
CONFERENCE ABSTRACT

Evaluation of a digital resilience monitor for informal caregivers of persons with dementia to prevent crisis: a pilot study

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Introduction

Crisis admissions of persons with dementia are more prevalent due to the rising number of people with dementia living longer at home. Moreover, societal dependency on informal care grows, which negatively impacts caregivers' wellbeing. This is often a direct reason for crisis admission of the person with dementia. Therefore, we developed REMIND, a digital tool for frequent monitoring of wellbeing and resilience of caregivers, which enables case managers to provide timely support, thereby preventing deterioration in caregiver wellbeing and eventually crisis admissions. The aim of this pilot study is to explore the usability and acceptability of REMIND.

Theory/Methods

During a 3-month period case manager-caregiver duo's used REMIND. The monitor was developed in co-creation with end-users during focus groups. The pilot version of REMIND consisted of a weekly set of questions on social support, reciprocity, burden, wellbeing, own activities and small crises, filled in via a chat on a smartphone or computer. Caregiver wellbeing was displayed in graphs on a dashboard for case managers to act upon. Usability and acceptability of the tool were explored in semi-structured interviews with the caregivers and case managers. Two independent researchers applied content analysis on the transcripts.

Results

Eight case managers and fourteen caregivers participating considered the tool easy to use. Caregivers appreciated REMIND, because it stimulated self-reflection regarding the burden of their caregiving processes. Case managers valued the tool's ability to gain better insight in the actual wellbeing of caregivers, because some caregivers find it hard to acknowledge themselves being burdened during a face-to-face conversation. The fact that REMIND provided insight in wellbeing patterns over time instead of a single assessment during a monthly home visit, was highly appreciated by case managers. The monitor outcomes were therefore considered a suitable starting point for conversations with caregivers. Suggestions for improvements included, more diverse set of questions and additional functions including peers support.

Discussions

In this pilot, REMIND was found highly usable and acceptable for both caregivers and casemanagers. The use a co-design approach in the development likely contributed to these findings.

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Conclusions

Pilot evaluation of digital monitor for caregivers and case managers showed that the tool was easy to use and stimulated self-reflection in caregivers. For case managers it provided a starting point for conversations. The tool is able to monitor wellbeing of caregivers and thereby has the potential to prevent crisis.

Lessons learned

Developing a monitoring tool for caregivers of persons with dementia in a co-creation design process with end-users led to a well-accepted and easy-to-use device.

Limitations

Casemanagers in this pilot study were early adopters. Further research should include a more diverse group of case managers.

Suggestions for future research

A future randomized controlled study with longer follow-up may determine whether its use prevents (small) crises.