

Developing a Supportive Tool to Facilitate Shared Decision Making in Dementia

Involvement of end users in the design phase

Marijke Span, Marike Hettinga, Carolien Smits, Leontine Groen-van de Ven, Jan Jukema
Windesheim University of Applied Sciences
Zwolle, The Netherlands
m.span@windesheim.nl, m.hettinga@windesheim.nl,
chm.smits@windesheim.nl, lm.groen-
vande.ven@windesheim.nl, js.jukema@windesheim.nl

Myrra Vernooij-Dassen
Radboud University Nijmegen, IQHealth Care and
Department of Primary Care, Kalorama Foundation,
Radboud Alzheimer Centre, Nijmegen, The Netherlands
myrra.vernooij-dassen@radboudumc.nl

Jan Eefsting
EMGO+ Free University Medical Centre of Amsterdam,
The Netherlands
j.eefsting@zgjiv.nl

Abstract— Developing an IT application facilitating Shared Decision Making (SDM) in dementia is complex. This is caused by the increasing cognitive decline associated with dementia and the number of involved people (people with dementia, informal caregivers and case managers). The aim of this study is to identify design issues in developing a user-friendly IT application facilitating Shared decision-making in dementia. Data collection in this study with an iterative participatory design based on the CeHRes roadmap included: focus group interviews with people with dementia, informal caregivers and case managers; a cognitive walkthrough with researchers; and a first usability test with case managers. This resulted in a list of issues addressing the quality of the system, content and service and a revision of the tool before informal caregivers and people with dementia will be invited to participate in usability tests.

Keywords—shared decision-making, dementia, supportive device, design, co-creation

I. INTRODUCTION

Dementia is a degenerative disease that increasingly affects people worldwide; from 66 million in 2030 to 115 million in 2050 [1, 2]. Decreasing abilities address memory loss, oute planning, behavioral change and orientation problems among other things. People with dementia and their informal caregivers are faced with many problems and decisions addressing both care and well-being [3, 4]. Unfortunately, participation of people with dementia in decision-making processes is not self-evident [5].

Shared Decision Making (SDM) is an approach that involves patients in making medical decisions in collaboration with professionals. [6, 7]. SDM increases patient autonomy and empowers the patient [5]. Several decision aids (digital or paper based) have been developed to facilitate SDM in medical decisions in the clinical setting. Our research program aims to develop an IT application to facilitate case managers in supporting SDM in care networks of people with dementia in a community setting.

This IT application distinguishes itself from existing IT applications in aiming to do justice to all involved parties, both in decision-making and in its design and development. With regard to SDM, the new IT application differs from existing decision aids. First, people with dementia and their caregivers have to make many decisions over time versus single –issue decisions. Second, the new IT application has to take into account the (decreasing) cognitive capacities of people with dementia versus decision aids that focus on cognitive able people. Third, SDM in dementia is characterized by a variety of involved persons, a network, versus regular decision aids focusing on patient-clinician relation. Fourth, decisions people with dementia and their informal caregivers have to make concern mainly care and well-being aspects, versus medical decisions in traditional decision aids.

The new IT application aims to increase the influence of people with dementia in decision-making by giving them a voice in the decision-making process of care and well-being related issues.

This paper is organized as follows. Section II elaborates on the complexity of designing an IT application in dementia networks. Section III describes the design and methods used. Section IV presents the main results: design issues. Finally, Section V provides a conclusion and future work.

II. BACKGROUND

Developing an IT application facilitating SDM in dementia is complex because it involves a variety of people (people with dementia, informal caregivers and case managers) with different capacities and different interests and the cognitive decline inherent to dementia. Computer interfaces do not fit all persons. Older persons and disabled persons, e.g., persons with dementia are not average web users. They have problems using a ‘one size fits all’ computer interface [8]. Zaphiris et al. [9] distinguished guidelines when designing computer interfaces for older people in their review (e.g., information should be concentrated mainly in the center; clear navigation should

be provided; screen layout should be simple, clear and consistent; colored text on colored background should be avoided). Savitch and Zaphiris [10] noticed that the terminology and phrases used when designing for people with dementia are extremely important – possibly more so than for the average web user. Several researchers give dementia related interface recommendations to designers: facilitating an easy orientation [11, 12]; using cues that are familiar; legible and distinctive [13]; using touch screens, large format screen and large font sizes, minimal use of text; use of a hypermedia structure with limited options for selection, and an attractive design [14]; using tablets [15]. Less information is available addressing design of interactive IT applications for users with different capacities. Nevertheless, involvement of end users is mentioned as an important feature [16]. Moreover, involvement of people with dementia leads to better attuned IT applications [17].

The present study, developing an IT application facilitating SDM in dementia, is part of a major research program on SDM in care networks of people with dementia aiming to improve professional care. Besides, developing theory building and competencies for case managers, developing a supportive IT application to facilitate SDM in dementia care networks aiming to contribute to dementia care practice. In a prior study we identified user requirements to determine the content of such an IT application [18]. This paper focuses on designing the computer interface that has to take these user requirements into account. The aim of this study is to identify design issues. The research question read: which design issues can be identified in developing an IT application facilitating SDM in dementia.

III. APPROACH

In this study with an iterative participatory design we consider involvement of end users, particularly people with dementia [17], as one of the key factors for developing a user-friendly and usable IT application.

We used the CeHRes (Center for eHealth Research and Disease Management) roadmap for the development of the IT application, because this approach connects a Human Centered Design with eHealth Business Modeling and emphasizes the importance of involving all stakeholders to develop sustainable innovations [19]. The CeHRes roadmap offers a holistic framework consisting of five phases: contextual inquiry phase; value specification phase; design phase; operationalization; and summative evaluation. This paper describes the third phase, the design of the IT application facilitating SDM in dementia.

A. Focusgroup interviews

First, eight focus group interviews were organized with end users including people with dementia, informal caregivers and case managers. The goal of these focus group

interviews was to receive feedback on the first mock-ups of the IT application, the DEcideguide (Figure 1). The mock-up, including 11 slides, was presented in the focus groups [19]. End users were asked to comment on the different slides in common, textual, in content, on user -friendliness and on the (attractiveness of) design.

Twenty-seven end users participated in the six focus group interviews. The two focus group interviews with people with dementia and informal caregivers consisted both of six and four participants respectively. The focus group interviews with case managers consisted both times of the same seven participants. Participants of the second focus groups commented both on the mock-up and the feedback of the first focus group. The principal researcher, assisted by another researcher or designer, moderated the focus groups.

People with mild to moderate dementia were recruited from two day-care centers. Informal caregivers were recruited from residential homes and the Dutch Alzheimer Association. Case managers were recruited from regional case managers' networks. All participants gave their written informed consent. The focus group interviews that lasted 1-2 hours were audio taped and transcribed verbatim.

Framework analysis was used to analyze the focus group interview transcriptions [20]. The three levels of assessing design quality of the CeHRes was used as framework to identify design issues: system quality (technology that is user-friendly and safe), content quality (content that is understandable and meaningful) and service quality (service that is timely and persuasive) [21].



Figure 1. Concept SDM application. Perspective of people with dementia used in focus groups

B. Cognitive walkthrough

Second, a cognitive walkthrough session with researchers was organized to test the first interactive prototype of the DEcideguide (Figure 2). During a two hours session three researchers tested the DEcideguide using a case with the perspectives of a person with dementia, an informal caregiver and a case manager to identify bugs, possible user problems and testing the user friendliness. The session was audio and video taped. The analysis of the

transcripts focused on identifying (additional) design issues to the focus group interviews related to system, content and service quality.

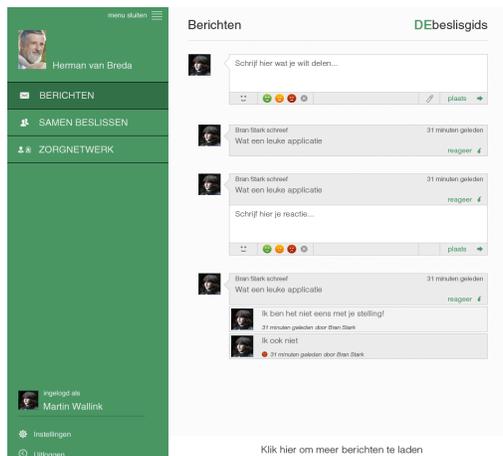


Figure 2. Chat in the DEcideguide used in cognitive walkthrough and usability test

C. Usability tests

Third, usability tests were performed with the adapted interactive prototype of the DEcideguide (Figure 2). The goal of these usability tests is to further refine the DEcideguide into a prototype that is robust enough to be used in a pilot study [22]. Case managers tested the working prototype in a two hour Think aloud session [20]. The session was audio and video taped and transcribed verbatim. The analysis of the transcript focused on identifying additional design issues. After adjusting the DEcideguide, usability tests will be conducted with elderly, informal caregivers and people with dementia in succession. We chose for this iteration in participants to iron out major bugs in an early stage in order to enable end users to focus on the refinement of the DEcideguide.

IV. RESULTS

A. Focus group interviews

All respondents participated because they experience decision-making in dementia as an important and difficult area. They expect a supportive tool to be very useful and helpful. The design issues that arose from feedback of respondents could be assigned to the three levels of design quality: system; content and service quality. Design issues addressed mainly the system quality and the content quality. Case managers were the only respondents who commented directly on the service quality. They considered the tool as very nice and useful for their practice. All respondents commented on the content quality and agreed about the difficulty of the content: too much and too difficult. Moreover, case managers’ comments on the content of the tool focused on extra options they would like: e.g., skype,

agenda, domotics, and separate communication with family members. Informal caregivers commented in particular on terminology. Similar questions were removed and synonym, more familiar, words given (e.g., ‘social contacts’ changed into ‘family and friends’). People with dementia advised simplifying the tool in words and size. Most feedback addressed the system quality. Main comment of all participants focused on the ‘ease of use’ that was failing (Table 1).

TABLE 1 DESIGN ISSUES IN DEVELOPING THE DECIDEGUIDE

Design quality	Identified design issues
System quality	
User-friendliness	<p><i>‘Nice to have’s</i></p> <ul style="list-style-type: none"> -Adding things like an agenda; personalized part in tool for case managers; linking with domotics; skype function -Alerts for daily activities (taking medication; eating etc) <p><i>Navigation structure/ease of use</i></p> <ul style="list-style-type: none"> -Too much screens for people with dementia (cm/ pwd)^a -Simplifying the screens for people with dementia (pwd) -Too many examples with too many colors with too small letters (not all pwd agreed) -messy screens with too much information (ic) -Messages in timeline with chat become a big mess (cm) <p><i>Presentation of content</i></p> <ul style="list-style-type: none"> -use of smileys is clear but not really nice (pwd) -use of colors red, orange and green is nice. Use of smileys is a bit childlike (if) -frequency of monitor question differs per network. Monitoring well-being is important (ic) -Attention for use of red color in tool. Red smiley is similar to feeling not well. Using also red color for a (neutral) theme suggests ‘danger’ (ic) - use of colors in messages is not clear/distinguishing enough (cm+ic)
Design persuasiveness	<p><i>Lens for design</i></p> <p>All network members view all messages because the starting point of the tool is transparency and open communication. This is not always advisable for person with dementia. (cm)</p>
Content quality	
Comprehensibility	<p><i>Comprehensibility/Terminology=semantic shortcomings</i></p> <ul style="list-style-type: none"> -Use of some terms is not clear enough and tool difficult; e.g., options and pros and cons of options (pwd) -Use of terms is not specific enough; e.g., ‘How are you right now?’ instead of ‘How are you today?’ (pwd) <p><i>Accuracy</i></p> <ul style="list-style-type: none"> - Date and year are incorrect (pwd+ic) <p><i>Relevance</i></p> <ul style="list-style-type: none"> - Open questions are less attractive than question that also offer examples. - tool is too directive (pwd) - tool is directive: easy to use because you don’t have to invent answers by yourself (ic) -adding a wish button... (ic)
Service quality	
Perceived usefulness	<ul style="list-style-type: none"> - the tool is very useful in facilitating SDM in dementia but how useful will it be for people with dementia? (cm)

^aPwd=person with dementia; ic=informal caregiver; cm= case manager

B. Cognitive walkthrough

The cognitive walkthrough with the research team resulted in a fundamental discussion that addressed the complexity of the context of decision-making in dementia. Researchers commented mainly on the complexity of the DEcideguide in particularly for people with dementia. Researchers argued that the desirable starting point of the DEcideguide, transparency between all network members, easily conflicted with the well-being of people with dementia. Researchers advised to simplify the DEcideguide for those end users.

C. Usability tests

The feedback of case managers addressed mainly the system quality. A variety of bugs was detected together with lack of user-friendliness and presence of too many technical errors. Case managers commented also on service quality. They experienced the tool as very useful and helpful to their daily practice but in the mean time they doubted whether the tool would be useful for the current group of people with dementia because of the lack of computer experience of that group. In their opinion the transparency in the DEcideguide can be confronting and therefore conflicting with the well-being of people with dementia. Many people with dementia are suspicious. On the one hand, transparency helps to decrease suspicion. On the other hand, transparency can give an overload of information that people with dementia cannot cope with and could result in restlessness. The comments of the case managers resulted in a revision of the DEcideguide. After this revision is finished other end users will test the DEcideguide (Table 1).

V. CONCLUSION AND FURTHER WORK

The design phase of the DEcideguide resulted in a list of design issues addressing mainly user friendliness and comprehensibility. Both researchers and case managers considered that the starting points of the DEcideguide, transparency and open communication, probably conflict with the overall well-being of people with dementia because it provides too much information. The usability tests with informal caregivers and people with dementia will show whether this dilemma will be confirmed or not. Developing an IT application for various end users with different capacities and interests requires involvement of all end users in the design phase of the development trajectory.

The next step, after finishing the usability tests, is conducting a pre-pilot with the refined tool with a dementia network consisting of a person with dementia, informal caregivers and a case manager acting in daily life. Then, a five-month pilot study will be conducted and evaluated.

ACKNOWLEDGMENT

The Dutch Foundation Innovation Alliance (SIA RAAK [Regional Attention and Knowledge Circulation] PRO), Zorgpalet Hoogetveen (Residential care organization for older adults) and Windesheim University of Applied Sciences funded this study.

REFERENCES

- [1] M. Prince, R. Bryce, and C. Ferri, "World Alzheimer Report 2011," 2011.
- [2] C. Ferri, et al., "Global prevalence of dementia: a Delphi consensus study," *Lancet*, 2005. 366: pp. 2112-2117.
- [3] G. Livingston et al., "Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK," *BMJ*, 2010, 341((aug 18 1) c4184).
- [4] H.G. van der Roest et al., "What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services," *International Psychogeriatrics*, 2009, 21(05), pp. 949-965.
- [5] M. von Kutzleben, W.Schmid, M. Halek B.Holle, S. Bartholomeyczik, "Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia," *Aging & Mental Health*, 2012, 16(3), pp. 378-390.
- [6] G. Elwyn, A. Edwards, and P. Kinnersley, "Shared decision-making in primary care: the neglected second half of the consultation," *British Journal of General Practice*, 1999, 49, pp. 477-482.
- [7] G. Elwyn et al., "Developing a quality criteria framework for patient decision aids: online international Delphi consensus process," *BMJ*, 2006.
- [8] P. Zaphiris, M. Ghiawadwala, and S. Mughal. "Age-centered Research-Based Web Design Guidelines," in *Proceedings of CHI 2005 Conference on Human Factors in Computing Systems*, 2005, Portland, USA.
- [9] P. Zaphiris, S. Kurniawan, and M. Ghiawadwala, "A Systematic Approach to the Development of Research-Based Web Design Guidelines for Older People," *Universal Access in the Information Society Journal*, 2007, 6(1), pp. 59-76.
- [10] N. Savitch and P. Zaphiris. "Accessible websites for People with Dementia: a Preliminary Investigation into Information Architecture," in *ICCHP*, 2006.
- [11] K. Day, D. Carreon, and C. Stump, "The therapeutic design of environments for people with dementia: a review of the empirical research," *The Gerontologist*, 2000, 40(4), pp. 397-416.
- [12] L. Mitchell et al., "Making the outside world dementia friendly: design issues and considerations," *Environment and Planning B: Planning and Design*, 2003, 30, pp. 605-632.
- [13] E. Burton and L. Mitchell, "Urban design for longevity," *Urban Design Quarterly*, 2003, 87, pp. 32-35
- [14] N. Alm et al., "Making software accessible for users with dementia," In J. U. Lazar (Ed.), *Niversal usability: Designing computer interfaces for diverse users 2007*, Wiley: New York. pp. 299-316.
- [15] F.S. Lim et al., "Usability of tablet computers by people with early-stage dementia," *Gerontology*, 2013, 59, pp. 174-182.
- [16] H. Beyer. and K. Holzblatt, *Contextual Design. Defining Customer-Centered Systems*, 2010, Morgan Kaufmann Publishers.
- [17] M. Span et al., "Involving People with Dementia in the Development of Supportive IT Applications: a Systematic Review," *Ageing Research Reviews* 2013, 12, pp. 535-551.
- [18] M. Span et al., "Towards an Information Technology Application that Supports Shared Decision Making in Dementia: Identifying User Requirements," Unpublished.
- [19] J.E.W.C. Van Gemert-Pijnen et al., "Introducing a holistic framework for eHealth technologies," *Journal of Medical Internet Research*, 2011, 13 (4):e111.
- [20] N. Nijland, "Grounding eHealth: towards a holistic framework for sustainable eHealth technologies," University of Twente, Enschede, 2011. ISBN: 9789036531337
- [21] J. Brender, *Handbook of Evaluation Methods for Health Informatics*. 2006: Elsevier Academic press, USA. ISBN-13: 978-0-12-370464-1
- [22] J. Ritchie and L. Spencer, eds. "Qualitative data analysis for applied policy research," in Bryman and Burgess, eds., *Analysing Qualitative Data*. 1994: London: Routledge pp.173-194.