The University Of Sheffield.

Burdett Trust for Nursing

Loneliness and Social Isolation in BAME communities in the UK

A digital resource

Dr Ashfaque Talpur & Prof Tony Ryan

Who is this resource for?

BAME Community

This resource was created with input from older BAME communities that can often experience feelings of loneliness and social isolation. This digital resource will be a useful guide for people to understand and recognise these feelings. The more you know about the causes, the easier it will be to address and manage them. At the end of this section we've also included a list of help-lines and organisations that are a great first step in getting help.

You might be most interested in part 1

Healthcare Workers

Health and social care professionals working with older BAME communities will find this resource a useful guide to identify ways to approach those people experiencing loneliness and social isolation, to explore contextual and cultural factors, to examine ways to engage older people in social activities, and to discuss possible solutions.

You might be most interested in part 2 + 3

And anyone else!

We also hope to draw the attention of other key stakeholders, including local councils, charity organisations and policy makers, to the rising prevalence of loneliness and social isolation among BAME communities, and to the development of resources, requirements, interventions and policies to address the problem.

You might be most interested in the recommendations in part 4

Contents

Part 1

Loneliness and social isolation

What is loneliness?

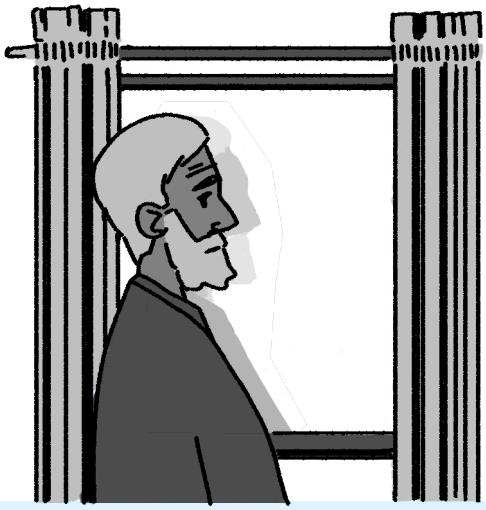
Loneliness is a subjective feeling and has been defined as **"the unpleasant experience that occurs when a person's network of social relationships is deficient in some important way".** Feelings of loneliness not only stem from a sense of lacking companionship but also from a lack of meaning and role in society.

Loneliness is experienced to a degree by everyone, regardless of age or gender, although there are things which can increase the severity of someone's negative experiences of loneliness. These factors could include the death of a partner or a loved one, poverty or financial pressures, and deteriorating health or disability.

What is social isolation?

Social isolation, on the other hand, is an objective phenomenon defined as **"a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and they are deficient in fulfilling and quality relationships".**

These social contacts include friends, family members or neighbours and at a broader level they are 'the society at large'.



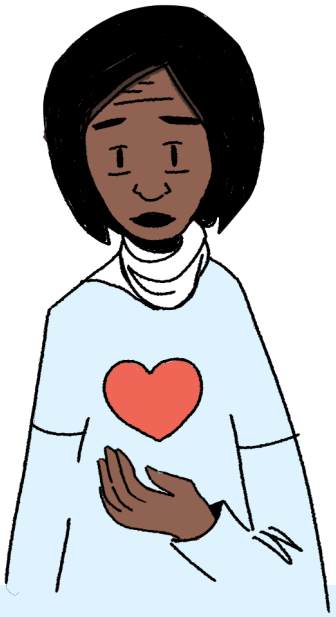
Loneliness and social isolation in BAME communities

The size of the problem

One-fifth of the UK population is from a black or minority ethnic community. By 2051, it is projected that 7.1 million people aged 50 and over will come from BAME communities

One third of older people are at risk of loneliness and approximately one half of older people will experience some degree of social isolation in later life.

In the UK, over a million people aged 65 and over say they often or always feel lonely.



The impact

The health risks and outcomes of loneliness and social isolation are comparable with those of smoking, obesity and physical inactivity.

They are both independently associated with detrimental physical and mental health consequences for older people.

Lonely and/or social isolated people have:

- an increased risk of cardiovascular disease
- a greater risk of high blood pressure
- an increased risk of suffering from mental health problems such as depression, anxiety and Alzheimer's disease and dementia
- decreased resistance to infection because of a weakened immune system
- an increased risk to be overweight and obese
- an elevated mortality rate.

What comes to your mind when you think of loneliness and social isolation?

How an individual perceives loneliness and social isolation is a key determinant for seeking support. This exercise can help people to identify the factor(s) causing their feeling of loneliness and isolation, the impact which it could have on them and the outcomes which they can achieve by discovering mechanisms of support.

Print this page to circle or make a note of the words that you associate with feelings of loneliness and social isolation.

Sad
Separate
Dissociated
Depression
Friends
Family
Traumatic events
Connectedness
Relationships
Social engagements
Nostalgia
Stigma
Future
Meaning
Integration
Worry

This is a space to add any of your own words or feelings, if you don't find them listed above.

If these concepts resonate with you, see the next page for links to help and advice.

Where to find help

If you are experiencing loneliness and/or social isolation, or have read the previous descriptions and find that they resonate with you, any of these organisations can be a great first point of contact to help make a positive change:

If you are viewing this as a PDF, you can click or tap the links to visit the websites

Age UK
Helpline: 08000556112
Website: www.ageuk.org.uk

Hourglass
Helpline: 08088088141
Website: www.wearehourglass.org

Mind (metal health)
Helpline: 03001233393
Website: www.mind.org.uk

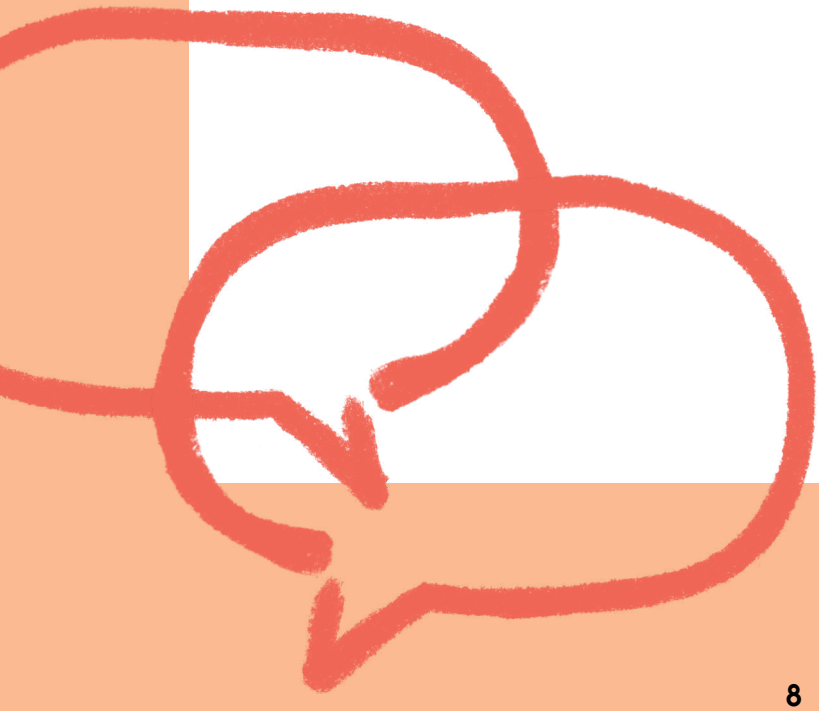
Black Thrive
Helpline: 03330902370
Website: www.blackthrive.org.uk

Campaign to End Loneliness
Helpline: 02038653908
Website: www.campaigntoendloneliness.org

Part 2

Voices of BAME communities

The following quotes and comments are taken from a publicly available study comprised of interviews and group discussions with people from BAME and Pakistani backgrounds. We've broken the responses into 5 main categories:



1. Health in old age

Older BAME people think poor health is a key reason why they feel loneliness and social isolation. People suffering from **chronic health conditions**, for example, find it more difficult to engage socially with their families and communities.

In later life, the **loss in physical strength** was viewed as being directly linked with their current mental, emotional and economic well-being. Being unable to do things important to them, they reported experiencing recurrent stress, emptiness and isolation. They found that disability and dependence were key factors distancing them from their intimate relationships as well as their broader groups of contacts.

Mr Habib

"We often feel loneliness. My daughter is in London. She asks dad to come to visit us. One daughter is in Bradford. She is close, she comes, and we too go to her but London. It is a bit far. I get tired, because I don't have the same strength."

Not all health losses – physical or mental – are visible, and may go unrecognised. Some people we spoke to demonstrated a loss of confidence in themselves and a fall into passive ageing – failing to maintain positive subjective wellbeing, good physical, mental and social health. An older participant of Black African origin said the following:

" I tend to see my family irregularly now because I get judged, because I have an invisible disability. I'm being prejudged because people don't think there might be something wrong with me and assume that I should be doing more things and should be more active."

Ms Sofia

2. Cultural exclusion of women

For the BAME participants, culture played a significant role in determining their social and personal life. In households in which **hierarchical and patriarchal systems** were predominant, rigid social boundaries exist. In these studies women were particularly restricted, with their social and economic choices and decisions being shaped by wider cultural values and beliefs. As a result, their exposure to the outside world was limited and the risk of loneliness and social isolation very high. An older Pakistani woman describes her experience of living in isolation under patriarchal control:

" I came here when I got married. I was all alone. I was not allowed to go out. He (my husband) didn't allow it. I was afraid. So, I was scared to go out as well. Therefore, I did not know much about the outside world, about the community outside. My husband was not bothered. He didn't allow to go out. Life went like this."

Ms Aisha

As their exposure to the outside world has been limited, many women felt a **lack of confidence** in going out on their own and exploring wider contacts and social life. Fear of 'becoming lost' as well as 'being lonely' are equally daunting and disturbing for women living in traditional households. Choosing between 'being lonely' and 'becoming lost' was an individual dilemma for these women. A woman who had spent her whole life in confinement and dependence explained her anxieties associated with 'life outside the home' after her husband's death:

Ms Nasrin

"I never went out on my own. I was completely dependent on my husband for everything; for shopping, for going out. If I had to go to someone's house, I went with my husband. If I go alone, then there was (a) problem. Even now, I can't go to town, alone. I can only go with someone because I don't know where to go or not. This is the problem."

3. Social Connections

The narratives of the BAME participants shows that social networks and social connections are vital for their happiness, mental health and well-being. A sense of being part of a wider community or **belonging to social groups** and living in a **safe and ethnic neighbourhood** gives older BAME older citizens confidence, shared trust and meaning. BAME communities predominantly rely primarily on their families and people from their country of origin.

Mr Harleem

" The good thing about Asian communities is you help each other. All my brothers live on the same street with me! I can leave the key next door, no issue. Lady across the road, we invited her in when she forgot (her house) key and had to wait for (her) husband - (It) was ten at night! Community gets together when there's an issue."

For many BAME elders, **social networks are often small and/or scattered**, with relatives and friends living distantly in different cities or countries. Those who strongly identified themselves with their country of origin or had fragmented families in the UK or/and had lost connections back home in their country of origin were more likely to express **feelings of being uprooted** and to experience stress through trying to adapt to the culture of their new environment. By becoming self-reliant and self-contained, they saw themselves living an excluded and isolated life:

" You can't just manufacture the family, the right people; they're either there or they're not. The rest of it is just coming here (a local support group), or just socialising, it's not real. You can spend some time with some people, but then you've got to go back on your own. It's not real."

Mr Jospeh

Other older people also recognised that **the large household is disappearing** and the family's basic function as a source of security and social connection is being lost. They saw that despite people living together, they could nevertheless be lonely in themselves. In the face of rapid social and cultural transformation, a changing household structure and increasing technological advances, older people **often saw themselves as an undervalued and less respected** part of the family.

4. Access to services

Social infrastructures and opportunities play a vital role in community cohesion and help people to build stronger and more diverse relationships and engage in worthwhile activities. However, the limited attention paid by services in both local and wider social structures determined older BAMEs' experiences of marginalisation and exclusion in society. Not having any purpose, engagements or activities of interest in their local services which describe their history, culture and values, they not only feel lonely but suffer its severe effects on their mental health:

"There is (a) lot of depression. I feel depressed, when I am doing nothing, when you don't know what to do tomorrow. How much TV are you going to watch?... Asian people have a problem, obviously that is having company. They don't have company. They don't have anybody to talk (to). They are lonely. Majority of old people from Pakistan are uneducated, both wife and husband, so they can't read books."

Mr Fahad

Older people see that the local services or/and activities of engagement such as lunch clubs, book reading clubs and other **social networks are often tailored for white communities** and as a result they don't find any interest in them. On the other hand, opportunities on the wider level were regarded as gender- and culture-insensitive. As a result, they see services as **biased or inaccessible** and uninterested in their mental and social well-being.

Ms Nasrin

" When You don't know the language (English) then also you face a lot of problems... You can't tell anyone your problems. There is a lack of translation services in many places. we did not know where to go and how. Older people have problems with language."

5. Racial Discrimination

One of the other reasons why older BAMEs feel excluded and isolated is their perception and **experience of racism in British society**. BAME elders experience discrimination because of their colour, culture, language, religion and other characteristics of their ethnicity, as well as their age. Being unwelcome gives a sense of being the 'untouchable' second-class citizens of the wider society. While the Muslims appeared to be reporting Islamophobia, black African participants had suffered racial exclusion, as this black woman explained:

Ms Adaliya

" I experienced racism a lot... People posted abusive messages through the door. I felt very unwelcome, and that was why I was so lonely and depressed when I lived here."

Daily experiences of alienation and marginalisation not only deter BAME people from attempting to integrate with British norms and values, but also affects them in terms of their mental and emotional wellbeing. These findings show that **BAME communities need more attention from services and healthcare practitioners** in seeking equal rights and fair treatment in society.

Part 2: Key findings

- **Loneliness and social isolation are complex and mutually reinforcing problems**
- **The causes of loneliness and social isolation are wide-ranging among older people from ethnic minority communities**
- **The failure of services and the stigmas attached to loneliness and social isolation are key barriers which people do not recognise or seek support for**

Part 3

Advice from nurses

We spoke with registered nurses from a wide range of specialties including community, emergency, ward settings, care homes and NHS 111. They shared their knowledge and experiences of providing care and support to older BAME people experiencing loneliness and social isolation.

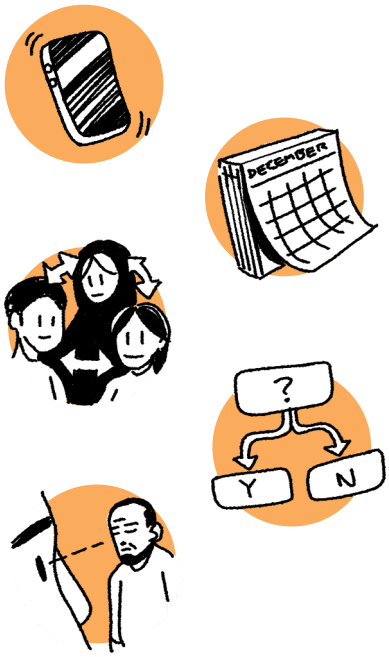
The challenges faced by nurses

Due to its subjective nature, nurses find quantifying feelings and emotions a **difficult task to measure**. Identifying people who are experiencing loneliness or isolation based solely on their physical or psychological characteristics was frequently cited as a challenge for multiple reasons. Variable factors including context, environment and individual personal traits were believed to increase the risk of a person feeling lonely and isolated.

Sonia

"Loneliness...is subjective and some people who are quite introverted, quite happy to see one person a week and that's more than enough and then some people need to have hustle and bustle around them and it's very much up to the individual and I imagine that would make it quite difficult for people to measure... easily anyway."

How nurses identify lonely or isolated people



- **Number of visitors or phone calls** with family members and relatives.
- **Informal assessment:** Exploring hobbies, routines and needs, nurses are often able to gauge whether a person is succumbing to loneliness and isolation.
- **Family relationships:** How an older person is treated in family activities and decision-making indicates whether he or she is valued and respected.
- **Pathways or guidelines** with questions which help them to explore older people's circumstances.
- **Physical observations:** Signs of withdrawal, changes in behaviour or habits, signs of depression, anxiety and stress can all indicate that an older person might be feeling loneliness and social isolation.

Insights from the nursing community

We asked nurses about the **barriers and challenges** which they had experienced, or which their clients had mentioned that they experience in tackling loneliness and social isolation.

Assumptions and stereotypes

It was suggested that health-care workers could **assume that older BAME people living in a large household are less likely to be experiencing loneliness or social isolation**. As a result, they believe that loneliness and isolation are not a major issue among BAME communities.

Emma

"I think, to me, I don't really have any sort of great understanding of BAME, when I see BAME, I think they are supportive with a lot of family members that come and visit quite often."

Not recognising loneliness

Rather than admitting to themselves or others, older BAME people **tend to associate their experiences of loneliness with other events**, as this nurse explained:

"They might be putting it down to something, sort of the medication that they are on or some of the health conditions that they have got potentially. I think that might be a barrier to sort of addressing that is actually not recognising the loneliness in the first place."

Alan

Inequalities

Inequalities in services and historical marginalisation, both perceived and actual, give rise to feelings of being unwanted and undervalued. Because of their experience of discrimination in health, social and other public institutions, the interviewed BAME nurses suggested that people from ethnic minority communities lack trust and confidence in services, heightening their risk of loneliness and isolation:

Language and communication barriers

Being non-fluent, older BAME people were viewed as lacking the confidence to approach services. In these situations, **the lack of an interpreter service or face-to-face communication exacerbates the risk** of isolation and deprivation of people with limited language skills.

William

"...that was exacerbated by the Covid-19 crisis because I work for a community rehab team and we have to change a lot of our services to be over the phone... if there is a language barrier there as well that means over the phone it will be more difficult. It means we don't get in touch often."

Health conditions

Conditions such as stroke, aphasia and memory loss in which **patients find it difficult to communicate their needs** increase their risk of neglect in care and communication. Nurses reported that these patients are mostly overlooked and become even worse off, as their **family have no knowledge of their predicament**, or services provide insufficient support to them.

Intergenerational gaps

Older BAME generations have relied on family members for support and protection, but recent social changes were said to be increasing the gap between them and younger generations. Because of differences in cultural upbringing, language skills, and beliefs and practices, nurses reported that **older people may not share common interests or goals with younger family members or community members**.

"There is a cultural gap and things they (young British people) talk older people actually don't understand what they are talking about because the media, politics...it is all different for the elderly."

Mr Nabeel

Socio-cultural factors

Stigma and shame: older people don't wish to accept that they are lonely because it adds to feelings of being undervalued or 'failure'.

Gender expectations: nurses find that older female BAMEs are more expressive in discussing their social life whereas older men do not speak openly.

Religious beliefs: older people believe that loss of belief in God is the main cause of their loneliness and isolation.

Cultural barriers: older people whose norms and values can differ from those of the white British society are more likely to live socially isolated lives.

Local services and support groups

There are many ways in which local services and small community groups contribute to the lives of the community, by arranging activities, providing advice and support, training and skills development. The nurses we spoke to identified three major issues related to service and support groups:

Availability - Accessibility - Acceptability

Factors preventing access

- lack of funding for social services/activities
- cultural and religious sensitivities
- gender and age specificity
- language and communication barriers
- distance and transport
- discrimination and an unwelcoming attitude
- health and disability
- information and knowledge of resources
- socio-cultural taboos

Strategies to tackle loneliness and social isolation

We asked nurses how they addressed loneliness and social isolation and what they would suggest to their colleagues and clients. Here are some of their responses:

1. Planning visits

- **Appointments:** make sure that your visit does not coincide with their prayers, cultural functions or other planned activities.
- **Family involvements:** check whether older people want their families to be involved in their individual problems. People might not discuss their true experiences of loneliness in the presence of other family members.
- **Gender preferences:** not all older females appreciate men asking them sensitive questions. Start by asking general questions and depersonalising the problem before moving on.
- **Interpreter:** a paid interpreter or family member can ensure that all parties have an authentic 'voice' in the conversation.
- **Risk assessment:** plan your journey and inform your team about your trips.

2. Building a relationship

- **Get to know them:** ask about their hobbies, wishes, culture, beliefs and daily activities. This will also give you an idea about their preferences and needs.
- **Listen:** being attentive and empathetic plays an important role in building trusting relationships and encourages participants to share.
- **Empower:** let them lead the conversation, this will help them to feel in charge of their story and make it more likely that they will talk about their true experiences.

3. Identify inclusive and diverse support groups

4. Referral to appropriate services

including mental health and wellbeing teams.

Part 4

BAME loneliness and social isolation measurement scale

&

Final Recommendations

BAME loneliness and social isolation measurement scale

A newly developed scale which still needs to be tested in order to evaluate its validity and reliability

As we have already established the idea of loneliness can be very subjective. Through answering **YES** or **NO** to a series of statements, the user will be provided with a score which corresponds to a scale ranging from **'Not lonely or isolated'** to **'Most lonely or isolated'**. This tool could be used by healthcare professionals, researchers or even members of the BAME community who think they might be experiencing loneliness and social isolation.

	Part 1: Loneliness	YES	NO
1	**There is always someone I can talk to about my day-to-day problems**		
2	**I find it difficult to get in touch with others when I need to**		
3	**I miss my close friends and family members** (For older people who are migrants, this may also apply to friends and family from your country of birth)		
4	**My interests and ideas are shared by those around me**		

	Part 2: Social Isolation	YES	NO
1	**I visit my friends and family, or they visit me at least once a month**		
2	**I usually participate in at least one social or leisure activity per week**		
	Each response in a red box scores 1 point	**Total Score =**	

Not isolated or lonely 0 1 2 3 4 5 6 **Most isolated or lonely**

Final recommendations

Inclusive services and support groups

- Local organisations in regular contact with people can help to identify and address loneliness and isolation.
- These groups should work to involve older people in social activities which interest them.
- Services are under-resourced and out of reach. Financial investment is required.
- Skills development programmes should be part of the service infrastructure.

Individualised approaches

- The diversity within ethnic minority communities is often unacknowledged, so isolated groups being even more marginalised.
- Mental well-being of older BAME people should be prioritised.

Education and awareness

- Racism and discrimination result in marginalisation and the stigma and shame attached to loneliness prevents people from seeking help.
- Services need to develop ways to avoid bias and discrimination in the provision of or referral to services.
- Education about loneliness and diversity should be developed.
- Services and local charities should advertise their services and activities through social media.

Tools to identify

- Existing tools to assess isolation and loneliness were developed from research conducted within white populations.
- Explore drawbacks in the current measurement tools and identify ways to broaden their applications to wider cultures and communities.
- New tools should be developed with the help of experts and stakeholders who have knowledge and experience of working with older BAME communities and these tools need to consider language issues and incorporate cultural values and context.

Thank you for reading!

About the authors

Dr Ashfaque Talpur is a Research Associate at the Health Sciences School in the University of Sheffield. His research spans the areas of ageing, ethnicity, elder mistreatment, palliative care, and loneliness and social isolation. For his PhD in health science, he conducted a study of elder mistreatment among older people from Pakistani communities living in the UK.

Professor Tony Ryan is Professor of Older People, Care and the Family at the Health Sciences School in the University of Sheffield. His work is focused on the care experiences of older people, especially those affected by dementia.

This is a summarised version of a more complete report. If you wish to learn more, see references or read the full report you can contact the authors at: **ashfaque.talpur@sheffield.ac.uk**

Acknowledgments

We take this opportunity to thank all healthcare workers who volunteered to take part in the study. We would like to express our special gratitude to all the experts and stakeholders who contributed; without their feedback and input, the new measurement tool would have been impossible. Finally, thanks to the Burdett Trust for Nursing, without that funding, this project would not have taken place.

Design and illustration by
Chris Redford

chrisredford.co.uk