The Design Adaptation of the Virtual Assistant Anne for Moderate Dementia Patients and Their Formal Caregivers in Protected Environment Tests

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Abstract. Dementia has become a major health problem with an equally important economic impact on our society and enabling patients with dementia and their caregivers to improve their quality of life and dignity is a great challenge. A significant solution to meet the challenge, could be the use of Personal Virtual Assistant (PVA). The aim of this paper is to share the know-how reached in the design and adaptation of the Personal Virtual Assistant "Anne" for moderate dementia patients and their formal caregivers. The paper presents the results of the first iteration of protected environment tests in Italy and Luxembourg.

Keywords: Personal Virtual Assistant · User Centred Design · Dementia

1 Introduction

Dementia has become a major health problem with an equally important economic impact on our society: approximately 47 million people have dementia worldwide and this is expected to almost triple by 2050. The cost associated with this disease is estimated to be at 818 billion dollars, and by 2030, this cost is expected to exceed one trillion dollars [1]. Enabling patients with dementia and their caregivers to improve their quality of life and dignity is a great challenge. A significant solution to meet the challenge, is the use of innovative technology. Avatars or Personal Virtual Assistant (PVA) are promising examples of technological solutions with a large potential in this field. PVAs are screen-based entities designed to stimulate human face to face

conversation skills and thus allow for natural interaction between humans and computer [2]. The extent to which this type of innovation may be able to support people affected by dementia and their caregivers along the progressive nature of this terrible illness, represents a great challenge for the entire scientific community. The changing needs of patients and those who provide care for them force the necessity of appropriate and effective technologies at the different stages of dementia. For example, exiting systems target memory support and self-care for people in the early stage of dementia whereas in the moderate to severe stages of dementia, assistive and safety technology (i.e. motion/fall detectors, environmental sensors measuring elements such as room temperature, smoke/gas/water presence) are mostly needed [3]. Unfortunately, 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 [4]. People with cognitive impairment seem to engage naturally with a screen agent [5]. Moreover, it is found that virtual agents provide a sense of companionship [6]. The aim of this paper is to share the know-how reached in the design and adaptation of the PVA "Anne" for moderate dementia patients and their formal caregivers, within the Living Well with Anne project.

2   The Living Well with Anne Project

The *Living well with Anne* project (http://livingwellwithanne.eu/) is co-financed under the Active Assisted Living Joint Programme of the European Commission (www.aal-europe.eu) and the National Funding Agencies of 7 partners out of 4 European countries (the Netherlands, Italy, Luxembourg and Switzerland). The project has started in June 2017 and the duration was set to 36 months. Living well with Anne is based on the AAL predecessor project *MyLifeMyWay* (http://www.mylifemyway-aal.eu/), and it operates in a promising research field based on new approaches in technical assistance systems and robotics with the focus on seniors suffering from forgetfulness, cognitive impairments and/or the early stage of dementia (Fig. 1).
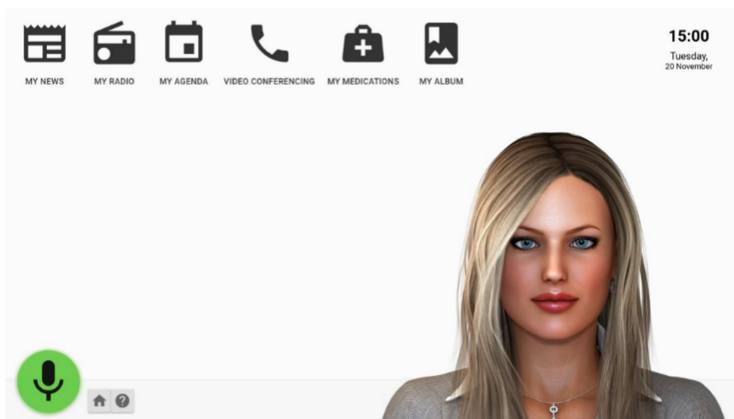

Fig. 1. The users interface. Copyright Virtask B.V.©

2.1   Component Overview of the Personal Assistant Anne

The LivingWell project features the Personal Virtual Assistant "Anne" that can support the users in all aspects of daily life: communication with the outside world, keeping track of items on the personal calendar, daily structure, medication, reading the news and re-laxation (games, music). While the technology in the background is quite complex, for the end-users the PVA is a friendly, human-looking avatar on their screen. They can interact with the PVA with their voice and touch. In this project, the personal assistant is extended with features that meet the changing needs of people with dementia (PwD). Anne will enable PwD to live independently for longer by giving them an easy-to-use, most natural way to interact with assistive technology. Anne is able to learn autonomously from its users and gets to know their personal preferences and needs. The PVA can assist and support PwD and their social environment in such a way that they can be active much longer be active and take part in social life. In addition, as end-users learn to use Anne and increase their autonomy, it is believed that it will have an unburdening effect on their informal and formal caregivers.

Anne works on a Surface Pro tablet under the Microsoft Windows 10 operating system. Currently the following languages are available: Dutch, English, German, Italian, French. Spanish and Portuguese are under development (Fig. 2).
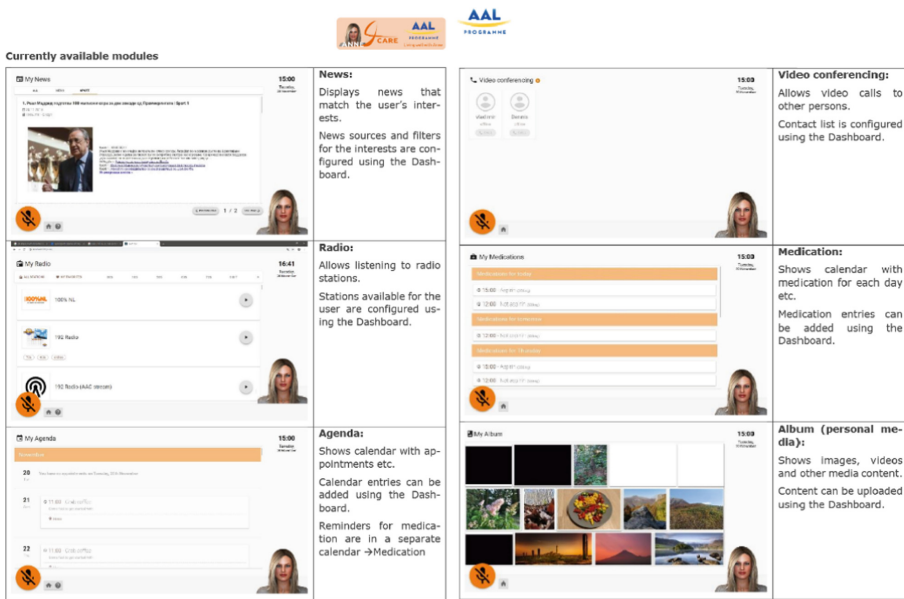

Fig. 2. Screenshots of current available modules that show an example layout. Depending on the abilities of the user, the layout can be different, or the module can be hidden or disabled. The challenges in the design development. Copyright Virtask B.V.©

In the Living Well project, we explore the following question: how Anne can be modified to the requirements of people with dementia in different stages?

Rather than to reinvent the wheel, the project uses on an already developed modular software solution and smartly combining several existing technologies such as language recognition and speech generation, 3D-rendering, adaptive decision control mechanisms etc. Building on the knowledge already attained in building the basic version of Anne, the project will go beyond the state of the art in avatar technology. The objective is to ensure that Anne will be able to adapt to the changings needs of the concerned people as the disease progresses. The new and innovative concept builds upon new functionalities of Anne advancing her in four major areas:

- **Dynamic state and progression analysis:** The avatar will be able to detect the state of the PwD living at home in order to get a close picture on what the person is still can and cannot do. This analysis continues dynamically and will get more precise while Anne learns. But Anne will also be able to detect changes in the behavior and the abilities of the PwD as the disease progresses.
- **Situational context analysis:** While in the previous area, the general abilities of the PwD living at home are analyzed on a more mid-term basis, Anne will also be able to find out more about specific situations and the typical day-to-day living patterns of a PwD.
- **Smart, context-sensitive service provision:** Once Anne knows more about the abilities of the PwD, she may choose the most suited ones among her standard and newly developed functional modules (Agenda, Radio, News, etc.) the most suited ones and decide on which level of complexity they should be provided.
- **Adaptive user interface:** Finally, Anne will be able to adapt her user interface to provide the selected services in a way that still make them accessible to the PwD.

This development requires the close involvement of end-users during the design process in conformity with the User-Centered Design (UCD) approach. A great challenge of the Living Well project is to provide a human-centered perspective that can be integrated in the main development cycles of the system [7]. The active involvement of users and a clear understanding of context of use are the key strengths to overcome the main barriers in applying technology for seniors in general and in particular for people who suffer of dementia.

In the light of this challenge, the research objectives of this particular part of the project are to obtain insights in: (i) how do patients experience the PVA in the stage of moderate dementia? (ii) how Anne can be modified to the requirements of people in the stage of moderate dementia?

3   Methodology

For this study, the method of protected environment tests was used as a phase of the UCD development process. Predefined small test sessions were performed in a safe and familiar environment where the end user met with a caregiver and a researcher for a short time (e.g. an hour or even shorter) to perform a particular activity. Each user interaction between the PwD and Anne was observed, analyzed and documented by the formal caregivers and researchers.

The protected environment tests scenarios were previously agreed between formal caregivers, researchers and technicians in order to establish the needs and requirements (pains and gains). In this way, Anne was experienced by patients with moderate dementia within a controlled setting and under the supervision of their formal caregivers and the risks of exposing PwD to the PVA (e.g. provoking paranoid reactions to the Avatar and leading to aggression behaviors) were mitigated. To supplement the observations, formal caregivers were interviewed at the end of each session of test using a semi-structured list of questions. In accordance with Preece et al. [8], our questions are conforming to the usual usability goals like effectiveness, efficiency, safety, utility and learnability. The interview included the following statements (Table 1):

Table 1. The semi-structured list of questions

Questions
1. Did the tool meet the predefined expectations? Why (not)? If not: what should be changed?
2. Is this tool useful in each stage of dementia?
3. On the basis of this experience, do you think that the system is useful in this specific stage of dementia?
4. Do you think that this tool can be used by the patient without the caregiver's supervision?
5. If not, what kind of changes will be necessary to adapt Anne for the needs of this stage of dementia?
6. What kind of behaviors did you recognize in the target during the interaction with Anne?
7. Do you think that these behaviors represent positive, negative or neutral feelings in the subjects?
8. Do you think that Anne could have some benefits/advantages on the target?

The protected environment tests were performed in two different settings:

- In Italy, 5 female patients with moderate dementia, 2 formal caregivers and 2 researchers working at the Alzheimer Daily Center of INRCA were involved in different iterations;
- In Luxembourg 1 female patient with dementia, 2 formal caregivers and 1 researcher were involved in the requirements session. Additional patients will be involved in the testing of the consequent iteration of the protected environment tests.

4   Results

This section provides the outcomes of the participants' interactions with the PVA. The results provided are the combined notes of the formal caregivers and researchers in Italy and Luxembourg.

4.1 Protected Environment Tests in Italy

Formal caregivers, researchers and technicians agreed to develop and observe two specific requirements in the Italian setting: prayers and the quizzes. These two functionalities respond to the general need of keeping the patients calm and relax and in parallel involve them in entertainment activities that can stimulate their procedural memory. The PVA was evaluated with the PwD in a setting familiar to the participants, at the day care centers where they are frequent visitors.

From a qualitative point of view, a result of the observations was that the older adults at no point exhibited fear, misunderstanding or inconvenience when seeing the avatar on the screen or, most importantly, when the avatar spoke to them directly. Moreover, nobody withdrew from the test. Another result to underline is that PwD freely spoke to her. The sample group responded verbally to the avatar but they did not use the touch control.

The interviewed informal caregivers recognized the potential of the PVA as a tool for their daily activities. For example, for them it appeared clear that the prayer evoked the procedural memory and acted as a "mantra" and the PwD seemed to feel soon comfortable. Nevertheless, the formal caregivers were strongly convinced that the use of the PVA is only useful for this stage of dementia if controlled by the professional staff. The proactivity of the avatar emerged as the most important aspect to improve the next iterations. The users need to experience the personal assistant as a companion. Other suggestions coming from the interviews put the attention on the leisure/games functionalities and the need to maintain the residual cognitive ability of PwD fostering cognitive training by means of painting pictures, paying quizzes and puzzles, reading books and listening to stories, and music (mainly classical).

All these improvements are being implemented for the second iteration of protected environment tests.

4.2 Protected Environment Test in Luxembourg

In Luxemburg Formal caregivers, the researcher and technicians agreed to develop and observe one specific requirement of the basic Anne: the puzzle. One lady with intermittently medium dementia (temporary loss of memory and cognitive functions), together with 2 of her formal caregivers at and 1 researcher, tested the basic Anne as she is currently being used by older adults without issues of dementia. The PwD quickly focused on the games section and in particular the puzzle because she already does puzzles as a means of exercising her memory and cognitive abilities. The problem she encounters currently is that when she does puzzles in the Day care Center, there is always a member of staff at hand to help and encourage her but at home, she gets too quickly frustrated to play. As she only attends the Day Care Center twice a week, the benefits of this activity are limited. Both the PwD and her caregivers are convinced that if Anne could take on the role of supporting and encouraging the PWD at home, she would be able to play a little every day and thus maximize the benefits on her memory and other cognitive abilities and thus maybe even slow down the development of her dementia.

In the post test interview, the formal caregivers expressed the belief that within the 10 SHD Day Care Centers, a large number of their PwD patients could benefit of such a development.

The following requirements were identified:

- The Puzzle needs to be simplified (cut into simple shapes) and provide several choices of complexity in order to insure that the Puzzle can be adapted to the PwD with severe cognitive problems while still challenging those who are still more able. For example, the client tried to play the normal puzzle and failed. Client herself said that the curly complex shapes made it difficult for her. The formal caregiver said that if we oversimplify, then other clients may get bored. So they expressed the need to have a choice of difficulty to meet the needs of all their clients and help them to challenge themselves.
- The pictures used need to be relevant to the PwD's life experience (e.g. pictures of Luxembourg or their country of origin, pictures of their Day Care Center building/bus/staff, pictures of their home or their family members).
- Anne needs to actively invite and encourage the PwD to play and provide choices on the level of difficulty.
- Anne needs to notice when the PwD has difficulties completing the Puzzle and offer appropriate help and/or offer to reduce the level of difficulty.
- Anne has to actively encourage and complement the PwD throughout the session and after each game.

These and other specifically designed features are being implemented to be tested in the 2nd iteration in the protected environment tests which will include other PwDs attending the SHD Day Care Centers.

5   Discussion

The goals of this study were to find answers to the research objectives introduced in Sect. 2.1.

5.1   How Do Patients in the Stage of Moderate Dementia Experience the PVA?

PwD and their formal caregivers enrolled in this study were positive regarding the PVA. All the participants interacted with Anne playing games, quizzes or praying with her. No problem behaviors (i.e., verbal, physical, and overall agitation), were observed, neither patients withdrew from the tests. This data suggested that people with moderate dementia can be engaged in interactions with a PVA. This results confirm the state of the art in the field [9–13].

However, patients experienced difficulties in using a touchscreen and navigating the different applications of Anne. This convinced the formal caregivers in Italy that Anne could be a useful tool for their daily working activities but that their patients could not use it independently. The caregivers in Luxembourg agreed that the daily living activities of the current Anne (e.g. Agenda, medication, video call…) were too

difficult for PwD to use independently at home. This is in line with recent researches that shown how the PwD needed permanent help and prompting while using natural user interfaces [14, 15]. However, the staff thought that once adapted appropriately, the Day Care Centre attendees with mild to moderate dementia could continue to play the games (e.g. puzzles) independently at home with Anne mimicking the support given by the formal caregivers.

The results showed very clearly the importance of personalized solutions: the design adaptation was conducted in close collaboration with the care organizations which provide daily assistance to the patients both in Italy and Luxembourg. This participatory strategy allows for easy adaptation and consequently helps to match the needs of future beneficiaries with the proposed technology [16, 17].

5.2 How Anne Can Be Modified to the Requirements of People in the Stage of Moderate Dementia?

In software design for PwD, user centeredness is crucial. User-centric design (UCD) implies developing in small steps, iteratively testing new versions with the end-users. This is only possible in a software environment where it is very easy to implement changes to the look-and-feel, without having to adapt many back-end functions, databases etc. We therefore decided to use a simplified version of the Anne software on stand-alone systems without backend integration, where we could provide software versions tailored very specifically for each protected environment test, without having to adapt many back-end functions not directly visible for the user. For each protected environment test, the researchers, carers and developers collaborated closely to design the test, to install and perform it. The development cycles were shortened further by creation of mockup images before implementing software. For installation and support of the test computers, direct remote access for the developers proved very useful. From the results of all these very specific tests and software versions, the following general results can be extracted for an Anne version suitable for PwD:

- Encouragement: Anne should encourage the user to continue if he/she has succeeded in doing something, has finished a subtask or done a step towards a goal.
- Immediate feedback: Whenever the user interacts with Anne, immediate feedback should be given, e.g. a visual effect when touching an active element on the screen, or an audible feedback when Anne has heard a speech command. This is a common truth for all user interfaces, but for PwD it is crucial.
- Give hints: When the user is stuck in a task, Anne should give hints or make suggestions what to try or what next step could be possible.
- Simplify screens to the absolute minimum: The PwD should not be confused with visual elements that are not important for the current task.
- Personalization: Anne should be personalizable very easily by the carers, not only to the overall wishes of the PwD (e.g. what modules should be visible in general), but also depending on current strength of the PwD, as this can vary from day to day. As the Anne software knows the interaction patterns of the user, it should support

the carers in this configuration process by recommending simplification possibilities. The associated machine-learning capability of Anne opens many research questions and, if proved feasible, even possibilities that future versions of Anne could self-adapt their user interface, based on the current condition of the PwD.

5.3   Limitations, Conclusion and Future Steps

While this study was limited by its small sample size, gender homogeneity (only females were included in the group) and very low ICT skills, its intent was to develop some specific features for the use of people with different stages of dementia and associated cognitive problems and pave the way for future studies of how PVAs can be adapted to fit the different stages of dementia. It is to underline that current PwDs had generally little experience with mobile technology before they became affected by dementia.

Nevertheless, future steps are needed. The first step is to conduct methodologically sound scientific researches in the community dementia care and support. This could lead to the urgent proof of the cost-effectiveness of such devices. The second step is to study in depth what are the factors that can influence the deployment of these technologies. In this respect, it could be very interesting to know if a participatory design strategy is the key to sell products to PwD but also to the caregivers (informal and formal) who will recommend or even buy the product for the PwD asking themselves "what is the added value for me?". In the future, interaction with technology may become less of a problem for PwDs. This increased IT literacy will open the way for broader application of ICT with PwD in a more severe stage.

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