Unpaid carers of people living with dementia: ICT-use, non-use and sources of digital support

J. Damant, D. King, M. Karagiannidou, M. Dangoor, P. Freddolino, B. Hu, R. Wittenberg

Purpose Close to a million people are living with dementia in the UK; over 80% of whom are cared for, unremunerated, by a spouse or relative (hereon in referred to as unpaid carers), many of whom are also of an advanced age. Unpaid carers often experience significant problems to their physical and mental wellbeing as a result of their circumstances (Alzheimer's Research UK, 2023; Lindeza et al., 2020). Evidence demonstrates the promise of information and communication technology (ICT) to support dementia care (Hassan, 2020; Caprioli et al., 2023, Lorenz et al., 2019). However, less is known about unpaid carers' current ICT-use and non-use, and how they acquire digital knowledge and skills that could support them to provide care for the progressive needs of a person living with dementia. **Method** We adopted a mixed-method approach. Descriptive statistics and regression analyses of 167 survey responses on the impact of ICT functions on unpaid carers' wellbeing (ONS4) and quality of life (QOL) (DEMQOL) were complemented by a thematic analysis of 35 one-to-one telephone or videoconference interviews with unpaid carers. **Results and Discussion** Survey respondents were predominantly female (73%) and a mean age of 68 years (range 32-85 years); 66% reported using mainstream, internet-enabled ICT (e.g., laptop and tablet computers, smartphones, virtual assistants) for information, accessing services, entertainment and reminder purposes; 31% used care-specific ICT such as care management applications (17%), and communication or alarm systems (22%) (e.g., telecare). 32% indicated they did not use any ICT; 7% reported they didn't have sufficient skills or needed help to use ICT. Unpaid carers' use of ICT for entertainment and accessing services was significantly associated better wellbeing ($p < 0.01$) and QoL ($p < 0.05$) respectively. Most interview participants reported mostly relying on ICT for information gathering, social networking and administrative support for themselves, as well as for the person they cared for. A small minority discussed their refusal to use - or lack of interest in – ICT. Interview participants discussed a range of ways in which they learned about ICT services to help them provide care. Several mentioned that their children, grandchildren and friends directed them to helpful apps and websites. A small number discussed the ICT guidance they received from local dementia and carer services. Some revealed they were self-taught and used "trial-and-error" methods to discover how ICT could optimally help them meet their circumstantial needs. Findings demonstrating unpaid carers' reliance on family, friends, and local services for digital support raises concerns about the large number of unpaid carers who are socially isolated (Carers UK, 2023) and/or have low digital self-efficacy (Dale et al, 2018). They also emphasize the need for improved mechanisms to identify the digital needs of vulnerable unpaid carers, and for accessible statutory ICT training and support services.

References

Alzheimer's Research UK. (2023). Statistics about dementia. Alzheimer's Research UK. https://dementiastatistics.org/about-dementia/

Caprioli, T., Mason, S., Tetlow, H., Reilly, S., & Giebel, C. (2023). Exploring the views and the use of information and communication technologies to access post-diagnostic support by people living with dementia and unpaid carers: A systematic review. In Aging and mental health. Routledge. https://doi.org/ 10.1080/13607863.2023.2196246

Carers UK (2023) State of Caring 2023. Impact of caring on: health, Carers UK: London, ISBN: 978-1-873747-75-9

Dale, J., Nanton, V., & Grason Smith, G. (2018) Coproduction of a theory-based digital resources for unpaid carers (The Care Companion): Mixed-methods study, *JMIR Aging, 1*(1). https://doi.org/ 10.2196/aging.9025

Hassan, A. Y. I. (2020). Challenges and recommendations for the deployment of information and communication technology solutions for informal caregivers: Scoping review. *JMIR Aging, 3*(2), Article e20310. https://doi.org/ 10.2196/20310

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *BMJ Supportive & Palliative Care*. https://doi.org/ 10.1136/bmjspcare-2020-002242

Lorenz, K., Freddolino, P. P., Comas-Herrera, A., Knapp, M., & Damant, J. (2019). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia, 18*(2), 725–741. https://doi.org/ 10.1177/1471301217691617