

The human dimensions of post-stroke homecare: Experiences of older carers from diverse ethnic groups in the UK

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Overview



- ▶ **Background**
 - Stroke & being an older carer

- ▶ **Our study**
 - Methods (secondary analysis)
 - Findings
 - Abeje, the wife of a stroke survivor
 - Themes highlighting humanly sensitive care

- ▶ **Conclusions & recommendations**

Definitions

- ▶ **Black & minority ethnic groups (BME):** Asian Indian, Asian Pakistani, Black African & Black Caribbean
- ▶ **Care workers:** paid carers who provide e.g. support with washing, dressing & meal preparation
- ▶ **Stroke survivors:** someone who has had a stroke
- ▶ **Social care services:** support offered in the community by statutory, commercial & voluntary sectors (e.g. personal care, day centres, respite & support groups) to support carers and/or the person they care for

Stroke & stroke carers



- ▶ 15,000,000 strokes annually worldwide
- ▶ Short & long term effects e.g. physical, cognitive, communication, social & emotional
- ▶ Many stroke survivors depend on others – often carers
- ▶ Challenges for carers include:
 - Depression, anxiety, hyper-vigilance & tiredness
 - Uncertainty
 - Reduced quality of life



Recruitment, methods & analysis

- ▶ Recruitment
 - SE England, charities & a stroke unit
- ▶ Recorded semi-structured interviews
 - Explored experiences of social care
 - Usually in English, usually in carers' homes
 - Averaged 45 minutes
- ▶ Thematic analysis in Nvivo focused on
 - Experiences of homecare informed by lifeworld-led approach to humanly sensitive care (Todres *et al.* 2009)



Dimensions of humanisation

- ▶ Todres & colleagues argue their lifeworld-led approach goes beyond patient centred care. It emphasises well-being & relationships (especially in understanding & ‘expertise’) between professionals & care recipients
- ▶ 8 values/dimensions of what it means to be human e.g.
 - **Uniqueness – Homogenisation**
Uniqueness: ‘met’ as a unique individual ↔
Homogenisation: emphasis on fitting into a particular group
 - **Togetherness – Isolation**
Togetherness: sense of belonging & human connectedness ↔
Isolation: separated from or feeling alienated from others
 - **Agency – Passivity**
Agency: having choice & freedom ↔
Passivity: externally imposed attitudes & practices render the person passive

Todres *et al.* (2009)

Participants & themes

- ▶ Carer participants (n=50)
 - 45–91 years
 - 64% females
 - 60% spouses & 30% adult children
 - 76% Black & minority ethnic
 - 24% White British
- ▶ Selected linked themes
 - Continuity, communication & rapport with care workers
 - Continuity, relationships & trust
 - Interconnecting theme – humanly sensitive social care

Anonymised quotes follow with pseudonyms

Abeje: a Black African carer

'I've got a very positive experience out of this... on one occasion when the lady came (from her BME support group) & met me, with all my attention based on caring, she advised me to go to the local college to try & see what I can do to help myself, because I was just sitting down at home being a carer to my husband which might not take me anywhere...

So I got a joint degree, nursing & social work & that was because of the support I was getting... But that wasn't so positive until, I took up the direct payment. So I could employ the carers (careworkers) that my husband can cope with because after the stroke he lost some of his English... because I could employ carers (care workers) from my Nigerian background, who were especially Igbo. So when he mixes things up, they will understand him... with direct payment I can actually tell the carer to stay an hour & a half, or two & a half hours & give him simple massage. Like in our own culture there is a particular cream we believe so much to use it to massage people that had a stroke. It's called shea butter. So, some people that are not from an African background, might not understand it... maybe they won't like to touch it, because it's not very good looking. When I have carers from my background, it's easy for them to support him & give him simple massage.

My husband wants his meal prepared fresh. So, with direct payment, I can actually extend a particular carer, I can actually tell him or her to stay for four hours at a time. Rather than people just coming in & out of our house... My husband doesn't like female carers so I look for male carers that will come in to support him.'

Communication & rapport

- ▶ Rapport & communication between care workers & the family were vital to satisfactory homecare but were hampered by poor continuity
- ▶ Personal rapport & friendly, caring conversation integrated into personal care were highly valued for stroke survivors' health & wellbeing, with a positive impact on carers

'It's always nice to see people cracking jokes & having a laugh & that kind of takes his mind away from the situation.' Baako, Black African wife

Continuity & relationships

- ▶ New care workers added stress & anxiety

'Every day this is a new story. They send in every day a new person that I had to train. It's a bad headache.' Banjeet, Asian Indian wife

'You know yesterday she (the care worker) rang me 15 times because she couldn't understand what Mum was saying... Mum can't make herself understood so that frustrates her even more. Then Mum lashes out & gets really aggressive ... so 15 times in a day is a lot of phone calls & you have to be responsive all the time... as soon as you can, you are over there & seeing what's going on.' Ikram, Asian Indian son

- ▶ In contrast, continuity meant

'The carers get to know her & they can understand her & everything. So they follow along with her.' Cecil, Black Caribbean husband

Trust

- ▶ Not trusting others to care properly led many carers to feel that only they could care & that they had to take on the entire caring role

'I felt alienated & I felt not really trusting. I didn't trust them with my Dad. As soon as he was able to come out, I took over his care, which was horrendous as I was working full-time.'
Vivienne, Black Caribbean daughter

- ▶ Over time where relationships developed & care workers were trusted, carers felt able to leave stroke survivors alone with care workers giving valued relief & respite

'For the first few weeks, we were looking after her & staying there. But once we realised she was happy with them, rather than her sons taking her to the bathroom & things like that, which isn't so nice, I had full trust in them, they were good.'
Omar, Asian Indian son

Humanity & humanly sensitive care



- ▶ Humanly sensitive care centred around relationships between carers, care workers & stroke survivors. Care workers' attitudes & personality were central

'Because they speaking my language & have kind of heart. It's work but helping is more in their nature, they have more humanity.'

Chetna, Asian Indian wife

- ▶ Some care workers responded to stroke survivors more as human beings rather than focussing on mechanical aspects of care

'They talk to him while they're doing his wash... He (the care worker) talks to him & asks how he feels, when turning him & everything, 'Are you comfortable?' This & that, while washing him they communicate as well.' Kalyn, Asian Indian son

Humanity & humanly sensitive care cont

- ▶ For some care workers, it was not *'just a job'*. In addition to practical work, good care workers demonstrated *'heart'* & *'humanity'* & *'went the extra mile'*

'It's not part of the job but he take the towel & dry it out for me, you know. Rather than just leave it there for me to take it out... when he finish, he'll sit there patiently & wait for him to finish, because he's very slow, he doesn't have to wait for him, but he still sits down & waits.' Tenneh, Black African wife

'He made sure he dressed him properly – his shirt wouldn't be out, he shaved him, he combed his hair & made sure (because he doesn't know) ... that he looked presentable, that's the caring role, you see? They need people that care about the job, that care about other people.' Upma, Asian Pakistani wife

Lifeworld-led approach

The lifeworld-led approach gives us several important foci

- ▶ **Uniqueness:** 'met' as a unique individual ↔ **Homogenisation:** emphasis on fitting into groups
Some carers felt they were seen as unique individuals. In contrast, others highlighted tick-box assessments
'You pour your emotions out, but they just put it down on a paper. It's not the same... They don't see the emotional side... what I say & the way they write it down is two different things. You're talking with tears, they're just writing down what they hear.' Sathinder, Asian Indian husband
- ▶ **Togetherness:** sense of belonging & human connectedness ↔ **Isolation:** separated from or feeling alienated from others
Carers often enjoyed camaraderie with care workers. This was linked to trust & shared cultural understanding
'My husband loves to play dominoes... One of the carers - he's from the Caribbean & he also loves dominoes. So after he finish doing what he have to do for him, he'll sit with him, maybe just for 15 minutes & plays dominoes with him... And he's happy, you'll hear him laughing, you know, bantering together. He loves that. I like that.' Tenneh, Black African wife
- ▶ **Agency:** having choice & freedom ↔ **Passivity:** externally & internally imposed attitudes & practices render the person passive
Choice & control over care workers & their timing, e.g. direct payments, gave choice & freedom for a life outside caring for some carers
- ▶ *'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 and run away.'* Abeje, Black African wife

Conclusions

- ▶ **There is a lot of good care worker support – we can learn from this**
- ▶ **The lifeworld-led framework of humanising care adds to our understanding of experiences of homecare highlighting examples of humanly sensitive care**
 - It emphasises the relational human to human aspects of care with implicit incorporation of respect & dignity for both users & care workers
- ▶ **Continuity is central**
 - Poor continuity hinders trust & the development of relationships & is therefore important to all users but is particularly significant to BME users & people with communication or cognitive difficulties
 - Having to build new relationships repeatedly is detrimental for everyone
- ▶ **Treating people as individuals with humanity & dignity is essential**
 - If done correctly, individual needs, whether related to stroke impairments or coming from BME groups would be met
 - The humanity of carers, those they care for & of care workers needs greater recognition. This would improve the experiences of carers, users & care workers

Thank you for listening

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Ethical approval

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