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STROKE MANAGEMENT AS A SERVICE - A DISTRIBUTED AND MOBILE ARCHITECTURE FOR POST-ACUTE STROKE MANAGEMENT

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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, which leads to enormous societal healthcare costs. In contrast to acute stroke treatment, the improvement of the complex processes during the post-acute stroke treatment in a regional healthcare service network (HSN) did not receive much attention. Currently, there are no post-acute stroke care management approaches in Germany that exploit the advantages of information technology even though it is one of the most expensive diseases. Unfortunately, chronic care concepts of other diseases cannot easily be transferred. Therefore, we investigated the state-of-the-art post-acute stroke workflows, identified requirements for a general architecture that supports the current post-acute stroke management and developed a novel stroke manager service according to the requirements using a combined service engineering and software engineering approach. The contribution of this paper is threefold: It lists requirements for an effective post-stroke management, describes the complex inter-institutional workflow of a novel stroke manager service and presents a prototypically implemented stroke manager architecture. The requirements and the stroke manager service as well as the architecture have been evaluated by domain experts.

Keywords: healthcare service network, service engineering, eHealth, stroke.

1 Introduction

In western countries, stroke is the second leading cause of death for people older than 60 (MacKay and Greenlund, 2004; WHO, 2004). Furthermore, it is one of the leading causes of adult disability, which results in necessary constant care for a large portion of stroke survivors leaving the major burden on ambulatory care (Lindig, Brüggenjürgen, Willich and Reinhold, 2010). Since it is an archetype of a chronic disease, advances in post-acute stroke management prospectively have a significant impact on improving the comprehensive chronic care management while decreasing the societal healthcare costs (Barzel, Eisele and Bussche, 2008; Heuschmann, Busse, Wagner, Endres, Villringer, Rother, Kolominsky-Rabas, Berger, Gesell and Stiftung Deutsch, 2010).

In Germany, for example, there are more than 200.000 newly diagnosed stroke patients every year (StatistischesBundesamt, 2010). The annual costs related to stroke incidents in 2008 were 8.1 Billion Euros (Lindig et al., 2010) and the prospected annual costs for 2025 are estimated to be 108 Billion Euros (Kolominsky-Rabas, Heuschmann, Marschall, Emmert, Baltzer, Neundorfer, Schoffski and Krobot, 2006) mainly because of the demographic shift. Due to an increase in the population's life expectancy, the prevalence for stroke rises. Additionally, with recent advances in emergency and medical treatment, the quality of acute stroke management increases, which in turn lowers mortality rates and increases stroke-related costs in the post-acute treatment.

There are three strategies to face the upcoming challenges: 1) prevention to avoid stroke incidents, 2) advanced acute stroke treatment to improve the medical outcome and decrease further complications, 3) support of post-acute stroke management to avoid reoccurrences and foster stroke rehabilitation (EuropeanStrokeInitiative, 2003). Particularly for the latter two, information technology (IT) can help to improve existing processes, connect the involved stakeholders, and increase efficiency as well as effectiveness. In the past years, there have been improvements mainly in the area of acute stroke treatment (e.g., TEMPIS, Stroke Angel, Tele Stroke Service, TASC, etc.).

However, to the knowledge of the authors, there are no post-acute stroke care management approaches that significantly exploit information technology and assess its advantages. This is rooted in the characteristics of the post-acute stroke care: it is carried out by different service providers, which offer a wide range of healthcare services in a healthcare service network (HSN), which is constituted by loosely connected stakeholders, like physicians, therapists, specialists and nurses performing outpatient or inpatient care as well as social and nursing services that offer healthcare services. Unfortunately, this loose connection implicates unfavorable structural features that all healthcare markets share, for example information asymmetries as a result of uncoordinated cross-sectorial and inter-institutional processes (Arrow, 1963). Most stroke patients have to administrate their outpatient care for themselves when leaving structured inpatient care settings because no central entity is responsible for coordinating the complete stroke patients' post-acute care pathway in the HSN.

An integrated post-acute stroke management has therefore been proposed by many stroke patient organizations to guarantee an adequate and comprehensive post-acute care (e.g. the German Stroke Foundation or the German Society of Neurology). However, this is difficult to achieve because of the above described HSN characteristics. The use of information technology has the potential to decrease these difficulties and researchers agree that its integration positively affects procedures, work practices and treatment outcomes in healthcare networks (Mäenpää, Suominen, Asikainen, Maass and Rostila, 2009), thus the contemporary post-acute stroke management's efficiency and effectiveness. The integration of IT into home healthcare has also been proven to improve clinical and financial outcome (Singh, Mathiassen, Stachura and Astapova, 2011). Since healthcare is a complex domain with many subtleties and entrenched work practices, the successful implementation of IT in healthcare can only be achieved through looking at the IT as an integral part of the whole process on a healthcare service network level rather than a singular social-technical tool. Particularly, technically driven solutions often lack the healthcare service network view. In order to close this research gap, we used a service

engineering approach to develop an IT-supported post-acute stroke management. This paper presents results of our systematic requirement analysis and the evaluation of the stroke manager's conceived workflow and its prototypically implemented infrastructure.

2 Methodology

We chose a multi-level approach using a service engineering approach combined with a software engineering approach to achieve technically sound solutions that fit the healthcare service network perspective. The framework methodology is service engineering, which is used to develop the post-acute stroke management service for the HSN considering existing processes and possible incentives for the stakeholders. We used Ramaswamy's cyclic and customer centered method because it supports the systematic creation of a service while focusing on service quality as well as customer integration throughout the service design and service management (Ramaswamy, 1996). During the service design phase, we used the software engineering approach evolutionary prototyping to directly transform the gathered requirements for an improved post-acute stroke management workflow into software and hardware. This practice allows fast design, build and adaptation of the envisioned post-acute stroke management architecture (Tate, 1990).

In detail, the service design phase incorporates an extensive literature analysis to identify state-of-the-art approaches and qualitative domain expert interviews to derive requirements as well as a novel concept for an improved post-acute stroke management service. Based on the general requirements and the designed stroke manager service, prototypes of the IT-architecture are developed and evaluated in expert workshops before being used in a field study during the service management phase.

2.1 Requirement Analysis: Literature Review and Expert Interviews

To establish the state of the art in post-acute stroke processes, we analyzed the state-of-the-art literature, especially medical guidelines for post-acute stroke management. For a comprehensive analysis of the current post-acute stroke management, we additionally administered three sets of expert interviews in which the interviewees were chosen according to the theoretical sampling method (Lamnek, 1995).

In the first set of interviews, 10 persons were interviewed about their view on information deficits of stroke patients and their caregivers. Two neurologists, four care-giving relatives, two home nurses, and two members of a German Stroke Foundation were asked about their view on the information deficits and problems that arise in the course of post-acute stroke management and if they could solely be solved by consulting the internet.

The second set of interviews was administered to gain more insights into the current post-acute stroke management processes. Twelve persons (two general practitioners, two neurologists, two persons from ambulatory care, two stroke patients, two care-giving relatives and two therapists) were interviewed to create an accurate process model and to identify the involved stakeholders' roles, interfaces, resources, and exchanged information. For a graphical illustration of the collaborative processes between the identified stakeholders in the HSN we used the Business Process Modeling Notation (BPMN), which has become the de facto standard in academic and practice communities for business process modeling (Recker, 2010). For each task the involved stakeholders, their respective role and the exchanged information are illustrated. Such BPMN models have been created for patient, care-giving relative, physician, neurologist, therapist, mobile nursing care, nursing home, and social services.

After a thorough analysis of these processes and the identification of possible process improvements, another set of interviews was administered to specify the requirements for the novel post-acute stroke management concept. In a hospital two neurologists, a paramedic, and a hospital employee were

interviewed. The latter two were included due to their knowledge about the local healthcare service providers and the intra-hospital organizational as well as the medical processes, respectively.

2.2 Evaluation: Prototyping and Expert Workshops

In three expert workshops the novel post-acute stroke management concept was evaluated by domain experts, such as neurologists, therapists, nurses, the future stroke manager, and employees of the hospital's social service, the administration, and the IT-support. The concept, i.e. the offered stroke management service, the underlying workflow and the IT-architecture were analyzed and evaluated.

The first workshop focused on intra-hospital workflow support through service and information technology while using a first prototype. In the second workshop, the stroke management's support for current inpatient and outpatient treatment was discussed while using a second prototype. Before the pre-test, a third workshop with domain experts was held to discuss and adjust the final prototype.

3 Post-acute Stroke Management Requirements

Following the methodology, a comprehensive analysis of the current post-acute stroke processes has been performed by analyzing state-of-the-art literature, especially medical guidelines for post-acute stroke management, and qualitative interviews with domain experts.

3.1 State-of-the-art Post-Acute Stroke Management Analysis

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 (Murray, Young and Forster, 2007). 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 (Hoffmann, Russell and McKenna, 2004; van der Meijden, Tange, Boiten, Troost and Hasman, 2000) or different information systems to support home-based rehabilitation (Egglestone, Axelrod, Nind, Turk, Wilkinson, Burridge, Fitzpatrick, Mawson, Robertson, Hughes, Kher Hui, Pearson, Shublaq, Probert-Smith, Rickets and Rodden, 2009). 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 (Sulch and Kalra, 2000).

Because of missing state-of-the-art literature, the requirements were derived from stroke-related healthcare guidelines and qualitative interviews with domain experts. According to our cyclic combined service and software engineering approach, requirements were constantly refined during the workshops.

3.2 Requirements for effective Post-Acute Stroke Management

We have identified information barriers between different healthcare sectors and information asymmetries between the stakeholders in the healthcare service network as one of the major obstructions to an effective convalescence of the patient. Therefore, an inter-institutional stroke management service that facilitates the information diffusion along the patient's medical pathway is necessary. Based on concepts like case management, the service needs to incorporate a person that supports the involved participants in the current post-acute stroke processes, thus a person-oriented and IT-supported service that centrally coordinates the post-acute stroke treatment and distributes the relevant information regardless of inter-institutional borders along the patient's medical pathway from hospitalization and inpatient as well as outpatient treatment.

From the literature review and the interviews, the following essential requirements became evident for the stroke management service:

(S1) an effective stroke management service has to take place **along all stages of the stroke patient's care pathway** because information that was gathered during the rescue might be important for the rehabilitation;
(S2) the service has to be **person-oriented** and consider the individual patient's care pathway;
(S3) the service has to provide **benefits for the involved participants**, otherwise they will not cooperate and provide their data;
(S4) during the service occasional **face-to-face home visits** are necessary because of the individual patient's context;
(S5) the service needs to be supported by sophisticated **information technology**;
(S6) the service must have a **patient's consent** to saving and distributing health data due to legal regulations, such as medical confidentiality;

as well as for the stroke management technical infrastructure:

(I1) the infrastructure needs to provide **device and location independent access** because it needs to be accessed from different locations;
(I2) the infrastructure needs to allow **incorporating existing databases** (e.g., hospital information systems) easily, otherwise multiple data storage might occur;
(I3) the infrastructure should incorporate a **workflow management system** due to the numerous involved stakeholders and their interconnections that the stroke manager needs to administer efficiently;
(I4) the infrastructure must have a **mobile component** in order to support patients and their relatives as much as possible (i.e., while being at home or on the road);
(I5) the infrastructure should be able to connect to **telemedicine devices** for incorporating assistive technology; and
(I6) **security issues** have to be considered because vulnerable healthcare data is handled.

4 Post-acute Stroke Management Workflow

Based on the identified requirements, a post-acute stroke management workflow was generated and evaluated in expert workshops. The following three phases can be distinguished.

4.1 Phase 1: Inpatient Treatment

The novel stroke management service encompasses the complete post-acute stroke management beginning in the hospital that performs the patient's acute treatment, and ending when the patient has left the inpatient treatment phase and a stable service network has been established. It is divided into three phases: the acute phase, the inpatient phase and the outpatient phase.

If the patient survives the acute treatment, continues to be treated in the hospital and gives his consent to being supported by a stroke manager, the service is started. This first phase during the acute treatment is illustrated in Figure 1. The stroke manager looks up the patient's data in the hospital information system and conveys relevant information to his own software. The stroke manager then approaches patient and care-giving relative if the latter is available to gather further information, particularly about the patient's environment. At the same time, the stroke manager already supplies individual information about the next steps of the treatment process to patient and care givers. As soon as the patient is stabilized and reliable predictions about the future prospects are made by the physician, the stroke manager continues the work in the next phase.

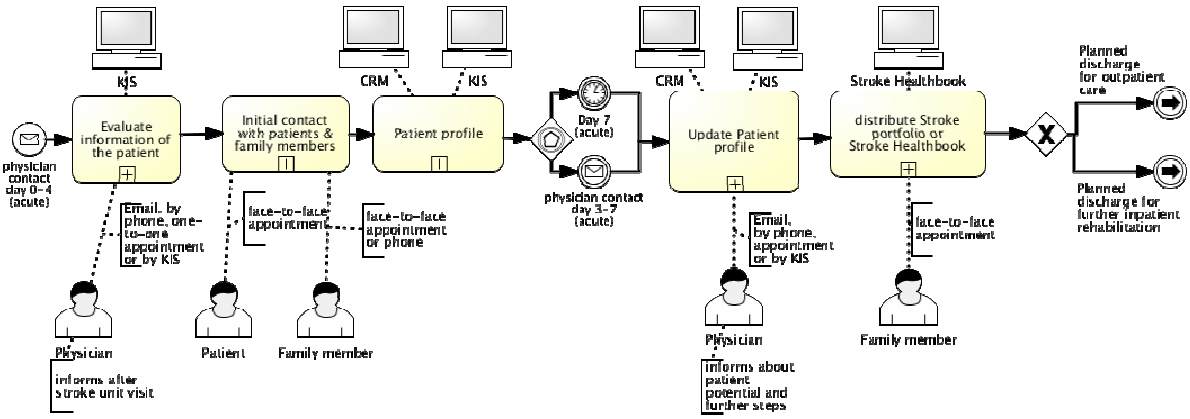

Figure 1. The stroke manager's workflow in BPMN when a new patient gets admitted to the hospital.

4.2 Phase 2: Preparing Outpatient Treatment

Figure 2 visualizes the stroke manager's process during the inpatient treatment. It has two starting points depending on the patient's next steps, either being discharged or staying in the hospital. The discharge process is illustrated on the top in which the stroke manager supports and coordinates the discharge by keeping patient and care giver up to date as well as networking with regional service provider that will perform the outpatient treatment. The figure's lower part illustrates the stroke manager's support during a continued inpatient treatment, for example during inpatient rehabilitation. Here, the patient and the care giver are also kept up to date concerning the next steps in the treatment process and individualized information are distributed to them. Additionally, the hospital staff is supported by making sure that up to date information about the patient are always available.

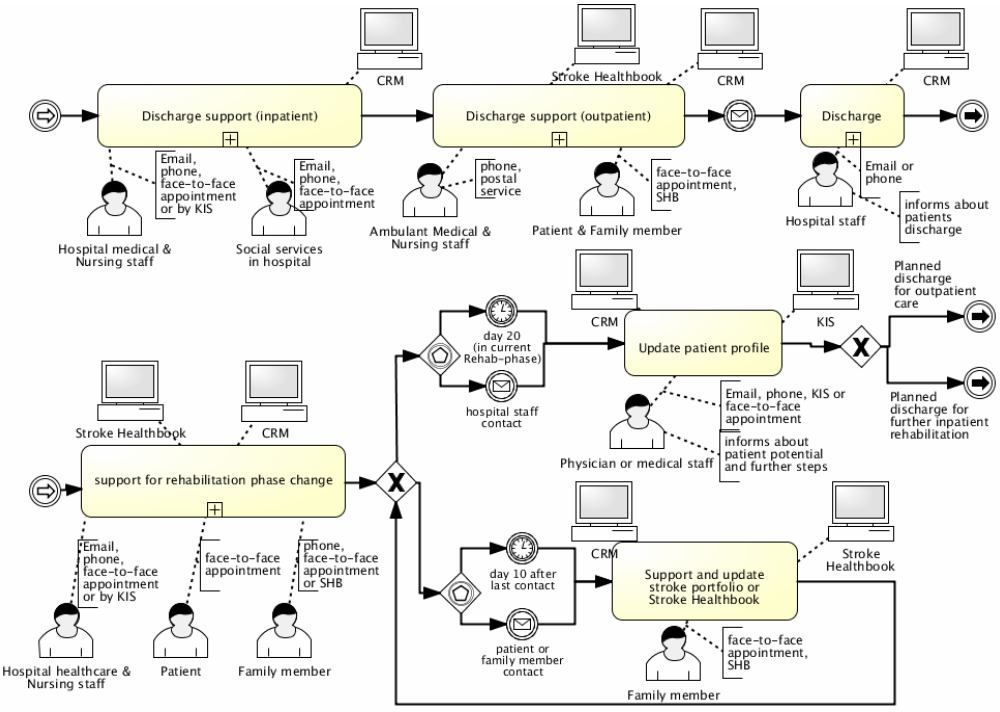

Figure 2. The stroke manager's workflow in BPMN before and during the patient's discharge and inpatient rehabilitation.

4.3 Phase 3: Outpatient Treatment

The third phase of the stroke manager service is the outpatient treatment and its workflow is illustrated in Figure 3. The first task of the stroke manager is to visit the patient at home in the first week after hospital discharge. After that, it is clearly visible that this phase includes several parallel activities. Depending on the state of the patient, there are both more visits and support necessary or the stroke manager service is terminated if the patient is successfully embedded in the regional HSN.

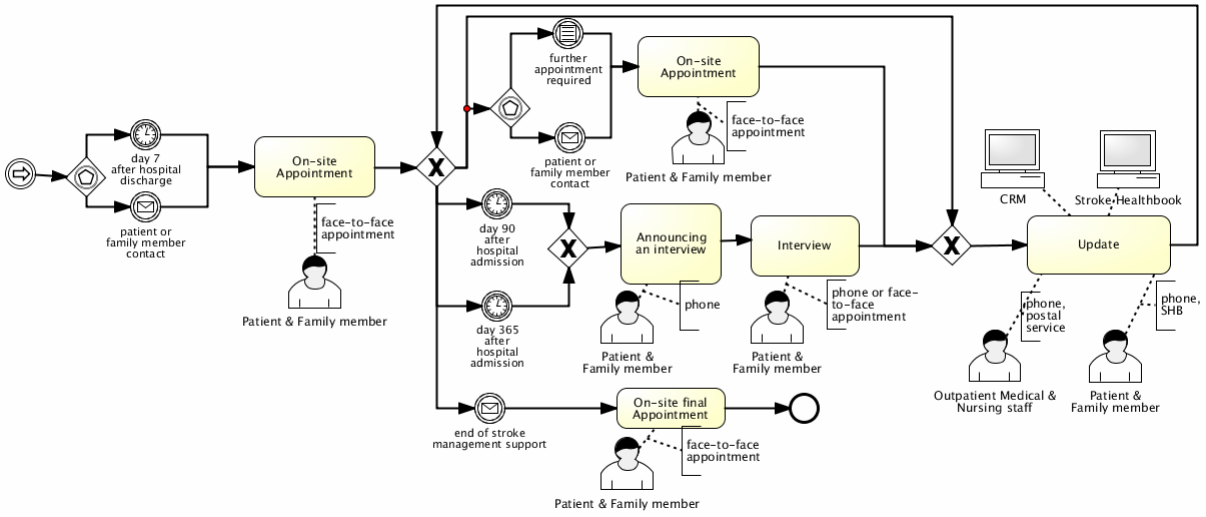

Figure 3. The stroke manager's workflow in BPMN during outpatient treatment.

5 Post-acute Stroke Management Architecture

Based on the post-acute stroke management requirements, the technical architecture was conceived, prototypically implemented and evaluated in expert workshops. It is depicted in Figure 4 and the major parts as well as their necessity according to the requirements will be described in the next paragraphs. The stroke manager is supported by a customer relationship management (CRM) software and two electronic patient records: a patient medical record (PMR) and a patient health record (PHR) that are mainly used by medical service providers and patients as well as relatives, respectively. There are different approaches to electronic health records' concepts depending on the users' requirements. Because of motivational and legal issues (see requirements S3 and S6), our post-acute stroke management architecture incorporates the two essentially different approaches -- one is patient-centered supporting the patient and the other one is case-oriented aiming at allowing different medical service providers (e.g., hospital staff and ambulatory clinic physicians) access to necessary data they need to treat the patient in the best way. The two electronic patient records are regarded separately because if, for example, a patient refuses to share important information of a personally controlled health record to the physician, the idea of an electronic health record is undermined. This might be the case if the patient cannot judge what information is important or if he simply refuses to share the data because of personal issues.

Additionally, the stroke manager makes use of a stroke health book that is distributed to the patients and their caregiving relatives. This allows both remote integration of assisting technologies (e.g. telemedicine devices) and an individual, patient-centered access to the patient health record.

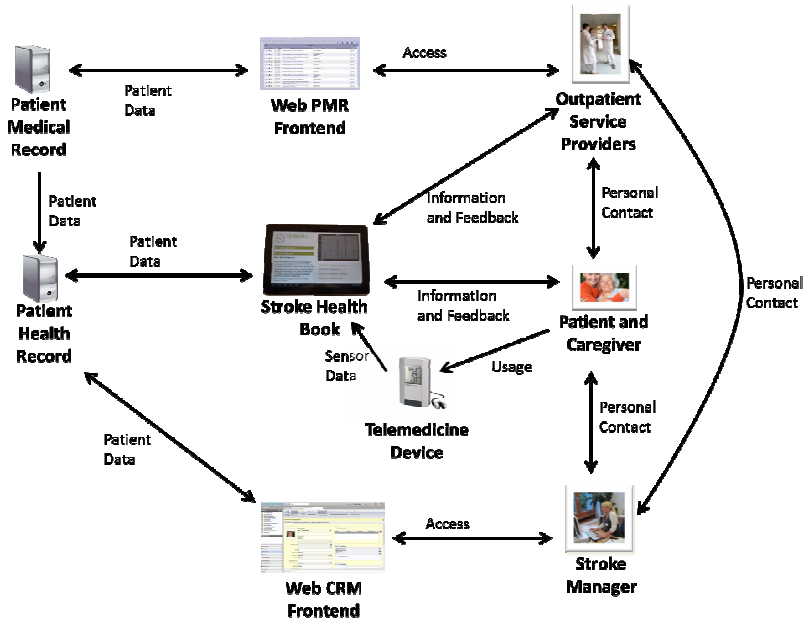

Figure 4. Envisioned post-acute stroke management infrastructure.

5.1 Customer Relationship Management (CRM Software)

The main part of our infrastructure is the customer relationship management (CRM) software that allows the stroke manager to efficiently coordinate and keep track of the patients, relatives and other involved stakeholders (see Figure 5). This kind of software permits a process-oriented workflow support of the stroke manager's daily work (see requirement S1, S2, S5, and I3). It is the control center that connects the two patient records, the stroke health book, and also the telemedicine device remotely. Our chosen CRM software is already used as a CRM software by care case manager. This facilitates the adaptation to the healthcare domain (e.g., healthcare instead of regular CRM notations were already used in the graphical user interface), and it satisfies the requirements for the post-acute stroke management service through its three main characteristics. It is cloud-based (requirement I1), it has a flexible technical base (requirement I2), and it allows automated workflow and documentation support (requirement I3).

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 HSN at the right point of time. For this reason, our CRM 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. The integrated automated reporting function provides additional documentation functionality.

Because of its cloud base, it is a distributed system that allows access at any time from everywhere. Other advantages are easy external technical support and maintenance as well as a general data security solution (requirement I6).

Due to the flexible technical base, the CRM connects different technical entities (e.g. patients' and caregivers' stroke health book and other software as well as hardware).

5.2 Patient Medical Record

The electronic patient medical record supports communication and data exchange between hospitals and associated medical service providers. In our infrastructure, according to requirements S1, S3, I2, I2, and I6 a web-based electronic medical record is integrated that allows medical service providers and involved physicians to easily exchange relevant information (e.g., diagnostic images and medical reports). For this exchange it creates a master-patient-index (MPI) that uniquely identifies patients' records regardless of their individual identification in the individual facilities. Yet, the only centrally stored data is the MPI as the documents are referenced at their original site and only made accessible through the internet. Additionally, this capsuled concept of a distributed EMR that is updated and used by medical service providers allows to independently add new functionalities (e.g., new image viewers, messaging or analysis tools) and participating institutions as well as a sophisticated user rights management on a patient case basis.

Nevertheless, according to requirement I6 a patient's agreement is a prerequisite for the possible medical data exchange and referencing of the patients' data in the patient medical record.

5.3 Patient Health Record

An electronic patient health record, albeit coordinated by the stroke manager, is also integrated in the stroke management infrastructure, more precisely in the CRM. It enables the stroke manager to provide individualized information to the patient corresponding to the current state. Furthermore, the stroke health record can store individual and stroke-relevant data that is assessed by the stroke manager, telemedicine, assisting technologies or the patient that is needed to provide personalized information (e.g., blood pressure, activity, and medication or therapy compliance). According to requirements S3 and I5 the interdependency between individualized information for patient and caregiver because of the data they are providing is an important part of the stroke health record.

In the process of designing the stroke management architecture, existing health records were examined. Based on the work of Sunyaev et al. (2010) and additional research, possible EHR were identified and evaluated. The two major requirements were open source and easy adaptability. However, no available product provided these characteristics at the time of screening. There are numerous EHRs of different dimension, but most of them are neither open source nor did any of them support the idea of storing individualized information adapted to the progress of the disease as well as patient-relevant data.

Consequently, we designed our own stroke health record which adopts most of the traditional PHR characteristics, but also implements additional data structures for individualized information, checklists, and personal schedules. During the qualitative interviews, the latter two were identified as very important by the respondents, but missing in current personalized electronic health records.

5.4 Mobile Stroke Health Book

The mobile stroke health book is distributed to patients and care-giving relatives (see Figure 5). 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 (Smith, Forster, House, Knapp, Wright and Young, 2008). Instead of simply granting patients and caregivers access to an electronic PHR or PMR, we designed a stroke health book that incorporates and enhances the PHR functionalities to meet the identified requirements (S3, I4, I5, and I6). Since nobody wants to store medical data just for the data's sake, the patients have to have an individual benefit. 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. Thus, a 10 inch tablet is used for the electronic version of the stroke health book or a regular folder for the paper-based stroke health book depending on the circumstances and abilities of the stroke patient. Both versions can be easily carried everywhere and provide useful functionality to patient, caregiver and other service provider because they have access to up to date information.

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 CRM tool by the stroke manager. They are either sent via a mobile communication network to the electronic device or as printed version via postal service. Likewise, patient and caregiver are individually informed and supported regarding the next steps in the treatment pathway, such as appointments or administrational tasks.

Figure 5. Mobile stroke health book (left) and CRM Software prototype (right).

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, its connection to the CRM software, and the underlying electronic PHR. They are connected to the CRM software either through the electronic stroke health book or, in case of the paper-based stroke health book, through an additional transmission device. The underlying PHR offers the data structure to store the individual data and its connection to the individual patient data already present in the CRM 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.

5.5 Telemedicine and Assisting Technologies

In addition to the core elements of the post-acute stroke management infrastructure, telemedicine and assisting technologies are integrated. According to requirement I5 other technologies should possibly be integrated into the post-acute stroke management architecture and following requirement S3 we exemplarily integrated an electronic blood pressure measuring device. Thus, patients can easily document their blood pressure, and doctors can access the data remotely to ask the patient to come to the doctor's office if necessary (see requirement S3). Although, currently there are few telemedicine devices that are technically sound and whose medical benefit has been proven, connecting other telemedicine technologies (e.g., scale, activity sensors, and so on) is also possible. Using medical devices incorporated in our stroke management architecture might provide the currently missing medically proved benefit.

6 Discussion and Outlook

In this paper we presented service and infrastructure requirements for an effective post-acute stroke management, the complex inter-institutional workflow of the stroke manager service, and our prototypically implemented, mobile, and distributed post-acute stroke management architecture. Our stroke management as a service addresses one of the three large challenges related to stroke: the missing individual yet comprehensive support patients and service providers in a HSN. The use case post-acute stroke management has been chosen because it is responsible for a large portion of the overall societal healthcare costs. Furthermore, it is one of the most complex disease pattern regarding inter-organizational management, which makes the introduced general post-acute management service and its associated architecture transferable to other diseases, e.g. myocardial failure.

In contrast to state-of-the-art approaches, we used a more comprehensive, service-oriented approach in which the technical as well as the healthcare service network level is taken into account. Hence, the multi-level architecture was designed using a combination of service engineering and software engineering methods. It consists of a person-oriented service for stakeholders in a regional HSN (e.g., patients, caregivers, physicians, therapists, and nursing services) that is performed by a stroke manager with IT-support. The integral part of the information technology is a CRM software combined with two electronic health records of which one supports the service provides and the other one empowers the patient. The latter is used in a mobile stroke health book that allows the stroke manager to distribute individualized information at the right time to patients and their care givers.

Through connecting the infrastructure with the service it becomes an integral part of the post-acute stroke management process. Instead of looking at isolated healthcare information systems or institutional processes, how it is generally done in the area of electronic health records (Collins, Stein, Vawdrey, Stetson and Bakken, 2011; Häyrinen, Saranto and Nykänen, 2008), we designed an architecture that is embedded in a HSN. Since the stroke manager uses IT to handle patient data from the start, there are no legacy paper-based records and traditional paper-based retrospective data collection is discarded. Furthermore, the regional healthcare service provides benefit from more data about the patient and using the patient medical record realizes a connection to different information systems. The medical service providers can also take advantage of the electronic telemedicine data that is produced by patients almost as a “by-product” while they use the stroke health book to get individual support and individualized information.

The developed person-oriented stroke manager service with its IT-architecture has been evaluated in workshops. Patients, care-givers and healthcare service providers have given their consent in an artificial test-bed environment. It is now ready to be deployed in a field study to gain first insights into usability problems or other obstacles, like data security issues, in a HSN.

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