

# Northumbria Research Link

Citation: Bailey, Cathy, Sattar, Zeb and Akhtar, Parveen (2018) Older South Asian women sharing their perceptions of health and social care services and support: a participatory inquiry. *Health Science Reports*, 1 (8). e55. ISSN 2398-8835

Published by: Wiley-Blackwell

URL: <https://doi.org/10.1002/hsr2.55> <<https://doi.org/10.1002/hsr2.55>>

This version was downloaded from Northumbria Research Link:  
<http://nrl.northumbria.ac.uk/id/eprint/34273/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



## RESEARCH ARTICLE

# Older south Asian women sharing their perceptions of health and social care services and support: A participatory inquiry

Cathy Bailey<sup>1</sup> | Zeibeda Sattar<sup>1</sup> | Parveen Akhtar<sup>2</sup>

<sup>1</sup>Health and Life Sciences, Northumbria University, UK

<sup>2</sup>Women's Centre, UK

**Correspondence**

Cathy Bailey (PhD), Associate Professor, Ageing and Health, Nursing, Midwifery and Health, Health and Life Sciences, Room H005, Coach Lane Campus East, Northumbria University, Newcastle upon Tyne NE7 7XA, UK.

Email: catherine.bailey@northumbria.ac.uk

**Abstract**

**Background:** The needs of older people in Black Minority and Ethnic (BAME) communities require culturally appropriate services provision, but little is known about how BAME older people support themselves and others, what they perceive to be their “needs”, and, critically, the extent to which they feel such needs are being appropriately met.

**Objective:** To enable older women from a BAME community to work with health and social care professionals and organisations, to support independent living.

**Methods:** In 2016, all 15 members of a BAME older women's social group attached to a Women's Centre in the North East of England, approached the research team to support achieving this objective. They did not wish to be co-researchers. A *collaborative* participatory inquiry was carried out. The research team and the older social group designed, together, 4 workshops that explored (1) health and well-being; (2) home and housing; and (3) services and support. There was also an evaluative session with stakeholders, and the research team managed research processes.

**Findings:** Most of the women described living with mobility and health challenges requiring change and adaptation. Language and literacy might be barriers to building confidential professional relationships with primary care professionals. The women emphasised needing a “little bit of help” in the home, that is affordable, culturally appropriate, and on their terms. They stressed such help would make them less reliant on busy family members and restore status, purpose, and standing.

**Conclusion:** Findings do not address all BAME older people's needs. They do, however, have implications for how health and social care services can work with older people from BAME communities, to promote and maintain meaningful independence, on their terms.

## 1 | INTRODUCTION

Reflecting a global trend, albeit from within differential rates, the population of England and Wales is ageing, and there is increasing diversity. Ethnic minority populations are not a homogenous group.

A report from the UK Centre for Policy on Ageing,<sup>1</sup> based on findings from the 2011 Census, suggests that with the exception of white Irish and black Caribbean, minority populations tend to be younger than the majority white British population. For example, the Indian ethnic minority group is the third largest in England and Wales, of which just

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2018 The Authors. Health Science Reports published by Wiley Periodicals, Inc.

over 8% are aged 65 years and over. The Pakistani group, comparable in size to the Indian group, have 4% aged 65 years and over, whilst the Bangladeshi group, although a much smaller overall population than that of the Indian and Pakistani populations, also has almost 4% of its population aged 65 years and older.<sup>1</sup> The Office for National Statistics<sup>2</sup> reports that, overall in the UK, those aged over 65 years accounted for approximately 18% of the total population. Those over 75 years account for approximately 8% of the total population.

As ethnic minority populations are, on average, younger than the majority white British populations, they have tended to use less health and social care services, with the exception of maternity services. This is likely to change significantly, as Black and Minority Ethnic (BAME) populations age.<sup>3</sup> BAME older people's perceptions of health and quality of life are under-researched,<sup>4</sup> and a seeming under-representation of this group using health and social care services might be due to reasons other than cohort age. For example, a 2015 study that included BAME service provider interviews and a review of policy and research literature explored current provision of targeted social care services for BAME older people in England and Wales.<sup>5</sup> The author concluded that more needs to be known about BAME older people's experiences of accessing care and support, and whether their needs are being assessed equitably.

A recent systematic literature review explored minority ethnic carers' perceptions of barriers to accessing community social care services and their satisfaction with services they were able to access.<sup>6</sup> The authors suggested there were barriers likely to be relevant to all carers, irrespective of ethnicity. These include (1) not wishing to involve outsiders and (2) not knowing about some services and their availability. Issues specific to minority ethnic groups focused on concerns about services' cultural or religious appropriateness and language barriers. This research is supported by findings from user experience surveys. Willis, Khambhaita, Pathak, and Evandrou,<sup>7</sup> in their study exploring satisfaction with social care services among South Asian and White British older people, suggest that these surveys are used by British public sector services to monitor quality and ensure accountability. Findings from these surveys consistently demonstrate how people from BAME groups are less satisfied with social services, compared with others (eg, The NHS Health and Social Care Centre<sup>8</sup>). Willis, Khambhaita, Pathak, and Evandrou<sup>7</sup> further emphasise that this is an important finding, as services should be appropriate for all needs. Research suggests that those who are satisfied with service provision are more likely to comply and seek support for future needs.<sup>9</sup>

A 2014 briefing, reviewing research on adult social care for UK marginalised communities,<sup>10</sup> acknowledges that social care has tended to be rooted in a philosophy of empowerment and inclusion.<sup>11</sup> However, the author contends that for those seldom heard from, such as minority groups with protected characteristics under the Equality Act,<sup>12</sup> social care provision may be perceived as inaccessible or disempowering.<sup>10</sup> For example, personalisation is a government policy seeking to give service users their own budget to choose (buy), and have control over, the services they deem appropriate to their needs. Moriarty,<sup>13</sup> reviewing the impacts of personalisation on service users from BAME groups, suggests that the little research there is, mostly focusing on mental health services, highlights that amongst BAME groups, there is low uptake of personal budgets. Moriarty<sup>13</sup> contends

that community organisations mediating for people from BAME groups purport that such low uptake is not surprising, given service users' negative experiences of social care services in general.

Increasing choice and control and building community capacity are interrelated personalisation policy objectives.<sup>14</sup> However, a recent systematic review on facilitators, barriers, and strategies for engaging "hard to reach" older people suggests there is still much to do to engage those who may feel marginalised. From within groups of older people from BAME communities, the authors found that both convening social group sessions and strengthening community connections facilitated health promotion activities. However, together with language and cultural differences, barriers included members not having the confidence or motivation to get involved.<sup>15</sup>

It is acknowledged that the needs of older people in BAME communities require culturally appropriate services provision, but little is known about how these older people support themselves and others, what they perceive to be their "needs", and critically, the extent to which they feel such needs are being appropriately met.<sup>16</sup>

## 2 | METHODS

### 2.1 | Hearing from BAME older women: Participatory inquiry

Members of an older women's social group attached to a BAME Women's Centre located in the North East of England, approached Y, a University researcher who is part of the women's wider community. The women wished to explore, together, some of the problems they have with getting help, support, and services they perceive they need to stay well and engaged with family, friends, and wider community. In turn, Y approached Z, a researcher at another University who has experience of participatory inquiry.

During an introductory meeting, researchers and group members agreed that they wanted "practical ways of knowing" and cooperative relations.<sup>17</sup> The women did not wish to be co-researchers. They wished to be heard and to speak collectively. They wanted to identify and agree on, key common problems, potential solutions and gaps, and present these to an invited audience, including public and charitable agencies working with older people, an English National Health Service (NHS), local Clinical Commissioning Group, and local GPs. The women also wanted invitees to work with them to collectively agree on "doable" current actions and longer-term goals. The research team's role was to collaborate with planning and initiating the inquiry and to coordinate the research process, including data collection and analysis. We suggest our participatory inquiry fits Cornwell and Jewkes<sup>18</sup> early *collaborative* participatory inquiry, that is, researchers and local people work together on projects designed and managed by researchers.

We also agree with Bergold and Thomas<sup>19</sup> that participatory methodologies have fundamental principles that we wished to comply with. These include being transparent about what participation involved, open about ethical considerations, including talking through with the women's group about what is a "trusted, safe space" in relation to how and what is reported and by whom. Echoing Holland et al,<sup>20</sup> we do not assert that striving for participatory research is

somehow better than other research. Participatory research does not necessarily produce morally good, inclusive, or “better” research than other approaches.<sup>21</sup> It does, however, provide space for researchers to be aware of their “expert” positioning and for participants to continue to be knowledgeable citizens, working together to highlight problems and work toward solutions.<sup>18</sup>

## 2.2 | Study site

In 2010, the population of Newcastle upon Tyne, in the North east of England, the location for this inquiry, was 292 200, and in 2009, 88% of Newcastle's population was white British, with 12% comprising of other ethnic groups.<sup>22</sup> Approximately 18.5% of Newcastle's population is aged 65 years and over, and this is slightly higher than the national average of 17.9%.<sup>22</sup> In Newcastle upon Tyne, 1 in 5 people have a limiting long-term illness, and the city has a high number of unpaid carers.<sup>22</sup>

## 2.3 | Recruitment and participants

The Women's Centre of which the study participants were members provides women-only services for BAME women across the English North East region. As well as frontline support, the Centre works strategically, ensuring that BAME women can be supported to represent themselves and to be heard. An older women's group meets every Thursday for lunch and social activities. The group, with approximately 15 members, has been running since the Centre formed in 1993. The women are aged between 50 and 80 years; they did not wish to give specific detail. Whilst the Centre works with women from a number of BAME groups, at the time of this study, the social group members were all of South Asian origin, representing a wide range of languages, cultures, and religions, originating from India, Bangladesh, and Pakistan. Two of the women lived alone but had regular contact with wider family. The majority of the women were illiterate in that they could not read or write. Most of the women could understand some English and a few had a basic vocabulary.

## 2.4 | Data collection

The research team applied for and obtained ethics approval from Northumbria University, including offering audio-recorded informed consent in the language most accessible to the women (Urdu). This was to ensure they felt supported, not hindered, by ethics documentation, designed to promote good and safe research practice.<sup>23</sup> All 15 members consented to participate. Within written and verbal communication, we stressed this was voluntary and if any member decided not to participate, this would not negatively impact their continued membership of the social group. The group facilitator has many years of experience working at the Centre, appropriate language skills, and understands literacy barriers. She and one of the authors (X) identified and met language and literacy needs. The main spoken language was Urdu.

The older women's social group asked the research team to facilitate 3 workshops, each focusing on a particular topic: (1) health and well-being; (2) home and housing; and (3) services and support. Participatory appraisal tools, such as time lines, dot counters, impact

ranking exercises, and prioritisation<sup>24</sup> were used to stimulate conversation and identify perceived key problems. These were designed to identify the positive and negative aspects of each of the 3 topics, and were followed by asking the women to rank the negative themes in terms of importance to them. The most important issues identified were further explored, and women were asked to suggest ways in which these could be resolved. In reality, these were often discussed together. Whilst the research team had prompts, such as drawings depicting their own families, the women very quickly steered the conversation using individual and collective stories. It should be noted that the participants fully cooperated and were responsive to the questions. However, as each of the group sessions evolved, the participants sometimes talked in small groups or talked over each other with little exchanges of conversation. Whilst the research team attempted to record the many separate conversations, mainly in small groups of 2 or 3 participants, the group dynamics were difficult to record and transcribe. Participant permissions were obtained to audio-record each workshop discussion. Feedback and comment were recorded and shared on post-it notes and flipcharts. The participants sometimes got confused or tired, so in some cases the number of questions were reduced.

At the request of the women, a fourth and final workshop considered and distilled the discussion across the 3 workshops into an agreed slide presentation of the key findings. These findings were to be presented at a planned evaluation and feedback session with invited health care professionals, a range of representatives from public and charitable agencies working with older people, and family members. The purpose of this session was to facilitate engagement between service providers and the participants, with the women being able to share their challenges but also their proposed solutions, and for all to consider resources needed to instigate proposed solutions.

## 2.5 | Data analysis

We used thematic analysis<sup>25</sup> with written and verbal (audio transcribed) data grouped under similar codes. Codes were compared manually and grouped onto overarching categories.<sup>26</sup> There was a level of interpretation; the 2 bilingual workshop facilitators verified the translation during and after the 3 workshops. At the beginning of each workshop, we summarised key themes emerging from the previous workshop. This was to validate and agree with the group, the identified themes. Within participatory inquiry, it is also important that participants are involved in both generating and analysing data, as it is during the analysis that much of the learning takes place.

## 3 | RESULTS

Findings are discussed from within the following themes: “we need to get moving!”, “we don't want to have to rely on family”, “When discharged [from hospital], make sure we know what is happening!” and “we need a little bit of help on our terms”. Several of the women would often talk at the same time. Others would affirm what another had said or encourage yet another to speak up. We did not feel we could accurately attribute all speech to the rightful speaker and,

therefore, omitted this entirely. Within the workshops though, we did not have any instances of just one or 2 dominant voices. Indeed, the women frequently talked “as a group”, either addressing their immediate neighbour or calling to someone from across the room to invite their opinion.

### 3.1 | “We need to get moving!”

Acknowledging that 2 members expressed being “relatively well”, most of the women described living with mobility and health challenges requiring change and adaptation. From within the first workshop on health and wellbeing, particular health problems were also discussed:

*“One side is affected because I had a stroke.”*

*“It's the eyes they are not so good now.”*

Physically, the women talked about being hindered with everyday home activities and personal care:

*“It's hard to get in and out of the bath.”*

*(Workshop 1: Health and Wellbeing)*

*“Arms and legs don't work like they used to and I can't stand for any length of time, so I can't cook and have to have someone there to help.”*

*(Workshop 1: Health and Wellbeing)*

*“I can't lift heavy plates anymore or washing, someone has to do that then I can “help” with the job.”(Workshop 1: Health and Wellbeing)*

One of the main topics in relation to home and housing, the focus of Workshop 2, was about moving around the house, in the face of increasing limiting mobility:

*“I can't walk much even in the house. I do something and then I have to rest for 20 minutes.” (Workshop 2: Home and Housing)*

As well as coping strategies such as frequent rests, the group discussed using aids and adaptations to augment mobility:

*“Stair lift.”*

*“I have a high chair I can sit in the kitchen and still do [some food] preparation.” (Workshop 2: Home and Housing)*

Having had surgery or being admitted to hospital was discussed as a common experience. Post-surgery or hospitalisation, some of the participants had received home visits from health and social care professionals, including community matrons and hospital reablement teams. Reablement is a home based, 6 weeks or less short-term assessment and support service with usually a team including an occupational therapist and support worker. Aids and adaptations, such as rails and a raised seat in the toilet, may also be installed. One participant talked about being eligible for a stair lift but her home was not suitable for this to be installed.

Socially, for at least a third of the women, getting out on their own, particularly with sight and hearing loss, was getting harder.

Most of the women also suggested they felt a lack of places to “go”. Public transport can be challenging (getting on and off buses, cost, waiting and standing for the bus, route not near enough to destination), taxis are deemed expensive, and relying on family is not easy.

Where once family gatherings might mean going out to a restaurant or community centre or even another family member's home, increased immobility, or long-term health conditions, may mean that family gatherings now take place in the participants' homes:

*“It's hard even to get in and out of the car now with my knees. I'm better in a high taxi but that's expensive and I think sometimes my son thinks it's better they come to me but I like to go out and also, I worry then that the grandchildren might break something. There is nothing for them to do in my house. I'm not ungrateful but I don't feel at the heart of it all so much now.” (Workshop 1: Health and Wellbeing).*

The participants want to “physically move” more as even in the Centre, they just tend to sit and they know this is bad for their health. They would like to join a dance or keep fit class, and incorporate moving much more into their daily lives.

### 3.2 | “We don't want to have to rely on family”

Workshop 3 focused on formal and informal services and support. Most of the women agreed they want to stay in their home and place where they raised their children. They like their neighbours and communities. However, some talked about being “scattered”, living with younger family members who have moved out of their familiar community. They recognise that adult children have their own pressures; they do not wish to be a burden and value positive family support but worry this may also increase dependency:

*“I can't get out on my own so much.”*

*(Workshop 3: Services and Support);*

*“Family are busy, they don't always have time to take me out”.*

*(Workshop 3: Services and Support)*

There was talk of feeling lonely, not seeing so many people, and not having places to go outside of the home. This was compared with when they were younger, busy, and engaged within the community:

*“We were busy [when younger], always busy and many of us worked outside the home [local factories, family businesses], we had the children, the cooking, the home, all the family matters, always something to plan” (Workshop 3: Services and Support).*

One woman described feeling lonely even though she lives with her family:

*“They are out at work all day, so I get lonely but also, I can't get on with things so much, doing the washing or cooking, even going up and down the stairs it's difficult since the [hip replacement]”.*

*(Workshop 1: Health and Well-being)*

There was a variety of living arrangements. Two members lived alone. Some, despite their own health problems, were carers, looking after spouses and helping other family members. One member described not feeling comfortable asking her son for help (who did not live with her) because he was already struggling with his wife being unwell and mother-in-law having cancer. She did not want to be an added burden on her son.

One member lived in a flat upstairs an “over the family business.” Increasingly, she is feeling trapped:

*“Oh it is hard now pulling myself up [the stairs] but the family are so good. I don't want to make a fuss and they would get fed up with my moans and groans!”*  
(Workshop 2: Home and Housing)

The women agreed they do not wish to rely on family members to “go out” and “get on with life”. They need accessible, affordable, and workable public transport, and somewhere outside of family networks where they can meet, socialise, and do something enjoyable.

### 3.3 | “When discharged [from hospital] make sure we know what is happening!”

Hospital admission had been a common experience. The women described knee surgery, pacemaker insertion, being hospitalised following a stroke, or “being kept in for investigative purposes.” One woman described what happened when she did not heed her GP's advice:

*“I had some pains [in my chest] and the Doctor he said he wanted to send me to the hospital for tests. I did not want that. I thought I would stay quiet, pottering around the house but two days later, I was not myself and had to call my daughter. I ended up having an emergency operation for a pacemaker”* (Workshop 1: Health and Well-being).

Some women thought the best way to get to hospital in an emergency was to use their own transport but experienced long waits when they got there (or sent home) and felt the nurses and doctors should have seen them sooner as they were an emergency. Other women explained they always call an ambulance; otherwise, they will not be classed as an emergency.

Whilst the women described good hospital care, there was some discussion about uncomfortable incidences. For example, 1 member described being talked about in a ward where she was recovering from heart surgery:

*“I was very upset. The cleaner had left the floor wet and when the nurse asked who spilled the water; some of the other ladies [patients] said it was I. I said nothing but I was speaking some English. When I was a little better the ladies, I think they were embarrassed, they said they did not mean to upset me. They didn't know I could understand and speak some English”* (Workshop 3: Service and Support).

Discharge from hospital can be a confusing and worrying time, and language and literacy needs can be barriers. The nurses usually gave tablets to the women in hospital but they were not always sure what they were for. One woman, who had a stroke, explained how she was asked to take many tablets during her hospital stay (this spanning several weeks). When she came home, her daughter in law gave her the morning tablets as soon as she woke up. These included her diabetes tablet and made her feel unwell. The family realised later that she should be taking some of these tablets, including her diabetes medication, after breakfast and suggested no one had explained this. This woman's daughter lives far away and does not speak English and it seems, she did not fully understand the nurse's instructions.

Another woman explained that if she was not sure of the medication or of anything else the GP said about her husband (who had dementia), she would ask them to write it down and ask one of her children to read it when they visited her at home. Some argued this was not a choice for them, as their children lived far away and they have had many difficult experiences with “managing their care”. The women noted that this was another reason why their weekly social group at this Centre was so important to them. Some just brought such letters to seek help with translation.

When the women were asked what services they accessed following their hospital stay, there were mixed responses. For the women who had had knee operations, some said they attended physiotherapy sessions for a few weeks, but others were unclear about treatment plans following hospitalisation, with at least one of the women suggesting she had not had physiotherapy or other interventions following her hospital discharge. There was talk of not following any exercise regime, but they would very much like to regain some lost mobility and were unsure of what they could do with overall general stiffness and some limitation to joints.

### 3.4 | “We need a little bit of help on our terms”

The women were interested in helping themselves and on their terms. They did not expect others to do everything for them. Many had worked outside of the home and had felt pivotal to the flourishing of their immediate and extended families, as well as to their local community. Some did just get on with it:

*“Of course I get lonely but I still do things I enjoy. I like the Indian films I can get from Sky TV although it can be a strain on my eyes even with these (spectacles) and this (hearing aid) [there is laughter when this is said and the group joined in; they too like these films and have similar problems!]”* (Workshop 1: Health and Well-being).

The women also discussed how they were uncertain about entitlements and services and where to go to get useful information. They agreed that there was sensitivity around family loyalties:

*“My daughter in law does so much and I don't want her to feel that I need to go to “strangers” for help. She might feel judged, “why am I going outside the family, do I not feel cared for?” You see, I tend to talk to my family about decisions, what to do, we do this together”*.  
(Workshop 3: Services and Support)

When the research team raised the issue of entitlements, such as a Disability badge to access parking or the Government run “Warm Homes Scheme”, a payment to help with winter energy bills for some people living with long term conditions, some of the women stressed they would consider this a family matter. They would like to know more and would take the information to their spouse and/or adult children. They would need to understand the paperwork, their commitment, and whether there were “strings attached”:

*“We know that there are schemes, like when you look after someone you can get an allowance but we need to be sure that it's all ok. Sometimes there are many questions and that might involve the family too, so then it is sharing the family business. It's the same for everyone”.*

*(Workshop 3: Services and Support)*

### 3.5 | Feedback to stakeholders

A feedback event was planned with the women. This was an evaluative session with stakeholders including public and charitable agencies working with older people, an English National Health Service (NHS), local Clinical Commissioning Group, and local GPs. The women requested that we did not record this session and, therefore, our reporting is in the third person. They agreed they know what will improve their quality of life. There seemed to be a common thread about “having a place, a role” in the family but also having a purpose. Practical suggestions included having more, improved, and accessible community facilities, and help with literacy barriers; it appears not to be just a matter of language. From within the Centre, the women would like more space so that they can have a variety of activities including exercising; this was emphasised. They would like more outings; getting out and being stimulated is important. Finally, the women would also like more practical information and practical advice, such as how they might access a service or arrange shared transport.

All 15 members of the social group attended the feedback event along with 2 family members. Whilst the women welcomed positive relations with their local GPs, they also raised some concerns with language barriers and the difficulty some of them faced when trying to book GP appointments, as they did not always want a family member accompanying them as an interpreter. The themes raised in the findings, particularly about discharge from hospital and medication, were also discussed. At the feedback session, GP representation offered outreach; a local umbrella organisation that works with a number of ethnic minority groups offered to put the group in touch with a local Hospital NHS Foundation Trust's, Equality and Diversity lead, whilst a local charity, Newcastle Elders Council offered to meet with the group and share information about existing services and supports. Other specialist organisations such as Alzheimer's Society, offered outreach, signposting of services, and other useful information.

The women concluded that the feedback session had been very useful and now they wanted the research team to help seek funding

to become an active group, offering both peer support and working with outside agencies and networks to ensure their needs are met and their expertise helps to make positive changes.

## 4 | DISCUSSION

The participating women know what will improve their quality of life. There was a common thread about “having a place, a role” in the family and having a purpose. Whilst language and literacy may be particular cultural barriers, these women also struggle with lack of affordable and accessible transport, appropriate activities, and places to go to, which is common in many older people. They also find it hard to secure that little bit of help that may enable them to carry on and to have their place and standing within their families and communities.

Similar to Greenwood, Habbi, Smith and Manthorpe's<sup>6</sup> research on minority ethnic carers' perceptions of barriers to accessing community social care services, for the participants, there was reticence in involving “outsiders” and there seemed to be genuine bewilderment about what they might be entitled to, what is available, and how they may access such support. The women spoke openly of the tensions of, on the one hand, “keeping it in the family”, accepting and being grateful for the support that younger and peer members can and do offer, and on the other, feeling it is “disloyal” to suggest that this support is not enough or that “outside help” may offer more. The women spoke of “counting their blessings” and “shutting up and putting up”. Perhaps, it is not so much lack of confidence or motivation, but rather, a discomfort about unsettling family relations.

This discomfort about unsettling family relations has been noted elsewhere. In 2010, in the UK, Adnan Ud-Din was commissioned by Bradford Council Adult and Community Services to explore changing social care needs of older people living in Bradford's BAME communities.<sup>27</sup> Bradford is an ethnically diverse city. The author notes complex shifts in family and household structure, with younger families more likely to be seeking economic independence from parents, by setting up their own homes. Ud-din,<sup>27</sup> however, stresses it is likely that nuclear households still form a community, wherein individual family units are very much part of an extended family network that mobilises when support is needed. In our research, some of the women living alone spoke of family members helping them when they asked, but for others, there was also awareness that sons or daughters are likely to have other familial obligations, and in addition to paid work, career, and other responsibilities, they did not wish to become the “too much of an ask” burden.

Cattan and Guintoli,<sup>28</sup> when exploring care and support for older people in Bradford and across ethnic groups, assert rather than extended family offering care, it is likely that “caring” may still be viewed as the responsibility of the lead female in a household. If this person is not available or overstretched, this may be a critical point when formal care is also needed. Interestingly, our participants spoke of their own working lives: of younger selves supporting family businesses or working in factories as well as “keeping the family and home ship shape”. The consensus was that these were the “good” and “social” days. They did not discuss being carers for older family members, and perhaps this is because the researcher did not raise this.

Earlier research points to both white British and South-Asian older people suggesting they would consider using 1 or more available public service, regardless of the quality or quantity of the informal care they were receiving.<sup>29</sup> The women also considered how in addition to family help, formal support might improve their quality of life. This also focused on “a little bit of help” to support a spouse or family member who is also living with physical change. Irrespective of cultural or ethnic background, many older people are likely to be giving and receiving informal care and support. This can be burdensome and, for some, financially unsustainable and insecure.<sup>30</sup>

Common barriers to seeking formal support seemed to have to do with family loyalties, as discussed earlier, and a lack of useful, accessible information about what support is available to them and at what cost. It might also be that shared negative experiences of health services are not conducive to seeking formal support. Although the participants did speak of some good hospital care, there were recalled incidences that may illustrate ageist attitudes and assumptions about ethnic communities. The women acknowledged that language could be an issue and, thus, vital information upon discharge from hospital, including medication instructions, or future care plans for a spouse or relative, can become horribly and, potentially, dangerously confused and misunderstood.

The women wanted a confidential, trusting, and dignified relationship with key gatekeepers such as their GP, but due to GP workloads and appointment systems, this was not always possible. These negative experiences of formal care might be one reason why Willis, Khambhaita, Pathak and Evandrou<sup>7</sup> found that surveys consistently demonstrate how people from BAME groups are less satisfied with social services compared with others. Other research also suggests that older people, in general, want to be actively listened to, with services tailored to their needs, and that professionals should give “good care” that respects diversity and individual choice.<sup>28</sup>

Needham and Carr's<sup>31</sup> review on support provision for people with protected characteristics under the Equality Act 2010 suggests low uptake of personalisation budgets, from within BAME communities.<sup>10,13</sup> Needham and Carr<sup>31</sup> suggest this low uptake might be because, unwittingly, statutory and mainstream social care provision may not be set up to respond quickly and flexibly to diverse need. The authors also suggest community-based and specialist “micro-providers”. Local, grass roots organisations and groups may offer wider choice for those who feel that larger, mainstream services are not available to them.<sup>31</sup> For this older women's social group, the Women's Centre might be described as one such “micro-provider”. It is paid and volunteer staff at the Centre, for example, to whom the women turn to with letters to be translated and explained; it is here they support each other, sharing local know how, and perhaps seek group reassurance that they can and should speak up and ask for what they are entitled to.

In agreement with Needham and Carr,<sup>31</sup> such activity needs recognition and investment, and its existence should perhaps complement, certainly not be in place of, mainstream services. This bringing together of statutory services and grassroots community support may help the women to realise and appropriately meet their request for “a little bit of help”.

Finally, we suggest that the women considered services and supports at a very human scale. The work of Liu et al<sup>32</sup> illustrates

the impact of the physical environment on wellbeing in later life. Physical characteristics, the pavements, seating, accessible toilets, entrances to shops, as well as close proximity to amenities such as post offices and pharmacies, and reliable and affordable public transport, can sustain social interaction and engagement with the local community. Burns, Lavoie, and Damaris<sup>33</sup> suggest that the meaning of and attachment to place, particularly in relation to proximity to family, friends, and neighbours, can also be very significant to older people.<sup>34</sup> They cite research that illustrates how a neighbourhood, particularly if there has been long residency, can provide “identity markers”,<sup>35</sup> and these can be unsettled with neighbourhood change. The women's recounted experiences, eg, moving away from their community to be with family, now finding it hard to get out and about, or suggesting that they do not have local amenities or accessible transport, seem to illustrate a need for local solutions. This is in agreement with the research presented here.

As for the implications of these findings for formal health, social care, and other services, the women speak clearly about the need to ask them as to whether they wish to have in attendance, or consult with, family members; many do, some do not. In relation to hospital and primary care, there are also critical health, safety, and quality assurance requirements such as the need to have and communicate accessible information and advice about medication, procedures, and ongoing treatment, as well as clear signposting to ongoing support if needed.

## 5 | LIMITATIONS

This was a small inquiry particular to 15 older women attached to a BAME women's centre in the North East of England. It is felt that one to one interviews or small focus groups with 2 or 3 participants may allow for deeper, richer data, particularly when these community groups are not often part of studies or evaluations, and it may take time to develop trust and confidence to talk on a one to one basis. Through the stakeholder feedback session, we only have minimal response from cross sector health and social care service providers. Further study should consider including interviews with such providers and focus groups that bring both service users and providers together. We are also aware that we have raised expectations about making a difference. There also needs to be research with older men from BAME communities.

## 6 | CONCLUSION

This participatory inquiry with 15 older South Asian women concludes that whilst language and literacy might be barriers to building confidential and ongoing professional relationships with primary care professionals, what they really need is a “little bit of help” in the home that is affordable, culturally appropriate, and on their terms. The women stressed that such help would make them less reliant on busy family members and restore their sense of status, purpose, and standing within their families and community. It was also evident that the BAME Women's Centre played a critical role in brokering with statutory support services to ensure that the women's needs and concerns



were, at least, listened to and acknowledged. This has implications for how health and social care services can work with South Asian older women to promote and maintain meaningful independence and on their terms.

## ACKNOWLEDGEMENTS

The authors wish to sincerely thank the 15 members of the BAME Women's Centre older women's social group, without whom this research would not have happened. Very many thanks too to Ms Rosie Lewis, Co-Director of the Centre for her involvement and in-kind contribution. Thanks also to the stakeholders who met with the participants to discuss and respond to project findings.

## FUNDING

There was no external funding.

## CONFLICTS OF INTEREST

None declared.

## AUTHOR CONTRIBUTIONS

Conceptualization: Participants, Parveen Akhtar, Zeibeda Sattar, Cathy Bailey

Funding Acquisition: Cathy Bailey, Parveen Akhtar

Project Administration: Cathy Bailey

Methodology: Participants, Parveen Akhtar, Zeibeda Sattar, Cathy Bailey

Formal Analysis: Cathy Bailey, Zeibeda Sattar

Writing—original draft: Participants Cathy Bailey, Zeibeda Sattar, Parveen Akhtar

Writing—review and editing: Cathy Bailey, Zeibeda Sattar

## ORCID

Cathy Bailey  <http://orcid.org/0000-0002-5509-2200>

## REFERENCES

- Centre for Policy on Ageing. The ageing of the ethnic minority populations of England and Wales: findings from the 2011 Census. A briefing paper for Centre for Policy on Ageing. CPA, 2013.
- Office for National Statistics. Population estimates 2016. Retrieved from: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates>
- Livesley N. The future ageing of the ethnic minority population of England and Wales. Published by Runnymede and the Centre for Policy on Ageing 2010.
- Becares L, Nazroo J. Social capital, ethnic density and mental health among ethnic minority people in England: a mixed-methods study. *Ethn Health*. 2013;18(6):544-562.
- Lipman V. Contracts and commissioning: what is happening to social care services for black and minority ethnic older people. *Working with Older People*. 2015;19(2):85-93.
- Greenwood N, Habbi R, Smith R, Manthorpe J. Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health Soc Care Community*. 2015;23(1):64-78.
- Willis R, Khambhaita P, Pathak P, Evandrou M. Satisfaction with social care services among South Asian and White British older people: the need to understand the system. *Ageing Soc*. 2015;36(7):1364-1387.
- The Health and Social Care Centre. Retrieved from: <https://www.gov.uk/government/publications/the-health-and-social-care-information-centre-annual-report-and-accounts-2012-to-2013.%202012>.
- Hausmann L, Gao S, Mor M, Schaefer J, Fine M. Understanding racial and ethnic differences in patient experiences with outpatient health care in Veterans Affairs Medical Centers. *Med Care*. 2015;51(6):532-539.
- Carr S. Social care for marginalised communities: balancing self-organisation, micro-provision and mainstream support. Policy Papers 18. Health Services Management Centre, University of Birmingham and Economic Social Research Council. 2014.
- Dominelli L. *Social work in a globalizing world*. Cambridge, UK: Polity Press; 2010.
- Equalities Act *Equalities Act* 2010. The Stationery Office 2010
- Moriarty J. Personalisation for people from black and ethnic minority groups. A race equality foundation briefing paper (Better Health 34). Race Equality Foundation. 2014
- Department of Health. *Putting People First: Personal Budgets for Older People—Making it Happen*. London: DH; 2010.
- Liljas A, Walters K, Jovicic A, et al. Strategies to improve engagement of 'hard to reach' older people in research on health promotion: a systematic review. *BMC Publ Health*. 2017;17(1):349.
- Badger F, Pumphrey R, Clarke L, et al. The role of ethnicity in end-of-life care in care homes for older people in the UK: a literature review. *Divers Health Care*. 2009;6(1):23-29.
- Heron J, Reason P. A participatory inquiry paradigm. *Qual Inq*. 1997;3(3):274-294.
- Cornwell A, Jewkes R. What is participatory research? *Soc Sci Med*. 1995;41(12):1667-1676.
- Bergold J, Thomas S. Participatory research methods: a methodological approach in motion. *Forum Qual Soc Res*. 2012;13(1). Art. 30
- Holland S, Renold E, Ross N, Hillman A. Rights, 'right on' or the right thing to do? A critical exploration of young people's engagement in participative social work research. *NCRM Working Paper Series 07/08.2008*. Retrieved from: <http://eprints.ncrm.ac.uk/460/>
- Roy A. Avoiding the involvement overdose: drugs, ethnicity and participatory research practice. *Crit Soc Pol*. 2012;32(4):636-654.
- Newcastle City Council. Equality Statistics, Research and Information.2017. Retrieved from: <https://www.newcastle.gov.uk/your-council-and-democracy/statistics-and-census-information/equality-statistics-research-and-information#population>
- Neiland A, Bennett E, Townsley P. Participatory research approaches—what have we learned? The experience of the DFID Renewable Natural Resources Research Strategy (RNRRS) Programme 1995–2005.2006. Retrieved from: [www.research4development](http://www.research4development).
- Pawson R, Tilley N. *Realistic Evaluation*. London: Sage; 1997.
- Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *Int J Qual Meth*. 2006;5(1). Retrieved from: [http://www.ualberta.ca/~iiqm/backissues/5\\_1/PDF/FEREDAY.PDF](http://www.ualberta.ca/~iiqm/backissues/5_1/PDF/FEREDAY.PDF):80-92.
- Tobin GA, Begley CM. Methodological rigour within a qualitative framework. *J Adv Nurs*. 2004;48(4):388-396.
- Ud-din A. *Black and Ethnic Minorities Older People's Changing Care Needs: A Study on Life Style Changes Affecting Access to Care in Bradford*. City of Bradford: MDC; 2010.
- Cattan M, Guintoli G. "Care and Support for Older People and Carers in Bradford: Their Perspectives, Aspirations and Experiences. Joseph Rowntree Foundation. 2010
- Sin CH. Expectations of support among White British and Asian-Indian older people in Britain: the interdependence of formal and informal spheres. *Health Soc Care Community*. 2006;14(3):215-224.
- Harrop A. *Care in Crisis: Causes and Solutions*. Age UK: Public Policy Department; 2011.

31. Needham C, Car S. Micro-provision of social care support for marginalized communities—filling the gap or building bridges to the mainstream? *Soc Pol Admin*. 2015;49(7):824-841.
32. Lui CW, Everingham JA, Warburton J, Cuthill M, Bartlett H. What makes a community age-friendly: a review of international literature. *Australas J Ageing*. 2009;28(3):116-121.
33. Burns V, Lavoie JP, Damaris R. Revisiting the role of neighbourhood change in social exclusion and inclusion of older people. *J Aging Res*. 2012;2012:1-12.
34. Cutchin MP. Agenda for future spaces for inquiry into the role of place for older people's care. *J Clin Nurs*. 2005;14(8B):121-129.
35. Clément S, Mantovani J, Membrado M. "Bon voisinage aux solidarités de proximité," in *Solitude et Isolement des Personnes âgées. L'environnement Solidaire*, pp. 105–138, Erès, Toulouse, France, 2004.

**How to cite this article:** Bailey C, Sattar Z, Akhtar P. Older south Asian women sharing their perceptions of health and social care services and support: A participatory inquiry. *Health Sci Rep*. 2018;1:e55. <https://doi.org/10.1002/hsr2.55>