

ORAL PAPER PRESENTATION 1: HOUSING AND DAILY LIVING

ICT and unpaid carers of people living with dementia: Addressing engagement, detachment, and unmet needs

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Purpose Approximately 700,000 unpaid carers spend over a billion hours per year to care for people living with dementia in the UK (Alzheimer's Society, 2021); at an estimated cost (in England) of over £10B (Wittenberg et al., 2019). Globally, the estimated societal cost of dementia is US\$1.3T (WHO, 2021). It is unclear how – and to what extent – unpaid carers engage with information and communication technology (ICT) to support them and the people they care for. **Method** In a series of online and in-person focus groups of between three and seven unpaid carers, we gathered views and experiences of using a range of ICT, barriers inhibiting their ICT-use and ideas for developing ICT functions that could assist them according to their variable needs. **Results and Discussion** Participants discussed their use of everyday technologies such as smartphones, smart speakers, cameras and tablet computers, remarking on the benefits in terms of simplifying their daily lives, especially during the COVID-19 pandemic, for banking, shopping, and keeping in touch with family, friends and care staff. Carers also explained that monitoring, reminiscence and reminder applications on smartphones and smart speakers afforded them respite and “peace of mind”, allowing them to carry out paid work and to improve their own health and wellbeing. Carers used devices specifically designed for dementia care, such as dementia clocks, GPS finder services, door sensors and fall pendant alarms; expressing mixed views about their benefits. Some participants explained that pendant alarms and finder services allowed the people they care for to continue pursuing their hobbies and outings; others elucidated that such devices were inaccessible and caused confusion, particularly for people in the advanced stages of dementia. Participants voiced the challenges to using ICTs including poor self-rated technical aptitude, lack of appropriate support, and a perceived inability to “keep up” with rapid technological changes and the related financial costs. Several carers explained the difficulties with accessing online healthcare appointments and expressed concern about a perceived reduction of face-to-face formal care services, post-pandemic. Furthermore, carers supporting relatives in residential settings articulated deep frustrations about the poor connectivity of many care homes in terms of broadband services and internet-enabled equipment, preventing them from communicating with – and remotely supporting - their family members. Ideas discussed for future ICT solutions that could facilitate caring for a person with dementia included simplified, interoperable television devices and services, remote assistance for people living in care homes and passive two-way communication systems. Notably, carers called for collaborative working between ICT developers, people living with dementia and their carers, at each stage of development and implementation, to arrive at devices and services that are both accessible and acceptable to people with care needs. Focus group findings will inform subsequent phases of the wider CareTek project (<https://www.lse.ac.uk/cpec/research/caretek>): assessing the effects of ICTs-use on the health and wellbeing of unpaid carers and people living with dementia; and conceptualising a toolkit to help carers, practitioners and decision-makers identify ICTs that meet the individual needs of people living with dementia and their carers.

References

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