Reconsidering Design Aspects for Socio-Technical Health Care Based on Experiences with an Ethnographical Study of Intensive Home Care

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Abstract. In this paper, we compare generalized hints and conditions for socio-technical design of health care information systems (proposed by Herrmann, Ackerman, Goggins, Stary and Prilla [1]) with the findings of an ethnographic study in intensive home care settings. The generalized hints are presented as a conclusion derived from 10 case studies [2]. The 10 case studies do not include the case of intensive homecare where caregivers have to be present all around the clock during seven days the week at the clients' private home. Thus, we discuss differences and similarities between the generalized findings and the intensive home care domain from a socio-technical point of view.

Keywords: Health Care, Intensive Home Care, Socio-Technical Design

1 Introduction: Designing for Health Care

The design of information systems for the domain of health care is specifically challenging and software-engineers or managers need specific practical experience in this context to develop or organize technical support in this domain. Challenges that might occur are e.g. the understanding and the importance of the social interactions between patients, relatives or clinicians. In addition, data security and privacy issues can be difficult to solve, as vital parameters of patients as well as the provided care activities have to be logged, transferred and saved in ways that they cannot be viewed by unauthorized third parties [3]. Another challenging aspect is the medical vocabulary for people with non-medical background [4], as understanding stakeholders and their needs is highly relevant for any requirements elicitation process.

To overcome these kinds of challenges, the socio-technical perspective for the design of information systems uses different methods and tools to uncover the needs and requirements for such systems. One approach can be to rely on more general findings and recommendations in the realm of socio-technical design. Another approach is more bottom-up oriented starting from the practitioners' activities and experiences. For example, ethnographic methods can be employed to uncover interactions and processes in the specific cases of interests [5]. These methods include fieldwork like observations

or qualitative interviews and allow for exploring a domain with focusing on the support of individual and cooperative work. The purpose of this paper is to compare the findings of an ethnographical study in the context of intensive homecare with more generalized findings derived from several different case studies. The question is whether one can completely rely on the generalized results that stem from several case studies or whether additional ethnographic studies reveal new insights.

For the generalized socio-technical view on information system design in health care, Herrmann et al. propose a variety of aspects that should be taken into account when designing such complex, socio-technical information systems [1]. In their view, the socio-technical perspective has to be considered throughout the whole design process, beginning with the analysis and ending with the design-in-use [6] of systems. We revisit these aspects and compare their relevance with results from an ethnographic study in the domain of intensive home care that we conducted to gather a deeper understanding of the field and to elicit requirements for the design of an information system based on the findings in the ethnographic data. Compared to other areas of health care, intensive home care takes a rather special place within the medical field. Trivially, the locality in which care takes place are the clients'[1] homes. In intensive home care, clients usually get assistance for twenty-four hours a day, seven days a week, as their health condition needs permanent assistance by professional caregivers. In contrast to intensive care units at the hospital, this leads to a rather complex social environment at their homes, as clients and their relatives have to acclimatize to the permanent presence of the caregiving staff.

In this paper, we present the results of our conducted intensive homecare study (referred to as IH-study) to prepare a comparison with the socio-technical aspects for designing information systems in health care presented in the conclusion of Ackerman et al. [2] by Herrmann et al. [1] (referred to as ST-conclusions). The succeeding comparison (section 3) seeks to find out how far the more general findings are compatible with the intensive homecare domain and which specific conditions have to be taken into account for socio-technical design in the intensive homecare context. In the conclusion we will highlight important aspects of our comparison for the design of solutions in intensive home care and reflect on the chosen method of our ethnographical approach for the data gathering.

2 Ethnographically Derived Insights in Intensive Home Care

Compared to other domains of health care, intensive home care has a number of specific characteristics [8], mainly:

- The clients cannot survive without continuous assistance.
- Being present in a private home all day establishes a specific social situation that has to be taken into account.

[1] As common in intensive home care, we refer to persons receiving care as "clients" rather than "patients" [7].

- Because usually a caregiver spends nearly the entire working time at the same place, there is no need for continuous delegation of tasks by a dispatcher. There is only a loose coupling between the caregiver and his or her employer.

2.1 Methodological Approach

The IH-study was conducted in nine intensive home care settings in Germany between July 2016 and February 2017. We interviewed 17 employees of three different care service providers and four relatives of four different intensive home care clients. Ten persons of this sample were also observed at their work during care taking. The outcome were ten observation logs of five different home care settings. The age of the interviewees ranged from 25 to 72 years. Two of the interviewees were male (both caregivers); eight out of 17 professional caregivers were qualified as caregivers for the elderly. The remaining nine caregivers were qualified in nursing.

To gain a deep understanding of the data, we used the Grounded Theory Method (GTM) [9]. The method offers a way to explore a domain with the emphasis on discovery of new insights and building up a deeper and holistic understanding of the relevant context. It proposes procedures of open and axial coding to tag and categorize raw data.

During the IH-study, three different coders started in a first iteration with open coding of the data to break it apart and to generate first concepts and preliminary categories. This iteration was followed by a comparison of the different coding results and an agreement on some more formal rules of exploring and documenting the data, like using some short and concise terms to describe first concepts. In the second iteration, we coded two more documents by open coding again to test whether our approach of coding worked for us as expected on the basis of the first round. This iteration resulted in over two hundred different codes. We merged codes with semantic similarities and used axial coding to find relations between codes and concepts. From these new results, we revised and adjusted our preliminary categories and created a detailed coding guideline, which consists of the name of categories, content descriptions for the main categories, subcategories and examples for the application of that category combined with an extract of raw data. We then tested our categories on two new documents and let the categorization of the data peer-review by an expert for health care before we applied the coding scheme to the rest of the raw data. Overall, applying GTM required an extensive amount of work and it seems obvious that this method can be a promising approach for research projects but the effort to be invested is not suitable for every software project in specific care settings. In particular, the discourse on organizing and comparing of the numerous description categories reveals as a sophisticated endeavor that goes beyond practicality. Thus, we try to extract our most relevant findings to provide some guidance for software-engineering projects in this domain.

2.2 Overview of Findings

In the end of the coding procedure, the categorization process resulted in eight categories for our data set. Each category contained multiple sub-categories. These categories are not meant to be encompassing all relevant aspects but, specifically, are the result of

our process of exploration and knowledge gaining based on our observation logs and interviews, as methods of GTM are a way to describe data and build abstractions based on that data [9].

1) Activities in intensive home care.

Work in intensive home care starts with the client admission, where caregivers try to get detailed information about clients' health condition, biographical information etc. from relatives and plan and arrange the home care setting. Activities in intensive home care range from personal-care services (e.g. feeding, washing) and technical nursing (e.g. skin care, oxygen administration) as well as organizational activities (e.g. scheduling appointments), but can also include domestic-aid services (e.g. housekeeping, food preparation), depending on the specific setting and the clients' health status.

2) Interpersonal interaction.

Intensive home care includes social interaction mainly between three types of actors: relatives, clients and the caregiving staff. This observation does not neglect the role of third parties (vendors, physicians, physical therapists etc.), but focuses on those actors whose interaction is decisive for the quality of the daily routines of intensive homecare.

We found importance in the relationship and interaction in-between the caregiving staff, between the caregivers and the relatives and between the caregivers and clients.

3) Documentation.

Documentation is highly important for not only documenting the health status and vital parameters of clients, but also for providing evidence of service by the care service provider (as this evidence is needed for the payment care service providers get from health insurance companies in Germany). Caregivers documented by writing vital parameters down into a specific documentation sheet.

We found different behavior patterns of caregivers for documentation. Some caregivers made pictures of the machine displays to copy them later to the documentation files; other caregivers were memorizing parameters over a certain timespan, leaving the risk to forget information or recoding it inappropriately.

4) Qualification.

There is no education and training that is specifically oriented towards the needs of intensive home care. Every caregiver was at least generally qualified as a nurse or as a caregiver for the elderly. Inexperienced caregivers usually get a guidance for about one to three days in a client's environment, within which they are supposed to learn all essential tasks and activities including the necessary technology usage. A lot of learning is based on the experiences that are gained by the job itself.

5) Interaction with technology.

The usage of technology is focused on the equipment needed for personal-care services (e.g. ceiling lift), for nursing the patient (e.g. ventilation machines), for organizational activities (e.g. smartphones, one desktop computer per setting) and for domestic-aid services (e.g. vacuum cleaner, washing machine).

6) Client autonomy.

Although the clients need potential support during 24 hours a day (depending on their health condition it may be a shorter period), caregivers are supposed to encourage clients in carrying out at least some everyday tasks autonomously. We observed rare cases of clients who were able to expand their autonomy by conducting personal-care services by themselves and even technical nursing activities.

7) History of medical records.

The history of individual medical records and biographies was characterized as highly relevant at multiple times during our observations and interviews. Caregivers reported cases where only background knowledge about clients helped them to intensify trust or to react on clients' preferences. In some cases, the caregivers found out these information bits by accident or by explicitly asking the relatives or by observing their behavior.

8) Feedback on intensive home care by relatives and caregivers.

During the interviews, a variety of statements was made about intensive home care, which we gathered under this category. Relatives generally appreciate intensive home care as a relief and as a way to return to their 'normal' lives. Caregivers, on the other hand, made much more diverse statements. For example, the long shifts were rated positive because they reduce the total number of working days per year, but on the contrary, these long shifts were rated as time consuming and in contrast to the need for free time.

3 Comparing the Results to Socio-Technical Conclusions

The concluding chapter of the book „Designing Healthcare That Works" discusses socio-technical consequences that were derived from 10 case studies. The ST-conclusions include three sub-sections "The extended view of socio-technical perspective", "consequences for design" and "Challenges and Problems" that we consider for the comparison with the results of our fieldwork and examine how their general statements apply to the special health care domain of intensive home care.

3.1 The Extended View of a Socio-Technical Perspective

Increased Scope of Social Interaction.

ST-conclusions emphasize that health care involves *complex social arrangements*, which cause an increasing complexity of the socio-technical systems. Health care is based on networks that, despite the medical staff, can also include *family caregivers or home-helpers* [10]. Comparably, the IH-study confirms that interpersonal interaction between the involved parties can get quite complex, as clients and relatives have to accept the presence of caregivers in their homes up to 24 hours a day. This can lead, for example, to misleading expectations to what extent caregivers have to participate in housekeeping activities by relatives and clients. As every client has an individual biography, every home care setting is characterized by an individual social arrangement to which a socio-technical information process has to be adapted.

However, in contrast to the ST-conclusions, the IH-study did not observe caregiving by family members (or other informal roles). Instead, the IH-study found that relatives mainly try to help with organizational tasks (e.g. setting appointments with physicians or retrieving prescribed pharmaceuticals) but less with caregiving activities. In fact, our category 'Feedback on intensive home care' shows that the relatives consider caregivers as a relief that allows relatives to focus more on their own lives again. However, some of the professional caregivers mentioned in our interviews that they have experienced helping relatives in rare cases, leaving this to be the exception rather than the normality.

In the view of the ST-conclusions, social interaction in the domain of health care also needs *translation work* between medical professionals and patients [11]. In our IH-study we found that caregivers are always the first contact for relatives, e.g. when the clients' health status changes or when they have problems understanding the medical need of certain treatments.

According to ST-conclusions, health care does not only include the "medical diagnosis and treatments but all kinds of activities that contribute to a healthy life are considered, relationships within and among families come into consideration" [1, p.188]. IH-study provides details to back this suggestion: caregivers try to work as much as possible in the background, leaving clients and their relatives as much space as possible. However, they also somehow depend on good functioning relationships within families for a healthy social climate in the home care settings and for example on relatives' willingness to take a part in the aforementioned organizational tasks. ST-conclusions mention a re-organization of formal and informal roles in health care, which, at least, we could not observe in intensive home care. Despite the organizational tasks, relatives of the IH-study were "glad that they didn't have to do it [technical nursing] on their own"[2].

ST-conclusions discuss the fact that motivation to live healthier lifestyles may be supported by socio-technical health care information systems. IH-study observed several cases in which caregivers tried to motivate clients to do some tasks autonomously. In their view, clients tend to rely too often on caregivers, even with tasks that clients can carry out by themselves despite their health condition. Here, a lot of potential exists

[2] Comment of the professional caregiver „WBR06".

for socio-technical arrangements where clients are motivated to pursue a healthier lifestyle.

Motivation, Values, and Interests for Health Care.

ST-conclusions argue that socio-technical design in health care has to understand the *underlying logics* driving people's work, as well as the organizational or institutional cultures [7]. This requirement is in compliance with the "psychological fir" and the "ethical fit" that are amongst other fits a basis of Enid Mumford's ETHICS-approach [12]. IH-study suggests that every activity that goes beyond the formal duties of the caregivers depends on their value system (e.g. challenging clients to take care of themselves and to live healthier). Additionally, ST-conclusions argue that there are, however, "logics of accounting and efficiency motivating a good deal of health care information technology" [1, p.189]. For intensive home care, this applies predominantly to the usage of the core medical technology and less to communication and information processing support.

ST-conclusions mention an *intersection of interests* [13], which can support or oppose each other. Therefore, flexibility is needed to address different logics. In the IH-study, we were able to observe this need on several levels. If, for example, relatives want to do technical nursing, legal issues have to be solved for situations where clients might get harmed (e.g. changing a tracheal tube). Other examples are the additional tasks of caregivers that have to be negotiated with respect to a specific household such as dealing with safety hazards, e.g., cables that are lying on the ground but are necessary for the machines observing the clients' health condition.

In the healthcare sector, increasingly the question has to be answered whether processes and involved decisions should be automated or whether these decisions should be reserved for people. ST-conclusions suggest that an appropriate answer is only possible if one knows for whom one designs the system, on whom it affects and how one considers the values of the affected persons. This problem is addressed by the ST-conclusions as well as the IH-study. If vital parameters, like e.g. the pulse, will be saved automatically, an additional gap between caregivers and clients may arise, since documenting these parameters manually is an occasion to initiate interpersonal communication. As health care has shifted its focus more on life goals instead of mere health care goals (ST-conclusions), IH-study reveals that caregivers tried to not only maintain the health condition of clients. They also tried to support them to maintain their social life (e.g. by motivating them to invite friends) or to respond on personal preferences or treats (e.g. serving sweetened coffee). Socio-technical design has to support the needs and values shared by individuals and families to gain trust and social coherence (ST-conclusions). IH-study supports such statements because one caregiver reported a case in which a client refused personal and technical care from the caregivers, with the exception of one who had won the client's trust. The client's biography showed that she had been misdiagnosed several times. This experience led to a lack of trust to most caregivers. This example shows how important trust can be for a successful care situation.

Time, Dynamics, Processes, and Places.

The health care domain is highly dynamic [1]. In intensive health care settings, this might not be as distinct as in other domains of health, as caregivers are usually assigned for one client. However, these settings can also get highly dynamic and unpredictable, if, for example, the general health condition of a client changes. In addition, illness of caregivers is challenging when the staff cannot compensate missing colleagues. In these situations, external caregivers step in or the client has to be temporally transferred to an intensive care unit. Socio-technical design has to integrate these potential dynamics. This example supports the ST-conclusions' suggestion that the characteristics of physical locations where technology is employed are of high relevance [1], as the intensive home care setting might include external staff or change the clients' location temporally.

Considering the home settings, we found that, depending on the clients' health condition, multiple machines have to be used to surveil the clients' vital parameters. These machines are using sound for alarms on a regular basis. Therefore, we see the challenge of seamlessly integrating the technical equipment into the patient's location without violating the coziness and privacy of client's homes.

Another central point for socio-technical design in health care is understanding the processes and workflows between patients and clinicians. For example, ST-conclusions argue that the design process should analyze and understand the as-is-processes. Here, technically supported health care should not only focus on efficiency, but should also support a more holistic view considering patients' health development and their trajectories. Even their care networks and social environments may continuously change. IH-study provides evidence for these aspects in the categories 'client autonomy' and 'history of medical records' as the health status of clients can change over periods of time, having an impact on their autonomy to live their own life. The time-orientation should incorporate clients' trajectories as care settings or services can change. Still, many tasks in intensive home care take place workflow-based, like technical nursing tasks or routines of personal-care services. Additionally, each client has his/her own day's schedule that is processed by caregivers.

The dynamics in the field of health care underlie a specific „betwixtness" [13], which states that multiple stakeholders with a variety of goals and interests have to be included into the socio-technical design (ST-conclusions). Intensive home care is also characterized by such dynamics, as social interactions can lead to tensions and conflicts between the different goals of involved people, for example relatives telling caregivers what to do.

Extending the Amount of Health Care Data.

Another important aspect for a socio-technical system in health care is the tracking of health-related data that, in addition might log vital parameters automatically. This statement should not neglect the fact that in intensive home care a lot of documentation is still carried out manually. For example, caregivers also document the overall condition and feeling of clients from their point of view. ST-conclusions state, "clinicians are often concerned with their workflow" [1, p.190] and attention to data would require

additional effort. It is questionable if caregivers (or others) would reflect on the client's health condition among such complete trajectories of health-related data.

However, new applications and tools that record and save patients' data will arise. Historically, health care has passed strong changes in the past. When, at first it focused on medical instruments, it changed to many other types of support like health applications, social networks or other communication systems. IH-study reveals that especially the communication of organizational issues between caregivers or between relatives and caregivers is often done via messenger apps. Problematically, these apps do not necessarily meet all privacy requirements. Therefore, a socio-technical analysis should also include the analysis of "self-established" technical support in the domain.

IH-study did not find usage of health-related data for further applications, leaving the scope of technology focused on medical needs. Here, medical machines and systems would need proper interfaces (with respect to privacy aspects) to import and export health-related data for other health-applications.

3.2 Challenges and Problems for Socio-Technical Design

Complexity and Limited Perspectives.

Based on the complex social structures and interactions as well as the missing transparency, involved persons might not always understand everything that happens in health care (ST-conclusions). Socio-technical design tries to dissolve this by incorporating the complex and maybe unstructured processes instead of minimizing its view on rule-based workflows. According to IH-study, the comparison of rule-based workflows (e.g. technical nursing) and the processes we could observe has opened up requirements for a potential socio-technical system and has helped to understand the work of caregivers. Here, the ethnographic approach of IH-study revealed different strategies of caregivers to solve tasks and points out the implementation of these strategies into existing routines. An example for such a process is the fact that caregivers took pictures of machine displays to save snapshots of vital parameters for writing them down into the documentation sheets afterwards.

Handling the Extended Amount of Health Care Data.

If electronic systems save and log data of patients continuously and permanently, physicians and the medical staff will probably never analyze a substantial part of these data. Even if, it includes the risk that physicians lose themselves in too many details instead of building up a holistic view over the patients' situation (ST-conclusions. Simultaneously it increases the risk of violating privacy.

As mentioned, in the context of the IH-study such systems for the accumulation of data were not used. However, it is necessary to document and save clients' vital parameters at several points a day. Here, a logging system could help caregivers, as the strategies to document can vary, leaving the risk of altering data. A possible solution could, for example log data temporally, so that caregivers could focus on their workflows before they document.

Trust in Design.

ST-conclusions speak of a possible mistrust of patients and physicians concerning the design of technical systems. This might refer to privacy aspects and is related to a *lack of transparency*. In the context of IH-study, clients and relatives had always had the possibility to examine the (physical) documentation files, as caregivers and the care service providers had a high demand for transparency in their work. Such demands have to be incorporated into a socio-technical system if mistrust should be prevented, especially as information systems are harder to comprehend compared to physical documentation files.

Lack of Willingness and Acceptance to Employ Technology.

Ackerman et al. [2] discuss in several chapters the lack of willingness to use new applications or technology. Tools might be used in a different way than designed for [14] or might be used only in the initial phase directly after their implementation but not continuously.

The IH-study observed the usage of messenger-apps by relatives and caregivers to communicate informally. From a socio-technical view, a design has to offer at least alternative apps that offer, from a legal point of view, enough technical measures to prevent the violation of privacy (e.g. because of unencrypted data stored on application servers). Here, we found a very specific need that was not solved and where such willingness to use a system already exists. The same appears with the data capturing of vital parameters via smartphone cameras (see Complexity and Limited Perspectives**.**). Caregivers changed their workflows by using their smartphone cameras to focus on the technical nursing task (e.g. changing a tracheal tube). Here, acceptance to use a supporting system would not lack, as the need for such a snapshot-function exists and the established workaround is not compatible with medical data privacy.

In other examples, IH-study shows that caregivers tend to skip technology-related tasks, if they do not feel confident enough to fulfill them, for example, the maintenance of wheelchairs or oxygen bottles. A workflow-oriented guidance would help them to fulfill these tasks systematically. Even if caregivers would use it only in a beginning phase, until they feel confident enough to do the task on their own, such a guidance by an information system would at least support them and train them how to do it correctly.

4 Conclusions

We derive some specific issues for sociotechnical design in the health care domain by the comparison of the generalized description of aspects (ST-conclusions) to be taken into account with the more specialized context of intensive home care (IH-study):

- In the IH-study context, the social interactions' complexity is similar to what is described in the ST-conclusions. However, the density of interaction between the main actors (caregivers, patient and relatives) in the same home includes the potential of informal communication and task delegation as well as conflicts. The support of information exchange has to flexibly mirror these constellations and their dynamics, since all three types of actors potentially

undergo continuous transitions with respect to their capabilities, attitudes, preferences, and willingness to share certain tasks.

- In the context of the IH-study, the interplay between roles and their task sharing does not only include tasks of health care or accounting in the course of documentation but all kind of other activities that are related to everyday life such as housework, social entertainment, organizational issues etc. Consequently, the data needed to support coordination are not limited to the health care issues. By contrast, the information system should mirror a mixture of handling formal information exchange (e.g. for documentation that supports accounting) and informal interaction (e.g. handovers between shifts, agreements between caregivers and relatives).
- With respect to trust, close interpersonal interaction and paper-based documentation allows for increased transparency – these possibilities have to be considered if an increased employing of computerized information processing takes place.
- Generally, health care information systems should consider the potential inclusion of relatives but it has also to be accepted that some relatives may not be willing to contribute. Professional caregivers cannot rely on sustaining contributions by relatives including the providing of information being needed. For example, certain bits of information may be disclosed to one specific caregiver but not to the others in the same home. This requires a confidential and selective information exchange between the caregivers.
- Maintaining the client's autonomy is an important value – this has also to be mirrored by the socio-technical system that integrates the care giving processes.
- The ethnographical approach supports detailed insights (beyond the more generalized conclusions) into the values and interests that are drivers of the caregivers activities and behaviors. It has to be taken into account that some of them are willing to take over informal tasks while others do not. For those who broaden the scope of their activities, information systems support has also to address the extended range of tasks. It is also of high relevance that the caregivers' motivation might lead to an employing of their own device, mainly smart phones. This is an important starting point for increased acceptance of a more sophisticated technical support. Obviously, as a non-functional requirement, various types of devices, such as smart glasses, tablets or PCs should be choosable by the users. However, it has to be avoided that the users have to transfer data between various media, in particular from paper to a tablet etc. We realize a tremendous gap between theoretically possible data integration and practical reality. Thus, we assume that information systems have to provide temporary solutions to bridge this gap before such a data integration is completely brought into reality.
- The information system should provide guidance for the caregivers to compensate the heterogeneous levels of experience and qualifications of them. Therefore, the system design should pursue a fluent transition between task

handling and learning support. The more irregularly or occasionally the challenges have to be met – e.g. when dealing with medical devices – the more guidance seems to be necessary. Furthermore, guidance can also be important for relatives, for example information about duties and liability has to be available. Apparently, the type and extent of information provided has to be highly adaptive with respect to situations and people's knowledge, experience and interest.
- Overall, the extent of technical support in the IH-study context is not very high compared to the available possibilities. This applies specifically to the exploitation of data for the purpose of improving the caregivers services.
- Medical machines and systems would need proper interfaces (with respect to privacy aspects) to exchange patient-related data between various health-applications.

Finally, the comparison between the use case study in intensive home care (IH-study) and the more generalized description of socio-technical aspects for health care (ST-conclusions) has uncovered concrete requirements for a socio-technical design. As the existing categories (Section 2.2) evolved on the coding process and the categorization of ethnographic data, the ST-conclusions have helped as a guideline to discover and explore these categories specifically for socio-technical aspects.

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