issue. There would have been a financial implication to having a diagnosis and receiving treatment that most families could not have afforded. Also, this generation were not aware of the underlying causes of many of their illnesses, such as a poor diet, high salt and sugar intakes, drinking alcohol, hereditary factors and lack of exercise.

Amongst this group there is a sense that the 'professionals' do not necessarily understand their needs or concerns, as well as not having the time to explain health/social care issues to them. For example, Balraj is upset about the extent to which his disabilities have affected his life, and feels that the doctors have not explained that to him fully.

There was, and continues to be, a lack of understanding that there are physical causes to having dementia. It is perceived to be a form of madness, which is contagious and hereditary. This can lead to ostracism from much of the community, including places of worship. This is particularly devastating given the interdependence of religious and cultural networks for this generation. Having access to information about possible health problems would have helped them make better choices for themselves and their families. It is only since becoming unwell that they have been informed of these issues.

Balraj stated, 'As science gets better, the more illnesses they discover'.

Expectations of family and community

This generation of South Asian elders came to the UK with definite ideas of what a family support network would provide. After all, they had grown up with that family and wider community support in the Indian subcontinent. It was the duty of the younger generations to care for the older generation, and in turn the older generation would bring stability to a family.

One factor that this group did not expect was the dramatic pace of social and cultural change. They have found that their values may not hold the same significance as they would have hoped for in the younger generations. Their children have adapted to a British way of life and their grandchildren may not even speak the languages of the Indian subcontinent fluently, making communication between generations difficult. Their grandchildren participate in activities they may not have allowed their own children to do, which has left them feeling obsolete. Their views and opinions do not hold the same importance as their own grandparents' views and opinions did. This has left people feeling unneeded and insignificant in the lives of their families.

For some of the group, the lack of family support or the pressures facing their children in their working and family lives has been difficult to understand.

We can only eat at set times,
everyone is at work or school.
Nobody is home.

(Balraj, older Asian man)

Generally it's all about extended
families and sometimes, often
they don't want to help you and
brothers and sisters – my own
sisters want her [Sarbjit] back in
a home.

(Kal, family carer)

Adapting to this change has come with a price. Older people have had to pay for carers to come into their homes to provide services that family members were expected to provide. Some are very resistant to that level of outside intervention. It is something that some of the older generations are reluctant to talk about, as it will lead to judgements about them and their families.

She wouldn't – was reluctant
to – have carers coming in,
and sort of like, "Who are
they to tell me to take my
medication?" and there were a
couple of incidents where she
wouldn't do what they wanted
her to do.

(Kal, family carer)

For Kal and Sarbjit, living with dementia has meant the loss of family support, which has been compounded by a lack of a wider community support. There is a sense of isolation from activities and places that were considered to be normal.

Mum and Dad wanted to go
to the temple ... they had
a position ... they actually
worked hard for that position
and what they achieved in
life and they are not being
recognised because they are
unwell!

(Kal, family carer)

For Pal, living alone means that his physical security is paramount. His son and grandson visit him on a daily basis and have installed a security system.

For Daljit, Chanan and Joginder, family support has been essential in helping them cope with their physical limitations. Their families have provided an environment where they have been

empowered to be independent and remain active within the wider community. Chanan stressed the importance of having a good support network:

Good family support has been my saviour. I wouldn't be here without them.

(Chanan, older Asian man)

Daljit had the support of her family and friends, which led to her desire to get better. She felt it was important to keep active. She is part of a knitting club where she has made new friends.

I can raise to the sky because I have family support. I am very satisfied with my family and my life.

(Daljit, older Asian woman)

Balraj finds it is his friends who provide him with support and understanding, instead of his family.

Alternative approaches to coping

All the people I spoke to stressed how important it is to maintain a 'normal' existence as far as physically or mentally possible. It was imperative that they had the opportunities to get as well as they possibly could.

Many Indian and Pakistani people go to the Indian subcontinent during the winter months as a form of remedy for physical and mental ailments, citing the difference in the air and homeopathic treatments as reasons for doing so.

Homeopathy allows this group to be more proactive in managing their health care needs. In the Indian subcontinent, where formal medical treatment would have been too expensive, homeopathy, with its strong basis in religious and cultural practices, has long provided a viable alternative. It is considered as a more natural form of therapy than seeing a medical doctor.

Pal's desire to be as physically well as he possibly can be means he spends time in India, where he receives homeopathic treatments and spends the majority of his days sitting in the open air.

The heat is dry, it provides me with relief from the pain I feel and the treatments I get help ease the side effects I suffer from the medications I take.

(Pal, older Asian man)

Pal is adamant that a positive mental attitude can make a significant impact on a person's ability to cope with illness.

When it comes to life, health or anything else, people find lies are sweet and the truth is bitter ... Never get depressed, I don't focus on what I don't have. Always keep your heart full. I have fallen on my face many times in life but I had to get up. You cannot spend your life eating dirt.

(Pal, older Asian man)

In order to provide her mother with a good quality of life, Kal had her mother's medication reviewed whilst they were living in Germany. It was decided that it was in Sarbjit's best interests to reduce the medication. Under the medical supervision of a German doctor and a homeopathic practitioner, it took five years to eliminate all the anti-psychotic drugs that had been prescribed. Sarbjit has also used homeopathic practitioners based in the UK.

Kal has created an environment where her mother is the centre of all the activities that take place. This includes gentle exercises that help Sarbjit to remain mobile and are designed to give her a sense of purpose.

The whole day is about mum.
I have combined the exercises
the physiotherapists gave
me with yoga. [They are] not
straining, just simple and gentle
exercises.

(Kal, family carer)

Chanan believes that it is vital to always give back to others. Even as he was recovering from his stroke he felt it was his duty to assist others who were less fortunate than himself: 'I believe I am alive because I have helped people'.

Joginder commented that her children spoke to the medical professionals and they alleviated the stress and anxiety she felt whilst Chanan was in a critical condition in hospital and during his subsequent recovery. She also turned to her faith to provide her with the strength to cope. She sprinkled blessed water over Chanan to ensure a quicker recovery. Joginder and Chanan went to India in 2007, where Chanan received hydrotherapy treatment. This provided Chanan with a psychological boost, allowing him to attempt to do more things for himself and gave him more confidence. Joginder feels that although it may not have improved his physical condition, it ignited his desire to assert his independence. He has continued to do more things for himself.

Daljit feels that in order to have a good quality of life, it is essential to make the effort to get well both physically and mentally: 'If you don't do anything, God won't do anything either'.

Daljit is aware that she is able to do more in the mornings and has very little energy in the afternoons. As a result, she schedules activities for the morning. She also stressed that the level of medical care she has received and the social interaction she has had from attending the day drop-in centre is significantly better than she would have got had she lived in India. She said she was incredibly grateful and it was imperative to bear that in mind.

Accessing culturally sensitive services

'Culturally sensitive services' refers to service provision, be it from the statutory sector or the third sector, that is respectful and responsive to the cultural and linguistic needs of its clients and families as well as the wider community. It involves the understanding of a culture, beliefs and behaviours within a context of working with an individual, family or community. This does not however imply that all a one size fits all approach should be taken; the needs of the individual and family should be considered. For example, there are many South Asian families who have a Sunday roast dinner, and rarely eat South Asian food.

Within the South Asian community, there is still a strong feeling of obligation to the ideals of our parents and to the perceptions of the wider community. For example, to stand up and talk about our issues and problems feels like we are bringing shame on the family; not just our immediate family but the whole extended family. This applies particularly to families living with dementia.

One of the most common cultural pressures facing this community is exemplified by Balraj. Balraj's daughter-in-law is a source of great unhappiness to him. Although he can talk to selected individuals about this, when he has spoken to the social worker, the suggestion is that he moves into his own flat – or that adult safeguarding procedures are instigated. These may be valid suggestions, but he needs to be allowed to take the first steps himself and to make his own decisions, with support. He does not trust the statutory services to understand the situation fully.

Information and advocacy

Kal found that she knew very little about the services that were available for her and her mother. She enlisted the help of a dementia advocate working for Wolverhampton Elder Asians and Disabled Group (WEAD) in order to access them. Whilst Sarbjit is in an environment where she feels secure, Kal feels that every service she has tried to access for her mother

has meant a battle with statutory services. This has caused her stress and left her frustrated with service providers. She has received a sitting service through the Carer Support team in Wolverhampton.

Getting direct payments took, with the help of Louise [Carer Support Officer, Wolverhampton] October to February – and it is not acceptable. I had someone who was fighting for me.

(Kal, family carer)

Kal felt she had to navigate through a maze of bureaucracy associated with the medical profession. The time it took from an initial referral to get an appointment with the incontinence nurses caused her great distress. She has had the same experience trying to access physiotherapists when her mother's mobility became an issue.

You have to tell your story time and time again. It can take six to eight weeks to get to see incontinence nurses.

(Kal, family carer)

Kal had hoped that, given her mother's condition, more physiotherapy would have been recommended, however once the prescribed amounts of sessions had been completed, the service was withdrawn. She had hoped that the service could be tapered off slowly instead of a complete cessation. She has therefore devised her own exercise regime for her mother to ensure that her general health and well-being can be maintained.

The onus is on the patient or the family to push for information or treatment. Daljit has found that information is not readily available, especially if someone is ill or a carer. She would like information to be easy to understand instead of the continued use of jargon. She feels this

I know, from all the meetings I go to, there are services out there but I can't access them. We have to wait until we have a crisis. You might as well shut up and not even try. All the strain is on me – the ones in the caring profession give up quicker than the carers do. We are the carers who need the advocacy. It all about awareness, awareness, awareness.

(Kal, family carer)

is particularly important if English is not the first language.

Kal has found that it is the third sector that provides her with moral support as a carer, as well as advice and guidance. She reported that no statutory organisation would contact her to ask how she is coping or talk through her fears with her in the way that the dementia advocate does.

Quality of services

Kal has found that cultural and age differences impact on the quality of services being provided, especially support schemes aimed at carers.

The facilitators do not necessarily have a caring experience or background. They have their qualifications and they cannot know what it is to be a carer.

(Kal, family carer)

Kal recently participated in Caring and Coping with Loss in Dementia, an eight-week course aimed at carers looking after someone with dementia.

“Caring and coping” – same culture, looking after a parent, the same issues, things that matter to us don’t necessarily matter to others. People say it doesn’t matter; it does matter.

The extended family doesn’t want to help, only talk about situations, as the other people in the group know/understand the experiences. This is what is really needed and other people from other cultural backgrounds don’t necessarily get that. There are cultural issues that aren’t being dealt with by statutory services. This generation have been born and brought up in a different country – the awareness isn’t there or acknowledgement of the cultural needs, especially for those who have dementia. It’s about honouring the person with dementia.

(Kal, family carer)

For Kal, this lack of understanding has been evident when she has made requests for respite services. The ideal scenario would be for Sarbjit to remain at home and for Kal to leave. This way Sarbjit remains in an environment she knows with carers she knows, and there is minimal disruption for her. Kal states that being in an unfamiliar setting catering for older people with a variety of mental health issues, with constant noise and people speaking a language she no longer understands would be too distressing for Sarbjit.

In accessing sitting services for Sarbjit via direct payments, Kal found that the agencies were not providing suitable professional carers. Some of the professional carers were not South Asians so there was a cultural and linguistic barrier. For example, Sarbjit refused to eat or drink anything as the professional carers would not eat or

drink. It is considered rude to eat or drink if the ‘guests’, in this case the professional carers, do not eat or drink. There was no understanding that this is a cultural norm and seen as a form of social bonding. Some of the South Asian carers were too young and did not understand the needs of Sarbjit or Kal. Instead, she has had to recruit older professional carers from a South Asian background.

In Joginder’s view, further training is needed for medical staff so that they understand the devastating impact that a long-term illness can have on carers. She also feels that there needs to be a greater collaboration between homeopathic or holistic therapies in the treatment of people with physical disabilities. Services for her husband were all arranged by the hospital social workers and her children. She was unaware of what could be provided and what they would be eligible for. The day drop-in centre that Joginder attends with her husband, Chanan, is only possible because it is run by a third sector organisation – she does not meet the criteria to attend a statutory day care centre. The drop-in centre allows her to socialise with other women in the same setting as her husband. She also attends another day drop-in centre for women only.

Chanan has found that receiving good quality services is ‘the luck of the draw’. He considers himself fortunate that he has always had good doctors and social workers, but also acknowledges that due to his political background he has had advantages that others may not have.

Daljit has noticed that there has been a huge change in the quality of hospital services since she came to the UK 43 years ago.

People are discharged far too quickly, everyone, especially the nurses, seems far too busy and as such appear less caring. Everything seems very stressed.

(Daljit, older Asian woman)

The impact of funding cuts

Daljit feels that localised medical services provided more stability and an opportunity to get more information. There used to be a diabetes/blood pressure service that would go to day centres run by third sector organisations to inform people of healthy living schemes and answer queries or concerns. That has ceased due to funding restrictions.

With the reduction of statutory services and the increased cost of those that are being provided, Chanan feels the specific needs of individuals or groups of people are no longer the priority. He has also been very vocal about the lack of information available to older people about the impact of the changing criteria, making accessing services more regimented.

It should be about respecting people and equality, but they [local and national government] don't do that for older people anymore.

(Chanan, older Asian man)

Charging is another issue. Both Balraj and Pal used to access statutory day care services until the introduction of the charging system. Although both still qualified for day care provision on the basis of their health problems, they felt that the means-tested system was biased against them. As a result they have both stopped attending, and now only attend the day drop-in centre run by a third sector organisation.

Balraj feels that it is unfair to introduce charges and expect older people to pay for services that they have worked hard for. Pal feels the charging system does not accurately reflect the quality of service being provided.

Everyone I have spoken to has placed a high degree of importance on good training of staff, whether in statutory services or the third sector, as well as financial investment in services, not

only to improve them but also to ensure future generations have the services they need when they need them.

Having a voice

Some of the South Asian community have been very actively involved in trying to change and improve services. Others have not been formally involved, but would still like their voices to be heard.

Chanan is very passionate about the loss of services, in particular the loss of culturally appropriate services. He feels that the situation reflects an unacceptable injustice and he has to speak out against it. He actively participates in various forums, such as the over 50s forum and National Pensioners Convention, and he has spoken at local Gurdwaras and Mandirs about the loss of services.

Information is power; people can only make informed choices if they have it. The problem is that they are not getting the information.

(Chanan, older Asian man)

As a result of her experiences battling for services, Kal has spent the last two years working on the local carers' strategy in order to effect change for carers. She has become disillusioned with the process, as it has taken a long time and she can see very little progress being made.

The other four members of this group have stated that they would like to have a better understanding of the full impact of the changes that will affect them. Both Balraj and Pal stated that, had they been fully aware of the impact of charges for services, they would have spoken up against them. They would like to have had the opportunity to have the proposals explained to them and then given the opportunity to think about them.

Carers are the ones who are in the thick of it and it is not acknowledged. When will any of it get implemented? Actions are just not being taken. Nothing will come out of it for myself. You'll do it once, you'll do it twice but you won't do it again. It should be about valuing what is being said, understanding it and then doing something.

(Kal, family carer)

This is particularly important if English is not their first language.

There is an expectation that if you don't ask questions then and there everything is okay, but you need time to think and understand fully before you can ask questions. So much is dependent on language skills that either we don't have or don't have enough of.

(Joginder, older Asian woman and carer)

For older South Asian women, it is important to have women-only consultation events. Cultural expectations mean that older women feel it is inappropriate and disrespectful to speak or question someone in authority in the presence of a group of older Asian men. The larger consultations, whilst being cost effective, prevent these women from participating in the process. They also want to have time to digest the information given.

South Asian elders would like people in authority to explain things to them, to see them and talk to them in the day centres, Gurdwaras, Mandirs, Mosques and Churches. They would like an opportunity to talk informally rather than have to go to official consultation events without fully understanding the subject. They would like to be visited more than once and to have regular

follow-up discussions, as they wish to be included in decision-making processes.

Summing up

Through listening to these stories I have learnt more about the pivotal role the family and wider community plays in the healing and coping processes of older Asians with high support needs. This is where individuals draw their strength from and seek solace. It is particularly important to maintain these networks for those people living with dementia, as it is difficult for the generations born and raised in the UK to relate to their parents' lives in the Indian subcontinent.

In my opinion, it is incredibly important to ask this generation about life in the Indian subcontinent when they were growing up. Adult carers such as Kal, who were born and raised in the UK, have a limited understanding of what life is like in the Indian subcontinent. This means that when a person with dementia makes reference to things or events it is difficult to put these in context. For the person with dementia, their attempts at communicating their needs become frustrating.

Listening to these people's stories could have a two-fold benefit. It could reduce isolation for older South Asians, who do not have dementia but are able to talk about the Indian subcontinent in general and at a specific time period, thereby providing a valuable insight into life in the Indian subcontinent. Secondly this information would provide carers with more support to be able to encourage reminiscence work and identify more clearly what the person with dementia needs. This is similar to the idea of drawing on memorabilia from the past. For South Asians, it is much harder to access this kind of information in the UK. Given the nature of oral history within the older South Asian community, many of whom are illiterate in their own languages, it would provide a valuable resource for many South Asians living with dementia in the UK. It may also provide a template for other communities living with similar issues.

As with many communities living in the UK, the pace of societal change has been unexpected



Pal

for South Asians and the loss of perceived key values has meant that some of this group feel unappreciated and undervalued. They would like to be kept informed about the changes taking place and feel that they can contribute to the improvement of services. This may mean approaching these communities in a different way, for example through single sex consultations, allowing older people more time to consider what has been said and visiting them repeatedly in order to get their views and opinions. Smaller group consultations and more face-to-face interaction with people in positions of authority would allow trust to be built and more open discussions to take place.

The members of this community have drawn upon their strength of character and faith in order to find and appreciate their quality of life. This provides them with resilience to cope with the changes that affect their health. This community, like many of their generation, will find ways of helping themselves rather than relying on statutory services. Their interest in homeopathic treatments and their desire to incorporate them alongside their medical regime gives them not only a sense of control, but also confidence in their own ability to affect their health. For this community, the integration of alternative therapies is vital in their recovery process.

This group of people are incredibly resilient as a community, but as individuals they are vulnerable. Maintaining and supporting families through culturally sensitive services is vital. A good support network, whether that is family-based or made up of friends and professionals, is important in helping this group of people feel valued as well as providing encouragement to aid healing.

I always thought I understood the community of South Asian elders that my parents were part of, but I have only really come to understand them in the last few years as I have worked with and supported them so closely.

About this project

This paper forms part of a series of *Perspectives* commissioned to support the five-year research programme, A Better Life. This programme investigates what will improve quality of life for some of the most marginalised, and least heard, people in the UK – older people with high support needs.

A microsite based on these *Perspectives* will launch in January 2012. It will provide a unique digital platform to showcase the voices of older people with high support needs and features photos of people who contributed their perspectives and a poem by Sir Andrew Motion. To find out more visit www.jrf.org.uk/work/workarea/better-life

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