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Carers of stroke survivors from diverse ethnic groups: a qualitative focus group study investigating experiences of accessing and engaging with social care services

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ABSTRACT

Objectives: Informal carers, often family members, play a vital role in supporting stroke survivors with post-stroke disability. As populations age, numbers of carers overall, and those from minority ethnic groups in particular, are rising. Carers from all ethnic groups, but especially those from black and minority ethnic groups frequently fail to access support services making understanding their experiences important. The study therefore explored the experiences of carers of stroke survivors from five ethnic groups in accessing and receiving social care services after discharge.

Design: This qualitative study used seven recorded focus groups with informal carers of stroke survivors. Data were analysed thematically focussing on similarities and differences between ethnic groups.

Setting: Carers were recruited from voluntary sector organisations supporting carers, stroke survivors and black and minority ethnic groups in the United Kingdom.

Participants: Forty-one carers from five ethnic groups (Asian Indian, Asian Pakistani, black Africa, black Caribbean, white British) participated in the focus groups.

Results: Several interconnected themes including: the service gap between discharge and home; carers as the best person to care and cultural aspects of caring and using services, were identified. Many themes were common to all the included ethnic groups but some related to specific groups.

Conclusions: Across ethnic groups there were many similarities in the experiences of older people caring for stroke survivors with complex, long-term care needs. Accessing services demands effort and persistence on carers' part. If carers believe services are unsatisfactory or that they, rather than formal services, should be providing support for stroke survivors, they are unlikely to persist in their efforts. Cultural and language differences add to the challenges black and minority ethnic group carers face.

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Key messages

- Ethnically diverse stroke carers have many experiences in common.

- These carers also share many challenges in accessing and engaging with services.

- Accessing services demands great effort and persistence by carers from all ethnic groups.

- Cultural and language differences add to the difficulties faced by minority ethnic carers.

Strengths and limitations

- We used a qualitative, in-depth approach with over forty participants giving a detailed understanding of these carers' experiences.

- We included both black and minority ethnic and white 'majority' participants which permitted direct comparison with minority ethnic group participants.

- However, all focus groups were conducted in English excluding carers with limited or no English. Finally, we only investigated five ethnic groups which are clearly very broad categories with inherent limitations.

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INTRODUCTION

Worldwide stroke is the major cause of long-term disability in adults [1] and leaves many stroke survivors dependent on their families (who are often referred to as carers or caregivers) [2]. Older people and those from black and minority ethnic (BME) populations are at increased risk of stroke [3,4] and as numbers of older people from diverse communities grow, it is becoming increasingly important to support the well-being of older, minority ethnic unpaid informal carers [5].

Systematic reviews of research investigating informal caring post stroke describe many challenges [6-8] and support needs shared by carers across ethnic groups and differing care systems [9]. Carers often report insufficient information and training about stroke and stroke services, particularly post-discharge from acute settings [10]. Reviews also highlight reduced quality of life, hyper-vigilance, anxiety, depression and having to cope with role and identity changes [11-13]. A third of spousal carers report exhaustion and depression which increases as carers age [14].

However, there is considerable evidence that carers' uptake of support services is low ([15-17] even though using such services can make significant differences delaying transfer to long-term care [18] and improving carers' quality of life [19].

In developed countries, numbers of carers from BME groups in particular are rising as the demographic profiles of these populations age [20]. In the United Kingdom (UK) carers from BME groups provide more care than white British carers and are also more likely to suffer from ill health [21]. Despite this, evidence suggests that compared to their white counterparts, these carers are less likely to use formal services [22], even though they express greater need for services [23,24]. Reasons for low service access are complex and multifaceted. For example, health and social care service uptake is influenced by cultural beliefs in terms of, for example, stigma associated with some health conditions [23]. A recent systematic review identified several main explanations for carers' failure to access and engage with services which included a mixture of attitudinal (e.g. a sense of duty) and practical explanations. Importantly, whilst such reasons may apply to all ethnic groups, their impact may be exacerbated by language difficulties or information provided in culturally

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inappropriate ways [25]. However, conclusions from research are limited by frequently failing to include majority groups for comparison, making it difficult to know if reasons for low uptake are restricted to minority ethnic groups or apply more widely.

The project therefore explored BME and white British carers' experiences of accessing and receiving social care services in the community, focussing on similarities and differences between ethnic groups.

METHODS

The research approach draws on ethnography with an emphasis on the meanings participants give to actions and behaviour [26] and was part of a larger qualitative project investigating carers' satisfaction with social care. Findings relating to the impact of the heterogeneity of the focus group participants on group interaction are reported elsewhere [27].

Participants were recruited from voluntary organisations in and around London, UK. To be included, participants had to be over 45 years old, self-identify as black African, black Caribbean, Asian Indian, Asian Pakistani, or white British, to have used social care, and to be either currently or recently caring for stroke survivors living in the community.

Focus groups were conducted in English, audio-recorded and facilitated by the research team using a topic guide which explored participants' experiences and perceptions of social care services in England. Ethical approval for the study was obtained from the National Social Care Research Ethics Committee and written informed consent was obtained from all participants.

Audio recordings were transcribed verbatim and anonymised with pseudonyms. Analysis and data collection were simultaneous allowing refinement of the topic guide and later data collection [28]. Data were entered into NVivo 10 and analysed thematically [29] permitting identification of both commonalities and differences between ethnic groups.

Using open coding, three members of the research team independently coded a selection of transcripts reading and re-reading them to ensure familiarity with the data. Open codes were then

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discussed by the research team and a preliminary coding framework developed. This was repeated with further transcripts and the categories identified were refined and reduced in number by grouping them together. Following development of the final framework, the remaining transcripts were coded and the original ones re-coded. All transcripts were analysed independently at least twice by two different researchers.

RESULTS

The seven focus groups averaged 80 minutes (50 to 90) and included between three and eight participants. In total there were 41 carers aged from 45 to 74 years. The majority (80%) were over 50. Approximately two-thirds were female and spouses. Two focus groups included only South Asian carers, two only white British carers and one only black African and black Caribbean participants. The remaining two focus groups included participants from several ethnic groups (Table 1).

Table 1: Participant demographics

Focus group (n)	Ethnic group (n)	Age category		Gender		Relationship	
		< 50 years	50+ years	Female	Male	Spouse	Other
1 (n=7)	Asian Indian (5) Asian Pakistani (2)	2	5	5	2	6	1
2 (n=7)	Asian Indian (7)	1	6	4	3	2	5
3 (n=5)	White British (5)	0	5	2	3	4	1
4 (n=3)	White British (3)	0	3	3	0	3	0
5 (n=7)	Black African (4) Black Caribbean (3)	3	4	5	2	2	5
6 (n=5)	Asian Pakistani (2) Asian Indian (1) Black Caribbean (1) White British (1)	0	5	3	2	4	1
7 (n=7)	Asian Indian (4) Black African (1) Black Caribbean (1) White British (1)	2	5	7	0	7	0

Total (n=41)		8	33	29	12	28	13

Several interconnected themes were identified. Some themes related specifically to ethnicity, culture and language but others highlighted common experiences across ethnic groups. These themes are described below with anonymised quotes.

The gap between hospital discharge and home

Irrespective of ethnic group, for most carers, the period after discharge following stroke was very difficult and was exacerbated by poor communication between services. Many carers were still suffering from the initial shock of the stroke and felt abandoned and ill-prepared. The apparent dearth of services after discharge left carers feeling lost and overwhelmed and the stark contrast between the support in hospital and limited community services, heightened their sense of abandonment.

> *'That panic sets in when you leave. It's like a bereavement leaving hospital.'* Graham, white British male

> *'When people are discharged there is definitely a gap. I mean I don't have an English or language problem but there is a big gap in the services once you've been discharged from hospital.'* Samiya, Asian Indian female

Carers often talked interchangeably about health and social care services sometimes struggling to distinguish between them. Overall, they saw the 'system' as confusing and opaque. Unfamiliar terminology made services difficult to navigate.

> *'... when you've come out of hospital, at first there's absolutely nothing ... Nobody tells you anything, or if they do, they are using terminology that you've never experienced before ... I didn't feel there was anybody there that spoke my language.'* John, white British male

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Carers as persistent advocates - knowing the system and fighting for support

In order to access services, carers across ethnic groups felt they had to fight 'the system'. They repeatedly commented on the necessity for 'speaking loudly', being tenacious and 'knowing the system'.

> *'If you don't make a song and a dance about ... you need to put yourself forward. And there are people who doesn't know, and they are not talking, so they are not getting any help. ... I sort of really fought for it... then the ball started rolling. .. I got my ramp...'* Upma, Asian Indian female

Carers often had multiple responsibilities and wanted increased support but felt their requests were ignored, either because services did not fully understand their difficult circumstances, or because they were deemed low priority.

> '*Mother had a hip replacement on a Wednesday, Dad had his by-pass on the Friday. I couldn't have anyone to look after her because all our family live far. So then I was constantly on the phone trying to get some help but they just don't listen, they don't care... well it's a priority thing, so obviously there's people worse off than you.'* Khayrah, Asian Indian female

Balancing the effort in accessing services with their needs and poor or unsuitable services

Carers from all the included ethnic groups reported that accessing and engaging with services required huge efforts. Their difficulties were exacerbated by unresponsive services and large amounts of paperwork. Communicating with service providers was very challenging leading to anger, stress and frustration furthering carers' already hard circumstances. Paperwork was described as lengthy and 'horrendous' adding to the considerable time required to access services. Assessments often came to nothing, adding to their frustration.

'The thing is, you pour your emotions out, but they just put it down on a paper. It's not the same … what I say & the way they write it down is two different things.' Sathinder, Asian Indian male

Stroke survivors' needs, choices and abilities played an important part in whether carers accessed services. Sometimes this related to stroke survivors' pre-stroke personality or age but often the stroke had affected what they benefitted from or enjoyed. For example, although support groups were generally viewed positively, carers sometimes highlighted post-stroke changes which made tolerating large numbers of people difficult.

'[After the stroke] my husband didn't like talking all the time or noise or anything.' Raameen, Asian Pakistani female

Once accessed, services were frequently seen as poor, adding to carers' ambivalence about using them.

'One girl came in and she took one rag. Mum had two face flannels. And I was looking at them, not saying anything. She washed [mimes washing her face]. The next thing you know, she went with the same rag, down [mimes washing bottom half of body.' Evelyn, black Caribbean female

This ambivalence meant they often gave up trying to access them.

'You get tired. Because many of the times, you call, and they don't give you the answer. They don't meet their promise. .. sometimes you reach a point where you get tired of it.' Marina, black African female

Persistence or abandoning efforts to access and engage with services was also influenced by carers' belief that they were the best person to care.

Carers as the best person to care

Carers from all ethnic groups, but particularly from BME groups, emphasised not only their desire to look after the stroke survivor but also the perception that they were usually the best person to care.

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This was explained by their unique, long-term relationship with stroke survivors and that they, unlike

paid care workers, genuinely care. This meant they were often ambivalent about asking for support.

'But what you have to do for your wife and parents, no one can care... I have a son... he suffers

from mental illness as well so I'm looking after two disabled people. But I'm happy. No

complaints. I'm very, very happy. I'm doing something for my family. As Peter (another

participant) *said 'What you can do for your relatives no one else can do. They [*care workers*]*

have no feeling.' Abdul, Asian Indian male

Another concern about paid care workers was their apparent constant rushing and the short time

allocated. As a result the care tasks were not done properly. Short visits also left limited time to

develop relationships and interact with stroke survivors which was particularly important if care

workers were providing personal care. In contrast, family members could take as long as needed.

'They are rushing. And they need to take time... and I say, 'Hold on. Patient with my mum,

she can't turn like that, take time.' Evelyn, black Caribbean female

Some BME carers saw their desire to care as culturally influenced.

'We're Muslims, so we do look after our elderly anyway at the end of the day. It's only in

extreme circumstances that they'll be put in to care homes.' Omar, Asian Indian male

This was also sometimes specifically related to cultural perceptions of family duty.

'In the end she's my wife. ... it's my responsibility to look after her.' Abdul Asian Indian male

'You worry for the partner. If one is weak you have to look after the other one. To do with

duty and love.' Raameen, Asian Pakistani female

However, other carers highlighted family relationships, rather than cultural expectations. This

participants emphasised she was doing what most wives would do.

'I mean we've never asked for anything, we've been married for 60 years and I just look after

him the best that I can.' Freda, white British female

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Cultural aspects of caring: ethnicity, culture, religion and language

Some discussions about social care were clearly and specifically related to ethnicity and culture. The

commonest of these concerned communication and accessing support in a second language. This

was usually, but not exclusively, discussed by South Asian carers and included not only language

differences but also other facets of communication.

> *'We are Guajarati and somebody coming in - English people - they don't understand same*
>
> *culture, same things.'* Chetna, Asian Pakistani female

Sometimes cultural differences related to the manner with which different groups communicated,

for example being uncomfortable talking about intimate health issues such as continence.

> *'I didn't know we could get pads on the NHS. For months and months we kept quiet and*
>
> *didn't tell anybody and we coped ourselves and it was very, very hard for my Dad …. We're*
>
> *very reserved people, Asian people, you know. And we don't know how to communicate, how*
>
> *to share information.'* Samiya, Asian Indian female

Differences in non-verbal styles of expression were mentioned by some black participants for

sometimes hampering rapport and interpersonal communication. Talking more loudly than other

ethnic groups was highlighted as potentially appearing rude.

> *'So there are differences between the black and the white culture... Because what I feel is*
>
> *respect, might not be respect for you. Or the way I would talk to you, another person might*
>
> *think 'Oh she is not respectful, she is not respecting me.''* Nancy, black Caribbean female

Amongst the Asian participants, having cultural backgrounds and languages in common with care

workers was perceived as facilitating communication and understanding. This made it easier for

carers to express their needs but it also influenced their trust in services.

> *'There are more and more agencies coming in now and they know the need of the Asians,*
>
> *and the other peoples. So they cater for the people… for instance my wife wants someone*

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Urdu speaking, or as the sister said [indicating another participant] Guajarati speaking.'

Abdul, Asian Indian male

Additionally care workers from their own culture were sometimes perceived as being more like

family members providing better, more caring support.

'We pay you money only but money is not only important. They give you heart as well. Love.

Just like daughter and Mum.' Chetna, Asian Pakistani female

Muslim carers emphasised that non-Muslim care workers often did not understand the importance

of their religious observances, highlighting praying and washing rituals. Employing Muslim care

workers made explanations unnecessary.

'So they [Non-Muslim care workers] *don't know about our needs, our religious needs and*

stuff like that. So obviously, like when she's trying to do her ablution she constantly has to

explain to them, what she needs to do and like they can't understand, they think it's a bit

stupid or a bit petty.' Khayrah, Asian Indian female

In some cases, carers described how short, rushed visits interfered with religious observances.

'They might have a 20 minute time slot to prepare her lunch. But if she's got to pray and

*she's got to go and do her Wudu [*washing ritual*] and she needs a bit of help... they are*

pushed for time.' Omar, Asian Indian male

However, other carers emphasised issues common to all service users and the importance of

treating everyone as individuals.

'How would we like to be treated? That's got to be the philosophy... 'What would I want?'

That should be the focus of it.' Peter, black Caribbean male

DISCUSSION

Carers from all included ethnic groups highlighted the challenges they face whilst simultaneously

emphasising their frequent ambivalence about accessing and engaging with services. The belief that

families are best placed to provide support for the stroke survivors and that services are frequently

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unsuitable, often resulted in failure to access or engage with services. Opaque systems, unfamiliar

terminology and onerous paperwork meant they were quick to abandon efforts to access support.

This struggle to access services can add to the 'burden' of their role [30] and may help explain carers'

reported low service uptake [15-17]. However, the tendency to perceive this as a problem situated

within carers rather than in service provision, needs to change. More attention should be directed at

unresponsive services failing to appreciate carers' changing needs and carers' huge efforts required

to access them. The negative impact on carers and consequent exhaustion and helplessness needs

to be better recognised. The period immediately following hospitalisation is often when carers need

most support, and yet this is when services are found most wanting. This service gap has been

identified before [31] but our research highlighted poor communication across and within health

and social care adding to the perceived gap. Improved multi-disciplinary working with all disciplines

working closely with carers prior to discharge is essential if the gap is to be bridged.

There were many similarities in experiences across ethnic groups here but the South Asian carers

stood out from other carers in several ways. Firstly, the additional challenges of accessing services in

a second language were highlighted. Secondly some Asian carers also said they would have

preferred support staff from their own cultural or religious backgrounds. This was expected to result

in greater understanding, respect and support for their religious observances but would also help

provide insight into cultural preferences in, for example, food preparation. However, matching care

worker religion or ethnicity may not always be practical and may set up false expectations. Indeed,

several participants expressed disappointment when such care workers had failed to live up to

expectations.

Explanations for why carers had taken on their caring role differed across ethnic groups. South Asian

participants tended to highlight their culture or religion. These participants emphasised 'duty', whilst

participants from other ethnic groups were more likely to suggest that this is what family members

do for each other. This is important because taking on a caring role out of duty rather than choice

and 'love' affect how the role is perceived in turn influencing support needs [32] and may

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additionally influence how long carers feel able to continue caring. It may also demonstrate how perceptions of cultural differences might be exaggerated in the literature. Even those carers here (mostly white British) who did not explicitly state that being a carer was their cultural duty or responsibility, were responding to their cultural norms. Families worldwide often take on caring roles and are usually unwilling to place family members in institutional care citing many reasons, not all explicitly culturally related. Rather than emphasising ethnic differences, it is important to value what carers do whilst recognising that many want the caring role and find it rewarding [33].

Strengths and limitations

Strengths of this study include the inclusion of white 'majority' participants which permitted direct comparison with minority ethnic group participants. The in-depth nature of the focus group discussions with over 40 participants also added to our understanding of their experiences with services. However, all focus groups were conducted in English excluding carers with limited or no English. This is important as these carers are likely to find accessing services more challenging than those with a good command of English. Participants were all recruited from the voluntary sector and had therefore engaged with services. Ideally future research would include carers who have not accessed any support services as this would add an important perspective. Finally, we only investigated five ethnic groups which are clearly very broad categories with inherent limitations.

Conclusions

In conclusion, older carers find interfacing with services challenging and need persistence and expertise to navigate the system and access support. Carers from all groups want to be treated as individuals whether this relates to their culture or other personal characteristics. The processes required to access services should be improved for carers from all ethnic groups but the extra challenges for carers from BME groups need recognition. Perhaps specific points in the caring trajectory, such as outpatient reviews, could be identified to ensure that carers are proactively asked about their support needs. Generally, carers want their role and feel they are best placed to

provide the individualised support their loved ones need. Services therefore need to demonstrate

how they can work with families to support them.

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Conflict of interests

None

Ethical approval

Disclaimer

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Authors' contributions

NG led the study in terms of design, analysis and writing the paper. JH, TE and NG collected and analysed the data. GM and GC supported the study design and were advisors to the project as it developed. All authors contributed to the manuscript draft and approved the final draft.

Data Sharing Statement

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No data are available to the unpublished data.

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ABSTRACT

Objectives: Informal carers, often family members, play a vital role in supporting stroke survivors with post-stroke disability. As populations age, numbers of carers overall, and those from minority ethnic groups in particular, are rising. Carers from all ethnic groups, but especially those from black and minority ethnic groups frequently fail to access support services making understanding their experiences important. The study therefore explored the experiences of carers aged 45+ years of stroke survivors from five ethnic groups in accessing and receiving social care services after discharge.

Design: This qualitative study used seven recorded focus groups with informal carers of stroke survivors. Data were analysed thematically focussing on similarities and differences between ethnic groups.

Setting: Carers were recruited from voluntary sector organisations supporting carers, stroke survivors and black and minority ethnic groups in the United Kingdom (UK).

Participants: Forty-one carers from five ethnic groups (Asian Indian, Asian Pakistani, black Africa, black Caribbean, white British) participated in the focus groups.

Results: Several interconnected themes including: the service gap between hospital discharge and home; carers as the best person to care and cultural aspects of caring and using services, were identified. Many themes were common to all the included ethnic groups but some related to specific groups.

Conclusions: Across ethnic groups there were many similarities in the experiences of older people caring for stroke survivors with complex, long-term care needs. Accessing services demands effort and persistence on carers' part. If carers believe services are unsatisfactory or that they, rather than formal services, should be providing support for stroke survivors, they are unlikely to persist in their efforts. Cultural and language differences add to the challenges black and minority ethnic group carers face.

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Key messages

- Ethnically diverse stroke carers have many experiences in common.

- These carers also share many challenges in accessing and engaging with services.

- Accessing services demands great effort and persistence by carers from all ethnic groups.

- Cultural and language differences add to the difficulties faced by minority ethnic carers.

Strengths and limitations

- We used a qualitative, in-depth approach with over forty participants giving a detailed understanding of these carers' experiences.

- We included both black and minority ethnic and white 'majority' participants which permitted direct comparison with minority ethnic group participants.

- However, all focus groups were conducted in English excluding carers with limited or no English. Finally, we only investigated five ethnic groups which are clearly very broad categories with inherent limitations.

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INTRODUCTION

Worldwide stroke is the major cause of long-term disability in adults [1] and leaves many stroke survivors dependent on their families (who are often referred to as carers or caregivers) [2]. Older people and those from black and minority ethnic (BME) populations are at increased risk of stroke [3,4] and as numbers of older people from diverse communities grow, it is becoming increasingly important to support the well-being of older, minority ethnic unpaid informal carers [5].

Systematic reviews of research investigating informal caring post stroke describe many challenges [6-8] and support needs shared by carers across ethnic groups and differing care systems [9]. Carers often report insufficient information and training about stroke and stroke services, particularly post-discharge from acute settings [10]. Reviews highlight reduced quality of life, hyper-vigilance, anxiety, depression and having to cope with role and identity changes [11-13]. A third of spousal carers report exhaustion and depression [14].

However, there is considerable evidence that in general carers' uptake of support services is low [15-17], even though using such services can make significant differences delaying transfer to long-term care [18] and improving carers' quality of life [19].

In developed countries, numbers of carers from BME groups in particular are rising as the demographic profiles of these populations age [20]. In the United Kingdom (UK) carers from BME groups provide proportionally more care than white British carers and are also more likely to suffer from ill health [21]. Despite this, evidence suggests that compared to their white counterparts, BME carers are less likely to use formal services [22], even though they express greater need for services [23,24].

Reasons for low service access are complex and multifaceted. For example, health and social care service uptake is influenced by cultural beliefs in terms of, for example, stigma associated with some health conditions [23]. A recent systematic review identified several main explanations for carers' failure to access and engage with services which included a mixture of attitudinal (e.g. a sense of duty) and practical explanations. Importantly, whilst such reasons may apply to all ethnic groups,

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their impact may be exacerbated by language difficulties or information provided in culturally inappropriate ways [25]. However, conclusions from research are limited by frequently failing to include majority groups for comparison, making it difficult to know if reasons for low uptake are restricted to minority ethnic groups or apply more widely.

The project therefore explored BME and white British carers' experiences of accessing and receiving social care services in the community, focussing on similarities and differences between ethnic groups.

METHODS

The research approach draws on ethnography with an emphasis on the meanings participants give to actions and behaviour [26] and attempts to ensure that what participants said was not taken out of context from what they had said previously or from what was said by others in the group. It was part of a larger qualitative project investigating carers' satisfaction with social care. Findings relating to the impact of the heterogeneity of the focus group participants on group interaction are reported elsewhere where the focus was on, for example, identifying consensus or disagreement amongst the participants, rather than focussing on the content as presented here [27].

Participants were recruited from voluntary organisations focussing on carers, BME groups or stroke survivors in and around London, UK. Some recruitment was face-to face with the researchers visiting the organisations during, for example, carer support groups. In other cases, the organisations distributed the study information and potential participants responded to them and they also set up the focus groups. Recruitment proved difficult because of their caring responsibilities therefore convenience sampling was used. To take part, participants had to be to be either currently or recently caring for stroke survivors living in the community. This could include family members or friends. They also needed to be and aged over 45 years old. This age group was selected to reduce some of the variability in the participants making comparison between the ethnic groups easier. They also had to self-identify as black African, black Caribbean, Asian Indian, Asian Pakistani, or

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white British, to have used social care, and. In this context, social care refers to support offered in the community by statutory, commercial and voluntary sectors and includes personal care, day centres, respite, and support groups. It includes both services aimed at supporting carers and the person they care for. It does not include services provided in long-term care facilities and care homes.

Focus groups were conducted in English, audio-recorded and facilitated by the research team using a topic guide. This guide was developed to improve understanding of carers' experiences of accessing and receiving services either for themselves or the person they cared for. The topics explored were broad and intended to help the participants describe and discuss their experiences in as little or as much detail as they wanted. Topics included participants' reflections of both how services may have changed over time and how services could be improved. Ethical approval for the study was obtained from the National Social Care Research Ethics Committee (ref: 12/IEC08/00) and written informed consent was obtained from all participants.

Audio recordings were transcribed verbatim and anonymised with pseudonyms by the research team and were checked for accuracy by others in the research team. Analysis and data collection were simultaneous allowing refinement of the topic guide and later data collection [28]. Data were entered into NVivo 10 and analysed thematically [29] permitting identification of both commonalities and differences between ethnic groups.

Using open coding, three members of the research team independently coded a selection of transcripts reading and re-reading them to ensure familiarity with the data. Open codes were then discussed by the research team and a preliminary coding framework developed. This was repeated with further transcripts and the categories identified were refined and reduced in number by grouping them together. Following development of the final framework, the remaining transcripts were coded and the original ones re-coded. All transcripts were analysed independently at least twice by two different researchers.

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RESULTS

The seven focus groups averaged 80 minutes (50 to 90) and included between three and eight participants. In total there were 41 carers aged from 45 to 74 years. The majority (80%) were over 50. Just over two-thirds were female (71%) and a similar proportion were spouses (68%). Others were primarily adult children or daughters-in-law. They had been carers for between 14 months and 20 years.

Two focus groups included only South Asian carers with an average of seven participants in each, two only white British carers (average four participants) and one only black African and black Caribbean participants (seven participants). The remaining two focus groups included participants from several ethnic groups (average six participants) (Table 1).

Table 1: Participant demographics

Focus group (n)	Ethnic group (n)	Age category		Gender		Relationship	
		< 50 years	50+ years	Female	Male	Spouse	Other
1 (n=7)	Asian Indian (5) Asian Pakistani (2)	2	5	5	2	6	1
2 (n=7)	Asian Indian (7)	1	6	4	3	2	5
3 (n=5)	White British (5)	0	5	2	3	4	1
4 (n=3)	White British (3)	0	3	3	0	3	0
5 (n=7)	Black African (4) Black Caribbean (3)	3	4	5	2	2	5
6 (n=5)	Asian Pakistani (2) Asian Indian (1) Black Caribbean (1) White British (1)	0	5	3	2	4	1
7 (n=7)	Asian Indian (4) Black African (1) Black Caribbean (1) White British (1)	2	5	7	0	7	0
Total (n=41)		8	33	29	12	28	13

Several interconnected themes were identified. Some themes related specifically to ethnicity, culture and language but others highlighted common experiences across ethnic groups. These themes are described below with anonymised quotes.

The gap between hospital discharge and home

Irrespective of ethnic group, for most carers, the period after discharge following stroke was very difficult and was exacerbated by poor communication between services. Many carers were still suffering from the initial shock of the stroke and felt abandoned and ill-prepared. The apparent dearth of both health and social care services after discharge left carers feeling lost and overwhelmed and the stark contrast between the support in hospital and limited community services, heightened their sense of abandonment.

> *'That panic sets in when you leave. It's like a bereavement leaving hospital.'* Graham, white British male

> *'When people are discharged there is definitely a gap. I mean I don't have an English or language problem but there is a big gap in the services once you've been discharged from hospital.'* Samiya, Asian Indian female

Participants frequently commented on poor communication both within and between services which hindered accessing support and widened the perceived service gap.

> *'… in this day and age, there's got to be notes passed on. Where is the computer? … Why is it that you speak to one social worker, it could be 'Oh she's on a course' or 'Oh she's away for a couple of days'. Before you know it, two or three days becomes two or three weeks, then it becomes a month.'* Omar, Asian Indian male

Carers often talked interchangeably about health and social care services sometimes struggling to distinguish between them. Overall, they saw the 'system' as confusing and opaque. Unfamiliar terminology made services difficult to navigate.

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'... when you've come out of hospital, at first there's absolutely nothing ... Nobody tells you anything, or if they do, they are using terminology that you've never experienced before … I didn't feel there was anybody there that spoke my language.' John, white British male

Carers as persistent advocates - knowing the system and fighting for support

In order to access services, carers across ethnic groups felt they had to fight 'the system'. They repeatedly commented on the necessity for 'speaking loudly', being tenacious and 'knowing the system'.

'If you don't make a song and a dance about ... you need to put yourself forward. And there are people who doesn't know, and they are not talking, so they are not getting any help. ... I sort of really fought for it... then the ball started rolling. .. I got my ramp...' Upma, Asian Indian female

Carers often had multiple responsibilities and wanted increased support but felt their requests were ignored, either because services did not fully understand their difficult circumstances, or because they were deemed low priority.

'Mother had a hip replacement on a Wednesday, Dad had his by-pass on the Friday. I couldn't have anyone to look after her because all our family live far. So then I was constantly on the phone trying to get some help but they just don't listen, they don't care... well it's a priority thing, so obviously there's people worse off than you.' Khayrah, Asian Indian female

Balancing the effort in accessing services with their needs and poor or unsuitable services

Carers from all the included ethnic groups reported that accessing and engaging with services required huge efforts. Their difficulties were exacerbated by unresponsive services and large amounts of paperwork. Communicating with service providers was very challenging leading to anger, stress and frustration furthering carers' already hard circumstances. Paperwork was

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described as lengthy and 'horrendous' adding to the considerable time required to access services. Assessments often came to nothing, adding to their frustration.

'The thing is, you pour your emotions out, but they just put it down on a paper. It's not the same ... what I say & the way they write it down is two different things.' Sathinder, Asian Indian male

Stroke survivors' needs, choices and abilities played an important part in whether carers accessed services. Sometimes this related to stroke survivors' pre-stroke personality or age but often the stroke had affected what they benefitted from or enjoyed. For example, although support groups were generally viewed positively, carers sometimes highlighted post-stroke changes which made tolerating large numbers of people difficult.

'[After the stroke] my husband didn't like talking all the time or noise or anything.' Raameen, Asian Pakistani female

Once accessed, services were frequently seen as poor, adding to carers' ambivalence about using them.

'One girl came in and she took one rag. Mum had two face flannels. And I was looking at them, not saying anything. She washed [mimes washing her face]. The next thing you know, she went with the same rag, down [mimes washing bottom half of body].' Evelyn, black Caribbean female

This ambivalence meant they often gave up trying to access them.

'You get tired. Because many of the times, you call, and they don't give you the answer. They don't meet their promise. .. sometimes you reach a point where you get tired of it.' Marina, black African female

Persistence or abandoning efforts to access and engage with services was also influenced by carers' belief that they were the best person to care.

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Carers as the best person to care

Carers from all ethnic groups, but particularly from BME groups, emphasised not only their desire to look after the stroke survivor but also the perception that they were usually the best person to care. This was explained by their unique, long-term relationship with stroke survivors and the belief that they, unlike paid care workers, genuinely care. This meant they were often ambivalent about asking for support.

> *'But what you have to do for your wife and parents, no one can care... I have a son... he suffers from mental illness as well so I'm looking after two disabled people. But I'm happy. No complaints. I'm very, very happy. I'm doing something for my family. As Peter* (another participant) *said 'What you can do for your relatives no one else can do. They* [care workers] *have no feeling.'* Abdul, Asian Indian male

Another concern about paid care workers was their apparent constant rushing and the short time allocated. As a result the care tasks were often perceived not to be done properly. Short visits also left limited time to develop relationships and interact with stroke survivors which was particularly important if care workers were providing personal care. In contrast, family members could take as long as needed.

> *'They are rushing. And they need to take time... and I say, 'Hold on. Patient with my mum, she can't turn like that, take time.'* Evelyn, black Caribbean female

Some BME carers saw their desire to care as culturally influenced.

> *'We're Muslims, so we do look after our elderly anyway at the end of the day. It's only in extreme circumstances that they'll be put in to care homes*.' Omar, Asian Indian male

This was also sometimes specifically related to cultural perceptions of family duty. During a discussion about their Asian culture, one wife said:

> *'You worry for the partner. If one is weak you have to look after the other one. To do with duty and love.'* Raameen, Asian Pakistani female

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However, other carers highlighted family relationships, rather than cultural expectations. This participants emphasised she was doing what most wives would do.

> *'I mean we've never asked for anything, we've been married for 60 years and I just look after him the best that I can.'* Freda, white British female

Similarly this man emphasised their relationship.

> *'In the end she's my wife. ... it's my responsibility to look after her.'* Abdul, Asian Indian male

Cultural aspects of caring: ethnicity, culture, religion and language

Some discussions about social care were clearly and specifically related to ethnicity and culture. The commonest of these concerned communication and accessing support in a second language. This was usually, but not exclusively, discussed by South Asian carers and included not only language differences but also other facets of communication.

> *'We are Guajarati and somebody coming in - English people - they don't understand same culture, same things.'* Chetna, Asian Pakistani female

Sometimes cultural differences related to the manner with which different groups communicated, for example being uncomfortable talking about intimate health issues such as continence.

> *'I didn't know we could get pads on the NHS. For months and months we kept quiet and didn't tell anybody and we coped ourselves and it was very, very hard for my Dad …. We're very reserved people, Asian people, you know. And we don't know how to communicate, how to share information.'* Samiya, Asian Indian female

Differences in non-verbal styles of expression were mentioned by some black participants for sometimes hampering rapport and interpersonal communication. Talking more loudly than other ethnic groups was highlighted as potentially appearing rude.

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'So there are differences between the black and the white culture... Because what I feel is respect, might not be respect for you. Or the way I would talk to you, another person might think 'Oh she is not respectful, she is not respecting me.'' Nancy, black Caribbean female

Amongst the Asian participants, having cultural backgrounds and languages in common with care workers was perceived as facilitating communication and understanding. This made it easier for carers to express their needs but it also influenced their trust in services.

*'There are more and more agencies coming in now and they know the need of the Asians, and the other peoples. So they cater for the people... for instance my wife wants someone Urdu speaking, or as the sister said [*indicating another participant*] Guajarati speaking.'*
Abdul, Asian Indian male

Additionally care workers from their own culture were sometimes perceived as being more like family members providing better, more caring support.

'We pay you money only but money is not only important. They give you heart as well. Love. Just like daughter and Mum.' Chetna, Asian Pakistani female

Muslim carers emphasised that non-Muslim care workers often appeared not to understand the importance of their religious observances, highlighting praying and washing rituals. Employing Muslim care workers made explanations unnecessary.

'So they [Non-Muslim care workers] *don't know about our needs, our religious needs and stuff like that. So obviously, like when she's trying to do her ablution she constantly has to explain to them, what she needs to do and like they can't understand, they think it's a bit stupid or a bit petty.'* Khayrah, Asian Indian female

On the other hand, care workers from their own ethnic background did not guarantee good support.

'... this lady, well she was Asian, from my own country. She was supposed to do the mopping in the kitchen... What she would do, she would just soak the mop in the kitchen sink instead of using the bucket.' Abdul, Asian Indian male

It was also suggested that care workers sometimes took advantage of families from their own

background, knowing they were less likely to complain if, for example, they left early.

> *'Afterwards I knew from other carers, he was doing it every job, you know. And because he*
>
> *was a Bengali, and he was working for other Bengali people... and they used to put up with it*
>
> *because he was the same ...'* Usha, Asian female

In some cases, carers described how short, rushed visits interfered with religious observances.

> *'They might have a 20 minute time slot to prepare her lunch. But if she's got to pray and*
>
> *she's got to go and do her Wudu [washing ritual] and she needs a bit of help... they are*
>
> *pushed for time.'* Omar, Asian Indian male

However, other carers emphasised issues common to all service users and the importance of

treating everyone as individuals.

> *'How would we like to be treated? That's got to be the philosophy... 'What would I want?'*
>
> *That should be the focus of it.'* Peter, black Caribbean male

DISCUSSION

Carers from all included ethnic groups highlighted the challenges they face whilst simultaneously

emphasising their frequent ambivalence about accessing and engaging with services. The belief that

families are best placed to provide support for the stroke survivors and that services are frequently

unsuitable, often resulted in failure to access or engage with services. Opaque systems, unfamiliar

terminology and onerous paperwork meant they were quick to abandon efforts to access support.

This struggle to access services can add to the 'burden' of their role [30] and may help explain carers'

reported low service uptake [15-17]. However, the tendency to perceive this as a problem situated

within carers rather than in service provision, needs to change. More attention should be directed at

unresponsive services failing to appreciate carers' changing needs and carers' huge efforts required

to access them. The negative impact on carers and consequent exhaustion and helplessness needs

to be better recognised. The period immediately following discharge from hospital is often when

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carers need most support, and yet this is when services are found most wanting. This service gap has

been identified before [31] but our research highlighted poor communication across and within

health and social care adding to the perceived gap. Improved multi-disciplinary working with all

disciplines working closely with carers prior to discharge is essential if the gap is to be bridged.

There were many similarities in experiences across ethnic groups here but the South Asian carers

stood out from other carers in several ways. Firstly, supporting earlier research [32] the additional

challenges of accessing services in a second language were highlighted. Secondly, again supporting

other research [33, 34] some Asian carers also said they would have preferred support staff from

their own cultural or religious backgrounds. This appeared to be particularly important when it came

to personal care and understanding, respecting and supporting their religious observances. It was

also expected to help provide insight into cultural preferences in, for example, food preparation.

However, matching care worker religion or ethnicity may not always be practical and it may be

worth considering it particularly in relation to personal care and religious observances. However this

sort of matching may set up false expectations. Indeed, several participants expressed

disappointment when such care workers had failed to live up to expectations.

Explanations for why carers had taken on their caring role differed across ethnic groups [35]. South

Asian participants tended to highlight their culture or religion. These participants emphasised family

'duty' as part of their culture or religion, whilst participants from other ethnic groups were more

likely to suggest that this is simply what family members do for each other, rather than having an

explicit cultural basis. This is important because taking on a caring role out of a sense of duty rather

than choice and 'love' affect how the role is perceived in turn influencing support needs [36].

Furthermore, this may have an impact on both initial attempts to access services and affect how

persistent carers are in remaining engaged with services. Additionally it may influence how long

carers feel able to continue caring at home. In relation to the literature, it may also demonstrate

how perceptions of cultural differences both in the reasons for taking on the caring role and, as a

consequence, accepting and engaging with services might be exaggerated in the literature. Even

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those carers here (mostly white British) who did not explicitly state that being a carer was their

cultural duty or responsibility, were responding to their cultural norms. Families worldwide often

take on caring roles and are usually unwilling to place family members in institutional care citing

many reasons, not all explicitly culturally related. Rather than emphasising ethnic differences, it is

important to value what carers do whilst recognising that many want the caring role and find it

rewarding [37].

Strengths and limitations

Strengths of this study include the inclusion of white 'majority' participants which permitted direct

comparison with minority ethnic group participants. The in-depth nature of the focus group

discussions with over 40 participants also added to our understanding of their experiences with

services. However, all focus groups were conducted in English excluding carers with limited or no

English. This is important as these carers are likely to find accessing services more challenging than

those with a good command of English. Participants were all recruited from the voluntary sector and

had therefore engaged with services. Ideally future research would include carers who have not

accessed any support services as this would add an important perspective. Finally, we only

investigated five ethnic groups which are clearly very broad categories with inherent limitations.

Conclusions

In conclusion, older carers find interfacing with services challenging and need persistence and

expertise to navigate the system and access support. Carers from all groups want to be treated as

individuals whether this relates to their culture or other personal characteristics. The processes

required to access services should be improved for carers from all ethnic groups but the extra

challenges for carers from BME groups need recognition. Perhaps specific points in the caring

trajectory, such as outpatient reviews like those undertaken in the UK regular intervals after

discharge [38], could be identified to ensure that carers are proactively asked about their support

needs.   Generally, carers want their role and feel they are best placed to provide the individualised

support their loved ones need. Services therefore need to demonstrate how they can work with

families to support them.

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Conflict of interests

No, there are no competing interests.

Ethical approval

Ethical approval was gained from the National Social Care Research Ethics Committee (ref: 12/IEC08/00).

Disclaimer

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Authors' contributions

NG led the study in terms of design, analysis and writing the paper. JH, TE and NG collected and analysed the data. GM and GC supported the study design and were advisors to the project as it developed. All authors contributed to the manuscript draft and approved the final draft.

Data sharing

No additional data available.

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A qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors

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A qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors

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ABSTRACT

Objectives: Informal carers, often family members, play a vital role in supporting stroke survivors with post-stroke disability. As populations age, numbers of carers overall, and those from minority ethnic groups in particular, are rising. Carers from all ethnic groups, but especially those from black and minority ethnic groups frequently fail to access support services making understanding their experiences important. The study therefore explored the experiences of carers aged 45+ years of stroke survivors from five ethnic groups in accessing and receiving social care services after hospital discharge.

Design: This qualitative study used seven recorded focus groups with informal carers of stroke survivors. Data were analysed thematically focussing on similarities and differences between ethnic groups.

Setting: Carers were recruited from voluntary sector organisations supporting carers, stroke survivors and black and minority ethnic groups in the United Kingdom (UK).

Participants: Forty-one carers from five ethnic groups (Asian Indian, Asian Pakistani, black Africa, black Caribbean, white British) participated in the focus groups.

Results: Several interconnected themes including: the service gap between hospital discharge and home; carers as the best person to care and cultural aspects of caring and using services, were identified. Many themes were common to all the included ethnic groups but some related to specific groups.

Conclusions: Across ethnic groups there were many similarities in the experiences of people caring for stroke survivors with complex, long-term care needs. Accessing services demands effort and persistence on carers' part. If carers believe services are unsatisfactory or that they, rather than formal services, should be providing support for stroke survivors, they are unlikely to persist in their efforts. Cultural and language differences add to the challenges black and minority ethnic group carers face.

Key messages

- Ethnically diverse stroke carers have many experiences in common.

- These carers also share many challenges in accessing and engaging with services.

- Accessing services demands great effort and persistence by carers from all ethnic groups.

- Cultural and language differences add to the difficulties faced by minority ethnic carers.

Strengths and limitations

- We used a qualitative, in-depth approach with over forty participants giving a detailed

  understanding of these carers' experiences.

- We included both black and minority ethnic and white 'majority' participants which

  permitted direct comparison with minority ethnic group participants.

- However, all focus groups were conducted in English excluding carers with limited or no

  English. Finally, we only investigated five ethnic groups which are clearly very broad

  categories with inherent limitations.

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INTRODUCTION

Worldwide stroke is the major cause of long-term disability in adults [1] and leaves many stroke survivors dependent on their families (who are often referred to as carers or caregivers) [2]. Older people and those from black and minority ethnic (BME) populations are at increased risk of stroke [3,4] and as numbers of older people from diverse communities grow, it is becoming increasingly important to support the well-being of older, minority ethnic unpaid informal carers [5].

Systematic reviews of research investigating informal caring post stroke describe many challenges [6-8] and support needs shared by carers across ethnic groups and differing care systems [9]. Carers often report insufficient information and training about stroke and stroke services, particularly post-discharge from acute settings [10]. Reviews highlight reduced quality of life, hyper-vigilance, anxiety, depression and having to cope with role and identity changes [11-13]. A third of spousal carers report exhaustion and depression [14].

However, there is considerable evidence that in general carers' uptake of support services is low [15-17], even though using such services can make significant differences delaying transfer to long-term care [18] and improving carers' quality of life [19].

In developed countries, numbers of carers from BME groups in particular are rising as the demographic profiles of these populations age [20]. In the United Kingdom (UK) carers from BME groups provide proportionally more care than white British carers and are also more likely to suffer from ill health [21]. Despite this, evidence suggests that compared to their white counterparts, BME carers are less likely to use formal services [22], even though they express greater need for support [23,24].

Reasons for low service access are complex and multifaceted. For example, health and social care service uptake is influenced by cultural beliefs in terms of, for example, stigma associated with some health conditions [23]. A recent systematic review identified several main explanations for carers' failure to access and engage with services which included a mixture of attitudinal (e.g. a sense of duty) and practical explanations. Importantly, whilst such reasons may apply to all ethnic groups,

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their impact may be exacerbated by language difficulties or information provided in culturally

inappropriate ways [25]. However, conclusions from research are limited by frequently failing to

include majority groups for comparison, making it difficult to know if reasons for low uptake are

restricted to minority ethnic groups or apply more widely.

The project therefore explored BME and white British carers' experiences of accessing and receiving

social care services in the community, focussing on similarities and differences between ethnic

groups.

METHODS

The findings reported here are part of a larger qualitative project investigating carers' satisfaction

with social care. Findings relating to the impact of the heterogeneity of the focus group participants

on group interaction are reported elsewhere where the focus was on, for example, identifying

consensus or disagreement amongst the participants, rather than focussing on the content as

presented here [26]. The research approach draws on ethnography with an emphasis on the

meanings participants give to actions and behaviour [27] and attempts to ensure that what

participants said was not taken out of context from what they had said previously or from what was

said by others in the group.

Participants were recruited from voluntary organisations focussing on carers, BME groups or stroke

survivors in and around London, UK. Some recruitment was face-to face with the researchers visiting

the organisations during, for example, carer support groups. In other cases, the organisations

distributed the study information and potential participants responded to them and they also set up

the focus groups. Recruitment proved difficult because of their caring responsibilities therefore

convenience sampling was used. To take part, participants had to be to be either currently or

recently caring for stroke survivors living in the community. This could include family members or

friends. They also needed to be aged over 45 years old. This age group was selected to reduce some

of the variability in the participants making comparison between the ethnic groups easier. They also

had to self-identify as black African, black Caribbean, Asian Indian, Asian Pakistani, or white British and to have used social care. In this context, social care refers to support offered in the community by statutory, commercial and voluntary sectors and includes personal care, day centres, respite, and support groups. It includes both services aimed at supporting carers and the person they care for. It does not include services provided in long-term care facilities and care homes.

Focus groups were conducted in English, audio-recorded and facilitated by the research team using a topic guide. This guide was developed to improve understanding of carers' experiences of accessing and receiving services either for themselves or the person they cared for. The topics explored were broad and intended to help the participants describe and discuss their experiences in as little or as much detail as they wanted. Topics included participants' reflections of both how services may have changed over time and how services could be improved. Ethical approval for the study was obtained from the National Social Care Research Ethics Committee (ref: 12/IEC08/00) and written informed consent was obtained from all participants.

Audio recordings were transcribed verbatim and anonymised with pseudonyms by the research team and were checked for accuracy by others in the research team. Analysis and data collection were simultaneous allowing refinement of the topic guide and later data collection [28]. Data were entered into NVivo 10 and analysed thematically [29] permitting identification of both commonalities and differences between ethnic groups.

Using open coding, three members of the research team independently coded a selection of transcripts reading and re-reading them to ensure familiarity with the data. Open codes were then discussed by the research team and a preliminary coding framework developed. This was repeated with further transcripts and the categories identified were refined and reduced in number by grouping them together. Following development of the final framework, the remaining transcripts were coded and the original ones re-coded. All transcripts were analysed independently at least twice by two different researchers.

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RESULTS

The seven focus groups averaged 80 minutes (50 to 90) and included between three and eight participants. In total there were 41 carers aged from 45 to 74 years. The majority (80%) were over 50. Just over two-thirds were female (71%) and a similar proportion were spouses (68%). Others were primarily adult children or daughters-in-law. They had been carers for between 14 months and 20 years.

Two focus groups included only South Asian carers with an average of seven participants in each, two only white British carers (average four participants) and one only black African and black Caribbean participants (seven participants). The remaining two focus groups included participants from several ethnic groups (average six participants) (Table 1).

Table 1: Participant demographics

Focus group (n)	Ethnic group (n)	Age category		Gender		Relationship	
		< 50 years	50+ years	Female	Male	Spouse	Other
1 (n=7)	Asian Indian (5) Asian Pakistani (2)	2	5	5	2	6	1
2 (n=7)	Asian Indian (7)	1	6	4	3	2	5
3 (n=5)	White British (5)	0	5	2	3	4	1
4 (n=3)	White British (3)	0	3	3	0	3	0
5 (n=7)	Black African (4) Black Caribbean (3)	3	4	5	2	2	5
6 (n=5)	Asian Pakistani (2) Asian Indian (1) Black Caribbean (1) White British (1)	0	5	3	2	4	1
7 (n=7)	Asian Indian (4) Black African (1) Black Caribbean (1) White British (1)	2	5	7	0	7	0
Total (n=41)		8	33	29	12	28	13

Several interconnected themes were identified. Some themes related specifically to ethnicity, culture and language but others highlighted common experiences across ethnic groups. These themes are described below with anonymised quotes.

The gap between hospital discharge and home

Irrespective of ethnic group, for most carers, the period after discharge following stroke was very difficult and was exacerbated by poor communication between services. Many carers were still suffering from the initial shock of the stroke and felt abandoned and ill-prepared. The apparent dearth of both health and social care services after discharge left carers feeling lost and overwhelmed and the stark contrast between the support in hospital and limited community services, heightened their sense of abandonment.

> *'That panic sets in when you leave. It's like a bereavement leaving hospital.'* Graham, white British male

> *'When people are discharged there is definitely a gap. I mean I don't have an English or language problem but there is a big gap in the services once you've been discharged from hospital.'* Samiya, Asian Indian female

Participants frequently commented on poor communication both within and between services which hindered accessing support and widened the perceived service gap.

> *'… in this day and age, there's got to be notes passed on. Where is the computer? … Why is it that you speak to one social worker, it could be 'Oh she's on a course' or 'Oh she's away for a couple of days'. Before you know it, two or three days becomes two or three weeks, then it becomes a month.'* Omar, Asian Indian male

Carers often talked interchangeably about health and social care services sometimes struggling to distinguish between them. Overall, they saw the 'system' as confusing and opaque. Unfamiliar terminology made services difficult to navigate.

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'... when you've come out of hospital, at first there's absolutely nothing ... Nobody tells you

anything, or if they do, they are using terminology that you've never experienced before … I

didn't feel there was anybody there that spoke my language.' John, white British male

Carers as persistent advocates - knowing the system and fighting for support

In order to access services, carers across ethnic groups felt they had to fight 'the system'. They

repeatedly commented on the necessity for 'speaking loudly', being tenacious and 'knowing the

system'.

'If you don't make a song and a dance about ... you need to put yourself forward. And there

are people who doesn't know, and they are not talking, so they are not getting any help. ... I

sort of really fought for it... then the ball started rolling. .. I got my ramp...' Upma, Asian

Indian female

Carers often had multiple responsibilities and wanted increased support but felt their requests were

ignored, either because services did not fully understand their difficult circumstances, or because

they were deemed low priority.

'Mother had a hip replacement on a Wednesday, Dad had his by-pass on the Friday. I

couldn't have anyone to look after her because all our family live far. So then I was constantly

on the phone trying to get some help but they just don't listen, they don't care... well it's a

priority thing, so obviously there's people worse off than you.' Khayrah, Asian Indian female

Balancing the effort in accessing services with their needs and poor or unsuitable services

Carers from all the included ethnic groups reported that accessing and engaging with services

required huge efforts. Their difficulties were exacerbated by unresponsive services and large

amounts of paperwork. Communicating with service providers was very challenging leading to

anger, stress and frustration furthering carers' already hard circumstances. Paperwork was

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described as lengthy and 'horrendous' adding to the considerable time required to access services. Assessments often came to nothing, adding to their frustration.

'The thing is, you pour your emotions out, but they just put it down on a paper. It's not the same ... what I say & the way they write it down is two different things.' Sathinder, Asian Indian male

Stroke survivors' needs, choices and abilities played an important part in whether carers accessed services. Sometimes this related to stroke survivors' pre-stroke personality or age but often the stroke had affected what they benefitted from or enjoyed. For example, although support groups were generally viewed positively, carers sometimes highlighted post-stroke changes which made tolerating large numbers of people difficult.

'[After the stroke] my husband didn't like talking all the time or noise or anything.' Raameen, Asian Pakistani female

Once accessed, services were frequently seen as poor, adding to carers' ambivalence about using them.

'One girl came in and she took one rag. Mum had two face flannels. And I was looking at them, not saying anything. She washed [mimes washing her face]. The next thing you know, she went with the same rag, down [mimes washing bottom half of body].' Evelyn, black Caribbean female

This ambivalence meant they often gave up trying to access them.

'You get tired. Because many of the times, you call, and they don't give you the answer. They don't meet their promise. .. sometimes you reach a point where you get tired of it.' Marina, black African female

Persistence or abandoning efforts to access and engage with services was also influenced by carers' belief that they were the best person to care.

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Carers as the best person to care

Carers from all ethnic groups, but particularly from BME groups, emphasised not only their desire to look after the stroke survivor but also the perception that they were usually the best person to care. This was explained by their unique, long-term relationship with stroke survivors and the belief that they, unlike paid care workers, genuinely care. This meant they were often ambivalent about asking for support.

> *'But what you have to do for your wife and parents, no one can care... I have a son... he suffers from mental illness as well so I'm looking after two disabled people. But I'm happy. No complaints. I'm very, very happy. I'm doing something for my family. As Peter* (another participant) *said 'What you can do for your relatives no one else can do. They [*care workers*] have no feeling.'* Abdul, Asian Indian male

Another concern about paid care workers was their apparent constant rushing and the short time allocated. As a result the care tasks were often perceived not to be done properly. Short visits also left limited time to develop relationships and interact with stroke survivors which was particularly important if care workers were providing personal care. In contrast, family members could take as long as needed.

> *'They are rushing. And they need to take time... and I say, 'Hold on. Patient with my mum, she can't turn like that, take time.'* Evelyn, black Caribbean female

Some BME carers saw their desire to care as culturally influenced.

> *'We're Muslims, so we do look after our elderly anyway at the end of the day. It's only in extreme circumstances that they'll be put in to care homes*.' Omar, Asian Indian male

This was also sometimes specifically related to cultural perceptions of family duty. During a discussion about their Asian culture, one wife said:

> *'You worry for the partner. If one is weak you have to look after the other one. To do with duty and love.'* Raameen, Asian Pakistani female

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However, other carers highlighted family relationships, rather than cultural expectations. This

participants emphasised she was doing what most wives would do.

> *'I mean we've never asked for anything, we've been married for 60 years and I just look after*
>
> *him the best that I can.'* Freda, white British female

Similarly this man emphasised their relationship.

> *'In the end she's my wife. ... it's my responsibility to look after her.'* Abdul, Asian Indian male

Cultural aspects of caring: ethnicity, culture, religion and language

Some discussions about social care were clearly and specifically related to ethnicity and culture. The

commonest of these concerned communication and accessing support in a second language. This

was usually, but not exclusively, discussed by South Asian carers and included not only language

differences but also other facets of communication.

> *'We are Guajarati and somebody coming in - English people - they don't understand same*
>
> *culture, same things.'* Chetna, Asian Pakistani female

Sometimes cultural differences related to the manner with which different groups communicated,

for example being uncomfortable talking about intimate health issues such as continence.

> *'I didn't know we could get pads on the NHS. For months and months we kept quiet and*
>
> *didn't tell anybody and we coped ourselves and it was very, very hard for my Dad …. We're*
>
> *very reserved people, Asian people, you know. And we don't know how to communicate, how*
>
> *to share information.'* Samiya, Asian Indian female

Differences in non-verbal styles of expression were mentioned by some black participants for

sometimes hampering rapport and interpersonal communication. Talking more loudly than other

ethnic groups was highlighted as potentially appearing rude.

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'So there are differences between the black and the white culture... Because what I feel is respect, might not be respect for you. Or the way I would talk to you, another person might think 'Oh she is not respectful, she is not respecting me.'' Nancy, black Caribbean female

Amongst the Asian participants, having cultural backgrounds and languages in common with care workers was perceived as facilitating communication and understanding. This made it easier for carers to express their needs but it also influenced their trust in services.

'There are more and more agencies coming in now and they know the need of the Asians, and the other peoples. So they cater for the people... for instance my wife wants someone Urdu speaking, or as the sister said [indicating another participant] Guajarati speaking.'
Abdul, Asian Indian male

Additionally care workers from their own culture were sometimes perceived as being more like family members providing better, more caring support.

'We pay you money only but money is not only important. They give you heart as well. Love. Just like daughter and Mum.' Chetna, Asian Pakistani female

Muslim carers emphasised that non-Muslim care workers often appeared not to understand the importance of their religious observances, highlighting praying and washing rituals. Employing Muslim care workers made explanations unnecessary.

'So they [Non-Muslim care workers] *don't know about our needs, our religious needs and stuff like that. So obviously, like when she's trying to do her ablution she constantly has to explain to them, what she needs to do and like they can't understand, they think it's a bit stupid or a bit petty.'* Khayrah, Asian Indian female

On the other hand, care workers from their own ethnic background did not guarantee good support.

'... this lady, well she was Asian, from my own country. She was supposed to do the mopping in the kitchen... What she would do, she would just soak the mop in the kitchen sink instead of using the bucket.' Abdul, Asian Indian male

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It was also suggested that care workers sometimes took advantage of families from their own background, knowing they were less likely to complain if, for example, they left early.

> *'Afterwards I knew from other carers, he was doing it every job, you know. And because he was a Bengali, and he was working for other Bengali people... and they used to put up with it because he was the same ...'* Usha, Asian female

In some cases, carers described how short, rushed visits interfered with religious observances.

> *'They might have a 20 minute time slot to prepare her lunch. But if she's got to pray and she's got to go and do her Wudu* [washing ritual] *and she needs a bit of help... they are pushed for time.'* Omar, Asian Indian male

However, other carers emphasised issues common to all service users and the importance of treating everyone as individuals.

> *'How would we like to be treated? That's got to be the philosophy... 'What would I want?' That should be the focus of it.'* Peter, black Caribbean male

DISCUSSION

Carers from all included ethnic groups highlighted the challenges they face whilst simultaneously emphasising their frequent ambivalence about accessing and engaging with services. The belief that families are best placed to provide support for the stroke survivors and that services are frequently unsuitable, often resulted in failure to access or engage with services. Opaque systems, unfamiliar terminology and onerous paperwork meant they were quick to abandon efforts to access support. This struggle to access services can add to the 'burden' of their role [30] and may help explain carers' reported low service uptake [15-17]. However, the tendency to perceive this as a problem situated within carers rather than in service provision, needs to change. More attention should be directed at unresponsive services failing to appreciate carers' changing needs and carers' huge efforts required to access them. The negative impact on carers and consequent exhaustion and helplessness needs to be better recognised. The period immediately following discharge from hospital is often when

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carers need most support, and yet this is when services are found most wanting. This service gap has

been identified before [31] but our research highlighted poor communication across and within

health and social care adding to the perceived gap. Improved multi-disciplinary working with all

disciplines working closely with carers prior to discharge is essential if the gap is to be bridged.

There were many similarities in experiences across ethnic groups here but the South Asian carers

stood out from other carers in several ways. Firstly, supporting earlier research [32] the additional

challenges of accessing services in a second language were highlighted. Secondly, again supporting

other research [33, 34] some Asian carers also said they would have preferred support staff from

their own cultural or religious backgrounds. This appeared to be particularly important when it came

to personal care and understanding, respecting and supporting their religious observances. It was

also expected to help provide insight into cultural preferences in, for example, food preparation.

However, matching care worker religion or ethnicity may not always be practical and it may be

worth considering it particularly in relation to personal care and religious observances. However this

sort of matching may set up false expectations. Indeed, several participants expressed

disappointment when such care workers had failed to live up to expectations.

As described elsewhere [35], explanations for why carers had taken on their caring role differed

across ethnic groups. South Asian participants tended to highlight their culture or religion. These

participants emphasised family 'duty' as part of their culture or religion, whilst participants from

other ethnic groups were more likely to suggest that this is simply what family members do for each

other, rather than having an explicit cultural basis. This is important because taking on a caring role

out of a sense of duty rather than choice and 'love' affect how the role is perceived in turn

influencing support needs [36]. Furthermore, this may have an impact on both initial attempts to

access services and affect how persistent carers are in remaining engaged with services. Additionally

it may influence how long carers feel able to continue caring at home. In relation to the literature, it

may also demonstrate how perceptions of cultural differences both in the reasons for taking on the

caring role and, as a consequence, accepting and engaging with services might be exaggerated

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in the literature. Even those carers here (mostly white British) who did not explicitly state that being a carer was their cultural duty or responsibility, were responding to their cultural norms. Families worldwide often take on caring roles and are usually unwilling to place family members in institutional care citing many reasons, not all explicitly culturally related. Rather than emphasising ethnic differences, it is important to value what carers do whilst recognising that many want the caring role and find it rewarding [37].

Strengths and limitations

Strengths of this study include the inclusion of white 'majority' participants which permitted direct comparison with minority ethnic group participants. The in-depth nature of the focus group discussions with over 40 participants also added to our understanding of their experiences with services. However, all focus groups were conducted in English excluding carers with limited or no English. This is important as these carers are likely to find accessing services more challenging than those with a good command of English. Participants were all recruited from the voluntary sector and had therefore engaged with services. Ideally future research would include carers who have not accessed any support services as this would add an important perspective. Finally, we only investigated five ethnic groups which are clearly very broad categories with inherent limitations.

Conclusions

In conclusion, older carers find interfacing with services challenging and need persistence and expertise to navigate the system and access support. Carers from all groups want to be treated as individuals whether this relates to their culture or other personal characteristics. The processes required to access services should be improved for carers from all ethnic groups but the extra challenges for carers from BME groups need recognition. Perhaps specific points in the caring trajectory, such as post-stroke reviews like those undertaken in the UK regular intervals after discharge [38], could be identified to ensure that carers are proactively asked about their support needs. Generally, carers want their role and feel they are best placed to provide the individualised

support their loved ones need. Services therefore need to demonstrate how they can work with

families to support them.

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Conflict of interests

No, there are no competing interests.

Ethical approval

Ethical approval was gained from the National Social Care Research Ethics Committee (ref: 12/IEC08/00).

Disclaimer

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Data sharing

No additional data available.

Authors' contributions

NG led the study in terms of design, analysis and writing the paper. JH, TE and NG collected and analysed the data. GM and GC supported the study design and were advisors to the project as it developed. All authors contributed to the manuscript draft and approved the final draft.