Involving people with dementia in the development of supportive IT applications: a systematic review

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ABSTRACT

Background: Involving people with dementia in research is not self-evident. Inclusion of people with dementia in the development process of user-friendly, supportive IT applications may be especially useful to improve the quality of these applications and may be beneficial to the person with dementia. The aim of this study was to gain insight into the involvement of people with dementia in developing supportive IT applications. The focus of involvement was on phase, methods, role and impact on the quality of the IT application and on the person with dementia.

Method: A systematic search was undertaken using Cochrane Library, PubMed, PsycInfo, EMBASE, and CINAHL. Publications were selected using the following inclusion criteria: publications had to address a development process of an IT application involving people with dementia. The BMJ checklist was used to assess the quality of the included publications.

Results: Twenty-six publications relating to 15 IT programs met the inclusion criteria. People with dementia were mainly involved in the exploratory and technical development phases. The methods most frequently used to involve the participants were interviews, observations and usability try-outs. In most studies, participants were objects of study and informants. People with dementia provided useful feedback and gave valuable recommendations for researchers and designers regarding the development of user-friendly, supportive, IT applications. Involvement in all phases may have empowering effects on people with dementia.

Conclusion
To develop valuable, user-friendly, supportive IT applications that increase the quality of life of people with dementia involvement in all phases of the development process is of great importance.
1. Introduction

Dementia is a progressive disease that affects not only the patients, but also their relatives. It has been predicted that worldwide the number of people with dementia will increase from 66 million in 2030 to 115 million in 2050 (Ferri et al., 2005; Prince et al., 2011). This will increase the pressure on healthcare systems. Policy-makers emphasize the importance of autonomy and self-management of both the patients and their relatives. It will be necessary for more patients with dementia to remain in the home environment, while nursing homes will have to care for more people in advanced stages of dementia. Thus, smart and creative solutions focusing on preservation of autonomy, self-management, and well-being are needed to support these patients living in the community or care institutions and their relatives.

Policy-makers and researchers often see information technology (IT) applications as promising solutions in this area (Dutch Ministry of Health et al., 2010; Magnusson et al., 2004; Schippers, 2012; World Health Organization and Alzheimer’s Disease International, 2012).

In the last decade, designers and researchers have developed many digital applications to support people with dementia and their formal and informal caregivers. Magnusson et al. (2004) gave an overview of existing supportive IT applications for frail older people including persons with dementia. Lauriks et al. (2007) presented an overview of helpful IT applications for people with dementia in their review. The main areas in which IT applications have been developed are: reminding (e.g. prompting devices), social contact (e.g. reminiscence tools and picture dialling), safety (e.g. tracking devices), daily activities (e.g. music players).

People with dementia often do not use new IT applications because they do not match their needs and capacities: many applications are too difficult to use, contain too many functions, and are not attractive (Hanson et al., 2007). These shortcomings may be due to the poor involvement of people with dementia in development processes of IT applications. Their voice is often ignored (Savitch, 2006; Wilkinson, 2002). Researchers, designers and clinicians focus mainly on caregivers because of the increasing cognitive impairment and frailty of people with dementia.

Exclusion of people with dementia in research may strengthen the stigma attached to dementia (Vernooij-Dassen et al., 2005; Werner and Heinik, 2008). Involvement of people with dementia in development processes may be a way of decreasing stigmatization. Furthermore, such involvement is suggested to increase their autonomy and empowerment, (Cubit, 2010; Hellström, 2007; Nygård, 2006).

Research shows that people with dementia can express their preferences consistently, even in an advanced stage of dementia (Whitlatch, 2009). Their participation in developing supportive IT applications may facilitate the usability and effectiveness of the applications.

Although various digital applications have been developed to support people with dementia and their caregivers, an inventory of their involvement and an overview of involvement methods and the impact of their involvement on the IT application and on the person are lacking. Such an inventory and overview may be useful to researchers, designers and clinicians of such applications. This systematic review aims to provide insight into the involvement of people with dementia in developing supportive IT applications. We consider four research questions:
1. In what phase of development of IT applications are people with dementia involved?
2. Which methods are used to involve them in subsequent phases of the development?
3. What specific role do they have in the development?
4. What is the impact of their involvement on the quality of the IT application and on the person with dementia?

2. Methods

2.1 Search strategy

We systematically searched the Cochrane library, PubMed, PsycInfo, EMBASE, and CINAHL databases. Quantitative, qualitative, and mixed-method publications in all languages with no restriction of date of publication were included up to July 2011. To identify relevant publications, our search was based on three categories key words: ‘dementia’, ‘IT application’ and ‘involvement’. Each category was explored for synonyms to find relevant key words (Mesh, Thesaurus and Tree) and resulted in a search string. We started in PubMed and translated the search strings to the other databases. The appendix shows the complete search string in PubMed.

We also cross-referenced reference lists of the included publications (backward and forward).

2.2 Selection of publications

For inclusion, the publications had to focus on the development of a computer application involving people with dementia, irrespective of the type or stage of dementia. Two researchers (MS and MH) independently screened the collected publications, by title, abstract, and full text respectively. Any discrepancy by researchers regarding inclusion were resolved by discussion.

2.3 Quality assessment of the publications

The BMJ checklist for qualitative research (www.bmj.com) was used to assess the quality of the publications on studies with a qualitative approach. No suitable checklist was available to assess the publications with a descriptive, quantitative, and mixed-method approach. Because most of the criteria of the BMJ checklist contain generic characteristics and address basic principles of reporting research (e.g. explication of theoretical framework and methods used, clearly described sampling strategy) we decided to also assess the quality of these publications with the BMJ checklist. MS and MH assessed the included publications independently. They rated publications that matched the quality criteria of the checklist as fulfilled (+), not fulfilled (-) and unknown (u) if the criterion was not described in the publication. Discrepancies were discussed until consensus was reached.
2.4 Analysis

MS and MH drew up an inventory of the characteristics of the publications focusing on the following research characteristics: type, quality, method of the study and type of IT application. The involvement characteristics described the participating people with dementia, the phase in which they were involved; the methods used to involve them; their role; and the impact of their involvement on the IT application and on the person with dementia. Analyses focused on these involvement characteristics.

2.4.1 Phases of the development involving people with dementia

We used Brender's classification (2006) to assess the development phases in which people with dementia were involved and to compare the phases of involvement of these effectively. The four development phases were the explorative, technical developmental, adaptation, and evolution phases:

1. The explorative phase consists of the analysis and planning phase along with the feasibility of realization. This phase ends with a user requirement specification.
2. The technical development focuses on technical requirements: whether the IT-based solution can be used in everyday operations. Assessment activities in this phase have an experimental character and are not assessed in real-life conditions.
3. In the adaptation phase (including the pilot phase), when the IT-based solution is put into daily operation, activities focus on extensive adaptations of the IT system. Errors, omissions, and shortcomings of the system (e.g. cognitive and ergonomic aspects) have to be identified to achieve a stable situation.
4. The evolution phase starts when the IT-based solution is in a stable condition and most important problems have been solved. In this phase new developments are initiated and any effects and impacts of the IT-based solution are measured. This phase ends when the IT-based solution is replaced by another one.

2.4.2 Methods used to involve people with dementia in different phases of the development

Our inventory of the methods used to involve people with dementia in the different phases of development was also based on Brender (2006) describing the involvement methods associated with each phase.

2.4.3 Role of people with dementia in the development

To assess the role of people with dementia, we developed a classification based on Steen (2008). Users participate in development processes in various roles, depending on the goals of the researchers. User roles are classified as: objects, informants, and co-designers or partners (Steen, 2008). When users are the object of study, researchers focus on observing what people do to understand the users’ implicit and nonverbal needs. In the second role, where users are the subjects of study or reactive informants, researchers are interested in what people say about the application. Interviews and focus groups are used as methods of gaining information from people. The third role, in which users participate as co-designers and partners in their role as consumers, enables users to cooperate creatively with researchers and designers in all phases of development.

2.4.4 Impact of involving people with dementia in the development
As there was no valid classification of the impact of involvement on the IT application at hand we used the descriptions of this impact that were provided in the studies included. The descriptions were subdivided in; impact on the quality of the IT application and on the person with dementia.

To gain insight into the impact of involving people with dementia on the quality of the IT application we made an inventory of aspects of the IT application reported on in the included studies on which people with dementia gave their feedback (e.g. interface, user-friendliness, effects and accessibility).

To analyse the impact of involvement on people with dementia as persons we extracted possible effects, positive ones as well as negative ones (e.g. increased feelings of well-being) from the included studies.

3. Results

The search strategy resulted in 893 potentially relevant citations (Figure 1). Screening of titles, abstracts, and full texts resulted in 19 publications that met the inclusion criteria. Additional hand-searching of the references of these publications identified another seven relevant papers. We included a total of 26 papers (related to 15 IT programs) published between 2003 and 2010. The most frequent reasons for exclusion were the involvement of others than people with dementia and the absence of a developmental process for an IT application.

3.1. Description of the studies

Of the included 26 publications 16 publications used a qualitative approach; four used a quantitative one; whereas six used a mixed-method one. The publications described a variety of developed IT applications: interaction tools, conversation aid, supportive system, tracking devices, music tools, activities of daily living and support at home. In four papers (related to two IT programs), the tool was unknown at the start of the project (Meiland et al., 2010; Meiland et al., 2007; Nugent et al., 2007; Sixsmith et al., 2007b). The tool to be developed was derived from an inventory of needs (Table 1).

As the IT applications varied, so did their aims: the tools were used to gather customized information, to get insight into personal needs, to give pleasure, to support interaction and communication, to increase autonomy, to test and evaluate the tool, to improve the device, and to improve the quality of life (Table 1).

People with mild dementia were most often involved: they participated in 12 publications. People with moderate dementia participated in 10 publications mostly in combination with involvement of people with mild dementia. The phase of dementia was often measured with the Mini-Mental State Examination (MMSE). Seven publications did not mention any classification at all. Two publications (one IT program) did not consider classification relevant, although the MMSE score was known (Sixsmith et al., 2007a; Sixsmith et al., 2007b). None of the publications focused exclusively on the involvement of people with severe dementia (Table 1).

The methodological quality of the 26 publications was modest (Table 2).
3.2 Phases of the development involving people with dementia

Most publications involved people with dementia in the first two phases: 13 publications involved in the explorative phase to identify user needs and 11 publications in the technical development phase by having them use the device. In this way, researchers gathered information about technical problems, deficiencies, omissions, and obstacles to improve the system. Only three publications involved people with dementia in the adaptation phase (Astell et al., 2007; Hanson et al., 2007; Riley et al., 2009), whereas none of the publications involved them in the evolution phase (Table 3).

3.3 Methods used to involve people with dementia in different phases of the development

The different phases in the development of IT applications showed different methods for collecting data: interviews were used, mostly to identify needs and to assess user satisfaction; usability research was conducted to assess user friendliness. Other methods used were observations, focus groups, workshops, questionnaires and self-assessments often combined with video records and audio records. All publications described two or more methods of collecting data. The publications described no standardized measure or protocol regarding the involvement of people with dementia (Table 3).

3.4 Role of people with dementia in the development

Although people with dementia were involved in all publications, their role differed depending on the aim of researchers. In most publications people with dementia were involved as object of study or informant; researchers were interested in information related to their research questions rather than in the effects of participation of people with dementia. In two publications researchers were also interested in the impact of participation of people with dementia on their well-being. It is striking that these researchers involved people with dementia as co-designers (Hanson et al., 2007; Robinson et al., 2009) (Table 4).

3.5 Impact of involving people with dementia in the development

3.5.1 Impact on quality of IT application

Depending on the methods used and their role, people with dementia gave their opinion, feedback, and useful comments: recommendations to researchers and designers to develop or improve the device. The feedback addressed various aspects of the development. The end users had problems with the interface: the screen was too small (Davies et al., 2009), the touch screen was too difficult (Topo et al., 2004) and the language used was too difficult (Riley et al., 2009). Two publications mentioned the importance of personalization to end users such as a private section on websites (Bewernitz et al., 2009; Nugent et al., 2008). In one publication involvement of people with dementia even resulted in the development of two new individualized devices, because the end users did not like the size, colour, and design of the first developed IT applications (Robinson et al., 2009).

3.5.2 Impact on the person with dementia

Most publications did not ask the question of impact on the person of dementia explicitly. No study reported negative effects. Publications focusing on involving people with dementia in the developing process emphasized the importance of their feedback as well as
the impact on people with dementia as persons. These researchers noticed “empowerment effects in an increased feeling of well-being and an enhanced sense of control” as results of participation of persons with dementia in the research. The participants enjoyed the involvement, were enthusiastic about technology design and were happy to learn a new skill (Astell et al., 2009; Astell et al., 2010; Hanson et al., 2007; Robinson et al., 2009).

One publication mentioned how involvement in the development enabled people with dementia to participate as equal partners (Astell et al., 2009).

4. Discussion
This review studied the research literature concerning the involvement of people with dementia in developing supportive IT applications. From a list of 893 potentially relevant citations, only 26 publications of modest quality related to 15 IT programs could be selected. In most of these studies involvement of people with dementia was limited to the first phases of the development process, although more recent studies seem to intensify and extend the involvement to the later phases.

Results show that people with dementia were most often involved in the explorative and technical development phases while interviews, observations, and usability were the most used methods. Researchers were mostly interested in information regarding their research questions and therefore people with dementia were most often involved in the development in the role of ‘object of study’ and ‘informant’. Their involvement improved the usefulness and acceptability of the device. Most researchers and designers of the 26 studies acknowledge the importance of involving people with dementia, although their view of when to involve them varied.

4.1 Possible reasons for lack of involvement of people with dementia
The distress of people with dementia when devices do not work is an often described phenomenon. For this reason, some researchers did not involve them until the prototype of the device had evolved into a fairly advanced version. They were afraid that the first versions of the prototype could distress people with dementia if they used these IT applications still being in their infancy (Orpwood et al., 2007; Riley et al., 2009). Other researchers, however, did not observe any such distress (Hanson et al., 2007; Robinson et al., 2009). The lack of involvement of people with dementia in application development may be partly due to this phenomenon of anticipated distress. Despite the possibility of distress, many respondents of the included studies enjoyed participating in the research, and their well-being seemed to increase. This confirms the assertions of Whitlatch and Menne (2009), Savitch and Zaphiris (2006), Hellström (2007) and Nygård (2006) concerning the importance of involving people with dementia in research.

Another factor hampering the involvement of people with dementia is their increasing cognitive impairment and frailty (Whitlatch, 2009). Several of the included researchers give recommendations to overcome these barriers; e.g. prioritize the well-being of participants, allow ample time, provide active and continuous support, and provide a satisfactory location for meetings. It is recommended to adapt procedures to the capacities and experiences of this target group (Hanson et al., 2007; Riley et al., 2009; Topo et al., 2004). The findings of this review suggest that cognitive impairment is no reason to exclude people with dementia from research. Nevertheless, ethical aspects and considerations are important when involving persons with dementia in development processes because of their vulnerability. A careful design is a conditio sine qua non.
The limited involvement of people with dementia in research may also be due to the stigma attached to dementia. Werner and Heinik (2008) report high levels of structural discrimination. Vernooij-Dassen and colleagues (2005) highlight the effect of the dementia-related stigma on professionals which resulted in delayed diagnosis and pessimism about prognosis. This professional attitude may also have led researchers to think that people with dementia may be incapable of contributing to the development of IT applications. This review shows that involvement of people with dementia in the development of IT applications contributes to the quality of the IT application and may have empowering effects on people with dementia. Therefore, involving them in developing supportive IT applications may help reduce the stigma that adheres to dementia.

Our findings may increase the optimism about the capacities of people with dementia. Recently, several authors have described the learning potential of people with dementia (Dechamps et al., 2011; van Halteren-van Tilborg et al., 2007; van Tilborg et al., 2011). Whereas Riley and colleagues (2009) mention the “inability of people with dementia to learn new skills” other researchers conclude the opposite: there were empowering effects on people with dementia who were happy to learn a new skill (Freeman et al., 2005; Hanson et al., 2007; Magnusson et al., 2004).

4.2 Methodological strengths and limitations
This review has some methodological limitations. There was no suitable tool for assessing the quantitative and mixed-method publications. Therefore, we assessed all publications (qualitative, quantitative, and mixed method) with the BMJ checklist for qualitative research. The availability of an adequate checklist assessing quantitative aspects of these publications would have led to more detailed feedback regarding the quality of these publications. However, the current evaluation of the quality of the publications seems to be valid given the generic characteristics of most criteria of the BMJ checklist. It provided an adequate insight into the quality of the included publications.

The data on the impact of involvement of people with dementia on the IT application and on the person with dementia were of limited quality. We recommend that future research incorporates research questions addressing these topics explicitly and uses adequate measures in systematic research.

The strength of this review lies in the rigor achieved in reviewing the data. This includes: (i) the extensive search of five databases and a complementary hand search of relevant and included publications, (ii) the absence of restrictions regarding language and year of publication, (iii) the independent reviewing of two researchers, and (iv) the use of a standard method to assess the quality of the papers.

4.3 Practical implications
Some practical implications can be noted. In this review, we found that people with dementia were involved in varying degrees in the development of IT applications. Researchers who were interested in and focused on involving them discussed the subject most positively and explicitly during the whole development trajectory (Hanson et al., 2007; Robinson et al., 2009). The publications of these researchers were the only ones that involved people with dementia as co-designers. This may be of interest for future studies. Researchers and designers are advised to elaborate on how they want to involve people with dementia in the development of supportive IT applications. They should decide in advance on the role of people with dementia: object of study, informant, or co-designer because
involvement of persons with dementia in research leads to better attuned IT applications. Furthermore, our study shows that designers may do well to take into account regular consumer matters such as the design, colour, and size to increase the usefulness and acceptability of IT applications. In choosing an IT application clinicians may consider whether and how persons with dementia were involved in the development process. Furthermore, they may want to know whether the stage of dementia of people with dementia involved in the development process matches with the stage of dementia of the users of the IT application in clinicians’ practices. Problems in the implementation of a tool may be due to the fact that persons with dementia were not adequately involved in the development process. Involvement of persons with dementia in the development process should be an important criterion for clinicians when choosing an IT application.

5. Conclusion
Involving people with dementia in developing supportive IT applications is a limited and fairly recent phenomenon. People with dementia were most often involved in the explorative and technical development phases. Only a few publications described their involvement in all stages of development (research question 1). Interviews, observations, and usability were the most used methods, and all studies combined two or more methods (research question 2). People with dementia were most often involved in the development in the role of ‘object of study’ and ‘informant’ (research question 3). Their involvement improved the usefulness and acceptability of the device and may have empowering effects (research question 4). The results of this review suggest that people with dementia can participate in research and provide useful feedback on IT applications. In future research we expect more involvement of people with dementia in all development phases of IT applications.

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Authors’ contributions
All authors contributed to the study design. M. Span collected the data and wrote the initial draft of the paper. M. Hettinga participated as the second assessor in the review process. C.H.M. Smits and M. Hettinga assisted M. Span in writing the article. M.J.F.J. Vernooij-Dassen and J.A. Eefsting critically revised the paper.

Conflict of interest
None.
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