

## Information and Communication Gaps in Intersectoral Healthcare Processes for Dementia Patients

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### Abstract

*In addition to general barriers of information exchange and communication in intersectoral healthcare processes, the healthcare process of dementia patients has unique requirements regarding the communication and information exchange of the various healthcare professionals and non-professional caregivers, such as relatives or their legal caregivers. We conduct a process analysis to determine the status quo of such healthcare processes in the region of Darmstadt, Germany and elicit existing gaps in the information and communication exchange. We identify key processes by performing a document analysis and conducting interviews with seven different healthcare professionals. The results of a weak point analysis based on advanced event driven process chains (EPC) point out 32 information and communication gaps summarized in four categories: "information exchange", "information transfer" "information provision" and "activity impulse". Our results show further opportunities regarding the support of caring relatives and primary care physicians.*

### Keywords:

Dementia; Intersectoral Collaboration; Workflow

### Introduction

Dementia is increasingly affecting people worldwide - in many regions, between five and seven percent of persons over the age of 60 have dementia [1]. Oftentimes, dementia patients suffer from multiple other diseases (multi-morbidity). For example, fractures are a commonly reported co-morbidity of dementia [2] due to impairments of cognitive functions related to dementia [3] and the resulting increased fall risk [4]. In order to address these different diseases, dementia patients are often in need of healthcare services from different healthcare providers and institutions, such as hospitals, specialists or care facilities.

Furthermore, because dementia patients are often neither able to provide information regarding their general state of health nor provide specific details in acute situations, the barriers of communication and information exchange existing between various professional and non-professional actors involved in healthcare provision, are exacerbated in this setting. This is particularly prevalent in unfamiliar situations, like a hospitalization following a fall or other traumatic experience. Hence, in order to offer optimal patient-centered care, healthcare providers involved should coordinate their services (intersectoral interlinkage). However, because the German Social Security System is divided into two separately

organized sectors – inpatient and outpatient care – communicating and cooperating (i.e., sharing information) across these sectoral boundaries is difficult [5]. New care concepts are needed to address these barriers and improve healthcare provision - strategic digital transformation may be instrumental in overcoming these challenges.

The collaborative project "Securing integrated care for multimorbid patients with dementia using an IT-based service concept" (SimPat) aims to (1) identify key processes (status quo) and deduce information and communication gaps in the care process of dementia patients following a fall experience to solve such problems, (2) determine caregivers needs, (3) develop and implement a resulting IT-supported case management system, and (4) evaluate the effectiveness of the IT-solution.

Even though many projects begin with a number of process analyses, the unique situations surrounding the care of dementia patients such as the limited patient participation and the complex, intersectoral care architecture, and the heightened social relevance of dementia as a healthcare challenge, we think it is important to publish the results of our process analysis at this early stage in the project. Therefore, we present the methods and results of the process analysis (point 1) in this paper.

### Methods

#### Setting

The process analysis focuses on multi-morbid patients with dementia after a traumatic fall event, e.g., a femur fracture, with subsequent inpatient treatment. The analysis period is defined as the time from hospitalization up to three weeks of post-treatment follow-up. The process data is collected at a local hospital (AGAPLESION ELISABETHENSTIFT Darmstadt) and various post-hospital care facilities in the region of Darmstadt.

#### Establishment of the status quo of care

##### Data collection

The data collection took place in two steps. First, we performed a document analysis of hospital-specific documents, geriatric assessments, and required documents from the nursing home. This basic knowledge was used to prepare the subsequent interviews with the different healthcare professionals that are involved in the examined process period.

Second, we conducted semi-structured, open-ended, interactive interviews with various healthcare professionals involved in the target care period. These interviews had an average duration of one hour. One representative (expert) from each category of professional healthcare providers and a self-help organization was interviewed by two researchers during each interviewer, except for the first interview where 2 respondents participated. We conducted a total of six interviews with seven respondents over a period of three months: one outpatient nurse, one hospital-based social worker, one geriatrician, one primary care physician, one nursing home social worker, and one representative from the local Alzheimer's society.

The interviews started with participants reporting their tasks and activities within the care process without interruption from the interviewers. Meanwhile, the interviewers illustrated this process information as a simple flow chart documenting only activities utilizing a flipchart supplement. This enabled participants to retain a continuous overview of the whole process as they were reporting their tasks and activities. This also facilitated an immediate enquiry on single activities for a more precise documentation of the status quo, especially regarding interfaces to other healthcare professionals.

Upon completion of the interviews, we compared the information of the document analysis with the process data generated from the interviews. In doing so, we were able to supplement any lacking entities, organizational units, and documents used and/or updated in the processes elicited from the document analysis.

#### Identification, modelling and description of processes

The information collected was summarized in an intersectoral care process, integrating the actions of the healthcare providers with those of the non-professional caregivers. Due to the complexity of this (intersectoral) healthcare process, the combined information was modeled as a simplified process flow chart (only activities and responsibilities), and divided into four (main) process-sections:

1. Admission and treatment at the emergency department, including surgery
2. Post-surgery therapy under the leadership of the trauma surgeon
3. Early rehabilitation under the leadership of the geriatrician, discharge management and discharge from hospital
4. Follow-up at home or in a nursing home.

The resulting flow chart provides a general overview of the comprehensive care process and illustrates relevant key processes for each part as well as sub-processes of intersectoral care.

An additional, more detailed visualization was conducted using advanced event driven process chains (EPC) to model the status quo of the key processes as accurately as possible. The model comprises entities, functions, organizational units, supporting systems as well as input and output information, material, or resource objects to conduct the subsequent weak point analysis. We then used those models to conduct the subsequent weak point analysis. Figure 1 exemplifies the depiction of a sub-process, describing the respective key process in more detail.

#### Event driven process chain-based process analysis

The EPC-based process analysis consists of three steps: (1) the establishment of performance indicators, (2) the analysis of the modelled EPCs and (3) the preparation and verification of the analysis results.

#### Establishment of performance indicators

First of all, performance indicators for the process need to be established in order to analyze the EPCs. Generally, a (sub-) process can be considered to be inadequate if it is disrupted or delayed. Depending on the aim of the process analysis to determine information and communication gaps in the care process, the influencing factors considered are the communication and the flow of information between the different healthcare professionals. Consequently, the following performance indicators can be used to analyze the current process in order to detect information and communication gaps: (1) information being unavailable, (2) information being not transferred or not exchanged, or (3) information being disclosed in an untimely manner.

#### Analysis of event-driven process chains

The analysis of the modelled EPCs based on the preassigned performance indicators was performed by three researchers (researcher triangulation). First, all gaps from the EPCs with regards to unavailable, not transferred or exchanged, or untimely disclosed information were extracted. After that, the identified weak points were aggregated and assigned to different problem areas - categories. The definition of categories was performed on the basis of an inductive derivation using the interviews and the overall process representation (open-ended coding). Figure 1 exemplifies the implemented method, detailing the modeled sub-process "initial anamnesis" within the key process "admission and treatment at the emergency department". The analysis of this EPC-detail highlights the lack of information from the primary care physician at patients' admission to the hospital.

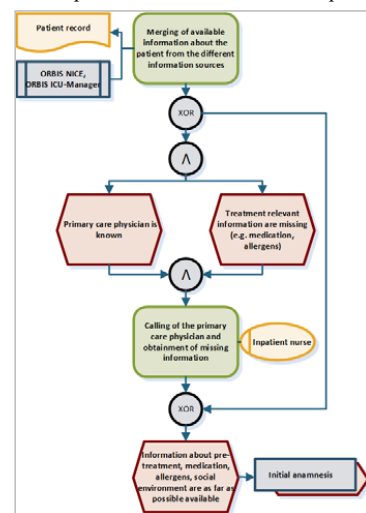


Figure 1– Detail of the sub-process “initial anamnesis” at the emergency department

#### Preparation and verification of the analysis results

The preparation of analysis results implies, amongst other things, a detailed description including reasons and consequences for each identified gap as well as the accompanying process part on which the gap could be identified. Furthermore, the healthcare professionals involved and the related direction of information flow (uni-, bi- or multidirectional) are documented for the assignment to a problem area. Following, the identified and prepared gaps were presented and verified in the project consortium (member checking). This interdisciplinary team of experts is

composed of medical informaticist, economist and different healthcare professionals from the hospital.

## Results

### Status quo of care

Overall, we identified five key processes, one for each process-section 1 to 3. Process-Section 4, the follow-up, was divided into two processes depending on the follow-up: (1) follow-up at home, or (2) follow-up at a nursing home. Furthermore 16 related sub-processes, as shown in Table 1, were determined.

Table 1– Identified key processes and related sub-processes

Key processes	Sub-processes
1 Admission and treatment at the emergency department	1.1 Initial anamnesis
2 Treatment at the surgical/geriatric ward	2.1 Admission at the ward and surgical treatment
	2.2 Treatment under the leadership of trauma surgeon
	2.3 Inpatient early rehabilitation
	2.4 Relatives initiated contact to the primary care physician
3 Social counselling and discharge planning	3.1 Planning and organization of aftercare at home
	3.2 Planning and organization of aftercare at a nursing home
	3.3 Clarification of admission related questions
	3.4 Social workers initiated contact to the primary care physician
	3.5 Verification and replenishment of social anamnesis
4 Treatment at home	4.1 Support by an outpatient nurse
	4.2 Care at day-care hospital
5 Treatment at nursing home	5.1 Admission to nursing home
	5.2 Treatment at nursing home
	5.3 Prescription of further measures
	5.4 Planning of an elective surgery

**Key process 1** - The care process of dementia patients following a fall event starts with the admission and initial treatment at a hospital, or more precisely, in the emergency department. Depending on the previous care of the patient (treatment at home or in a nursing home) and the type of admission (admission through the primary care physician or as an emergency), varying amounts of information in terms of medication, medical history, and social environment is available for the initial anamnesis (see Table 1 - 1.1). Currently, a short dementia-check takes place in the emergency department to determine, whether the patient needs to have an interdisciplinary treatment due to a manifested dementia. If the patient displays symptoms consistent with dementia, the geriatrician is consulted for a treatment and a risk assessment in the emergency department. Depending on the results of the risk assessment, the patient either undergoes immediate surgical therapy or a conservative, pre-surgical acute geriatric therapy followed by surgery.

**Key process 2** - Following the surgery, the patient is transferred to the surgical/geriatric ward for seven days of post-surgery therapy under the care of the trauma surgeon (see Table 1 - 2.1 to 2.2). This is then followed by the inpatient early rehabilitation including nursing and medical treatment as well as physio- and ergotherapy aimed at achieving the best-possible recovery of independence and mobility (see Table 1 - 2.3).

**Key process 3** - A continuous social anamnesis is performed by a social worker in the surgical/geriatric ward. Its purpose is to adjust the individual treatment to the patients' needs and to timely plan discharge (see Table 1 - 3.1 to 3.3). Here, information about the patient (e.g., social environment, demands and characteristics) are continuously collected. The collection of information starts with the admission of the patient at the ward. Different sources (e.g., relatives, neighbors, present nurses) are used to gather the necessary information. At the latest, the social anamnesis must be completed before the concrete planning of discharge time and aftercare possibilities starts (see Table 1 - 3.5). To guarantee an adequate and smooth planning of discharge and aftercare at home or in a nursing home, communication and information exchange between relatives and hospital, hospital and follow-up care givers (i.e., outpatient nurse or nursing home) as well as relatives and follow-up care givers is essential (see Table 1 - 3.1 to 3.2). In addition, it is very important to integrate the primary care physician (if known) as soon as possible (see Table 1 - 3.4).

**Key process 4 and 5** - Depending on the patient's situation before admission, the social environment and the condition of the patient, the patient can either be discharged to his or her home or to a nursing home. Should the patient be discharged to a nursing home, care-relevant questions concerning the care level, financing, or necessary health aids, must be settled before admission can take place (see Table 1 - 5.1 to 5.2). Should the patient go home, relatives or legal caregivers must determine whether the support of outpatient hospital services or an in-home nurse is necessary (see Table 1 - 4.1 to 4.2). Regardless of where the aftercare takes place, the primary care physician is responsible for the subsequent therapy, including the prescription of medication and any necessary health aids as well as the suggestion and planning of an elective surgery (see Table 1 - 5.3 to 5.4).

### Definition of gap categories

To classify the identified weak points – gaps – into various problem areas, we defined the categories shown in Table 2. Here, the designation does not refer to a possible solution but rather to the existing problem.

Table 2– Gap classification and definition

Designation	Definition
Information transfer	Active disclosure of information from one healthcare partner to another (unidirectional).
Information provision	Passive disclosure, therefore provision of information for one or more healthcare partners.
Information exchange	Mutual disclosure of information between two healthcare actors (bi-, or multidirectional).
Activity impulse	Encouragement of an activity which delays the executive process when not or delayed performed.

### Identified gaps

In sum, we identify a total of 32 weak points within the four defined categories: 6 in “information transfer”, 13 in “information provision”, 4 in “information exchange” and 8 in “activity impulse”. Tables 3 to 6 show the identified gaps according to the pre-defined categories (Table 2).

Table 3– Gaps concerning “information transfer”

No.	Lack of information transfer...
1.1	... to primary care physician about hospital admission
1.2	... to primary care physician just before hospital stay
1.3	... to hospital about existing care at home
1.4	... to outpatient nurse about aftercare demands and health aids
1.5	... to outpatient nurse about hospital admission
1.6	... to primary care physician about patients death

The results show a particular lack of information transfer (Table 3) and information provision (Table 4) from the hospital to the primary care physician during the hospital stay. Commonly, the primary care physician is neither informed of a patients’ admission and discharge nor about the treatments undertaken. The primary care physician only receives this information if the hospital has treatment-relevant questions at admission (and the primary care physician is known) or if relatives inform the primary care physician about the admission.

Table 4– Gaps concerning “information provision”

No.	Lack of information provision...
2.1	... from local Alzheimer society
2.2	... about the primary care physician at hospital admission
2.3	... about the patient’s condition after discharge
2.4	... about contacts for specific questions to caring relatives
2.5	... about prescribed drugs
2.6	... about changes of prescriptions
2.7	... about inpatient physio- and ergo therapy (within the discharge documents)
2.8	... about outpatient care possibilities
2.9	... about the treatment at hospital to the primary care physician
2.10	... about nursing relevant questions to relatives
2.11	... from the outpatient nurse to the hospital at admission
2.12	... about the patient to the outpatient nurse before discharge
2.13	... about existing medical and nursing care of the patient to primary care physician

The results show that the healthcare providers have very little to no joint knowledge about the patient. Information about their medication regimens, social environment, and current treatment is often missing or incomplete. This is usually not an issue as the patient is often able to fill these gaps by transmitting missing information themselves, e.g., to the primary care physician. However, as we describe above, patients with dementia may be highly restricted in their communication and cognitive abilities and as a result, cannot provide the necessary information. For instance, should the hospital change the current treatment and medication plan, this information along with the driving reasons behind the change is lost, so that ultimately, the primary care physician has no

knowledge of the change and therefore cannot uphold the new regime, reverting the treatment back to the original regimen. The primary care physician also has difficulty accessing this information. The categories “information provision” (Table 4) and “information exchange” (Table 5) address those problems.

Table 5– Gaps concerning “information exchange”

No.	Lack of information exchange...
3.1	... between the different healthcare professionals during the anamnesis at hospital
3.2	... between outpatient nurse and hospital for discharge planning
3.3	... between hospital and primary care physician about previous medical treatment
3.4	... between the different healthcare professionals concerning the medication plan (joint access)

Occasionally, some parts of the healthcare process are interrupted or delayed by the failure to complete preceding activities on time. This is not only attributable to a lack of information exchange and communication, but rather to a missing impulse that must be given automatically or from one actor to another to initiate the activity. As seen in Table 6, caregiving relatives are affected in a number of ways. During the hospitalization, they must complete many tasks in order to ensure an appropriate follow-up at home or at nursing home. However, they are often not aware of when and where information can be accessed, or at which time certain information needs to be transmitted. Especially, tasks such as 4.3, 4.5 and 4.8 are neglected by the caring relatives due to the growing work load as well as the physiological burden.

Table 6– Gaps concerning “activity impulse”

No.	Missing impulse...
4.1	... to perform the detailed social anamnesis
4.2	... to initiate necessary actions of non-professional caregivers regarding medical aids and appliances prescriptions and application
4.3	... to bring discharge folder to re-admission of patients
4.4	... to perform dementia-check in the hospital at the right time
4.5	... to inform primary care physician about discharge of hospital by the non-professional caregiver
4.6	... to sign the discharge documents by two physicians
4.7	... to inform outpatient nurse at hospital admission
4.8	... to clarify questions for the admission at nursing home by the non-professional caregivers

### Discussion

This process analysis attempts to describe the status quo of the intersectoral healthcare processes of dementia patients after a traumatic event in the region of Darmstadt. To achieve this objective, we determined the intersectoral care processes and identified information and communication gaps between healthcare professionals and non-professional caregivers. Using EPCs and an EPC-based weak point analysis, we illustrate the identified key and sub-processes, and classified information and communication gaps. These modelling methods enable a simplified depiction of complex processes with parallel and alternative activities [6]. Furthermore EPCs can be used “[...] to find parts of the process that are never

used or find parts where users deviate from the prescribed procedure" [7], and are thus instrumental in also identifying weak points or gaps.

The results show that significant gaps exist in the process concerning the transfer, provision, and exchange of information. The gaps often occur when coordination or communication between the healthcare sectors is necessary for a seamless process, such as the transfer and provision of information between a hospital and a primary care physician. Moreover, contrary to healthcare professionals, non-professional caregivers are often unfamiliar with typical activities in the care process, and are unaware of the activities expected of them. For example, when a loved one suffering from dementia is admitted to the hospital due to a fall, caregiving relatives may be unaware that the hospital needs basic information such as patient history and a medication plan in order to optimally plan further treatment steps. Reminders or information requests, or other activity impulses, may or may not be in place to collect this information from external parties. Impulses, given by the healthcare professionals, may in fact initiate those activities. Our analysis lead us to deduce that the care process may be disturbed when those impulses are missing.

There are, however, some limitations to our study. In order to identify the key processes, we conducted an extensive document analysis. The document analysis refers to the documents of one hospital in the region of Darmstadt. The hospital, previous to our study, established a structure promoting a tight cooperation between the surgery and geriatric ward, placing special attention to the care of patients with dementia. During the interviews, some respondents emphasized the fact that the communication with this hospital is better than the communication with other hospitals in the region. On the one hand, this must be considered when interpreting the results (transferability). On the other hand, we were still able to identify gaps that represent general requirements for a functioning intersectoral care process. We also interviewed a limited number of healthcare professionals. However, although the perception of the care process might differ between individuals, the activities within the process remain similar. The key processes were described in a very similar manner and respondents also supplemented the key processes reported by defining the sub-processes.

Finally, limitations of the method implemented are manifest in the modeling of processes. Due to the limited number of modelling components and modelling rules, an intersectoral illustration with a large number of interfaces, overlappings and merged processes is very complex and hardly executable.

## Conclusion

In order to provide optimal patient-centered care, healthcare providers involved in the care process should coordinate their services (intersectoral interlinkage). However, because the German Social Security System is divided into two separately organized sectors – inpatient and outpatient care – communicating and cooperating across these sectoral boundaries is difficult. Dementia patients are especially in need of integrated care, because they are often neither able to provide information regarding their general state of health nor provide specific details in acute situations. Because of the unusual demands caring for dementia patients in acute medical situations places on professional and non-professional actors, as well as on the patients themselves, we publish the results of our process analysis to further the field and encourage discussion on important developments in this field.

In this paper, we analyze the intersectoral care process of multimorbid dementia patients that have suffered a traumatic event with a subsequent hospital admission to identify key processes and weaknesses in the care process. We determine the existence of five key processes in the care process and identify and describe 32 gaps in the information and communication exchange of the care process that have the potential to significantly impact the quality and efficiency of care provision. We also find that healthcare professionals may be in a unique position to generate activity impulses in order to overcome these communication and information deficiencies, thereby securing optimal care for the patients.

To solve such identified problems, further steps involve the establishment of functional and non-functional requirements as well as the development and implementation of an IT-supported case management system supporting the communication and information exchange beyond the sectoral boundaries via a holistic view at the patient.

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