

AN INDIVIDUAL PATIENT-ORIENTED STROKE MANAGER ARCHITECTURE

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Abstract

Stroke is the second leading cause of death for people older than 60 and the most common cause of disability for adults worldwide. This paper presents an architecture for post-acute stroke care management that (a) minimizes information asymmetries between patients and healthcare providers, and (b) supports the required behavioral changes to prevent another stroke. The developed stroke manager architecture comprises telemedicine devices as well as a tablet- and web-based platform. All components have been developed and evaluated in close cooperation with domain experts and end-users.

Keywords – *Stroke, eHealth, telemedicine, user centered design, mobile computing*

1. Introduction

The second leading cause of death for people older than 60 in western countries is stroke [1, 2], which also leads to adult disability frequently [3]. In Germany, for example, there are more than 200.000 stroke incidents every year [4]. The annual costs related to stroke were 8.1 Billion Euros in 2008 and the prospected annual costs for 2025 are estimated to be 108 Billion Euros[3, 5]. Advances in post-acute stroke management prospectively have a significant impact on improving the comprehensive chronic care management while decreasing the societal healthcare costs [6]. Since post-acute healthcare services are carried out by many different and loosely connected service providers in a healthcare service network, e.g. physicians, therapists, specialists and nurses performing outpatient or inpatient care as well as social and nursing services that offer healthcare services, there are numerous information barriers and communication gaps. Thus in a post-acute phase, informed and empowered patients, who act with self-interest, are the key to effective and efficient healthcare service provision for stroke patients [7].

However, due to the complexity of the situation, patients and care-giving relatives need to be supported. Unfortunately, chronic care concepts of other diseases (e.g., diabetes as the most prominent one) cannot easily be transferred because of patient variability, pre-existing practice or dependence on external factors [8]. To the knowledge of the authors, there are no post-acute stroke care management approaches that exploit information technology supporting patients and caregivers individually. Our envisioned stroke manager architecture connects the service providers and the patients. This innovative connection is realized by a service called stroke manager concept that is realized by a person, who guides and coordinates patients as well as care-giving relatives after a stroke using IT-support. Moreover, by employing the presented architecture, the stroke

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manager supports the required behavioral changes for successful rehabilitation and prevention of another stroke.

The following chapter outlines the specific challenges imposed by the stroke care process and its participants. The architecture section presents the technical response to these challenges, before the resulting prototype is described. Our contribution is summarized in the conclusion.

2. Post-acute Stroke Care

The state-of-the-art post-acute stroke workflow and possible improvements through IT-support have been gathered through three sets of qualitative interviews with 10, 12 and 4 domain experts (stroke patients, care-giving relatives, general practitioners, neurologists, therapists, and nursing services staff) and an extensive literature review. Despite its societal importance and impact on the global chronic disease burden, there is little literature on post-acute stroke management overall. It is yet dominated by prevention and early-care treatments [9]. The existing post-acute stroke-related literature is mostly of medical nature discussing effectiveness and predictors of different stroke treatments, medical procedures or medications. The few information systems research publications either address post-acute IT-supported information management [10, 11] or different information systems to support home-based rehabilitation [12].

Because of medical advances most stroke victims survive the stroke; nevertheless most patients need an individual rehabilitation, a complex outpatient treatment, and thorough changes in their daily living environment [7]. After a stroke, patients and their relatives are facing significant decisions in their life that require a good understanding of the new situation and much support. One of the most important decisions is related to the further living environment and the general way of living. Obviously, most patients want to stay at home as long as possible in spite of their disabilities. This usually requires some changes in the house to be made, the need of ambulatory nursing services, regular medical appointments, individual medication and much more. However, since the situation is very complex, uncommon and arises suddenly, patients and relatives have high information deficits. Seldom, they know local services, official process, and opportunities for organizing the outpatient post-stroke on their own. Patients and caregivers are in need of access to the right information at the right time to make an adequately informed decision [8]. Furthermore, healthcare service providers also need correct and thorough information to give advice on or administer medical services. Thus, the situation in the healthcare service network is characterized by large information asymmetries between the involved stakeholders. The patients and affiliated caregivers are overwhelmed by the new situation and cannot judge correctly what the next steps should be and what opportunities they have. In contrast, healthcare service providers have the relevant information because of their expertise, but they lack the individual health data from the patients, e.g. amnesia and therapy compliance, which are vital for the next medical step.

On the one hand, the stakeholders in a healthcare service network are in need of individual support and information to manage medical and administrative services adequately. On the other hand, patients also have to profoundly change their life, starting from regular therapist appointments to daily medication and blood pressure measurement. These changes appear small but in sum are overwhelming. It takes time before these chores become routines. In this time additional support is required to remind of these chores and to spot possible barriers to their adoption.

Furthermore, the average stroke patient is rather old and may be handicapped in result of the stroke, e.g. hemiplegia allows only the usage of one arm. Any application for this user group has to account for this limitations, e.g. by using simplified user interfaces and large fonts. Moreover, the expected computer literacy is very low. Therefore, the hardware itself has to be very intuitive and

configuration has to be done largely automatic. An internet connection at home is most likely not available or cannot be reconfigured by the user to cater for the needs of the device.

3. Stroke Manager Architecture

Based on the post-acute stroke management requirements that were discussed in expert workshops, two main goals shaped the resulting architecture: (a) minimizing information asymmetries and (b) supporting behavior change. The conceived IT-supported concept is depicted in *Figure 1*. On the left side the case and care management software (CareCM) that is used by the stroke manager is illustrated. It implements the underlying workflow and stores the patient data connected to the individual case. It has also access to the current healthcare service network. The stroke manager uses this data to provide advice and information in face-to-face meetings, phone calls and via a new information and coaching platform, the stroke health book (SHB). The stroke health book is envisioned as a mobile device that is distributed to the patients and their caregiving relatives. The SHB allows both remote integration of assisting technologies (e.g. telemedicine devices) and an individual, patient-centered access to the provided information.

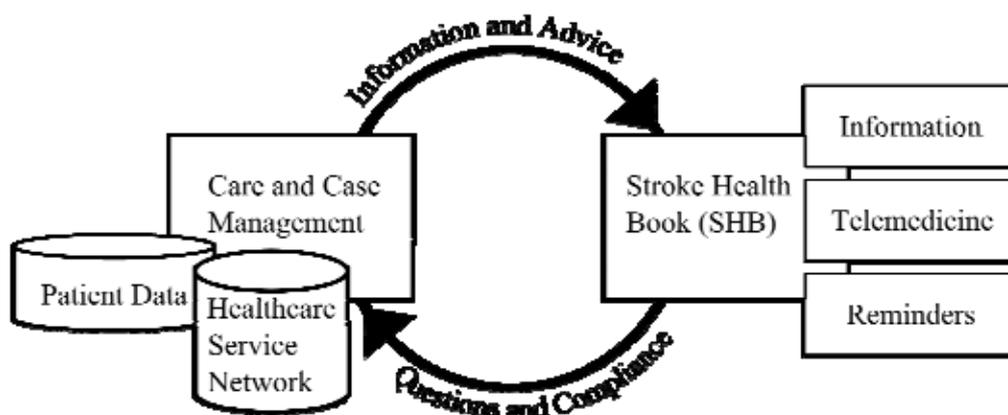


Figure 1: Envisioned post-acute stroke manager architecture

The SHB provides feedback to the stroke manager about current problems and behavior. For instance, going to the physiotherapy and regular measurements of the blood pressure are required and can be measured by asking the user for feedback or directly integrating with telemedicine devices, such as a blood pressure meter.

Therefore, by using the Stroke Health Book in combination with the care and case management software both goals, (a) minimizing information asymmetries and (b) supporting behavior change, are realized. Details of the involved components and their implementation as well as their necessity according to the requirements are described in the following sections.

3.1. Care and Case Management Software (CareCM)

The main part of our infrastructure is the care and case management software CareCM, which allows the stroke manager to efficiently coordinate and keep track of the patients, relatives and other involved stakeholders. It is based on an underlying Customer Relationship Management (CRM) system. This kind of software permits a process-oriented workflow support of the stroke manager's daily work. It is the control center that connects the patient data, the available services and the stroke health book remotely.

The automated workflow and documentation support is indispensable for the stroke manager to assist in organizing patients, caregivers, and other contacts as well as distributing the relevant

information in the healthcare service network at the right point of time. For this reason CareCM offers a clear and systematic documentation. Dossiers for patients, relatives, physicians, therapists, and other service provider are filed and associated with each other. Furthermore, depending on the stroke patients' actual state, necessary tasks are either automatically performed or the stroke manager is prompted and reminded. This includes, for example, performing assessments, information distribution, coordinating the next tasks along the patient's treatment pathway, and organizing appointments.

3. 2. Stroke Health Book (SHB)

The stroke health book is distributed to patients and care-giving relatives. The goal of the stroke health book is to actively provide personalized information and support patients as well as caregivers while they in turn provide data about their current status. There is strong evidence that this increases patient satisfaction, mood and compliance while reducing information deficits concerning stroke and organizational knowledge [13].

Moreover, the stroke health book should facilitate the required behavior changes by (i) providing the correct information at the right time, (ii) simplifying daily chores through telemedicine, and (iii) support through appointment and task reminders. To accomplish these task effectively, the designed stroke health book has to be accessible from anywhere, provide individualized and relevant information regarding the patient's state, and allow connecting additional technologies (e.g. assisting and telemedicine technologies). Accessibility everywhere can only be achieved through a mobile stroke health book. Therefore, a 10 inch tablet is used as stroke health book.

Individualized and relevant information have to be provided to patient and caregiver. Therefore, the stroke health book is accessible by both parties. Apart from general information about post-stroke management, individual information is also provided depending on the patient's state recorded in the care and case management software by the stroke manager. They are sent via mobile communication network to the electronic device. Likewise, patient and caregiver are individually informed and supported regarding the next steps in the treatment pathway, such as appointments or administrative tasks.

Additional telemedicine or assisting technologies (e.g. electronic blood pressure measurement devices, automatic stove control, etc) are integrated easily because of the stroke health book's mobile character and its connection to the CareCM software. CareCM offers the data structure to store the individual data and its connection to the individual patient data already present in the CareCM allows utilizing the additional data provided by the patient to modify the information presented by the stroke health book. This in turn, is an incentive for the patient to provide current data.

4. Stroke Manager Prototype

The stroke health book was developed with a strong end user involvement. Different designs were tested in two workshops and several independent meetings. Starting from paper prototypes, first user interfaces were developed that were tested with different end users. The general feedback was positive, e.g. one participant said "The device can be easily used with only one hand".

The prototype is supposed to be installed and used in an unknown environment by the users themselves. This requires a simple configuration and reliable network connection. Administrative tasks like changing batteries and wiring of components have to be minimized.

As shown in *Figure 2*, the developed prototype uses a gateway provided by BioComfort to connect SHB, CareCM and a blood pressure meter. The uplink to CareCM is established via a GSM module that allows a reliable connection without configuration in most homes. If problems occur, users can use their mobile phone to find locations with better GSM connection, e.g. next to a window. The Gateway acts as WiFi HotSpot for the Stroke Health Book and establishes a proprietary low power connection to the blood pressure meter. This low power connection ensures that battery changes are only necessary once every three month.

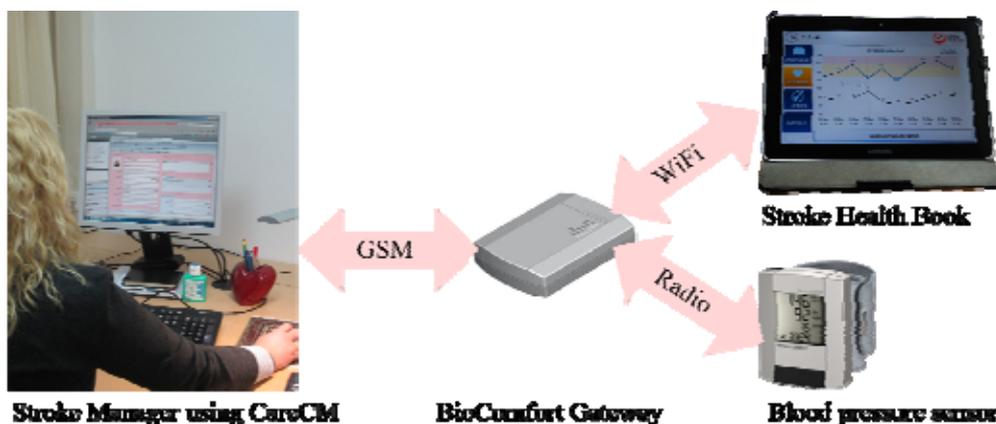


Figure 2: Stroke manager prototype

Patients or caregivers receive preconfigured sets containing the three components: BioComfort Gateway, Stroke Health Book and blood pressure meter. The installation effort is limited to finding a location for the BioComfort Gateway that offers a GSM connection and a power supply. All wireless connections are automatically initialized. The Stroke Health Book can assist, if trouble shooting is required.

4.1. Minimizing information asymmetries

Through using the stroke manager prototype, the stakeholders in a healthcare service network are provided with individual information corresponding to the current state of the patient and the opportunities that are possible. Thus, the Stroke manager architecture supports patients as and healthcare service providers and helps to decrease existing information asymmetries. It focuses on patient empowerment through the stroke manager person that grants IT-supported individual information, personalized reminders and medical documentation through telemedicine. Moreover, even healthcare providers get access to up-to-date medical data and benefit from a better coordination as well as general information flow through the stroke manager service.

4.2. Changing behavior

According to Fogg [14], software design that aims at behavioral change should focus on minor interventions that are easy to measure and implement. These small changes can trigger further changes. Measuring blood pressure is one small chore that is new to stroke patients. However, measuring blood pressure can raise awareness of other problems, e.g. the blood pressure will rise if medication has been forgotten. Hence, this small change may raise the awareness of the patient towards her own influence on their well-being.

The stroke health book supports the usage of the included blood pressure meter by an interactive manual and assistance. The measured values are mirrored back to the user to shed light on the

current physiological state. The patient could although decide to bring the tablet to the doctor's office to discuss her data. Further, telemedicine devices could be integrated to broaden the scope of the application, e.g., scale, activity sensors, and glucose meter.

The stroke manager cannot access the measured values for privacy reasons, but can see how often the blood pressure is measured. Therefore, the stroke manager can assess the compliance of a patient to spot possible problems. A similar compliance value can be calculated by asking the user, if she attended all scheduled appointments. For instance, there might be complications because care givers are not aware of special taxi services that are paid by the insurance company.

5. Conclusion

This paper presents an architecture for post-acute stroke care management, which we implemented prototypically. In order to successfully implement the new stroke manager concept, several expert workshops with hospital staff (neurologists, hospital manager, social worker and nurses), nursing home staff, and registered doctors were vital to understand the post-acute stroke management and to develop the post-acute stroke management process. Furthermore, we performed a literature analysis about stroke management and other management concepts for chronic diseases. The developed prototype was then evaluated with older people and a regional stroke support group concerning usability. In close collaboration with the hospitals' data protection officer we discussed and clarified issues of privacy and security and the stroke manager project was approved by the healthcare ethics committee of a hospital in the region of Bad Neustadt/Saale, Germany. There, the stroke manager field test will start in March 2012 and a stroke manager, employed at the hospital, will start to manage approximately 50 stroke patients. The study aims at evaluating the stroke manager prototype and the complete post-acute stroke manager concept.

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