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Original article

Development and usability of a decision support App for nurses to facilitate aging in place of people with dementia



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ABSTRACT

Aim: The aim of this study was to develop a decision support tool for nurses to facilitate aging in place of people with dementia and to test its usability.

Background: Nurses play an important role in detecting practical problems preventing persons with dementia (PwD) from aging in place and advising them on possible solutions. These are complex and challenging tasks for nurses.

Methods: A mixed methods study was conducted. The content development of the App comprised a literature and internet search, and individual and group interviews with professionals (n = 8) and researchers (n = 5). The technical development was an iterative process in which usability was tested by the project team (n = 4), experts (n = 6), and end-users (n = 9), using heuristic evaluation, a think-aloud approach, and a questionnaire (PSSUQ). *Results*: The App contains a structured problem assessment for three problem domains—self-reliance, safety, and informal care—based on validated questionnaires and self-formulated questions. The problem assessment is linked to an overview of possible solutions for the problems detected. Three prototypes have been developed. The users of the third prototype were overall satisfied with the App as they scored on average 1.7 on the PSSUQ (range 1–7 and lower scores indicating higher satisfaction).

Conclusions: A user-friendly prototype of the decision support App is now available. Users indicated to be very willing to use to App in daily practice. However, besides further technical development, implementation of the App into practice requires evidence supporting its efficacy, feasibility and effectiveness.

1. Introduction

The incidence and prevalence of dementia worldwide is rapidly increasing as a result of the aging population (World Health Organization & Alzheimer's Disease International, 2012). Currently, about 270,000 persons with dementia (PwD) live in the Netherlands, of whom around 70% are living at home supported by family members and professional care providers (Alzheimer Nederland, 2017). During the course of their disease, PwD become increasingly dependent on support from their network and over time often become susceptible to nursing home admission (Eaker, Vierkant, & Mickel, 2002; Prince, Prina, & Guerchet, 2013). However, PwD often prefer to continue to live a normal life in their own home for as long as possible (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). In many Western countries, facilitating aging in place and delaying or even preventing nursing home admission is a common policy aim (Moïse,

Schwarzinger, & Um, 2004). This is also the case in the Netherlands where, since long-term care reform in 2015, only people who need 24-hour supervision are eligible for residential care (Maarse & Jeurissen, 2016).

Despite both the wishes of the older persons themselves and policies focusing on aging in place, living at home can become extremely difficult for PwD. Dementia is characterized by ongoing cognitive and functional decline as well as behavioral changes, causing increased problems in daily functioning and dependency (MacNeil Vroomen et al., 2015). As the dementia process proceeds, people often experience problems in performing instrumental activities of daily living (IADL) (e.g. handling finances or preparing hot drinks) (Giebel, Challis, & Montaldi, 2015) or more basic activities of daily living (ADL) (e.g. going to the toilet or eating) (Risco et al., 2015). A recent study of practical problems preventing PwD from living at home has shown that problems in three particular domains seem to be the most striking.

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These domains are decreased self-reliance (e.g. inability to conduct ADL activities or to plan and structure a day), safety-related problems (e.g. improper use of electronic devices, wandering, or fall injuries), and informal care/network-related problems (e.g. high burden or absence of informal caregivers) (Thoma-Lürken, Bleijlevens, Lexis, & Hamers, 2018).

To facilitate aging in place of PwD the focus should be on the early detection of practical problems and the introduction of possible solutions. Various technological solutions (e.g. lifestyle monitoring, screen-to-screen care, GPS systems, and internet-based interventions) as well as social solutions (e.g. respite care facilities, day care at green-care farms, and case management) to support PwD and their informal caregivers are currently available (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014; Gibson et al., 2014; Schols & van der Schriek-van Meel, 2006; Thoma-Lürken, Bleijlevens, Lexis, Hamers, & de Witte, 2015). Nevertheless, PwD and their informal caregivers might not be aware of all these options (van der Roest et al., 2009; Wolfs, de Vugt, Verkaaik, Verkade, & Verhey, 2010).

Professionals in community-based dementia care play an important role in assessing practical problems and searching for possible care and treatment options for PwD and their caregiver(s) in order to deal with the problems that PwD experience in daily life (Wolfs et al., 2010). In the Netherlands, district nurses and case managers often fulfill this coaching and coordinating role (de Bont, van Haaren, Rosendal, & Wijboldus, 2012; MacNeil Vroomen et al., 2015). Professionals are expected to have insight into the needs, problems, and preferences of their clients and their informal caregivers, which may change over time. They should be able to advise them continually on possible solutions (e.g. professional care options, assistive technology, information sources, or informal caregiver support) to deal with the practical problems identified and to develop an individual action and intervention plan to facilitate aging in place (Alzheimer Nederland & Vilans, 2013; de Putter, Francke, de Veer, & Rademakers, 2014). District nurses and case managers are thus faced with complex diagnostic and advisory tasks, as these professionals need to have detailed insight into the constantly changing individual situation of a client and be aware of possible and evolving solutions.

There are various tools (e.g. questionnaires, checklists, and assessment forms) that professionals can use to gain insight into the different aspects of problems that PwD and their informal caregivers might experience. In the Dutch guidelines for community-based dementia care it is stated that individual need for care should be assessed according to the 'state of the art' (Alzheimer Nederland & Vilans, 2013). However, the guidelines provide freedom for professionals to choose between various tools. From research it is known that besides the explicit use of tools, nurses also rely on their intuition and experience when making judgments and decisions (Thompson, Aitken, Doran, & Dowding, 2013). Consequently, problem assessment and advice on possible solutions to these problems may depend on the knowledge and experience of the individual professional.

A decision support tool that combines a structured problem assessment with an overview of possible solutions could assist case managers and district nurses in their coaching and coordinating role. In these times of electronic client files and the use of tablet-computers by nurses and case managers, a computerized decision support tool for these professionals could be easily integrated into their work process. Computerized decision support for nurses is defined broadly by Dunn Lopez et al. (2017, p. 441) as "providing clinicians (nurses) with computer-generated clinical knowledge and patient-related information which is intelligently filtered and presented at appropriate times to enhance patient care."

As facilitating aging in place is the central aim of community-based dementia care in the Netherlands, a decision support tool for district nurses and case managers should focus on the three most important practical problems preventing PwD from living at home, as described above (decreased self-reliance, safety-related problems, and informal

care/network-related problems), and provide solutions to these problems. To develop a successful tool that will be used in daily practice, it is essential to involve end-users from the start of the process to make sure that the tool is adapted to their needs (Jaspers, 2009). Therefore, a stepwise, user-centered development process was considered the most appropriate method for designing a decision support tool for professionals with a coaching and coordinating role in community-based dementia care.

The aim of this study was to develop a decision support tool for district nurses and case managers to facilitate aging in place of people with dementia and to test its usability. The tool aims to support the process of problem assessment and provide solutions for problems within the domains of decreased self-reliance, safety-related problems, and informal care/social network-related problems.

2. Materials and methods

A mixed-methods study was conducted to develop, in close collaboration with potential end-users (district nurses and case managers), a decision support tool in the form of an application (App) to be installed on a tablet PC. Fig. 1 shows that the stepwise, user-centered development process was divided into two phases: content development and technical development. For the content development a literature and internet search, and individual and group interviews, were conducted. The technical development took the form of an iterative process of prototype development and usability testing using a think-aloud approach, heuristic evaluation, and a questionnaire to assess level of usability.

2.1. Research setting and subjects

The study was conducted in the region of Limburg in the south of the Netherlands. Participants were recruited from four, long-term care organizations that provide home care and participate in the Living-Lab in Ageing and Long-Term Care, South Limburg (Verbeek, Zwakhalen, Schols, & Hamers, 2013), the Centre of Excellence for Innovative Care and Technology (Centre of Expertise for Innovative Care and Technology, 2015), or the regional care network for dementia care (Hulp bij Dementie, 2016).

The tool was developed for professionals with a coordinating and coaching function in community-based dementia care (e.g. case managers and district nurses). In the Netherlands a case management program has been introduced into community-based dementia care over the past decades (MacNeil Vroomen et al., 2012). Case management is defined as "a collaborative process which: assesses, plans, implements, co-ordinates, monitors and evaluates the options and services required to meet an individual's health, social care, educational and employment needs, using communication and available resources to promote quality cost effective outcomes" (Case Management Society UK, 2017). District nursing can be described as follows: "Home nursing care (wijkverpleging) is provided by district nurses (wijkverpleegkundigen). District nurses assess the needs of their clients and coordinate the care between client, informal carers, GPs, other healthcare professionals and social care professionals involved in the care for the client. They provide nursing care and personal care, such as dressing and bathing" (Kroneman et al., 2016, p. 143).

We purposely selected three groups of participants for the content and technical development of the App. These groups were: first, experienced professionals (district nurses or case managers) working in community-based care, as potential end-users; second, researchers with particular knowledge in the field of gerontology or assistive technology; and third, experts in the field of application development in health care. Table 1 provides an overview of the distribution of participants in both development phases.

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