The human dimensions of homecare following a stroke: experiences of older family carers from diverse ethnic groups

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Overview

- Overall aim of presentation
  - To demonstrate how the humanising care framework can be useful for understanding & providing homecare

- Background to the study
  - Unpaid, informal or family carers
  - Stroke
  - Importance of the experiences of older, black & minority ethnic (BME) carers

- The framework of humanising care (Todres et al. 2009)

- Study details
  - Methods (secondary analysis)
  - Findings
    - A positive experience
    - Linked themes highlighting the dimensions of humanly sensitive care

- Conclusions & implications
Definitions

- **Carers** – someone who provides unpaid care & support, usually to a relative or friend
- **Care workers** – paid caregivers who provide e.g. support for washing, dressing & meal preparation
- **Black & minority ethnic (BME) groups** – Asian Indian, Asian Pakistani, Black African or Black Caribbean
- **Stroke survivors** – someone who is living with the effects of a stroke
Stroke, BME groups & social care

- Strokes are common
- They are a leading cause of disability (1/3 of stroke survivors depend on others)
- Stroke risk increases with age (doubles each decade after 55 years)
- BME populations are at increased risk of stroke
- Being a carer of stroke survivors can be challenging
- Compared with White British carers, BME carers:
  - provide more informal care
  - are less likely to access health & social care
  - are more likely to rate services as unsatisfactory
Humanising care approach  
(Todres et al. 2009)

- This approach is grounded in a phenomenologically inspired philosophy of what it means to be human & is concerned with identifying the nature & practices of humanly sensitive care.

- It emphasises people as individuals & can help identify practices that dehumanise care recipients. E.g. practices not concerned with unique human experience but driven by organisational priorities & bureaucratic processes.

- Lifeworld led care stresses interconnectedness & relational understandings of care rather than individualised approaches prioritising the care recipient.

- Emphasis on care recipients/client-centred care can mean services struggle to negotiate the complex, dual roles of family carers as both co-workers & co-clients.
Dimensions of humanisation (Todres et al. 2009)

- Todres & colleagues’ framework describes a set of values underpinning both what it means to be human & ways services can provide humanising or dehumanising experiences with health & social care
- Eight humanising care dimensions:
  1. Uniqueness/Homogenisation
  2. Agency/Passivity
  3. Togetherness/Isolation
  4. Sense of place/Dislocation
  5. Insiderness/Objectification
  6. Sense making/Loss of meaning
  7. Personal journey/Loss of personal journey
  8. Embodiment/Reductionist view of the body
- Not polar opposites but interconnected implying one another with positive & negative values representing a scale of more or less humanising experiences
Dimensions of humanisation (Todres et al. 2009)

- **Uniqueness – Homogenisation**
  - **Uniqueness**: ‘met’ as a unique individual ↔ **Homogenisation**: emphasis on fitting into a particular group

- **Agency – Passivity**
  - **Agency**: having choice & freedom ↔
  - **Passivity**: externally & internally imposed attitudes & practices making the person passive

- **Togetherness – Isolation**
  - **Togetherness**: sense of belonging & human connectedness ↔
  - **Isolation**: separated from or feeling alienated from others

- **Sense of place – Dislocation**
  - **Sense of place**: sense of familiarity, security, & ‘at-homeness’ ↔
  - **Dislocation**: feelings of not fitting in, feeling a stranger in your home or a stranger when exposed to unfamiliar routines & cultures
Study aims & recruitment

- **Aims:** to explore the experiences of stroke carers from diverse ethnic groups using social care (homecare) using qualitative methods

- **Recruitment:** 11 voluntary organisations & 1 hospital stroke unit
  - *Inclusion criteria:* currently or recently caring for a stroke survivor; 45+ years old; Black African, Black Caribbean, Asian Indian, Asian Pakistani or White British
Methods & participants

- Recorded semi-structured interviews exploring experiences of care
  - In English, usually in carers’ homes
  - 45 minutes average
  - Transcribed & entered into NVivo 10

- Participants (50)
  - 32 females, 18 males
  - 45 – 91 years
  - Mostly spouses (30) & adult children (15)
  - 21 South Asian (Asian Indian & Asian Pakistani)
  - 17 Black (Black African & Black Caribbean)
  - 12 White British
Data analysis

- Phenomenology seeks to understand how individuals experience & make sense of their personal & social worlds
- A phenomenologically informed lifeworld led lens was used to analyse data using a thematic approach
- After data familiarisation, initial codes were generated
  - an iterative process revisiting data & identifying meaningful patterns with potential themes & conceptual relationships. Initial themes were reviewed against data & revised
Findings: selected, linked themes

- Time & timing
- Continuity, communication & rapport with care workers
- Trust & safety
- Overarching, interconnecting theme – humanly sensitive homecare

Anonymised quotes with pseudonyms
‘I’ve looked after my husband who had a stroke, for the past 16 years. He suffered three strokes that’s left him with one sided weakness. …..

It wasn’t really positive until, I took up the Direct Payment so I could employ the carers that my husband can cope with, you know. Because after the stroke he lost some of his English – he speaks mainly Igbo, & Italian... so, when Direct Payment was introduced, things became a lot easier because I had to employ carers from my Nigerian background, who were especially Igbo. So that sometimes, when he mixes things up, they will understand him... so, things have really worked out better for me since then.’

Abeje, Black African female
Positive across several levels

Cultural

‘So with Direct Payment I can actually tell the carer to stay an hour & a half, or two & a half hours to give him simple massage. Like in our own culture there is a particular cream we believe so much that when you 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... may be they won’t like to touch it because it’s not very good looking. But when I got carers that are from that background, it’s easy for them, you know, to support him & give him simple massage.’

Preference

‘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, you know, so I have to look for male carers.’
Homecare visits often constrained & dominated carers’ days. Care workers were frequently late adding to carers’ challenges, compounding already strained relationships: ‘We keep ringing them ‘Oh we’ll be there in 5 minutes, ‘Oh we will be there’…& that builds up the tension in the house & then we [carer & stroke survivor] start arguing.’ Upma, Asian Indian female
Continuity & relationships

- ‘Morning different face, lunch time different face... sometimes they turn up, sometimes they don’t turn up.’ Ada, Asian Pakistani female

- New care workers added stress
  ‘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 female
  ‘You know yesterday she (care worker) rang me 15 times because she couldn’t understand what Mum was saying... Mum can’t make herself understood so that frustrates Mum even more. Then she 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 male

- Familiarity really helped develop relationships
  ‘The carers get to know her & they can understand her... they know her, they understand her & everything. So they, they follow along with her.’ Cecil, Black Caribbean male.

This can’t be good for care workers either!
Communication & rapport

- Communication & rapport between care workers & the family are vital to satisfactory homecare but are hampered by poor continuity.

- Care workers who established personal rapport & integrated friendly, caring conversation into personal care were valued for supporting stroke survivors’ health & wellbeing. This also had a positive impact on carers who could relax knowing their loved-one was happy.

'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 female
Trust or lack of trust with care workers was often grounded in previous experiences of health & social care provision. Not trusting others to care properly led many carers to feel that only they could care & they alone had to take on the full 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 the care, which was horrendous, because I was working full-time.’ Vivienne, Black Caribbean female

Language similarity helped with trust

‘When we are ill, your trust is gone, you don't trust anybody... You know, so if you see somebody, like somebody speak your language, somebody you know, you think, “I'm safe, somebody's here with me.”’ Tina, Black African female

Where care workers were trusted, carers felt they could safely leave stroke survivors giving valued periods of relief & respite reducing hyper-vigilance

‘And Mum liked her, although um, sometimes she just sat & Mum slept in her chair. But at least for me it was a relief to know that I wasn’t going to come back & find Mum in a state or, or anything like that.’ Dorothy, White British female

‘We were, first few weeks, we were off work. We were looking after her & staying there. But once we realised they'd come on time & 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 British Indian male
Humanly sensitive care centred around relationships between carers, care workers & stroke survivors. Care workers’ attitudes & personality were central.

‘Because they speaking my language & er, kind of heart to helping. It's work but their helping is more in their nature, they have more humanity.’ Chetna, Asian Indian female

Care workers who responded to stroke survivors as individuals & as human beings rather than focussing on mechanical care routines were valued.

‘They talk to him while they’re doing wash... he talks to him & asks how he feels, ‘OK?’, when turning him & everything, ‘Are you comfortable or not?’ This & that, you know, while washing him they communicate as well.’ Kalyn, Asian Indian female
For some care workers, it was not ‘just a job’ & in addition to practical work, good care workers demonstrated ‘heart’ & ‘humanity’ & ‘going the extra mile’ with carers & stroke survivors.

‘He was a caring person, he loved his job, to him money wasn’t there. He cared for people. So he made sure he dressed him properly – his shirt wouldn’t be out, he shaved, he combed his hair & made sure (because he doesn’t know). ... he make him look presentable, that’s the caring role, you see? They need people that care about the job, that care about other people. This is what the caring is all about.’ Upma, Asian Pakistani female

‘It’s not part of the job (drying the towel) but he take it & dry it out for me. Rather than just leave it there for me to take it out ... ... & when he finish, he’ll sit there patiently & wait for him (stroke survivor) to finish, because he’s very slow, he doesn’t have to wait for him but he still sit down & wait.’ Tenneh, Black African female

‘When it was my birthday they both [the care workers] gave me birthday cards which I thought was wonderful ... & they wrote a lovely message in it...& said words like ‘We come in & you’re like a mother to us’.’ Marjory, White British female
Humanity & human dimensions of care: poor care

This related mostly to care worker behaviour – sometimes this fell short of expectations. E.g.

- Stroke survivors & carers were kept waiting & uncomfortable
- Care workers took personal phone calls whilst working
- Care workers talked over stroke survivors in languages they & the carer did not understand
- A single flannel was used for intimate washing & face washing
- Stroke survivors were rushed through personal care

Carers highlighted sometimes rushed, routinised, task-focussed care that gave few opportunities for developing relationships & trust

‘I tell them – ‘Take your time, don’t rush Ola’, you know. So that Ola is not then forced to do things quickly. Because she has to take her time to do things.’ Abike, Black African female
Conclusions: Humanising dimensions

- The lifeworld led approach takes us beyond client-centred care giving a slightly different focus. It adds to our understanding of experiences of homecare highlighting the importance of human relationships. It implicitly incorporates respect & dignity for users, carers & care workers.

- **Sense of place**: sense of familiarity, security, & ‘at-home-ness’ ↔ **Dislocation**: feelings of not fitting in, feeling a stranger in your home or a stranger when exposed to unfamiliar routines & cultures.

  For some carers the creation of institution-like homes was reinforced by the presence of special beds & hoists, as well as the unfamiliar presence of care workers. Friendly, reliable care workers who supported both carers & those they care for & found ways to ‘fit in’ with families may help regain a sense of being ‘at home’. E.g. when personal budgets enabled carers to employ care workers from the same language & cultural background facilitating trusting relationships & social connectedness & giving a sense of control.

- **Agency**: having choice & freedom ↔ **Passivity**: externally & internally imposed attitudes & practices make 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.

  ‘So with Direct Payment I can actually tell the carer to stay an hour & a half, or two & a half hours & you know, give him simple massage.’ Abeje, Black African female.
More examples

- **Togetherness**: sense of belonging & human connectedness ↔ **Isolation**: separated from or feeling alienated from others
  
  Carers often enjoyed camaraderie with care workers. This was frequently linked to shared cultural understanding & trust
  
  ‘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 female
  
  ‘Very good because she liked reading her bible & they will read a passage for her & sometimes it’s a laugh. They (the care workers) say they’re getting good training with her & the bible!’ Evelyn, Black Caribbean female

- **Uniqueness**: ‘met’ as a unique individual ↔ **Homogenisation**: emphasis on fitting into groups.
  
  Some carers felt they & those they cared for were treated as unique individuals
  
  Care workers who prepared meals as carers & stroke survivors wanted or who incorporated e.g. time for prayers into personal care were highly valued
  
  ‘They understand her religious & 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 & the carers don’t need to be told because they understand.’ Huzaifah, Asian Indian male

- But others highlighted the prescriptive nature of homecare
  
  ‘Rather than having, you know, strict guidelines ‘This is what they can do & this is what they can’t do’ just let them go in & whatever the needs are for that person, just to get on with it.’ Shahnaz, Asian Pakistani female
Conclusions: service implications

- **Expectations & experiences of social care are similar across ethnic groups**
  - Much of what BME carers & stroke survivors need from homecare is not specific to either stroke disability or being from specific BME groups but is relevant to carers of people with many health conditions from all ethnic groups – i.e. Being human

- **Late care workers & unresponsive services hinder trust & the development of relationships**
  - Timely, responsive services are important for many reasons but lack of them impacts on carers & those they support affecting dignity, overall trust in services & willingness to use services

- **Continuity of care worker support needs improvement.** Continuity fosters relationships & trust & 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
Conclusions: service implications (cont)

- **Treating people as individuals & with humanity is essential.** Everyone would like to be treated as individuals & their dignity respected. If done correctly, individual needs, whether related to stroke impairments or coming from BME groups would be met
  - The humanising care framework adds to our understanding of experiences of homecare highlighting the importance of human relationships. It implicitly incorporates respect & dignity for users, carers & care workers
  - Care workers have to negotiate a difficult balance recognising the needs of both stroke survivors & family carers. The concept of ‘at homeness’ is a particularly useful concept here & greater understanding of this by care workers from the carers’ perspective could enhance care
  - The humanity of carers, those they care for & care workers needs greater recognition. This would improve the experiences of users, carers & care workers
  - Care workers need to be encouraged to use any care opportunities for social interaction with both stroke survivors & carers

- **Finally – there is a lot of good care worker support –** we can learn from it.
Thank you
Any questions?

References


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