Requirements guideline of assistive technology for people suffering from dementia

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ABSTRACT
This paper presents valid concerns on current status of elderly population suffering from dementia, why societies should focus more attention in helping them and how this could impact healthcare and social services. This paper also discusses the requirements and methods, which can be used to improve the design process of wearable procam device using Picture based Input Method Using Tapping on Wall Surfaces (PiTaSu) that can help people suffering from dementia. A guideline of proposed requirements is presented that takes into account several different types of problems people suffering from dementia face. An improved user interface (UI) is proposed for people suffering from dementia, as well as the need to implement separate tele-assistance functionality for the informal and formal caretakers.

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D.2.2 [Design Tools and Techniques]: User interfaces  
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1. INTRODUCTION
Several nations around the world are facing a problem with aging society structures in the near future, which taxes the economy and overburdens healthcare and social services. Growing number of elderly population needs more health and social services. This will create problems later on as there will not be enough manpower at industry. In addition, taking care of the elderly population increases spending for mandatory healthcare and social services. To match the needs of elderly care, current percentage of healthcare and social service employees e.g. in Finland should rise from 14% to 24% by 2035 if current consumption to Social and Healthcare Services stays constant [7]. This can be seen unrealistic in terms of current economy projections and younger generations focusing more on fields outside of social services when entering the labor market.

From the aging population some require more specialized assistance than others. In Finland alone there are 110 000 people suffering from dementia. This number can be assessed to rise to 210 000 by the year 2030 based on prevalence of dementia to population projections of Finland [1,2,3,4]. This estimate does not even include mild cases of neither dementia nor memory disturbances. When a person is diagnosed with pre-dementia symptoms, usual recommendation is introducing assistive technologies and other aid devices as soon as possible for the person suffering from dementia as well as for the formal or informal caretakers [9, 10]. This is due to the fact that learning new things becomes slower or halts as the dementia symptoms become worse, so familiar devices should be created for the users when they still can learn how to use it. Suspiciousness towards new things in their environment also hinders the introduction of these new devices for the person suffering from dementia. In addition, old devices that have become obsolete have to be replaced with new aid devices that are suitable for the new, more difficult problems of daily activities. This creates a clear problem when multitudes of devices are available, but there is no single device that could be taught to the user, or at the very least be recognized by the user as something he has used before for assistance. A device should be introduced that would be easier to use, offers clear selection choices to the user and should require little to no learning when used daily.

Lack of social and healthcare services personnel and growing funding problems in the future might be solved if focus is aimed at assisting the elderly population in their homes. Elderly prefer to live this way as they can have more independent lives [8] outside of institutional care and thus lessening the burden to states. For example in Norway 50% and in Italy 80-90% of the elderly population live in private households [10]. Assisting the formal and informal caretakers in their tasks with more efficient tools is a way to lessen their workload and stress related to dementia and improve current situation. Remote assistance by the caretakers from an external site can be considered useful when help cannot be offered on-site when help is needed.
Aimed at people suffering from dementia and their formal or informal caretakers, this study outlines the basic requirements for the design of technological aid devices associated with dementia. Based on the study, we can deduce four active skills and activated people suffering from dementia to be more successful in managing daily activities, helped in maintaining their suitability for demented persons and from dementia [9]. The project’s task was to find out what kind of devices was constant, which is also present in other similar research conclusions. This is due to the degrading nature of the disease, which presented new problems the aid devices should handle. The devices had to be changed to match the problems. It would be beneficial to create aid devices that can more easily adapt to the requirements of changing needs of people suffering from dementia. Unlike people with dementia, caretakers can learn new skills but prefer not to constantly learn them, or would like to have more usable, effective systems that don’t require much learning. An aid device that is introduced early on to the user was also shown to be beneficial when the symptoms of dementia were still in their early stages.

Use of aid devices in some cases was shown to be unique to the users’ preferences. Different persons used the same aid device differently. Also people suffering from the same severity level of dementia in the same kind of living environments did not always require the need of the same devices. Aid devices that can display individual and tailored information would lessen the need to introduce new devices and would be familiar to the user throughout the process of dealing with dementia.

Symptoms of different dementia types can also present physical or mental related limitations. For example, dementia resulting from vascular disease may be accompanied by focal neurologic findings such as aphasia, agnosia and dyspraxia.

- ‘Aphasia’ is “an impairment of language, affecting the production or comprehension of speech and the ability to read or write.” [13] i.e. a user knows what a cup is, but cannot remember the exact word ‘cup’, or cannot read the word ‘cup’ written on a piece of paper.
- ‘Agnosia’ refers to the loss of ability to recognize objects, people, sounds, shapes or smells, when the required sense is not defective, i.e. the user would not know what a ‘cup’ is.
- ‘Dyspraxia’ is the partial loss of the ability to co-ordinate and perform certain purposeful movements and gestures in the absence of motor or sensory impairments [12,14]. This could be experienced when picking up a cup from the table, or using a user interface that requires complex movements.

These particular impairments present challenges for the use of any user interface, as the user might not understand what they see, read or interact with. Presenting guiding text in addition to pictures of items or persons can prevent the user from confusing what they must do. Using only a single touch-action as the input function can help when the user has dyspraxia impairment, as the input can be successful if the user can tap a single icon.

2. DEMENTIA BASED REQUIREMENTS

Aging related cognitive skills decline such as age-associated cognitive decline (AACD) or mild cognitive impairment (MCI) are quite normal age related difficulties for elderly e.g. mental processing speed, reasoning and executing tasks. In addition to these problems, dementia presents additional requirements for technology design. According to Alzheimer’s Association [5] Alzheimer's disease is the most common type of dementia with 50 to 80% prevalence of dementia cases. Typical symptoms of it are:

- ‘Memory loss’
- ‘Disorientation’ of time and place
- ‘Forgetting’ location of items

Dementia also sometimes manifests as [6],

- ‘Apathy’ or ‘passiveness’ due to lack of initiative
- ‘Frustration’, ‘agitation’ or ‘irritability’
- ‘Suspiciousness’ due to personality changes

Nordic countries (Finland, Iceland, Norway, Sweden and Denmark) made a collaborative case study to 29 persons suffering from dementia [9]. The projects task was to find out what kind of aid devices are used, their suitability for demented persons and their caretakers as well as gathering feedback of proposed improvements. This two-year study concluded that introducing aid devices into the homes for people suffering from dementia improved management of daily activities, helped in maintaining skills and activated people suffering from dementia to be more active in society, which lessened feelings of loneliness often associated with dementia. Based on the study we can deduce four basic requirements for the design of technological aid devices aimed at people suffering from dementia and their formal or informal caretakers:

- Combining device functionalities
- Lessening the amount of devices
- Creating adaptive and tailored user interfaces
- Implementing tele-presence assistance

Usage feedback was gathered as interviews from the users, informal caretakers, such as a spouse, or from formal caretakers.

Based on the collected data, the need to learn usage of new devices was constant, which is also present in other similar research conclusions. This is due to the degrading nature of the disease, which presented new problems the aid devices should handle. The devices had to be changed to match the problems. It would be beneficial to create aid devices that can more easily adapt to the requirements of changing needs of people suffering from dementia. Unlike people with dementia, caretakers can learn new skills but prefer not to constantly learn them, or would like to have more usable, effective systems that don’t require much learning. An aid device that is introduced early on to the user was also shown to be beneficial when the symptoms of dementia were still in their early stages.

3. PiTaSu SYSTEM OVERVIEW

Previous research in Value Creation in Smart Living Environments for Senior Citizens (VESC) project has introduced the use of a projection-based display system called PiTaSu to be used by people suffering from dementia as an assistive technology tool. Its main advantage is displaying a big screen of information on flat surfaces like tables or walls and offering interaction.
capability with tapping actions when necessary. Advantage of a mobile aid device is that it can offer help anytime and regardless of place. As a wearable system, PiTaSu can be taken wherever the user goes to, but as long as the user doesn’t forget to wear it. There is the possibility that the device is left behind by the user who is suffering from dementia, so a reminding function to this has to be implemented. PiTaSu provides a projected display on physical surfaces in front of the user. Due to this there is lower chance of blocking the users view in the physical world, which might present any danger. Head-mounted displays (HMD) have been used in most study of wearable computing to present information to a user. Compared to PiTaSu, this can be seen dangerous in some situations because VR information might block something physical. In addition, PiTaSu can show information also to other people around the user. PiTaSu also focuses on picture-based communication. Advantage of using pictures provides concrete information to the user that is easier to understand compared to just using text. Current system has a tapping input interface. Previous tests with elderly users confirmed that a simple tap is a very intuitive way to use the system as the user also gets haptic feedback from tapping a real surface. A tapping interface can provide an easy input method for everyone. These elements have a potential for personal use applications added in mobile or wearable computing.

PiTaSu’s functionality and user interface designs however need to be evaluated and a more detailed requirements gathering has to be done. Gathering the necessary requirements for the design of a suitable device for the users is important. We hypothesize that using PiTaSu for people suffering from dementia, would offer an easier-to-use device, it would be easier to see the required information and interact with PiTaSu due to large screen display. The main device would be compact enough to be carried around in daily activities indoor and outdoors, so there would be less need of additional devices.

4. SCHEDULING AND ORGANIZING

Current implementation task focuses on offering assistance on problems regarding scheduling, making daily decisions and offering reminders. To enable these features presented in Fig. 2, adding remote assistance functionality is designed for informal and formal caregivers. The user suffering from dementia will use the basic tap-action interface with added audio, video and icon guidance. Informal and formal caretakers can create reminders or propose a schedule e.g. medication consumption or visiting a museum. They will be able to create scheduling of activities from an external site using a PC or mobile application. Any information used will be backed up on external server. This is done to prevent data loss and to ease device replacement.

User interface presented in Fig. 3 focuses on offering a more robust way to interact in the case the user needs to use any UI functions compared to earlier concepts [11]. Text and picture based UI can be considered an improvement, because a picture-only based solution cannot offer assistance for users that suffer from aphasia or agnosia. The user interface in Fig. 3 (left) is divided into three main alternating interactive elements (function icon a-b-c) and two alternative interaction elements (main menu, picture area). This will minimize the amount of information provided to the user, which might create confusion. An emergency button should be available, however, in case of UI projection being unavailable, or unusable, there should be a separate physical button the user should be able to press e.g. wrist alarm, making the use of it faster and reliable. In the example Fig. 3 (right), interaction with the user interface can be done with only tapping the icons. Hovering over an icon highlights the icon and will display a separate guidance text box of the function. Additional guidance can be given via audio feedback every time the UI is displayed the first time, when the UI screen changes to a new one, or if the user hovers on top of an icon. Using only tap and offering constant guidance on the use of the UI can prevent the need to learn the use of the system. Fig. 4 shows an example of the possibilities of using PiTaSu in a bedroom environment. The UI elements in this case focus on offering reminders for the user of their daily activities. These UI elements are interchangeable to any other information the user needs.

5. WEARABLE TECHNOLOGY GUIDELINE

Literature review on existing devices and design recommendations has offered relevant demands for wearable devices that would suit a person suffering from dementia. Design of assistive technology has to provide answers to multiple questions during the design process. Bjørneby, Topo & Holthe [10] talk about offering help for instrumental daily activities that might require assisting, such as shopping, cooking, taking

Figure 2. External site assistance for PiTaSu user

Figure 3. Left: Design-for-all user interface's main structure, right: example of user interaction with reminder functionality after a passive reminder

Figure 4. Example of PiTaSu projection in bedroom environment for the user regarding a meeting with a doctor
medication, making daily decisions and using a telephone. Additional tasks that are considered important are also presented. These are not instrumental but more emotion based e.g. enjoying life, participating in social activities, getting motivation, doing leisure time activities, feeling competent in ones actions, maintaining personality, privacy, time allocation and entertainment.

A suggested wearable device abilities guideline for our project groups system is presented as follows, based on earlier literature findings [6, 9, 10, 12, 13] and an assessment of the current solution.

- ‘Scheduling’: Calendar and daily activities reminder and scheduler is an important feature. It activates people with dementia and with tele-presence capabilities informal and formal caretakers can update the desired tasks to the user, and inquire if a task has been done. Involving the user in the creation of the daily schedule is assumed to be a task that creates feeling of competence to the user.

- ‘Simplicity’: Learning new things is slow or not possible for people with certain level of dementia, and in some cases there is also agnosia and dyspraxia caused impairment. The user interface has to be intuitive and easy to learn, offer instructions and guides, or have no learning involved.

- ‘Tailoring’: People need different devices because of personal habit differences. A multitasking device that can be optimized for the users needs might create trust for the device. Taking into account person’s physiological capabilities is also important.

- ‘Reliability’: Devices that don't work as planned or stop working during use create no trust for the device. This might create situations where the device is not used at all. Ensuring the device works or if it fails to work replacing the device as quickly as possible is essential. Backing up the contents of a device for easy replacement should also be considered.

- ‘Support’: The device has to be supported effectively from the moment it is taken into use, and has to be maintained effectively during the total time it is used.

- ‘Passive’: Devices that are mostly passive and require little or no interaction from the user, require less learning and are easier to take into use. Implementing as much passive features as possible should be considered.

- ‘Durability’ or ‘perceived durability’: Technical devices that seem like they might break are sometimes left unused by the user. Demonstrating that the device is tough should be considered. Alzheimer's symptoms can include frustration or agitation, so if the user mishandles the device because they are frustrated, it should be durable enough for misuse.

- "Being like the rest": Not separating the user suffering from dementia from the general population based on what they wear (aid device) is important. Wearing a device that looks like the person has a disability creates a sense of unwanted attention to the user. This should be avoided by using device designs that don’t differ too much from the normal technology design.

6. DISCUSSION AND FUTURE WORK
This paper presents a flexible guideline that can be followed when designing a wearable device for people suffering from dementia. Implementation of a tele-presence assistance service could provide help for the user suffering from dementia regardless of place and time. Earlier studies have shown that in addition to the demented persons need to feel safe and assisted, there was also needs for the informal caretakers such as a spouse to be able to know what the demented person was doing while they were not at home to help them. Aid device with tele-presence capabilities could offer improved ways to help and inform caretaker. Software that can help the informal and formal caretakers to be more effective in assisting a person suffering from dementia is suggested. Comparing user requirements presented by Bjørneby, Topo & Holthe [10] and other requirements of dementia, this paper presents a requirements guideline that could improve the current PiTaSu system. We can conclude that using a tap-based interface with picture and text information offers simple input that should require less learning. Especially people suffering from aphasia, agnosia and dyspraxia have to be considered a test group because of the requirements of these particular impairments to the system.

Focus group members for this research are people suffering from dementia on MMSE (Mini-mental state examination) scale of 30 to 18 and GDS (Global deterioration scale) on a scale of 1 to 4. This will include pre-dementia, mild dementia and partly people suffering from moderate dementia. Assistive technologies in this project will be presented at first mainly for persons suffering from established pre-dementia symptoms (MMSE 30-24) or mild dementia symptoms (MMSE 26-22). Follow through on the usability and suitability for the users will be done until the devices are deemed unnecessary for the tasks it was created for, invalid to the users, or if the MMSE of the user reaches 12. New devices will be also introduced to people with MMSE of 22-18 to evaluate the simplicity and ease-of-use of the devices user interface functions.

Personal consent from the users as well as their informal and formal caretakers will be applied. A testimonial from the Ethics Committee regarding the rights of the focus group will be applied in August. Interviews with seven dementia patients and their informal and formal caretakers will be done during this calendar year to assess the needs of the users. Additional interviews will be done in with Japanese dementia patients and caretakers during 2012. Based on observations done in previous research projects [9], guidebooks and articles [9, 10], observing people suffering from dementia is important. A hands-on approach helps in understanding the daily problems of a person suffering from dementia and it helps in gathering problems that might not be noticed if the informal caretakers only collect the data. Also a person-centered approach is crucial because design requirements might otherwise be inaccurate.

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8. REFERENCES


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