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Abstract. Although there exist various product and services to support people with dementia in their everyday activities and challenges, people with dementia and their informal caregivers experience many unmet needs. In this paper, we present the ongoing development process of a decision aid that aims to reveal these unmet needs and match them with relevant support and care solutions. This entails investigating the needs of people with dementia and caregivers, making an inventory of the product and service solutions, co-creating the question articulation to be used in the decision aid and developing and testing three design concepts. We aim that the insights we gained from the tests will inspire interaction designers and researchers that investigate person-centered dementia care.

Keywords: dementia · decision aid · designing for dementia · care and wellbeing services · user testing

1 Introduction

Dementia is a syndrome with a set of symptoms linked to neuron death and vascular damage of white matter in the brain, which causes a progressive loss of cognitive functioning, memory, and ability to learn, reason and communicate [20]. Dementia, for which there currently exists no cure, gradually limits everyday activities and imposes a heavy physical, emotional and social burden for people

living with dementia and their informal caregivers. Adequate and timely post-diagnostic support is important to care for people with dementia, prevent overburden of caregivers and premature admission of people with dementia to nursing homes, as this is very costly [16].

This post-diagnostic support increasingly exists of assistive technologies, which may enable more personalized support, attuned to the heterogeneous and changing needs of people with dementia and their caregivers, more comfort in use and also more efficient, time and money saving support [17]. Such technologies support coping with the symptoms of dementia, maintaining autonomy and independence, reducing care burden and risk of harm, and improving quality of life [3, 10, 15, 22]. A wide range of devices enters this description, from simple low-tech products such as pill dispensers to high-tech products such as care robots and autonomous fall detection systems. Yet, research and practice show that not all the needs of people with dementia are met despite the solutions in the market and care services offered [1, 18, 19]. People with dementia and their caregivers frequently report that they receive insufficient support in memory, eyesight and hearing problems, finances, transport, information about dementia and available care, finding social company and daytime activities, coping with distress, and preventing accidental self-harm [27, 28]. However, a lack of services or technologies to assist them in these needs may not be the main problem. A gap analysis in the Netherlands, for example, showed that for these unmet needs various types of services are available [7], but people with dementia and their caregivers seem to have difficulty in accessing products and services that can support them. Reasons are that they are not aware of the availability of the relevant services [6, 27], do not know where to go for help [4], or think that taking up the service would not be helpful [32]. Furthermore, the uptake of the support solutions is also low because the information provided about the support is unclear [27] and services are insufficiently attuned to individual needs or situations [14, 15, 17, 27, 28].

There is a clear need for a means that can help people with dementia and caregivers to find out the available relevant support. In the project FIT, we develop a digital decision aid that helps clarifying the specific personal and contextual needs of people with dementia and their caregivers, and offers flexible and personalized advice about available assistive technologies and care services that can alleviate unmet needs. FIT is a collaboration between two design research institutes, three research institutes in healthcare, three care organizations, and an SME in the Netherlands, and has three living labs where the decision aid is being tested. We envision that the FIT decision aid (from now on FIT) will support the independent living of people with dementia and increase their and their carers' quality of life with the well-fitting solutions offered.

Decision aids in the health domain are interventions designed to help people make well-informed and deliberative choices among options by providing information about the options and outcomes relevant to a person's health status [23]. Similar online tools were developed for dementia care, such as DEM-DISC [26, 29] or the DecideGuide [21, 22], however more research is needed to create a

tool that offers a better clarification of individual demands [26], reveals needs that could be latent or not well-articulated, and is pleasant to use and interact with by people with dementia, caregivers, and care professionals. This is what we aim in FIT.

In this paper, we briefly present the concept development of FIT and insights we gained from the pilot tests conducted with users. We identified some tips to be taken into consideration when developing a decision aid for dementia, and hope our approach will add onto the knowledge on designing for person-centered healthcare in the HCI field.

2 Developing the FIT Decision Aid

The primary users of FIT are the informal caregivers and care professionals, such as general practitioners, case managers or social care providers. Informal caregivers can use FIT together with the person with dementia as a communication tool to investigate needs, or use it by themselves as a tool to find solutions for problematic situations they encounter. People with dementia and caregivers are most likely to learn about possible solutions from their GP's or case managers [15]. In order to inform their clients well, care professionals should be up-to-date about the current developments in assistive technologies and services. FIT can help care professionals to get informed and transfer this knowledge to their clients.

When it comes to people with dementia, we considered them to be the secondary users of FIT. If they are in the early stage of the disease and still cognitively able to use FIT, they may not associate the tool with themselves since it is common to deny having dementia or acknowledging the need of help in early stages [24]. If they acknowledge having dementia and needing help, they may not be able to use FIT anymore. For these reasons, people with dementia were not targeted as autonomous users of FIT. However, we aimed to design FIT to be accessible and inviting for them so that caregivers and care professionals can use it together with them.

The needs and motivations of people with dementia and their caregivers change continuously with the progress of the disease and contextual circumstances. Therefore, we envisioned FIT to be used frequently in the course of the disease. We also aimed for a mobile website that could work in a tablet as well as on a computer so that the care professionals can bring it easily to their home visits.

The development of FIT involved four main overlapping activities: (1) investigating the needs, (2) co-creating the conceptual structure and content of the decision aid, (3) making a comprehensive inventory of the product and service solutions, and (4) generating prototypes. For the first activity, we conducted interviews in the homes with eight people with dementia and their caregivers and two focus groups with 4 people with dementia and 4 informal caregivers separately. These studies helped us extract 10 main need categories that people

with dementia and their caregivers experience—daily activities, mental wellbeing, physical health, pleasurable activities, social contact, care relations, information, finances, household, and safety—and gave insight into the attitudes of our user group toward looking for help and support regarding their needs [30]. We distinguished three user groups: (1) people who are not aware that they experience a problem or have unmet needs, (2) people who are aware of their unmet needs but never realized that there are solutions to alleviate these, and (3) people who are aware of their unmet needs and heard of a potential solution, but they do not know which specific solution they want and how to access to it.

We created a conceptual structure intended to accommodate all these user groups in FIT (2nd activity). The structure starts from a higher "need" level, proceeds by asking questions to specify a "goal" to fulfil that need, and ends by finding the "product category" that can realize that goal (Fig. 1). Needs are implicitly felt states of deprivation [27], for example the need of social contact. A goal is a concrete way to fulfill a need, for example "I would like to have someone to talk to" or "I would like to find some activities to do with my loved one". Product category is the type of care and support solutions that can realize those goals, for example playing games (e.g., puzzles, memory games, ball games special for people with dementia) or going to the Alzheimer choir together.

If the users are not aware of their needs, they can start exploring from the need level. This is done by showing our 10 need categories that enable users to select the one they would like to learn more about. Users are then guided via a tree structure of questions to a specific goal they would like to accomplish. This is also the level in which users who are aware of the problems they experience, but not of the solutions, could enter the decision aid. The current understanding of care is not treating illness and its limiting consequences, but on coping with the demands of illness to participate and preserve the good things in life [8]. For this reason, we formulated the goals not in terms of problems, but as "topics of improvement" and "aspects of wellbeing".

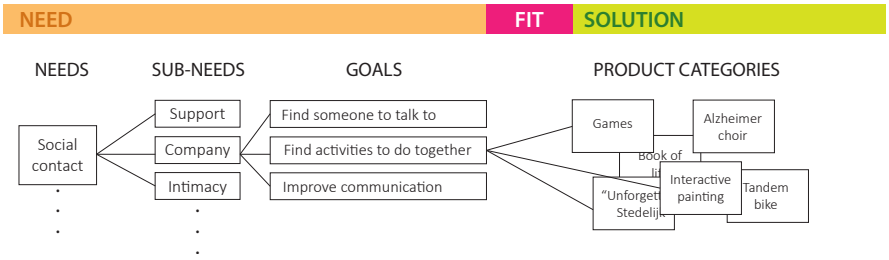

Fig. 1. Conceptual structure of FIT with the social contact need as an example

The list of goals per need was compiled via multiple co-creation sessions. Four sessions were conducted among the authors of this paper in order to create an initial long-list based on the dementia-needs literature and the topics in the intake forms

of various care institutions in the Netherlands. Afterwards, two sessions were conducted with two nurses that experience the everyday life of people with dementia at first hand in order to examine which activities and goals are relevant for the dementia context and which activities and goals are missing. For example, the nurses indicated that the eating and drinking sub-need should have sub-categories such as hand-mouth coordination, chewing, and swallowing since people with dementia may have specific needs regarding one of these issues. This list was shared with all the project partners from academy and practice with care research, nursing, and design backgrounds; each partner contributed to finalizing the list by restructuring categories, taking out doubles, filling gaps, and re-labeling terms from their own area of expertise.

After the users select the goal they would like to achieve, FIT gives advice on care and support that may realize this goal. These could be products (e.g., puzzles, tandem bike), care and welfare services (e.g., meeting events, telephone helplines, respite care), and websites or apps (e.g., Dementia app, the Netherlands Alzheimer Association website). FIT provides information about how this solution can help, examples of available products, where to buy/get it from (information on reimbursement by National Health Service packages or healthcare funds, and links to external sellers). The users, who know what they need but do not know which specific product and where to get it, can enter FIT from this level.

Information about products and services was obtained as the third activity in the development through a comprehensive inventory of current products and care services in the Netherlands [2]. We gathered 1100 unique products and services that are intended for people with dementia or elderly in general. These products and services were matched to specific goals they can realize through two sessions between project partners. In these sessions we included two experts—one owned a web shop that sells products for dementia care and the other created a platform for finding dementia care services in the Amsterdam region—in order to get an in-depth understanding of the benefit and potential of the products and services. For example, we categorized V-shaped or Batwing pillows as products for comfortable sitting, but the web shop owner pointed out that these products are also helpful for the goals of falling asleep, calming down, or increasing the feeling of safety. The majority of the product and service solutions in the decision aid realize multiple goals.

After setting up the conceptual structure of FIT, we created three distinct medium-fidelity concepts (4^{th} activity) to turn the structure into a digital decision aid that users can interact with (Fig. 2). In the creation of these concepts we considered different design aspects regarding navigation, playfulness, and familiarity. The first concept offered a linear way of proceeding through the structure, like an online questionnaire wherein needs, sub-needs, and goals are presented in separate screens and the users choose the options that apply with ticking checkboxes. The second concept was designed as a card game in which the users were asked to drag the cards representing needs, sub-needs and goals into two piles representing “need support” and “don’t need support”. The last concept had a

standard web shop look and feel, in which the solutions could be explored by using the goals as filters at the right side.

1

2

3

Fig. 2. Creation of three concepts of the decision aid (1: Linear, 2: Card game, 3: Website)

3 Testing the FIT Decision Aid

The three concepts were tested with 3 informal caregivers in individual sessions (two daughters and a wife) and 13 care professionals (1 male nurse + 8 female nurses + 4 female case managers) divided in three focus groups with 4, 6, and 3 participants. Informal caregivers were recruited through the network of the care institutions in the project consortium. Nurses and case managers worked at one of these three participating institutions. The aim of the sessions was gaining insights about the usefulness and usability of the concepts from the potentially varying perspectives of informal caregivers and care professionals. The care professionals also discussed how to integrate the decision aid into their standard workload and procedures.

The sessions were conducted at the workplaces of the participants. We started by explaining the project and the aim of the session. Each concept was displayed in a separate tablet and the tablets were given to the participants one-by-one in a random order. All the main functions of the three decision aids were interactive, but we used the actual content for only two need categories in all concepts (i.e., daily activities and care relations) and for the rest we displayed dummy content and image placeholders. The participants were asked to explore each concept and while doing so think-out-loud about plus and minus aspects for each (the care professionals were asked to pair up when exploring the concepts). After the exploration phase, the participants were asked to present their comments and preferences. The discussions were guided with questions regarding the usefulness and usability of each concept and improvements therein.

Starting with the evaluations about the usefulness of the concepts, the participants were very positive about the potential of a decision aid to support fulfilling unmet needs. Especially its "educative dimension", i.e., giving a comprehensive overview of all the possible needs as well as relevant solutions, was appreciated by all of the participants, irrespective of being an informal caregiver or a professional. As one of the nurses stated, "it is also an aid for us, not just for the client"; the decision aid seemed to attain its aim to provide up-to-date information about product and service solutions that are relevant.

Regarding the Linear concept—which is initiated by choosing from 10 main need categories—one of the informal caregivers stated, "It is very good to see all the needs together. There are issues you do not experience right now, but in the future you can encounter them. So you can prepare yourself." Three of the nurses were also specifically positive about this dimension of the Linear concept, as it can be a communication tool to use when talking with the informal caregivers and people with dementia. According to their experience, some of the informal caregivers are unreceptive and unwilling to communicate when it comes to the needs of their loved ones with dementia. This tool would be a means to make problems visible, help focus the conversation, and make the discussion more in depth and to-the-point with the immediate solutions offered. These nurses suggested the decision aid to be a standard part of their intake procedure for home care and also reuse it every 3 to 6 months together with the person with dementia and informal caregiver.

The Card game concept was appreciated for its interactivity and playfulness, but was also considered time consuming. Informal caregivers and care professionals mentioned that they already have enough responsibilities to take care of, so they would prefer the straightforwardness and the overview provided by the other two concepts. However, almost all of the participants considered this concept to be the best fitting option if people with dementia would use the decision aid by themselves. We designed the card game in a way that all the sub-needs and goals are presented as a deck of cards and the users sort the card at the top in one of the two categories without knowing which card will be next. In this way users are forced to think about only one issue at a time and decide if they need support or not for that issue only. Therefore this interaction reduced the memory load of the users, which was also pointed out by all of our participants. However, playing this card game with people with dementia was considered to be burdensome by care professionals and informal caregivers due to their other urgent requirements.

The website concept was mainly appreciated by some of the care professionals, as they could immediately get a long list of product and service solutions and filter among the solutions according to the goals that are relevant. However, this way of interaction was seen as complex by all the informal caregivers and majority of the care professionals.

When it comes to the usability of the concepts, we gained valuable insights regarding the navigation, visual style, and language of the prototypes. We will shortly summarize these below, together with providing some design tips for the design researchers who are investigating similar challenges as ours. Both for informal caregivers and care professionals, the concept Linear was a clear winner in usability. The main reason was that it gave a good overview of all the needs, the hierarchical structure between needs, sub-needs, and goals were clear, and the users would always know where they were in this structure. The ticking checkboxes way of proceeding was also familiar to all of the participants, so they intuitively knew how to use the decision aid. Sorting cards and filtering out from a long list was considered to be burdensome and counterintuitive, respectively *(Tip 1: "Provide the users a clear overview of the content and an indication of where they are in the system at all times")*.

In the design of all the concepts, we allowed the multiple-selection of sub-needs and goals. However, this option caused the users to end up with rather long lists in the follow-up screen. For example, if they selected "eating & drinking", "day structure" and "mobility" as sub-needs under the daily activities main need category; they would end up with a list of 15 goals to choose from. This was considered to be an overwhelming amount of information to process. Also scrolling in this list was considered a problem. Surprisingly, almost all of the participants said they would prefer more screens than having to scroll down in one screen, so that all the information comes in blocks of one screen's worth. Scrolling is considered a usability problem when designing websites for people with dementia [5, 11]. Although our users were not suffering from dementia, they also had similar problems when interacting with the prototypes *(Tip 2: "Minimize choice and complexity, too many options overwhelm the users"* and *Tip 3: "Avoid forcing users to scroll")*.

When designing the visual elements of the prototypes, we paid attention to color use and contrast, and aimed to provide a "calm" look by positioning the items on a white background and having blank spaces around them. All the participants mentioned that they found the appearances of the screens appealing and clean. The participants found the big images we used in the card game concept attractive and suggested us to apply the same approach in the other prototypes as well. Furthermore, some of the older nurses found the 10-font text we used in some screens too small *(Tip 4: "Use high contrast and pay attention to white spaces"* and *Tip 5: "Use big images and large text sizes")*.

Lastly in the language used in the prototypes, we aimed for an empathetic and descriptive tone, e.g., "There are many activities we perform on a daily basis, such as going to bed, getting dressed or preparing food. In the case of dementia, these could be the things to experience difficulties in. With which activities below would you need support?" Although all the participants appreciated the tone of voice, such explanations were sometimes found too wordy. Especially the care professionals stated to prefer short and direct language. Furthermore, some terms such as respite care, mouth-hand coordination, and daily structure were not clear for the informal caregivers *(Tip 6: "Use empathetic and respectful, but short and direct language"* and *Tip 7: "Avoid jargon and technical terms")*.

4 Conclusions

The initial results of this pilot study indicate that the FIT decision aid meets the needs of the informal caregivers and care professionals to get tailored information about products, services and support that can reveal and fulfill unmet needs of people with dementia. The prototypes were perceived as useful and generally user-friendly aids to support them in their caregiving responsibilities. Our findings contribute further to the usability and design requirements that are being developed for people with dementia and their formal and informal caregivers. Our special contribution lies in designing in a flexible way, to accommodate different user groups, and for the decision aid to be usable in different stages of dementia. Underlying these prototypes we also created a comprehensive inventory of needs and goals of people with dementia and informal caregivers, as well as product categories that may meet these needs. We consider this conceptual structure and content of FIT especially applicable for the wider HCI community working in relation to dementia.

The results of this pilot study will be used in the further development of FIT to become a tool to be recommended and used by care professionals in various healthcare institutions in the Netherlands. We are aware that the technological development will constantly add new treatments, tools and systems for supporting dementia. One of the long-term aims of our project is to create a sustainable business model that can keep up with and include such developments in the tool. Further research will focus on (1) building up on the user-friendliness of the Linear concept, (2) implementation of FIT into existing healthcare infrastructures

and tackling related issues such as keeping the information on products and services up-to-date, and (3) long-term effect of using FIT on increasing the quality of life of people with dementia and their informal caregivers. In the long run, a decision aid like we developed for dementia care could be developed for people with other chronic diseases such as Parkinson's disease, Multiple Sclerosis, or Rheumatoid Arthritis, since these patients face similar problems in unmet needs and lack of support in the course of their disease.

With the changing description of "health" from the absence of diseases to a capacity to maintain one's integrity, equilibrium and wellbeing [12], the idea of "social health" is gaining importance to help people in the capacity to fulfill potential, managing life with some degree of independence, and participation in social activities [9]. Additionally, the emergence of perspectives on personhood in HCI have invoked recent attempts to consider changes in patient care and involving patients and caregivers in design processes [31]. Dementia care, like any other aspect of care, requires a holistic, person-centered approach that deploys people's strengths rather than focusing on cognitive deficits [13]. This is our long-term aim in FIT as well.

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