

Users requirements in the design of a virtual agent for patients with dementia and their caregivers

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ABSTRACT

Over 50 million people worldwide are living with dementia and it is expected that this will double every 20 years. With our project “Living well with Anne” we aim to develop a virtual agent, called Anne which can help people with dementia to continue living independently in their own homes and support their caregivers in their caring tasks. The project started in June 2017 and will last 3 years. Using a user-centered approach, the virtual agent will be developed so that it can progressively meet the needs of the people as the level of dementia changes. The project has already undertaken some work related to the end-user needs and requirements which will be followed by extensive field trials. This paper reports on the results of the first part of our project: end-user and stakeholder requirements analysis. This requirement analysis has been obtained through focus groups which were held at end-user organizations in Italy and Luxembourg. Results show that Anne can be useful to help people with dementia to continue living independently at home given specific adjustments. It may have an impact on the Quality of Life of both the users and (by proxy) their caregivers but its relevance needs to be explored in more detail within the forthcoming field trials.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)**; *Interface design prototyping*; *Empirical studies in interaction design*; • **Social and professional topics** → *People with disabilities*; *Seniors*; • **Security and privacy** → Social aspects of security and privacy;

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KEYWORDS

Dementia, Virtual Agent, Screen Agent, Quality of Life, Focus Group, User Centered Design

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1 BACKGROUND

According to the World Alzheimer Report 46.8 million people worldwide are living with dementia in 2015. This number will almost double every 20 years, to 74.7 million in 2030 and 131.5 million in 2050. The global societal economic cost of dementia is estimated to reach US\$1 trillion in 2018 [22].

Dementia can affect multiple areas of cognitive functioning, including memory, thinking, comprehension, learning capacity, orientation, judgment, and language, and many people experience an impact on motivation, social behavior and emotion [23]. Lack of activity, or boredom, is reported by people with dementia, whether they are still living at home or have moved into care services [8][10]. Engaging in meaningful activities can decrease boredom and increase positive emotions [15]. Cognitive assistive technologies have been put forward as a solution to support older adults with dementia in living independently at home for longer while not increasing the burden on family caregivers [19]. Such technologies, often coupled with a form of artificial intelligence, facilitate compensation for lost functions by prompting the user through different steps of certain acts of daily living (ADLs), thereby enhancing the user’s autonomy. Amongst these technologies, an emergent interest has arisen for the so-called ‘virtual agents’.

Specific studies on the efficacy of virtual agents within the dementia context are rare, nevertheless some research has shown significant results: an animated conversational agent can be used as a trusted exercise adviser [1]. People with cognitive impairment seem to engage naturally with a screen agent [6][21]. Moreover, it is found that virtual agents provide a sense of companionship [27].

One of the latest reviews [17] in this field has clearly shown how in the moderate to severe stages of dementia, technology can play a role in supporting the ability to remain independent and to maintain the necessary skills. In this sense, assistive and safety technology continues to play a role for people with advanced dementia and their caregivers. For people with moderate to severe stages of dementia the largest set of technologies are those that enhance safety. These include a range of technologies such as motion/fall detectors, environmental sensors measuring elements such as room temperature, smoke/gas/water presence. All these sensors/detectors raise timely alarms when a situation of actual or potential danger is detected. At this stage of dementia, active use of safety technology tends to shift to the caregivers, while the person with dementia often becomes a less active user.

Technologies can also be used for 'therapeutic' interventions, often delivered through devices such as tablets or digital music players. These technologies can help people with dementia to reminisce and to experience pleasure from their favorite music, films, or looking at pictures. Yaghoubzadeh et al. [28] researched virtual agents in their role as daily assistants for the older adults and conducted studies on acceptance and interaction feasibility. They raised two main concerns: (i) Are virtual agents accepted as assistants by these user groups, and which system design would be particularly preferred? (ii) How can the interaction between the agent and such users be made feasible, i.e. sufficiently robust and effective? Bearing in mind these questions, this paper aims to contribute to the understanding of the ability of a virtual agent to help and support people who are living independently and are dealing with memory and other cognitive issues.

This paper reports the first iteration of a comprehensive user-centered development process. In this first iteration, professional and informal caregivers were invited to participate in a series of focus group to discuss the user requirements.

2 THE LIVING WELL WITH ANNE PROJECT

The 1st of June 2017th saw the start of a three-year project called 'Living well with Anne' which aims to develop a virtual agent to help and support people dealing memory loss and cognitive impairment to continue to live independently in their own home. The project is financed by the Active and Assisted Living AAL program under the Call subject 'Living well with dementia'. The second aim of this call is to support innovative, transnational and multi-disciplinary collaborative projects with a clear route to market and added value for the diverse types of end-users. A key priority underlying this challenge is to bring together technologies and services to create ICT based solutions addressing the aspirations and challenges that will enable the well-being of people with dementia and their communities (family, caregivers, neighborhood, service providers, care system, etc. . .)

The aim of the project is to support the end-users (people with dementia and cognitive impairment) as well as unburden their informal and professional caregivers by implementing the virtual agent 'Anne' in their daily lives. Anne is being tailored to the changing needs of persons with dementia (PwD). At the start of the project Anne already had three features: agenda (personal and medication), news and video calling which had been previously developed within



Figure 1: Virtual agent Anne (one of the possible avatars)

another AAL project. With these adapted and improved features, Anne is set to enable PwD to live longer independently by giving them an easy-to-use, most natural way to interact with a virtual agent. Anne will be able to learn autonomously from its users and get to know their personal preferences and needs. The complex technology to control and interface the services Anne provides is hidden by a face talking to the users and interacting with them and showing emotions.

2.1 The system

Anne (see Figure 1) is a possible solution to support elderly with cognitive impairments to live at home for as long as possible while maintaining Quality of Life (QoL). There is a prototype of Anne which has already been adjusted based on results from previous AAL projects. It is already equipped with the following features:

Agenda Anne has a diary function in which appointments and activities are displayed. The users or their carers can add their appointments and activities over a linked Google Calendar. Anne helps users to remember their appointments and planned activities through reading out the appointments. For users with symptoms of dementia (forgetfulness) Anne's Calendar can be filled with appointments and positive user moments. Like: who will visit, when she is going to the hairdresser, with whom she will be drinking a cup of coffee/tea, etc. Anne can say what is going to happen all day long and can give the user peace of mind.

Medication/other reminders The medication intake can be filled in by informal or professional caregivers. Anne reminds the user to take and confirm the intake of medication. Anne reminds the user when to take what medication to what dosage. Anne can be programmed to give all kinds of other reminders. For example: drinking or eating something, use the bathroom, check on deliveries or incoming messages. The caregiver can check the confirmation messages of the user.

News Anne can read headlines and short articles of various newspapers via RSS-Feeds. Anne can read it as often as the users wants her to. The user selects the news in which he is interested.

Video calling The user can have a video call with a select list of people. For example, with the informal caregiver, the professional caregiver, family, friends, etc. There is an additional web app, that allows the setting up of a safe connection between the user and the informal caregivers on their own devices.

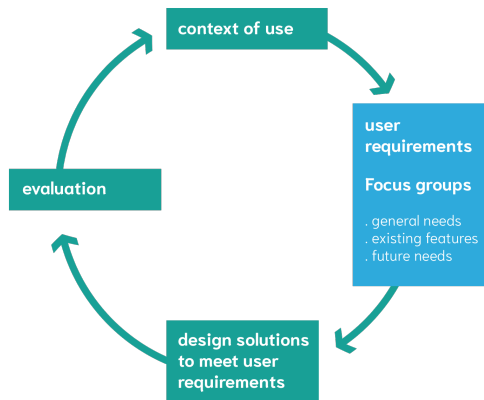


Figure 2: User centered design

3 METHOD

This project adopts a user-centered design approach (see Figure 2) following the ISO 9241-210 in which potential users are involved in all stages of development. In our view this is close to the concept of a ‘technology probe’. We use the social science to collect information about the users, the engineering goal of field-testing the technology and the design goal of inspiring both users and caregivers to think of new kinds of technology which support their needs [11].

This paper presents the analyses of user requirements and is part of the first out of two iterations. The analysis aims to understand the needs and desires of the system in development thus manage to build a usable and effective system [18].

3.1 Participants

In the light of scientific articles and discussions with professional caregivers and experts, we agreed that the older adults with already diagnosed dementia would not be able to express their needs eloquently and would risk getting perturbed within a focus group setting. It was thus decided to allow only professional and informal caregivers to participate in the **requirement focus group**.

The general inclusion criteria for participants to take part in the focus groups was that they have previous experience in the care of patients with dementia as a caregiver (informal or professional), researcher, project manager or adviser and that they freely agreed to share their own experience on this topic. Written informed consent and non-disclosure agreements were required for participation at the focus groups.

In Luxembourg, six qualified nursing assistants and four informal carers were recruited. The informal carers were all retired and aged 65+. No actual end-users were included in the focus group. In Italy, three professional and three informal caregivers participated in the focus group.

3.2 The focus group

To identify the requirements and to review the current features we made use of focus groups. We used this method because it explores people’s knowledge and experience, what they think and why they think that way [12]. We were interested to hear the participants positive and negative feelings about the technology and Anne in particular, their reactions to other group members and how they value the various topics. The technical partners use this input to adjust the initial prototype and then the improved Anne is tested again, thus starting the iterative process.

In February 2018 focus groups took place at two different European organizations: National Institute of Health and Science on Aging (INRCA, Italy) and Stéftung Hëllef Doheem (SHD, Luxembourg). Each focus group was moderated and facilitated by the local project staff, whereas other trained researchers participated as observers and note takers. Moderators were instructed based on a moderator manual. The questions asked in our focus group were predetermined and sequenced. The moderator used open-ended questions as much as possible and started with a general question to help people talking and thinking in an open manner. Decisions were made together with the participants, first individually later as a group. There was a relative structured interview, with high moderator involvement.

The focus groups took approximately 120 min for each session; discussions were audio taped and transcribed. The focus group setting included: 1) a short welcome and introduction, 2) a verification of the general needs, 3) a brief explanation of the ‘Living Well with Anne’ project concept, 4) the use of three main themes to guide the discussion during the session and 5) verification of possible new features. The focus groups finally discussed tips for existing features and potential future features that could be added to Anne. These existing features serve as the known unmet needs like: support for memory problems (agenda function), information about their own condition and care and support capabilities (agenda function), social contacts and companionship (news function / video chat function) [26].

The first topic of the focus group session concerned the general needs of both users and caregivers (from the caregiver perspective). Using the nominal group technique two specific questions were asked: What are the current problems PwD are facing today? And: What are the current problems you are facing today as a caregiver? Five minutes were given per question to think as many issues they could come up with (individually). These needs were written down on two flip charts and then each participant had to individually vote in accordance to their priorities. As a group they then had to agree on the top 5 issues per subject.

The second topic was focused on the existing specific features of Anne (Agenda, medication, news, video calling). Besides asking questions about the functionality as such, a different method was used to explore the topic a bit further. For each function, a scenario was discussed within the group and the discussion ended with the following: Will it be useful for people with mild or severe dementia? Do you think it is important to use an active or passive Anne? Do you think this will improve the QoL of the PwD? Do you think this will save you (the caregiver) time? These questions are according to other studies in the field [5][9].

3.3 Data analysis

For the data analysis we made use of content analysis. Data of the focus group session was recorded on a digital audio recorder, transcribed by two researchers independently and finally interpreted by another researcher. The three researchers then compared, discussed and agreed on the results of the different themes.

Documents related to the individual views (general needs) and summaries of each discussion (general needs, existing and new features) are saved in pseudonymised form. Results of the focus group were used as input for the developers and will be evaluated by the user in the protected environment test and the field research.

4 RESULTS

The results of the focus group activities are reported in relation to three subject groups: general needs, existing features and possible future needs. The results of each subject group are further discussed in terms of usefulness, level of interaction and impact on QoL. When citations by the participants are reported, we indicate whether the participant was a Professional caregiver (PCG), or an Informal caregiver (ICG).

4.1 General needs

A common view amongst participants was that dementia is more than just 'forgetfulness': memory problems are certainly a vital component of dementia, but communication, emotional issues, and behavioral problems are also significant problems. As professional caregivers they reported the presence of depression and boredom that patients don't understand, the sense of powerlessness and lack of control and support, and social withdrawal: "At the beginning of dementia, some people are aware that they are forgetting things, and they are ashamed, so they isolate themselves" (PCG). Moreover, the refusing or forgetting to drink, eat and take medication as well as the loss of orientation in space and time are frequently major issues confronting the PwD and their caregivers.

Professional caregivers are confronted with issues related to their work with PwD and the care they must provide. They experience issues like: unsuccessful visits as the PwD was absent or refused to cooperate; visits exceeding time allocated; aggression and violence towards staff. "One major problem is that some people with dementia are very changeable in their Day form. Sometimes they are very good and cooperative, on other days they fight you at every step. Some days they call me names and may even attack me and the next day I am the best, and they keep hugging and kissing me. Either way, it's difficult to get them washed and dressed" (PCG).

The key problems identified by the informal professional caregivers are issues that they are frequently confronted with and often directly related to the disease such as: the lack of support after diagnosis to understand how the disease will change QoL of caregivers and patients; the necessity to have psychological support to conciliate the needs of the whole family; the lack of knowledge about services or medical information; the lack of caregiver network to share experience, fear and ways to cope with the disease. To some extent, they are complementary to those experienced by the professional caregivers, but their own problems are more focused on anxiety, stress and responsibility.

It is well-known that caring for an individual with dementia can be challenging and, at times, overwhelming. For example some informal carers remarked that for them the hardest issues are those related to them not being able to relax when leaving PwD alone; to have no rest at night, battling with safety issues in the house, struggling with ethical dilemmas such as whether or not to lock the PwD in the house or observing them using cameras and running around trying to find the right medical care and support.

During the discussion of this topic it was mentioned that people with dementia cannot be seen as one group. There are different forms of dementia all with its own special signs and symptoms. Within the same diagnosis, people react and respond differently. Thus people with dementia cannot be treated as a homogeneous group and cannot be treated in the same way. There is no 'one right way' to nurse them and you cannot create one tool that will 'fit all'.

4.2 Needs of each specific feature

As mentioned earlier, Anne has three main features: agenda, news and video calling. All three features were discussed during the focus groups.

4.2.1 Usefulness during stages of dementia. The majority of participants were particularly critical about the usefulness of each specific feature during the several stages of dementia. It was suggested that each feature should be adapted to a specific stage of dementia. The agenda medication feature for example is only useful in the early stages of dementia. The risk and the lack of control that the user might take an overdose or do not take important medicines is too high. On the contrary, the news feature is useful for different stages of dementia although it needs to be adapted during the period of dementia: "The first thing our clients look at in the paper are the death notifications. That sounds morbid to us, but to them it is all important as somebody they know may have died, and they would want to know that" (PCG). As different participants suggested, the video call feature could be adapted with photos of relatives where the PwD could push on instead of the label with the name: "Keeping in touch with people back in Portugal would be really super. Some of our clients do this together with their children over Skype" (PCG). One important concern expressed regarding this specific feature was whether the video call service is a concern of privacy for severe dementia and PwD might experience stress.

4.2.2 Active or Passive. The overall agreed opinion amongst all of the focus group participants was that they prefer an active virtual agent which means that the agent would take the initiative to propose specific activities like reading the news or to listen to the radio. This active mode differs from the current feature as the system has to be initiated by the user who asks the virtual agent to perform a task, while the agent just listens (is passive). If the user forgets how to ask for a certain thing or uses the wrong command, then the virtual assistant will not respond appropriately. This could cause a lot of frustration and even stress for the person with dementia. However, this active approach will need to be applied with caution, especially with regards to taking medication or videoconferencing as illustrated by the following comment: "Anne should propose things first. She should take the initiative (ICG): Yes, she should ask: Did you take your pills today" (ICG). And: "We could not have

had the camera also pointing into the room as my father-in-law had a habit of stripping naked. He even opened the front door a few times with no clothes on” (ICG).

4.2.3 Level of QoL. For the majority of carers it was difficult to give a definite answer to whether or not a virtual agent could improve Quality of Life (QoL). They were however convinced that specific features could help. For example the news function: keeping their interests alive; the video call function: to keep them in touch with loved one’s in different countries. Social inclusion seems to be an important factor of QoL: “It could help them to feel less isolated” (PCG), “Yes, but at the same time it could make informal caregivers visit even less (PCG)” but this notion led to a lot of discussion, “Yes, that could be an issue with some families, but others may relax more because Anne is there. Anne can inform them about what the person has done with Anne or caregiver and PwD could work together to input new appointments and so on. This could be a good way of communicating together” (PCG). The carers do not perceive a virtual agent as a time saver. They expect that as the PwD have low experience with new technologies, it is the carer that will have to spend additional time to teach and support the PwD in using the tool. However, once the PwD manages to use a feature properly (i.e. reading the news or playing a game) the carer could do something else or take a bit of rest.

4.3 Comments on existing features and possible new features

From a professional caregiver’s perspective it would be helpful if the PwD was reminded of the caregivers visit and is ready to receive care and not anxious or agitated. Besides that, there is need for daily activities for the PwD, one could think of games, play music or radio, crosswords. A photo album could be useful to remember old days or recognize persons. Most needs and input were focused on daily activities, day structure and helping them to memorize and were practical oriented.

4.4 Conclusion and discussion

The participants of this study confirm the ability of a virtual agent to help and support people who are living independently with memory and other cognitive related issues. According to professionals and informal caregivers (i) Anne should be active instead of passive, (ii) some features (Video call and News) could improve QoL, (iii) these features are not strongly mentioned as time savers but engage the PwD in various activities and help them pass the time in a more meaningful way (News). This is in accordance with some other studies [2][3][13][25].

The outcomes of the group discussion were discussed with our end-user organization consortium partners in Luxembourg and Italy and were prioritized with points (1-5) and this resulted in a list of input for the developers of our consortium team. The most important things to do from the perspective of our end organizations are listed below:

- Set up video call with actual picture;
- Possibility to choose for video or speak function (video call);
- Voicemail for Anne: she should be able to read the message;
- Give structures to PwD (your obligations today are);

- Anne tells you what day it is and time;
- Anne should be able to STOP if asked;
- Shortcuts instead of long sentences (user commands);
- Activity suggestions;
- Detect presence in front of device.

Although we tried to determine the possible effect of the different features on the Quality of life we should be aware that it is a catch-all term [24]. It is therefore important to operationalize this term in future research and point out the different aspects like in Droes et al.[7] where they differentiate the domains of QoL: affect, self-esteem/self-image, attachment, social contact, enjoyment of activities, sense of aesthetics in living environment, physical and mental health, financial situation, security and privacy, self-determination and freedom, being useful / giving meaning to life and spirituality. From a health context perspective an interesting question is: does the caregiver have the same defining and operationalization of QoL as the person were they care for. Therefore we will make use of QOL-AD [16] in our field research to find out which specific element of QoL is being experienced by carers and PwD. Along other measures, it appears to be the most researched of all other measures of QoL [4].

As a research method we chose focus group sessions. According to Morgan [20] we did rely on (a) a relatively structured interview with high moderator involvement and (b) had six to ten participants per group. But we did not meet (c) homogeneous strangers as participants, we had two or three different homogeneous strangers per group, and (d) a total of three to five groups per project, we had two. According to the four critical qualities of focus group analysis of Krueger [14] the analysis was systematic. With our moderator manual we tried to avoid making mistakes and attempted to be logical and orderly. The fact that data was not analyzed by one and the same moderator, because the focus groups took place in two different countries and different languages, is a weakness. The analysis is verifiable in a way that the moderator and partner discussed the data afterwards, dissonance has not been reported. Our analysis will continue as the findings of the focus group will be part of the basis of our field research which will be undertaken with people with light to mild dementia and/or cognitive impairment.

However, further work is needed to fully understand the implication of delivering a virtual agent who adaptively changes her behavior to better support the elderly through various stages of dementia and cognitive impairment. In addition, the consortium partners have decided to add a set of testing with people who have more severe forms of dementia and higher cognitive impairment. A special set of tests within a protected environment (different cases, different clients, different needs and requirements) are being undertaken in parallel to go beyond the current limitations and extend the range of people that could use a technically adapted tool like Anne. The results of the focus group sessions leads to adjustments that are being implemented to create a new version. Given some of the radical changes, the new prototype will be tested by all the professional caregivers in the three countries prior to the actual field trials with the older adult end-users. This product test trials will ensure that all potential problems (such as IT bugs) are found and removed and that the changes correspond to the needs expressed during the Focus Groups. This way, we are ensuring that

the prototype which will be tested by the older adults in their own homes for 8 weeks are as stable and performant as possible. All risks of potential harm to end-users is thus removed.

During the field trials, other research approaches will be used to, amongst other objectives, establish the long term effects of Anne in this specific target.

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