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Empirically Grounded Design of a Nutrition Tracking System for Patients with Eating Disorders

Philipp Menschner, Andreas Prinz, and Jan Marco Leimeister

Abstract

In this chapter we present a nutrition tracking system as a solution to improve the quality of life of patients suffering from chronic diseases with progressive paralysis (e.g. Amyotrophic Lateral Sclerosis, Multiple Sclerosis, Parkinson) by improving coordination processes and information logistics of patient nutrition. We followed a needs driven approach and analyzed the situation of patients and shortcomings of current treatment processes. Conducting interviews with experts and patients, workshops and analysis of treatment processes derived from shadowing patients and physicians, we identify information and interaction needs. Based on the empirically identified needs we develop reference processes for nutrition tracking. From these findings, we derived requirements for a user centric socio technical system design for nutrition tracking. As a result, we present a first-level prototype for a mobile Near Field Communication (NFC)-based nutrition-tracking-system. The objective is to introduce a technically stable, socially acceptable and economically viable system that allows patients to use a cost-effective and easy to handle nutrition tracking system. This would enable a self-managed active life in patients' home environments. The solution simplifies medical and nursing processes by self- and outside evaluation as a basis to optimize coordination processes.

Keywords: NFC, Needs Driven Approach, Customer Integration, Health Care Services.

Background and Introduction

Patients suffering from chronic diseases often have to cope with limitations and a reduced quality of life. In particular, ALS patients (amyotrophic lateral sclerosis) suffer from progressive paralysis. This accounts for instances of insufficient dietary intake and, in the long run, leads to unnoticed reduction of weight due to malnutrition (Meyer, 2009), problems that are also found in other diseases such as Dementia, Parkinson´s Disease or Multiple Sclerosis. From a certain point in time, enteral nutrition by use of percutaneous endoscopic gastronomy (PEG)- tubes becomes inevitable, which causes a dramatic decrease in patients' quality of life (Löser *et al.*, 2007). By maintaining adequate nutrition, especially in the early phases of disease, this process can be slowed down. For this purpose, due to the limitations caused by the disease, patients admittedly need medical care and attendance of physicians, as well as the support of family members and nursing staff. What we advocate in this paper, however, requires enhanced information logistics which are presently not available.

By use of mobile networks and information systems, the insufficient information logistics amongst physicians, patients and nursing staff concerning actual nutrition could be improved. Therefore, the objective of our work is to provide a simple, effective and efficient patient self-management of the current nutrition status. Furthermore, the potential solution would allow patients a cost-efficient and easy-to-handle self-management of their current nutrition status and enable an autonomous life style for a longer time span. Telecommunication networks allow a flexible, location-independent monitoring of the current nutrition status of patients even in real time. Additionally, costs can be reduced, as patients take over data acquisition tasks. An intelligent nutrition tracking system thus can improve productivity of medical processes not only by being more cost efficient, but also by accounting for improved standards of medical care as well as quality of life. This is rendered possible by integration of patients into the treatment processes.

The presented case examines the situation of ALS patients. The outcomes are intended to be transferable to other chronic diseases which encounter nutrition issues, such as multiple sclerosis or obesity.

1.1 Amyotrophic Lateral Sclerosis (ALS)

Amyotrophic lateral sclerosis (ALS) is a progressive, degenerative motor neuron disease which,

on average, leads to death within three to five years after diagnosis. It is considered to be a rare neurological disorder and whose origins are at present still unknown. In 100,000 people, approximately six to eight people suffer from ALS, and each year another two develop the disease (Borasio and Pongratz, 1997). As both the lower and upper motor neurons degenerate, the disorder causes muscle weakness, and spasticity atrophy throughout the body. The consequences are indications of paralysis, amongst them disturbance in swallowing or chewing (Cleveland and Rothstein, 2001). According to current medical research, healing for ALS is unknown and inevitably leads to death. Therefore, actual treatments aim control symptoms of ALS or can be considered as palliative care.

In the result of ALS, undesired weight loss occurs due to malnutrition or cachexia (Cleveland and Rothstein, 2001). The loss of weight is affiliated by high morbidity and mortality, and leads to a decreased quality of life (Desport *et al.*, 1999). Due to medical complications and social consequences, malnutrition and cachexia are of significant socio economic importance (Ludolph, 2006).

Supplementary nutrition by increased calories or the use of PEG-tubes for enteral nutrition is beyond that associated with significant effects of personal, logistical and financial expenditures for service providers, as well as insurance and funding agencies. Estimates caused by malnutrition following the German public health and welfare system costs an annual amount of about 17 billion euro (Löser *et al.*, 2007). The annual costs for enteral nutrition for one patient is about 15,000 euro (Löser *et al.*, 2007); considering the additional costs of complex care expenses, the total expenditures for a patient sum up to approximately 50,000 Euros per year (Schauder, 2006). Hence, innovations in ameliorating patients' nutritional status are relevant from an economic perspective as well as for quality of life.

1.2 Scenario

Several months ago Hans obtained the diagnosis of ALS ago which started with a gait disturbance and progressive paralysis of his legs. During walking he stumbles repeatedly, and he also encounters balance problems while going upstairs. Furthermore, swallowing increasingly causes him problems. Especially solid food (eating an apple), but also liquids are an absorption problem for him. His physician creates a nutrition plan where the daily calories requirement is noted. Visits at the ALS out-patient department are scheduled every three months – too late to counteract early unnoticed weight loss. During the process of ALS the PEG-tube is necessary at

a particular time. If sufficient calorie intake prevents malnutrition, the installation of the tube system can be delayed and the complication rate of the PEG-nutrition reduced. The physician has notified the patient about a new nutritional tracking system (currently researched and evaluated) with the simple and uncomplicated possibility of recording and analyzing the daily food by information technology. If too few calories are ingested, the patient receives a warning. In the process, the nursing staff and family members, as well as the physician will be informed. Although Hans has never been interested in technical equipment previously in his life, he can easily enter the data with the NFC based nutritional management system. Everything is operated from his mobile phone: by touching the corresponding food images on a specially produced poster with the mobile phone, the data will be sent to the system. Twice touching the poster is sufficient for the data to be send. Despite the process of the ALS induced paralysis, Hans can independently record his daily nutrition through touching the food images on his mobile phone. With this continuous recording and the warning through the system, Hans has retained most of his original weight.

1.3 Related Work

NFC is relatively novel in healthcare research. For home healthcare solutions NFC in particular becomes more and more popular. (Morak *et al.*, 2007) used NFC-technology for monitoring heart failure patients as a self-management process; (Iglesias *et al.*, 2009) describe a NFC-based health monitoring system to improve quality of life for elderly patients. Patients transmit health related data to a central database, by touching medical devices with the mobile phone. Physicians or nurses can view the entire data and guide the patient to the best possible health status. (Bravo *et al.*, 2008) used NFC for supporting nurse activities in an Alzheimer's day center.
In clinical context NFC is used by various researchers. (Lahtela *et al.*, 2008) developed a NFC-based solution to avoid medication errors in hospitals. As an additional path of medical data acquisition (Fikry *et al.*, 2006) and (Morak *et al.*, 2009) describe different NFC based solutions, which allow physicians or nurses to collect data by easily touching medical devices with a mobile phone. Prinz et al. {Prinz, 2011 #274} used an NFC-based self-reporting questionnaire for patients with impaired motor skills to report their current health status.

Research Design

This section describes the key objectives of the research project, the methods that will be used to

collect and analyze data, as well as how the research process will be implemented. The objective is to plan, build, introduce and evaluate a nutrition tracking system based on mobile services and an IS platform. According to (Schwabe and Krcmar, 2000b), pilot projects are a special version of interventionistic science: they develop and implement technological innovations in their natural organizational and social environment.

The starting point is a socio-organizational problem (in this case the situation of ALS patients suffering from malnutrition). It begins with an in-depth analysis of the current situation of ALS patients. Therefore, a literature review and case studies, using interviews, questionnaires, observations and document analyses (Yin, 1989), will be used. The perspectives on the research objects for analysis are deduced from the Needs-Driven-Approach (NDA) by (Schwabe and Krcmar, 1996). Originally, the NDA was developed to design tele-cooperation (Schwabe and Krcmar, 2000a), but it has already been successfully applied to other settings, for example, for the development of virtual communities for cancer patients (Leimeister *et al.*, 2002). It analyses tasks, work processes, interactions of actors, social structures, tools and shared material, adoption and diffusion of technology, and information storage (Schwabe and Krcmar, 1996). These perspectives are the basis for designing interview guidelines, analyzing documents in self help groups, constructing questionnaires and all other methods used in the phase of field studies. The results of the analysis are used for designing a nutrition tracking system. This system is then implemented in the field, and finally improvements in the system are made during the remainder of the project. At all times and on all levels a continuous evaluation takes place, and, in this way, iterative learning steps can be augmented at all stages. Thus, this pilot project can be considered a level-three pilot project, since it consists of analysis, design and implementation of an information system (Schwabe and Krcmar, 2000b).

Requirements Analysis for Nutrition Tracking System

Analysis of actual state and processes

The objectives of this analysis are to evaluate ALS patients' needs and to elevate current information and interaction processes between physicians, patients and nursing staff. Therefore, we analyzed the ALS patients' current situation by qualitative interviews and workshops with experts (physicians, nursing staff, and medical technicians), followed by workshops with ALS self help groups consisting of patients and family members. To elevate current processes,

observation and shadowing techniques were used. Based on these findings, target processes were formulated which were also discussed and evaluated in workshops with experts and self-help groups. The following analysis is based on the perspective of Needs Driven Approach (NDA). This method facilitates the transfer of the results into system development requirements.

ALS patients' current situation (interviews with patients, family members, physicians): Malnutrition is not only caused by swallowing disorders, but also by respiratory insufficiency, increased caloric needs due to hyper metabolism, inability to use the upper extremities or by depression. Additionally, dehydration often occurs. Thus, the nutritional state of the patient is an independent risk factor for survival (Desport *et al.*, 1999). At a particular time, total enteral nutrition by use of PEG-tubes is inevitable. In such cases the quality of the patient's life decreases dramatically, and the mortality in the first months after installation of a PEG-tube is increased (Forbes *et al.*, 2004, Ludolph, 2006). Established treatment options include nutritional advice by aiming for hyper caloric nutrition. In the case of swallowing disorders, use of logopedic measures or supplemental nutrition by use of specialized aliments is possible. If these measures cease to work, PEG-tubes will be applied. Hence, the course of malnutrition encompasses three phases:

- Phase 1: intensified nutrition: the patient can still nourish himself, but already needs more calories than he actually ingests.
- Phase 2: adapted nutrition: the patient needs to enrich his nutriment with high caloric products in order to ingest enough calories.
- Phase 3: total enteral nutrition: without use of PEG-tubes the patient cannot be nourished any more.

Progression of these phases is different from patient to patient. Due to increased risks and limitations aligned with phase 3, it is desirable for patients to remain autonomous as long as possible. Thus, securing and managing a sufficient and well-balanced nutrition is of utmost importance in the earlier phases of ALS in order to delay total enteral nutrition. This can only be accomplished if nutrition and care processes are adopted efficiently and at the right time. Therefore, family members and nursing staff rely on information provided by physicians at the appropriate time.

Ethnographic analysis of treatment processes: Six observations of current treatments, consisting of shadowing and narrative interviews with physicians showed that there is a lack of information

and interaction possibilities in general. The observations took place at an ALS specialized clinic. Usually, patients show up there every three months to document the status of their disease and to adjust current treatment procedures. The physicians at this special clinic have no medical follow-up of their patients during the three months interval between visits; additionally they do not receive any information from family members, nursing staff or the family doctor. Therefore, the physicians need to rely completely on the information presented by the patient, which in turn has several major disadvantages: Patients fail to give the correct information (either done willingly or accidentally), information from nursing staff or the family doctor are sent via the patient, and sometimes, caused the progressive paralysis, the patient has difficulties in communicating at all. Hence, the basis of decision-making is often an insufficient data set, which additionally consists of secondary data ("Chinese whisper effect" or time lag). On top, about 90% of the consultation time is used for information retrieval. At the end of the consultation, patients are given instructions and information intended for family members and nursing staff.

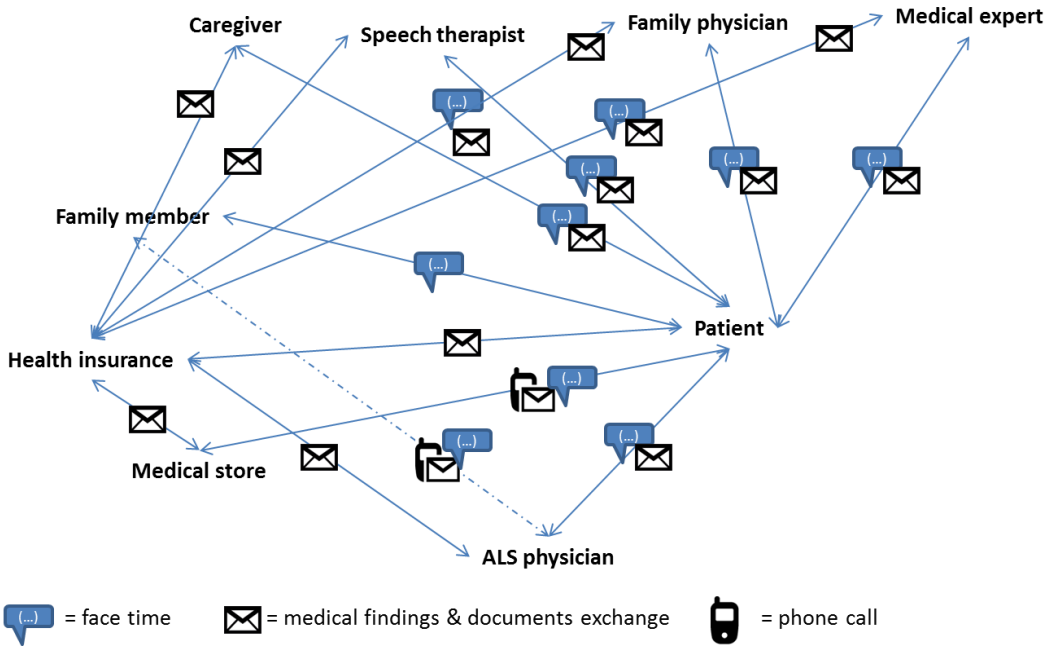

Figure 1: A typical interaction network of an ALS patient

Social structure: The social structure describes who is interacting with whom and in which way. Although there were some minor differences in the observed cases, a dominant pattern was identified: In the case of ALS patients, most interactions took place between the physician and

the patient. Instructions and information intended for nursing staff or affiliates were sent via the patient. Correspondence between the ALS-physician and family doctor only took place, if at all, in the form of doctors' notes. In rare cases, family members did accompany patients during consultations. Care and assistance in patients' daily life were carried out by either family members or by professional nursing staff.

Processes and interactions: Figure 2 shows the treatment process of ALS in an ALS specialized clinic as a service blueprint. Service blueprinting is a process analysis methodology proposed by (Shostack, 1982, Shostack, 1984). (Zeithaml *et al.*, 2006) define service blueprinting as a tool for simultaneously depicting the service process, the points of customer contact, and the evidence of the service from the customer's point of view.

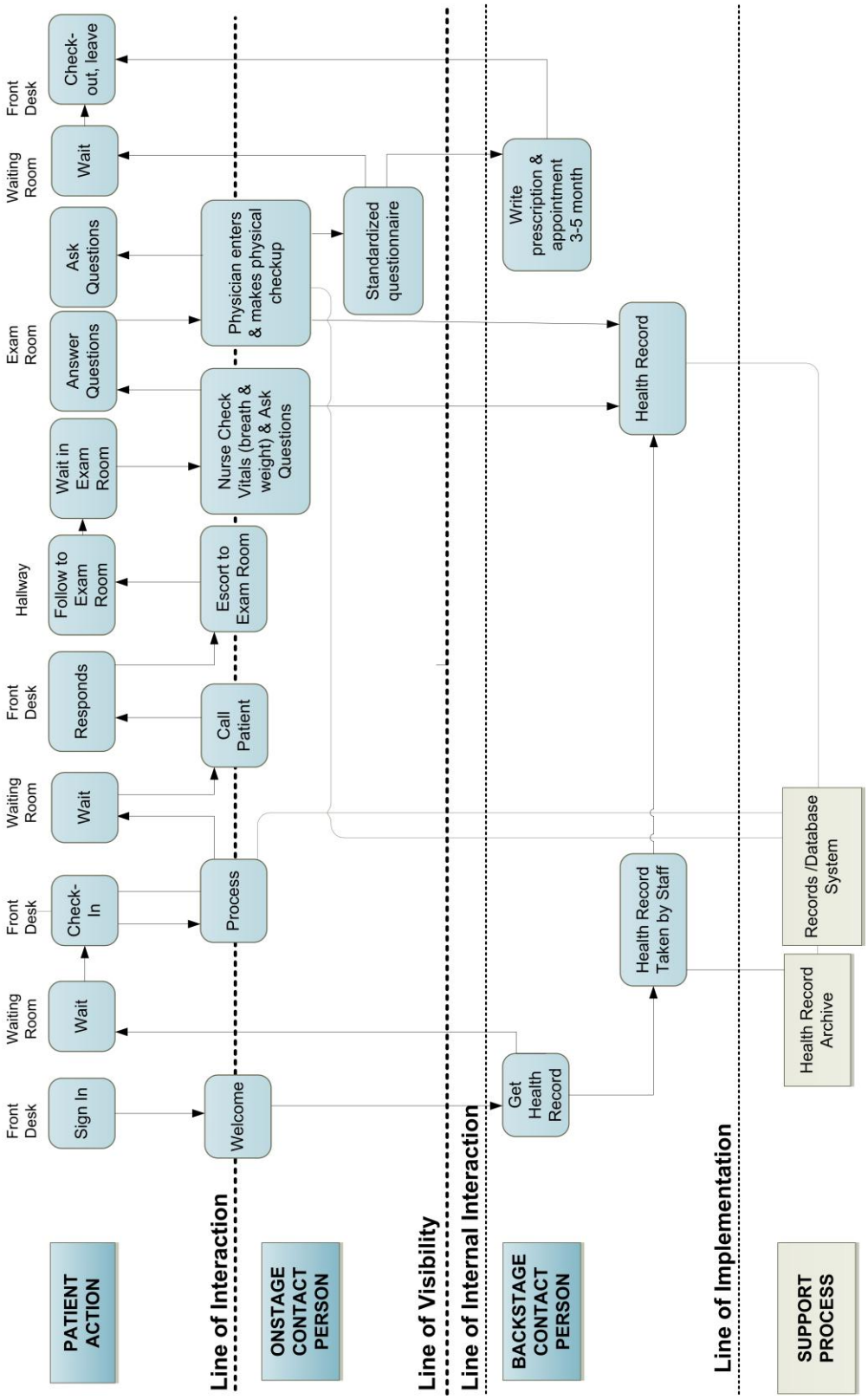

Figure 2: Service Blueprint of ALS-clinic {Menschner, 2011 #371}

Analysis of materials and tools: In the case of ALS-Patients, the use of materials and tools, such as mobile devices, seemed to be dependent on the stages of amyotrophic lateral sclerosis and the average age of the patient. In early stages the patients could handle most communication tools, such as mobile devices, computer and writing tools. As the course of the disease progress further, the fine use of the mobile phone becomes a problem. For example, writing a short text message proves to be difficult in the progressive paralysis of extremities. The fine motor skills that are needed for pressing small buttons on the mobile phone to navigate through the menu in order to choose a name in the telephone directories and to start a call are restrained, as the motor activity of the hand is able only to press big buttons. If the linguistic ability is lost, due to progressive paralysis, sometimes a communication system is used. Younger patients use more modern communication tools than older patients who prefer to use paper-based materials. If progression of paralyses reaches a certain level, patients need assistance from either family members or nursing staff.

Information storage: No structures for regular collection and transmission of nutrition data exist from a patient's home environment to the medical decision-makers. Thus, a progressive loss of weight or dysphagia (swallowing disorder) can remain unnoticed between planned consultations, which means that there are no interventions by physicians and the treatment processes are not arranged.

There is also at present no acquisition of nutrition data by means of information technology during therapy. Any discrepancy between the actual state of nutrition and the target state in home care is not recorded. This results in further weight loss despite enteral or supplemental nutrition.

Our results confirm the dire demand and need for information and interaction services to improve nutrition tracking for ALS patients. As no solutions for the specific problems of ALS patients have been offered thus far, target processes were elevated and requirements for a nutrition tracking system designed for ALS patients were elicited.

3.2 Target state and requirements elicitation

The nutrition tracking system needs to aim for increased quality of consultations and perceived quality of life by preferably the same or even reduced costs. This can be obtained by improving the interface problem between the involved actors in nutrition management (Schweiger *et al.*,

2007). By active participation and integration into cure and care processes, better documentation and the resulting improved basis for treatment and nursing can be achieved. Thus, an intensified integration of patients is required. The proactiveness while recording their nutrition status allows patients to gain a deeper understanding of their disease and fosters their ability to cooperate in the treatment and consultation processes.

As ALS patients suffer from motor limitations, they need to be provided with an easy to handle nutrition surveillance system that can be used via mobile phone. Thus, Near Field Communication (NFC) technology has been selected for implementation. NFC, is a short-range high frequency wireless communication technology, based on the frequency of RFID, which enables the exchange of data between devices over about a 10 centimeter (around 4 inches) distance (ECMA-340, 2004, Want, 2006, Forum, 2007). NFC allows the launching of applications and initiation of actions by simply touching a RFID-tag with a NFC-enabled mobile phone. This very intuitive and easy to use user interface is especially suited for ALS patients, who are fighting certain restraints of fine motor skills with progression of the disease.

The elicited requirements are presented according to the stakeholders:

Patient: The patient plays a decisive and very important role in the management of nutrition. The patient can act autonomously and is responsible for his food intake, especially in the earlier stages. Later in the course of the disease, he will increasingly be in need of help from his family and care service.

Requirements:

- easy, intuitive and user-friendly system for the documentation of the daily food intake
- possibility to analyze the data on his own
- automatic memory signal in case of undernourishment
- solution must also be usable in case of progressive paralysis
- possible trends in weight development
- advice concerning a change in diet
- patient control of the access to the collected data by a third person

Family members: The relatives face severe challenges, since they are not only members of the family or friends, but they are often caring relatives. During the course of the disease, they need to deal with massive physical and mental strain.

Requirements:

- A support system for the management of nutrition should help the relatives by giving warning signals and concrete options for action, e.g. in the form of advice concerning a change in diet.
- Possibly an evaluation feature for the total food input and a function of external monitoring.
- Visibility of trends in the weight development.
- In case of a patient's progressive paralysis, the system must be intuitive so it can be operated by relatives.

Physicians: In general, the physician only sees a patient every three months for the medical examination and for making a diagnosis of the course of the disease. By the time a physician notices a drastic weight loss, it can be almost irrevocable. The physician has not been able to recommend a change in diet since there is no information system which documents, monitors and analyzes the complete nutrition data of patients.

Requirements:

- The system should help physician to anticipate early trends and troubles and therefore prevent a drastic loss in weight.
- The system should allow the observation of the eating habits of patients that is independent of time and place. When necessary, physician and supportive staff can work together to prevent malnutrition.
- Reception of warnings concerning patients to ensure transfer to appropriate staff
- Evaluation feature for the total food input and possibility of a long-term analysis for the patient.
- Visibility of trends in weight development.

Nursing staff: In the early stages of amyotrophic lateral sclerosis the care services are of lesser importance; however, later in the course of disease, they patients need more intensive care.

Requirements:

- Reception of advice concerning a change in diet and/or concrete instructions
- Easy, intuitive and user-friendly system for the documentation of the daily food intake if the patient is not able to do this on his own any longer
- Automatic system warning if the loss in weight is progressive or the patient takes in too little calories

- Analysis of the quantity and quality of the patients' food intake so that the members of the care service are able to recognize early trends of the patients' weight development. If necessary, the consistency and composition of patients' food can be changed.

To summarize, one of the most important issues is to improve the information logistics between physicians, patients and nursing staff. An information flow between physicians and nursing staff is especially important to be established, as the sole transmission of information via patients bears certain risks. Further, the position of the physician needs to be considered carefully. As it is a most rare and expensive resource in medical processes, real time surveillance needs to be automated to a high degree so that a cost-efficient care process with improved quality can be realized.

Figure 3 illustrates the service blueprint of the target process. This process has been evaluated and reviewed by physicians, clinical staff and self-help groups. Based on this process, a system design has been developed. In contrast to the current process, it encompasses a higher patient integration enabled by the use of information and communication technologies that enable improved information logistic.

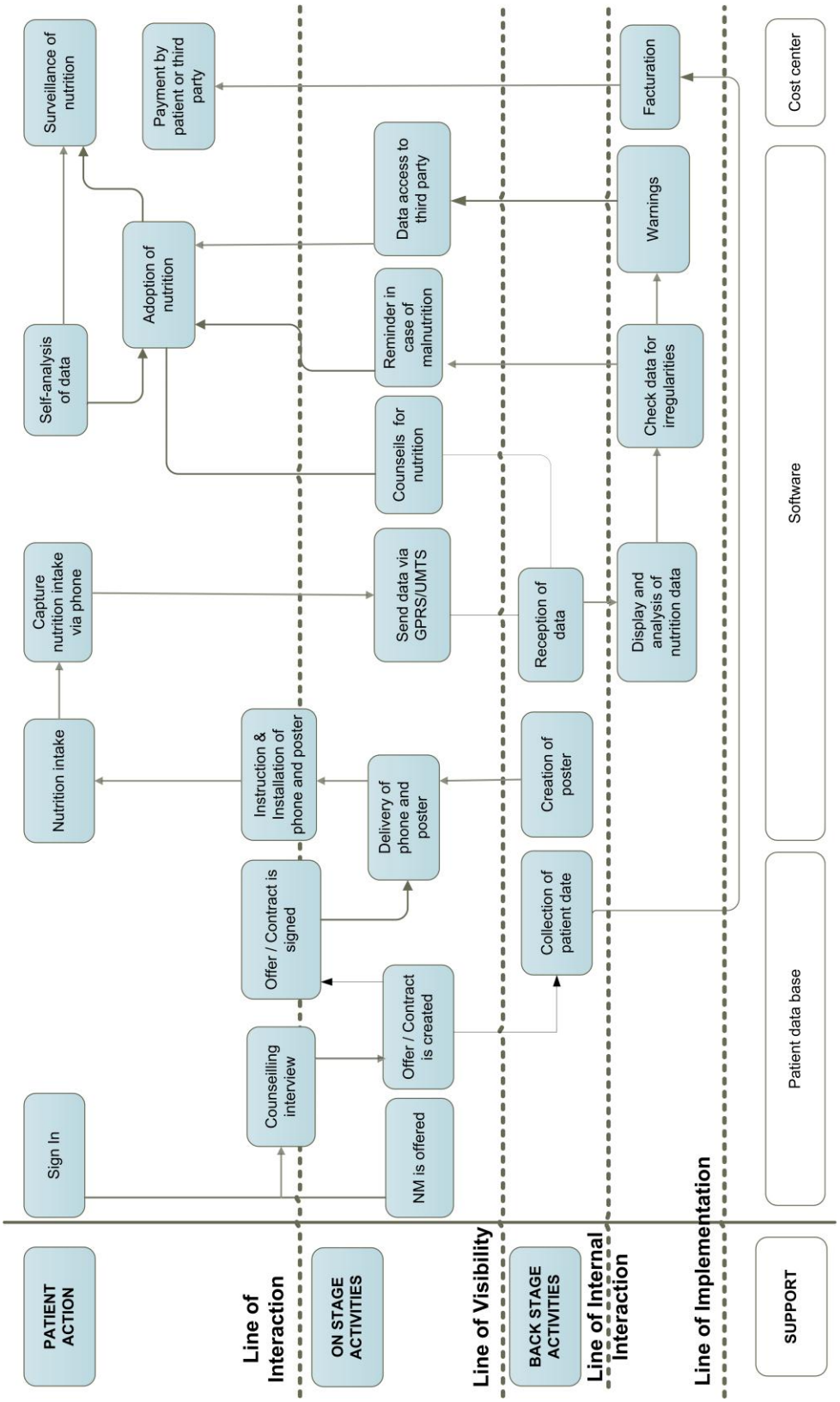

Figure 3: Service Blueprint of Nutrition-Management>> {Menschner, 2011 #371}

Solution of System Design

The approach presented in this paper is the practical implementation of a NFC-based nutrition-tracking-system. This helps the prospective collection of data to detect malnutrition in the early stages.

Patients have access to the platform through mobile devices and computers. They can see the formatted data and can check target-performance comparison if they have taken sufficient calories. If the patients have enabled the analysis of data to more people, such as relatives, physicians or nursing services, then those can view the data of the patient, and therefore if necessary, changes the nutrition accordingly.

Figure 4 shows the system architecture of the NFC-based nutrition-management system with a potential connection to a hospital information system (HIS). For selecting the food to be eaten, a touch with the NFC-mobile phone to a picture on the NFC smart poster is sufficient. Once contact is made, the mobile device gives audible, haptic and visual feedback to the patient. Audible the name of the chosen food is spoken, haptic the vibration function of the phone is activated, and visually the chosen food appears on the display. If the patient wants to send the chosen nutrition to the database, a second touch on the sending tag of the mobile device is enough. Again, the mobile device confirms the transmission of data with audible, haptic and visual feedback.

An ID is stored on the tag, which is read-out and then compared with data already stored on the mobile phone. Further, in this solution a NFC-weighing scale is integrated, which sends the measurement data via the mobile device to the database. Depending on the mobile phone contract, the data can be send to the server via SMS or via a mobile web based data transaction. Information that is transmitted to the server shows the date, time, the chosen food and the user ID. This can be done through the mobile device, as well as an identification number that is assigned while installing the software on the device. When transmitting the data of the weighing scale, the same basic data is transmitted, but instead of selecting food data it will be measurement data transmitted.

The central unit of the solution is a relational database that will store the whole data. Patient and involved persons on the care process have got role-based access to the aggregated and analyzed

data via the web interface.

The transmitted and aggregated nutritional and vital data are processed and analyzed by rules stored in the systems. If the previously calculated and deposited thresholds of the physician are exceeded, the predefined stages of alert are triggered:

- The system finds small shortfalls of the intake of calories and alerts the patient via SMS, email or an automatic call.
- After several days of insufficient food intake of patients, selected members, nurses and physicians will be automatically notified.

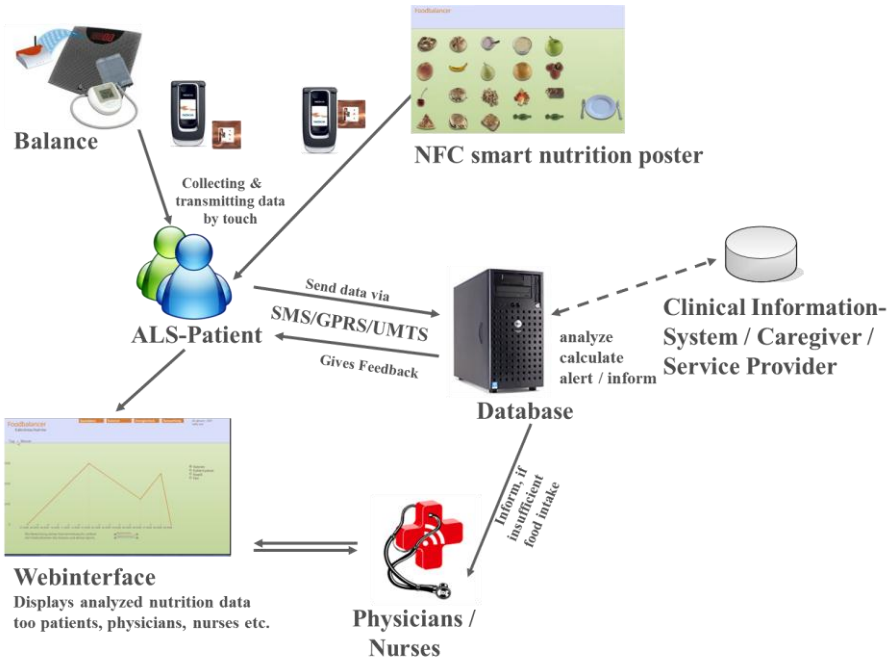

Figure 4: Overview of Nutrition-tracking architecture

The mobile device software is programmed in Java language. For use on mobile devices, an optimized version of Java 2 Micro Edition (J2ME) is used. The client software stores the multimedia files, such as photos of the food and sound data. Thus, only small amount of data between the mobile device and the server need to be transferred. The choice of client application, rather than purely server-side architecture, is based on the fact that, especially in rural areas, mobile communication networks are insufficiently developed for broadband connection in order to exchange data intensive multimedia files between the sever and mobile devices (BMWi,

2009).

Summary and Outlook

Actions and measures that improve nutrition tracking and the nutritional situation of patients have great economic potential. Although the case of ALS is specific and there are no reliable figures available, numerous studies do present clinical aftermaths, e.g., in the case of malnutrition of elderly people. These studies document that malnutrition is an independent risk factor that causes not only consequences for the patients' health, but is also responsible for immense additional costs for the public health care system (Stratton *et al.*, 2003, Volkert *et al.*, 2006). Apart from increased nursing and care expenditures, this also encompasses additional hospitalization or medication. According to (Stratton *et al.*, 2003), disease related malnutrition accounts for 16 billion euro of additional costs in Germany alone.

With our nutrition tracking system, we have presented a practical example for the intelligent use of mobile services and information technology to improve the quality of life of patients suffering from chronic diseases. Thus far, we have conducted a requirements elicitation and presented a solution of system design. However, our results present an exploration only and need to be verified in real-world settings. For this purpose, a field study is planned during the next months to evaluate the system with patients and physicians. Beyond this stage, further studies are necessary to evaluate the effects and consequences of an improved nutrition situation for the progression of the disease from a medical perspective.

The example of our nutrition tracking system already shows the potentials and possibilities that technical support systems can offer to patients. During evaluation, it will be essential to test our solution for acceptance by patients, family members, nursing staff, physicians and funding agencies. The obtained results will be integrated into the further development processes. In the end, the deployment of technical support systems, as our nutrition tracking system, can only be successful if the involved stakeholders accept the system and actively and regularly use it in everyday life. After the questions of usability, the actual benefit to patients, physicians and nursing staff are subject to close scrutiny.

Additionally, the system needs to be checked for robustness, stability and scalability. Further, it needs to be evaluated to see whether the technology works in a real world setting and if all processes and organizational issues run and perform as intended or whether they need to be

optimized.

Further, an extension of the proposed system to other data and functions is possible. For example, it would make sense to collect data on the current emotional situation or for self-assessment of disease progression. It has already been shown that by completing specific questionnaires, the disease progression in the future can be forecasted (Kaufmann *et al.*, 2005). Another opportunity is offered by the integration of sensor data, especially when the system will be applied in a modified form to other diseases such as multiple sclerosis or adipositas. The extent to which the system can be integrated in existing clinical and medical IT systems also needs to be verified. The required data integration in this context needs to consider new technical and legal developments and conditions in telemedicine and health care. For example, the implementation of new electronic health insurance cards and systems will establish new standards for transmission and storage of data in health care.

To conclude, the use of mobile services and information technology will have a great impact on medical processes and services. In addition to improvements of communication and interaction processes that have a positive influence on quality of patients' life, cost savings can also be realized. A modified patient-physician relationship, caused by improved patient information and autonomy, offers new possibilities for the design of novel medical services which are only made possible by modern technical support systems. With this system design, we intend to provide an exemplary case that shows the potential of technology enabled health care processes.

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