

QuoVadis – Definition of Requirements and Conception for Interconnected Living in a Quarter for Dementia Patients

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Abstract

The choice of a suitable living and care arrangement for dementia patients is a difficult decision for the patients themselves and their relatives. This decision becomes even more difficult if only classical arrangements are considered. Such arrangements, like care in long term care facilities or care in the own apartment administered by the relatives, often do not address the needs of dementia patients appropriately or cause significant stress for the relatives. Therefore, a new living arrangement concept is developed in the research project QuoVadis, which is called “interconnected living in the quarter”. In this new living arrangement dementia patients can stay in their own accommodation while they are integrated into a care concept at the same time. In a quarter, a “quarter manager” is responsible for organizing care and help for the dementia patients. To empower the quarter manager to support the residents, an intelligent sensor-based system is developed. This system will be integrated into the apartments of the dementia patients. This article presents the requirements definition for the technical system. Furthermore, a concept to fulfil these requirements is presented. As part of this concept, an adaptive decision support system (ADSS) will be presented.

1 Introduction

Every person with dementia and his or her family face the same question: Which living arrangement is the most suitable? In many cases, elderly people prefer to stay at home rather than moving to long-term care facilities [1, 2]. The transition to care facilities has several disadvantages for dementia patients. One disadvantage is the necessity to adjust to new circumstances. Especially, dementia patients may have problems to adjust to their new environment [3]. Additionally, living in care facilities seems to have a negative impact on the self-perceived quality of life [4] as well as the mortality rate of dementia patients [5]. However, if people who suffer from dementia decide to stay in their own apartments, the situation can be very challenging for the patients and their relatives alike [6]. What this all amounts to is that people with dementia face risks and challenges, indifferent whether they stay at home or move to a long-term care facility home. To enable dementia patients to feel homey, while ensuring their safety and adequate accommodation conditions at the same time, novel living arrangements have to be developed. One of these alternative living arrangements is the assisted living community for dementia patients. In this living arrangement people with dementia share a household. In such an assisted living community there is always a carer or a caretaker available to provide support for the inhabitants if needed. Additionally, caretakers organize the activities of daily living. As a result, the residents are able to lead a self-

determined life, while being cared for appropriately [7]. However, assisted living communities still require the dementia patients to move out of their own home.

The aim of the research project QuoVadis is to develop a new concept of “community living” that does not require dementia patients to move out of their well-known surroundings. In this concept, elements of assisted living communities will be transformed into a living quarter. Therefore, a local infrastructure is implemented in a quarter of the town or the village where dementia patients live. In each quarter a “quarter manager” is situated. The task of the quarter manager is to support the dementia patients and their relatives. In order to empower the quarter manager to support the patients without visiting them personally every time, ambient assistance technologies will be used in the apartments of the dementia patients. An overview of the relevant technologies is presented in chapter 2. Furthermore, the requirements of patients in a quarter-based care concept (chapter 3) and the concept to meet these requirements (chapter 4) are presented in this paper.

The developed concept will be tested in two quarters in Oldenburg and Brake, Germany. Each quarter will comprise five dementia patients and a quarter manager.

2 State of the Art

The state of the art of technological components for the assistive system enabling the quarter manager is discussed in this section.

2.1 Detection of Wandering

In order to discuss systems that detect wandering, it is useful to distinguish between two different approaches. In the first approach the person affected has to carry a device with an integrated GPS sensor. The GPS sensor may be integrated into a watch or a mobile phone. Several studies show that these devices may help to find or navigate wandering people [8, 9]. However, a disadvantage of GPS-based systems is that they have to be carried whenever the user leaves home. Dementia patients are likely to forget these systems at home.

The second approach is to place sensors in the flat of the patient and to inform the caregivers if wandering is detected. This approach can improve the sleep quality of caregivers [10] and help to prevent the diseased person to leave the house at inappropriate times if the caregiver is able to stop the person before he or she leaves. However, the sensor-based approach does not help outdoors. Furthermore it is necessary that a caregiver lives in the same accommodation or in the close proximity.

As shown, both approaches have disadvantages. It seems that currently available systems are only capable of wandering detection in specific surroundings.

2.2 Detection of Abnormal Behavior

A lot of research has been conducted to evaluate sensor setups and algorithms to detect abnormal behavior. The studies presented below have been selected because their approaches do not need the dementia patient to interact with the system. In addition, setups using cameras or microphones to monitor residents are considered dubious both from an ethical and a user acceptance perspective by the authors and were, therefore, not included in this section.

Steen et al. [11] described a system to model individual behavior using motion sensors. The user behavior was modeled based on timeslot and duration. In the timeslot-based model the probability of being present at a certain location at a certain time was computed. The duration-based model computed the probability of being present at a specific location with certain duration.

Lotfi et al. [12] used motion sensors and door sensors in their study. The sensor data was used to train different recurrent neural network approaches. As a result, the Echo State Network was identified as the most promising technique.

Wilken [13] identified activities by the data collected from a power sensor connected to the main fuse of an apartment. He defined activities as sequences of activations/deactivations of appliances. In his work, Wilken did recognize patterns of repetitive activities, but abnormal behavior patterns were not recognized by his system.

Taipa et al. [14] tagged domestic appliances using RFID technology to gain information about the activities of daily living. Their study showed that they were able to detect activities like toileting, bathing and grooming.

Most systems presented in this chapter are based on binary sensor data using simple home automation sensors. The advantage of these sensors is that they are cheap

and easy to install. The presented systems are able to detect patterns of activities and abnormal behavior. However, they do not evaluate whether the detected anomalous behavior is relevant. Furthermore, these systems do not include information from caregivers (e.g. about expected behavior considered normal for a certain patient).

2.3 Stove deactivation systems

In case a person with dementia forgets to turn off the stove, fire may break out. To prevent this, stove detection systems are used. There are several commercial systems available which are described below. Many systems use a heat detector to monitor the temperature above the stove [15, 16, 17]. These systems deactivate the stove in case a predefined temperature is exceeded.

Another stove deactivation system includes an activation button [18]. If the user presses the button the stove is activated for an adjustable amount of time. After that time, the stove is turned off automatically. If the person wants to continue to use the stove, he or she has to press the button again. This system has a “comfort version”, that uses a motion detector instead of the button.

2.4 Emergency alert system

Emergency alert systems are used to ensure a stable connection between a household and an emergency alert center. In this subsection the emergency alert system of the Johanniter-Unfall-Hilfe [19] is described. This emergency alert device is connected to the telephone station. It contains an alarm button. If this button is pressed the device establishes a telephone connection to the emergency alert center and the resident can speak with an employee over loudspeakers. This employee assesses the situation and organizes help if necessary.

The emergency alert system has several additional features: Firstly, the alarm button can be used wirelessly. This enables the resident to set up an emergency call from every room in his apartment. Secondly, smoke and flood detectors can be connected to the emergency alert device. If these detectors transmit an event to the alert device, an automatic alarm will be transmitted to the emergency alarm center. Thirdly, a second button is placed on the emergency alert device. This button resets an internal alarm clock. If the button is not pressed for a predefined amount of time, an alarm call will be triggered.

3 Definition of Requirements

In this section the requirements definition for a quarter-based care concept is presented. To determine the needs of dementia patients and their relatives a workshop with caregivers (N=15), interviews with relatives (N=12) and interviews with experts (N=5) have been conducted. Furthermore, the requirements for the ambient assistance system have been determined using the information provided by the caregivers, relatives and experts. The results of the workshop and the interviews are presented in the following section. In the second part of this chapter the requirements for the quarter-based care concept are described,

based on the caregiving principles in assisted living communities.

3.1 Requirements derived from the Workshop and the Interviews with Relatives and Experts

As a first step of the requirements analysis, a workshop with professional caregivers was conducted. In the workshop, the “world café” method which is a good method for structuring large group discussions [20] was used. The four topics were:

- the own house – technical assistance opportunities,
- interconnections in the quarter,
- interconnections of caregivers and their services,
- individual situation – problems and obstacles with supplying dementia patients, wishes and ideas for the future.

As a general result it can be said that dementia patients vary significantly in their needs. Therefore, any technical assistance system in the flat has to be modular und adjustable to individual (and perhaps changing) needs of the patient. Another finding was that people who suffer from dementia are not able to learn any new interactions with technical systems. Thus, the patients should not have to interact actively with technical systems in any manner and known appliances have to remain in use as long as possible. Furthermore, a need for better connecting relatives, physicians and caregivers was reported. Finally, it could be observed that a sensitization to the needs of all actors involved in the quarter is necessary. These actors include not only the caretakers and the quarter manager, but also physicians, pharmacists, local stores, banks, police stations, etc.

After the workshop, relatives of dementia patients were interviewed. For this purpose a questionnaire was designed to serve as a guideline. Each interview lasted about one hour. In the interviews the relatives talked about their experience with their caretaking of dementia patients, especially in the early phase of the disease. Because most of the patients in question had already been suffering dementia for a long time (4-17 years, average 8.6 years), the relatives had to recall their experience from that time. The patients in question were in the age from 63 to 90 years. The majority of them had additional diseases and needed several hours of care each day. Although the number of patients discussed during the interviews is small (N=12), some general conclusions can be made.

Generally, it was confirmed that dementia patients have a diversity of needs, which was also a finding of the workshop with professional caregivers. To exemplify this, the following table lists a range of symptoms which were reported by relatives answering the question: “Which symptoms of dementia made it impossible or very difficult for your relative to stay in his/her own apartment?”; it was possible to report more than one symptom.

Table 1: Symptoms reported in the survey and their frequency (N=12, multiple answers allowed)

Symptom	Frequency
Emotional abnormalities	6
Problems with the handling of money	4
Disorientation	3
Wandering	3
Nutrition problems	2
Misjudgment of daytime	2
Forgetting to turn off the stove	2
Failure to correctly assign household articles to their functions	2

The symptoms reported in Table 1 allow for several conclusions. Firstly, eight different symptoms were reported for only twelve people. Secondly, no symptom was reported in more than 50% of the interviews. Thus, the diversity of dementia patients is confirmed. The impression of this diversity becomes even sharper if the combinations of the mentioned symptoms are taken into account. Every answer was unique in terms of the combination of symptoms.

The diversity of the dementia patients was not the only finding gained from the interviews. It was confirmed that people with dementia are incapable of learning how to operate new technical devices. Even one-button systems turned out to be too complicated for almost all of the dementia patients in question. In addition, the interviews helped to prioritize the problems related to dementia. Generally, it can be said that physical well-being and safety turned out to be more important for dementia patients and their relatives than social needs, such as participation and entertainment. Therefore, Maslow’s “Hierarchy of Needs” [21] has been confirmed for the patients in this study, at least from the perspective of the relatives interviewed.

The interviews also showed that the relatives have a great need for information and organization. The majority of them expressed that they had not known about local care possibilities like occupational therapy or group therapy for a long time.

Finally, some relatives mentioned that they were overstrained with planning the upcoming days for their diseased family members. There is a need for a supporting third party that has an overview about the schedule of the patient, the relatives and the caretakers. In the QuoVadis project, this third party will be the quarter manager.

As the third step in the requirements analysis, experts were interviewed. This group consisted of a gerontologist, two department leaders from the city government of Oldenburg and two leaders of care facilities. In general, they confirmed the findings of the workshop and the interviews. In addition, it was mentioned that people with dementia are often also affected by other diseases. This adds to the finding that dementia patients are very diverse and need individual support. Finally, housing

counselling was mentioned as useful non-technical method to reduce the risks of falls and disorientation.

3.2 Study of Assisted Living Communities for Dementia Patients

To determine effective care principles and assistance opportunities for technical systems, existing assisted living communities for demented inhabitants were evaluated. For this purpose, an assisted living community in Oldenburg, Germany was visited and the person in authority for the community was interviewed. Furthermore, two people with relatives in assisted communities were consulted. It was examined how the guidelines for caregiving for dementia patients in Germany [22] are applied in assisted living communities. Several interesting insights could be gained.

Firstly, there is always a carer or caretaker in the assisted community who can conduct measures if needed. Thanks to this, problems can be addressed immediately at any time of the day. In the QuoVadis project this 24/7 presence of a caretaker cannot be translated directly into the quarter based setup. This has to be addressed by a technology-based security concept that is presented in section 4.1.

Secondly, the caregivers and carers in assisted living communities are well aware of the individual needs of every resident. Therefore, they are able to organize necessary measures for the patients. Such measures can be occupational therapy, physical activities, art therapy, etc. The aim of the QuoVadis project is to realize individual care organization as described above. Therefore, technical assistance will be necessary since the quarter manager is not with the dementia patient all night and day and, therefore, not fully aware of all individual needs. The technical assistance concept to meet this requirement is presented in section 4.2.

Thirdly, the inhabitants of the assisted living community participate in activities of daily living of the inhabitants, such as cooking. This participation structures the day and makes the inhabitants feel accepted and useful. In a similar manner, the quarter manager will organize group activities for the inhabitants in the quarter.

Fourthly, the relatives are relieved with respect to the organization effort, because they do not have to organize the daily care for their demented relative on their own. This does not mean that the relatives are not involved in the care process in assisted living communities. On the contrary, the caretakers strongly rely on the help from the relatives. In the QuoVadis project it can be the quarter manager who relieves the relatives in organization. Similar to the assisted living community the quarter manager will need the help of the relatives to ensure good care for the residents.

4 QuoVadis System Architecture

This chapter describes the derived QuoVadis system architecture. The focus is mainly on the technical aspects of the

concept. The technical concept can be divided in two systems, or modules: (1) the security system and (2) the individual care system. The security system addresses the needs of safety and security that have been found to be most important to dementia patients and their relatives. The individual care system will enable the quarter manager to organize individual care measures for the affected people. Furthermore, the individual care system will inform the quarter manager about abnormalities, based on the feedback to previously reported abnormalities and additional information that the quarter manager has reported to the system.

4.1 Security

The security system consists of three subsystems: an emergency alert system, a wandering detection system and a stove-deactivation system.

The emergency alert system has been designed such that residents who are still able to learn how to operate an alarm button are enabled to call for help this way, whereas autonomous ambient sensors are integrated into the system for users unable to remember the alarm button.

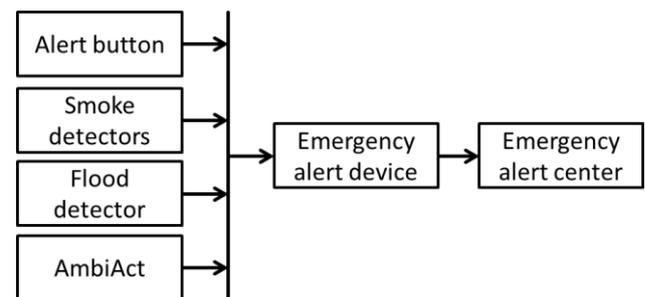


Figure 1: Emergency alert system

The structure of the emergency alert system is shown in Figure 1. Every flat of the participants in the project will be equipped with an emergency alert device. On the input side this device receives information from sensors in the flat of the dementia patient. The wirelessly connected sensors are the alert button, which can be pressed by the inhabitant in case of emergency, smoke and flood detectors that autonomously raise alarms in case of emergency and the AmbiAct. The AmbiAct is a smart power sensor that detects the usage of electrical appliances [23]. If the usage of an appliance is detected, the AmbiAct sends a signal to the emergency alert device, which in turn resets an internal alarm clock. If the alarm clock is not reset for a configurable period of time (normally 24 hours), the emergency alert device generates an alarm signal because of unexpected inactivity in the flat.

On the output side, the emergency alert device connects with the emergency alert center. The emergency alert center is called in case one of the sensors transmits an alarm or the AmbiActs do not reset the internal clock before the configured timeout. In case the emergency alert center receives an alarm call, an employee tries to contact the inhabitant by telephone. If it is not possible to contact

the resident, the employee calls for help to come to the apartment of the dementia patient.

The wandering detection subsystem is designed to detect wandering of the resident outside of his or her usual daytime. At first, a system to learn the circadian rhythm of the resident will be realized. For this purpose, motion sensors and a power sensor in the main fuse of the flat will be installed. Using the data of these sensors, the circadian rhythm can be estimated. Furthermore, to detect wandering a wireless contact sensor will be placed at the entrance door. The contact sensor transmits events to a computer that serves as core element for the assisted living system in the flat of the dementia patient. If the contact sensor transmits events at times beyond the learned circadian rhythm, a message will be sent from the computer to the emergency alert center. This alarm will be handled by the employees in the alert center in the same manner as the alerts from the emergency alert device.

However, the system presented does not include any assistance to localize a wandering person once he or she has left the home. Since there are currently no systems available that would not require the user to carry a GPS transmitter, no wandering detection or localization will be used outdoors. To prevent people from getting lost, a sensitization of the actors in the quarter is planned that will increase the probability that a wandering person receives help.

The stove deactivation system will prevent the stove from staying activated if the resident forgets to turn it off. Although some commercial products exist a different solution needs to be developed for the QuoVadis project. The disadvantage of commercial stove deactivation system is that they are stand-alone systems that can not be connected to our assistive system. In order to inform the quarter manager whether the stove is not turned off regularly, a connection between stove deactivation and the computer is necessary. Hence, a stove deactivation system will be developed in the project.

Finally, counseling on housing will be provided to the residents to lower the risks of falls and disorientation in their own apartment.

4.2 Individual Care

The individual care system addresses long-term changes of the behavior and the needs of the dementia patient. It can be divided into a technical component, called the Adaptive Care Support System (ACSS), and an organization and activation effort.

4.2.1 Adaptive Care Support System

The adaptive care support system (ACSS) will enable the quarter manager to organize and optimize personalized support for the dementia patients in his or her quarter. This system does not require the residents themselves to interact with technology in any manner. The aim of the ACSS is to use information from the quarter manager along with information on activities that have been recognized by technical systems to identify and predict behavior problems.

The ACSS contains four subsystems, which are presented in Figure 2.

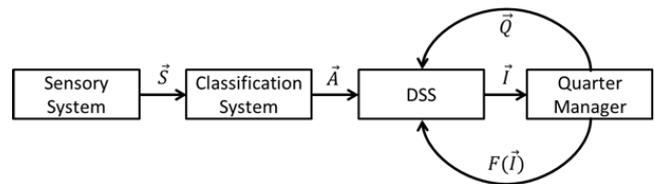


Figure 2: Adaptive care support system

The first subsystem is denoted as the sensory subsystem. This system consists of multiple wireless sensors that are connected to a computer in the flat of the resident. A power sensor will be placed in the main fuse to detect the use of electrical appliances. In order to identify the activation and deactivation of the appliances, supervised machine learning will be used. Once the identification of appliances is known only one sensor is necessary to monitor the usage of all electrical devices. This is a great advantage of this sensor type. Sensors to monitor the water consumption will be used in the bathroom and the kitchen of the apartments. Additionally, motion sensors will be placed in every room to monitor the movement of the inhabitant. The sensors in this setup communicate wirelessly with the computer in the apartment. All the used sensors are unobtrusive as this was a requirement defined in the previous section. The events of all sensors in the apartment will be mapped into the sensor data vector (\vec{S}). This vector will be used in the classification system to determine activities of daily living. The following activities of daily living should be recognized by the classification system:

- eating,
- cooking,
- toileting,
- grooming.

Furthermore, the activity (movement) of the resident in the flat will be estimated. Since the QuoVadis project focuses on the interaction between quarter manager and the technical system it is not the aim to improve algorithms for the detection of daily activities. Therefore, an existing algorithm will be used in the classification system to determine the activities of daily living. To identify a suitable algorithm, a pilot study will be conducted. This algorithm will have to be more complex than most of the solutions presented in chapter 2 because the data at the input of the classification vector is generated by different non-binary sensors. Once an algorithm to identify activities is selected and implemented, the classification system will report the recognized activities in an activity vector (\vec{A}). Additionally, the duration and the daytime of each activity will be stored in this vector.

This information from the sensory system will then be transmitted to the third subsystem of the ACSS, the Decision Support System (DSS). The DSS is the link between the quarter manager and the technical system. It accumulates activity information (\vec{A}) from the technical sys-

tems and from the quarter manager (\bar{Q}). The quarter manager reports information on activities that have taken place outside of the apartment (i. e. walks, meals, visits, etc.) and his or her observations regarding the overall health of the patient. This information is mapped in the second input vector (\bar{Q}). Based on these and additional information from the quarter manager, the DSS is autonomously able to inform the quarter manager when relevant changes in behavior occur.

The quarter manager receives an information vector (\bar{I}) if the DSS detects abnormal behavior. To enhance the quarter manager to understand the information vector (\bar{I}), this vector needs to be presented in an understandable way. Subsequently, the quarter manager verifies the received information by contacting the dementia patient and reports his feedback on this information ($F(\bar{I})$) to the DSS. This feedback can be one of the following statements:

- positive: the abnormality reported by the DSS is relevant for the quarter manager;
- positive, but based on exception: the abnormality reported is relevant, but is based on exceptional circumstances (i.e.: patient is on vacation, patient is visited by many people and therefore a lot of movement is registered);
- negative: the abnormality reported by the DSS is not relevant for the quarter manager;
- false: the abnormality reported by the DSS is based on technical errors. Therefore, the related data should not be used for further predictions.

The feedback from the quarter manager is used by the DSS for future predictions.

4.2.2 Organization and Activation

In knowledge of the information gained by the ACSS, the quarter manager can provide individual activation measures for the patient. These activation measures can be walks with volunteers, shared meals, group activities and many more.

To relieve the relatives in the organization of daily activities, an individual calendar will be implemented for each resident who is involved in the quarter care concept. The calendar is accessible by the residents, their relatives and the quarter manager. Additionally, some information of the resident will be stored in the calendar (name, age, photo, medication etc.). This information can be accessed by the quarter manager in case of emergency.

5 Conclusion

This article presented the requirements and the system architecture for the QuoVadis project. So far, this general concept has been discussed with two quarter managers, who confirmed its utility. In addition, the concept will be evaluated in a workshop with professional caregivers and interviews with experts.

In the first half of 2016 the technical systems will be implemented. The DSS and the infrastructure for the communication between a professional caregiver and a technical system will be developed. It will be examined how the information vector can be transformed into understandable information for the quarter manager. Similar to this, a method to map the feedback and the information from the quarter manager in the feedback and information vectors will be determined. Furthermore, sensitization of the quarter will be conducted by this time.

A pilot study to evaluate the technical systems will be conducted in the second half of 2016. The data gained in this study will help to compare different machine learning algorithms for the DSS. In addition, the detection of activities will be tested at that time.

The start for the realization of the project is planned for the beginning of 2017.

6 Acknowledgement

This work was funded by the Central Federal Association of the Health Insurance Funds of Germany (GKV-Spitzenverband).

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