



Greater Manchester, Ethnic Minority Experiences of Caring

Research Report 2020

Wraparound Partnership

Acknowledgements

We would like to thank all the carers that gave their time to tell us about their experiences for this project.

Introduction

On 19th January 2018, 33 organisations in the Greater Manchester Health and Social Care Partnership Care Partnership made a historic commitment to deliver on the rights of carers as set out in the Greater Manchester Carers Charter. It was identified that the region has around 280,000 unwaged carers.

The Greater Manchester Carers Charter works to ensure that carers:

- are identified as early as possible, respected and included by health and social care professionals.
- have choice and control about their caring role and receive personalised support which meets their needs and that of their family.
- are able to stay healthy and well themselves.
- are socially connected and not isolated.
- are supported to fulfil educational and employment potential.
- young carers or young adult carers are protected from excessive or inappropriate caring roles.

The Greater Manchester Support for Carers programme will deliver on the National NHS Long Term Plan priorities for Carers, including:

- Early Identification of Carers.
- Improved health and wellbeing
- Getting the right help at the right time
- Carers as real and expert partners

- Young Carers and Young adult carers
- Carers in and into employment.

A significant focus across all Greater Manchester priorities is the reduction of health inequalities, ensuring that there is fair and equitable access to support. To reduce the postcode lottery and encourage a greater understanding of the lived experience of people who live in marginalised communities and those with the greatest levels of deprivation. This understanding allows the 'system' to accommodate these communities including any cultural and/or faith considerations.

The Greater Manchester Carers Partnership and associated governance mechanisms ensures that there is accountability and responsibility across the health and social care landscape, whilst focussing on what is working the Carers Partnership Board is always looking to gain wide knowledge and understanding of what it means to be a carer across Greater Manchester and has worked to ensure that lived experiences from people who are carers truly drive this agenda forward across the 10 local areas.

THE CARERS CHARTER WAS DEVELOPED IN COLLABORATION WITH CARERS AND LOCAL VOLUNTARY GROUPS TO ENSURE THAT THE ROLE OF A CARER IS ACKNOWLEDGED AND RESPECTED, THEIR NEEDS ARE MET AND THAT THEY HAVE ACCESS TO THE SERVICES AND SUPPORT THEY NEED.

- GREATER MANCHESTER MENTAL HEALTH NHS FOUNDATION TRUST

Introduction to the research

Across Greater Manchester, as is the case across England, there exist large communities of marginalised groups, often living in areas which have the most health inequalities, such as parts of Oldham and Rochdale where there are large Asian communities, along with areas with large communities of Afro Caribbean and African carers.

Wraparound has substantial networks and connections into these communities, such as support groups in Oldham for women of Asian heritage, families living in Stockport where parents of Asian background are isolated, networks across the Greater Manchester Community and Voluntary sector, including social enterprises. Along with significant connections into the Afro Caribbean and Black Communities. This research aims to give an insight into their world. The research links the themes of:

- health and wellbeing,
- right help at the right time,
- identification and carers as real and expert partners.

The research also aims to support these outcomes by identifying further where Greater Manchester and locality support could be focussed to identify and support hidden carers and under-represented groups, working towards ensuring that all carers in Greater Manchester have the same level of access and support no matter where in Greater Manchester they live.

Carers often do not become known to statutory services until there is a crisis situation, those carers from marginalised communities and who do not readily engage with services are at greater risk of having poor health outcomes, both physical and mental, reaching burnout and not being able to cope.

This research investigates the lived experiences of this group of carers and provides insight into how the 2020/2021 carers programme could incorporate this evidence to enhance the health and wellbeing of this group of carers across Greater Manchester.

Project aims

- To investigate the lived experienced of carers in ethnic minority communities.
- To record and understand their experiences of being a carer.
- To understand in greater depth what barriers they face in accessing support.
- To understand what support, they feel they would benefit from which may include from VCSE organisations and local community groups.
- Investigate where they find their current support from, in terms of locality areas and local community and faith-based groups.
- To make recommendations and propose further actions to the Greater Manchester Carers Partnership Board as to what the priorities for implementation of support are for this group of carers.

Research methodology

The research took an ethnographic approach and where possible focuses on the voices and lived experiences of carers from ethnic minority backgrounds. Data was collected via two methods:

- Telephone interview with 13 carers
- Online survey of 26 carers.

Whilst we endeavoured to speak to as many carers as possible however the research was limited by the 2020 Corona Virus lockdown see Appendix 1 for more details.

About this report

Being a carer is rarely easy. We asked in our survey how demanding carers feel their role is, and none all responded that it is 'difficult' or 'very difficult'. In many respects, the experiences of ethnic minority carers are the same as any other person with caring responsibilities - in nine of our 24 survey responses, carers reported that they did not feel that being from an ethnic minority made any difference to any support they receive.


But rather than focusing on similarities, this research focuses on the different experiences of ethnic minority carers and the issues that this group report as being unique to them. For example, some carers told us about carer experiences related to technology, mobility and time. But these were not specifically related to ethnicity and so are not covered in detail in this report.

Areas that have been identified as specific are:

- lack of community support,
- food and dietary needs,
- language and translation,
- culturally sensitive support and racism.

These areas do not affect the experiences of all types of care – food and translation appear to predominantly affect the experience of carers supporting older adults, whilst racism is an experience predominantly expressed by those caring for children. Both groups however had shared experiences that they wished to share about

the support (or lack of) that they experienced within their communities.



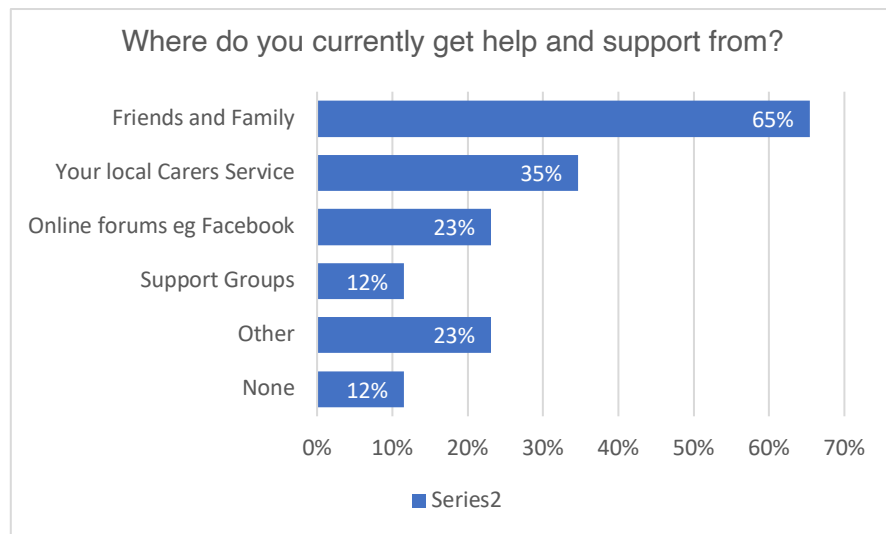
I BELIEVE THE CULTURAL AWARENESS IS NOT
ALWAYS THERE AND THERE IS A LOT OF
COMMUNITY PRESSURE TO TAKE CARE OF YOUR
FAMILY MEMBERS

- BLACK-BRITISH CARER FOR AN OLDER
ADULT

Lack of community support

Most carers who responded to our survey told us that they were supported by family and friends, and most would turn to family in a crisis or if they were ill. This may not always be through choice though, for example one carer explained: *“Dad recognises he is deteriorating but doesn’t want to admit it... [he] refuses to have support from anyone except family members”*

In general, a reoccurring theme from our interviews was a lack of support or understanding from within the carers own community. This applied both to carers who were caring for their children, and for carers who were caring for their parents or elderly relatives, although in slightly different ways. The impact of not being able to even talk about their experiences was very challenging for a number of carers, as one explained *“its hidden and out of our control.”*



Caring responsibility for older adults

A number of carers told us how they had not revealed to other members of their community that they were caring for an elderly relative, and in some cases they faced added pressure by being specifically asked by their relative not to reveal the extent of the difficulties they were facing.

One carer, who was looking after both his parents explained to us that his father had asked him not to tell anyone: *“it’s better if we don’t tell anyone... no one will know”* and another explained that her terminally ill father *“didn’t want people to know what was wrong with him”* another explained *“Dad wanted to be at home, and he dies at home, mum didn’t want to be seen as a carer.”*

A number of carers linked this issue specifically to Asian communities, one interviewee who explained: *“it’s our culture... everything is done by family members all is hush hush”*.

Caring responsibility for children

It is much harder to keep hidden caring for a disabled child, yet many carers still told us of a ‘hush hush’ attitude and a stigma that around a child who needs care.

One carer whose son has is on the autism spectrum, has complex needs and attends a special school explained:

“our reality has been denied by our own family the most destroying thing is the family and community lack of acceptance. Many parents are pushed into not accessing the support their child needs due to stigma.”

Another explained how she felt disability is a *“stigma”* in the Asian community.

Food and dietary needs

Food was a key part of a number of ethnic minority carers' experiences. This was buying (or being given), cooking and eating food.

WHENEVER WE GO ROUND MUM IS COOKING, ITS OF VITAL IMPORTANCE TO HER, SHE ALWAYS OFFERS US FOOD AND STILL WANTS EVERYONE TO EAT.

- FEMALE CARER FOR AN OLDER ADULT OF PAKISTANI, IRANIAN AND ASIAN HERITAGE

Getting food

Those people in receipt of supported food provision – either from food banks or from other services – told us that in many cases the food provided wasn't culturally appropriate. One carer explained that the *"local food bank doesn't provide food we can eat"*, whilst another said, *"it's pointless having food bags as they are not all Halal."*

As a result, it can become an additional responsibility for the carer to shop or get food. One carer explained that his parents' text him a list of what food they need every Friday and he has to go to the shops that sell the halal food. He saw this as the start of his caring responsibility:

"my caring role has just happened, I didn't see it as a role but it's the little things that add up... starts with can you just

get my shopping, then it evolves in to support at appointments, and so on."

Cooking and eating

Some carers told us how in their community, cooking and eating food together is culturally important. Without access to the right type of food (and with some of the community issues discussed above) this becomes an additional role for carers:

"my family is from Iran, all the family cook... food is a big social event of the day... [but] there has been no culturally specific food, so I have to buy it and cook it myself."

Some carers also told us about their experience supporting their family members to eat, explaining the role that eating communally plays in their culture and how this is a challenge both to those who are caring and those who are being cared for.

EATING WAS A BIG DEAL IN OUR COMMUNITY, IT'S A SOCIAL EVENT AND AS DAD WAS NOT EATING ANYTHING SOLID MUM WOULDN'T EAT IF DAD WASN'T SO WE HAD TO GO ROUND AND HAVE MEALS WITH HER SO SHE WOULD EAT. WE HAD A LARGE FAMILY, BUT THE LAST FEW WEEKS TOOK ITS TOLL ON MUM SHE ALWAYS MADE HOME COOKED FOOD, SHE WOULD NOT ASK FOR HELP FOR HER AND ONLY IMMEDIATE FAMILY KNEW.

- FEMALE CARER FOR AN OLDER ADULT OF INDIAN HERITAGE

Language and translation

Language was a challenging part of the experience of many ethnic minority carers and their families. It was predominantly recounted in the experiences of those who were caring for older adults.

In order to interact effectively with support services and medical staff, carers needed to either translate conversations themselves or seek interpreters who can help.

SOMETIMES WE OVERLOAD PEOPLE WITH TOO MUCH INFORMATION THIS CAN CAUSE ANXIETY ESPECIALLY WHEN THE INFORMATION IS NOT IN THEIR MOTHER TONGUE.

- MALE CARER FOR AN OLDER ADULT OF ASIAN HERITAGE

Carer as interpreter

Some took on the role of translator themselves, meaning that they had to be available for many meetings and appointments:

“both [parents] have hospital... telephone appointments, but they struggle with English so we have it on loudspeaker so I can interpret what is being said.”

Even when English proficiency is good and an interpreter isn't needed, some carers told us that things like British regional accents can be a barrier and result in the carer taking on additional tasks, such as arranging medication. One carer, who himself works in the NHS explained that his mum has *“many problems with*

understanding doctors and other health workers especially if they have an accent, [so] I sort out all my mums medicine.”

THEY HAD CARERS IN FROM SOCIAL CARE BUT IT WAS TOO STRESSFUL... MUM DIDN'T UNDERSTAND THEM AS SHE ONLY SPEAKS BENGALI, AND IN ORDER TO SUPPORT HER AT MEDICAL APPOINTMENTS WE NEEDED A GOOD ENGLISH – BENGALI TRANSLATOR – SOMEONE WHO IS BILINGUAL BUT THERE WASN'T ONE.

- FEMALE CARER FOR AN OLDER ADULT OF BANGLADESHI HERITAGE

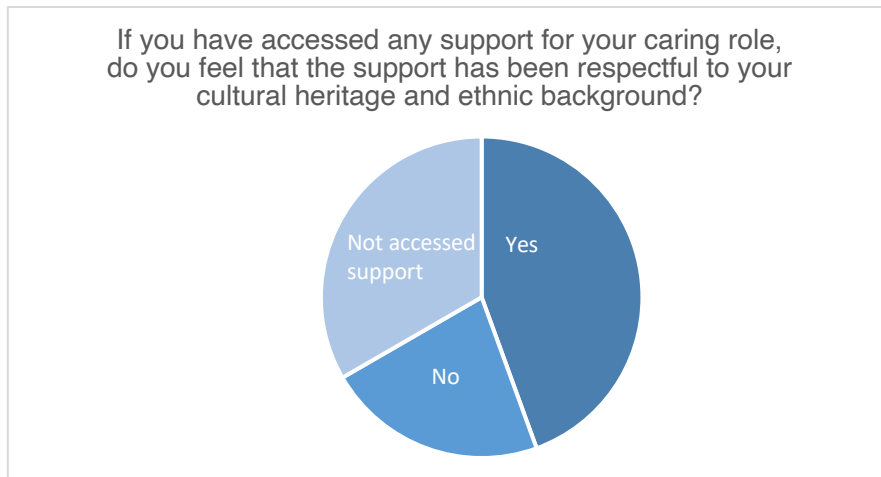
Shortage of appropriate interpreters

When carers can't (or are not permitted to) fulfil the role of interpreter themselves, many reported a shortage of appropriate translators.

Culturally sensitive support

When carers needed to access additional support, most told us that this was respectful to their cultural heritage and ethnic background. However, a small proportion of survey respondents and interviewees told us that their experience would be improved if more cultural sensitivity were shown.

This might include awareness of gender sensitivities, e.g. *“it would be good if there were some culturally sensitive carer support available as mum will need to wear her hijab if it’s a male carer,”* or just someone who had experienced a similar cultural background, e.g. *“Mum doesn’t want other carers in she doesn’t trust them. Her mum needs a family carer, someone who knows you and who you know, someone who can talk to mum about Jamaica, goats and plantations.”*

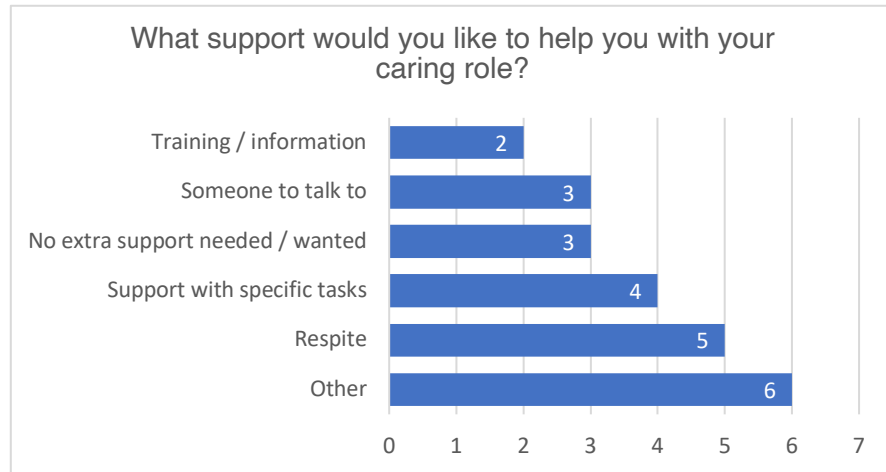


But even if such support can be found, it can still present problems. One carer told us of her experience when her child was allocated a case worker from within their own community:

“Our third case worker in as many months was actually a lady living within the community and had much background information before coming on board and was in contact with my husband’s family prior to meeting us. We felt prejudged and the visits consisted of her asking about family and essentially trying to guilt us for the 3 hours a week we were receiving. It was soul destroying in all honesty and I don’t think we should have ever been allocated a person living within the community with ties to family in this way.”

When we asked what support carers would like, many spoke about respite, e.g. *“some ‘me time’ away from the person living with dementia but knowing that they are happy where they are.”* Others suggested that they would like more people to talk to about their situation and opportunities to get information and/or training: *“someone to talk to when I feel like I am overwhelmed.”*

A small number of carers told us that they would not like any support, that arranging support was just extra work for them: *“I don’t want support because it’s just extra hassle.”*



Racism and diagnosis issues related to race

All the carers that spoke of experiences of racism were caring for children rather than older adults, and many were related to identification of needs, e.g. *“we had a lot of ‘lets just leave it’ and ‘just see he’s a late developer’ from the health visitor. There was a willingness to dismiss us and an unwillingness to understand.”* The issue appears to compound identification, as the rarity of the need within the community may lead to others not being identified either, as one parent care explained: *“there are rarely diagnosis of autism in the Asian community, minority ethnic communities have a lack of diagnosis”* and another told us that her daughter is *“the only known child in the Asian community to have this condition”*.

In some cases, carers spoke of the effects of being in a minority group, within a minority group:

“We are treated like second class citizens, - if your child has SEND you are second class citizens, third class if you are

then Asian... a lot of times they think you are just straight off the boat.”

Recommendations

We asked all of the carers that we spoke to what recommendations they would make to improve their experience of caring, and the experience for other people like them. They suggested:

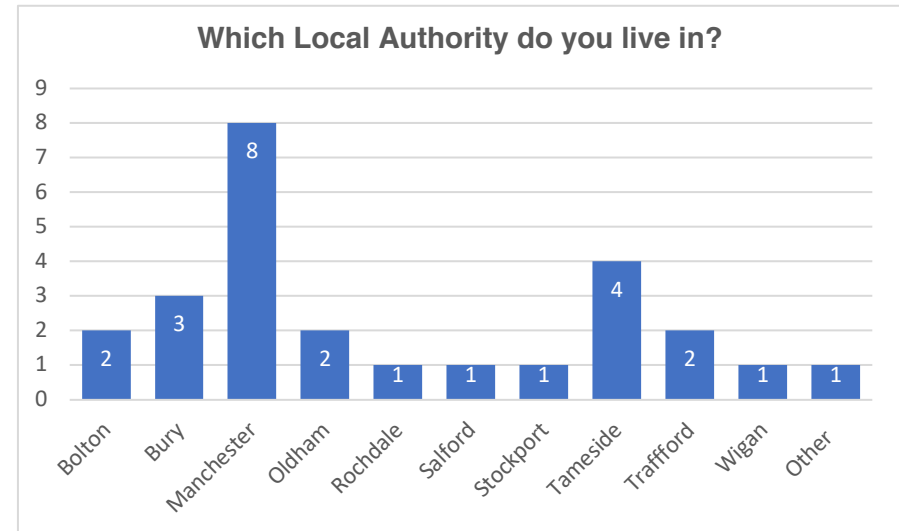
- Social events and information provision for carers from similar ethnic backgrounds
- Promoting support services to ethnic minority carers so that more access them and stigma reduces
- Events to raise awareness in ethnic minority communities about the role of carers
- A respite service where those with additional needs are cared for by people of similar cultural backgrounds or heritage
- Halal shopping support.

Appendix 1. Methodology

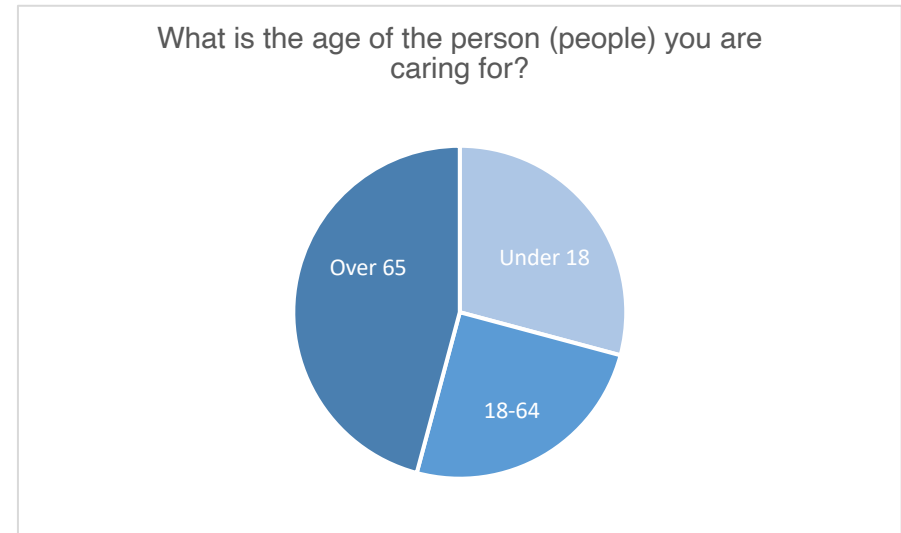
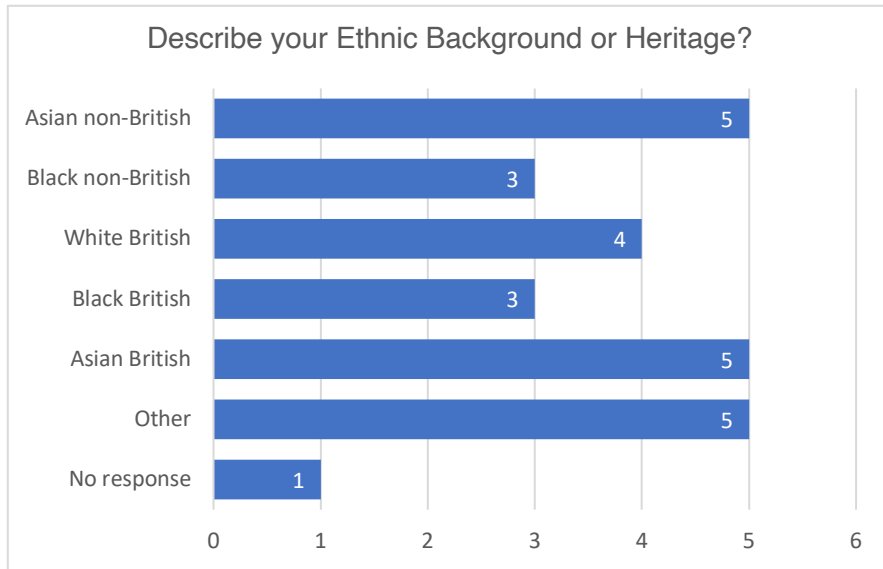
Survey

An online survey was conducted between 5.4.20 and 5.5.20 Carers were recruited by email and via networks. The data was analysed in Excel.

In total 26 carers responded to the survey. Carers lived in Local Authorities across Greater Manchester, although Manchester and Tameside were more represented than other areas.



Carers were asked to describe their ethnic background or heritage in their own words. They have been grouped together in the chart below. Around half used the term 'British' (or English) to describe their background, and around a third spoke only of a non-British background, e.g. Pakistani or Jamaican.



Around half (11) of the carers who responded to the survey were caring for older adults (aged over 65). Seven were caring for children aged under 18 and 6 were caring for adults aged between 18 and 64.

Telephone interviews

Telephone interviews were conducted between 15.4.20 and 5.5.20. Carers were recruited by email through our networks and a £10 gift token was sent to all participants.

The interview data was transcribed and coded using an iterative process to identify key themes and trends.

Recruitment of carers was severely restricted due to Coronavirus pandemic, as carers were taking on more responsibility.

Report by Wraparound Partnership a Greater Manchester Social Enterprise, Written by Karen Wespieser