

COUNT US IN

Meeting the changing needs and expectations of ethnic minority older people in Scotland



By Rohini Sharma Joshi FCIH

Older People Services Project

Trust, Hanover (Scotland) and Bield Housing Associations



HAPPY TO TRANSLATE

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Message

Trust, Hanover (Scotland) and Bield Housing Associations are committed to inclusive service delivery and to reaching out to those who face barriers in accessing services. The Older People Services project was borne out of a proactive initiative launched by our three housing associations to investigate the needs of ethnic minority older people in Scotland and the barriers they face, and then use that research data to inform and drive our equal opportunities programmes.

The project has been a huge success, not only in developing a depth and breadth of unprecedented insights into the needs of Scotland's ethnic minority older people, but also changing the lives of over a thousand older people by helping them access benefits and services.

We are proud to have completed this comprehensive report. We have learned so much by listening to this most vulnerable group of older people. And we are now excited by the opportunities we have identified where we can make a real difference in improving services for them and changing their lives for the better.

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1. FOREWORD

Scotland may be a small country, but it has a big heart. It's a country that wants to reach out to the world and to be recognised as welcoming and tolerant. It has hopes and aspirations to be a model for multiculturalism and inclusiveness.

According to the 2011 Census, 84% of Scotland's population reported their ethnicity as 'White: Scottish' and a further 8% as 'White: Other British'. Together, minority ethnic groups and white non-British groups (which include 'White: Irish', 'White: Polish', 'White: Gypsy/Traveller' and 'White: Other white') made up 8% of the total population. Compared to the 2001 Census the percentage of people in Scotland from minority ethnic groups was shown to have doubled from 2% to 4%. The 2011 Census report also recorded 17,511 people in the 50 to 64 age brackets and 7,394 ethnic minority people in Scotland over 65. Given the high proportion of people in these categories, it would be fair to assume that this population could double again between 2011 and 2021.

These statistics reflect a small but significant population group in Scotland which need attention to address their issues. Throughout the country, government, government agencies, charities and private companies have developed and published commendable equality strategies and action plans which are widely discussed at meetings and events and 'put out' for consultation.

But too often it all stops there.

It is imperative for Scotland to put the dream of integrated, multicultural, inclusive communities into action. And this can only be done when we start to really grapple with the issues at the core of this ideal and take positive, practical steps to start making it a reality.

We can't change everything at once, but we have to move beyond discussions, statements and papers.

To be truly inclusive and impactful at a grassroots level, we need to really understand our communities and their needs. And we need to get to know the people who live in our communities, irrespective of who they are, where they come from, where they live or what their culture is.

The most vulnerable people in our society, such as ethnic minority older people need to be the focus of our attention. They are so often overlooked, partly because their numbers are few and partly because service providers and policy makers find them hard to reach due to language barriers and cultural differences.

It is time for the over-used phrase "hard to reach" to be replaced with "reaching out". It is time to realise it's not an unachievable goal to reach out to this group of vulnerable people, just because it involves taking differences into consideration. It's time to shake off the inertia induced by a "hard to reach" label and find proactive solutions for "reaching out", defining the needs that need to be met and the challenges that need to be overcome.

To do this effectively we need to collectively find solutions to address the challenges, develop new approaches and tackle issues with open minds and with real determination. It is the only way forward.

If we are able to do this with a genuine commitment to learn and to deliver for all – we will be able to make a very real difference.

2. INTRODUCTION

The Older People project has been funded for 14 years by the Lottery Fund. However, work with Scotland's ethnic minority older people started in 1999 when three national housing associations, Trust, Hanover (Scotland) and Bield took the first steps to reach out to ethnic minority older people.

After identifying a need to help ethnic minority older people who faced language barriers and were not aware of their entitlements to support, the housing associations sought and secured funding. This was used to develop a project which not only helped and supported older people who faced multiple barriers but also provided real insight into their lifestyles, struggles, challenges and some heart-breaking situations. The project staff earned the trust of these ethnic minority older people by delivering for them – by providing access to benefits which they were entitled to and also helping to support their complex needs which increased with age. The project has been part of their journey over the last 20 years, a journey of growing older and often facing up to deteriorating physical and mental health.

This report represents the first steps on a journey of further discovery – to identify and understand the issues and challenges faced by ageing ethnic minority older people in Scotland today.

This report is not what we think – it is very much a record of what Scotland's ethnic minority older people have told us.

This community of older ethnic minority people have worked hard and managed with little to make a life for themselves and to give their children a better start in Scotland. Now they deserve respect and we owe it to them to help them live their lives with dignity. We need to take real, tangible steps to ensure that they are receiving the holistic care they need instead of being left to cope with deteriorating mental and physical health, loneliness and unmet dietary needs.

We hope that the report will help give an insight into the growing needs of ethnic minority older people and provide a platform to developing clear strategies with a will to deliver.

3. METHODOLOGY

For this report we made a conscious effort to listen to older people tell us about their life journeys, their achievements, struggles, concerns and resilience. And in their older age, we wanted to listen to what they have to say about a life they never planned for or anticipated.

The research took the form of a questionnaire covering the key topics of:

- Home Environment
- Financial Wellbeing
- Health
- Care and Caring Roles
- Participation in Society

In total **43 individuals** were interviewed by project staff and case studies written to capture life journeys of past challenges and struggles as well as their current individual situations, many of which involve complex care needs.

The project staff also held **20 focus group** discussions on the research questionnaire with over **355 participants** in Glasgow, Edinburgh, Irvine, Aberdeen, Hamilton, Fife, Stirling, Livingston and Dundee. These focus groups were attended by men and women from different religious and cultural backgrounds. All the discussions were in their first spoken language to ensure they could explain and express their views in the language they feel most comfortable and to ensure that terminology or jargon did not create barriers to communication. Participants were of different religions – Islam, Hindu, Christian, Buddhist, Sikh and no religion and different backgrounds – Indian, Pakistani, Chinese, Bangladeshi, Malaysian and Vietnamese.

Two focus groups in Edinburgh and Glasgow were held with the staff of the community organisations and day care centres working with ethnic minority older people. In total, **19 community staff** representing their different organisations participated in the discussions.

The current research project started in April 2017, but the wider work has been in existence for nearly 20 years, funded by the lottery fund, now known as the National Lottery Community Fund. The project has helped and changed the lives of more than one thousand ethnic minority older people in Scotland. It has provided information and access to benefits and services and tackled many topics with a social stigma attached to them, which were never discussed openly. It has empowered older people to make their voices heard and have their contributions recognised.

It also highlights feedback from the consultation with the Scottish Ethnic Minority Older People Forum for – A Connected Scotland: Tackling social isolation and loneliness and building stronger social connections strategy.

Listening to the views of Scotland's older ethnic minority people, by Rohini Sharma Joshi FCIH, Equality, Diversity and Inclusion Manager for Trust Housing Association 27 April, 2018

During the course of this work the project staff has acquired in-depth insight into the lives and needs of thousands of Scotland's ethnic minority older people, and have been able to highlight those issues, hidden problems and challenges which they are facing in their later years.

4. HOME ENVIRONMENT

“ I moved here for two reasons – its location and the fact that the warden is bilingual. The sheltered housing is on a quiet street and there is easy access to local shops, the post office and parks.”

Introduction

If we are to understand the most pressing concerns and the most urgent needs and aspirations of Scotland's ethnic minority older people, we must start where they spend most of their time – in their home.

For most people in Scotland, their home is the most important place in their lives, and it is the same for ethnic minority people. Their home doesn't just provide a roof over their heads, it is a hub for gathering family together, for food, for festivals and for prayer.

A person's home should be a place where they feel most comfortable, a 'safe haven'. It should meet their needs, reflect their taste and provide them with the freedom to make the decisions that best suit their lifestyle.

A home is somewhere people raise their families and create the memories which weave the fabric of their lives. The basic requirements which make a house a well-functioning home are safety, warmth and connectivity – connection both to the people in the community around them and to local amenities with good transport links.

For ethnic minority older people who own their own homes, it is their biggest investment and their biggest achievement – the pinnacle of all they have worked for. They have an enormous sense of pride in owning a home which has met their needs and where they brought up their children.

But when their children grow up and fly the nest, the emotional connection to the house remains. Add in the familiarity of the location and the environment and many ethnic minority older people find it difficult to think about moving away, to make a move to a smaller, more suitable house.

This is particularly the case for women who have lost their partner and are now living alone in a large house. They find it extremely difficult to make a decision to move and instead use and heat only a small part of the house. They find themselves in a quandary – they are torn between staying in unsuitable accommodation with their familiar furniture because of an emotional attachment to their home or moving in with their children with the fear of the loss of independence.

For men who have lost their wives it is perhaps more straightforward – because they have been accustomed to their wives looking after both them and their house all their lives, they tend to quickly or more readily recognise that they are not able to live on their own. They are therefore more prepared to consider moving to more suitable accommodation with support.

The importance of location

Many of the people interviewed stressed the importance to them of the location of their homes. This often meant that if a smaller house or social housing was not available in a desired area they would choose to stay in highly unsuitable accommodation, believing this was the only choice they had.

In creating a safe haven for their families, there was a very real sense of the importance to Scotland's ethnic minority older people of feeling safe in their neighbourhood and being able to access local amenities easily.

For example, when interviewed, some expressed their appreciation of having easy access to local amenities and feeling safe:

Mr X lives in Edinburgh with his family in a four-bedroom semi-detached house which he owns. Despite the challenges of his adult son's mental health issues, Mr S's home environment meets the needs of the whole family. He says:

“ I appreciate my good fortune. I have lived in the same area for more than 20 years and I know every local shop, bank, post office, petrol station and food store like the back of my hand. I feel safe walking alone at night as petty crime, vandalism and neighbourhood violence is close to zero. And I have good neighbours who are tolerant of my son's disruptive behaviour when he has an unsettled day.”

Mr C lives in sheltered housing. The flat comprises one bedroom, a bathroom with a walk-in shower room, a living room with full size windows and a kitchen.

“ I moved here for two reasons – its location and the fact that the warden is bilingual. The sheltered housing is on a quiet street and there is easy access to local shops, the post office and parks.

“ My flat is on the first floor, accessible by a lift and there is plenty of free parking within the development. The accommodation meets my needs as I'm living in a safe neighbourhood where petty crime is low and I feel safe returning home late as it's only a short walk from the car park. The sheltered housing development is away from schools, so school kids don't hang around the street after school time.”

Mr M (92 years) lives in a ground floor, two-bedroom flat and reported that he has all the facilities he needs both in the house and outside. He said:

“ My location is ideal because I can easily access the bus stop, nearby shops and Leith baths where I take a shower twice a month. In my flat I have only the furniture I need.

“ I feel safe where I stay and can easily leave the house during the day, although I try to come back home at 2pm. I don't leave the house after 2pm because I feel there is no need to leave and I prefer to stay in. My neighbours are nice to me and I have never faced any harassment from neighbours or anyone in the street or the city.”

Mrs B however is one of many older people who are reluctant to leave their family home and neighbourhood, even when the house is in disrepair.

Mrs B (60 years) lives in a detached four-bedroom terraced house which she has owned jointly with her husband for the last 32 years. She lives with her ill and disabled husband, one son, one daughter and her seven year old grandson. Parts of the house are badly water damaged and need repairing. Her husband has agreed to refurbish the house and will extend it with a further three bedrooms. She said:

“ I am very fortunate to live in this area and to have great neighbours. I know all my neighbours and always greet them and see them regularly. Morrisons is nearby and I have easy access to the bus stop. I would not like to move from this neighbourhood. I feel safe here and the accommodation is suitable for my needs.”

Mrs M (65 years) also values her location, despite dampness and a lack of effective heating in her home. Mrs M has lived in a housing association property for the last six years. The single bedroom ground floor accommodation is not very healthy as it has problem with damp and only has storage heating which does not heat the flat up very effectively. The white appliances do not work properly and Mrs M finds it difficult to cook. The flat has an old bathroom and old kitchen units.

The bathroom does not have enough support rails and Mrs M finds it hard to get into the bath without a seat. However, she said that:

“The location is not too bad and I can easily access public transport.”

Mr R lives in a three-bedroomed third floor flat and is currently happy with his living arrangements. However, like many of his generation he values his location so highly that he is determined to stay where is, even if his mobility deteriorates. He said:

“I have the best neighbourhood, a bus stop right opposite my flat, and I can access all the amenities and can get to my GP surgery very easily.”

“I can just manage the stairs at the moment but in the future, if I am not able to, then it will be a real concern. However, even if climbing stairs becomes a challenge, I will still not consider moving because of my good neighbourhood and area.”

Safety

In the worst situations, the home environment for Scotland's ethnic minority older people is very far from a safe haven. Some are living in real poverty with a fear of vandalism, racism and break-ins. They are targeted because of their ethnicity, their vulnerability and their lack of English which means they are unable to report incidents to the police. Some are afraid to leave home after dark, which cuts them off from both their community and the amenities around them.

Mr C (67 years) it was the neighbourhood and behaviour of neighbours that had a major detrimental impact on his family's home life. He told researchers that he had experienced years of physical and verbal racial abuse. He said:

“My children faced a lot of racism at school and my daughter had stones thrown at her and received nine stitches behind her ear as a result of the attack. I moved to Scotland from Hong Kong in the hope that my children would be treated and respected as decent human beings, that they could live without fear and free from being prosecuted for who they are. I believe that the war on racism cannot win without education on racial harmony as part of the curriculum in schools. I believe racial equality can only be achieved not by looking at the differences between two cultures but instead people should look at the similarities between the two.”

“We also endured rudeness and urinating both outside and inside our takeaway and stones were frequently thrown in to smash the front window.”

Mrs T (75 years) has faced all sorts of racial harassment since she arrived in the UK in the 1970s and has felt unsafe and isolated in her home environment. She said:

“From the first day our family arrived in Scotland we faced all sorts of racial attacks, from being called racist names to physical attacks on the children at school or in public places and verbal abuse while we walked down the street. The hateful racist attacks prevented our family from going out and led to feelings of isolation. I couldn't leave home after school hours for fear of being picked on by school kids wandering on the street and being a target for stone throwing practice. My children also distanced themselves from their peer group as they were laughed at for having oriental faces and small eyes.”

The suitability of the home changes as people age

For many ethnic minority older people, whether they own or rent their home, their needs change as they age. As does the suitability of their home.

Perhaps their children have flown the nest and a house, which was once their pride and joy, has become a burden to upkeep or an asset which is too expensive to maintain. For others they can't afford to keep their home warm or they struggle with the maintenance of the house and the garden. Others may have accessibility issues with stairs to the house or access to the bathroom if it's on an upper floor.

In many homes, there is an urgent need for many adaptations outside and inside the house. Frail older people need more space when moving around in the house to accommodate wheelchairs, zimmers or even walking sticks. Sometimes flooring is not safe and loose carpets or items of furniture can be hazardous. Insufficient lighting or natural light can also be an issue for older people with poor eyesight, making them prone to accidents and falls.

Because many can't afford to keep the house warm, they heat only one room and live there, moving their bed into the living room, and in some instances kettles and microwaves to avoid going into colder rooms. This ultimately causes dampness in the house and in the long run necessitates additional repairs to the property.

Mr L (93 years) has been living in his home for 25 years. The house is located on the main road and there are eight steps to his front door with no handrails. Three bedrooms are on the upper floor and the interviewer found broken furniture in the living room and an overpowering mouldy smell which indicated dampness. Mr L has shortness of breath, knee problems and diabetes, which the interviewer believes makes his current living conditions highly unsuitable.

Mrs X spoke out at a focus group and her story describes the extreme physical challenge of continuing to live in her own home and the difficulty of getting it adapted effectively so that she can go upstairs safely.

“Where I live in my house, I have stairs and they are very steep, and I got referred for a stair lift. I have had three heart attacks, and in three weeks’ time, there will be treatments which I am not sure, but maybe a bypass.”

The day centre I attend called someone about the stairlift and said the process would take some time. She visited me and said my stairs are quite steep and she was concerned because it was an old property – it has stairs going down to another property and stairs going up to the second part of the property and has an extra 18 steps to my room. They said they will not be able to do an electric chair because of the steep stairs. They suggested if I wanted to do it privately I could. Privately is very costly and I will not be able to afford it. I am living with my son at the moment and my son is trying to find another home which would suit my needs, but houses are very expensive.

There is no solution for my bad health and I am concerned about my heart condition. Every time I climb upstairs to my bedroom, I have to lie on my bed slightly tilted.

I don’t know what will happen in the future, but I know that with my condition I cannot stay alone. All my daughters-in-law look after me well.”

Mr C has steps up to the front door which cause him difficulty, especially when carrying the groceries or other shopping bags. The stairs inside the house are also difficult to climb and he used to take a breakfast tray to his room, which he cannot carry anymore. He worries about not being able to enter his house due to the steps at the front door. He requires adaptations in his house to move around for daily living and a handrail in the bathroom. He is aware that the process of getting a stair lift fitted can take up to a year. He said:

“My wife and I, we both want to stay in our home as we have been living there for 45 years. We feel safe here. The neighbourhood is very good and kind to us. However, our ideal setup would be to be in the centre of town with many shops nearby and a grocery store.”

Lack of planning for the future

One of the major issues identified by interviewers was a lack of thinking ahead by ethnic minority older people to a time when they may find their current home environment challenging. Even amongst those older people who are affluent, living independently and in well maintained homes, concern was expressed that they did not know what they would do if they were unable to manage their home or if they lost a partner. They do not feel that they have the ability or the information required to plan ahead to a time when they will not be able to look after themselves.

During a number of group discussions in day care centres across Scotland, it was clear that most older people were not thinking about their future needs.

Out of the 14 women who attended the day centre in Kirkintilloch discussions – some lived on their own and some with their children. All of them were managing well and most said it was important to live where they could access all the amenities. However, when challenged, no-one in the group had thought about their needs in the future.

When another group of ethnic minority older people were asked about their home environment, most of the group said they were living comfortably in their own homes and that when the time came, they would think about other options. However, they reported that they had not thought about the future or downsizing.

Mr and Mrs M are fairly typical of a widespread “head in the sand” approach to the future.

The couple are both 74 and have lived in a detached house for 44 years. They both need help with walking and showering and Mr M finds it difficult to walk upstairs and believes that some modifications in the house would make day to day activities easier to carry out. He said:

“All amenities are easily accessible and we are happy. We are living comfortably as we are, although some things need to be addressed like a walk-in bath or shower and stair lift. If we ever had to move to a flat we would do it but we haven’t thought about it.”

For many ethnic minority older people, not planning for the future is bound up with a belief that they can always move in with their children. Whilst they would prefer to stay in their own house which has been their home for 30 or 40 years, they often believe that if living independently becomes challenging, the only solution is to sacrifice their independence and move in with their children. They are aware of the difficulties of this situation as their children will be out working all day, and when they are at home, they will be occupied with maintaining their homes or looking after their children. This means older people are often sitting alone all day with no one to speak to. By re-locating to live with their children, older people lose contact with their friends, become dependent on their children and lose a degree of autonomy. They also have to cope with adjusting to their children’s and grandchildren’s lifestyles.

Most of the older people we interviewed who live with their families were in good physical health and were able to help their children and their families by preparing meals and looking after grandchildren and they were happy with this arrangement. When asked what will happen when they are not able to help and need care, they had no answer or thought that social services would look after them if their children were unable to. They had no concept of costs or the level of care or support available or the cost if they had to pay for extra care or support.

Some people would like to continue to live with their children and be looked after by them in the same house despite it becoming increasingly difficult. Some are happy to pass on the house to their children in return for being looked after in their older age. But when it does not happen the family relationship breaks down, where both parties fail to deal with the dilemma or understand each other’s expectations and limitations.

Others realised how challenging living with their family could be:

One male member of a lunch club, said:

“ We as elders always look at our children and relatives expecting them to help us in old age. They have their own responsibilities to take care of and we cannot be dependent on them. If you cannot look after yourself properly and cannot manage your daily living it is better to shift to a care home where at least you are looked after better.”

Sheltered housing for ethnic minority people

All older people we spoke to said that if there was sheltered housing for ethnic minority older people which met their social, language and dietary requirements they would consider moving there and would benefit from having people to socialise with and with whom they could enjoy their festivals and other cultural activities.

All those who attend day care centres specially run for ethnic minority older people feel it is a lifeline for them and believe that having similar facilities in sheltered housing or any other housing option would be the most desired accommodation option for them.

It was further acknowledged that when they are not able to look after themselves and their care needs are high, they would like to move to care housing where there are staff who speak their language and understand their dietary, cultural and spiritual needs.

Some of the respondents' views are as follows:

Mr C (83 years) was never able to save enough money to buy a house for his family during his working life. When he became unfit to work, Mr C and his wife moved to sheltered housing for the Chinese community. He said:

“ There is no language barrier between residents. The warden provides language support for all the residents – arranging medical appointments, orally translating letters and informing us about upcoming events. And because I can speak to my neighbours in my native language, I feel part of the community.”

Mr S (85 years) came to the UK in 1989 and secured UK nationality 13 years later. His wife has still not been able to join him as she is supporting his daughter in India. He has spent many years sharing a room with other people with no privacy or space of his own. Mr S has now been in a council sheltered housing flat for the last three months. He said:

“ I am very happy to have my own space and my own privacy. I was not aware that I could have applied for sheltered housing due to my lack of knowledge. I now feel I am living in a safe place and I haven't come across any hassle as yet.”

Mrs A (66 years) is an old widow who suffers from Parkinson's and who needs a lot of help with personal care such as washing her hair, bathing and eating. She has had a number of problems with her accommodation and said:

“ I would have preferred to move to sheltered housing if there was one for Asian people where there were other women who I could chat to over tea.”

Mrs L (79 years) has a diagnosis of dementia and is increasingly concerned with her condition. She has concluded that sheltered housing is the solution but said:

“ Moving to sheltered housing where most of the residents speak English will not solve the problem of isolation that I already suffer. Being alienated because of the language, living in a new environment and struggling to recognise the new faces of care staff would just create additional anxiety and stress. The best solution for me would be to live in Chinese sheltered housing, a place where there is no language barrier, where I can communicate with the warden, care staff and other residents in my native language.”

A male member at the Southside Elderly Lunch Club group meeting said:

“ We would like to fill in a petition and put forward our point of view of the difficulties that we would have in a shared care home. We would like a care home for us separately. We have our own religious and other needs. Living in a care home with other communities who have a completely different perspective would not understand our adjustments that a normal being would be able to adapt in their own home. For example, for Muslims they can develop a care home and people will start to think about moving to these homes.”

A male staff member at the lunch club suggested that for many older people when they have a carer coming to their home, they actually become lonelier as they experience greater loneliness when they leave. He said:

“ It isn't good to be dependent on them all the time because you cannot depend on them all day. If we had a care home for our community that would be better.”

Two females in a focus group were very vocal about care homes for Asian people said:

“ Do you not think we Asians need our own care homes? If we have our own community homes we can start to think about it but at the moment we don't think about it at all. You can debate on the fact that your children don't have time for you and they can't help you all the time.”

“ If there is a care home only for Asians people I will move. If there is a care home for our community, we will feel more comfortable.”

A group discussion at the Hamilton day centre felt that they lacked awareness about other housing options available to them for when they are unable to cope in their own homes. Most of the participants said that a small place with a friendly environment is ideal for older people. They said that people living alone are experiencing loneliness and isolation and that it's a good idea for them to move to a sheltered housing development. However, they all shared an anxiety about the extreme expense and were reluctant to spend their savings as they did not know what would happen in ten years' time when their savings ran out. They asked who should they rely on then.

One female member of the group said that she was looking for sheltered housing but was still not sure which development to move to and was also looking for advice on whether she has to sell her own house and pay the taxes, land registration etc.

Review and recommendations

In the course of the extensive interview process, a number of common themes emerged in the area of the home environment, all of which provide important insights into the daily lives of Scotland's ethnic minority older people – the challenges they are facing today and the more complex challenges they envisage facing in the future as they become older, more frail and more in need of support and care. Indeed, in many situations there is an absence of any thought about the future and how they will manage.

It is clear from the research findings that Scotland's ethnic minority older people value their independence and in almost all cases want to stay in their own homes. Their ideal home environment is to be living independently in their own home with easy access to good local amenities. Being able to get to the shops and a bus stop easily is of paramount importance as this provides them with the independence to get to appointments, visit friends and family and do their own shopping.

Sadly, for some ethnic minority people their home environment has not felt safe as they have experienced physical and verbal racial abuse. Their fear has led to an avoidance of going out and isolation within their community.

In situations where people are struggling with mobility issues, their immediate priority is to access support from social services so that adaptations can be made to their homes, such as handrails and stairlifts. Difficulties are encountered when these, sometimes crucial, adaptations take too long to be installed.

The research also reveals that the majority of the older people interviewed have not given much thought to their future needs, when even with adaptations made to their homes, they will be unable to sustain independent living with increasing care needs. Many believe that they will be looked after by social services and all their needs will be met until their deaths. They expect that social services will deliver free 24/7 care services when they are not able to manage themselves.

Few interviewees expressed a desire to live in an extended family home environment but nor did they fully embrace the concept of sheltered housing or a care home. This appeared to be for two major reasons – a lack of understanding of how supported accommodation is funded and a concern that their social and cultural needs would not be met.

Actions which could be taken to respond to the research in terms of the home environment are as follows:

- **Earlier intervention by social services with regard to ensuring adaptations are made to the home environment before they become urgent.**
- **More accessible information and support on housing options for older people if they wish to downsize.**
- **The development of a service which provides advice and support for ethnic minority older people who need or want to plan for future housing needs.**
- **More accessible information available on how supported housing works and how it is financed.**
- **Development of sheltered housing and care accommodation for different language/cultural populations which meets their needs.**
- **Community based programmes to tackle racism in specific areas where it is affecting the quality of life and home environments of ethnic minority older people.**

5. FINANCIAL WELLBEING

“ We live in a stable and work like a horse all our lives so that our children can work like a human being and live like a King without worries.”

Introduction

In order to live dignified, secure and meaningful lives, older people need to be assured of financial wellbeing. It is similar for many vulnerable ethnic minority older people. For older people, financial wellbeing involves having a sense of security that they have enough money to meet their needs. It's also about being in control of day to day finances and having the financial freedom to make choices that allow them to lead a fulfilling life. Ethnic minority older people have worked hard all their lives and deserve to have the reassurance of financial wellbeing in their older age.

For many older ethnic minority people who have had a professional career or owned their own businesses, this is indeed the case. However, for many others, they are consumed with worry about financial matters and are ill equipped to source information, access their entitlements and make appropriate decisions.

For many, illiteracy means they are unable to read correspondence which comes through the door related to financial matters. Similarly, computer illiteracy means they are unable to manage online banking, services and benefits. Many people of this generation have never used technology and are instead familiar with using passbooks and payment books for managing their money.

Even the relatively straightforward use of bank cards can be challenging. ATMs have instructions in English which ethnic minority people may not be able to read and their older fingers are too weak to manage the keys. For those with age related memory problems, remembering PIN numbers is far too difficult and retrieving lost passwords or PIN numbers requires following instructions in English and is simply too daunting.

Many ethnic minority older people do not want to set up standing orders and prefer going to banks or the post office every month to pay bills. It helps them monitor their payments, using a system they understand. They do not trust online banking or other online systems as they have a very real fear of fraud, knowing that they will not be able to identify it if it happens to them. As the UK's network of local bank branches contracts, there is the additional problem that older and often very infirm people will be forced to travel increasingly further distances in order to manage their finances directly.

Even once they reach a bank or post office, they are not over the line. Many organisations have introduced cards to be used to make a payment and these new payment options are very confusing for older people. They confuse them with debit and credit cards and much prefer the system they are accustomed to which details payments and debits in a book, as even with no literacy, they can recognise the numbers and are able to feel more in control of their finances.

These problems with contemporary banking practices are also a problem for the older population who have English as their first language and many of them too, depend on children to set up and manage direct debits and online banking. Within the ethnic minority community there is a worrying tendency for children and extended family members to exercise excessive control and even financial abuse.

However for ethnic minority older people, it is not only the challenges of banking technology that cause distress and worry when it comes to finances. Their financial wellbeing is further compromised by a range of complex issues, often embedded in cultural norms, attitudes and traditions. There is an assumption that the male in the family controls the finances, leading to women becoming disempowered in this area and subsequently set adrift following the death of their husband. For some, it is a mutually agreed “division of labour” within the family, but for others it is the source of financial control and even financial abuse.

In the course of talking to hundreds of ethnic minority older people across Scotland, it became very clear to the research team that for many in this group of vulnerable people, financial wellbeing did not simply depend on how much money they had. It was considerably more complex and involved a range of issues associated with cultural attitudes, language and technology.

Cultural attitudes

In exploring the issue of financial wellbeing across Scotland's community of ethnic minority older people, the researchers encountered some serious problems, predominantly stemming from the fact that in many ethnic minority homes, the male controls the finances. During their working lives, they were always the breadwinner and in retirement, they remain in control of the finances, even in failing physical and mental health.

This is particularly problematic as joint benefits are paid to one recipient and in ethnic minority households this will always be into the husband's account. From the evidence presented to the researchers, in some cases this had created very real problems. Women reported that they were given very little to live on and often not enough to socialise or pursue hobbies.

In cases where the relationship was particularly troubled, dysfunctional or abusive, this resulted in extreme distress, poverty and social isolation.

Even in cases where the relationship was good, when their husbands died, the wives were left in a very vulnerable position, with no knowledge of what shape the finances were in or how to take on the responsibility of managing them. There is an increase in the number of older women who have lost their husbands and don't know where to begin to manage their finances, from banking to paying bills. They have never had to deal with banks or payments and have had no knowledge of their financial situation. Some even reported finding significant levels of debt and having to sell off the business and the house, with the result that they ended up living in poverty.

Many women turn to their children for help or rely on nephews and nieces. Unfortunately, with some, the role model of their fathers is ingrained, and they perpetuate an environment of control, subjecting their mother or aunt to the same kind of financial control she was previously subjected to when her husband was alive.

The two scenarios which follow are fragments of conversations with elderly Chinese women whose husbands have died. Their experiences are typical of the way in which ethnic minority men control the finances and it is interesting how they express a sense of liberation and enjoyment of their new found financial control. Children are more likely to help their mothers when they become widowed but do not offer similar support to their fathers, as they assume they should be able to manage finances even if they are not, due to older age and memory loss.

Mrs L (93 years) is typical of many Chinese women of her generation. She did not receive any formal schooling in China and she is illiterate. Her husband however, had three years of schooling and was able to communicate in English and managed all the finances. True to cultural assumptions that it is the male members of the family who control the finances, Mrs L's husband collected Mrs L's pension for her from the bank and took a portion of the money as her contribution towards bill payments and food costs.

After Mr L died, Mrs L's son collects her pension. He knows her PIN number and withdraws the cash but always hands the money over to her directly. Mrs L values a new sense of financial wellbeing. She said:

"Since my husband passed away I feel as if I have regained control of my finances."

Mrs T had a similar experience. On the death of her husband, Mrs T was able to get help from a relative to open a bank account and instructed the bank to transfer her benefit entitlement to her account. Mrs T expressed how much she appreciated her new financial autonomy. She said:

"Now I feel I have more control of my finances."

Many however, find being left in control of the finances very daunting, such as Mrs C below.

When Mr C became unwell, Mrs C was left financially vulnerable. She was unable to cope with managing the family's finances as Mr C had been in sole charge, collecting the state pension, paying all the utilities bills and keeping track of income and expenditure. Mrs C said:

"Since my husband's illness my daughter comes to visit once a week, helps to collect the benefit money and pays the rent and other bills."

In some extreme situations, the male's control over the family finances can be extremely abusive. In the case of Mrs T, her husband's financial control led to emotional stress. She quoted the Chinese proverb to our researchers as an illustration of what some older men like her husband think:

"Do not feed your wife well. Only feed her stomach 60 per cent full until she reaches the age of 60."

Mr T controlled all the money they both earned from their takeaway and all the money went into a business account under Mr T's name. He was the only one with access to the bank account. Mrs T worked in the takeaway without pay and her husband used her as a free source of labour. All important financial decisions were taken by Mr T without her involvement. On his death, Mr T left every penny to his son which made Mrs T feel unequal and trapped in a male dominated family environment. Mrs T has never had a bank account because Mr T paid all the household bills and any household expenses. If Mrs T needed money for clothing or going out to meet friends at restaurants, she had to ask for money from her husband.

Mrs X also told a story of significant levels of financial abuse in her marriage. She said her husband only contributes to the bills and does not pay any money to her and the children. He owns a business and all the income received from it is paid to his brother with whom he jointly owns the business. Mrs X said:

"My husband gives more financial support to his brother and his family than he does to us. I have experienced mental and financial stress all my married life because of my husband."

When men have control over the finances they are in a position to hide debt problems from their wives. Within the Chinese community, gambling is a particular problem as the men use casinos as a place to meet their friends and hidden gambling debt is a fairly common problem.

Ms X explained how bad this problem could get.

"Since I have been married to my second husband I have suffered financial stress due to his gambling problem. We have moved five times because each time he was not able to pay the mortgage. He did not manage to save any money for the future and I have suffered from financial stress. I was liable for all the bills so had to work full time to pay them."

Ms N's story was one of the most extreme examples of cultural attitudes creating a situation of severe financial abuse.

After her partner Mr C's death, Ms N became increasingly dependent on Mr C's children and their families which caused significant stress. Ms N suffered extreme control of her finances and ultimately financial abuse as the family challenged her to hand over all her cash. When she refused her home was ransacked for valuables and her gold jewellery and debit cards for her pension and welfare benefits were taken.

Further exploitation was incurred as family members used her cards to withdraw cash and when Ms N confronted them, she was physically pushed. With her pension money diverted away from her, Ms N reported that she was forced to live in poverty. She said:

“ I have to live without an income and this means I can't go out. I can't meet friends at restaurants and I am lonely.”

This case of elder abuse by family members was officially unreported within the ethnic minority communities for it was treated as a private or 'closed door' matter. The victim never reported it to the local authorities because she feared family support would decline even further or be completely cut off.

Another cultural attitude which impacted on the financial wellbeing of the older people interviewed, particularly amongst the Chinese community, was a commitment to saving for their children's inheritance. Interviewees reported that they spent little on themselves as they wanted their children to have more than they had. They quoted a proverb:

“ We live in a stable and work like a horse all our lives so that our children can work like a human being and live like a King without worries.”

Mr X from the South Asian community says however that he does not save money because he doesn't believe in it and so spends it where it is needed. His children are very well established so they don't need his property or his money.

Language and literacy issues

Illiteracy is a major contributing factor to the lack of financial wellbeing in the older ethnic minority population in Scotland. Without literacy, older people are hugely disadvantaged as they simply do not have the resources to understand and manage their finances.

Mr M (92 years) lives alone and is typical in that his illiteracy causes him to worry about his finances.

He reports that he is financially stable and that his pension and attendance allowance is sufficient for him to live a comfortable life. He is proud of his independence and that he manages to pay his bills, take cash out from the post office and also buy his shopping on a regular basis. He does not worry about money, however, his low level of literacy means he worries about when his bills are due to be paid and gets very anxious about paying them on time.

He regularly accesses help from the local community organisation. He said:

“ I visit them regularly with queries and take along any letters that I receive. They advise me how and when I have to pay any bills and when my appointments are due. I am very pleased with the service they have been providing and I feel perfectly comfortable sharing my financial and personal issues with them.”

But sadly, not everyone is able to access the help they require. Mr S (85 years) lives on his own. He is illiterate.

Mr S came to the UK in 1989 in search of work. He worked in shops and in restaurants and just managed to earn up to £200 a week. After a few years he managed to pay back the fee and interest to the agent who got him to the UK and then started saving for his children's marriages. Life was a struggle and he was not able to afford a place of his own. Mr S has worked in restaurants for most of life but following a stroke he has had to rely on his pension and housing benefits. When the project staff spoke to Mr S, he was struggling financially and unable to meet his daily living expenses. His illiteracy has meant that he was not aware of the additional help and services that were available to him.

Even those ethnic minority older people who have basic literacy struggle with the social welfare system. Whilst some commend it highly, the majority feel it is too complex to understand and navigate.

There are two key problems here.

The first is that they do not have sufficient literacy to understand information and the process nor access the internet to research what benefits they are entitled to.

The second problem is that, even if they are in receipt of benefits, they are not able to keep track of them. Many can't read bank statements and can't read any letters which come in through the post, so they don't even open the correspondence. Many benefits are abbreviated on a bank

statement, compounding the difficulty. If there is to be a change in their benefit entitlement or some additional information is sought, they are unable to read it. Some don't have children to help them, others don't trust their children or some children don't have the time or patience and the problem escalates. Some older people reported ignoring letters and ending up having to repay a significant overpayment and being left in poverty. Other older people said they didn't know they had to report a change in circumstance and have been caught out with demands for repayment after they failed, for example, to report a death.

A focus group of 15 ethnic minority older men and women was convened in Aberdeen and all participants were found to lack awareness of benefit entitlement due to language and communication barriers. Even for those who had a professional career, benefits are complex and difficult to understand and they also did not know where to go for advice or how to find information.

They explained to the project staff that they accessed certain types of benefits by comparing their conditions with other benefit applicants and if they believed they were entitled to that benefit, they approached the project's bilingual staff to assist them completing the forms in English.

The participants of this group also said that some benefits must be applied for online and in English and that most of them don't know how to use a computer and don't have internet access at home. They said they found applying for benefits on the phone also created unnecessary stress as most of them are not even able to pass the security check.

Case Study

Mrs W (88 years) is Malaysian Chinese who was married to a Scottish man she met in Malaysia. She has been living in Scotland for 41 years. Mrs W is unable to speak, read or write English and, since her husband passed away eight years ago, has found managing her finances extremely difficult.

Mrs W worked as a sewing worker in a garment manufactory in Malaysia where Mr W worked as a manager. Their loving relationship was able to overcome the fact that they married with only a limited ability to communicate as each spoke a different language. Mr W barely spoke Malay and Mandarin, the languages in which Mrs W was fluent. At the age of 47, Mrs W left Malaysia and reunited with Mr W in Aberdeen. Mr W managed his retirement funds very well and they had a comfortable life. Mr W left everything to his wife after his death and since then, Mrs W's finances have been subject to abuse.

As Mrs W is unable to speak English, all bank statements and financial reports needed to be verbally explained. Mrs W sought the help of friends, but as none of her friends spoke English, she used an interpreter who was paid for each verbal interpretation.

Mrs W employed a family member in Malaysia as her personal assistant, but lately she found out that her account was being exploited by her assistant. Mrs W dismissed her assistant and turned to the warden and a nurse based in the sheltered housing complex where she lives for help.

Mrs W then noticed that money she received weekly and kept at home was going missing. At first she thought her memory was poor and that she had forgotten that she had spent the money, but then she began to question why and how the money was disappearing. Mrs W claimed that not all money she kept at home went missing at once – between £20 and £40 was going missing from the £300 weekly money she kept at home. Mrs W claimed nobody has keys for her flat apart from the warden and the nurses who work for the housing association.

Mrs W kept all her bank statements for her annual tax return and was told by the lady who did her accounts that there were large amounts of cash being withdrawn from the account. Mrs W had no memory of these withdrawals and was encouraged to speak to the bank for records of the withdrawals. Due to a lack of language support, Mrs W's request was ignored, despite the fact that the bank claimed that staff members had tried to communicate with Mrs W via Google Translate.

Mrs W believes she has been the victim of financial abuse and that someone has taken advantage of the language barrier. Mrs W strongly denies that the large money withdrawals within two months were made by her. She asked the question why an elderly woman would require so much money between January and February last year, especially as her bank statements also show that she made her usual weekly withdrawals.

The bank failed to provide language support to Mrs W, which resulted in her not being able to enquire about her finances over the years. This meant that she was not able to report or explain issues due to the language barrier and her age meant that it was perceived that she had become forgetful.

For the people around her from whom she sought help she was an easy target. She had money in the bank, cash at home and was not able to manage or ask about her finances. This is not an isolated case. There are some older people who, due to the language barrier, are being financially abused. Clients with a language barrier barely receive support from the bank staff, partly because staff are not trained in using interpreting and translating services. The banks should provide assistance to clients in different languages and ethnic minority clients should be able to receive written communications in different languages to ensure their right to fair and transparent services.

Use of Technology

The increasing centrality of technology in financial affairs is having a disproportionate effect on Scotland's older ethnic minority people. Whilst many older people struggle with new technology, if English is not the first language, it is usually impossible to access support online or in the banks. However, if they are illiterate and speak little English, entrusting their finances to both a technology and a language they don't understand is terrifying.

Opting out of the use of technology is possible, but it brings with it enormous disadvantages – both practical and financial.

If an ethnic minority older person does not have online banking, they will need to pay their monthly bills at a bank or post office. Banks are closing down in communities all over Scotland and increasingly, the nearest bank is getting further and further away. For many people, paying a bill involves a morning's outing on the bus. Sometimes they will be unwell, too frail, too challenged by the weather or memory impairment to make the trip and they will incur charges for the late payment of bills.

To avoid this, ethnic minority older people can be helped to set up direct debit payments to pay the monthly bills but they have to be able to trust a family member or friend to do it for them and that's not always possible. For ethnic minority communities, where there is often an accepted dependence by older people on their children, it was clear that the older generation are very heavily dependent on their children to help them with their banking.

For those who manage to get direct debit accounts set up, that's not always a perfect solution either. Payment terms change and as they are not able to read any correspondence which they receive related to the payments, they will often ignore it and incur charges and fines.

Many bank accounts will simply cost more to run as providers will charge for monthly paper statements. They will also not be able to access comparison sites to ensure they are getting the best value for money for their banking provision.

In a number of interviews with ethnic minority older people, it was clear just how many individuals were unable to access and use online banking. Many didn't have Wi-Fi and others simply found it too daunting.

Mrs K receives a pension and uses it for everyday living. When her husband was alive they used to work together in a catering business but now she works from home making savoury snacks and this bit of additional income keeps her going.

Mrs K is very independent, understands her bills and manages them by herself. She is grateful for this but said:

“ I find digital banking very difficult and I also find it hard to make payments over the phone.”

Mrs X has a degree of control over her finances but needs help.

“ I can't withdraw money from the bank by myself. I would always need to ask for assistance from the bank staff.”

Mrs S, who is blind, also finds going to the bank difficult. She said:

“ I do not go to the bank. My granddaughter takes care of my finances. She is a 27 years old lawyer and I trust her.”

Mr X manages his own finances but goes to the bank when he needs to make a transaction.

He said:

“ I can't do it online or over the phone as I don't understand the IT system. I prefer a face to face service and do not like the use of machines everywhere.”

Mrs X was one of many older people interviewed who don't have access to Wi-Fi.

“ I do not have any Wi-Fi at home and due to that I cannot carry out online banking.”

But it's not just banking that older people struggle with online. Many benefits and credits have to be applied for online and this is another area where ethnic minority older people are disadvantaged. For many, this could mean not accessing crucial support which could make a very real difference to their lives.

This was not reported extensively in the research, simply because the interviewees who weren't accessing certain benefits online, didn't know what they were missing. However, one researcher in the course of her day to day work talked to an older person who believed she was entitled to further support but wasn't able to access it. Unfortunately, her family was not very supportive. She said:

“ Everything, every benefit needs to be applied for online and we always have lots of questions. But the children never have time to help. They just fob us off by saying 'you're not entitled to it' or 'you won't get it' or 'you don't need it'.”

Coping well

However, despite the problems outlined above, the financial wellbeing landscape was not unrelentingly gloomy. There were many reports of ethnic minority individuals and couples who were managing well, using technology and feeling financially comfortable and secure. It was interesting to note how closely these stories correlated with relationships which were equal and loving.

Mr and Mrs L (both 76 years) have a joint account where all retirement funds and benefits are deposited. They share equal access to the funds and both of them can withdraw money with their own signature. The couple do not have any financial concerns. They do not drink, smoke, gamble or misuse substances and use their funds for food, bill payments and social events.

Mrs L is well informed about the stock market and helps her husband to invest his retirement funds wisely. As a result of this she has full control of both accounts. Mr L never complains about that because the returns on his investments are good. Also, Mrs L pays all household bills, does the shopping, drives him around for socialising, plans holidays for both of them, buys air tickets and books hotels online and pays for it by credit card.

Mr L said:

“ There is no need for me to keep track of the account. My wife is my partner, friend, financial adviser and personal assistant.”

Mrs L expressed a similar attitude to their relationship. She said:

“ Financial transparency between married couples could build stronger relationships, based on trust.”

Mr and Mrs C reported that they were comfortable with their financial circumstances for now, but that Mr C was worried about his health deteriorating and how that may mean they would struggle financially and physically. Mr C was able to do his own banking and online banking. Mr C is in the process of giving the power of attorney to his wife, so she can make decisions for him when he is no longer able to do so.

Mr and Mrs X are financially comfortable and they can manage online banking. If they have any problems, they ask their daughter-in-law and son. They can pay their bills via online banking. They have a will in place, and they feel it is very important. The house and account are in their joint names. They think it is important to save in old age in case of an emergency.

Financial insecurity

In the course of the hundreds of one-to-one interviews conducted throughout the time of the Older People Project, financial wellbeing or financial distress was predominantly defined by how much control ethnic minority older people had over their finances.

However, the conversation in two focus groups held in Irvine took a different course and reported concerns over the amount of money they received.

In one group, all participants reported that they fell into financial insecurity when they retired. Six participants were supported by the state pension and/or welfare benefits. They feared that the benefit system would collapse and there would be no social safety net to support them in later years. All participants believed that social security will dry up because of the increase in the ageing population. All participants noticed that their pension increased slightly each year but claimed that the rise was inadequate to meet the cost of living. They feared that the state pension isn't enough to support them to pay for necessities such as food and pay their bills.

Five female participants said they were limited in what food they could afford and changed their food shopping choices, purchasing food with poor nutritional value in order to keep their homes warm. However one male participant said he wouldn't give up good nutritional food for warmth. He claimed that a healthy body could cope with lower room temperatures at home. All participants agreed that they were unable to meet an unexpected expense such as the need to replace a broken washing machine. They reported that financial insecurity limited their social life which led to loneliness and isolation as there was no extra money to meet friends at restaurants or drive to visit friends.

From other discussions the researchers have had with older ethnic minority people, they have reported that the most vulnerable group of people are those who are not entitled to much benefit as they have never worked and not contributed towards a pension. This group of people are mostly women who have helped their husbands in their businesses, but who did not make any or sufficient NI contributions.

Review and recommendations

From the Scotland-wide interview programme and the conversations that the researchers have had in the course of their day to day work with ethnic minority communities, it is clear that financial wellbeing is not just about money. In fact, some ethnic minority older people complained that they did not have enough money. By far the most pressing concern was that they did not have enough control over their money.

For the ethnic minority men, financial issues were due to illiteracy, lack of language skills and an inability to navigate online banking and associated financial technology.

For women, the problem was far more grave. Due to cultural traditions, their husbands always managed and controlled the finances and women have been financially disempowered. They have developed no financial understanding and competencies and are left vulnerable when their husbands die. Whilst their husbands are alive, they have, at best, limited control over their finances and at worst they suffer financial abuse, poverty and social isolation.

Actions which could be taken to respond to the research in terms of improving financial wellbeing could include:

- **Help from bilingual staff with expertise on the social security systems to complete benefit forms – similar to the older people services project which helped hundreds of struggling ethnic minority older people who did not know where to go.**
- **For the social security system to understand and deal with the lack of information and language barrier faced by ethnic minority older people.**
- **Education programmes aimed at ethnic minority men to encourage them to pay NI contributions for their wives if they are working in their family businesses.**
- **Pensions and benefits to be paid into separate accounts.**
- **Financial wellbeing classes for older women to be run at community organisations.**
- **“Get your Mum online” campaign aimed at the younger female generation who are language and computer literate. This initiative would empower older women to use the internet (but would still depend on them being able to speak English ...).**

6. HEALTH (PHYSICAL AND MENTAL)



“ My wife cooks for me and helps me bathe and change. She is exhausted with all the added work and I have concerns about when she cannot care for me. I have no idea what will happen.”

Introduction

In the course of the research and the extended experience of working with ethnic minority older people over 18 years, a number of key themes emerged from both one-to-one conversations and group discussions on the issue of physical and mental health.

In many ways it is difficult to separate the concerns and challenges under separate headings, as the ethnic minority older people interviewed were articulating complex needs which by definition, overlap and inter-relate.

Perhaps the most significant overlap expressed by the ethnic minority older people is illness or lack of mobility and isolation and loneliness, leading sometimes to depression. The more a person is forced to retreat from the world and social contact due to their physical health, the more their mental health is affected.

The physical problems could be long-term illness such as diabetes or osteoarthritis, long-term medication with debilitating side effects, joint problems causing mobility issues or alcohol addiction. These physical problems all impact on social engagement and many older people with these physical challenges also reported a sense of isolation, loneliness and depression.

For many older people with dementia, or who had a partner with dementia, the isolation was even more extreme. The emotional, social and financial consequences experienced by individuals with poor mental health have a significant impact on family and carers. Family responses to having a family member with dementia include care burden, fear, and embarrassment about the condition. Uncertainty about the course of the condition, signs and symptoms, lack of support and stigma add to the challenges dealing with it.

In addition to the older people who reported the impact of health challenges on their daily lives and wellbeing, the other major issue associated with their health which concerned them greatly was the language barrier. In many cases issues related to their physical health were made significantly more challenging to manage because they did not know where to seek information or support, how to complete the required forms, make appointments or ask for what they needed over the phone.

Not everyone expressed difficulties with their health and a number of respondents said they were coping well. However, even in these cases, project staff reported a lack of awareness of the challenges which may arise in the future if they didn't put some safeguards and support systems in place.

Long-term illness

A common situation for older people, who suffers from joint pain caused by arthritis or other illnesses, is that their capabilities deteriorate incrementally. One month they can dress themselves and put their shoes on and the next month they need help to do the same task. They are often on significant amounts of pain medication with the concomitant challenging side effects. Whilst they may be just about managing, they are slowly finding it harder to perform daily tasks and this is taking its toll, not just on their physical health but on their mental health too.

Another area of concern with regard to long-term illness, particularly within the Asian community, is the extent of reported diabetes. Most older people are not changing their eating habits as they age and continue to indulge in Asian sweets, traditionally enjoyed as a celebratory treat for all sorts of life events, from weddings to passing a driving test. In other Asian cultures, the consumption of traditional sweets and fried savoury treats are eaten on a regular basis. There is a cultural sense of "you only live once", sweets are a good thing and should be enjoyed.

Unfortunately, this is resulting in the over-consumption of sugar and widespread problems with Type 2 diabetes.

The problem is compounded as the information on diabetes distributed by health professionals is culturally British – aimed at discouraging the consumption of chocolate, biscuits and cakes. If ethnic minority older people are able to read the leaflets they assume it is irrelevant to them as they are not consuming these types of treats.

English language diabetes literature is even more irrelevant to older Chinese people for whom red bean soup, heavily laden with sugar, is the treat of choice. And this, of course, is not cited in the current diabetes literature as something to be avoided.

Mrs R (82 years) has a long-term illness. She suffers from tuberculosis which makes her very weak and restricts her mobility. Although she cannot leave the house on her own due to her illness, her children take her to the doctor's and other appointments and her daughter-in-law is her carer.

She says:

"I have to depend on my daughter-in-law for daily meals because I don't have the energy to stand up. I need help to mobilise indoors and outdoors and my daughter-in-law helps with most of my personal care."

Whilst Mrs R may seem to be in a situation where her long-term illness and severe mobility issues are being looked after, the situation remains fragile. There are concerns that if circumstances change so that Mrs R's daughter-in-law can no longer support her either in the short or long-term, she will be very vulnerable.

Mrs M's (65 years) Chronic Obstructive Pulmonary Disease has a significant impact on her lifestyle and her mental health. She says:

"I always feel out of breath and wheezy. I get very stressed and cannot organise myself and often cannot focus and finish a task."

I hardly go out and about because in order to save money and for health reasons, I only go when I need to. I do occasionally visit a local lunch club and enjoy going to it. Most of the time I spend my day watching TV. I do not go to the gym or do any exercise and I do not eat healthily."

Mr C (80 years) has diabetes, is hard of hearing, has eyesight problems and limited mobility. He is cared for by his wife but worries about the future. He also worries about his wife as she is also 80 and he is concerned about what will happen to her when he is not around.

He says:

"My wife cooks for me and helps me bathe and change. She is exhausted with all the added work and I have concerns about when she cannot care for me. I have no idea what will happen."

I worry about mental health because dementia is very common. I'm anxious and worried at times thinking about my future and my wife."

Mrs A (80 years) has several health issues, including diabetes and manages her medication and insulin by herself. Her condition worsened after her husband passed away and she now has mild dementia.

She finds it difficult to concentrate and focus and to keep up her healthy lifestyle. She says:

“ I mostly rely on frozen food, which my daughter or other people supply and I will heat it up and eat it. I can only manage to make or cook quick meals for myself. If I don't feel well enough, I will make a pot noodle.”

Mrs A hasn't thought about what she will do when she becomes less able. She believes that God will help in her bad times. She says:

“ At night I rely on sleeping pills for a good few hours' sleep, otherwise I am not able to sleep at night. In the morning I struggle to get out of bed and I feel very depressed and have a low mood. Once I'm out of bed, I manage the day as it goes by.”

Case Study

Mrs C (90 years) lives alone in sheltered housing. She does not have her own children but has stepchildren. However, since her husband passed away two years ago her stepchildren started to distance themselves from her and now she no longer has contact with them at all.

Mrs C has an account at the Post Office, the type of an account which uses a cash card to withdraw benefit money. With the advance of dementia, Mrs C was finding it hard to remember things including the account PIN number to withdraw cash. On two previous occasions, she received language support from the warden. The warden wrote to the Post Office, on behalf of Mrs C, with her signature, and usually the request was granted to withdraw the money. However, on one occasion the signature did not match the one the Post Office held on record so her request was rejected. As a result, Mrs C was not able to withdraw cash to buy food and she started to live on cakes and biscuits which seriously damaged her health as she is a diabetic.

The project co-ordinator involved in this case acted as an advocate – contacting the Post Office Head Office, presenting the case and seeking a solution. The advice received was to obtain a letter from Mrs C's GP to confirm that Mrs C has progressive dementia and to include a letter with Mrs C's personal details. When the Post Office received all the relevant documents, they would issue a new card with a new PIN.

However, when the project co-ordinator contacted Mrs C's GP, she was informed that the GP medical practice could not deal with the request as she did not have power of attorney. The medical practice requested a consent form from Mrs C, however they could not accept the consent letter as Mrs C had dementia and had lost capacity to make decisions.

The surgery secretary was on holiday for two weeks and no action could be taken. The project co-ordinator was frustrated with the lack of urgency on the case and was unable to find a solution to support Mrs C's situation which needed immediate, urgent action. The project co-ordinator felt that that all parties failed to recognise the seriousness of the case. They did not seem to understand that people living on benefits depended on the money to support their weekly living. If there was no money, there was no food and if there was no nutrition, health would deteriorate.

The project co-ordinator referred the case to Social Care Direct and requested the allocation of a social worker to support Mrs C to manage her finances. However, the department claimed social care wouldn't get involved in this case but referred the project co-ordinator to a senior social worker who offered to help by phoning the GP to discuss the case with him. He suggested the GP contact the project co-ordinator and provide the necessary letter to support Mrs C's claim. The co-ordinator received a call from the GP who promised to have a discussion with another work colleague to get a memory test done the following week. A GP report and the co-ordinator's support letter were sent immediately. After the letter was sent to the Post Office, they claimed that they could only discuss the issue with a person who has Power of Attorney. Mrs C has no Power of Attorney. The Social Work Department wanted to appoint a family member as Power of Attorney. However, the project co-ordinator intervened and met with the social worker to prevent that happening as Mrs C's family were abusing her financially.

Meanwhile, the co-ordinator contacted the Chinese Elderly Lunch Club and arranged for hot meals to be delivered to Mrs C and also contacted a volunteer organisation for food donations until the crisis was over.

During a meeting with the social worker, the co-ordinator was advised that she could write to the DWP to redirect Mrs C's benefit money from the Post Office to Mrs C's bank account. Also, a co-ordinator could be appointed to withdraw cash for Mrs C on a weekly basis. Mrs C now has a council worker to take her out for shopping once a week and it seems that she is the right person for the task for her. The transfer was completed within days, Mrs C received a new cash card with no need for a PIN. However, the council worker did not want to be appointed to withdraw cash for Mrs C, and Mrs C would not trust anyone to get hold of her bank card after so many bad experiences.

It was heart-breaking for the co-ordinator when all parties involved in the situation failed to recognise the urgency of the case and situation. All parties follow procedures to safeguard themselves without looking for solutions and identifying where the procedures were being a real hindrance. Following the rules and procedures is necessary, but they do not help individuals when most in need and in the most desperate of situations. They failed to recognise the anxiety caused by not having the money to pay for food, pay rent and bills. If the parties involved had focused more on the person in a desperate situation rather than only relying on procedures to finding solutions, they would have been better placed to help Mrs C. It should never have been such a complicated, long drawn out process.

Mobility

When mobility is restricted, for whatever reason, it is widely reported amongst the interviewees that they suffer from loneliness. They lose contact with their friends and they withdraw from social engagement. They become lonely and often depressed. But it is not just their mental health which suffers, it is also their physical health.

For some ethnic minority older people their diets have suffered from the lack of mobility. Being unable to get to the shops on their own and buy fresh produce, they have grown dependent on ready meals and junk food and a number were discovered to have only biscuits in the house. Sometimes, it is the family who find it easier to deliver a supply of ready meals, rather than fresh food.

Whilst some older people with mobility problems are still able to use public transport, this can become difficult or even dangerous in bad weather when they can fall or are exposed for too long at cold bus stops. For those able to use hospital transport to get to appointments, they can find if they are the first pick up in the morning and the last to be dropped back home it can mean a very long and exhausting day.

Mrs B (60 years) is an example of an interviewee whose lack of mobility is part of a situation of complex needs where her physical and mental health problems are intertwined. She reports poor mobility because of pain in her legs, knees and back.

She says:

“ I find it hard to take part in any activity at home and outside. I suffer from mental stress caused by my husband who does not listen to me or the children who give him advice about looking after himself and the house.”

Mrs A (66 years) is in a similar position and also has restricted mobility. She suffers from Parkinson’s disease, has a shaky hand, arm and leg and finds it difficult to cope with daily living. She says:

“ I feel very lonely and spend most of my time indoors watching TV or on the laptop when I get bored. I watch TV to pass the time but I used to like going out to attend computer and other learning classes.”

Mental health

The mental health of ethnic minority older people as mentioned above is often intrinsically associated with isolation, loneliness and depression. (The issue of dementia will be reviewed in a separate section)

However, there are also a number of mental health situations which are uniquely related to cultural areas of life.

For instance, some women reported serious mental health problems associated with the fact that their children were not married. For Asian parents it is the pinnacle of their life’s achievement to have their children married and for previous generations they were able to control this. However, today’s generation of ethnic minority young people want to make their own life and career decisions and choose their own partners, as and when they find a suitable person. For the older generation when they fail to do this, and they are not able to manage the situation, they can suffer serious stress and mental health issues.

Mrs S (76 years) reports good physical health but says:

“ My only stress is my son in London who remains single. I worry for him and want him to get married.”

Another area where language and cultural differences come into play in the area of mental health is simple friendship. For ethnic minority older people, who perhaps only have the rudiments of English, they find they can’t participate in the daily interactions of their neighbourhood. They can’t manage small talk, can’t chat in the street or the shops and don’t get invited to pop in and out of people’s houses for a cup of tea. They miss out on a significant amount of social interchange and particularly if they are on their own, they feel isolated.

When older people are left on their own after the death of a spouse, this can sometimes trigger extreme feelings of loneliness and depression. Men are especially vulnerable to isolation when they are left on their own. Their wives have often been the glue of their social engagement and when they die, the husband is unable to sustain a social life.

One male participant of a focus group had this experience. He says:

“ When I became single I started coming to the day care centre and it has been of great help for my mental health and general wellbeing.”

Mr D (80 years) gets breathless walking after a certain distance. He has degeneration of the spine and neck and the discs are pressing on nerves so it affects him when he walks. He still manages with his car and wheelchair.

He says:

“ My wife passed away six years ago and I felt very lonely at that time. I believe it is harder for a man at the time of bereavement.”

Mrs B (76 years) thinks living alone is a big worry. She says:

“ Living on your own has an impact on your mental health. I do not know what will happen when I cannot manage so I will be relying on social services. I cannot expect much from my son and daughter-in-law because they are very busy and how can I ask for help from them?”

All older people are mostly mentally ill and the NHS is having to face these issues. Dementia is becoming very common and I fear it can happen to me in old age. I’ve asked my GP about it but he said it’s a bit too early to say.”

Participants in a West Lothian focus group reflected that most of them felt lonely when they were in the house but when they visit the coffee morning club they feel happy and believe that there should be more places for them to visit and to enjoy. They also agreed that going out and meeting people is very healthy for their mind and body, but most of them prefer to sit at home and watch TV. Unless they are actively encouraged or taken out they will not leave their houses.

When they talked in more details about mental illness and why dementia is widespread in their communities, they said they thought it was due to staying home, not going out and meeting people.

A different minority ethnic group felt the same with a spokesperson summing up by saying:

“ Everyone should mix up, because it helps us to get out of isolation. Staying at home makes you depressed.”

Another group discussed the role of lunch clubs more extensively and reported that gatherings like these can help tackle loneliness and social isolation. However, the group also highlighted how Asian communities have segregated among themselves and only want to mingle with their own community and do not integrate as much as they could due to cultural or religious reasons.

One participant mentioned that she lives in rural Scotland and does not have many people from her ethnic minority living there so she has to travel all the way to another town to attend a group. A spokesman summed up the group's sense of the importance of getting together for mental health and wellbeing.

“When you get to a certain age and are vulnerable you need a place where you can sit together, talk and listen to music like we used to do back home. We are very lucky that we have a group running once a week, where we can come and enjoy a few hours listening to music, having a laugh, a joke and lunch together. It is worrying for those who are unable to attend these groups due to the lack of accessibility or transport reasons. Also not every area has a group or centre for ethnic minority older people as it is not possible to cater for every ethnic minority need.”

Volunteering

For some people, a sense of community and connection can be found in volunteering. Many ethnic minority older people volunteer within their own communities and enjoy being able to give and very much value the opportunity to contribute to society. It gives them a morale boost and a sense of pride. However their involvement is not widely recognised as mainstream volunteering as many do not speak English.

Mrs C endured a troubled marriage to an alcoholic who eventually died and the death of her son in an industrial accident. She then succumbed herself to emergency liver failure and needed a transplant. She turned to volunteering in a Chinese nursing home and found it hugely beneficial to her wellbeing. She says:

“The volunteering work makes my life better and stronger. I believe volunteering improves my quality of life. Offering a helping hand establishes a real spirit of humanity and helping others is an experience that I will treasure for life. It has helped me to develop inner growth and has boosted my self-esteem.”

Mrs L (78 years) also finds volunteering good for her mental health. She is a former nurse and has good English. She used to do a lot of volunteering to support Chinese older people, including letter reading and oral translating, providing advice on health and general advice about immigration. Due to her responsibilities as a carer she no longer volunteers. She says:

“I believe physical wellbeing starts from a healthy lifestyle and that my mental wellbeing is achieved by providing a helping hand to those in need.”

Addiction – Alcohol and Gambling

Alcohol and gambling addiction is a hidden physical and mental health problem within the ethnic minority community. It is strictly “taboo” and families go to considerable lengths to ensure that it is kept hidden. The culture across a number of ethnic minority groups is that admitting that someone in their family has an alcohol or gambling addiction would result in a loss of face and a reduced standing in the community.

Mr L (66 years) and became an alcoholic and gambler 10 years ago when his wife had mental health issues. Whilst it is generally culturally acceptable in some ethnic minority cultures for males to have a few drinks at home, to seek advice about alcohol problems is deemed to indicate weakness in the male-dominated society.

Mr L says:

“I used alcohol as a coping mechanism to deal with the stress. I started to have a drink or two in the evening after work to help me block out my self pity about the misery of my life and the alcohol helped me sleep better. When I woke up, and thought about the children, my wife's mental health problem and work issues, the only thing that would make me feel a little bit better was another glass of wine. Alcohol became part of my life and over time it became everything.

I became concerned about my daily alcohol intake when I realised my hands shook uncontrollably throughout the day. When I started drinking early in the morning rather than before bedtime I knew I had a problem but I never sought help or advice for fear of rejection by my community.”

At this time Mr L also turned to gambling to feel wanted. He says:

“The casino environment made me feel like I was at home because the staff served me like a king. I felt great when I won because other gamblers ‘eyed’ me as a hero and it was this winning feeling that led to me spending most of my hard-earned money on gambling until there was little money left for food and fuel. I wanted to speak about my problem with friends but I felt like a loser if I did and this inability to communicate made me feel helpless.”

Mr L is a diabetic patient and his excessive drinking in the past has caused substantial damage to his liver. Mr L believes that there is a lack of awareness of drinking problems in ethnic minority communities and that a lack of family support and the fear of rejection by the community causes excessive drinkers to suffer in silence.

Language barrier

The language barrier faced by many of Scotland's ethnic minority older people is particularly concerning in the area of their health. In some cases, it has caused significant grief and suffering.

What may be obvious are the problems ethnic minority older people face in communicating with health professionals, accessing NHS24 and sourcing information and support.

What is perhaps less obvious is that in the area of health there are often complex situations, emotions and personal issues to communicate. When these are not able to be expressed or understood, they can lead to inadequate responses.

For example, ethnic minority older people without fluent English are not able to access condolence and comfort from health professionals, causing more anxiety and distress than English speakers would suffer. It is difficult to imagine, for instance, what it would be like to be given a cancer diagnosis without the information and support from specialist counsellors.

Mr C (71 years) had a number of criticisms of the NHS. Based on his experiences he says:

“I strongly believe that bilingual medical staff are vitally important to improve NHS services because a word of condolence or a word of comfort in a language the patient or the patient's family members understand can have a ‘calm a wounded soul’ effect.”

Mr L (66 years) explained how difficult he found it over the years to gain access to health services due to the language barrier and his unfamiliarity with the British health and social care sectors. He says:

“ There is no collective voice for some smaller communities to express their needs and concerns so local government don’t think there is a need to recruit bilingual speaking workers to provide help and support. There is a lack of services with language support, health information and day centres for ethnic minority older people.”

Mrs C (76 years) had got used to having her children act as interpreters for the daily needs of her and her husband. However, when the children left home for good, there was no one to provide language support.

Mrs C explained how the local authority had established an Interpreting and Translating Service – a community interpreter – which bridged the gap between medical professionals and patients. However, the service was aimed at providing support for NHS professionals and didn’t respond to the needs of people who cannot speak or understand English and who cannot communicate sufficiently to book a GP appointment, make a phone call to the hospital for a test result, or make an appointment for the optician or dentist. This meant that due to language barriers, older people like Mrs C and her husband, were missing out on a bi-annual eye check, a regular dental check and an annual flu jab.

When Mr C started to show symptoms of mental health problems such as regular falls, forgetfulness, getting lost on a short walk to the post office and leaving home early in the morning claiming he had work to do in one of the shops he had worked in years ago, a lack of language support meant it was difficult for Mrs C to express her concerns to the GP and to request further investigations and tests for her husband. Due to a lack of effective communication between the patient and the medical professionals, there was a delay in diagnosis, which in turn meant that social services were unable to plan and deliver support at the right time.

Mrs N (88 years) worked for many years in a food chain business in London, during which time she had many physical health problems. These problems were ignored by her employer and at that time there was no language support for workers like her. She says:

“ This meant that I looked for alternative treatment, such as herbal treatment or acupuncture when it was needed, because the herbalist was able to communicate with me in my native tongue. I did not have the language to explain to a doctor that I had abnormal, extensive bleeding caused by an infection in my tubes. The delayed diagnosis and treatment led to a blockage in my tubes which meant I was never able to conceive.”

Mr S (65 years) told the project staff that he would like to be seen by a GP but that he won’t be seen until an interpreter has been arranged. Mr S is not allowed to bring in a family member or a friend as his interpreter.

Whilst it is good practice not to use family or friends as interpreters due to confidentiality issues, there is a need for improved access to interpreters. Family members can choose not to pass on the full information when it is life threatening or someone has to tell their loved one that they don’t have long to live. Male members of families find it difficult to explain or discuss women’s personal issues if they are interpreting for their mother or sister.

And it can be very hard for younger family members to interpret on sexual or contraceptive discussions, as culturally these issues are not openly discussed.

Other difficulties arise when ethnic minority older women are asked to keep an insulin diary which they are not able to do or when they are reluctant to talk about incontinence issues and ask for help, particularly when they depend on their son.

When members of a lunch club for ethnic minority older people were asked about their health concerns, all the participants complained about the difficulty of booking appointments with their GP.

They explained that when they needed an appointment with a GP on the same day, they had to phone the medical practice, explain to a receptionist the reason they wanted an appointment, then a GP would call them and listen to their concern. The GP would then ask questions related to their ill health to decide whether they can be seen on the same day or not. This was a very challenging process for people with little or no English.

The language barrier was also a problem when they needed to call the GP surgery for a lab test result. Due to language difficulties, they needed someone to call on their behalf for the lab report. However, medical staff cannot release the result to anyone, not even to a carer, under the General Data Protection Regulations.

Participants of another focus group in Aberdeen reported similar language barriers associated with the GP service.

Having to relate all their symptoms firstly to the receptionist in order to get a non-urgent appointment and then to the GP was a very real barrier. If interpreters are involved, they reported that three-way conference calls are also difficult to negotiate, especially if the older people have hearing problems. Participants who lived alone were particularly disadvantaged as they could not call the GP to explain their illness, nor were they able to understand the questions they are being asked on the phone.

One lunch club participant spoke about her sister who attended a GP appointment and even though her medical notes clearly stated she would require an interpreter, none was provided, so she lost her appointment.

Others at the lunch club confirmed that similar cases had occurred to them and when the project staff asked if they had complained they said they didn’t know how to.

Another issue which was raised at a group discussion was a more complex problem associated with the language barrier. When asked to explain symptoms or pain levels, participants in the focus group said that they may end up with paracetamol for chronic pain or a condition, such as severe arthritis. Had they been able to explain their symptoms more effectively, they may have had different, more effective treatment.

But some report they are content

Despite all the health issues and challenges navigating the system reviewed above, in the course of the interview process, many people were positive and reported that they were coping well.

Mr M (91 years) has several health conditions which mean he is not able as he used to be. He has a pacemaker and takes several types of medication. His mobility is slow but he manages to walk, although if he walks for too long he gets out of breath. He does not need hearing aids and only wears glasses for reading.

He says:

“ I know how important it is to live a healthy life and how important it is to eat well and on time. I can only praise my local NHS services and the help I receive from them and I am grateful to the government who financially support me in my old age.”

Mr L¹ (76 years) and lives with his 76 year old partner and 30 year old son, who has a mental health condition.

He has recovered from bowel cancer. He keeps all follow up appointments and takes medication to prevent the return of the cancer. He has no problems with vision or hearing and his thinking is sharp. He has his own thoughts about politics, follows a well-balanced diet, takes regular exercise, thinks positive and loves and respects his partner. Mr L aims to have a long life, a healthy body and to be able to provide the best and most comfortable environment for his son.

He said:

“ It is not my choice to have a son with a mental condition but at least I can provide the best I can for him.”

Dementia

According to Alzheimer’s Research UK there are currently 850,000 people with dementia in the UK, more than ever before and this number is projected to increase.

Whilst this is a problem right across Scotland’s population, ethnic minority older people have additional situational and cultural challenges. There is little understanding of dementia within these communities. For instance some groups think you can catch it, some think it can be cured by a pill and others believe it is due to “karma” or you haven’t lived a good life.

Mostly, family, friends and carers simply do not know how to deal with a person with dementia. They are unable to recognise the initial symptoms and don’t know of how to start planning for the future. Dementia symptoms are often seen as being age-related forgetfulness and can create frustrations for both the person with dementia and the family. Family members are often not sure why there is change in someone’s behaviour. They sometimes believe the repeated questions are deliberate and that the person isn’t listening and sometimes they even believe the behaviour is a personal attack. Sometimes there is a sense of shame, resulting in the sufferer themselves withdrawing or people in the community withdrawing from them, compounding the problem of isolation. All of this puts an enormous strain on family relationships.

It can be very dangerous for people with dementia who live alone as they can go without food for many days. This is because they forget to eat, forget how to use their bank card to buy food or simply forget to go shopping. There are also the hazards of older people with dementia eating out of date food, wandering outside and not knowing how to get home, forgetting to take medication or not being able to maintain personal care.

These widespread problems are compounded by not being able to speak English or losing the English they once had because of their dementia. Even with an interpreter, subtleties of behaviour can be difficult to express accurately and can compromise treatment and support.

There are also enormous pressures for an older person whose partner has developed dementia. If he or she is already frail and perhaps needing care themselves, the burden of caring for someone with challenging or aggressive dementia behaviour can be overwhelming. Also, older people who have a partner with dementia will often report the loneliness of not having someone to talk to and to share household tasks and responsibilities.

Whether it’s a spouse or other family member, it is often the case that the carer desperately needs support and respite but does not know how to access it and make use of the resources available.

In general, families do not know where to go to ask for help as there are no organisations that can provide support to ethnic minority people with dementia whilst also meeting their language, dietary and cultural needs. There is also no technology which can support people with dementia living at home. And of course, it is even worse for those who live alone and are not diagnosed because they don’t have family to help them to get them medically checked.

Ethnic minority day centre staff report that they are finding it difficult to look after and support their clients with dementia, as it puts additional care demands on untrained people.

Ethnic minority older people can be resistant to thinking and planning for the future and who they would like to help them when they are no longer capable of making their own decisions. This attitude is particularly problematic in the area of dementia and deteriorating mental health.

People with severe dementia requiring 24/7 care, where the family are unable to look after them at home, can be considered for a move into a care home. However, care homes do not have staff who can speak ethnic minority languages and understand dietary and cultural needs and the danger is that they will be further isolated in a place which is alien to them, where no-one looks like them or shares their experiences.

In summary, there is no provision for ethnic minority older people with dementia and they are often left without care and support services. The burden is shouldered by their families whose physical and mental health suffers as they become tired, isolated and depressed seeing no escape from their challenging care role.

There is a very urgent need for action and a programme of practical interventions and support. Services need to gather information, look beyond regarding cases in isolation and focus on the bigger picture to find solutions.

¹ Whilst Mr L reports that things are going well, we are concerned that Mr and Mrs L are in their late 70s and just about keeping their heads above water. It won’t be long before they will be challenged by their own deteriorating health. Their son is not able to manage his own personal care and this will be increasingly difficult for his parents to manage.

Case Study

Mrs L (79 years) is a widow living alone who was diagnosed with dementia two years ago. She has two adult children living abroad.

Before her diagnosis, Mrs L had led an active life and was capable of looking after herself and enjoyed living independently. Before her illness she remembered where the local shops, bank and post office were.

Mrs L has lived at the same address for more than 30 years. She used to recognise neighbours' faces and exchange greetings in broken English. She went out regularly, visited her friends for a cup of tea, or went out with them for lunch with them, travelled abroad with them and studied English as a second language together. She was able to manage all medical appointments with an interpreter, to collect her pension from the bank and do shopping and light domestic work.

With dementia, Mrs L is no longer able to recognise the area she lives in and she finds it hard to remember where the local shops are. She is not able to collect her pension from the bank or post letters at the Post Office. She can't find the way back home and is frequently helped by the police. She has lost her confidence to go out alone as she could forget which bus took her to the lunch club, her friend's house or where the GP practice is located. She has become alienated from her neighbours. When she could not recognise their faces she distanced herself from these 'strangers'. Mrs L refused to leave her home. She felt so helpless, unable to control her life. She felt completely isolated and caged in at home by this condition.

Mrs L is increasingly concerned with her condition and has concluded that sheltered housing is the solution. But moving to a sheltered home where most of the residents speak English would not solve the problem of isolation that Mrs L already suffers. Besides being alienated because of the language, living in a new environment and struggling to recognise the new faces of care staff could create additional anxiety and stress. The best solution for Mrs L is to live in a Chinese sheltered housing development, a place where there is no language barrier, where Mrs L can communicate with the warden, care staff and other residents in her native language. The power of communication could bring back a sense of control for Mrs L. It could also boost her confidence in living independently. However, there is currently a long waiting list for a place in Chinese sheltered housing, which means that she will continue to live in isolation, confusion and depression, a prison built by dementia.

Review and recommendations

Scotland's ethnic minority older people are struggling with their health and even those who report that they are managing well are not looking ahead to a time when they may be less fit.

The more physical and mental health issues people have, the less they engage with others and the more they report problems of loneliness, isolation and depression as a result.

The other major battlefield is engaging with medical practitioners – navigating the language challenges of the often complex systems for appointments and test results.

The language barrier and cultural attitudes create additional issues for ethnic minority older people accessing healthcare and support, but nowhere more problematic than in the area of dementia.

Actions which could be taken to respond to the research in terms of the physical and mental health are as follows:

- **Further research into how dementia is affecting ethnic minority older people and their families.**
- **The existing lunch clubs seem to be crucial to combating loneliness and giving ethnic minority older people a sense of engagement and identity. These need to be resourced and staff need to be trained and supported.**
- **How additional transport can be funded so that more people with mobility problems can be offered transport to lunch clubs.**
- **Health services to be accessible and procedures put in place to deal with and overcome the language barrier which is particularly vital for older people with complex health issues. Current provision of inadequate information and support by GPs needs to be improved.**
- **Advice provided to ethnic minority older people on the importance of having power of attorney or the appointment of next of kin before they lose the capacity to make decisions or develop dementia. They should also be advised what it means to have a guardian appointed when they are not able to make decisions about their life.**
- **Dementia workshops could be developed and run in community centres and lunch clubs to give ethnic minority older people and their families a better understanding of what dementia is, what services are available for them and how their family member or carer can be supported.**
- **A diabetes workshop could be delivered along the same lines or even combined into a single session with a dementia workshop.**
- **Both dementia and diabetes workshops could be supported with take home literature in community languages.**

7. CARE NEEDS AND CARING RESPONSIBILITIES

“*Nowadays children are far too busy to care for their parents. Our generation had high expectations from our children, that they would care for them in their old age, but it has all changed and has left us with no choice but to depend on social services, which I believe is very worrying.*”

Introduction

For many of Scotland's older people, simply living daily life can become very challenging. This paper has already explored the difficulties presented by unsuitable living accommodation, financial concerns and health problems, all compounded in the case of ethnic minority older people by language barriers and cultural attitudes which impede access to available resources or render existing resources unsuitable.

However, over and above these challenges a generation of older ethnic minority people are also shouldering the almost insupportable burden of caring for a spouse, parents or a child, often whilst being frail or needing care themselves. And again, as with the other challenges of older age, their complex caring and care issues are exacerbated by language and cultural barriers.

Across the spectrum of older ethnic minority people who told their stories about how the responsibilities of caring impacted their lives or their own experiences of care, the overall impression was of suffering. Whilst a minority of older people were being cared for by their families, the overwhelming picture was of older people stoically trying to cope on their own in extremely challenging situations and without appropriate support from social services. And for many others too, there was a sadness that the tradition of joint families is disappearing as children, who grew up in western culture, reject the tradition of continuing to live in multi-generational households and have moved out to set up their own family units.

For those who care and for those who are cared for, ethnic minority older people are in crisis. The structure of the extended family and an acceptance by children of a cultural duty of care for their parents is breaking down without a viable alternative being in place. Many ethnic minority older people are trying to hang on to the old ways, whilst realising that dependency on their children strains relationships.

However, for those who are prepared to consider moving out of their own homes into supported living such as sheltered housing or a care home, there is nothing available to meet their needs. Moving into sheltered housing accommodation where no-one speaks their language and where the food and culture is alien to them, is a frightening proposition and in some cases even a damaging one, risking increased isolation and depression.

Reviewing the conversations and encounters with hundreds of Scotland's ethnic minority people who are carers or who are being cared for, a number of common themes arose. The need for care is a problem that radiates out from the frail older person to all those around them, causing a myriad of challenges and stresses.

Impact on spouses

For the majority of older ethnic minority people their caring role involves supporting a spouse. And for many of these carers the impact of this demanding role is not only physically demanding but can be mentally crushing too, leading to a sense of isolation, loneliness and depression.

Mrs C (76 years) has a chronic illness and is typical of this group of carers. She reported that she felt that social services ignored the needs of the carer in reviewing the care needs of her spouse with dementia. She said:

“*If I am unable to look after myself, how can I manage my caring role looking after my husband? The local authority should play the main role in care rather than using family members as unpaid carers, as they do not have the skills and resources to look after a dementia patient.*”

Mrs G (86 years) is also facing the considerable physical challenge of caring for his 79 years old wife who cannot walk far. He finds it very challenging and is unable to leave her on her own in case she has a fall. If she does have a fall it is hard for him to lift her.

Mrs M (65 years) cared for her husband for six years whilst working part time. She said:

“It was very stressful for me. I myself suffer from multiple health conditions which have had a great impact on my daily life.”

Mrs T (75 years) looks after her husband who suffered a stroke six months ago and whose illness has caused mobility problems with his hand and leg on the right side of his body. Mrs T has found it extremely difficult to assist her husband down the stairs to attend medical appointments or physiotherapy.

Mrs T reported that not only did she find the physical requirements of her care role challenging but that she also found it difficult to express her concerns about her husband's treatment or her own health to medical professionals.

She said:

“I couldn't discuss my concerns that the medication my husband was taking had possible side effects or that I had problems in my caring role. Scottish NHS should recruit more bilingual workers to provide language and emotional support for more patients as well as for ethnic minority carers.”

Case study

Mrs L is in her early 50s and is an unpaid carer to her 79 year old husband. Mr K suffered a severe heart attack which resulted in restricted movement in his arm and leg on one side, incontinence and mobility problems.

Mrs L works part time and did not want to apply for benefit because she did not want to be a burden to society and on the state. She kept saying: “Let the money be used for those that need it most.” Mrs L needed support of a different kind – not an assessment of benefit entitlement but language support to access services as a carer, as she does not speak English.

When the project co-ordinator became involved, Mrs L's support needs were assessed. The co-ordinator realised that Mr L was unable to swing his legs across a bathtub during bath time. Physically he is a big and heavy man and Mrs L is petite. As Mr L does not have any movement in one leg, he fell in the bathtub and Mrs L was unable to pull him out.

When Mrs L is at work, Mr L is left at home alone wearing incontinence pads. Sometimes Mr L is covered in urine and faeces. When she returns from work, Mrs L needs to wash and change Mr L again. The project co-ordinator contacted the local authority and requested for an occupational therapist to visit Mr L for an assessment for home equipment such as a bath seat which can be raised, as well as a handrail. A joint home visit with an Occupational Therapist was arranged at the time of installation to ensure the equipment was installed securely.

Mr L received a wheelchair from the NHS when he was discharged from the hospital. Sixteen months after being discharged, a wheel of the wheelchair started to buckle inward causing the wheelchair to need extra strength to push it. Mrs L continued to wheel her husband to medical appointments on this broken wheelchair for months. It was very tiring and difficult for her, but she did not know how to report faulty equipment or request the hospital to repair it. Also, she had no idea where and how to apply for a zimmer frame to help Mr L to walk in the house. Mrs L had no information and was not able to find out as she does not speak English.

The project co-ordinator contacted a physiotherapist for a further assessment for a walking aid or a zimmer frame and to repair the broken wheelchair. During the assessment with the physiotherapist, the project co-ordinator acted as an advocate for Mrs L to explain her needs and to help with the equipment requirements. As a result, the wheelchair was replaced, and Mr L received a zimmer frame and was also granted personal care three times a week to reduce the strain on Mrs L.

Ethnic minority older carers are not being adequately supported by mainstream health services; the language barrier is the main and most common reason for having difficulties accessing social services. Also, health care professionals never visit with interpreters for those with language barriers or with information in community languages to explain/advise on how to report/return broken equipment after receiving it. There is a lack of information on how the social work department could help carers if the person receiving care has unmet needs or if a carer needs an assessment for respite entitlement. However, the lack of information on carer support means that there is low take up of social care services and it is sometimes perceived that they are looking after their own. Older carers need language support

to be an effective carer. They need support to book GP appointments, make a phone call for a test result, phone for repeat prescriptions, make an appointment with the optician or dentist, re-order incontinence products and manage incontinence issues. Older carers have the right to community language support in all medical appointments and for when they need to make decisions on future care and treatment for their loved ones.

Impact on family

The role of children in caring for their parents in ethnic minority communities is changing. Some older ethnic minority people accept that their children have busy lives with their own families to care for and want to be independent of their children. However, for other older people they still expect to be cared for in their older age and are disappointed and upset when their children are unable or unwilling to carry out this role.

In 93-year-old Mrs L's case, she reported that after her husband died, her son, daughters-in-law and grandsons have taken up the caring role. Mrs L's family provides her personal care, dressing and undressing, food preparation, keeping up with medical appointments, transport and emotional support. Because Mrs L receives 24/7 care from relatives, she requires no extra assistance from social care.

Mrs R (85 years) is also cared for by her family. She has been a widow since 1973 and lives with her son, daughter-in-law and two grandchildren. She has had tuberculosis and became very weak, restricting her mobility. She relies on her daughter-in-law for help with most of her personal care. She said:

“ My son and daughter-in-law stay with me and this is a very straightforward arrangement. They currently don't have jobs or income. My son cares for me a lot. I am lucky to have a son who looks after me. Not all people are the same and those parents who have caring and loving children are lucky.”

In the course of a focus group in Aberdeen three participants reported how they live with their children to support one another (the older generation look after their grandchildren in exchange for language support, bill payments and transport to all medical appointments provided by their children).

For these participants, they were unable to manage the regular activities of day to day life independently. They felt frustrated with ongoing medical problems and the increasing number of medications as they found it difficult to follow directions on how to take medication, manage medical appointments and medical tests. They agreed that living with adult children under the same roof has the advantages of immediate attention and action taken if they fall ill during the night. Even if it caused some relationship concerns, they reported that there was the comfort of having someone around.

However, for other ethnic minority older people, it was very clear that there were cracks appearing in the relationships between the generations, as the younger generation is beginning to pull away from the traditional ties of the extended family.

Mr M (83 years) lives with one of his sons, daughter-in-law and his two granddaughters. His wife died a year ago and he is still struggling. Whilst he is living with one of his sons and his family, he would prefer to be surrounded by his wider family. He said:

“ My wife's death has left a big hole in my life, and this has left me feeling lonely, especially when I have spent nearly 49 years of my life married. I then had to go through the sadness of my older son, who I am very close to, moving out with his family and now I have very little contact with him. My son does make an effort to come once a week to see me, but it is not the same.”

This loosening of the ties of extended family life is difficult for the older generation and many expressed a wistfulness for the way things used to be.

Mrs B (76 years), for instance, worries about what will happen when she becomes frailer. She is a wheelchair user and does not think there is enough support from social services for people who use wheelchairs. She said:

“ I think living alone is a big worry. Girls are closer to their parents. I can't expect much from my son and daughter-in-law because they are very busy and how can I ask for help from them?”

Mrs A (66 years) is a widow and no children. She lives alone and suffers from Parkinson's. She has incurred a lot of debt and lives in poverty. She is supported by her extended family who pay for a cleaner and bring her cooked meals which she can reheat.

“ I have family support and they visit occasionally but everyone is busy. Family do what they can but they are busy with their own families. I want family around me as I do not feel safe at night. If I had family around me I would feel comfortable. The weight would be lifted from my shoulders and I could relax. Sometimes I just watch TV and stare at the walls which makes me feel anxious and want to run out into the street in bare feet.”

It was the same for 79-year-old Mr B who had triple bypass surgery nine years ago. He has looked after himself since then and is quite able to take his own medication and keep an eye on his diet. However, he is also a carer for his wife and sometimes worries what he would do if he could not manage or became ill and was unable to look after her.

He is disappointed by the way in which times have changed and the onus of care has moved from children to social services. He said:

“ Nowadays children are far too busy to care for their parents. Our generation had high expectations from our children, that they would care for them in their old age, but it has all changed and has left us with no choice but to depend on social services, which I believe is very worrying.”

Mr S (85 years) and lives on his own. He fears something will happen to him when he is at home alone and is representative of many ethnic minority older people of his generation when he said:

“ I believe that parents who have looked after their children and given them their full attention should be looked after by those children in their old age.”

However, during a lunch group discussion in Irvine this view was challenged and a number of participants reported that the traditional idea of “bringing up sons to support their parents” is changing and that no-one wanted to be a burden on their children.

For some ethnic minority older people in this discussion group, sheltered housing has been the best solution to meet their needs and for their family dynamics. In a focus group of 15 participants, 12 lived in sheltered housing because they did not want to be full time babysitters for their grandchildren or to be a burden on their children, whilst they are capable of looking after themselves. They all agreed that the generation gap causes problems that could damage relationships with the younger generation. They said that the younger generation has their way of life in the same way that the older generation has their way of life and that the best way to minimise conflict between two generations is not to live under one roof.

These 12 participants agreed that the increased dependency of ageing parents caused emotional stress for their children and damaged their relationship. Living independently gave the participants a chance to learn things, such as managing their own finances and cooking for themselves. They do not need to cook for the whole family and to think about who does not like what. They can travel and plan holidays without thinking of what time they have to pick up grandchildren from school. Because they are free to do the things they like, they have a sense of confidence and control.

Impact of caring for a child

The assumption is that ethnic minority older people who are carers are caring for a spouse or a parent, but in the course of hundreds of interviews with Scotland's older people, it was concerning how many were also looking after adult children with physical or mental disabilities.

This group of people have been carrying out this role all their lives, often without any support from social services. Older age creeps up on them and gradually the caring regime becomes more and more demanding and challenging. However, as they have been outside the social services system all their lives, there is no external support structure in place and they often do not know where or how to start to build one.

Mrs F (82 years) has been a carer for her son with Down's Syndrome (DS) all her life and is typical of this group of carers. She has never received support from mainstream resources. He could not join a support group for DS because he had a hearing problem and he couldn't join a support group for deaf children to learn sign language because he has a learning difficulty.

Mrs F felt that as a mother and a carer, she was unable to fight for her son's right to be part of a formal support programme, because of the language barrier. She said:

"I had neither the language or the confidence to fight against the decisions made by professionals. Back in 1979 I was a victim of government policy and practices and local government's lack of resources to support ethnic minority carers. If only there had been someone to represent my case, my son would have received more training to overcome his disadvantages."

Now at the age of 82, Mrs F is facing a whole new set of problems. Like many others she is getting worried about her child and who will look after him when she is no longer able or around to do so. She is exhausted and finding it increasingly difficult to look after her son because he has the onset of dementia. She has been looking for a nursing home to suit her son's needs. However, during this process, Mrs F found out that she needed legal guardianship to manage the finances and decide on a care plan for her son. The guardianship is far beyond her understanding and it has caused her a lot of stress. Mrs F said she wished that guidelines and information on guardianship could be printed in community languages.

Mrs F said that if there had been earlier intervention some of these major stresses associated with her caring role could have prevented the lasting effect of "burn out" that she was experiencing. She said:

"Carers deserve some form of quality of life for themselves."

Male carers

The cultural tradition of the extended family and how it functions in the second decade of the 21st century is creating massive cracks in a self-sufficient care system within Scotland's ethnic minority community.

However there is another area, less well recognised, in which cultural attitudes create a complex and problematic dynamic in the care role. That is a sense of propriety which is intrinsic to many ethnic minority cultures – a principle of what is acceptable practice for female and male carers and female and male receivers of care. On the whole, ethnic minority older people will only receive personal care from a person of the same sex.

For a male carer, looking after his father for example, the challenge of the role is even more complex as it is considered an unmanly and even shameful role. The implications of a man believing he must hide his caring role, can be very destructive.

For men like 61 year old Mr C, who became an unpaid carer for his father after his mother passed away in 2010. There is also the burden and sense of responsibility of looking after parents, knowing there is no-one else who can do it and unable to access suitable support.

Mr C's sisters all live abroad and Mr C's father won't allow anyone to take care of him apart from his son. Under these circumstances, Mr C had no choice but to take over the role of carer for his father. Mr C does not describe himself as a carer to others as caring is perceived to be a sign of emotional weakness within his male dominated society.

Mr C did not tell his employer that he was caring for his father and as a result, Mr C's employer did not understand the reason for him turning up late at work or not being able to work late or why he takes an hour break during work to take his father to medical appointments. This has led to his employer perceiving him as lazy with no commitment to his work. Mr C has struggled for years with a full-time job and a role as carer.

Mr C's father rejected any services provided by the social work department. He has turned down home help, he was not interested in sitter services and refused to receive personal care. However, he was in need of these services.

Mr C was very critical of the social care service as they were unable to meet the cultural needs of his father who would never accept personal care from another female apart from his wife, nor would he be alone in a room with another female. Mr C accused social care services of being unable to provide care staff of the same ethnicity who spoke the same language. He said:

"Ethnic minority older service users do not receive the food they are accustomed to such as noodles or rice. They will definitely not eat sandwiches or a tin of soup every day."

Mr S (65 years) who became a carer for his father, was also floundering. As a male carer he faced additional difficulties. He said:

"Being a male carer is not easy at all. I felt so isolated, stressed and sometimes depressed. However there was no way to channel my emotion as I have been trained since a child that "big boys don't cry". But I was bleeding without tears. I think male carers try too hard to manage things they cannot manage. I felt uncomfortable with some tasks a carer must do such as personal care or taking the person on a toilet trip. But it was my duty and who could help my father if I did not do it?"

When 67 year old Mr L became an unpaid carer for his parents, his already difficult situation was made worse by the cultural attitudes of the Chinese tradition. Culturally, in the Chinese community the caring role for ageing parents falls to the daughter or daughter-in-law of the family. However, Mr L has no sister and Mr L's wife was also a carer for her own ageing parents. Mr L had no choice but to be a carer for his parents and took early retirement to become a carer. The difficulty of his role was compounded by the fact that Mr L did not want to identify himself as a carer as that would lower his social status within the Chinese community, where he would be seen as performing a female role and would be perceived as weak. This had the knock on effect that he did not receive the support he needed. He said:

“ I clearly remember the exhaustion I suffered. It was hard to undertake personal care, incontinence care, to take on domestic tasks and to dress and undress my parents. I missed out on spending time with friends and family members as the result of being a carer.”

Mr L continued:

“ The local authorities must recognise ethnic minority male carers and should look to develop services to support them. It should identify male carers and provide signposting to local carers' organisations which can provide them with information and training to return to work when their caring role ends.”

The impact of losing a spouse

Whilst the challenge of caring for a spouse is demanding, older people who had been left behind after the death of a spouse reported extreme difficulty in adapting and being able to lead a fulfilling life.

For ethnic minority older women in a male dominated society, their lives had often been lived around their spouse and they were dependent on them. Mrs S is perhaps typical.

Mrs S lives alone and is partially blind due to diabetes. She sometimes gets very upset and feels lonely. She said:

“ I was very happy when my husband and I were together. Life was amazing. But now I worry at nighttime. I feel lonely. I have this fear about something happening in the night. My husband had a heart attack in the middle of night and I had to rush to the neighbours.”

For ethnic minority older men, in addition to the loneliness, they reported a sense of floundering with domestic tasks and a neglect of nutrition as they could not cook.

For example, Mr S (81 years) has lived alone since his wife died of a sudden heart attack. He has found it very hard to cope or adjust and has been very lonely. He said:

“ I don't think my care needs are being met because I need someone from social services to come and visit each morning to keep an eye on me and give me my medication. Some days I can manage but I still require some help. I do not cook when I am not feeling well.”

Mr R's wife passed away eight years ago with heart failure. While she was in hospital for six months, he visited her every day after work, driving to Edinburgh from Glasgow. He said he believed men grieve differently from women. He said:

“ I felt very lonely after my wife's death and was drinking a lot to make the grief easier. However, unlike women who have to grieve in the house because they can't leave their homes or talk to Asian men, I was at least able to leave the house and get back to a normal lifestyle.”

Transitioning from the caring role

Associated with the grief of losing a spouse and having to adapt to a life that is very different and perhaps very lonely, the research showed that many older people were reporting the impact of losing the role of being a carer.

Mr C (71 years) expressed this well. He was the primary carer for his mother, his wife and then his elder daughter who died from cancer at the age of 45 last year. As a carer for three of the most important females in his life, Mr C reflected:

“ Life seemed like riding a roller coaster with big drops and sharp turns.”

He then made the interesting point that after decades of caring, he felt there was no support to help him transition from this role. He said:

“ I did not receive a consultation or any support when I was no longer needed as a carer. I think a session on preparing for ending the caring role is very important, as when people receiving care pass away, the carers need help adapting to significant changes in their lives.”

Mr S (65 years) who had looked after his father agreed. He said:

“ The local authority should continue to support carers after the person they were caring for moved into a care home or passed away or the caring role comes to an end.”

Care solutions not appropriate

Given a situation, as they have described above, where Scotland's ethnic minority people are bending and buckling under the strain of caring for family members in their own homes, what is the alternative?

Unfortunately, there is no viable option. They have no choice, no real alternative.

And the reason for this is that there is a comprehensive and acute lack of ethnic minority carers and culturally appropriate services.

The author of this report has already discussed this problem in a paper entitled Keeping Body and Soul Together, as part of the Scottish Care Cameo series.

The current care support package for older people at home allows for a visit by a carer/worker. However, if that person cannot speak the language of the ethnic minority older person then the service is not meeting one of the most basic of human needs – to communicate. A care visit is not only about providing personal care, it's perhaps the only time the older person will see anyone during the day and it's a vital point of engagement.

The other key issue is gender-related as an ethnic minority older man will not want a female to provide his personal care and a woman will not want a male carer. However in most situations, this culturally important preference would not be accommodated.

Some older people have hired carers from their community but more often than not they are not trained or vetted. This situation puts older people in potential danger and at risk of abuse.

There is an urgent need for specialist, vetted agencies to be set up or a recruitment drive by existing carer providers to recruit multi-lingual carers who can deliver a service which overcomes language and cultural barriers.

For other ethnic minority older people, some will just do without a carer, even when their need is great, if they cannot access a carer from within their own community.

The lack of culturally appropriate services is also an issue in residential care. For instance, if food is being provided as part of the home care service, for older ethnic minority people, it will not meet their dietary needs or observances. A sandwich or microwaveable ready-made meals would be the last thing they would want to eat.

This situation is strongly reflected in the attitude of 88 year old Ms N who has refused the suggestion of a move to a nursing home with care supplied by nursing staff as she is worried she may not adapt to the new change and will miss her Chinese neighbours.

“ If I moved to a nursing home with more support, I would certainly miss my neighbours of more than 30 years. I am used to eating traditional Chinese food and the nursing home would be unable to provide Chinese food as an option for me. I would be forced to eat Western food that looks and tastes unfamiliar. I also wouldn't be able to communicate with the care workers who only speak English.”

And equally, by 71-year-old Mrs S who lives alone and is partially blind because of her diabetic condition. She has managed to get Self Directed Support (SDS) but has been sent male carers and would prefer to have female Asian women in her house.

Mrs A (66 years) needs a lot of help with personal care and eating. She lives alone but would have preferred to move to sheltered housing if there was one for Asian people and there were other women to chat with.

Participants at the Irvine lunch club all agreed that if they were unable to look after themselves they would like to live in a sheltered housing development for older Chinese people where they could communicate with each other in their mother tongue, have their own food and share experiences and lifestyle.

Mrs K (69 years) strongly believes that specific sheltered and care housing is needed for Asian older people as it would provide companionship and care and would meet dietary and cultural needs. She said:

“ I would not think of living in sheltered housing which does not meet my needs. Care at home is a big issue when the carers can't speak the language, make appropriate food or understand cultural needs.”

The problem of being in residential care when there is a language barrier is illustrated by the case of 87 year old Mrs L.

Mrs L's social worker reported that it was proving difficult for the staff to know if she was in pain or needed to go to the bathroom. They had to frequently call her son. Mr L made some cards with Chinese words on one side and English on the reverse.

While all Mrs L's care needs had been met during the six months she had thus far been living at the care home, she was unable to speak to anyone or have any social interaction.

Accessing ethnic minority carers and culturally appropriate services is equally as difficult in the community as it is within the care home and sheltered housing sector.

Mr L's story is typical of many when he tried to get support from his local authority for his father. The local authority allocated a female care worker to provide personal care for Mr L's father. However Mr L's father was unable to accept the concept of being seen naked by a female apart from his wife as he believed that exposure of his naked body to other females was disrespectful to all females and also that it constituted dishonour to his long-term partner. Personal care for Mr L's mother was also a disaster as the local authority had arranged for a female care staff to support Mr L's mother with personal care each morning at around 7:30am, despite knowing Mrs L got up late each morning. Mrs L preferred having a shower before bedtime rather than in the early morning. She believed having a shower in the morning could lower her immune system and make it easier to catch a cold as a result.

Mr L was very critical of the service providers and said that they had been insensitive to his parents' needs and, as providers, delivered services from a Scottish perspective and ignored an individual's cultural norm.

When Mr L's parents declined to use the services, the decision was reported as 'not needing' or 'not wanting' the services rather than the fact that the services were not culturally appropriate.

The Self Directed Support (SDS) challenge

For Scotland's population of ethnic minority older people requiring care, there is not only the problem of sourcing ethnic minority carers and culturally appropriate services. There is also the widely reported and almost insurmountable problem of navigating the route to financing the care.

Even if they are able to secure SDS, the challenge of managing the budget within its reporting terms is daunting. Many ethnic minority older people can't set up the required bank account or write a report of when and how payments are spent.

Mrs C (76 years) who cares for her husband with dementia is in exactly this position. Mr C receives three hours' support for personal care each week from social care through the SDS scheme. Under this scheme, the applicant has control of the funding to purchase their own care need. However, as Mrs C explained, this is unworkable for them:

“ We can't manage the fund by ourselves as we don't have any resources to set up a bank account for Direct Payment. We would have to recruit a personal assistant to help us produce and manage a quarterly report to the Social Work Department on how we used the money.”

Self Directed Support (SDS) is immensely complex for native speakers of English. It is incomprehensible for people with little or no English. Even with the use of interpreter services, ethnic minority older people are often unable to present their case accurately.

Typically, they often underplay their health and care needs and because SDS involves and often depends on assessments and conversations, this can result in their situation not being accurately reflected in an assessment report.

During a discussion on social care, a number of participants explained that when ethnic minority older people answer questions during a care assessment, they follow a cultural pattern of demonstrating how well they are coping and how effectively they can look after themselves, even when this is not the case. They tended to talk about their physical condition on their good days and not mention how desperately they need help on bad days.

Mrs T's (82 years) story of coping with the demands of her husband who suffered a stroke which then triggered dementia is heartbreaking. Mr T frequently suffers a type of seizure which has led to episodes of unconsciousness, incontinence and mobility problems. Mr T often slips out of his home and wanders off. Once he suffered a seizure, fell and was taken to hospital by the police. Mrs T finds it difficult to simultaneously prepare a meal and keep a close eye on Mr T's activities.

To cope with these enormous challenges, Mrs T requested language support from a nonprofit organisation to act on her behalf and to contact Social Care Direct. She was allocated a worker who opened a file, carried out a community assessment and reviewed Mr T's needs based on the details he gave them.

Mr T passed away while waiting for services. This is not an isolated case.

Case Study

Mrs F (81 years) lived with her son, his children and her daughter, who looked after her. Mrs F received some benefits and her daughter claimed Carer's Allowance. Her daughter applied for and collected all benefits on behalf of her mother. Mrs F's son was unaware of his mother's benefit entitlement and he continued to provide food and shelter for his mother and sister.

Mrs F has mobility issues due to a diabetic condition. She is on injected insulin which her daughter administered twice a day. Mrs F has also been diagnosed with dementia and incontinence. She refused to wear continence pants and the urine caused skin sores. Every day the bedding, clothing and carpet were soaked in urine and the smell of urine was so overwhelming that her son and his family did not want her to live with them anymore. They wanted her moved to a care home with a dementia unit where she would receive professional care. Mrs F could not afford to pay for private care as she was on low income.

The project co-ordinator's involvement in this case was by negotiation with the social work department. The social worker claimed Mrs F did not know what happened around her because of her dementia. It was suggested by the social worker that if an individual lost the capacity for decision making about care arrangements, then the social work department have the power to take over the care arrangement. However, Mrs F's family wanted her to have a say. Mrs F's son did not arrange Power of Attorney when Mrs F was mentally capable to appoint an adult as her attorney and without one, Mrs F's children could not act on her behalf.

Mrs F's son arranged to have the Power of Attorney documentation completed, however the lawyer requested to speak to Mrs F without her children present. The project co-ordinator was invited to the meeting with the lawyer as Mrs F did not speak English and also to act as witness.

The next step was to find a care home with a dementia unit close to her children. The project co-ordinator worked with a social worker to find a care home that would meet Mrs F's needs and staff who were qualified to support her. Once the care home had been found, the co-ordinator also worked with the social worker to deal with the communication barrier between Mrs F and the care staff by using picture cards with Chinese on one side and English on the other. Mrs F was trained to use the cards while waiting to be moved to the care home. Mrs F received an invitation to view a unit which would be available, and she moved to the care home with a dementia unit within six weeks.

The social work department did not invite the co-ordinator for a six-monthly review. According to Mrs F's daughter, her mother settled in well. However, each time she visited her mother at the care home, her mother invited her to stay overnight for a chat as she was not able to communicate with anyone due to the language barrier. Mrs F was encouraged to wear incontinence products and the sore skin was treated. She was on sugar-free desserts because of her diabetic condition. Although Mrs F's personal care needs are being met, there is no social interaction or reminder of who she is. She talks to staff and other residents in Chinese all the time, but they can only smile in response.

Before moving to the care home, Mrs F used to attend a Chinese lunch club weekly to mingle with her own community where she shared the same language, beliefs and values. She enjoyed the few hours listening to music, reading a Chinese newspaper, having a laugh and lunch together. Now, Mrs F has stopped attending the Chinese lunch club as there are no care staff who understand her or who are able to take her there.

People with dementia regress to a previous time of their life. Therefore, places where they used to be, cultural foods they used to eat, cultural music they used to take pleasure in and chat about shared culture and history should all be encouraged as good practice in all care homes. In this case, the question must be asked – are Mrs F's needs being met?

What about the future?

What about the future of care for Scotland's ethnic minority older people?

Some of Scotland's ethnic minority people are worried about who will look after them and their loved ones when they can't manage on their own. Others have put their heads firmly in the sand and refuse to think about the future.

The following are snapshots of how ethnic minority older people are thinking about the future.

Mr L (76 years) and lives with his 76 year old partner and 30 year-old son who has mental health issues.

Mr L is concerned about what will happen when he and his wife are unable to provide care due to ageing or physical incapacity and ultimately when they pass away. He has pressing questions about who will look after his son. He says:

"I don't know if the local authority will take up the responsibility when I pass away or become unable to look after him?"

Mr M (92 years) does not feel he needs to be cared for because he manages to look after himself and his time passes quickly. He is able to cook and feed himself. He does not have a bath in the house and prefers going to the local baths which is convenient and easier for him. However, he has not thought about the future. He said:

"I do not worry about how I will manage my needs when my health becomes worse. I am aware of how to ask for help but so far I have not required any help."

Mrs K (67 years) has a slipped disc and finds it hard to walk on her own and struggles with everyday chores. However, her husband cooks for her, does all the household chores and supports her emotionally. She said:

"My husband looks after me and I am very happy with him."

Mrs A (80 years) has experienced several falls due to balance impairment and trips over easily. She does not feel she requires any personal care because she can manage. She has not even thought about when she will become less able or what she will do to meet her care needs. She said:

"I believe that God will help me in bad times. At night I take sleeping pills for a good few hours' sleep, otherwise I am unable to sleep at night. In the morning I struggle to get out of bed and feel very depressed, but I manage the day as it goes by."

Mrs A is reluctant to ask for help. She said:

"I am able just now and when I become less able, I will think about it."

It is maybe not surprising that these quotes from interviews are a little vague and reflect an uncertainty about what the future will hold and how people will cope.

Because the future is uncertain for them. There is no viable alternative to "just keep going". There is no suitable option of gender appropriate carers coming into their homes, speaking their language and understanding their needs. Apart from some Chinese sheltered housing developments across Scotland, there is no sheltered housing or care home option where they can be with other older people who speak their language, celebrate the same festivals, share a faith, culture and reminiscences.

Review and recommendations

From the Scotland-wide programme of interviews and the conversations that the researchers have had in the course of their day to day work with ethnic minority communities, it is clear that there is a crisis in the area of care.

Scotland's ethnic minority older people are struggling to be self-sufficient in the area of care, partly because they are unable to navigate the support services and partly because they are reluctant to accept that the cultural tradition of being looked after by the next generation is breaking apart as their children integrate into a western lifestyle.

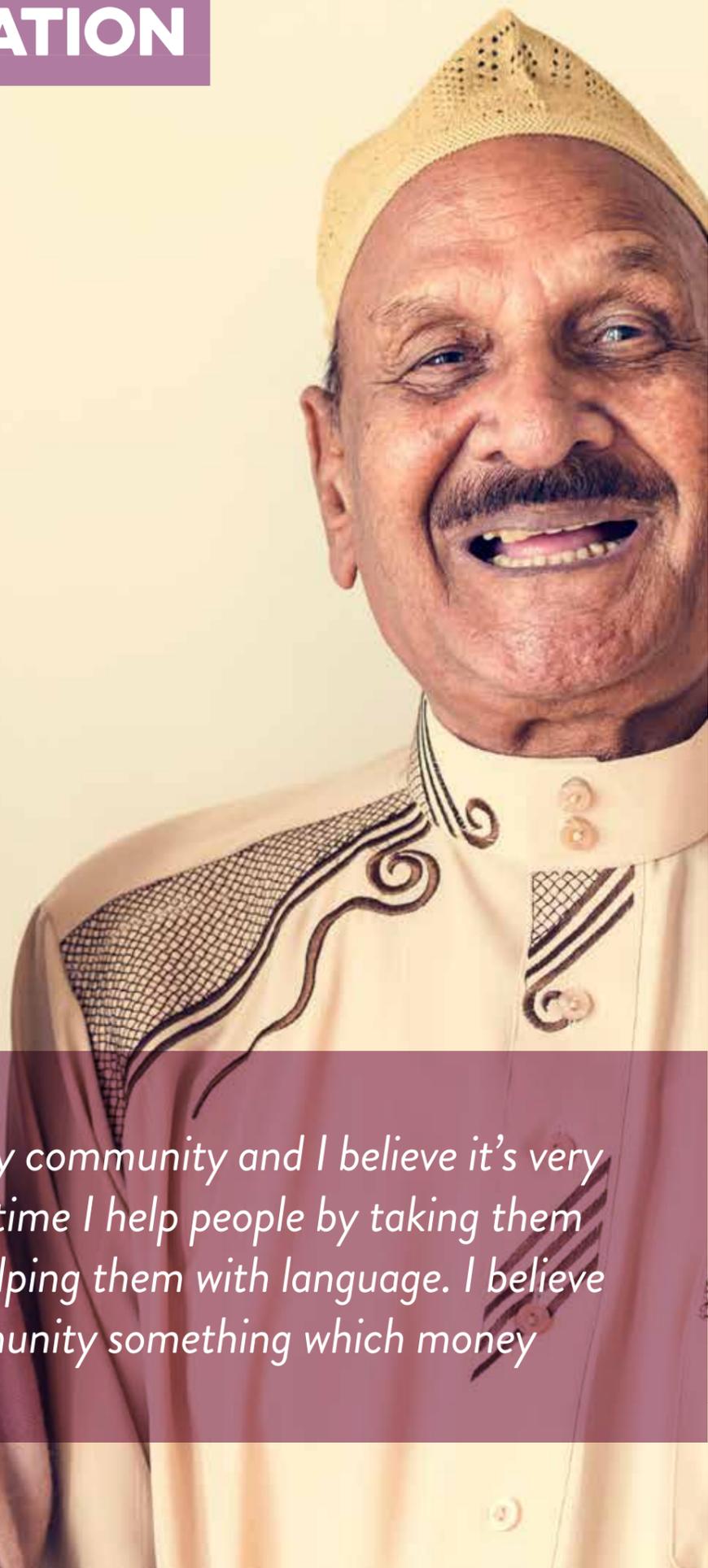
There is also the pressing need for choice of where and how they can be cared for appropriately when they are no longer able to do so for themselves or for others. There is a desperate need for culturally suitable care homes and sheltered housing, where they can live out their last years surrounded by people who understand them and where they are comforted by familiar food, culture and faith.

Actions which could be taken to respond to the research in terms of addressing the issues faced by carers and those who need care might include:

- **Recruitment across Scotland to the SDS service of bilingual ethnic minority staff who can support older people and their families through the process of accessing SDS and then maintaining support for all the reporting requirements which are ongoing.**

- **Scotland's ethnic minority community need choice. Ethnic minority carers need to be recruited so that older people can choose to stay at home where their care needs are met by carers who speak their language, understand them and can cook familiar food if needed.**
- **Sheltered housing and care homes offering ethnic minority older people the choice of having all their care needs met. This kind of accommodation would ensure that they maintained social connections and overcame social isolation and loneliness.**
- **A respite service is required for ethnic minority people who are caring for their families – but this is obviously dependent on a facility being available where the cared-for person would feel comfortable.**
- **In order to address the huge numbers of unidentified older people struggling with care issues, an outreach programme could be developed to identify older people who might have caring issues, with guidance as to where help could be accessed.**
- **For ethnic minority older people who have been bereaved and are isolated, there needs to be an outreach service to get them involved in their local social clubs.**
- **A programme of support for ethnic minority carers when their care role ends due to death of the person for whom they were caring.**

8. PARTICIPATION IN SOCIETY



“ I socialise within my community and I believe it’s very important. In my spare time I help people by taking them to certain places and helping them with language. I believe I am giving to the community something which money cannot buy. ”

Introduction

According to statistics from Age Scotland, 100,000 older people in Scotland feel lonely all or most of the time. 200,000 will go half a week without a visit or call from anyone. www.ageuk.org.uk/scotland/what-we-do/tackling-loneliness

Age Scotland also reports that this national crisis is being addressed by the Scottish Government through the delivery of a national loneliness strategy.

Whilst this is good news, it does not address the problem of Scotland’s ethnic minority older people who are experiencing overwhelming levels of loneliness and social isolation which cannot be ameliorated by the current strategy, because their needs are so different.

When our researchers asked ethnic minority older people about their participation in society, by far the most common response was that participation was very limited. And the reasons why they didn’t participate tended to be because of the universal problems and challenges of older age – compounded by historical, social and cultural factors unique to ethnic minority older people.

However, the flip side of this was the reports by many older people who had successfully counteracted loneliness and social isolation by volunteering and by attending day centres and lunch clubs within their communities.

This chapter focuses on two main areas:

- **the universal challenge of ageing**
- **cultural behaviour and barriers**

both of which have an impact on participation in society for ethnic minority older people.

Similarly, there proved to be a few areas where ethnic minority older people enriched their lives through their participation in society, specifically volunteering, lunch clubs, and day centres. This chapter will also look at the feedback researchers had from older people engaged in these activities in their communities.

Health

For many of the older people interviewed, the key factors which prevented their participation in society were failing health and frailty. They expressed anxiety about using public transport, and about driving and were concerned that they would fall. Bad weather was reported as a major impact as it leads to a greater fear of falling. Similarly the dark mornings and evenings in winter, particularly for those living in rural areas, constrain older people’s participation in society and often lead to a greater sense of isolation over the winter months.

There were also those who recognised their own or their partner’s failing mental health and the problems of getting out and about, without also having to factor in dementia.

Almost without fail, as the interviewees in this chapter illustrate, the older people reported not only a lack of ability and confidence to participate in society, but as a consequence, reported a very real sense of loss, loneliness and even depression.

Mrs M (65 years) has a few friends who live close by and visit occasionally. However she said:

“ I don’t tend to go out too much due to health reasons. I only go when I need to. I do occasionally visit a local lunch club and enjoy going to it. Most of the time I spend my day by watching TV. ”

Mr C used to socialise with his friends regularly, but his diminishing eyesight means he drives less and doesn't socialise as much anymore. His sons and friends visit him every so often but he misses socialising.

Failing eyesight was also raised as an issue where one of the members said:

“ Older people are often too scared to drive as their eyesight is getting worse. The council provides door to door service for some things – but it should be more available.”

Mr and Mrs G (86 and 79 years respectively) told researchers that they go out less often now. Their house is on a hill, walking is a challenge and there are no local shops. They have lived in their house for 40 years and are not willing to move as it is their home. Mr G said:

“ Walking and getting out on the road are difficult. We go out shopping weekly in a taxi but there is no bus stop nearby, and we have problems walking.”

Mrs B (76 years) said:

“ I am stuck at home in the winter due to the wet and windy weather and fallen leaves on the pavements which are very dangerous for older people. I experienced a fall while posting a letter. I fell on the road and it was 4.30pm and luckily one gentleman was passing by and helped me to get up and lifted me from the road.”

Mrs A (66 years) said:

“ I have always been independent and enjoyed going out, but due to my illness I have lost my independence and feel very depressed about it.”

Mrs B (60 years) reports that she suffers from mental stress and does not leave the house much because she finds it stressful to meet other people. She says:

“ I have become isolated and stay home most of the time because I don't want to share my family issues with anyone outside.”

Mrs B said she did not wish anyone to question her about her personal life as something had happened and she did not wish to discuss it.

“ My greatest fear is loneliness. I do not want to be alone and I don't think anything can be done to tackle older people suffering loneliness. I see my neighbours living alone. I feel lucky that I have family around me who speak to me but I still fear loneliness.”

A number of older people reported that failing health and physical fragility meant that they were not able to attend their place of worship, which in the past had been a big part of their lives and a source of social engagement and community. They were disheartened that when they had a great need of the support of their faith, they were unable to visit their places of worship for prayer.

Affordability

For many of the older people interviewed, finances were limited to their pensions and that proved to have an effect on their ability to participate in society.

This was certainly the case for Mrs L (77 years) who used to spend most of her income on rent, council tax and household fuel to keep warm and was left with very little money for socialising. However, when Mrs L was helped to claim the additional benefit she was entitled to, she was able to afford to meet her friends at a restaurant or attend the weekly Chinese lunch club. Going to a restaurant was particularly important for Mrs L as this is an integral part of traditional Chinese socialising, a practice which developed because the houses in Hong Kong are very small. She said:

“ I believe that seeing people and being active is the best way to tackle elderly social isolation.”

Cultural behaviours and barriers

Many of the ethnic minority older people interviewed described an introverted lifestyle, confined mainly to the home, watching TV and talking on the phone to relatives. This proved to be a complex area as the reasons behind this seeming inertia were often less about the language barrier and more about the passing of a way of life which had shaped their social lives.

For ethnic minority people, socialising is traditionally predominantly centred around visiting friends and relatives and participating in a wide range of celebratory events and festivals. For many of the people interviewed, their friends had died or moved away to be near their relatives and their own family had also often moved away or were caught up in busy lives.

Mr M (92 years) did not complain but he reported an isolated lifestyle as a widower: with no family around him.

“ Most of my day is spent talking to my children and grandchildren in Pakistan over the phone and I take part and contribute towards their studies or any training they wish to take. I have always taken an interest in my grandchildren's studies as I want them to become independent and financially strong. My time is mostly spent worrying about my children's and grandchildren's wellbeing.”

Mrs A (66 years) reported that she thought her current lifestyle was not healthy and that she would like to move back to Pakistan where she can live with her brother, sisters and their children. She said:

“ When I lived in Pakistan I used to pass my time teaching the local kids for free. Spending time with them kept my mind healthy. However, now I feel I am wasting days of my life by not using my brain and getting lonely and isolated due to the lack of social contact.”

* Mrs A reported that her only social contact is via phone with her family in Pakistan as she does not have her own children and is a widow. She speaks to them every day to update them on her health and daily life. She misses not having a family and talks to her nephew and nieces in Pakistan and how she misses not being with them while they are growing up. She feels she can have a better life in Pakistan by being with others, which will keep her mind occupied.

* (Because of her feelings of loneliness and isolation Mrs A has subsequently moved to Pakistan)

Mrs A (66 years) is typical of many of the stories the researchers heard which reported women, in particular, restricting their social engagement to their homes and families. Mrs A said:

“Asian community lifestyle is very different to Scottish people’s lifestyle, because they don’t make an effort to go out and always stay home to look after the house, family and children and grandchildren. Due to their busy routine women don’t look after themselves and in old age become very ill and isolated because all their lives, they have just given time to their families and to housework. Our community worries a lot about their families.”

Another older person who was a participant in the loneliness and social isolation workshop made the point that another trigger for loneliness, particularly for women, is when the children leave home. She said:

“Sometimes it’s when women are around 50, when the children have grown up and leave home.”

Participants of a women’s focus group all reported that they spent most of their time in the home cooking and doing housework. They said they spent their ‘free time’ on housework, self-care, watching TV, listening to the radio and reading and that these had become their leisure activities.

Whilst a number of older people reported that they were content to watch TV, there is a concern that there is a growing dependence on or even addiction to TV, due to the fact that older people can now access channels from their home countries in their own language. The result is that they have reduced physical or mental stimulation.

However, other older people did report that they tried to keep physically active, as far as their health permitted and would walk and practice yoga.

No lifelong model for participation in society

The other major factor which impacted on many ethnic minority older people’s lives was that for decades their families had been pre-occupied with building businesses and working long hours, often in convenience shops where the hours from 7am until 10pm, left little time for socialising with neighbours and making friends. At the time, the close-knit ethnic minority communities helped and supported each other. This meant that they never had the opportunity to build and sustain a model for participation in wider society. Now these people are old and few have friends outwith their communities.

This situation was clearly expressed by two male contributors at a loneliness and social isolation workshop. They said:

“50% of us here are from the business community and we have been too busy professionally to develop our own interests and hobbies and that is the main reason for our isolation.”

“One of the main reasons people are socially isolated is their lack of need to get out of their own shell – or lack of ability to get out of their shell. When they retire they no longer need to leave home early and get use to staying in. They also lose all their social contacts from their place of work.”

Loss and grief

Many ethnic minority older people interviewed were on their own and reported feeling overwhelming loneliness when their partner died, compounded by the fact that they felt unsupported in their grief and loss. As single people they said they continued to find socialising difficult, particularly due to the fact that they faced cultural barriers to straightforward participation in society.

Mr M (83 years) is a widower and said that he rarely has visits from friends or relatives. He explained that this was a cultural issue.

“There’s a family cultural issue in Asian families that means that men rarely visit their male friends in their houses. The only place they will meet is in the mosque or other formal or informal gatherings. I would not go to visit my friends in their homes. I prefer to be socially active but due to my current circumstances I don’t have much contact with them.”

Mrs B (76 years) told researchers that she believed grief was very isolating in Scotland. In Asia the custom is for family to surround the bereaved for up to 14 days, ensuring that they are eating and always have someone with them. As this is not the case in Scotland, these can be very testing times for ethnic minority older people who have lost a partner. They are finding that their own generation are often too frail themselves to travel or to help and the younger generation are too busy and not necessarily inclined to observe this tradition. She said:

“My husband had a sudden heart attack when he was 67 years old. I was very shocked and I did not know how to manage my loss. I really miss him and wish he was here. Grieving is more difficult in the UK because you are left alone and people do not have much time for others.”

Mrs S (81 years) has found it very hard to cope since the death of his wife. They used to travel everywhere together, to groups and on trips to India. He says:

“Since my wife’s death I have travelled on my own and felt lonely. It was very hard to adjust to my new life although my children were there to help and support me. After my wife’s death I became very lonely but I have slowly started to visit the groups again and have managed, with difficulty, to get back to a normal life. I now come to the day care centre twice a week and at the weekends I go to the Gurdwara.”

Racism

A number of the older people spoke about bad experiences of racism in the past, back in the 1950s, 60s and 70s when it was accepted as a part of life and when ethnic minority people suffered in silence and did not report the incidents to the police.

Very sadly, there are still a number of instances where an ethnic minority older person reported that they were unable to participate fully in society because of racism.

Mrs H (63 years) told researchers that she had experienced so much racial harassment from her neighbours that she had to change which bus stop she used and where she parked her car. This all had a considerable impact on what she was able to do outside her house. She said:

“I constantly feel under strain and my attention switches on immediately when I hear my neighbour. I am constantly thinking about moving out, getting away from the situation altogether. I feel I’m not able to enjoy my normal day to day activities.”

Neighbours

Many ethnic minority older people have minimal contact with their neighbours as they have little in common – having different food, culture, language and experiences. And during their working lives, their long hours meant they had little time to build relationships.

During this research, whilst some ethnic minority older people reported incidents of outright racism, others reported an attitude of reserve from their neighbours. For instance Mrs M (76 years) told researchers that she has a good relationship with her neighbours. However, it was not easy for her. She said:

“ I keep in touch with them and always ask how they are doing and whenever I can, I will go and visit them. However, I have to make the first move. They are all nice people but they do not want to interfere in your life, so they stay away from you. If I do not make friends, I will be very isolated. If my curtains don't move and if my son does not phone, God knows what would happen.”

Language barrier

Surprisingly, there were not many people interviewed who reported that language was the biggest barrier to social engagement. From the author's experience, this may well be because those ethnic minority older people who have fluent English are engaging in English language events and have the opportunity to develop a wide network of friends and neighbours – with the result that they are not lonely or isolated.

And equally, the ethnic minority older people who have not learned English are only looking to the ethnic minority community for social engagement and therefore language is not one of the major challenges they face.

Mr L (76 years) lives with his 76 years old partner and both are relatively active. He was one of the few interviewees who highlighted the barriers faced by ethnic minority older people due to language.

Mr and Mrs L go out every day, shop together and have a walk after lunch. They go to the gym three times a week. Mr L also enjoys playing cards with friends. They used to attend a Chinese lunch club but stopped a few years ago.

Whilst Mr and Mrs L are active, their activities are restricted to their own language community. Mr L said:

“ We don't attend any of the free events hosted by mainstream organisations due to the language barrier. However, we don't feel isolated or marginalised by society because we have a close circle of Chinese friends where people support each other.”

The other reference made to language was by members of a women's focus group who all agreed that they did not join in any physical activity groups with members of mainstream community because of the language barrier.

Volunteering

It was very clear from the feedback from interviewees and from the author's experience over decades of working with ethnic minority older people, that volunteering is a hugely important channel for effective and life enhancing participation in society.

For many ethnic minority older people, and particularly for women, nurturing and caring for people have been part of the fabric of their lives. When their children leave home, or they lose a partner, they reported that volunteering gave them purpose, a reason to get out of the house, enjoyment, a sense of being needed and a role to play in their community.

Mr M (80 years) speaks English very well and helps people who have little or no English in his community. Language is not a barrier for him. He said:

“ I socialise within my community and I believe it's very important. In my spare time I help people by taking them to certain places and helping them with language. I believe I am giving to the community something which money cannot buy.”

When Mrs C (68 years) lost her husband and son, the two important men in her life and then had an organ transplant herself she felt she had been given another chance of life and said that she had asked herself how best she could now live a full life. She said:

“ I tried different ways to answer that question, but the final answer was to put myself back into the community as a volunteer – doing volunteer work in the Chinese community. I work in a Chinese nursing home two days a week, one day in a Chinese day centre and do volunteer work for the church where I worship. I also visit lonely older people as part of my befriending volunteering – helping elderly people combat loneliness is the most rewarding feeling and it has taught me how valuable it is to simply be listened to. Volunteering has definitely improved my quality of life.”

Mr and Mrs G (86 and 79 years respectively) told researchers that they go out less often now. Mr G said:

“ Walking and getting out on the road are difficult now but in the past I used to give talks in schools about culture and religion. These days I do some talks as a volunteer in universities when called for.”

Mrs C (83 years) has dementia but before he was ill, he was a well-known volunteer for a charity organisation where he did shopping for people, provided transportation, food preparation and cooked meals for members of the organisation. This had obviously been important to him.

Whilst the activity of volunteering clearly provided the volunteers with opportunities for satisfying social engagement and a sense of self-worth, it was very much the case that the ethnic minority older people interviewed focused their volunteering activity within their own ethnic communities.

During a discussion with the Aberdeen Focus Group meeting, all participants said they believed they would be rejected as volunteers by mainstream charity organisations because of the language barrier despite being naturally helpful people.

Lunch clubs and day centres

According to the feedback from ethnic minority older people across Scotland, attendance at community lunch clubs and day centres was resoundingly the single most important way of participating in society and enjoying social engagement.

In older age, people from all backgrounds enjoy sharing past experiences, looking back over their lives, enjoying familiar food, music and traditions. Reminiscing is used in many care homes as a therapeutic activity, which endorses the importance of this kind of shared experience.

So, for ethnic minority older people, lunch clubs and day centres are a lifeline, a place where they can spend time relaxing with people who speak their language, understand their history and all the influences that have shaped their lives. For some people it is the only place where they can enjoy hot food which meets their taste and dietary requirements. For others it is a place where they can enjoy special festive days and activities or give their children or carers a break if they are living in extended families. And for others the centres are a focus for securing support and information.

Mrs R (85 years) is a typical enthusiastic attendee of her local day centre where she has been involved for the last 20 years. She believes that day centres are crucial for older people. She said:

“Previously we used to live in close proximity and everyone used to visit each other and cared for each other. Now lots of people have moved to a new house and away from the cities and have minimal contact with each other. I believe that coming to the centre and seeing others every day makes a difference to my lifestyle. If you are alone you think a lot and you start suffering from several illnesses, isolation and loneliness can kill people and harm their health.”

Mrs B (79 years) attends a day care centre with his wife five times a week. He said:

“We both look forward to going in every day due to the friendly environment, also being around people of the same age is the best way to tackle our loneliness. The staff are very good and welcoming. We are very well looked after at the centre which caters for our needs.”

However for many people, whilst the lunch clubs and day centres are a lifeline, they often depend on transport being provided in order to attend. Whilst most day centres provide transport to and from the centre, it is very difficult for those centres where their funding has been cut and where they are consequently unable to offer transport. In these cases, ethnic minority older people are dependent on their children and friends to take them as they are often not able to use public transport due to physical fragility or dementia.

Mrs B (76 years) said:

“Every week I manage to go to the Heart & Stroke club because they provide door to door transport.”

Mrs S (71 years) also depends on transport to get her to the day centre. She said:

“I don’t travel on my own and can’t go anywhere unless someone takes me. I visit the day care centre only when someone can take me but I would like to attend four times a week.”

Mrs B (79 years) said:

“We always use the centre’s transport service, so we have no excuse not to attend. It is a great way to get older people out of their homes.”

Unfortunately, older people reported dropping away from these centres when transport became an issue.

Mrs L’s (93 years) social life has been restricted since her husband died as he used to drive her around. As she has a mobility problem, using public transportation is beyond her capability and she cannot go out and about without support. Mrs L used to attend the Chinese Lunch Club where she met friends and would go to church on Sunday and also attend free events such as health talks or celebrations for cultural events.

Whilst virtually all the lunch clubs and day centres were aimed at providing a service for older people from different ethnic minority groups, one of the focus groups expressed a desire to reach out into the wider community.

These participants were all regular attendees of a Chinese lunch club where they went to socialise with friends and to make new ones. Due to funding cuts and high rental charges in the current property, day centre organisers were looking for somewhere else to host the weekly lunch event. All participants expressed that they wished local government could grant their wish to have a local building which is free of charge for them to use at least once a week. Their proposal was that the building could be shared with different groups from different ethnic backgrounds so that they could learn from one another. They said they would like to share their culture, food, cultural events, beliefs and values and to enjoy and celebrate the diverse culture in Scotland.

However, many day centres are closing as the funding has been stopped entirely or cut to a minimum. This is having a huge negative impact on the physical and mental wellbeing of older ethnic minority people.

Review and recommendations

As is the case with the other chapters of this report, there is significant crossover related to the issues reported by Scotland’s ethnic minority older people which make their lives challenging. For instance, caring responsibilities affect people’s health and people’s health impacts on their ability to participate in society, as does their available finances.

And again, many of the issues that prevent ethnic minority older people participating in society are the same as for all older people – many of whom are struggling with the challenges of failing health, decreased mobility, reduced finances and loneliness caused by friends dying or moving away.

However, for ethnic minority older people these universal challenges are compounded by the historical and cultural problems of not having had many opportunities to socialise in their younger days because of working long hours and the cultural and language barriers that prevent them from participating freely and fully in the life of wider Scottish communities.

However, it was very heartening to hear from the older ethnic minority people interviewed how motivated they were to combat loneliness and isolation and how successfully lunch clubs and day centres were providing a lifeline, if only there were more of them and they were better funded. Volunteering within their own communities was another area where the ethnic minority older people interviewed expressed a real sense of fulfilment and involvement.

In the course of one-to-one discussions, group meetings and consultations and the researchers' own experiences and involvement, it was clear that opportunities for volunteering and the availability of lunch clubs and day centres, with transport provided, seemed almost universally to be suggested as the best solutions to increase participation in society and combat loneliness.

One major consultation group was asked:

“Who is key at a local level in driving change in your community to reduce social isolation and loneliness and increase the range and quality of social connections?”

The answer was very simple. The group responded:

“Us – we should be driving the change. Only we can make the change.”

Many of the actions suggested below as to how ethnic minority older people could participate more fully in society came directly from suggestions by ethnic minority older people themselves.

- **Develop a wider network of lunch clubs, drop in centres and day centres. And then publicise them well and work on motivating people to attend.**
- **Create a programme of “workshops” where ethnic minority older people are encouraged to discuss some of the issues they face and consider solutions.**
- **Develop a concept where the lunch club concept is taken “on the road”. Perhaps developing a programme of individuals or groups who would go to the homes of lonely and isolated people for a cup of tea and a chat.**

- **Develop a “befriending” service, which would allow some more active older people to benefit from volunteering and more isolated older people to benefit from the service offered.**
- **Offer a service to schools, showcasing other cultures and providing older people with a sense of purpose in their community.**
- **Active recruitment to day centres and lunch clubs. Identify the people who are lonely and facilitate their attendance, by phoning and offering lifts or arranging transport.**
- **Make day centres and lunch clubs accessible by increasing funding for transport.**
- **Encourage religious organisations to do more in terms of creating inclusive events and opportunities for sharing and friendships.**

For further insights into how Scotland's ethnic minority older people believe loneliness and social isolation can be tackled in their communities, please see attached report:

‘A Connected Scotland: Tackling social isolation and loneliness and building stronger social connections.’

Listening to the views of ‘Scotland's older ethnic minority people’ by Rohini Sharma Joshi FCIH, Equality, Diversity and Inclusion Manager for Trust Housing Association

27 April, 2018

9. RECOMMENDATIONS – CALL TO ACTION

The report highlights several issues and barriers faced by ethnic minority older people and calls for action by politicians, policy makers and service providers. Below are some actions which need immediate attention. They should be meaningful steps to make a real difference, rather than simply statements.

Home Environment

- **Earlier intervention by social services to ensure adaptations are made to the home environment before they become urgent.**
- **More accessible information and support on housing options to plan for future housing needs, how supported housing works and the cost.**
- **Development of sheltered housing and care accommodation which meet their language, cultural, social and dietary needs.**

Financial Wellbeing

- **Help from bilingual staff with expertise on the social security system to advise and complete benefit forms.**
- **For the social security system to understand and deal with the lack of information and language barrier faced by ethnic minority older people.**

Health (Physical and Mental)

- **Further research into how dementia affects ethnic minority older people and their families. Dementia workshops could be developed and run in community centres and lunch clubs to give ethnic minority older people and their families a better understanding of what dementia is, what services are available to them and how their family member or carer can be supported.**
- **The existing lunch clubs seem to be crucial to combating loneliness and give ethnic minority older people a sense of engagement and identity. These need to be resourced and staff need to be trained and supported.**
- **Health services to be accessible and procedures put in place to deal with and overcome the language barrier, which is particularly vital for older people with complex health issues. Current level of provision of information and support by GPs is inadequate and needs to be improved.**

- Provide advice to ethnic minority older people on the importance of appointing a power of attorney before they lose the capacity to make decisions or develop dementia. They should also be advised what it means to have a guardian appointed when they are not able to make decisions about their life.
- A respite service is required for ethnic minority people who are caring for their families – but this is obviously dependent on a facility being available where the cared-for person would feel comfortable.

Participation in Society

Care Needs and Caring Responsibilities

- Recruitment across Scotland to the SDS service of bilingual ethnic minority staff who can support older people and their families through the process of accessing SDS and then maintaining support for all the reporting requirements which are ongoing.
- Ethnic minority carers need to be recruited so that older people can choose to stay at home where their care needs are met by carers who speak their language and understand their food.
- Sheltered housing and care homes offering ethnic minority older people the choice of having all their care needs met. This kind of accommodation would ensure that they maintained social connections and overcame social isolation and loneliness.
- Develop a wider network of lunch clubs, drop-in centres and day centres. Publicise them well and work on motivating people to attend and encourage them to discuss issues they face and consider solutions.
- Develop a concept where the lunch club is taken “on the road”. Perhaps developing a programme of individuals or groups who would go to the homes of lonely and isolated people for a cup of tea and a chat.
- Develop a “befriending” service which would allow more active older people to benefit from volunteering and more isolated older people to benefit from the service offered.

A final word from the author

I am heartened by the care and passion so many of Scotland’s ethnic minority older people have shown for empowering lonely people in their own communities.

This first generation of ethnic minority older people, who struggled and worked hard, took pride in making Scotland their home. This pioneering generation needs services now. Further delay by years of planning and discussion will not help the current dire situation of many. Immediate action is needed; we cannot continue to ignore them.

They are part of the Scottish population and must be included when planning or reviewing services. An ad-hoc practice here, a small project there should not be used as examples of achieving equality and being inclusive. There has to be a real, tangible and lasting commitment to reaching out to the most vulnerable in need. Ethnic minority older people should know that they do not have to suffer in silence or to try to manage and cope with the most unbearable and horrendous situations. No one should have to.

As you can see from the recommendations above, the older people have focused on day centres and lunch clubs as a lifeline and an effective solution for widening participation in society.

I believe it is now the responsibility of all those working across Scotland’s services to ethnic minority older people to work together to look into their existing needs. Although they are complex, through collaboration, a greater understanding and most importantly the will to deliver, we can help make a difference.

This report has been produced as part of the Older People Services Project and funded by the Community Fund. The project was jointly run by Trust, Hanover (Scotland), and Bield Housing Associations.

This report is available in pdf format on the following websites:

www.EqualityScotland.com

www.trustha.org.uk

www.hanover.scot

www.bield.co.uk

