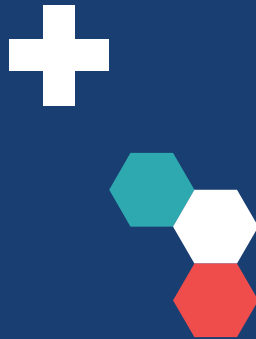


# Older carers and their spouses living at home with dementia: a relational approach to understanding responses to service disengagement during the pandemic

Jayne Astbury, Phil Drake, Debora Price and Neil Allen.  
University of Manchester

*This paper presents independent research funded by the National Institute for Health and Care Research Policy Research Unit in Older People and Frailty. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care*



# Research Project Overview

- **Aim:** to investigate the impact of the Care Act 'easements' introduced under the Coronavirus Act 2020 on co-resident carers, aged 70+, supporting a spouse or partner living with dementia at home
- **Objectives:** included understanding and documenting urgent challenges for carers and local authorities
- **Mixed methods:** semi-structured interviews with 48 carers and 20 Principal Social Workers/Safeguarding Leads, and a national survey of carers' experiences

**This presentation reports on the findings from a subset of interviews: people supporting a spouse living with dementia in receipt of home care**

# Participant Characteristics

- Recruitment via research team and local networks, two national partner organisations, and Join Dementia Research.
  - Recruitment and sample limitations
- Wider study included 48 carer interviews. Subset of participants utilising home care included 20 carer interviews.
- Home care conceptualised broadly; included homecare arranged by or in conjunction with local authority, arranged privately via home care agency, private arrangements with individuals

Carer: 11 Male/9 Female  
Age range carer: 71 – 86

Local Authority: 8 Easement/12 non-easement  
Age range PLWD: 71 - 90

# Analysis

- Initial thematic analysis undertaken as part of wider project revealed that carers' perceptions of care quality underpinned events which happened and action taken
- Further analysis undertaken applying lens of relational sociology:
  - The idea that individuals, their action, and their agency are fundamentally constituted by social relations
  - Social phenomena cannot be understood in static or substantive terms, but instead exist insofar as they are produced, maintained, and transformed by the multitude of relations that direct and constitute the interdependent interactions that occur between various social actors (Abbott, 2022)

# Findings: Perceived Care Quality

- Of 20 interviewees receiving home care, 7 were satisfied, the remainder lay on a continuum of dissatisfaction, 4 carers (home care arranged by or in conjunction with the LA) had made a decision to disengage with home care services completely due to concerns relating to care quality (despite needing service).
- Key concerns centred around consistency of carers, lack of control over timing of visits, and reliability.

I was finding it was different people coming at times that weren't suitable for us. They'll come in at seven o'clock in the morning and then, as I say, with [partner] that generally is too early for her. Then I was noticing I was having to advise people, you know, where's the towel, where's this, where's that, because they were different people. I thought well, I might as well be doing this myself. So, yes, I know that service is available in terms of people coming in and changing her or whatever, but at this point in time, it didn't work for us. (C19)

# Impact of home care on relational roles and responsibilities

- For some participants, home care created difficult-to-manage changes to relational roles, responsibilities, and routines.

I used to give him his medication, his breakfast, so I found it difficult because sometimes they said, well we'll do that. It was just very, very different and difficult for us as a couple, the way we've lived. (C22)

[Partner] wasn't terribly happy about them being, you know, somebody – because he couldn't understand. He was saying, “Why can't you help?” (C40)

# Interplay between relational disruption & perceived care quality

I didn't really like them looking after him. I felt that if there was anything there, while they were changing him and washing him, I felt that he would be really mortified by this. Although I think – I don't know whether he would have said anything, but they – it just wasn't convenient. They never came at a time really when his pad needed to be changed, or when he'd had an accident or anything. So, it just didn't fit in with our timeframe, so it just didn't work so I stopped it. (C34)

It didn't work for us; we were both finding it extremely stressful. So, I cancelled the evening, but stuck with the morning, and sometimes - they didn't, obviously, come on time and I appreciate that it's exceptionally busy. So, I used to shower [partner], while I was showering myself – between one another, we did it between us. But when these carers were coming and obviously, I had to pass over to them, [partner] didn't really like it. And then the odd morning when they didn't turn up I, obviously, couldn't leave him, so I showered him again. I found it very, very hard. (C22)

# Raising concerns regarding care quality difficult

I would always ask, “Have you had your vaccines?” Because at that point having the two vaccines was supposed to help protect yourself and others. But one of them was one of these disbelievers. Called the government fascists and hadn’t had any vaccines, didn’t believe in them. Didn’t think there was a pandemic, but the care company was still using him. And whilst I might have been able to ring the company and say, don’t send him. I just felt I couldn’t, you know, that I needed the support. (C40)

[social worker] said that we are private, so they can’t really do very much. I don’t understand. (C15)

[Care agency] virtually refused to speak to me because I think they look on the, their client isn’t me; their client is the Social Service. You know, they’re the ones who are paying them the money. (C37)



# Concluding thoughts

- Disengagement with home care contributed to increased carer stress and burden
  - Potentially leads to unmet need
- Perception of care quality influenced by and situated within relational contexts
- Important to explore what care quality means to different stakeholders
  - for understanding how best to support families in need of help
  - crucial for the functioning of health and care systems
  - an essential part of the framework for preventing crisis breakdowns of care