Maintaining multiple sclerosis patients' quality of life – a case study on environment control assistance in a smart home

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ABSTRACT

This paper presents a case study on how smart-home technology can improve the quality of life for multiple sclerosis patients by implementing personalized environment control assistance. We developed a prototype that allows users with diminished motoric skills to use voice recognition software on a smartphone to control a house's front door, lights, telephone, TV and PC. We focused on affordable hardware and open-source software to maximize adaptability and extensibility, which is required for individual solutions. The development followed a user-centric design process, where a group of 10 multiple sclerosis patients participated in workshops to assess their requirements and evaluate the usability of the implemented prototype.

CCS CONCEPTS

• **Human-centered computing** → **Interaction design; Ubiquitous and Mobile Computing; Smart Home; Accessibility**

KEYWORDS

Ambient Assisted Living, Environment Controls, Multiple Sclerosis, Smart Home, User-Centred Design

1 INTRODUCTION

Our case study investigates how off-the-shelf smart home products can be utilized to maintain the quality of life of multiple sclerosis patients, who are losing their ability to control their environment (using normal push-buttons and remote controls) over time and finally require permanent assistance for activities of daily living by care givers.

Multiple sclerosis (MS) is a chronic disease with inflammatory disorder causing lesions (*sclerae*) in the central nervous system. It is assumed that inflammation causes demyelination of the axons that connect neurons, so that they lose their ability to transmit signals. Clinical manifestations indicate the involvement of motor, sensory, visual, and autonomic systems; many other symptoms can occur as well [1]. Demyelination of the optic nerve is a frequent symptom and causes blurred vision and a reduced field of view. Lesions in the cerebellum are related to tremor, clumsiness and poor balance. Damage in the spinal cord can cause weakness, stiffness and painful spasms in arms and legs, as well as bladder dysfunction. Inflammation of the cerebrum can cause cognitive

impairment and depression, while an affected brainstem may lead to impaired speech. The disease can finally lead to total loss of motor skills in some body parts. The clinical course of MS is highly individual, and the symptoms vary between patients and over time, so that there are not even two MS patients with identical symptoms and course [2]. Symptoms and signs can appear in several patterns. Most patients experience MS as acute episodes that last between hours and weeks, followed by full or partial recovery until the next attack. Episodes occur randomly, but not more than five times a year. Over time, persistent disabilities accumulate. Most patients enter a secondary phase of progressive neurologic decline after twenty years [1].

Regarding the design of assistive systems for MS patients, it is obvious that most patients initially will only need assistance during acute episodes, if necessary at all. However, as disabilities accumulate over the years, assistance will be required more often and needs to be adapted to support more and more functions according to the individual clinical course.

The ever-growing market for smart-home retrofit components, such as digitally connected light bulbs and door locks, motivated us to develop a personalized assistance system based on affordable hardware and open-source and community-driven middleware.

We followed a User-Centred Design process focused on user integration as described in the guidelines published by the Ambient Assisted Living (AAL) Association [3]. In preparation to the case study, we tested two commercial products for disabled users in a home environment, and reviewed literature on interoperability-related research projects in the AAL domain (Section 2). In order to understand the users' needs, we organized a workshop with ten primary end-users where we discussed typical activities of daily living and simulated how an assistance system could help them in their tasks (Section 3). Based on the resulting list of required services to control the users environment, we developed a prototype, which was permanently installed in one of the user's home environment (Section 4). Finally, another workshop was organized to evaluate the usability of our prototype (Section 5). Section 6 concludes the paper.

2 RELATED WORK

In the following, we will present two commercial systems for environment control and have a brief look at research projects that develop frameworks to support interoperability in the AAL and smart home domain.

2.1 Commercial Systems

Sybility PILOT¹ addresses private as well as nursing homes and provides a voice recognition interface; it is available in three

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¹ <http://www.sybility.de/> retrieved 24.3.2017

versions. The versions *One* and *Plus* control devices via infrared. We tested the *Pro* version, which additionally supports 433 Mhz RF communications, to control two lights, a telephone, and two TV sets. The speech recognition engine must be trained to the voice of its user. While this reduces the number of false-positives, it also requires precise speed and pitch, which may be difficult to reproduce. Some commands had to be repeated up to 10 times. The *Plus* and *Pro* versions can be adapted to personal needs using a proprietary programming language.

Abilia Control Omni² is a proprietary smartphone with touch screen, that can be used to control devices via infrared and RF. It can also be controlled with external buttons or a joystick of an electric wheelchair. Using the touch screen requires good motoric skills, so that it is not handy for users with advanced disabilities. Besides such dedicated solutions for disabled users, several companies offer lighting systems that can be controlled by apps, e.g. *Philips Hue*, *Mi-light*, and *Osram Lightify*. Some of them are compatible with **agent-based user interfaces** that are promoted by Apple (*Siri*), Amazon (*Alexa*), Microsoft (*Cortana*), and Google. In conjunction with smart home platforms, a range of compatible devices can be controlled by voice. While these systems are very promising, they are currently restricted to their respective ecosystems (*HomeKit*, *Android*, etc.) and support only a subset of all devices at home. There are also some usability issues with voice-only operation, i.e. how to end a phone call.

2.2 Research Projects

The development of assistive systems for elderly users is in the focus of Ambient Assisted Living. The use of speech and gesture to control devices in the environment has been investigated, among others, in the Bremen Ambient Assisted Living Lab [4, 5]. The **UniversAAL** project [6] developed an open platform that provides a standardized approach making it technically feasible and economically viable to develop AAL solutions. The *universAAL* platform has been recently applied in the project **ReAAL**³ that created various AAL applications at 13 pilot sites for 6000 users. The **openAAL**⁴ middleware provides semantic service matchmaking and a publish/subscribe mechanism to share contextual information. A different approach towards user interfaces for people with special needs is given by the **URC**⁵ (Universal Remote Console, ISO 24752) standard. The idea is to separate the user interface from the device via an abstraction layer, so that individual “pluggable” controls can be implemented.

3 UNDERSTANDING THE USER

To get started, we observed one patient at home over a couple of days and took notes about his daily routine (this method is known as shadowing [3]). This patient suffers from progressive MS for many years, requires a wheelchair and is unable to manually control any things or devices in his home environment and hence needs full-time care. The observed care activities, which were provided by his wife, are documented in Table 1. Based on these activities, we outlined the requirements for an assistance system and sketched a prototype. Due to the large number of potential

support functions, we organised a workshop with 10 users to discuss and prioritise the requirements.

Table 1: Exemplary daily routine of a MS patient.

Time	Care giver activity
8:00	After waking up, help with washing und getting dressed Air the room, pull curtains
9:00	Prepare and serve breakfast
9:30	Read a newspaper out Assist with phone calls
10:30	Bladder emptying
10:40	Serve a yoghurt
10:50	Training arms and legs with a movement training device
11:20	Bladder emptying
11:25	Assist with office work Assist with phone calls
12:00	Set wheelchair to resting position
12:30	Prepare lunch
13:00	Serve lunch, Using Cough-Assist to clear respiratory tracks, Cleaning of nose and eyes
13:45	Place to resting position at the balcony Open the front door, receive visitors
14:30	Bladder emptying
14:40	Going for a walk
15:50	Place to rest in the garden
16:05	Coffee break in the garden
16:45	Place back home
16:55	Bladder emptying
17:00	Video games for concentration, logic exercises Make phone calls
18:00	Prepare dinner
18:15	Serve dinner and drink
18:30	Use Cough-Assist, Cleaning of nose and eyes
18:50	Video games for concentration, logic exercises
19:20	Place in front of the TV, assist with watching TV Close windows, pull curtains
20:30	Transfer to the bed
21:00	TV or reading a book

3.1 Questionnaire

The goal of the first workshop was to find potential answers to questions such as: what are the specific problems of the patients? Which of them can be solved with technology? Will the patients accept assistance from a technical system instead of humans?

We invited ten multiple sclerosis patients (6 male, 4 female), aged 56-76. Four of them (2m, 2f) have severely diminished motoric skills and currently use a wheelchair; two of them only have motoric skills in their arms. Three have difficulties to walk and need a cane; their motoric skills of arms and hands are slightly impaired. Two patients have no recognizable impairments so far. All participants have basic experience with ICT systems.

The main purpose of the questionnaire was to identify activities that would require assistance. However, if users are asked about potential problems in their daily life that could be solved by technology, there is a risk that they tend to ignore problems that they have accepted simply because they got used to them over time. In order to make sure that the workshop participants consider all relevant issues, we introduced the exemplary daily routine from Table 1 and the potential assistive functions that we have identified earlier. Next, the participants were asked to anonymously fill out a questionnaire about their personal care situation and the desired level of technical assistance.

Six out of ten participants currently need help at home, which is provided mostly by their partner or family members; only one person depends on professional care. All agree that they prefer to stay as long as possible at home, and all would accept technical assistance for this purpose; seven would further prefer technical

² <http://www.abilia.com/> retrieved 24.3.2017

³ <http://cip-reaal.eu/> retrieved 24.3.2017

⁴ <http://openaal.org/> retrieved 24.3.2017

⁵ <http://openurc.org/> retrieved 24.3.2017

over human assistance. When asked about situations that require assistance (now or in the near future), the participants chose the following options: opening the front door (6/10); communicating with visitors at the door (5/10); opening and closing windows (5/10); moving the wheelchair (2/10). The following activities were voted once each: using the telephone; operating the TV/radio; using the PC; turning the lights on/off. When participants were asked about other activities, they mentioned the following: operation of other devices; support in writing letters; hanging washes; applying compression stockings. All rejected the idea of technical/robotic support for body care and hygiene; they would rather prefer human assistance for these tasks.

3.2 User-Task-Environment Analysis

As a next step, we verified our assumptions about the prototype design using an UTE (User, Task and Environment) analysis [3]. This method helps us to identify basic requirements that are based on the user characteristics, the task process and environmental conditions. For each identified use case, we discussed how the patients would interact with the assistance system and how they would interpret the actions of the system. We made the assumption that the user has severely diminished motoric skills and depends on a wheelchair, and that the device to be controlled (light, door, TV) is out of reach. The interaction is limited to voice commands, where the user must activate the system by a key word (“Computer”) and then speak a syntactically correct command (e.g. “open door”, “turn on light 1”, “channel BBC”). The analysis revealed that opening the front door with a simple voice command is critical, since the user would not be able to close the door again in case of a misinterpreted command. The users requested a confirmation dialogue from the system. Regarding the use case of PC operation, the user sits in front of the PC and controls the pointer by gaze (via eye-tracker) and a big physical push-button. Finally, we evaluated a preliminary interaction design in a *Wizard-of-Oz* study [3]. This means that the patients believed that a system prototype would respond to their spoken commands, but in fact a human “wizard” controlled the devices according to their utterances. We learned from this experiment that the patients had some difficulties to learn and use specific command syntax and were frustrated when the wizard (on purpose) did not accept similar sentences. Based on the results of the questionnaire and the experiments, we identified the requirements listed in Table 2.

Table 2: Ranked list of identified functional requirements.

Requirement	Priority
The system must allow its user to open the front door by voice command.	high
The system must allow its user to communicate with visitors at the front door from everywhere at home.	high
The system must allow its user to open and close the windows with voice commands, or control them automatically (schedule).	high
The system must allow its user to move the wheelchair.	medium
The system must allow its user to operate the PC efficiently with diminished motoric skills via an eye-tracking device.	low
The system must allow its user to operate radio and TV with voice commands.	low
The system must allow its user to make outgoing phone calls and to answer incoming calls with voice commands.	low
The system must allow its user to control the lights with voice commands, or automatically.	low

For our case study, we dropped the window and wheelchair assistance, since their realization would require a high investment

and similar functionality has already been implemented and investigated by us in the *BAALL* lab [4, 5]. Regarding non-functional requirements, *usability* is very important, i.e. *learnability* of command syntax. The system must also be *adaptable* to changing needs over time; as explained in the introduction, the clinical course of multiple sclerosis is highly individual. *Interoperability* matters as well, as the system must be integrated with various existing components at home. The system will be able to open the front door, which cannot be closed by the disabled user without help. Hence a confirmation action must be implemented to provide *safety and security*. Regarding *reliability*, the system provides functionalities to disabled persons that cannot be performed otherwise. In case the system is off-line, conventional controls must be available to the caregiver. In case of a power failure, the system should automatically restart.

4 SYSTEM PROTOTYPE

Having identified the functional and non-functional requirements for our environment control assistance system, appropriate hardware and software platforms must be chosen. AAL research advocates the use of the open *universAAL* platform (see Section 2.2) to achieve interoperability and to create a central marketplace for applications. While this platform would be beneficial for product development and distribution, we favoured the open-source *OpenHAB* (Open Home Automation Bus) ⁶ middleware for prototyping due to pragmatic reasons. *OpenHAB* is developed and maintained by a large active community, and provides code to connect almost all Smart Home and IoT components on the market today through a unified API. At its core, *openHAB* provides a graphical user interface to view and control the home environment. In addition, the German company *KAndySoft UG* offers the *Talk to HOME* app for the Android operating system. This app allows the user to control all *OpenHAB*-connected devices with simple voice commands; user-defined keywords can be assigned to all devices available in *openHAB*. The mobile phone is mounted to the wheelchair and powered by an external 26800mAh battery that provides enough power for one week. The smartphone wirelessly connects with the *openHAB* server’s RESTful interface via a WiFi network at home.

The *openHAB* framework is implemented in Java and does not require too many resources, so it can be installed on small, embedded devices. We have chosen second-generation *Raspberry PI* micro-PCs running *Raspbian* Linux. We extended them with hardware modules to enable bi-directional infrared and RF (433Mhz) communication, which are supported by the *lirc* and *433Utils* software packages for Linux.

The resulting prototype has been set up to control lights (via lamps in remote-controlled mains sockets) and the door buzzer using 433Mhz components. In addition, two TVs and a radio were controlled by infrared, which required two Raspberry PIs (one per room). The Raspberry PIs have been equipped with an additional touch-screen for the convenience of non-disabled users. For more details about the system architecture and implementation, see [7].

As requested by the users, the process to open the front door has been implemented with a confirmation. First, the user activates the voice recognition saying “Computer!” and then requests to open the front door. The mobile app transmits the command to the *openHAB* middleware server, which starts a 30 second timer. Now

⁶ <https://community.openhab.org/about/> retrieved 24.3.2017

the user has to confirm the request before the timer elapses, otherwise *openHAB* would not send the control sequence to the door buzzer, and the user would have to repeat the request.

5 USABILITY EVALUATION

The prototype has been permanently deployed in the home environment of the same user that has been observed beforehand to gain insights into his daily care routine (see Section 3). We invited the same patients as before to a second workshop in order to let them experience and evaluate the prototypical system. They were asked to perform certain tasks, such as controlling the lights, TV, and front door, using voice commands. In the following, they rated the system using the standardized SUS (System Usability Scale) questionnaire. The system received a good score of 84.5 points; the detailed scores are given in Table 3.

Table 3: System-Usability-Scale Results.

Nr.	Statement	Rating	Score
1	I think that I would like to use this system frequently.	5	4
2	I found the system unnecessarily complex.	1	4
3	I thought the system was easy to use.	3.8	2.8
4	I think that I would need the support of a technical person to be able to use this system.	2	3
5	I found the various functions in this system were well integrated.	5	4
6	I thought there was too much inconsistency in this system.	1	4
7	I would imagine that most people would learn to use this system very quickly.	5	4
8	I found the system very cumbersome to use.	3	2
9	I felt very confident using the system.	4	3
10	I needed to learn a lot of things before I could get going with this system.	2	3
Total Score:			84.5

6 SUMMARY AND CONCLUSIONS

We conducted a case study on environment control assistance for disabled users, based on off-the-self components and open-source software. We integrated ten multiple sclerosis patients in the development process to assess their needs and to evaluate the usability of our prototype. The interesting question is whether the developed system can help to increase the patients' autonomy and decrease the workload of caregivers. The presented prototype empowers its users to manage small things related to activities of daily living and relieves their family members from the burden of permanent availability. In this context, it must be said that some activities, such as operating the telephone or TV, cannot be accounted for by professional care. Hence, the advantage cannot be quantified as cost savings. Furthermore, due to the highly individual clinical course of the MS disease, no general estimate about cost savings for society can be made. However, the prototype has shown that it allows patients to stay at home for longer and avoid institutional care, which corresponds to their expressed desire and significantly contributes to their quality of life.

In this study, we only considered the needs of the primary end-users (patients). For the future, it will be interesting to investigate the opinion of secondary end-users, such as family members and professional care. We expect that their quality of life will also increase through the assistance system.

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