User Centred Gathering of Requirements for Mobile Assistance Services for People with Mild to Moderate Dementia

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Abstract: The European AAL project Confidence aims at creating a mobile safeguarding assistant for people with mild to moderate dementia and the people who care for them. Identifying the real needs of both user groups and come up with a set of features that truly supports them in their daily lives is a challenging task. An adaptable, user-centred approach, which considers the specific profile of the target groups as well as their different cultural backgrounds, has been applied. The paper describes the process tailored for Switzerland and its results.

Keywords: user centred design, ambient assisted living, system supporting people with dementia, mobility safeguarding assistance service

Introduction

Today 110’000 people in Switzerland suffer from dementia, resulting in a percentage of over 8% of the elderly aged over 65 [1]. In Europe the number of patients has increased to about 7.3 million [2] and it is expected that it will double within the next 25 years. Dementia, as a general umbrella term for different cognitive impairments, can be categorized into 3 levels of severity: mild, moderate and severe [3]. People diagnosed mild-to-moderate (Mi-Mod) dementia suffer from mild cognitive, functional and behavioural impairments. Besides the loss of memory, spatial and temporal disorientation belong to the earliest and most easily perceived symptoms [4]. Often, the personal situation leads to anxiety and fear of undertaking tasks, which affects the patients’ autonomy and mobility. Confusion, irritability, inactivity and even depression can be the results. However, in general these people are still quite independent and are capable of executing their daily live activities. And first experiences with Mi-Mod patients indicate that they are motivated and able to use modern, intuitive technology, especially smartphones and tables, to assist them. This is why this group has been chosen as the main target group for the mobility assistant developed in Confidence which heavily relies on the capabilities of the latest generation of smartphones. On the one hand, the idea is that the people suffering from dementia (primary end users) are equipped with such a device giving them the confidence to always be able to get assistance or call for help in an emergency wherever they are. On the other hand, a Confidence community with people belonging to their direct personal environment as well as professional caregivers and volunteers (secondary end users) are prepared to help and get the support they need in order to assist the person in need. The concept relies on combining technological services running on the smartphone and on servers in the cloud with the personal human help. However, before the requirements analysis phase it was still open what services are wished and accepted by the end users, what tasks shall be fulfilled by humans and where do people trust in the help of a personal electronic assistant.

Methods

To gather and evaluate the requirements a common user-centred design process (UCD) has been set up and specifically implemented in the three countries were end user organisations of Confidence are present: Austria, Romania and Switzerland. The UCD is a widely known, well-defined process for designing interactive systems, which offers many benefits to all involved projects parties. These benefits address the active user involvement as well as working together in a heterogeneous, interdisciplinary project team [4]. The methods applied in the iterative process in Switzerland mainly consisted of generating a consortium internal view (catchword catalogue) first and then validate and refine this view by talking to different end user groups in workshops and focus groups as well as asking experts opinions through questionnaires and guided interviews. Fig. 1 depicts this process and its outcomes resulting in a “Swiss user scenario” including the description of the personas involved, a collection of short user stories derived from this scenario and finally a set of the features considered most useful by the Swiss end users and expert groups.

Results

The first survey of potential end users of the system and an internal review resulted in a list of around 81 user stories in the form of “<Primary Enduser> wants to be able to call for im-
mediate and competent help in an emergency case”. These stories were categorized in four application groups: (1) orientation and navigation (2) reminders, information and daily activity management (3) personal human assistance (4) calming down a person. After filtering and pooling these user stories again in a workshop with care givers experienced in the care of people suffering from dementia, a set of 48 features resulted. These were listed in questionnaire and finally rated by a selected group of dementia experts ranging from employees of the Alzheimer federation Switzerland, to professional care givers and their trainers and medical doctors of memory clinics. Fig. 2 depicts the survey’s.

![Image of survey results]

Figure 2: Results dementia experts’ survey

From these results the Swiss group derived the final scenario, the user stories to be implemented and a feature list that can be summarized within 6 high level feature groups: (1) Emergency detection and alarming. Whereas the alarming can happen on manual request of the primary enduser as well as automatic if the primary end users leaves or enters a pre-defined area, gets of a given path, falls, stays at a spot longer than a predefined time period or drastically changes his daily routine (e.g. walking around in the middle of the night). (2) Easily request help over a voice channel (the video alternative was considered as “nice to have”) (3) Information, primary end user locating and voice call as services for the secondary end user in order to be able to help adequately (4) Find lost way again. First maybe provide a map or navigation feature directly to the primary end user and if he/she is not successful let him/her acquire help from the secondary end user (5) Public transportation guidance (which bus to take, when to change the tram etc.) (6) Daily schedule and reminders for medication, appointments and drinking.

**Discussion**

Besides the 6 high level features groups, indicating that the emergency call and personal voice assistance are the most wanted features, the requirements analysis turned out very useful to find out more about the real needs of the end user groups and the way to design the solution as a whole. Some of these “design rules” sound simple and straight forward, yet they are not followed by many of today’s solutions.

In Switzerland, the main conclusion that was drawn out from the workshops and interviews was that “less is more”. Especially focus on simplicity in the design of the features and the interaction patterns for the primary end-user. Another important message was to introduce the system as soon as possible to the people. As most diagnoses of dementia happen quite late, it seems important to design the Confidence services in order to be attractive to elderly people in general. They should find the system fun and useful when they are still fit and be able to gradually switch on dementia specific app features in a later state when they are needed.

This also goes in line with the often mentioned need to modularize and tailor the system to the specific needs of the primary end-users and the secondary end-users. The discussion about a natural, non-stigmatizing interaction with the primary end-users seems important to us. The interface should be simple and direct to adhere to those requirements. And privacy issues were often raised. So the consortium should think about how to treat the positioning data and other sensible information. If there is no trust in the Confidence system also in regard to privacy, it won’t be accepted.

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**Bibliography**