

IT Supported Coordination of Elder Care

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Abstract In Denmark, elder care is currently distributed across various care providers, including a care center where the elderly citizens live, and numerous specialized care providers. This poses strong requirements on the abilities of the involved care providers to align and coordinate their activities in order to support the life, care, and comfort of the residents. At the care center in this study, planning of the residents' activities is currently supported by a care administration system that allows caregivers to maintain schedules of the residents' activities. However, in practice, this system mainly supports local planning and not coordination of care, which is arguably necessary among the members of the distributed ensemble of care providers that constitute elder care. In this paper we present preliminary findings from a project aimed at designing improved IT-support of collaboration elder care. By studying how the care administration was appropriated in use, currently unsupported communication and collaboration needs became visible, including a lack of support for caregivers in prioritizing activities in cases where the care providers have opposed interests and expectations.

Introduction

Coordination of healthcare is among the core interests of CSCW. However, few studies have addressed how coordination among care providers involved in elder care can be supported by IT. This is challenging, as elder care requires the coordinated effort of a heterogeneous ensemble of care providers, including healthcare professionals, pharmacists, hospitals, insurances, as well as the patient and the relatives (Consolvo et al., 2004; Bricon-Souf, 2005). As these actors often harbour diverse ideas and attitudes towards the common activities, collaboration in elder care requires that activities are carefully articulated (Christensen and Grønvall, 2010). In elder care, like other types of distributed care, it is therefore important to support articulation work, or the extra-ordinary background work such as planning, coordination, delegation etc. that enables the primary work to be carried out (Strauss, 1988). Studies of how IT can support people in coordinating and articulating their work is arguably a *raison d'être* for CSCW. Such technologies have been conceptualized as *coordination mechanisms* - or artifacts that objectifies a coordinative protocol and thus enable people to articulate collaboration (Schmidt & Simone, 1996). Other studies have uncovered *common information spaces*, for instance central archives that are maintained by

people in distributed settings, which can contribute to articulation of activities (Bannon & Bødker, 1997). In the case of elder care it has been argued that such central archives, for instance paper records and information systems hold significant potential for augmenting collaboration in elder care (Petraou, 2007; Bossen et al, 2013). However few studies have specifically addressed how IT can be designed to support articulation of activities among the members of the heterogeneous and distributed ensemble of health providers, patient and relatives in elder care. As argued by Fitzpatrick (2011) health IT design is generally challenged by some level of opposition between the perspectives of health professionals and patients. On the one side, health professionals typically see care as episodic events that takes place that require a great deal of structure and planning. For patients, care is typically ongoing and integrated in daily life. Health IT must therefore be designed to both be fit for life and care (Fitzpatrick, 2011). In elder care, we argue, this challenge is no less apparent. Here, the residents are supported in receiving care and in living the daily life, and the caregiver are responsible for the challenging task of coordinating and balancing these activities. In this position paper we present preliminary findings from a project aimed at designing improved IT support of planning and coordination of elder care. We specifically focus on a field study of how the existing care administration system is appropriated in use, and how this manifests as currently unsupported needs. Overall we found that the caregivers fulfill a crucial role in balancing the interests for *care* and *life*. However, in many cases this is not well supported by the existing care administration as this does not provide them with information about the priorities of the involved actors. We therefore see a strong need for developing a common information space that convey information about the requirements, wishes, and priorities of the involved actors, including clinics, dentists, bus transport, and relatives.

Project Description

Our study has been carried out to develop improved support for coordination of elder care in a municipality in Denmark. Following a Participatory Design approach to development of health information systems (Pilemalm & Timpka, 2008; Clemensen et al, 2007) this study builds on a lengthy involvement with stakeholders from the domain, including caregivers from a care center, and representatives from an activity center and from a bus transportation system. Methodically, this project is based on field studies of current work practices, and collaborative prototyping whereby a software prototype was developed and through three iterations tested in real use at the care center.

This field study was conducted during three months. Data was collected through 15 field visits and informal interviews with 26 informants. We particular focused on the experiences of the informants with using the current care administration system and the coordinative challenges in elder care. Besides observations and interviews, we also used video recordings and field notes as data collection tools.

Distributed Elder Care

In the municipality of our study, elder care is distributed across numerous institutions. The main actor is the *care center* where the citizens live and are supported by caregivers who provide daily care and manage the residents' appointments with other care providers. One of those is the *activity center*, where residents go, sometimes on a daily basis, for leisure and for physical exercise.

As the residents in care centers are typically elderly, they often must attend health care outside of the care center, for instance at the dentist, at the general practitioner, at medical specialists, or at hospital inpatient clinics. Because of this distributed organization of care, it is necessary to transport the elderly citizens to the individual care providers. This is taken care of by a municipal patient transport system where buses transport residents to their appointments on preplanned schedules. The general organization of healthcare, and in particular the patient transportation, necessitates that activities must be carefully planned and coordinated.

Unlike many other institutions in healthcare, the residents live on a permanent basis at a care center. The tasks here involve managing the residents' appointments with the activity center, with external care providers, and with relatives.

Currently, the caregivers manage the residents' appointments by using a care management system to keep schedules of the activities for each resident. The system is intended to be used by the caregivers, when an appointment is made on behalf of the resident, for instance with the dentist or the general practitioner. Schedules of the residents' activities are then available for the responsible caregivers on that particular day. The system is also intended to be used to introduce changes to the schedules, for instance when an appointment is cancelled.

In practice, plans and changes however often need to be coordinated or aligned with other actors in elder care or prioritized in relation to other activities, which requires some amounts of articulation work. While the care administration system in general provides good support for care management at the care center, it offers less support for the caregivers when balancing the sometimes unmatched priorities of the involved actors, as shown by the following vignettes.

Coming Over For Lunch

The family calls the center to make a lunch appointment on behalf of their relative, and often these appointments are not written down. When the family arrives to pick up their relative, this person is often not ready or is already seated for lunch. Dentist appointments or scheduled visits at an outpatient clinic are also forgotten. This problem is very visible, when the driver from the transport arrives to collect the resident. (Excerpt from field notes)

In this case a caregiver received a phone call from a relative who wished to visit one of the residents for lunch a bit later the same day. This is a typical situation,

and sometimes relatives also arrive unannounced. In these situations the caregiver receiving the call will either write this down in the shared notes or pass on the information by word of mouth without taking notes. This is necessary, as the caregiver who is responsible for the specific resident will need to be informed about any changes. In some cases, because of the busy work caregivers cannot always immediately locate one another, and nor rely on new notes being read immediately. While this typically makes little differences unless the resident has other appointments, it may in some cases require rescheduling.

In this particular case, the resident was in fact scheduled for a dentist visit later the same day, which was not identified by the caregivers who therefore did not reschedule the dentist visit and the transport. As a consequence, the resident came late for the municipal patient transport and thereby missed his appointment.

This case shows how residents are often met by priorities that are not fully aligned, in this case the tight schedules of the dentist and the patient transport, and the relatives' wish to have lunch with their family member. As the caregiver who made the appointment was not fully informed about the other activities of the resident because of inadequacies of the care administration system, she was not able to balance priorities well.

Ready For Surgery?

One of the residents enters the room saying he is ready to get clothed as he is going to the hospital. The staff replies he should eat some breakfast first. He replies that he is not allowed to eat before his surgery. The staff looks through the IT care scheduling system, the whiteboard and their calendar. In one place it says he is not allowed to eat, in the two others it says he is allowed to eat. Staff tells him to eat and tells him they will get him ready afterwards. (Excerpt from field notes)

In this case, a resident had to go to the hospital for surgery. At the morning meeting at the care center, some confusion emerged whether or not the operation required anesthesia and consequently if the resident should show up fasted at the hospital. While the resident recalled to have heard it to be a requirement, the caregivers could not find any information about this in the information systems, in this case a calendar, a whiteboard and the care administration system on the computer. Instead, they prioritized the resident's comfortable morning and let him have his breakfast. Once at the hospital, this however proved to be an unfortunate decision. Here the health professionals informed the resident that he, because of the necessary anesthesia, could not go into surgery with a full stomach. He was therefore sent home to the care center, and the operation was scheduled for another day.

In this case, the activities of the care center and the hospital clinic were not aligned, because the caregivers at the care center were not fully informed about the specific procedure that was supposed to be carried out at the hospital clinic and the requirements for this, they were not able to align their concerns for supporting the resident in having a calm and comfortable morning at the care center, with the clinic's concern for carrying out a safe clinical procedure.

This vignette therefore brings to light an unfulfilled coordination need in the

current care administration system that prevented the caregivers in prioritizing these opposed interests.

Discussion

Within healthcare, it is commonly argued that the fragmentation of care, that among other things derives from the tendency towards distributing care across multiple health providers with non-integrated information systems, can be resolved by introducing more comprehensive, shared information system. In terms of CSCW, this often builds on a *common information space* approach to development of IT support for articulation work. However, experiences from hospital settings show that while such systems by emphasizing structured data from an administrative point of view may be an advantage, this is often not the case for the delivery of care. One possible cause is that the daily work practices, including the necessary articulation work, is often not taken fully into account (Greenhalgh et al., 2009). While a care administration system seen as a common information space in principle could support coordinative work in distributed elder care by allowing the involved care providers to actively stipulate and articulate collaboration, in practice this proved not always to be the case. More specifically, we observed how the caregivers in some cases did not have access to all the information that was necessary to balance the, at points, opposed priorities of the involved actors. The first vignette showed how the rigor of the patient transportation system was in opposition to the family's wish to improvise a visit, and how the caregivers, because of a lack of information about the upcoming dentist appointment, was not able to balance these. The second vignettes depicted how clinical requirements, in this case from a hospital clinic, were in opposition to the daily life at the care center. In both cases the caregivers had to prioritize between these apparently incompatible interests, but because of the inadequacies of the care administration system, this was not possible. By observing how the current care administration system was appropriated in use, we have identified a strong need to develop a common information space for distributed elder care, that enable caregivers to get information about upcoming activities and the priorities of the involved actors, and thus to provide them with opportunity to balance the interests for *care* and *life*.

How this in practice can be achieved, remains for a following design project to explore. However, this project indicate a need to help the caregivers with prioritizing activities, for instance by providing a multiple-input communication channel, that allow the members of the distributed care regimen to add information regarding their specific activities, while making it easier for the caregivers to decide on the importance of the events in the context of other events.

Conclusively, the findings in our study indicate a need for a care administration system that not only supports the meticulous planning of activities that is needed by the healthcare system, but also the need to prioritize activities in order to balance the interests of care and life.

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