



ARCBITE



Brokering Innovation Through Evidence

Decision making for receiving paid home care in dementia during the COVID-19 pandemic

Background

Dementia affects over 850,000 people in the UK alone, with numbers steadily growing.

Receiving paid home care is a key component of social care provision, supporting people with dementia live independently at home for longer.

With the sudden nationwide UK lock down on the 23rd of March 2020, attitudes towards receiving paid home care and the delivery of home care is likely to have changed.

What was the aim of the project?

We wanted to understand how unpaid carers are making decisions about having paid home carers enter a person with dementia's home during the pandemic.

What did we do?

We interviewed 15 unpaid dementia carers over the phone during April, and asked them about their experiences of receiving paid home care, amongst others.



Picture credit: House of Memories website

How did we involve people?

One person living with dementia, several current and former unpaid dementia carers, and service providers form part of our team. Everyone helped shape the study and the interview questions, helped interpreting the findings and also assisted with the dissemination.



What we found and what does this mean?

We identified three themes:

- (1) Risk;
- (2) Making difficult choices and risk management; and
- (3) Implications for unpaid carers.

Unpaid carers, such as spouses and adult children, faced difficult decisions in terms of continuing to receive various paid carers in the home and potentially bringing with them the virus.

Some unpaid carers could not cope without additional help from paid carers and thus needed to keep the support, although not all unpaid carers wanted to have them entering the person with dementia's home. Carers also reported great variations in how paid carers were using personal protective equipment.

To date, there are no support guidelines helping unpaid carers and people with dementia reach decisions about whether and how to receive paid home care.

Giebel, C., Hanna, K., Cannon, J. et al. Decision-making for receiving paid home care for dementia in the time of COVID-19: a qualitative study. BMC Geriatr 20, 333 (2020). <https://doi.org/10.1186/s12877-020-01719-0>

What next?

As a next step, we will look at how paid home care has changed since the initial lock down. For this purpose, we have done a number of follow-up interviews with carers and are currently analysing the data.

We will also be recommending improved decision making strategies for paid dementia home care via the Alzheimer's Society.

Who was involved - partners?

- University of Liverpool
- The Brain Charity
- Together In Dementia Everyday (TIDE)
- Mersey Care NHS Trust
- North West Boroughs NHS Trust
- Lancashire and South Cumbria NHS Trust
- House of Memories
- Me2U

What is NIHR CLAHRC / ARC North West Coast?

The Applied Research Collaboration North West Coast (ARC NWC) superceded CLAHRC NWC in September 2019. It is a partnership between universities, NHS, public, etc.

Its mission is to undertake applied research to improve public health, wellbeing, quality of care & reduce health inequalities across the North West Coast region.

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