

System Architecture for Palliative Care in the Home Environment

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Abstract. To establish modern technical communication and monitoring systems also in the private homes of patients with palliative care needs a special and complex architecture behind. With the help of modern communication technology the existing social network such friends, family or social services will be strengthened. Additionally a monitoring system helps to detect an upcoming crisis of the patient at an early stage to defuse the situation betimes, or - in case of eventuation - to cope with a crisis in an appropriate way with the help of a well elaborated information forwarding system. On that way depressive and unnecessary hospitalizations should be avoided, if possible. Medical care and business models in the sense of end-of-life-care will be evaluated within the PAALiativ project. The models will be developed with two groups of patients exemplarily, patients with pulmonary cancer and patients with Chronic Obstructive Pulmonary Disease (COPD).

1 Introduction

Background of the demographic change is a double-ageing-process of the society. On the one hand there are an increasing number of elderly persons, while on the other hand the number of new born children is decreasing. Due to the advances in health treatment, many previously fatal diseases have been turned into chronic diseases and the lifespan increased. The consequence is a growing demand for care, especially for elderly persons or persons with a disability. The objective of the PAALiativ¹ project is to improve the palliative care of patients with end-stage pulmonary diseases by integrating modern assistance and medical monitoring techniques in their home environment. Within the PAALiativ project we address the health care and business cases of the two patient groups: Chronic obstructive pulmonary diseases (COPD) and lung cancer. Two disease patterns which currently show the highest accession rate [1].

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2 Motivation

Patients with palliative care needs often wish to stay at home instead of being cared for in a hospital or another specialized institution. They want to stay close to their partners, relatives and friends and they want to keep going in their normal life as long as it is possible [2]. However, a number of measures have to be taken to make sure that care at home really is an improvement or at least a positive aspect for the patient and his affiliates. In home care, conflicts may arise because the patient feels him- or herself to be a burden for relatives and friends; especially the partners of patients often have to live with a double pressure of on the one hand having to continue with their life and work to keep up the (financial) provisioning, and on the other hand having to care for a loved one, who is dying. In case of lung cancer and patients with COPD occurrences of acute dyspnoea may result in emergency calls followed by hospitalization even though it could have often been treated on the spot. This is because the emergency staffs have no or few information about the patient's disease history, which plays an important role for an adequate evaluation of the situation. Unnecessary hospitalization can be very wearing and stressful for the patient and his or her affiliates. It also produces avoidable costs for the health system.

To address these problems the following measures should be taken: Monitoring, supporting medical decisions, and creating and supporting a social network.

2.1 Monitoring

The disease pattern of patients with lung cancer and COPD is known and to some extent predictable. Continuous monitoring of selected parameters like pulse, pulmonary function, of the patient and his or her environment and providing this information to the care personnel can help them to refine the treatment of the patient. Figure 1 shows two kinds of typical illness trajectories for people with progressive chronic illness. Patients with cancer have a long period of preserved function followed by a precipitous drop that starts within a few months before death (top). Patients with COPD have an overall gradual decline in function punctuated by periods of exacerbations with acute drops in function followed by a return to near their previous level (bottom). The intent is to predict and deescalate bad trends, and to avoid periods of exacerbations best possible. Based on single vital parameters as well as composite disease markers (e.g., Bode Index, [4], result of data aggregation, consisting on weight, dyspnoea, obstruction, and the physical capacities/ exercise), and further assessments, upcoming crises should be detectable and can be medicated at an early stage. Crisis is here defined as any change of the situation which makes intervention from outside necessary. It includes physical as well as psychological or psychosocial developments. The patient might also perceive the fact that the data is taken and forwarded as a reassurance that he or she is under the surveillance of professionals while at his/her home.

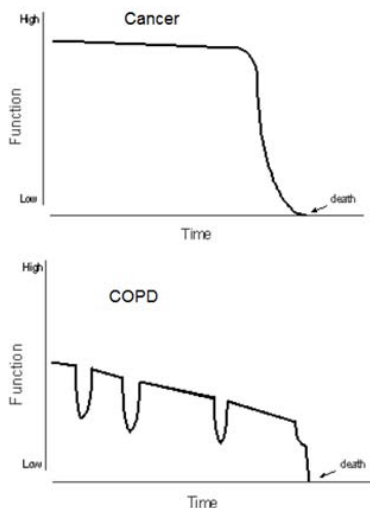


Fig. 1. Typical illness trajectories for people with progressive chronic illness. Top: Patients with cancer have a long period of preserved function followed by a precipitous drop that starts within a few months before death. Bottom: Patients with COPD have an overall gradual decline in function punctuated by periods of exacerbations with acute drops in function followed by a return to near their previous level [3].

2.2 Supporting Medical Decisions

In case of an emergency or a crisis as much relevant information as possible about the patient and his or her situation should be accorded to the emergency decision maker. Relevant information includes the medical history as well as current values of selected vital and environmental parameters, supplemented by subjective self evaluations. Short term as well as long term changes in behaviour or variations in the health status of the patient can be a meaningful instrument for deciding the right measure. Based on diverse information the emergency physician has the possibility to assess the situation correctly and to decide, if there is really the need to send the patient in the hospital, or if it is possible to treat the patient at home.

2.3 Creating a Social Network

To address the psychological and psychosocial conflicts that can arise for the patient and his or her affiliates, it is important to structure a close net of formal (professional) and informal support groups [5]. These groups differ a lot. Formal, professional groups include the medical professionals in the general practitioner (GP) practice or in the hospital, as well as the home care nurses and the medical decision makers in case of emergencies. They are trained, often specifically for palliative care and have formal ways to obtain and manage information. Informal

groups can vary from voluntary groups, carers and relatives, to close and distant friends and neighbours, who come to visit and talk, or e.g., to take over some work in house or garden or supporting the patient in any other way. All these different groups build the social network of the patient. To make them work effectively, it is necessary to link them. E.g., if the home care nurse knows about the volunteer, who is dealing with the authorities in the patient's name, she might ask him or her to help with upcoming insurance issues; if the operator in the emergency centre knows about the neighbour, who has got a key to the patient's house, he or she can contact him or her to quickly check on the patient, if a situation is unclear; if relatives have knowledge about the situation, they can offer to help with household work or other tasks, possibly relieving some of the pressure from the patient and his or her partner.

3 State of the Art

‘“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”’ defined the World Health Organisation [6]. Today the main part of the day to day palliative home care is undertaken by close relatives and professional home care nurses, ideally ones specifically trained for palliative care. Nurses visit a patient two to three times a day, according to a care plan and support e.g., the daily hygiene, and they take care of medical provisions such as infusions. Nurses document their visits in care protocols, which are seldom electronic based. These care protocols are then used for the accounting at the insurance. The medical responsibility for the patient lies with the family GP, supported by the applicable specialists. He or she might also be specifically trained for the palliative treatment of terminally ill persons. The GP keeps a record of the medical history of the patient, as far as it is known to him or her. He or she gets records of the findings of the specialists and keeps them with the patient's data. How the data is organized and stored varies a lot between the practices: There are still many paper based file card systems, but there are also a number of software systems available. In-house emergency call systems enable emergency calls from a fixed base station and a corresponding radio calling device in the patients' home. In case of an emergency call, the patient's system is uniquely identified and the operator in the call centre receives previously stored patient information on a computer screen, when he or she takes the call. This information includes name, address, age, general medical status (i.e., care level, diseases, allergies), address of the GP and contact numbers of affiliates. It also comprehends the call history of the patient. Based on the call and the information in the system the operator decides on his next steps [7]. Due to the technical development in the past few years especially regarding wireless data transfer, and in the area of disease management, a number of telemedical approaches emerged, which aim to support patients and their GPs in the management of chronic diseases. Bolz et al. present some examples where vital

parameters of patients are monitored continuously or discretely and are analysed either at the base station or transmitted to a remote server for evaluation there [8]. In both cases a health professional is contacted if the parameters violate a predefined range of values. The information is presented to support the diagnosis of the situation. The data is stored in a patient health record and therefore also available for further or long term analysis. Telemedical approaches including remote monitoring like these have been evaluated by Clark et al. and their findings show that they have a positive effect on the management of a chronic condition like chronic heart failure [9]. Social networking in the area of palliative (home) care has also grown in the past few years, mainly probably owed to the fact that new guidelines in some countries [10] call for the development of new and multi disciplinary ways of care for patients at the end of life. The WHO describes the content of palliative care as holistic, i.e., integrating the psychological and spiritual aspects of patient care, and advocates that palliative care should be applicable early in the course of life-threatening illness, for all patients and any setting [11]. There are also special Care Pathways for dying patients, like i.e. the Liverpool Care Pathway, that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life [12]. Cities and communities are looking for ways to link the different care providers like hospitals, hospices, medical practices, ambulant nursing services, psycho-oncological services and so on, voluntary, non-profit organizations, affiliates, friends and even neighbours, who offer their support. An example is the ‘ “Palliativstuetzpunkt Oldenburg” ’ [13], where different relevant institutions within the city work together to provide a central point of contact and coordination for palliative (home) care for the city of Oldenburg and the surrounding area.

3.1 Limitation of the State of the Art

The main limitation of the previously described state of the art lies in the consequences of the lack of information and information exchange between the different stakeholders in palliative homecare, which is the base of coordinated, linked care cooperation. As can be drawn from the previous sections, the number of stakeholders is bigger than two; the communication between parties is seldom more than a two-way communication though, with the patient and his or her partner being on one end. The different groups of formal and informal carers are not linked and the information exchange between them is rarely and seldom structured. E.g. there is no formal way in which the ambulant nursing service receives relevant information about the patient’s visit at the GP’s. Information could therefore be lost to the nurse, if the patient him or herself does not convey it. Also in-house emergency call system operators do not receive updates of important information like a change in the general medical status. Medical professionals in hospital or GP’s practice often have only got their own documentation [14] of the patient’s history and a GP’s letter as information about the patient’s treatment at other institutions, but no continuous documentation. Miller and Sim found a lot of key barriers to physicians’ use of electronic medical record instead of paper based documentations [15].

The patients themselves often have none or only an incomplete documentation of their illness, even though the institutions are obligated to provide all information if patients want to give it to another institution. As with the current approaches to telemedical systems, they are often focussed on one or two aspects of a condition, e.g., oxygen saturation and heart frequency in a system, which detects cardiac problems like atrial fibrillation. When dealing with patients with palliative care needs, who suffer not only from sensor-measurable, physical problems, but also very often have to deal with psychological and psychosocial problems, this approach to monitoring is too limited. More integrative monitoring is called for:

- Objective (vital) parameters like weight or temperature and also aggregated composite markers should be monitored along with subjective ones like the patient’s perceived level of pain or degree of dyspnoea.
- Assessment of mobility and activity values could be used as indicators not only for the physical but also for the psychological state of the patient [16].
- Environmental parameters like meteorological or indoor air quality parameters [17] should also be included. For patients with lung diseases the air quality is quite important [11].

4 Approach

Our new approach to support patients with COPD and lung cancer in their home environment is to compose a system which provides a collective source of information and a central linking point for all groups and persons involved in the care process. Keeping information up-to-date and distributing this information between the different parties is one focus of our system. Since all of the information in question is directly related to the patient, and especially because care for the patient is very individual the installation of a supporting system in the home environment is the only reasonable way:

- One of the most important data sources of the system, the monitoring of vital and environmental parameters, must be located in the patient’s home. Storing and processing the data where it is collected, requires less effort in enabling and especially securing data transfer to external systems.
- The patient is the owner of all data and he or she is the only one who can allow or disallow access to the information or part of the information. Keeping all in the home further supports this ownership.
- Most of the care, especially the day-to-day care by the ambulant nursing service, is carried out in the home of the patient.

The information derived from the monitoring system combined with an up-to-date patient’s medical history and up-to-date information about the patient’s social network (e.g., continuously updated in-case-of-emergency contacts) should be presented to the emergency call operator as to facilitate his decision process. Figure 2 illustrates the medical decision support: The collected medical data are

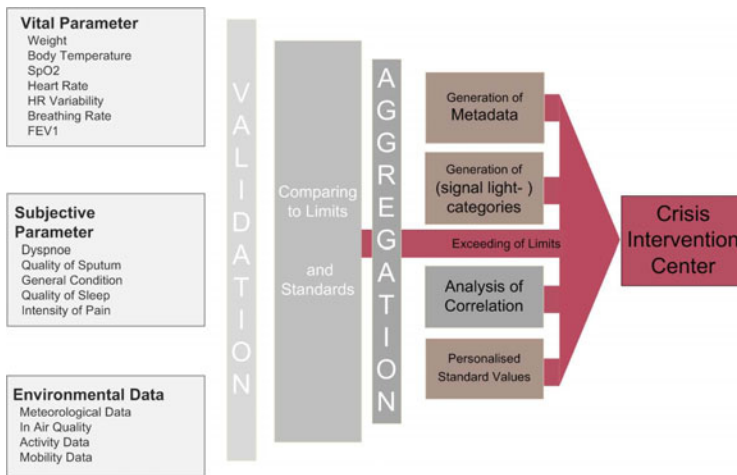


Fig. 2. Illustration of the medical decision support. The collected data are validated, compared to standard and extreme values, aggregated and compacted to metadata, categories and personalised standard values. If the data exceed some limits, the Crisis Intervention Centre is informed immediately.

validated and compared to medical standard and extreme values. If the data exceed some limits, the Crisis Intervention Centre is informed immediately. In a second step the data are aggregated and compacted to personalised standard values, metadata (like the Bode Index [4], a composite disease marker, aggregated from several single parameters to a composite index), and categories (like signal light categories, green means ‘‘all seems to be alright’’, orange means ‘‘better avoid every kind of stress’’ and red describes an ‘‘acute serious health state’’). Again, if these aggregated data exceed some limits, the Crisis Intervention Centre is informed immediately.

- The monitoring data are interpreted, aggregated and concentrated for meaningful metadata
- Exceeding of medical limits is reported immediately to the Crisis Intervention Centre.
- Changes of the monitoring data will be evaluated and graphically prepared for easy perceivable views
- Data and metadata can be used to identify changes in behavior as well as in well-being; emergencies can be prevented while a crisis will be recognized earlier within the Crisis Intervention Centre.

All involved medical professionals and the nurses of the ambulant care services should be able to view and review the patient’s status and his developments which are both derived from monitoring and metadata, and thereby receive access to the complete patient’s history. The establishment of super ordinate boards, where stake holding institutions work together is only one step to link

all the different support groups. Voluntary groups and also informal supporters, relatives, friends, neighbours should be involved in such a way that information exchange and mutual, unbureaucratic support is possible. Keeping all information at and distributing it from one central point also ensures that all parties share the same information. The possibility to integrate all the different data can enhance the value of the information in such a way that a crisis and even a growing risk of a crisis can be conveyed to a crisis intervention centre by the system itself. Along with the notification of the crisis or of the change of the risk of a crisis, relevant, aggregated data can be sent to the operator, who can be sure to have up-to-date information about the patient. The requirements, the realisation and the concept of our in-house communication platform are described in detail within the next section.

5 Architecture

The designed architecture of our approach follows the suggested user centralized approach with the main data storage and processing located in the patient's home. Requirements derived from the centralized approach are kept in mind during the realisation phase.

5.1 System Requirements

Installing the system in the home environment leads to a number of requirements, some of which are:

- The system needs to be usable for technical non-professionals.
- It has to be robust and low-maintenance, because service technicians will not be available quickly at all times.
- It has to be low cost to account for the fact that patients at the end of life often have to deal with a financially difficult situation, when the patient has to stop work
- Especially the hardware of the system has to integrate itself smoothly in the home environment. A system which blends in with the patient's familiar surroundings is more likely to be accepted.
- In case of COPD and lung cancer the decline is following a pattern over time, in case of COPD it is also peaked by exacerbations. Hence the system should be adjustable to the patient's growing needs.

5.2 Realisation

Television means a well accepted, quite popular medium. Germany's residents watch TV for about 188 minutes per day, the elderly for 273 minutes [18]. The number of households owning set top boxes (STB) is still increasing, especially since the change to DVB standards. Additionally the trend of high definition television (HDTV) is followed by improved performance of the STBs. A STB for

receiving HDTV typically works with 256-512 MB RAM, whereby about 30% are preserved for decoding the TV signal. CPUs show 300-400 MIPS. The characteristic of the processing unit is the ability to deal with encryption algorithms like AIS and 3DES. The normal use is decoding the TV signal, but it also enables to encrypt local data. The size of the flash memory where the system software and the applications are preinstalled are very variable and range between 16 MB to several GB. Interfaces as USB and RJ45 allow the exchange to other devices, as well as home net and internet. But rarely the systems are used to capacity. The system software is increased Linux. STBs show a lot of advantages against commercial PC:

- An everyday accessibility in all age classes is warranted by the constant use of the TV set
- The acquirement is cost-effective, the power consumption low
- STBs are made for continuous duty and are nearly maintenance-free

As a closed system and with the ability to support actual encryption algorithms hardware sided, the STB features increased safety. Sensors and devices can be adapted to the In-House Communication Platform with ZigBee or Bluetooth wireless. The data exchange between the In-House-Communications System and the ‘‘Out-House’’ can be realized via a secure internet access.

5.3 In-House Communication Platform

Figure 3 shows the system architecture for an In-House Communication Platform for palliative home care. Located at the patient’s home is the set-top-box. The sensors for the monitoring are connected to the In-House Communication Platform through a device abstraction layer, which abstracts the platform from the underlying sensor system hardware. On top of the device abstraction is a database and backup, base services for the management of the data. Some of the sensor data is stored here directly. Other data is taken by the monitoring system, which also takes and writes data from and to the database to fulfil its tasks. Data processed by the monitoring and master data - basic information about the patient, including e.g., the medical history, are both used in the medical decision support system, which calculates the risk of a crisis, or respectively detects a crisis. A communication system provides the basis for communication services like video telephony or other messaging services. Information going out of the monitoring, the medical decision or the communication system is encrypted through the hardware encryption services of the set-top-box, where applicable. The next layer presents the different ways of information distribution and reception. A (web) server provides access to the data. For the patient this is realized through the display and manipulating of the data in a browser application which runs on the TV. Keeping all information at and distributing it from one central point also ensures that all parties share the same information. Any persons outside the patient’s home can access the information through a web browser. In that case a user has to identify him or her with personal login data, which also identifies

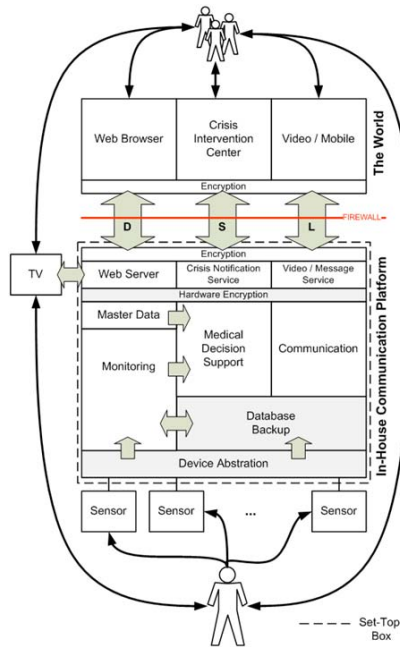


Fig. 3. System Architecture for an In-House Communication Platform for Palliative Home Care.

him or her as belonging to a user group. His access to the information will then be restricted to the information available to the respective group. The diverse accesses show not only different information availability, but also different possibilities of data inputs. E.g. to change some medical instructions is only allowed to medical professions, to comment or estimate some situations or processing is allowed also to family members or friends. The use of the calendar functions is allowed to all parties. All data input and reading rights are assigned from the patients themselves and can be updated if required.

5.4 Medical Decision Support

The monitoring provides different kinds of data. In case of objective vital parameter like heart rate, blood pressure, body temperature, the interpretation is quite clear: there are existing standard parameter ranges, between the values have to be. Comparing these metered or computed values with the standard ranges allows estimating a first impression of the patient’s health status. Furthermore some metadata or collections of several data like Bode Index are computed. If the data exceed some maximum or minimum values, the Crisis Intervention Centre will be informed immediately. This kind of rule based evaluation is realized with the help of Medical Logic Modules (MLM), which include medical knowledge and standards, implemented in the Arden Syntax [19]. Over the time

the general medical standard values will be supplemented by personal or typical values for the patient himself, medians or means of the monitored parameters; deviations within these personal standard values can be evaluated additionally, especially over time, to detect individual trends and histories.

Subjective data are collected via digital questionnaires and the replies can be evaluated as necessary amendment, to monitor i.e. the success of certain medication (pain/ dyspnoea) or therapies.

Some others of the collected data are less univocal, like mobility or activity values. These parameters have to be evaluated in the individual context. To evaluate these values there have to be some initializing working theories defined first, such as ‘ “if the patient doesn’t move, he or she suffers pain” ’, but they have to be examined and enhanced continuously over monitoring time. Last but not least there are data whose influence we do not know for a fact, but we assume they must have influence, i.e. meteorological data. For these kinds of data the observations are initially necessary to determine correlations between the meteorological data and the status of the patient. These can then provide a basis to find a correct individual interpretation. Based on these findings the system can warn the patient, if there are special circumstances which might impair on his or her health status.

Example: *patient with COPD since 25 years, age of 68 years, living at home with his wife. The system gives notice that the heart rate and breathing rate of the patient is ascending; the actual heart rate is about 26% above the mean rate of the last three weeks, the breathing rate about 31% above the personalized standard. An accurate sight in the electronic health record of the home platform shows more detailed information: The patient’s normal temperature is on average 36.2 degree, today his temperature is about one degree higher, but still in the normal range. The sleeping quality is not as good. The patient describes his perceived vitality as normal to low, and ranked the actual dyspnoea as rather wearing. The sputum colour has changed, from a transparent pertinacious to a slightly yellow-green. The activity values show that the patient was very immobile during the whole morning and the Medical Decision Support-Report attests an orange signal light category and an actual downward trend over the last three days.*

The operator in the Crisis Intervention Centre calls the patient to ask him some more details and to tell him, that he wants to send the GP to him, because he is assuming that an infection is on the way. The patient appreciates this approach that the operator is attending to the doctor’s visit directly. In the afternoon the GP is coming and diagnosing an infection. The GP brought the antibiotics with him because he already assumed its need based on the information the operator in the Crisis Intervention Centre gave him.

The GP tries to prevent a hospital admission in treating the infection early in the home care setting. After this intervention, the patient is getting better after three days in close assessment and supervision by the CIC and the GP. He is back to a normal health status after a week without the need of hospital support.

6 Conclusion/Discussion

The presented system architecture confirms not only the networking and the information exchange processes. It also allows conducting and organising the diverse stake holders' engagements and medical applications. The electronic medical health record helps to collect and manage the health data in a manner also laymen have access to their medical data at any time and are able to comprehend. With the help of the system the success of therapies can be examined. The system gives the possibility to study the changes of the patient health to evaluate correlations between single symptoms and to develop a more patient centred treatment in this way. Combining objective, subjective and environment data helps to find more indicators for a crisis and enable the medical team to react not only immediately, but also in time. Emergency situations and hospital stays, which are very exhausting for patients and relatives can be avoided. Based on the collected knowledge of personalised long term vital parameters, subjective self-assessments, and environment parameters, it should be possible to model the patients behaviour related to certain changes of these parameters. Especially with a view to the meteorological and indoor air quality data the system can help to bring some interrelations in the awareness of the patient. A behaviour change in easy all-day operations like proper heating and ventilation can help to reach adequate air moisture and can prevent infections and therewith exacerbations particularly during times with high risk of infections, e.g., during the winter months.

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