

HOW could technology be used to facilitate domiciliary dementia care?

Perspectives of people with dementia, their families and care providers

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What is this study about?

Many people with dementia (PwD) would like to remain living in their own homes for as long as possible (van der Roest et al, 2007; Rapaport et al, 2020). This is often enabled by support from partners, family and friends ('unpaid carers'). As their dementia progresses, paid-for support from domiciliary care workers may also be needed to help with practical tasks and personal care, as well as provide social and emotional support.

Research has highlighted various challenges faced by families in initiating or organising home care, such as concern about loss of independence, feeling bound by inflexible schedules and experiences of poor care (Hughes & Burch, 2019; Lindeza et al, 2020; Olsen et al, 2020). This can lead to families not engaging with home care, placing unmanageable demand on unpaid carers. Conversely, domiciliary care workers face high levels of stress, long shifts, sometimes unpredictable hours and low pay; this leads to high staff turnover, making the future of home care increasingly precarious (Afolabi et al, 2025; Fleming & Taylor, 2007).

Matching care worker skills to the specific needs and preferences of PwD can improve care (Dawson et al, 2015); knowledge that they are making a positive difference to the lives of PwD in turn improves care worker job satisfaction and resilience (Donnellan et al, 2022).

There is potential for technology to help address some of the problems in organising and providing domiciliary dementia care, by using algorithms to match care workers with families and enable more flexible scheduling. However, it is first essential to **understand the needs and preferences of all those involved in receiving and delivering care.**

What did we do?

In this user needs study, we conducted online focus groups and interviews with four populations in the UK: people with dementia (n=3), unpaid carers (n=18), domiciliary care workers (n=20) and managers (n=5). In the focus groups/interviews, we first explored the preferences and experiences of service users and providers. Vignettes of potential digital platforms for organising domiciliary dementia care were then presented for participants to critique.



What have participants told us?

Key challenges, raised by all groups, in the way that domiciliary dementia care is currently organised include:

- Care plans are slow to be developed and updated, do not provide a comprehensive or up-to-date view of what PwD need
- Lack of clear communication channels between all groups leads to inconsistent care, confusion and breakdown in relationships
- Short care visits do not allow time for care workers and PwD to get to know each other; practical/physical needs are prioritised over socioemotional needs
- Minimising travel time needs to be a priority in organising care worker schedules both for financial viability and to minimise care worker stress

'If you get a good carer and you work as a team and you share strategies, even when that person isn't there, it makes life a lot easier.' (Family carer)

'it is sad when someone wants to talk to you and an extra five minutes can make all the difference in someone's wellbeing' (Care worker)

Considerations for technology in organising domiciliary dementia care:

- Care works best when all involved work together as a team, technology can facilitate this by enabling communication and information sharing in real time that is accessible to all parties, including information to supplement care plans and provide a more holistic picture of the individual with dementia. BUT need to avoid providing an information overload.
- Using algorithms to match PwD and care workers based on personality, interests and skills holds promise BUT...
 - To be financially viable care providers have to prioritise geographical proximity for scheduling
 - Both families and care workers recognised that it takes time to 'match' a client and care worker - even if people look like a good match on paper, clashes can occur
- A digital platform that enables quickly identifying care workers to take a last-minute request for a care visit would be appreciated BUT caution is needed to ensure this provides equal opportunity to care workers.

What next?

This study is part of a larger project that aims to improve dementia care in the home by designing a digital platform that matches the preferences of people living with dementia, unpaid carers and care workers, and enable 'live', needs-informed rostering (the process of creating schedules for care workers and clients). Findings from this study are informing the development of a digital platform. At the end of the project we will have a co-designed prototype of a new digital platform. We will then seek further funding to test the prototype with domiciliary care agencies and understand if/how the new platform benefits people living with dementia, their families/friends, and care providers.

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