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**Title:** The human dimensions of post-stroke homecare: Experiences of older carers from diverse ethnic groups

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## **Abstract**

**Purpose:** Very little is known about how older people from black and minority ethnic (BME) groups caring for someone after a stroke access and engage with social care services. This paper explores both the experiences of carers whose relative was receiving social care services in their own home and the value of a theory of humanising care to understand and explain these experiences.

**Method:** Semi-structured interviews were undertaken with 50 carers from five different ethnic groups: Asian Indian, Asian Pakistani, Black African, Black Caribbean and White British. Data were thematically analysed within a phenomenological framework.

**Results:** Five interacting themes emerged: Communication and bureaucracy; time and timing; communication and rapport building; trust and safety; humanity and the human dimensions of care. Many of the experiences could be interpreted within a conceptual framework of humanising care underpinned by eight interacting dimensions of what it means to be treated as an individual and human.

**Conclusions:** Carers from BME and White British groups share many experiences of homecare although language and cultural difference may exacerbate common pressures and stresses. The framework for humanising care is a useful tool to evaluate aspects of home care that are responsive to dignity and diversity.

Keywords: stroke, ethnicity, carers, social care, humanising care

### **Implications for rehabilitation**

- Explicitly identifying, describing and valuing the human dimensions of care may support services to respond appropriately to homecare users from minority ethnic communities as well as those from white majority groups

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- Unresponsive services and poor communication may lead to loss of trust with care agencies and undermine BME carers' sense of entitlement and competence in engaging with homecare services
- Care worker continuity and investing time in building relationships and careworker familiarity is important to many families who access social care services.
- Building strong interpersonal relationships with consistent careworkers is especially significant for carers of stroke survivors from different language backgrounds or those who have post-stroke communication difficulties

## **Introduction**

Stroke is the major cause of complex long-term disability in adults in the United Kingdom (UK) [1] and worldwide [2]. Older people and those from a range of black and minority ethnic (BME) populations are at increased risk of stroke [3,4]

Researching the relationship between impairments acquired later in life and their impact on the everyday life and wellbeing of first generation migrants represents an important new research challenge [5]. As populations of older people from diverse communities increase, an escalating priority is to maintain the wellbeing of older informal carers [6], by offering support that is culturally appropriate as well as being person and family-centred [7-9]. The difficulties of developing effective models of self-management for people living with long term conditions in the community [10,11], whilst responding to the needs of growing numbers of older carers and shrinking social care budgets [12] represents a major challenge for health and social care policy and systems [13].

This paper describes the experiences of older carers (45 years or older) from five different ethnic groups (Asian Indian, Asian Pakistani, Black African, Black Caribbean and White British) who have a family member receiving social care in their own homes after a stroke. For the purposes of this paper, the term 'carer' refers to people who provide unpaid care and support, usually to a family relative or close friend. We use 'careworker' to refer to paid carers who are employed by agencies, councils, social services or on a private basis to provide support for activities such as washing, dressing and meal preparation.

### **Caring after stroke**

Stroke has lasting effects on the physical, social, emotional and psychological wellbeing of both those who experience a stroke and their families [14]. Those caring for individuals who have had a stroke face a complex array of challenges as a consequence of the multi-faceted and long-term nature of stroke impairments. Community dwelling carers of people with stroke frequently report less satisfaction with community services than services received in the acute stage of illness [15]. Many long-term carers of people with stroke perceive that the pressures of caring increase rather than diminish over time [16,17].

Systematic reviews of qualitative and quantitative studies of caring after stroke highlight a range of recurring issues and coping challenges [18-20]. These support needs are common across countries and care systems [21]. Carers report insufficient information and training about stroke and stroke care services, particularly post-discharge from acute settings [17,22]. High levels of anxiety and stress are commonplace as carers deal on a long-term basis with change and uncertainty [19,23]. Carers also face major role and identity changes [24,25] and many spousal carers describe feeling trapped at home as they suppress their own needs, often adopting hyper-vigilant behaviours as a way to manage their caring situation [26]. Depression and exhaustion has been reported by one third of spousal carers, with some indication that this may increase as carers themselves age [27]. Some carers,

and particularly those of people with post-stroke communication difficulties, also report growing isolation that may mirror the diminished social activity and social participation of the person directly experiencing the stroke [24, 26, 28]. This, in turn, may reduce carers' access to social support and impact negatively on their coping and wellbeing [20].

### **Ethnicity and caring after stroke**

Informal carers from BME groups provide more unpaid care and experience worse health outcomes than majority White populations [29] yet are less likely to access formal health and social care services [30, 31]. They are also more likely to describe their experiences of services as less satisfactory than White British service users [32]. Stereotyped assumptions about minority ethnic groups preferring to care for disabled relatives within the family have been widely discredited in favour of more complex and diverse interpretations of informal caring [33,34]. For example, in addition to the importance of family and cultural beliefs, barriers to engaging with statutory care services may include perceptions of need, individual coping styles, poor information and concerns about the quality of care services [31]. However there is evidence to suggest that people from BME populations provide more informal care than white carers [7] and have stronger beliefs regarding filial obligations of care [35]. Currently, people from minority ethnic groups are under represented in cardiovascular research [36] yet may have higher levels of unmet needs [37].

Studies exploring BME carers' experiences highlight the importance of communication, trust and attention to personal caring preferences if services are to respond in meaningful and culturally appropriate ways [34,38]. Language and culture are cited as important barriers to access, particularly where older people (and /or their family carers) are not fluent in English [38] and may have difficulties reading, writing or using the telephone [31]. In some respects carers from BME groups share features of carers of people with aphasia, where

communication difficulties exacerbate difficulties experienced by carers of stroke survivors in general [39], for example, accessing information, training and support [24, 40].

Shared language and culture is acknowledged as a powerful tool in facilitating strong caring relationships between service users and service providers and many older carers from culturally and linguistically diverse backgrounds express a preference for ethno-specific and multi-cultural support services [41]. However whilst language differences and the need to be sensitive to translational issues are important, most reports caution against drawing simplistic conclusions about the role of language in engaging with services [38, 42]. There is recognition within policy and practice that increasing mainstream access to truly person-centred care that is flexible and culturally sensitive will support the wellbeing of all groups of informal carers [43].

### **Lifeworld-led approaches to care and support**

One potential approach to developing meaningful understanding of carers' experiences of engaging with caregiving services is to use a lifeworld approach [44]. Grounded in a phenomenologically inspired philosophy of what it means to be human, a lifeworld-led approach is concerned with articulating the nature and practices of humanly sensitive care [45]. Intertwining dimensions of the lifeworld: temporality, spatiality, intersubjectivity, embodiment and mood, form the foundations for articulating the shared and unique dimensions of illness and/or caring experiences [46]. Thus, a lifeworld-led approach champions the human individual and exposes practices that tend to depersonalise or dehumanise those receiving care. This may occur, for example, through practices driven more by organisational priorities, system-led categories and bureaucratic processes than concerns for unique human experience.

Lifeworld-led care also has a strong emphasis on interconnectedness and relational understandings of rehabilitation and social care rather than individualised approaches that prioritise the needs of the stroke survivor. An over-emphasis on person or client-centred care has meant that services often struggle to negotiate the complex dual roles of carers as both co-workers and co-clients [47]. Lifeworld-led approaches have been used to explore the experiences of being a close relative of a person with a stroke and/or aphasia [48-50]. These have tended to emphasize the existential dimensions of caring such as changed identity, existential loneliness and the challenges of acting as a bridge between isolated stroke survivors and their surrounding world [49]. To our knowledge, no lifeworld-led studies have focussed on the experiences of older carers from BME populations receiving home-based social care after stroke.

The conceptual framework of Todres et al. (2009) [51] describes a set of values underpinning both what it means to be human and ways services meet people in their humanising/ dehumanising experiences of using health and social care. The authors describe eight humanising dimensions of care: agency/passivity; insiderness/ objectification; uniqueness/homogenisation; togetherness/isolation; sense making/loss of meaning; personal journey/loss of personal journey; sense of place/dislocation; and embodiment/reductionist view of the body. Todres and colleagues argue these dimensions are not distinct entities or polar opposites. Rather each imply one another in an interconnected way with positive and negative values representing a means of emphasising possibilities along a scale of more or less humanising experience. They further suggest these dimensions may prove useful when considering how well services respond to both individual vulnerability and relational, existential wellbeing as service users engage with care services. The framework therefore offers a more theoretically grounded approach to understanding experiences of dignity.

## **Aim**

This paper explores the post-stroke experiences of older carers from BME and White British populations receiving home care. A secondary aim was to consider how well the framework for humanising care [51] might act as a tool to understand and explain these experiences and potentially help services to identify and develop homecare support that is responsive to the needs of older carers in culturally sensitive ways.

## **Methods**

Ethical approval was granted from the National Social Care Research Ethics Committee (ref: 12- IEC08-0003).

Data reported here represent a secondary analysis of data gathered for a large study exploring satisfaction with social care services. The secondary analysis was conducted by the first author, who had full access to the whole data set.

## **Participants and recruitment**

Participants came from 11 voluntary sector organisations and a local hospital stroke unit. Inclusion criteria required participants to self identify as Asian Indian, Asian Pakistani, Black African, Black Caribbean or White British. They had to be over 45 years old and with either current or recent (over the last two years) experience of caring for community dwelling stroke survivors. Fifty of the 57 participants in the original study had direct experience of using home care services. Data from the other seven carers are not included here.

## **Data collection**

Carers were interviewed using a semi-structured interview schedule. This covered exploration of experiences of using social care and used the critical incident technique [52, 53] and cognitive interviewing [54,55]. The critical incident technique encouraged carers to

describe examples of satisfactory and unsatisfactory incidents relating to experiences of accessing and using social care. The ‘think aloud’ technique [55] employed in cognitive interviewing enabled carers to provide richer, more detailed descriptions of both their expectations and actual experiences of social care. Interviews were undertaken in a place of the carers’ choice, usually their homes, and were audio-recorded and transcribed verbatim. Interviews were conducted in English, though on one occasion an interpreter was also present to offer communication support. Data were entered into N-Vivo 10 data management software [56] to support data management and retrieval.

### **Data analysis**

The first author reviewed the transcripts of participants with experience of receiving social care services at home, identified data extracts referring specifically to homecare and carried out a six-phase thematic analysis [57] on these data consistent with a phenomenologically informed approach. Phenomenology seeks to understand how individuals experience and make sense of their personal and social worlds [58]. It concerns existential issues, and key lifeworld themes such as lived space, lived body, lived time and lived relations [59]. These issues help shape a lens through which to analyse data and review themes.

Following familiarization with data and generation of initial codes, an iterative process of revisiting data and meaningful patterns of data identified potential themes and conceptual relationships. These initial themes were reviewed against data and where necessary revised or reworked. Key themes were defined and named and the scope and internal consistency of themes were checked against the data extracts referring to homecare. In the final stage of the thematic analysis [57], a narrative account consistent with the study’s main research questions was produced illustrating themes with participant quotes and stories.

Consistent with the 'reductive-reflexive dance' [60] (p 81) of the phenomenological attitude, the researcher approached the data with openness, empathy and an iterative, reflexive interrogation of assumptions and early understandings. Findings relating to the homecare data were also fully discussed with NG, the Chief Investigator on the original research study, to check understandings and contextualise emerging themes within the broader data set.

## **Findings**

Interviews lasted 45 minutes on average. Thirty-two women and 18 men described experiences of using home care services during their interview. Participants ranged between 45 and 91 years of age. Relationships with the person with stroke were predominantly partner or spouse (30), though participants also included, adult children (15), parents (2), daughter in laws (2) and a sibling (1). Seven participants were non-resident with the stroke survivor.

Insert table 1 about here

Amounts of home care accessed ranged from two hours per week, to up to four visits daily, to 24/7 live-in care. A majority of participants had experience of interacting with different agencies and a range of careworkers.

Five overarching and interconnected themes were prominent in the data regarding participants' experiences of social care in the home setting:

- Difficulties communicating with opaque and bureaucratic systems
- The impacts of time and timing
- Communication and rapport with careworkers
- Trust and safety

- Humanity and humanly sensitive social care

Anonymised quotes are provided below with pseudonyms.

### **Communication and bureaucracy**

Regardless of ethnicity, many carers described significant information barriers at the point of access. Although interviews focused on experiences of social care, many participants had difficulty understanding the distinctions between health and social care staff and services. In some instances, carers felt well-informed by hospital social workers and early supported discharge or reablement teams about finding support at home. However, many carers who embarked on accessing homecare described not knowing what to ask, what support they might be entitled to or where to find help. The process of trying to find out what was available left many feeling abandoned and ill-equipped to participate in informed decision-making about care.

And um, everybody that I go to send me somewhere else. In the end it pitter out. Nobody bother about it at all. (Paulina: Black Caribbean, wife, 76-80, cohabiting)

I think they should have, the ethnic minorities, the ones who cannot speak English, should have a, a carer of, an Asian carer, or whatever who can explain them, in their language, clear. You know, that this is what you can get ... from us. This is what's provided, it's up to you whether you want it or you don't want it. (Sachi: Asian Indian, wife, 71-75, cohabiting)

Social care systems were frequently described as intimidating and alien with structural barriers imposed by unclear criteria, apparently evasive staff and impenetrable terminology.

I found it intimidating trying to access benefits, trying to access information. And so somebody that didn't have that background and wasn't necessarily particularly

intelligent or intellectual it must be a huge thing to overcome. (David: White British, husband, 61-65, cohabiting)

Social care has its own language, which if you don't use, if you don't say you don't, they cannot understand you. (Abeje: Black African, wife, 45-49, cohabiting)

Social care jargon and unnecessary layers of bureaucracy were perceived to keep carers at arms' length and could also undermine carers' self-confidence.

Explaining things well to me in lay terms. Not using jargon. Because sometimes they come, I don't know if, not intentional that you will not understand. But not coming from that world, they use their words or abbreviation. And then you would not, I didn't have erm, how would I say? Oh, confidence. To ask questions. And then when they've gone, I start to wondering, what did they say to me? So I am confused. So that's what happened with my mum. I didn't have confidence to talk to them. (Nancy: Black African, daughter, 50-55, not cohabiting)

In response to this, some participants, particularly female carers from Black African and Black Caribbean groups described how, over time, they taught themselves to 'speak' social care language and develop a more assertive, direct style of communication.

It seems to be like your volume mattered - your volume or your banging on the table or something mattered to how you've got action. (Vivienne: Black Caribbean, daughter, 50-55, not cohabiting)

You have to be bold enough to have the confidence to say okay, I need this, and you know your rights. If people don't know their rights they won't have services. (Tenneh, Black African, wife, 66-70, cohabiting)

Assessment processes were frequently cited as a stressful, impersonal experience disconnected from their everyday reality of caring, and governed by pre-determined categories rather than individuality.

The thing is, you pour your emotions out, but they just put it down on a paper. It's not the same. And then when they read it, they don't see the emotional side and the, you know, the other stress side of that, you know. They only see what the person, and what I say and the way they write it down is two different things. You know, you're talking with tears, they're just writing down what they hear. (Sathinder: Asian Indian, husband, 50-55, cohabiting)

Its just quick, quick. Already typed, they just ticking. (Abeje: Black African, wife, 50-55, cohabiting)

Carers from all ethnic groups, including White British, highlighted difficulties following the 'language' of assessments. Difficulty using and understanding English exacerbated these communication barriers. Lack of linguistic and cultural support with paperwork sometimes reduced access to potentially valuable and more ethnically specific choices, such as using direct payments from social care budgets to arrange and pay for care independently.

I mean in terms of erm recruiting personal assistants from the BME community for people that need them. Direct payments, loosely it works but ... .. I found it a real challenge trying to make people from the BME Communities understand what exactly what the direct payments is a lot of people can't read or write English and so they find the paper work ... awful, erm and you'll really push encourage people to take up those personal you know personalised budgets and things but there's no support there for people that can't do the paper work. (Shabnam: Asian Indian, daughter-in-law, 50-55, cohabiting)

The paucity of services available in different languages highlighted inequalities in service provision. However, lacking fluency in English also made complaining more difficult.

Salma [carer]: I was frightened. I can't do fighting.

Interviewer: Yeah.

Husband [stroke survivor] She's not the fighting type.

Salma: Because I have a foreign language.

Husband: She can only fight me that's it (laughs).

Salma: I can't fight in English language. So it's difficult for me.

(Salma: Asian Pakistani, wife, 50-55, cohabiting)

### **The impacts of time and timing**

Across all ethnic groups time and timing was raised repeatedly as a major frustration and stressor. This related both to delays in accessing information and in acquiring feedback about the progress of claims for care support. Carers described having to make repeated calls to check what was happening. Not understanding why delays were occurring could fuel participants' suspicions about council motives. For example, some carers questioned whether saving money was the hidden agenda behind these delays, further undermining their trust in the process of social care assessment and allocation. Carers described their confusion where communication and home care services stopped and started apparently at random.

It does come in stops and starts and we don't know exactly why they are stopping at a particular time or starting at a particular time.

(Tina: Black African, sister, 56-60, not cohabiting)

In addition to heightening distress, lack of timely feedback caused some carers to give up or begin to question their own competence as communicators.

It would take days before anybody would speak to you and they didn't know anything about you, you'd have to go through the whole thing, and as it is you're distressed and you want something done. And sometimes you just give up you know. (Usha: Asian Indian, wife, 71-75, cohabiting)

Interviewer: What do you think is the, has the most impact on you?

Samiya: This complete um, not getting back to me. Not replying to me, yeah? Ignoring me and making me feel that I'm incont..., incompetent... in, in communicating with normal people. (Samiya: Asian Indian, daughter, 50-55, not cohabiting)

When care routines eventually became established, some carers contrasted the short, fleeting visits of care staff to their own 24-hour routines. Many carers described how their own timetables as well as the stroke survivors' were constrained and dominated by care visits. Careworkers arriving late or the arrival of an unfamiliar careworker added to fatigue and could compound already strained domestic relationships.

And we keep ringing them 'Oh we'll be there in 5 minutes ... Oh we will be there'...and that builds up the tension in the house and then we [carer and stroke survivor] start arguing. (Upma: Asian Indian, wife, 50-55, cohabiting)

Morning different face, lunch time different face. From Monday to Friday sometimes they turn up, they don't turn up. (Ada: Asian Indian, wife, 50-55, cohabiting)

Every day this is a new story. They send in every day a new person I had to train. It's a bad headache.' (Banjeet: Asian Indian, wife, 71-75, cohabiting)

Timekeeping and the way careworkers used allocated care time in a flexible, responsive way was one of the most frequently cited causes of satisfaction or dissatisfaction with careworkers. Keeping carers waiting, or uninformed about delays was frequently perceived as undermining their sense of control as well as reflecting lack of respect for the comfort and dignity of stroke survivors.

It was at the timing, inconsistent times you see. So you'd be sitting there and waiting for them. (Stuart: Black Caribbean, son, 50-55, cohabiting)

My wife was not happy with those people. Because first of all they were not, never on time. And she's very particular with her timings. (Abdul, Asian Pakistani, husband, 71-75, cohabiting)

I tell them, 'Take your time, don't rush Ola', you know. So that she's not then forced to do things quickly. Because Ola has to take her time to do things. (Abike: Black African, mother 66-70, not cohabiting)

### **'It was very important to connect with someone': Communication and rapport building**

At an interpersonal level, many participants talked about how communication and rapport between careworkers and the family affected by stroke played a critical role in successful homecare. Careworkers who established personal rapport and integrated friendly, caring conversation into the routine of personal care were perceived as valuable resources to the general health and social wellbeing of the stroke survivor. Done skilfully this could distract the stroke survivor from the difficulty of dependence, and gently reassure the carer.

It's always nice to see people, you know, cracking jokes and having a laugh and that kinda takes his mind away from the situation. (Baako: Black African, daughter, 61-65, not cohabiting)

It was very important to connect with someone. It's not all about just sending anyone in. You have to understand ... the person you're working with. (Samiya: Asian Indian, daughter, 50-55, not cohabiting)

They talk to him while they're doing wash... he talks to him how he feels, 'OK?', when turning him and everything, 'Are you comfortable or not?' This, that, you know. While washing him they communicate as well. (Kalyn: Asian Indian, wife, 56-60, cohabiting)

Participants described the high value they placed on careworkers who shared a similar language and cultural background with the stroke survivor. In many cases this was perceived to stimulate rapport building and trust, and help them 'fit in' with the family. For example, seeing that a careworker prepared food appropriately or incorporated time for prayers into personal care routines was reassuring to carers.

Very good. Very good because she liked reading her bible and they will read a passage for her and sometimes it's a laugh. They say they're getting good training with her and the bible. (Evelyn, Black Caribbean daughter, 71-75, not cohabiting)

Yeah. Not um, but if anybody come I don't mind. But we are, but our people are, very satisfied, you know. Same language, same food, same things, you know? (Chetna: Asian Indian wife, 70-75, cohabiting)

The challenge of establishing good relationships with careworkers was described as more complex and time-consuming where stroke survivors had post-stroke communication difficulties or where they or the careworkers spoke little English. In both cases this added to the stress experienced by carers especially where careworkers were new and unfamiliar

and did not have the necessary time to get to know the cared for persons' needs and ways. Whilst having homecare provided by trained and consistent carers was a critical issue for most participants, this was particularly important when stroke survivors had impaired language or were unable to use English.

You know yesterday she (careworker) rang me 15 times because she couldn't understand what mum was saying...she can't make herself understood so that frustrates her even more then she lashes out and gets really aggressive. So then 15 time in a day is a lot of phone calls you know and you have to be responsive all the time ...and then as soon as you can you sort of go out there and seeing what's going on. (Shabnam: Asian Indian, daughter in law, 50-55, not cohabiting)

The carers get to know her and they can understand her.., they know her, they understand them and everything. So they, they follow along with her. (Cecil, Black Caribbean, husband, 91-95, cohabiting)

### **Trust and safety**

Trust was perceived to operate both at a system and interpersonal level. Some carers made references to feeling disbelieved and worrying that services and others viewed them as 'scroungers' or as someone taking advantage of welfare benefits. Several participants described how this perception increased their discomfort and difficulty in communicating with social care gatekeepers and undermined their sense of entitlement, despite a long history of contributing to work and taxation in the UK.

Sometimes I feel, well you're not understanding what I am saying. You know, if I said to you well look I need, but you still got to do your assessment, you know, you as if I'm disbelieve. The help I need, I don't need it... ...You know what I mean. It makes you feel that way. (Rosa: Black Caribbean, wife, 66-70, cohabiting)

I say to myself, 'Do they think I might be trying to take something from the government?' 'It's my home I should do this'. That battle in your mind. (Nancy: Black African, daughter, 50-55, not cohabiting)

Many carers linked a perception of trust in those providing personal care with a sense that their relatives were more likely to be safe from falls, accidents or emotional abuse. For some carers, trust was a powerful counterbalance to feelings of vulnerability and fear that pervaded their experience as a carer.

When we are ill, your trust is gone, you don't trust anybody. You know, so um if you see somebody, like somebody speak your language, somebody you know you think, 'Oh that, you know I'm safe' 'Oh, somebody's here with me', you know. (Tina: Black African, sister, 56-60, not cohabiting)

In some cases, trust or lack of trust with/in careworkers was grounded in previous experiences of health and social care provision. Not trusting others to care properly led some to feel they themselves were always the best carers and therefore had to take on the full caring role themselves.

I felt alienated and I felt not really trusting. I didn't trust them with my dad. As soon as he was able to come out I said I would take over the care, which was horrendous, because I was working full time. (Vivienne: Black Caribbean, daughter, 50-55, not cohabiting)

Carers reported having less confidence in new careworkers or those who lacked personal rapport with the stroke survivor. Trust on the other hand was built over time and with demonstrated proof of reliability.

We were, first few weeks, we were off. We were looking after her and staying there, whatever, but once we realised they'd come on time and she was happy with them,

rather than her sons taking her to the bathroom and things like that, which isn't so nice, I had full trust in them, they were good. (Sadar: Asian Indian, son, 61-65, not cohabiting)

Where trust was high and carers felt the stroke survivor could be safely left alone with careworkers, they described precious moments of everyday relief and respite that punctuated daily routines of concerned hyper-vigilance.

Because as long as he comes here I don't have to worry about Augustus until I'm ready to give him his breakfast. (Paulina: Black Caribbean, wife, 76-80, cohabiting)

And mum liked her, although um, sometimes she just sat and mum slept in her chair. But at least for me it was a relief to know that I wasn't going to come back and find mum in a state or, or anything like that. (Dorothy: White British, daughter, 50-55, not cohabiting)

### **Humanity and humanly sensitive social care**

Carers described a range of careworker behaviours that fell short of expectations of dignity and respect. Aside from keeping vulnerable people waiting and uncomfortable, these behaviours included taking personal phone calls whilst working, two carers talking over a stroke survivor in their own language, rushing stroke survivors through personal care routines, and careworkers using a single flannel for intimate washing and washing the stroke survivor's face.

Whilst describing their perceptions about good careworkers and systems of social care, many carers referred to people and practices that went beyond the practical and the clerical to the human. Such caring practices were those where careworkers responded to service users on a human level rather than treating them as anonymous cases or numbers.

I found that with them [poor agency] the whole erm thing about caring is *caring* whereas this was just clerical. You approached them and they treated it like a clerical worker. (Usha: Asian Indian, wife, 71-75, cohabiting)

More humanly sensitive care was not always easy to put into words, though the perception of something more meaningful was palpable for some participants.

It's deeper. It's hard to explain but there's much more deeper. (Tenneh: Black African, wife, 66-70, cohabiting)

Mmm. I think it's more about the people providing the care. I think they seem to relate to Louis very well and there isn't that kind of formal distance between them. They are kind of very friendly. (Fred: Black African, son, 61-65, not cohabiting)

For some, this depth was linked to careworkers passing time companionably in culturally attuned activities.

He loves to play dominoes, my husband, he sometimes he play by himself because there's nobody else to play with him. So one of the carers that comes, he's from Caribbean and he, he also love dominoes. So after he finish doing what he have to do for him, he'll sit with him, maybe just for fifteen minutes and play dominoes with him... And he's happy, you'll hear him laughing, you know, bantering together, yeah he loves that. I like that. (Tenneh: Black African wife, 66-70, cohabiting)

For others it went beyond routine care tasks to careworkers offering something additional which carers valued as directed at them rather than the stroke survivor, such as helping hang out the towels or engaging in reciprocal acts of kindness.

When it was my birthday they both [careworkers] gave me birthday cards which I thought was wonderful ...and, er, they wrote a lovely message in it...and said words

like we come in and you're like a mother to us. (Marjory: White British, wife, 76-80 cohabiting,)

A greater sense of togetherness and connection were grounded in fitting in with the family system.

He [careworker] just came here and fit into the house. And this chap now is the same thing, fit into the house. Yeah. (Paulina: Black Caribbean, wife, 76-80, cohabiting)

Some participants held clear views about caring not being just a job but a way of being. Beyond the practical work, good careworkers demonstrated 'heart' and 'humanity'.

That carer he used to come he was a caring person he loved his job, to him money wasn't there. He cared for people so he would do it, so he made sure he dressed him properly his shirt wouldn't be out, he shaved, he combed his hair and made sure because he doesn't know he is ... His carer make him look presentable, that's the caring role, you see? They need to take people that care about the job, to care about other people this is what the caring is all about the people who care about other people. (Upma: Asian Indian wife, 50-55, cohabiting)

Because they speaking my language and er, kind of heart to helping. It's work but their helping is more in their nature, they have more humanity. (Chetna: Asian British Indian, wife 71-75, cohabiting)

A number of participants questioned the nature and quality of careworker training. One woman described how employing careworkers through direct payments gave her the opportunity to coach careworkers in the art of caring as opposed to performing functional tasks driven by time and money.

Um, it gave me the space to monitor them and train them closely. And it gave me the space to teach them that social care is not all about making money, they have to really be able to do care work, not just quick, something you will do quick, quick and run away. (Abeje: Black African, wife, 45-49, cohabiting)

### **Relevance of the humanising care framework**

Carers in this study identified numerous experiences resulting from their interactions with homecare services that were consistent with the eight dimensions of the Todres et al. framework [51]. Illustrative examples of more (or less) humanising dimensions of social care are presented in table 2.

Insert table 2 about here.

Several of the dimensions were particularly salient. A number of carers spoke of how managing to access and care for their relative aided by careworkers employed through direct payments, developed a sense of agency and being in control. They had greater control over the cultural and language background of careworkers and the timing of visits as well as, in some cases, customising careworker training to meet their relative's needs. Aside from heightened sense of familiarity (Sense of Place) and cultural sensitivity (Togetherness) enjoyed by both stroke survivor and carer, some carers described how personal budgets also enabled them to access more care for their money.

They understand her religious and personal needs ...they understand that she needs to pray five times a day so they will help her to do that. They will prompt her to say her prayers...So generally she gets a lot more and the carers don't need to be told because they understand. (Huzaifah: Asian Indian, son, 61-65, and Ikram: daughter-in-law, 56-60, not cohabiting)

Communication struggles with care staff could amplify the embodied experience of caring as being both physically exhausting and emotionally humiliating and leave carers feeling services showed no understanding of their situation (Sense making/ Loss of meaning).

The way I was treated the way I was spoken to I felt horrible. I felt almost like I was begging for help and it wasn't being giving to me. It was awful, it was a horrible experience...I know what is there and yet I still struggled so it made me feel really awful. (Shabnam: Asian Indian, daughter-in-law, 50-55, not cohabiting)

Carers appreciated careworkers who were sensitive to the unique personality and needs of the stroke survivor rather than those considered to provide a more homogenised form of homecare.

Rather than having you know strict guidelines 'This is what they can do and this is what they can't do' just let them go in and whatever the needs are for that person, just to get on with it, just to get on with it. (Shahnaz: Asian Pakistani, daughter, 50-55, not cohabiting)

Another dimension prominent in the homecare data was the way careworkers were described as 'fitting in' and enabling a Sense of Place rather than Dislocation. Whilst shared language and culture facilitated this, it was also evidenced through careworkers' friendly manner or the skilful way they normalised potentially difficult care routines (see Baako above). An aspect of Embodiment concerned the way care went beyond a focus on the body, attending to the social wellbeing of the stroke survivor and their engagement with the world.

Person doesn't speak the language, you still have to communicate with them. To learn to treat them as human beings. To talk to them properly...Now that doesn't mean you shut them off or you put them in the corners for one hour, two hours a

day. Now you provide care that actually allows them to communicate and use their day. (Sadar: Asian Indian, son, 61-65, not cohabiting)

## **Discussion**

As suggested by Todres et al., [52] the humanising values framework was supportive both in illustrating the range of humanising and dehumanising features of homecare and in offering an evaluative basis from which to envisage different possibilities along a spectrum of care. Understanding experiences of social care which take account of agency, mood, identity and feelings of kinship and belonging [61] may offer practice-based directions for responding to the shared and unique expectations of dignity expressed by diverse ethnic minority groups who access social care [62].

Whilst the framework for reviewing humanising elements of care work shares characteristics of person-centred care for those with long-term conditions [8], lifeworld-led care with its existential view of what it means to be human may offer additional insights for what constitutes human-centred social care [44, 46].

One salient phenomenological concept in this context is the experience of being 'at home'. Heidegger described the phenomenon of 'not being at home in the world' as a potential consequence of illness and poor health [63]. The often relentless effort of full-time caring for participants in this study associated with feelings of anxiety, fatigue and isolation and the drastically changed rhythm of life could be seen as 'unhomelike attunement' [64 p 95]. For some carers in this study, the creation of alien, institution-like homes was reinforced by the presence of special beds and hoists, as well as the invasive presence of careworkers. Friendly, competent, reliable careworkers who acknowledge and support the carer (and the cared for person's) being in the world, and find ways to 'fit in' may support a more meaningful, balanced, rhythm of life and the possibility of some regained sense of being 'at

home'. Conversely, care that reinforces experiences of isolation, and anxiety, or transforms home space and personal routines to disorientating, other-centred activity may trap carers in the perpetual discomfort of 'unhomelikeness'.

Given the need to tailor home care to the unique social and cultural worlds of the stroke survivor, carer and family environment the humanising framework may enable care providers to deliver services that meaningfully explore the possibilities of recreating homelikeness in the context of the limitations imposed by the nature of stroke. Examples in this study were embodied by expressions of relief and respite when home caring was provided in a skilled and humanly sensitive manner, or when personal budgets enabled carers to employ careworkers from the same language and cultural background facilitating trusting relationships, and social connectedness as well as some restored sense of control.

Our findings resonate with evidence that current policy rhetoric of supporting carers as partners can be at odds with many carers' experiences of engaging with support services [13]. Many of the additional struggles expressed by carers in this study relating to poor access, lack of continuity, inflexibility, and difficulties communicating with and navigating opaque systems of care have been highlighted in previous studies of informal caring in BME populations [34, 42, 65]. The inclusion of White British carers here corroborates findings that experiences of poor communication and difficult navigation are common to many carers irrespective of language and cultural background [65,66]. However the study also highlights how language and cultural barriers can widen the communication gap and exacerbate feelings of dissatisfaction and alienation.

The experiences described here align with other reports where older carers perceive services as largely determined and controlled by available resources and budgets rather than the priorities of service recipients [12,38]. For some participants in this study, mistrust

between provider agencies and carers also seemed fuelled by prominent media discourses about 'benefit scroungers' and the negative portrayals of the impact of wide scale immigration on services. This running internalised dialogue became a further barrier for some BME carers when engaging with care services and systems.

### **Limitations**

The relatively small numbers of carers in the five ethnic groups may have obscured some of the diversity and heterogeneity that exists within each of these ethnic groups [67]. The study focused on carers from BME groups and did not explore other important ethnic groups within the populations covered by super-diversity [68], for example minority groups from Eastern European and Latin American countries. However, the similarity of issues shared by older carers from BME and White British groups suggest many of the challenges of caring for a relative post-stroke are common to all irrespective of ethnicity.

Participants were predominantly recruited via voluntary sector organisations and may be more representative of groups and individuals who have successfully negotiated access issues or are better informed and rehearsed in expressing arguments [69]. The interviewers were White British females and interviews were conducted in English, though interpreting services were offered. There are advantages and disadvantages to researchers sharing a language and cultural background with participants from BME populations requiring a careful, reflexive approach throughout all aspects of the research process [70]. A potential advantage of researchers from different ethnic backgrounds is the ability for interviewers to ask more naïve questions so that participants respond with more detailed, explanatory accounts that do not assume shared cultural knowledge [71,72].

The findings reported here relate to a secondary analysis of the data. A weakness of secondary analysis is that analysts may lack knowledge of the earlier study's context and

conceptualisation [73]. However, the authors of this paper were involved, throughout the first round of data analysis. The secondary analysis was directly prompted by the numerous examples relating specifically to homecare and humanising aspects of care that were identifiable in the primary data, suggesting the importance of examining these areas in more detail. Future research would benefit from an explicit focus on experiences of homecare together with a longitudinal perspective on the impact of care services on carers coping strategies and wellbeing [20].

## **Conclusions**

Participants in this study described the significant value they placed on information and navigation skills acquired through contact with peers and carers in similar situations. Before carers lose contact with health services and at any follow-up reviews it is important that these support and advocacy networks are promoted and valued. The additional communication and information barriers faced by some carers from BME groups suggest that they may require more time and skilled one-to-one brokerage about understanding and utilizing systems of arranging and paying for their own care and support services through direct payments and personal budgets [74].

This paper also outlined the possibilities of using the humanising care framework [51] as a backdrop to understanding experiences of vulnerability, agency and connectedness of older carers from diverse communities. Further work is required with a more explicit focus on how the theory of humanising care [51] can best support the growing statutory and private need for delivering homecare that engages carers as partners in care as well as attending to their wellbeing. Careworkers are uniquely placed to help 'restore' or conversely to 'rupture' experiences of dignity in the home [75]. This paper has suggested that post-stroke, older carers engaging with home care services encountered a mixed range of experiences. Expectations of caring interactions based on respect, dignity and safety were not always

met. Our findings suggest that more attention to making the humanising (and dehumanising) dimensions of social care visible and explicit may support the delivery of more humanly and culturally sensitive homecare.

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