

An integrated digital care collaboration platform to support home-based dementia care: A mixed-methods evaluation

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Background: While extended independent living is preferred by most people with dementia (PwD), it also puts more pressure on their informal caregivers such as spouses or children. The increasing need for support of informal caregivers of PwD has led to solutions including digital platforms to facilitate the organization of care and collaboration among the (in)formal care network. In the Netherlands, the free platform "Caren" has become one of the largest care collaboration platforms supporting informal care. However, insight into its added value and boundaries is still lacking. This study therefore aimed to analyse the experiences of informal caregivers of PwD with the care collaboration platform "Caren".

Method: A large-scale cross-sectional online survey was offered to users of Caren, covering questions related to a set of evaluation criteria: usability, impact on caregiver-caregiver communication, impact on the organization of care, trust in the platform, and intention to continue using it. A number of users was invited to take part in interviews to provide more context to the survey results.

Results: 7118 informal caregivers of community-dwelling PwD (M(age)= 58.7; 97% caring on distance) completed the survey. Most of them used the platform more than 6 times per week (68%). Overall, participants judged the platform positively regarding its usability and trustworthiness and reported a positive impact on caregiver-caregiver communication and the organization of care. Participants with high burden of care evaluated the platform significantly less positive than those with low burden of care ($p=.00$). Results of the interviews ($n=7$) mirrored those of the survey but also revealed that asynchronous communication with care professionals was not always seen as helpful, especially in case of urgent matters.

Conclusion: The study showed that integrated digital care collaboration is promising. Future research is needed to determine optimal ways of digital communication between informal and professional caregivers of PwD.