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User-Centricity in the Development of Services for People with Mild Dementia

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Abstract: A main goal in the care of persons with dementia is enhancing their autonomy in daily life, by providing compensation for their disabilities. In the last decade another important aspect in caring for people with dementia has been recognized: enhancement of their quality of life. This has led to an increased interest in the way persons with dementia experience their disease and how to optimize their quality of life. The Ambient Intelligence vision foresees a world where people live in intelligent surroundings that can respond to and even anticipate people's wishes and needs. Ambient Intelligence is likely to provide major benefits for the individual patient. Our health is maintained in a complex process of social interaction, involving professional care practitioners, lay carers, health insurers, regulators, producers and governmental bodies. A user centric approach is needed to guarantee an added value also for the user. In this paper, a user centric design approach and its application in a field test is presented towards the development of assistive services for people with dementia.

1. Introduction

The vision driving technological development like Ambient Intelligence foresees a world in which people live in intelligent surroundings that can respond to and even anticipate people's wishes and needs. Ambient Intelligence, as defined by Aarts [1] implies something more than a setting full of 'smart' devices; it implies the presence of intelligence everywhere, and intelligent use of the latest generation of computers to improve our quality of life. The computer – whether in the form of a laptop or a smart mobile phone – is already an integral part of everyday life. Sensor and actuator systems that are easy to deploy wirelessly and directly to the Internet are emerging with standardised interfaces. Such surroundings form a promising solution to support the elderly in their own environments. However, today's equipment is often difficult to use and may even impinge upon the privacy of the user. Therefore the Ambient Intelligence vision is predicated upon a world where people, rather than technology, take centre stage. The vision foresees computers that,

while remaining largely unnoticed, adapt autonomically to the user's needs. In a recent study in the Netherlands [2], a critical look is taken at the considerable potential that the new generation of computers have for monitoring and managing individual health.

Developments in the care sector are being shaped by the desire to move towards personalized care: a form of provision that is not supply-driven, but patient-centred and demand-led. Ambient Intelligence is seen as having the potential to add significant momentum to this movement. However, it is important to consider how far the potential of Ambient Intelligence is likely to be translated into actual benefit for the individual patient. Our health is looked after in the context of a complex process of social interaction, involving professional care practitioners, lay carers, health insurers, regulators, producers and governmental bodies. In [2] it is concluded that it cannot be assumed that patients' personal needs and preferences will always take precedence. To ensure that user needs are better understood, taken into account and included in the design of services, we therefore argue that user involvement at an early stage of development is essential. This is especially important during the development of technologies and services for elderly with disabilities due to the complexity and variety of their needs. Furthermore, early business assessment should ensure that there is a good value proposition for this target group (and exclusion of subgroups is prevented), and that a business model is chosen that supports a sustainable business network for innovative products and services [3].

Dementia is a progressive, cognitive disabling disease affecting 5% of all persons above 65 and over 40% of people over 90. The disease has symptoms involving impairments of memory, speech, thought, perception and reasoning. There are also often changes in personality, behaviour and mood, such as depressive symptoms, apathy and aggression. Needs mentioned both by people with dementia and carers that often remain unmet by professional care or welfare services include: support for memory problems of the person with dementia and support to maintain in contact with the social environment, to undertake meaningful activities and to enhance feelings of safety.

In the last decade, the development of services in the field of elderly care is increasingly focusing on support for elderly in their own environment, mainly due to the increase of ageing population, and the shortage of professional care providers [4]. Furthermore, it has been shown that more benefits are achieved when elderly people, with impairment, receive care in their own environment. The COGKNOW project (www.cogknow.eu), aims to achieve a breakthrough with research that addresses the main frequently mentioned unmet needs of those with mild dementia, particularly those still living in their own home. The project started in September 2006 and will end in August 2009. This paper describes the user centric iterative approach and the first findings of developing, field testing and evaluating a set of services to support people with mild dementia and their carers in their own environment. More information on the status of the technical development, human factor analysis and business assessment approach can be found in [5], [6], [7], [8]. This paper was developed to explore the user-centred design process developed by the consortium, providing detail on the discrete aspects of the process, as well as highlighting those areas that caused problems or benefits. The paper is written for an audience of fellow practitioners in user-centred design for healthcare services, in particular for those who are seeking best practice in service provision for those living at home.

2. The Need for a New Development Approach

One of the main goals in the care of persons with chronic diseases such as dementia is enhancing the autonomy in their daily life by providing compensation for their disabilities. In the last decade another important goal in caring for these persons has been recognized: enhancement of their quality of life. In the case of persons with dementia this has led to an increased interest in the way they experience their disease and how to optimize their quality

of life [9],[10],and [11].This has in turn led to the development of emotion-orientated care for persons with dementia [12], and also to another perspective on care ethics that pays more attention to the experience of the sufferers themselves [13].

In order to improve the quality of life of a person, it is important to know what determines the person's feeling of quality of life; in other words, to know what they themselves find to be important domains of quality of life. This has led to a new field of knowledge in dementia care: the uncovering of the experience of persons with dementia [14],[15]. Several studies demonstrate that a collaborative and person-centred approach is feasible in people with early-stage dementia [16].

From the perspective of the development of innovative products, user-centred design (ISO13407) [17] is seen as an empirical research and product development orientation that utilises end-user information for making better and thus more commercially successful products. This is achieved by involving the end-user in the product development process. It is an approach that supports the entire development process with user-centered activities in order to create applications which provide added value to the intended users and that are easy to use. In healthcare this process is of vital importance. According to Elizabeth Rosenzweig, Founder and Director of World Usability Day, the importance of user-centered design in healthcare is truly about life and death [18].

User centred design (UCD) cannot be encapsulated in one stage of product design but needs to be applied through the whole process of design. Rubin [19] outlined several aspects to consider for UCD. To start with, UCD is a phased approach where user input is needed at all crucial points. User centricity is more likely to take place in multidisciplinary teams. This ensures that user needs are well translated to appropriate product specification. In COGKNOW, it was noticed that the gap between an expressed user need and its mapping to functional requirements and design specifications is sometimes difficult to achieve in a single step, for the simple reason that expressed user needs can have many interpretations. Several iterations between needs analysts and system designers are therefore needed before the prototype development can start. Users and user testing are the key source of uncertainty which should be tolerated and is even beneficial for the outcome. Kirk [20] even claims that if everything goes as expected, then it is unlikely that the project was user-centric. To conclude, in UCD there exist no one single process description but rather a potential of methods and tools that can be implemented flexibly, case by case. The choice of methods and tools depends on the application to be build and on the target group. Furthermore, user centricity and usability are highly context-dependent. In practice, processes, requirements, guidelines and lists are interpreted and redefined for the purpose of each individual. In the case of the COKNOW project, it was noticed that between the three project locations (Amsterdam, Lulea and Belfast) as well as between the people with dementia who participated in the needs inquiry workshops and field tests differences existed in many aspects, such as living situation (alone or together with a spouse or family caregiver), specific disabilities, social network, the willingness to openly discuss needs within group workshops or individual interviews, the habit to use mobile phones, preferences for reminders, the design of the stationary and mobile device.

3. Iterative and Multi-Stakeholder Perspective

In the COGKNOW project, persons with dementia are the primary target group and they are seen as active collaborators in the process to develop a system that aims to support them in different aspects of their daily life (remembering, maintaining social contacts, performing daily life activities and feeling safe). Three iterative development cycles of one year each are performed, in which persons (15 to 18 per cycle) with mild dementia (GDS 3-5 or MMSE > 14) and their carers participate. The cycles consist of user needs workshops, interviews, formulation of functional requirements, development of a (more advanced

version of the) prototype and evaluation during a field test. During the Field Test (FT), the COGKNOW prototype is installed in the participants' homes. The duration of the FT is one or more days for FT#1 and several weeks for FT#2 and FT#3). Evaluation takes place by formulating research questions and assigning appropriate methods for data collection before, during and after each field test. The figure below shows the iterative design process from the three perspectives and how they increasingly result in an updated prototype implementation for each of the field Tests (FT#1, FT2 and FT#3).

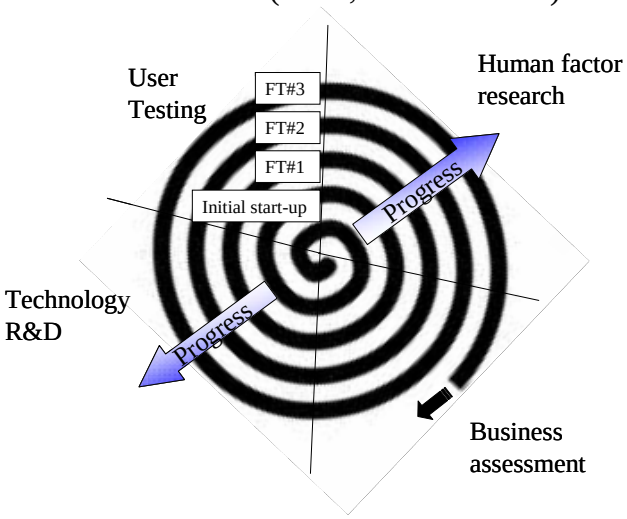

Figure 1 Development Cycles

The evaluation plan established aimed to assess whether or not the mobile and home based cognitive prosthetics met the user-based functional requirements and technical specifications. The evaluation process addressed three perspectives: human factors, technical factors and business factors. From the human factors perspective, insight into the user needs was addressed through evaluation of the user-friendliness, usefulness, efficacy and the impact on the previously described four areas and, overall, on autonomy and quality of life. From the technical factors perspective, evaluation was focused on how the resulting prototype advanced the state-of-the-art. From the business factors perspective the evaluation focused on the viability of the business opportunities and the identification of critical business success factors. The evaluation was planned to be performed following the in-situ assessment of the cognitive prosthetics at each of the three test sites. In our current work we have focused on the evaluation of the first field test according to our overall methodology and have focused at the human and technical factors. The business factors perspectives will be addressed in later field tests and will be carried out through business workshops in Belfast, Luleå and Amsterdam, where the field tests are carried out. The main research questions were defined in the following areas:

- Evaluate basic user friendliness with a focus on hardware-related factors such as form factor, basic interactions, wearability, charging, etc;
- Evaluate assumptions about the user friendliness and usefulness of basic concepts used e.g., reminders; and
- Collect basic data about activities and context in order to inform the design of context-aware features e.g. location detection, activity recognition, anomaly detection.

Evaluation methods include semi-structured interviews with the persons with dementia and carers, observations, in situ measurements for collecting data in a naturalistic way and inventory of bottle-necks. The aim of the FTs is to test the developed prototypes with target users (people with dementia) in three cycles each at three sites: Amsterdam, Belfast, Luleå. This is done by introducing increasingly complex levels of functionality for consecutive trials and to iteratively improve usability during and between tests. Besides, a number of

research questions where defined for the evaluation. To answer the research questions, several methods where applied: pre-test interview, semi-structured interviews, observation and a bottle-neck list. COGKNOW is developing a user driven, cognitive prosthetic device that is encompassing and combining functionality that previously required many assistive devices. Though the first cycle of the project validated the usefulness of the integrated COGKNOW concept, in 2008 the prototype will be significantly improved with regard to usability and personalization possibilities. New test results will guide the project into its final validation phase. Business assessment workshops will be organized to explore the COGKNOW business opportunities. The COGKNOW review of the state of the art shows that previous research seldomly-developed devices and services together with the target group. Also very few research tested the developed devices within the target group. As a consequence many devices and services have mixed or little success when applied to daily living conditions among ageing people with dementia [2].

4. We-Centric Multimodal Service Prototypes

COGKNOW is exploring a people-orientated, we-centric approach, and explores the use of multimodal interfaces for information delivery. The concept of we-centric services is 'context-aware services that support interaction between people in dynamic personal social contexts' [21]. This we-centric concept is different from the classic ambient intelligence-originated I-centric perspective [22] primarily in its view that relations between people are potentially reciprocal. We-centric also has a strongly service-orientated approach, which provides potential flexibility via dynamic bundling/unbundling of service offering in ubiquitous computing environments and interleaves well with the context management framework to be developed in COGKNOW. It is necessary, given the intricate linkage between the envisaged technical elements within the project, that each individual component is evaluated in terms of integration performance with the other system components in addition to its own functionality. From a technical perspective, the COGKNOW service consists of four main components: a stationary device, mobile device, a server and a sensorised environment. The stationary device is located at a fixed position within the person's home and consists of a 17inch touch screen LCD and concealed processing unit. The stationary device is the main hub within the home environment responsible for collecting all information, passing it to the server, and interacting with the other components in the system. The services can be accessed through the graphical user interface and include reminder messages, a means of social contact through a picture dialling service, support of activities of pleasure through easy turning on/of the radio and play-back of pre-stored music; and safety warnings e.g. when the front door or fridge is left open. The mobile component has a small 2.8-inch touch screen display used to interact with the user. The mobile device provides a mirror of the services offered by the stationary device which can be accessed from anywhere with possibility to access additional services once the person is outside of the home environment, e.g. navigation support. The server acts as the information repository for the entire system and provides a means whereby the carer can configure and schedule patient reminding schedules. The sensorised environment supports the sensors and actuators. A door sensor was installed to alert the user if the door was left open and an actuator used to facilitate remote operation of a manual tuning radio.

5. Discussion and Conclusions

The first project cycle has been successfully completed. The COGKNOW Day Navigator (as the system is termed) was installed in the homes of sixteen people with mild dementia, and tested. A range of user friendliness and usefulness issues were identified, such as issues of interaction with the interfaces of the devices and the desire to be able to adjust functions

and design aspects to individual needs and wishes. This first phase has also validated the usefulness of the COGKNOW concept of integrating the functionalities for memory support, social contacts, helping with daily activities and enhancing feelings of safety, into one single solution. In January 2008 the second project cycle started with user needs workshops in which new participants commented on the first prototype and expressed their wishes about functions they would like to be added to the device. Valuable information was collected, that will guide the further development of the COGKNOW Day Navigator.

The semi-structured interviews from the first field test have shown that the people with dementia participating in the field test at all three locations in general appreciate the user friendliness and usefulness of the COGKNOW Navigator positively. Although this first evaluation result increases the likelihood that other people with dementia will also judge the system as valuable for their daily life, of course there is no guarantee that this actually will be the case. In the first field test the system was used by a limited number of people with dementia (n=16) for half a day. The aim was to validate the software and hardware implementation and get initial feedback. Yet the results were satisfactory and gave a valuable feedback for adapting the system. In general the system was seen as useful, easy to operate, easy to understand. The interaction with the touch screen was problematic. The reminders where not attuned to the personal situation and therefore not always useful. The reminders on the mobile device were too small. Concerning the picture dialing, it was seen as very useful but with too many stages for people with dementia to operate. The daily activity of operating a radio and listening to music was valued high. It was easy to use. The music was not attuned to personal preferences. The safety function could not be tested properly but was expected to be useful in the future. In the second field test another 15 people with dementia will use the system for several weeks and a better indication of usability can be obtained.

We believe that multidisciplinary teams are a critical success factor of user-centered approach. There is a big discrepancy between identified user needs (e.g., a help function) and the technical specification of a service provided to aid in supporting this need. That is due to the different ways of 1) interpreting the needs into functional requirements, 2) technical specifications and 3) ways of implementation. Therefore, the project team should consist of human factors as well as technical experts that make several iterations on the functional requirements and technical specifications before implementation. In the COGKNOW project this effort was underestimated in the beginning. This is quite common in innovative development processes. However, the experience from the first development phase is very valuable input for the second and third iteration phases of the project.

The project followed the process of identifying the needs of people with dementia, translating that to functional requirements, prioritizing the functional requirements according to a set of criteria, defining research questions for evaluation, developing methods for evaluation, translating the functional requirements to technical specification, design and implementation and then testing. The project followed that process yet flexibility was required for unplanned last minute development efforts to make the concepts really testable with the end-users. Design activities are not only about finding solutions to predefined problems, but also about finding new problems. For example, it was discovered that the picture dialing functionality needed to be simplified. Recommendations for FT#2 were to have fewer steps for picture dialing, more logical sequence of steps, personal configuration and possibility to extend the address book.

One of the biggest challenges is the evaluation of the social dimension of the applications. The SeniorXensor, an in situ user experience measurement software modules was developed. In the first field test it worked on the mobile device only. Data was also logged on stationary device for evaluation purposes. This complemented the data collected

through semi-structured interviews and observations. This aspect was not tested in the first field test due to the short duration of the test but will be tested in the second field test.

Furthermore, there is no single method that guarantees generating good designs and useful ideas. It is important to start with a well-defined process and a set of tools and methods that adequately suit the project objectives. In the first field test we applied several evaluation methods in different phases of the development. Some of the methods overlapped in the data collected as for example the semi-structured interviews and observation list. The in-situ measurement that collected data from user interaction with the system was complementary to these methods. The evaluation methods applied in the first field test will be adapted and attuned to the new system functionalities for the second field test, redundancy will be avoided as much as possible. The project will further develop methodology for an overall analysis of different kinds of collected data (qualitative and quantitative data). Last but not least, having flexible dedicated multidisciplinary team members in the project is as important as the development and application of the methods.

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