



## A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia

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### ABSTRACT

**Objectives:** The objectives were to (1) systematically review the literature on the implementation of eHealth interventions for informal caregivers of people with dementia, and (2) identify determinants of successful implementation.

**Methods:** Online databases were searched for articles about eHealth interventions for informal caregivers of people with dementia, providing information on their implementation. Articles were independently screened and inductively analyzed using qualitative analysis. The analysis was mapped onto the Consolidated Framework for Implementation Research (CFIR; Damschroder et al., 2009).

**Findings:** 46 articles containing 204 statements on implementation were included. The statements on implementation were grouped into four categories: Determinants associated with the eHealth application, informal caregiver, implementing organization, or wider context. Mapping of the determinants on the CFIR revealed that studies have focused mostly on characteristics of the intervention and informal caregiver. Limited attention has been paid to organizational determinants and the wider context.

**Conclusions:** Despite prolific effectiveness and efficacy research on eHealth interventions for caregivers of people with dementia, there is a critical dearth of implementation research. Furthermore, there is a mismatch between eHealth intervention research and implementation frameworks, especially concerning organizational factors and wider context. This review underscores the importance of future implementation research in bridging the gap between research and practice.

## 1. Introduction

Informal caregivers are essential to providing home-based care for people with dementia. Research has shown that the quality of care received by a person with dementia positively relates to a longer time spent being cared for at home, which is critical to the physical and mental health of the person with dementia (Alzheimer's Association, 2015; Spijker et al., 2008). However, informal caregivers of people with dementia often experience significant physical and psychological problems themselves as a result of this caregiving process, including increases in depression, stress, social isolation, financial burden, and disturbed sleep (Peacock and Forbes, 2003).

Given these adverse consequences, it is crucial to provide caregivers

with tools to help them receive caregiving support, as well as to allow them a life outside of caregiving. With the dementia population (47 million people worldwide) expected to grow threefold by 2050 (Han et al., 2014), this increasing need for support has led to many innovative approaches, including those emerging from the promising field of eHealth research. The term 'eHealth' describes "the use of information and communication technologies (ICT) for health" (WHO, 2018). eHealth interventions are "treatments, typically behaviorally based, that are operationalized and transformed for delivery via the Internet" (Ritterband et al., 2006). For instance, eHealth interventions can take the form of an online course, administered via computer; they can also be smartphone or tablet applications designed to provide psychological support from peers and professionals alike. eHealth

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interventions have the advantage of a lower threshold of access for participation, as well as the ability to reach more isolated populations who struggle to access traditional services (Topo, 2009). Recent reviews have shown that eHealth interventions for informal caregivers of people with dementia are effective in improving a range of psychological outcomes in caregivers, such as the reduction of caregiver depression, anxiety, stress and burden, as well as increasing positive aspects of caregiving, caregiver self-efficacy, and confidence (Boots et al., 2014; Jackson et al., 2016; Lee, 2015; Parra-Vidales et al., 2017; Scott et al., 2016; Tyack and Camic, 2017).

However, despite this proven efficacy, little is known about how to ensure that these interventions are successfully implemented (i.e. put into practice). Previous research on eHealth interventions has shown that, despite their proven efficacy, as well as enthusiasm regarding eHealth from funding and policy institutions, the implementation of eHealth interventions in ageing populations has proven difficult. Reasons for this include older individuals' changes in their perceptual, cognitive, and motor abilities, in combination with the continuing rapid development of new technologies (Preschl et al., 2011). The objectives of this review are (1) to explore the evidence on the topic of implementing eHealth interventions for informal caregivers of people with dementia, and (2) to identify determinants that influenced whether the intervention was successfully implemented. The results of this study will help bridge the gap between our knowledge of the efficacy of eHealth interventions for informal caregivers of people with dementia, and the translation of this knowledge into practice.

## 2. Methods

### 2.1. Search strategy

A systematic literature search of bibliographic databases PubMed, CINAHL, PsycINFO, Cochrane Library and Web of Science was conducted in May 2017. The search was aimed at finding articles that contained information on which factors determined the implementation of eHealth interventions for caregivers of people with dementia. In order to accomplish this, the aforementioned databases were searched for articles that contained terms related to all three of the following main concepts: 'dementia', 'eHealth' and 'caregivers'. Relevant MeSH and Thesaurus terms were used, as well as additional non-MeSH terms, so as to identify the full range of indexed and non-indexed articles. Appendix A details the employed search strategies: first the union ('OR') of terms to capture articles related to each single main concept, and second the intersection ('AND') of main concepts to focus on the purpose of this review.

The search strategy does not contain relevant terms related to 'implementation' (such as 'facilitators and barriers', 'determinants' or 'implementation'), because the authors anticipated that such terms are often not mentioned in the title and/or abstract. Instead, implementation issues may only be discussed in the body of the text, potentially using different terms. This information could only be assessed by reading the full-texts in a later, post-abstract screening phase. Thus, we aimed to have a complete overview of all research on implementing eHealth interventions for caregivers of people with dementia, without missing important information due to terminology constraints.

### 2.2. Study selection

Titles and abstracts of the identified citations were imported into Endnote, deduplicated and independently evaluated by first reviewer (HLC) and second reviewer (SLB). Included references had to involve an (1) eHealth (2) intervention for (3) informal caregivers of people with dementia and (4) provide information on its implementation. In order to assess whether references met criterion 4 (provides information on implementation), the full-texts were scanned for the presence of determinants of implementation. These were statements about factors that

either facilitated or impeded the process.

Non-intervention studies such as reviews, trial protocols, book reviews and consensus papers were excluded. Otherwise, any design was judged as suitable for inclusion. Studies on assistive technology that were not specifically designed to improve caregiver well-being, as well as telephone-only, video-only and CD-ROM-based interventions were also not included. Non-English-language publications and articles published before 2007 were excluded from this review. 2007 was chosen as the cut-off year for this review. It was believed that studies from more than 10 years ago would not provide much additional, relevant information due to the evaluated technologies having become outdated, as well as policies and organizations having changed greatly in the interim. After searching for eHealth [All Fields], the PubMed-generated histogram 'Results by year' showed a rise in eHealth research after 1994, followed by a plateau from 1998 to 2007. After 2007, the number of references recommenced its rise. The authors concluded that 2007, the year of the first iPhone, signified a turning point in mobile technology (Cuthbertson et al., 2015) and a relevant cut-off point. Any disagreements about inclusion were resolved through a consensus meeting consisting of three reviewers; HLC, SLB and MEdV.

### 2.3. Data extraction

Articles that met all four criteria were compiled into a standardized data extraction instrument as recommended by Cochrane Handbook for Systematic Reviews of Interventions (Higgins and Green, 2011) (see Appendix B) detailing primary study characteristics (author/year, design, setting, study population, intervention, measures, findings and country of study), as well as the extracted determinants. The PRISMA guidelines (Liberati et al., 2009) were used to guide the process of study selection and data analysis. However, not all elements of this guideline were followed as this systematic review focused on process characteristics and not on effectiveness.

### 2.4. Data analysis

A qualitative thematic analysis was performed in which statements related to eHealth implementation ("the process of putting the intervention into practice") issues were coded and labeled 'determinants'. The determinants were inductively grouped to form thematically similar categories, subcategories and groups. The authors opted for an inductive method in order to best scope the available literature and contrast the findings with existing implementation frameworks. Reviewers HLC and SLB independently coded and mapped these determinants by hand, identifying the article as 0 (contains no determinants) or 1 (contains determinants) and mapping these determinants into inductive categories using an online 'mind mapping' tool (Google Mindmap 2 software, October 2017 version, developed by Sauf Pompier Ltd.; <https://drive.mindmup.com>). In the next step a consensus meeting was held between reviewers HLC and SLB, with the input of reviewer MEdV. Finally, to structure and contextualize the findings, the resulting analysis was compared and mapped onto the Consolidated Framework for Implementation Research (Damschroder et al., 2009). The Consolidated Framework for Implementation Research (CFIR) was chosen because it is a commonly used, practical set of constructs, which were readily applicable to eHealth intervention research for caregivers of people with dementia.

## 3. Results

Fig. 1 depicts a flow chart illustrating the process of inclusion and exclusion. The search strategy described in Appendix A resulted in a total of 2524 records after deduplication. 2401 articles were excluded because they did not meet the criteria of involving an (1) eHealth (2) intervention for (3) informal caregivers of people with dementia. After screening these full texts for the fourth criterion ("provides information

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