Towards an Interactive Web Tool That Supports Shared Decision Making in Dementia: Identifying User Requirements

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Abstract— To support shared decision making in care networks of people with dementia, an interactive web tool for people with dementia, informal caregivers, case managers and other professional caregivers is being developed. This study aims to identify user requirements for such a tool. A multiple method study with an iterative, participatory design was conducted. Data collection involved 50 semi-structured interviews with end users (people with dementia, informal caregivers, case managers and other professional caregivers), eight focus group interviews with end users and experts, a dementia expert consultation, and two multidisciplinary workshops. Content analysis was applied to the data and resulted in two sets of user requirements for the interactive web tool. The first set of user requirements consists of care and well-being related topics addressing decision making in dementia. Most important topics are care, daily activities, mobility, safety, future, finances, living, and social contacts. The second set of user requirements addresses additional needs and preferences of end users such as: participation of the person with dementia in the decision-making, insight into the decision history, anticipation of possible future problems and decisions, and the degree of self-management and autonomy preservation of the person with dementia. The two sets of user requirements form a solid basis for the further development of a user-friendly, interactive web tool facilitating shared decision making in care networks of people with dementia.

Keywords- dementia, decision making, user requirements, participatory design, assistive technology.

I. INTRODUCTION

This study focuses on the development of an interactive web tool to facilitate shared decision making in care networks of people with dementia [1]. Dementia is a degenerative disease affecting increasing numbers of people worldwide [2][3]. Over a prolonged period of time people with dementia and their caregivers are faced with many problems and decisions [4][5][6]. Decision-making in dementia is complex; it involves multiple participants with different capacities and interests [7].

To better understand the needs and preferences of people with dementia, it is important to include them in the decision-making [8][9][10][11]. Research shows that involving people with dementia in decision-making increases well-being [9] and quality of life [12] for both the person with dementia and the informal caregiver. Informal caregivers also show lower levels of depression and lessened relationship strain [12]. However, professionals and informal caregivers do not include people with dementia in decision making as a matter of course [8][9].

Shared decision making (SDM) is a way to involve patients in decision making by emphasizing the collaboration between professionals and patients in making a shared decision [13]. There are seven consecutive steps in SDM: identifying problems, information exchange, clarifying preferences and values, presenting and exploring options,

discussing pros and cons of the options, deciding together, and evaluating the decision [14][15][16][17]18]. SDM increases patient autonomy and empowers the patient [19]. This could also benefit people with dementia, who are well able to express their needs [8]. Moreover, they are capable of expressing their preferences, even in an advanced stage of dementia [20].

Case management in dementia is implemented differently. In Europe, Canada, and the United States, community-dwelling patients diagnosed with dementia and their caregivers may receive case management support [21]. In The Netherlands case management is offered to people with dementia. Case management in the Dutch context aims to support informal caregivers and people with dementia during the complex care trajectory. Moreover, it aims enabling people with dementia to live independently as long as possible [22]. As case management for dementia is a fairly recent phenomenon, case managers need support to address the complex needs and preferences of people with dementia and their caregivers, possibly in the form of tools [23].

Although research increasingly focuses on dementia, SDM or supportive tools separately, studies that combine these elements are lacking. Thus far, existing decision aids have supported SDM in various patient groups by means of supporting discussion of value-based choices and options about single decisions [24]. Most decision aids facilitate SDM in single medical decisions in the clinical area [18][25].

The new interactive web tool differs from existing decision aids in at least four aspects. First, people with dementia and their caregivers have to make many decisions over a prolonged period of time in the order of years, as opposed to single-issue decisions. Second, the web tool has to take into account an ongoing cognitive decline in contrast to existing decision aids that focus on cognitively able people. Third, the person with dementia is part of a network of informal and professional caregivers who may participate in decision-making. Regular decision aids focus mainly on the patient-clinician relation. Fourth, the decisions of people with dementia and their caregivers are not just about single medical decisions, as the existing decision aids are, but also about multiple care and well-being decisions. Besides, aimed end users of the interactive web tool are people with dementia, informal caregivers, case managers and other professionals.

To develop user-friendly and useful tools involvement of both end users [26][27] and other interested parties [28][29] in developing IT applications is important. We used the Center for eHealth Research and Disease Management (CeHRes) roadmap to increase a structural embedding of the new interactive web tool in practice [29]. This roadmap offers a holistic framework of five phases: contextual inquiry, value specification, design, operationalization, and summative evaluation. This paper describes the phase of value specification (analyzing the preferences of all those concerned). Therefore, this study aims to identify user

requirements for an interactive web tool facilitating shared decision making in dementia of all participants involved (people with dementia, informal caregivers, case managers and experts).

The research questions are: 1) What topics can be identified for an interactive web tool facilitating shared decision-making in dementia? 2) What additional needs and preferences regarding an interactive web tool facilitating shared decision making in dementia can be identified?

This paper is organized as follows. Section II describes the design and methods of this study. Section III presents the results in detail. Section IV addresses the discussion of the findings of this study. The paper closes with the conclusions in section V and the acknowledgment.

II. DESIGN AND METHODS

This multiple method study with an iterative participatory design is part of a larger longitudinal study on decision making in care networks op people with dementia [1]. To guarantee rigorous development, we used multiple data sources to answer the research questions [30]. For both research questions the same data set was used: 50 interviews and 8 focus group interviews. The focus group interviews were organized on the basis of the findings of the individual interviews to enhance data richness [31][32]. In addition, an expert consultation was undertaken for research question 1 and two multi-disciplinary workshops for research question 2. Table I provides an overview of the characteristics of methods used.

All participants gave their written informed consent. Special attention was paid to the informed consent of people with dementia in order to be sure of their voluntary participation. In line with Murphy and colleagues [33], we invested in ongoing consent. This started with time for social talk in order to get to know the person. After gaining initial consent we checked their consent during the interview. We ended the interview with a positive affirmation by emphasizing the importance of their contribution. The investigators were careful to notice any signs, non-verbal or otherwise, of discomfort or restlessness. In such a case, the participant was given ample opportunity to quit. People with dementia who were unable to give written consent because the form confused them were asked for their verbal consent (recorded on audio tape). The focus group participants at the day care center were first informed and then asked for their consent in a group meeting. Afterwards, they were explicitly and individually asked for their consent for participation.

A. Analysis

To answer research question 1, content analysis was used starting by reading and rereading the (focus group) interview transcripts [30]. For this research question paragraphs in the text that addressed problems and decisions were of interest. Therefore, two researchers coded the interviews independently focusing on experienced problems and decisions. They then clustered the identified problems and

TABLE I. CHARACTERISTICS OF METHODS USED ADDRESSING RESEARCH QUESTION 1 AND 2

Research Questions			
1. What topics can be identified for an interactive web tool facilitating shared decision-making in dementia? 2. What additional needs and preferences regarding an interactive web tool facilitating shared decision making in dementia can be identified?			
1,2	*1,2*	*1*	*2*
Methods			
Interviews	*Focus group interviews*	*Expert consultation*	*Workshops*
Respondents			
Fifty members of ten care networks of people with dementia (mild to moderate) were individually interviewed about decision making: - 10 persons with dementia - 20 informal caregivers - 10 case managers - 10 other professional caregivers	8 focus groups (n=34) were conducted: - 2 groups with people with dementia (n=9) - 2 groups with informal caregivers (n=11) - 2 groups with case managers (n=14) - 2 groups with dementia experts (n=13) We chose this approach of homogenous selection to enable respondents, and especially people with dementia, to speak for themselves.	7 national dementia experts were consulted via email. Member check was performed in a central meeting.	2 multi-disciplinary workshops were performed with de same participants (n=7): - Interpretation workshop - Affinity diagramming workshop
Recruitment			
The participants were recruited via case managers, Alzheimer cafés, the Dutch Alzheimers' Association, residential homes, and daycare centers.	People with mild to moderate dementia and informal caregivers were recruited from daycare centers, residential homes, and the Dutch Alzheimer Association. Case managers were recruited from regional case managers' networks.	Via the consortium of the SDM research program.	Via the consortium of the SDM research program.
Sampling/inclusion criteria			
The network inclusion was based on maximum diversity of sex of the person with dementia, stage of dementia, type of dementia, type of informal caregiver (e.g., spouse and child), type of formal caregiver (e.g., case manager and home care nurse), and the socio-economic status of the person with dementia. Participation of people with dementia required the ability to converse with a researcher. This corresponds with a score of 2-5 on Reisberg's Global Deterioration Scale and excluded people with severe dementia [34].	Participation of people with dementia required the ability to converse with similar people in a group and a researcher (corresponding with a score of 2-5 on Reisberg's Global Deterioration Scale). In order to create a safe environment, a daycare center was approached in order to recruit people with dementia who knew each other. Furthermore, the principal researcher (i.e., the focus group leader) attended the daycare center for 6 days, 5 before and 1 after the focus group interview.	Inclusion focused on diversity of organizations: e.g., Dutch Alzheimers' Association, University/University of Applied Sciences, and elderly care lobby.	Inclusion focused on diversity of the disciplines: e.g., older adults/dementia experts, technicians, and developers.
Topics			
The interviews were based on a topic list addressing decision-making elements such as: values, problems, decisions, personal considerations, options, and information need. The interviews were semi open and explorative, as we wanted to get insight into participants' personal experiences. The interview guide started with the questions: "How are you right now?", "What has changed for you lately?" and "What choices did you have to make because of these changes?". We then elaborated on respondents' answers. The face-to-face interviews took thirty to seventy five minutes.	Based on the findings of the interviews focus group members were asked to check the information of the interviews and to give additional information. Two researchers moderated all focus group interviews, that lasted 1 to 2 h each. The principal researcher led the focus group using an interview protocol to direct the interview. The second researcher assisted the principal researcher.	The consultation focused the refinement and prioritization of the dementia related topics identified in interviews and focus group interviews. Experts were invited to comment on the clustered experienced problems and decisions and what experienced problems and decisions were in line with the aim and scope of the interactive web tool.	The workshops aimed to align project members' views of the new IT application and identify user requirements emerging from the needs and preferences of the interviews and focus group interviews.
Both interviews and focus group interviews were audio taped, transcribed verbatim, and analyzed with Atlas.ti software.			

decisions in categories using Affinity diagramming [35] till consensus was reached. The clustered list of problems and decisions was then presented in focus groups for a check of this list and gathering supplementary problems and decisions and to enhance data richness [31][32]. Participants were asked whether they recognized the items on the list, and whether they had additional items for the list. Then, in an expert meeting with national dementia experts the results of the interviews and focus groups were discussed and a priority of decision-making topics was determined that addressed the aim and scope of the interactive web tool.

To address research question 2 the interviews were analyzed using content analysis for fragments containing implicit or explicit information regarding needs and preferences of end users about what a new interactive web tool should offer. Relevant fragments identified by the principal investigator were peer-reviewed by a second researcher.

The focus groups were used to check whether participants recognized the selected needs and preferences and gathering additional needs and preferences. The principal researcher made an initial clustering of these fragments using Affinity diagramming [35] with a second researcher. This resulted in a clustered list of fragments. The findings of the focus group interviews provided input for the consecutive workshops. Finally, the clustered list of needs and preferences was discussed in two consecutive multidisciplinary workshops; an "interpretation workshop" followed by an "affinity-diagramming workshop".

The workshops aimed to align project members' views of the new interactive web tool and identify user requirements emerging from the needs and preferences. Therefore, in the first workshop, the participants interpreted and translated the identified needs and preferences of end users in user requirements ("the tool facilitates/clarifies/supports/provides …"). Subsequently, they defined initial categories of needs and preferences. Disagreements were discussed until consensus was reached [35]. In the second workshop, the definition of categories was reviewed, summarized, and reformulated. Moreover, views of the workshop participants were explored, the boundaries of the new interactive web tool were clarified, and the categories were clustered in domains using Affinity diagramming [35]. Determining boundaries of the interactive web tool was necessary. Not all needs, preferences and expectations of participants could be addressed in view of the aim of the interactive web tool. The two workshops, both consisting of the same seven respondents, were audio taped and field notes were taken.

B. Ethical considerations

The principal investigator contacted all interview participants, who gave their informed consent individually, mostly in written form. We paid special attention to the informed consent of people with dementia in order to be sure their participation was voluntarily [33]. The institutional review board of the regional medical ethics committee gave written approval for the study.

III. RESULTS

Analysis of the data resulted in two sets of user requirements addressing the two research questions. The first set of user requirements consisted of decision-making topics the new interactive web tool should address. The second set of additional user requirements consisted of needs and preferences the new interactive web tool should address.

A. Research question 1: decision making topics in dementia the interactive web tool should address

Eighteen topics of clustered experienced problems and eight topics of clustered decisions addressing decision making in dementia arose from the interviews (characteristics in Table IIa) and focus groups (characteristics in Table IIb). In the data of experienced problems and decisions eight similar topics emerged: social contacts, daily activities, mobility, safety, living, future, care, and finances (Table III).

Besides, other topics of clustered experienced problems were: decreasing autonomy of people with dementia, involvement of people with dementia, participants in decision making, communication, information, role of professionals, role of informal caregivers, options, and timing of decisions. These experienced problems show an overlap with the identified user requirements based on users' needs and preferences (research question 2).

More problems were identified than decisions. Moreover, the problems (e.g., loneliness, mobility, managing behavior of person with dementia, lack of safety, and overburdening of the informal caregiver) were more related to well-being than the decisions, that were more often related to care (e.g., decisions about household assistance, home care, resuscitation, and personal alarm devices). Informal caregivers and professional caregivers named more problems than people with dementia did. People with dementia reflected more on important values (e.g., autonomy and staying at home) than the informal and professional caregivers. Focus group participants (except people with dementia) were very well able to indicate problems in the decision-making. Expressing preferences for the new interactive web tool proved to be more difficult for the people with dementia.

B. Research question 2: needs and preferences regarding the new interactive web tool

Two hundred fragments were generated from the interviews (characteristics in Table IIa) and focus group interviews (characteristics in Table IIb). These fragments, containing implicit and explicit participants' needs and preferences about the new interactive web tool resulted in 36 additional user requirements that were clustered in eleven categories and three domains (Table IV) [29]. These three domains stemming from the data are: "involved people and their roles", "timeline", and "information and communication".

TABLE II. CHARACTERISTICS OF PARTICIPANTS

A. Characteristics of participating care networks in interviews										
Network	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Age of PWD[a)]	82	83	80	84	70	89	83	73	86	87
Gender of PWD Male=M/ Female=F	F	F	M	F	M	F	M	F	M	F
Education of PWD[b)] Low (L)/Medium (M)/High (H)	M	H	M	L	H	M	M	H	L	M
Type of dementia Alzheimer (AD)/Vascular (VD)/Lewy Body (LBD)	LBD	VD	AD	?	AD	AD	?	AD	?	AD
Marital status Married=M/Widowed=W/Single=S	W	W	W	W	M	W	M	S	W	M
Living situation pwd at T0 Nursing home=NH/Independent living=IL	NH	IL	IL	IL	IL	IL	IL	NH	IL	IL
Type of informal caregivers interviewed[a)]	D D	D F	D S	GS GDiL	Sp S	D SiL	S D	Si N	S S	Sp D
Type of formal caregivers interviewed[c)]	PA CM	E CM	HCN CM	HCN TLN	E HCN	HCN CM	E CM	PA CM	CC HCN	HCN TLN

a) PWD= person with dementia, D=daughter, F=friend, S=son, GS=grandson, GDiL=granddaughter in law, Sp=spouse, SiL=son in law, Si=sister, N=niece. b) Low: primary/secondary school graduate, medium: high school graduate, high: college graduate. c) PA=principal attendant, CM=case manager, E=employee day care center, HCN=home care nurse, TLN=team leader nurse, CC=care coordinator

B. Characteristics of focus groups' participants				
Characteristics people with dementia attending a daycare center (n=9)				
Gender	*Age*	*Education[a)]*	*Type of dementia[b)]*	*Marital status*
5 Male	68-86 (M=79,2)	3 low	4 AD	5 Married
4 Female		4 medium	1 VD	4 Widowed
		2 high	1 FTD	
			3 MCI/D	
Characteristics of informal caregivers (n=11)				
Gender	*Age* *(2 did not fill in)*	*Education[a)]* *(2 did not fill in)*	*Relation pwd*	*Experienced caregiving*
3 Male	41-83 (M=64,6)	0 Low	7 Spouse	5 Heavy
8 Female		4 Medium	3 Daughter	6 Medium
		5 High	1 Friend	
Characteristics of case managers (n=14)				
Gender	*Age*	*Experience as case manager*		
1 Male	25-58 (M=42,1)	6: < 1year		
13 Female		7: 1 -5 year		
		1: > 5 year		

a) Low: primary/secondary school graduate, medium: high school graduate, high: college graduate. b) AD= Alzheimer's Disease; VD= Vasculair Dementia; FTD= Fronto Temporal Dementia; MCI/D= Mild Cognitive Impairment/Dementia

The first domain, "involved people and their roles", relates to the categorized user requirements: participation of the person with dementia in decision-making as a central user requirement named by all interested parties; roles of informal caregivers, case managers, and other professionals; self-management and autonomy; and organization of care around the person with dementia. The different parties involved have their specific roles in the network. They all focus on preserving the self-management and autonomy of the person with dementia for as long as possible. The degree of this preservation depends on the endurance capacity of the network. Furthermore, the degree of preserving self-management and autonomy changes over time as informal care givers and professional caregivers take over from persons with dementia when the disease progresses. Participation of people with dementia and self-management and autonomy were the only two categories of user requirements where all participants contributed to.

The second domain, "timeline", refers to the categorized user requirements: decision history and anticipation. One side of the timeline shows the decision history: information addressing decisions, values, and preferences of the network members in the past. Knowledge of decision history gives valuable information that can support network members in coping with current problems and decisions. This information is not always available. Reasons stated for this

TABLE III. FIRST SET OF USER REQUIREMENTS: IDENTIFIED TOPICS

Topics (experienced problems and decisions by participants) identified in decision-making in dementia		
Topics	*Problems*	*Decisions*
Social contacts	Decreasing social contacts of PWD[a)]. PWD Lonesomeness of PWD. PWD Incomprehension of the neighborhood. PWD, IC Gender differences in social skills. PWD Sensitiveness of the word 'dementia'. IC, CM, OFC PWD and IC avoid situations and people: shame about the disease dementia. CM, OFC	Church attendance of PWD. PWD, IC, CM No invitation of PWD at home. IC
Daily activities	Loneliness of PWD. IC, CM, OFC Lack of adequate daily activities of PWD. IC, CM, OFC	Starting day care. PWD, IC, CM, OFC Increasing day care. IC, CM, OFC
Mobility	(Limitation of) mobility of PWD with driving. PWD, IC, CM, OFC (Limitation of) mobility of PWD with cycling. IC, CM, OFC (Limitation of) mobility of PWD with walking. IC, CM, OFC	Driving. PWD, IC, CM, OFC Cycling. PWD, IC, CM, OFC Going outside alone/walking. IC, CM, OFC Scoot mobile. PWD, IC, CM, OFC Traveling with public transport. PWD, IC, CM, OFC
Living	Bureaucracy of indication institutions. IC, CM Stay at home. IC	Registration for nursing home/home for the aged. IC Location: where register/admission (which home and which village/town). IC Admission to an home for the aged/nursing home. IC Internal removals. IC, CM, OFC Timely admission to a nursing home of PWD during timely holiday/drop out of IC. PWD, IC, CM, OFC Forced admission to a psychiatric institution. IC
Safety	Wandering of PWD. PWD, IC, CM, OFC Unsafe behavior of PWD with gas-tap; smoking; electricity. IC, CM, OFC	Measures that limit PWD's liberty. IC, CM, OFC Enclosure of gas-tap; smoking; electricity. IC, CM, OFC Personal alarm device. PWD, IC, CM, OFC
Future	Life of IC after admission (to a nursing home) of the PWD. IC Discussing the future with the PWD is difficult. IC, CM Uncertainty regarding the future, for the PWD as well as the IC. IC, CM Settle things early to enable the PWD to co-decide: authorization, advanced directives/last will and testament. IC Delay of decisions. It's difficult to look in an early stage to the future. IC, CM Fear of PWD of early death of IC (and conversely). PWD, IC	Resuscitation. IC Timely setting things (e.g., authorization). IC Euthanasia wish/statement. IC Advance care planning. IC, CM
Care	Supply and demand of care do not match. IC Accessibility of care. IC Availability of care. IC Bureaucracy of care and welfare. IC, CM Supply of well-being and activities is not used. CM Call in CM in the dementia process is often too late. CM Too many organizations appeal to the PWD and the IC. This leads to commotion and conflicting advices. CM, OFC Timing: it is difficult to get PWD at the right moment in a good (and preferred) situation. CM Lack of relief centers in own region. Distance between family and PWD. Family does not want to travel too far. IC, CM Involved professionals (too many with conflicting opinions). IC Lack of realistic options; no real choice. IC Attention to financial part and consequences of care for PWD. IC	Household assistance. PWD, IC, CM, OFC (Increase of) home care (washing, showering, care, clothing, medication). IC, CM, OFC Housekeeping: checking refrigerator, medication, nutrition. IC, CM, OFC
Finances	Financial and economic consequences for IC influence decision-making. IC Availability of finances. IC	Settle/handling finances. PWD, IC Handling administration. PWD, IC Handling mail. PWD, IC
Autonomy	Encroachment of autonomy of PWD. PWD Increasing dependence of PWD. PWD, IC, CM	
Involvement of person with dementia	How to manage the PWD when he/she can't co-decide anymore? IC Involvement of the PWD in decision-making depends on the stage of dementia. IC, CM Single PWD don't want to burden their children. They don't want to appeal on them. PWD	
Participants in decision-making	Unclearness about who decides. IC, CM, OFC Involvement (yes/no) of PWD in decisions. IC, CM, OFC	
Communication	Lack of communication between members of the care network. CM, OFC	

	Diverging views of IC on situation PWD. CM Different views of involved ones regarding discussion point. CM The decision has unexpected consequences. PWD, IC, CM Not everything is expressed regarding the discussion point by involved ones. CM Promises that cannot be honored by IC. CM Uncooperative family systems. CM Family members are not on the same wavelength. CM, OFC The meaning of a decision has not been well expressed. IC	
Information	Lack of timely and available information (e.g., authorization). IC Lack of (the same) information. IC Insufficient information and/or conflicting information. IC	
Professionals	Balancing of the CM between interest PWD–IC. CM Burden of IC changes at some point in overburdening (no sliding scale). CM Lack of consultative/advisory experts. IC CM is available but in need of education. IC Relation with General Practitioner (not at hand and not well informed). PWD, IC Involvement of CM in the dementia process is too late. CM Lack of overview of the system of PWD/IC by CM (PWD or IC stop this). CM Lack of attention regarding the IC after the initial phase of the dementia process. IC) Formal caregivers are solution minded. PWD experience their help as invasive. PWD, IC	
Burden of informal caregiver	(Over)burdening of IC. IC, CM, OFC Overburdened IC have unrealistic expectations of relief work. CM Overburdening is not always visible and can lead to a crisis decision. CM Feelings of guilt and powerlessness of IC. IC, CM Mourning process of IC. IC, CM Feelings of shame of IC about the disease and therefore avoiding situations and people. CM Difficulties with decision-making of IC. IC, CM Coping with difficult behavior of the PWD. IC, CM	
Vulnerability of informal caregiver	Vulnerability of the IC/partner. What if IC is forced to stop caregiving? IC IC/spouse sometimes does not permit required care for PWD because breakthrough of daily routines. CM	
Options	There is no choice. IC Limited offer of options. IC, CM Formal caregivers offer familiar care that is quickly available and effective. CM	
Timing	Timing of admission (to a nursing home) is too quick/too slow. IC, CM What is the right moment to make a decision? IC, CM Sometimes people are not ready to face certain problems or to make certain decisions. CM, OFC Early diagnose, yes/no? An early diagnosis has negative aspects (no car driving; no change of insurance company; consequences for income). IC, CM	

[a)]PWD = people with dementia, IC = informal caregivers, CM = case managers, OFC = other formal caregivers

are lack of discussion within the network, replacement of professional caregivers, and a lack of information recording. The other side of the timeline shows anticipation: early discussion of possible problems in the future, and important values of network members, specifically of the person with dementia. This enables network members to support and decide in line with the wishes and needs of the person with dementia and the endurance of the informal caregivers.

The third domain, "information and communication", including the categorized user requirements of information, communication, and support, seems to be more generic. These user requirements are lubricants for SDM in care networks of people with dementia and are therefore indispensable. Network members often do not have the same information starting point. There is a lack of information exchange between network members, and network members do not always have access to the same information. Furthermore, important information within the network is not (always) shared; interaction between all network members is not self-evident. Interaction between network

members is characterized by a one-on-one contact, rather than interaction between all network members "around the table". Moreover, informal caregivers need the support of fellow sufferers.

IV. DISCUSSION

In this multiple methods study with an iterative participatory design, we determined the user requirements for a new interactive web tool based on experienced problems and decisions (social contacts, daily activities, mobility, safety, living, future, care, and finances), and needs and preferences of participants (participation of the person with dementia in the decision-making, insight into the decision history, anticipation of possible future problems and decisions, and the degree of self-management and autonomy preservation of the person with dementia among others). The extensive and thorough research procedure for identifying user requirements resulted in divers and rich user requirements.

Most identified user requirements address aspects of well-being. User requirements addressing care, financial matters, and future are recognized by Livingston and colleagues [4]. Zwaanswijk and colleagues [5] emphasize experienced problems with social networks. In both studies only the informal caregivers were interviewed about their needs. Van der Roest and colleagues [6] interviewed both informal caregivers and people with dementia. Most important needs they experienced address daytime activities, company and information. Each of these studies affirms some of the topics that are identified in this study that involved not only the perspectives of informal caregivers and/or people with dementia but also the perspectives of case managers and other professionals.

In our study, people with dementia described fewer problems than informal and professional caregivers. This is in line with findings of van der Roest [6] and de Boer and colleagues [36]. They suggest that this discrepancy could be due to different perspectives; informal caregivers and professional caregivers experience and rate problems differently from people with dementia (e.g., behavioral problems). People with dementia seem to be very capable of describing what is important to them: their values (e.g., loss of control, autonomy, and independence). De Boer and colleagues [36] consider also, as in our study, the contribution of people with dementia as very valuable to improve care to the experience and wishes of people with dementia.

Results show that identified problems are more related to well-being, whereas decisions (in the sense of solving problems) are more related to care. This discrepancy may be due to the focus of professionals on care. Most professional caregivers and case managers in dementia care have a professional background in nursing. This might influence the options they provide. It can be argued that, if professional caregivers focus more on well-being, the options they offer will also likely be more focused on well-being. Improving person centeredness in dementia care may support such an attitude change of professional caregivers [37]. For the new interactive web tool it is of importance that we should take into account the character of problems and decisions in order to avoid a mismatch.

The user requirements show no conflicts. However, some user requirements are complementary or overlapping. Ten clustered topics of experienced problems with no decision counterpart (e.g., communication, information, role of professionals, and involvement of person with dementia) overlap with user requirements based on the needs and preferences. Furthermore, the contributions that the participants made to the user requirements differ. Only two items were stated by all participants: "participation of the person with dementia in decision-making" and "self-management and autonomy". The informal caregivers contributed broadly; they gave input to all user requirements. In this study, people with dementia participated in the development. They made varying contributions. The information they provided could not always be easily derived from their answers. This might be due to the abstraction level of our study object: decision making. Nevertheless, people with dementia contributed to the requirements: participation of the person with dementia in decision-making, self-management and autonomy, anticipation, social contacts, mobility, living, and daily activities. Comparison of the user requirements with national dementia care standards show that they are compatible with important domains of these care standards such as participation of people with dementia in decision-making as long as possible, monitoring the well-being of the person with dementia and the endurance capacity of informal caregivers, the case manager as a coordinator, the importance of information exchange, and communication with all those involved [38][39][40][41][42]. Participation of end users in the development of the interactive web tool is a key feature in our study. A previous review showed that participation of end users, and especially people with dementia, may contribute to the development of a user-friendly and usable interactive web tool [27]. We therefore conducted this study with maximum participation of the end users. To maximize inclusion of people with dementia researchers invested in the relationship with them by spending time with them [33]. This provided us with valuable user requirements. People with mild to moderate dementia were well able to participate in interviews and focus groups and could express their preferences. This affirms Whitlatch and colleagues' assertions [20]. The recruitment of people with dementia for the interviews was sometimes difficult. Informal caregivers and formal caregivers tended to shield them from participating. They were sometimes afraid that participation would be too intrusive for the person with dementia. This is in line with Savith & Zaphiris and Wilkinson [43][44]. Another reason for non-participation of people with dementia and informal caregivers was the risk of overburdening of the informal caregiver. The people with dementia who participated in the study enjoyed the conversations and stressed the importance of their participation. They hope that their contribution will benefit future dementia patients.

TABLE IV. SECOND SET OF ADDITIONAL USER REQUIREMENTS: NEEDS AND PREFERENCES

Additional domains and categories of user requirements addressing needs and preferences of participants		
Domains of requirements	*Categories of user requirements*	*User requirements addressing needs and preferences of end users*
Involved persons and their role	Participation of the person with dementia in decision-making	The tool: - facilitates involvement of the person with dementia when discussing issues and decisions. - facilitates acting in accordance with the uniqueness of the person with dementia. - gives insight into explicit choices about the participation of the person with dementia. - strengthens the position of the person with dementia in decision-making. - supports and strengthens the person with dementia as a (co-) decider.
	Self-management and autonomy	The tool: - supports the wishes of the person with dementia about self-control and independency. - facilitates a gradual takeover of tasks appropriate to the needs of the person with dementia
	Role informal caregivers	The tool: - facilitates the monitoring of the limits of informal caregivers regarding their burdening. - supports informal caregivers in deciding in accordance with the wishes of the person with dementia. - monitors the (possibly changing) need of informal caregivers in coordinating activities.
	Role case manager	The tool: - facilitates the role of the case manager - provides the case manager with supporting methods (e.g., network analysis, options). - monitors the activities and agreements made by the case manager. - facilitates the case manager to involve the person with dementia as co-decider. - supports the case manager in strengthening the communication in the network.
	Other professionals	The tool: - facilitates adding other professionals (e.g., GPs) to the network. - facilitates one medical contact for the person with dementia and the informal caregiver.
	Organization around the person with dementia	The tool: - facilitates efficient access to underlying (care) possibilities. - detects errors and delays in the settlement of processes and procedures. - facilitates the alignment of roles and self-management tasks within the care network.
Timeline	Anticipation	The tool: - facilitates timely information about possible future issues and decisions within the network. - facilitates timely discussion about possible future issues and decisions within the network.
	Decision history	The tool: - offers information about decisions made with regard to medical, care and welfare aspects. - supports providing insight into what was discussed by whom and from what perspective.
Information and communication	Information	The tool: - provides relevant and consistent information to network members about: dementia in general; the issues that may occur regarding the disease dementia; experience knowledge of network members; information about regional dementia provisions. - supports the accessibility to the same information for all network members. - facilitates the professional (case manager) as a signpost regarding information.
	Communication	The tool: - facilitates an open communication between all network members. - facilitates exchange of information between network members. - facilitates case managers in maintaining a regular contact with the family. - facilitates the network members to be informed about what is going on within the network.
	Support	The tool: - facilitates sharing experience knowledge of network members. - facilitates professionals in supporting network members proactively. - supports decision-making, timing of decisions, and the implementation of decisions. - supports the participation process of the person with dementia.

Aims of the interactive web tool facilitating SDM in dementia are open communication, transparency, deciding together step-by-step, and giving voice to the person with dementia. The user requirements determined in this study contribute to these aims and can be used in outcome metrics of the current pilot study: does the interactive web tool enable what it promises regarding topics of decision making and preferences of end users?

A.   Strengths and limitations

This study has some methodological limitations. A first limitation concerns the fact that we did not quantify the occurrences of problems and decisions because we were interested in diversity. Several methods, in sequence, were used to determine the content of a new SDM interactive web tool. In order to gain as much information as possible, we gathered all the views of the respondents that related to decision making and their situation. This highlighted a wide range of needs and preferences, and problems and decisions. The frequency of occurrence was not a criterion for acceptance or refusal. Although there was some overlap, many single problems were inventoried.

The strength of this study lies in its extensive and thorough approach. Data triangulation, using multiple methods, in-depth and comprehensive data collection, thorough analyses, and the iterative participatory approach strengthen the results of this study. Furthermore, the findings complement each other; similar results came from several data sources. We paid special attention to thorough design and procedure of the study, especially with regard to the vulnerability of people with dementia. Attendance of the principal investigator at a day care center for six days made people with dementia more at ease in the focus group meeting. Nurse education can support this change by focusing increasingly on gerontology and well-being. This change nowadays is perceived in the Netherlands that are transforming from a welfare state to a participation society [45].

V.   CONCLUSIONS

With the iterative, participatory, and sequential approach we identified needs and preferences of participants, as well as experienced problems and decisions. This resulted in user requirements for a user-friendly interactive web tool that facilitates SDM in care networks of people with mild to moderate dementia. People with dementia and their informal and professional caregivers made valuable contributions.

Decision making in dementia care networks addresses predominantly problems of the well-being of people with dementia and informal caregivers. Eight categories of problems and decisions addressing decision-making in dementia are identified: social contacts, daily activities, mobility, living, safety, future, care, and finances. Additional identified user requirements for the new interactive web tool concern: the participation of the person with dementia in decision-making, insight into decision history, anticipation of future problems and decisions, communication, information,

and the degree of self-management, and autonomy preservation of the person with dementia and the informal caregivers over time. The next steps will be designing, developing, and improving the interactive web tool in collaboration with the end users, then testing it in experiments. In due course, a pilot study and its evaluation will follow.

REFERENCES

[1]   M. Span, C. Smits, L. M. Groen-van de Ven, A. Cremers, J. S. Jukema, M. J. F. Vernooij-Dassen, et al., "Developing eHealth technology for people with dementia: towards a supportive decision tool facilitating shared decision making in dementia," The Fifth International Conference on eHealth, Telemedicine, and Social Medicine (eTELEMED 2013) IARIA, Feb. 2013, pp. 69-72, ISBN: 978-1-61208-252-3

[2]   M. Prince, R. Bryce, and C. Ferri, "World Alzheimer Report 2011," Available at: http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf. Last access date 20-10-2014.

[3]   C. Ferri, M. Prince, C. Brayne, H. Brodaty, L. Fratiglioni, M. Ganguli, et al., "Global prevalence of dementia: a Delphi consensus study," Lancet, vol. 366, pp. 2112-2117, 2005.

[4]   G. Livingston, G. Leavet, M. Manela, D. Livingston, G. Rait, E. Sampson, et al., "Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK," BMJ, vol. 341, 2010.

[5]   M. Zwaanswijk, A. P. A. v. Beek, J. Peeters, J. Meerveld, A. L. Francke, and S. Van Beek, "Problemen en wensen van mantelzorgers van mensen met dementie: een vergelijking tussen de beginfase en latere fasen van het ziekteproces [Problems and needs of informal caregivers of persons with dementia: a comparison between the initial stage and subsequent stages of the illness process]" Tijdschrift voor Gerontologie en Geriatrie, vol. 41, pp. 162-171, 2010.

[6]   H. G. van der Roest, F. J. M. Meiland, H. C. Comijs, E. Derksen, A. P. D. Jansen, H. P. J. van Hout, et al., "What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services," International Psychogeriatrics, vol. 21, pp. 949-965, 2009.

[7]   R. M. Epstein and R. L. Street, "Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness," The Annals of Family Medicine, vol. 9, pp. 454-461, September 1, 2011.

[8]   M. von Kutzleben, W. Schmid, M. Halek, B. Holle, and 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, vol. 16, pp. 378-390, April 2012.

[9] S. L. Dupuis, J. Gillies, J. Carson, and C. Whyte, "Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services," Dementia, vol. 11, pp. 427-452, 2011.

[10] K. Cubit, "Informed consent for research involving people with dementia: A grey area," Contemporary Nurse, vol. 34, pp. 230-236, 2010.

[11] L. Nygård, "How can we get access to the experiences of people with dementia? Suggestions and reflections.," Scandinavian Journal of Occupational Therapy, vol. 13, pp. 101-112, 2006.

[12] H. L. Menne, S. S. Tucke, C. J. Whitlatch, and L. F. Feinberg, "Decision-Making Involvement Scale for Individuals With Dementia and Family Caregivers," American Journal of Alzheimer's Disease & Other Dementias, vol. 23, pp. 23-29, 2008.

[13] 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, vol. 49, pp. 477-482, 1999.

[14] D. Stacey, F. Légaré, S. Pouliot, J. Kryworuchko, and S. Dunn, "Shared decision making models to inform an interprofessional perspective on decision making: A theory analyis," Patient Education and Counseling, vol. 80, pp. 164-172, 2010.

[15] F. Légaré, D. Stacey, S. Pouliot, F. P. Gauvin, S. Desroches, J. Kryworuchko, et al., "Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model," Journal of Interprofessional Care, vol. 25, pp. 18-25, 2011.

[16] C. A. G. Wolfs, M. E. de Vugt, M. Verkaaik, M. Haufe, P. J. Verkade, F. R. J. Verhey, et al., "Rational decision-making about treatment and care in dementia: A contradiction in terms?," Patient Education and Counseling, vol. 87, pp. 43-48, 2012.

[17] G. Makoul and M. L. Clayman, "An integrative model of shared decision making in medical encounters," Patient Education and Counseling, vol. 60, pp. 301-312, 2006.

[18] P. D. A. Ottawa Hospital Research Institute. Available: http://decisionaid.ohri.ca/index.html. Last access date 24-11-2-14.

[19] E. Duncan, C. Best, and S. Hagen, "Shared decision making interventions for people with mental health conditions," Cochrane Database of Systematic Reviews, 2010.

[20] J. Whitlatch, Menne, H, "Don't forget about me. Decision making by people with dementia," Journal of the American Society on Aging, vol. 33, pp. 66-71, 2009.

[21] Alzheimer Europe, Alzheimer in Europe Yearbook 2008. Available at: http://ec.europa.eu/health/ph_information/reporting/docs/2008_dementiayearbook_en.pdf, Last access date 24-11-2014.

[22] J. Peeters, J. de Lange, I. van Asch, S. P., M. Veerbeek, A. M. Pot, et al., "Landelijke evaluatie van casemanagement dementie [National evaluation of case management in dementia]", NIVEL, Utrecht 2012.

[23] T. Koch, S. Iliffe, J. Manthorpe, B. Stephens, C. Fox, L. Robinson, et al., "The potential of case management for people with dementia: a commentary," International Journal of Geriatric Psychiatry, vol. 27, pp. 1305-1314, 2012.

[24] A. M. O'Connor, H. A. Llewellyn-Thomas, and A. B. Flood, "Modifying Unwarranted Variations In Health Care: Shared Decision Making Using Patient Decision Aids. A review of the evidence base for shared decision making.," Health Affairs Web exclusive, pp. 63-72, 2004.

[25] Med-Decs. De internationale verzamelplaats voor hulp bij medische keuzen [Med-Decs. The international meeting-place

for medical choices support]. Available: http://www.med-decs.org/nl/. Last acces date 24-11-2014.

[26] F. Meiland, A. Reinersmann, S. Savenstedt, B. Bergvall-Kareborn, M. Hettinga, D. Craig, et al., "User-Participatory Development of Assistive Technology for People with Dementia - From Needs to Fucntional Requirements. First Results of the COGKNOW Project," Non-Pharmalogical Therapies in Dementia, vol. 1, pp. 71-91, 2010.

[27] M. Span, M. Hettinga, M. J. F. J. Vernooij-Dassen, J. Eefsting, and C. Smits, "Involving People with Dementia in the Development of Supportive IT Applications: a Systematic Review," Ageing Research Reviews vol. 12, pp. 535-551, 2013.

[28] S. Visser, T. Haaker, R. Menko, and M. Hettinga, "From Buzz to Business: eHealth Innovation Matrix". Abstract submitted and accepted for Med-e-Tel 2012, Luxembourg, April 18-20, 2012.

[29] J. E. W. C. Van Gemert-Pijnen, N. Nijland, M. A. H. Van Limburg, S. M. Kelders, B. J. Brandenburg, H. C. Ossebaard, et al., "Introducing a holistic framework for eHealth technologies," Journal of Medical Internet Research, vol. 13 (4):e111, 2011.

[30] A. Bryman, Social Research Methods, third edition ed. New York: Oxford University Press, 2008.

[31] S. D. Lambert and C. G. Loiselle, "Combining individual interviews and focus groups to enhance data richness," J Adv Nurs, vol. 62, pp. 228-37, Apr 2008.

[32] M. Bloor, J. Frankland, M. Thomas, and K. Robson, Focus Groups in Social Research. London: Sage Publiations Ltd, 2002.

[33] K. Murphy, F. Jordan, A. Hunter, A. Cooney, and D. Casey, "Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies," Dementia, January 8, 2014.

[34] B. Reisberg, S. H. Ferris, M. J. de Leon, and T. Crook, "The global deterioration scale for assessment of primary degenerative dementia.," American Journal of Psychiatry, vol. 139, pp. 1136-1139, 1982.

[35] H. Beyer and K. Holzblatt, Contextual Design. Defining Customer-Centered Systems, Morgan Kaufmann Publishers, 2010.

[36] M. E. de Boer, C. M. Hertogh, R. M. Dröes, I. I. Riphagen, C. Jonker, and J. A. Eefsting, "Suffering from dementia - the patient's perspective: a review of the literature," Int Psychogeriatr. , vol. 19, pp. 1021-1039, 2007.

[37] P. J. Doyle and R. L. Rubinstein, "Person-Centered Dementia Care and the Cultural Matrix of Othering," The Gerontologist, August 6, 2013.

[38] L. J. Boomsma, D. F. R. Boswijk, A. Bras, A. H. M. Kleemans, J. M. G. A. Schols, A. W. Wind, et al., "Landelijke Eerstelijns Samenwerkings Afspraak Dementie [National dementia collaboration agreement]", Huisarts & Wetenschap, vol. 52, pp. S1-S5, 2009.

[39] L. J. Boomsma, M. De Bont, C. Engelsman, J. Gussekloo, C. Hartman, A. Persoon, et al., "Landelijke Eerstelijns Samenwerkings Afspraak Dementie [National dementia collaboration agreement]", Huisarts & Wetenschap, vol. 48, pp. 124-126, 2005.

[40] Richtlijn Diagnostiek en medicamenteuze behandeling van dementie [Directive diagnostics and medical treatment of dementia], K. v. d. G. CBO, 2005. Available at: http://www.platformouderenzorg.nl/uploads/files/guidelines/dementie1.pdf. Last access date 20-11-2014.

[41] E. Moll van Charante, M. Perry, M. J. F. Vernooij-Dassen, D. F. R. Boswijk, J. Stoffels, L. Achthoven, et al., "NHG-Standaard Dementie (derde herziening) [General

practitionars' dementia standard]" Huisarts & Wetenschap, vol. 55, pp. 306-317, 2012.

[42] AlzheimerNederland and Vilans, "Zorgstandaard Dementie," ed [Dementia care standard], 2012. Available at: http://www.alzheimer-nederland.nl/media/19342/Alzheimer%20Nederland_Brochure_Goede_Zorg_Dementie_LR.pdf. Last access date 24-11-2-14.

[43] N. Savitch and P. Zaphiris, "Accessible websites for People with Dementia: a Preliminary Investigation into Information Architecture," in ICCHP, 2006, p. 8.

[44] H. Wilkinson, "Including people with dementia in research: methods and motivations". In: The perspectives of people with dementia, research methods and motivation. London: Jessica Kingsley, 2002.

[45] C. H. M. Smits, H. K. van den Beld, M. J. Aartsen, and J. J. F. Schroots, "Aging in The Netherlands: State of the Art and Science," The Gerontologist, September 2, 2013.