

Computer-Supported Coordinated Care: Using Technology to Help Care for Elders (Version #1, Submission date: Dec 22, 2003)

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Abstract

In this paper, we define the space of Computer-Supported Coordinated Care (CSCC), an approach that focuses on using technology to aid the entire community of people who support an elder who lives at home. We conducted interviews with people involved in the care of elders to identify their needs. We subsequently conducted an in-situ evaluation of a prototype technology to study how a CSCC system may help satisfy these needs. Based on the results, we identify challenges faced by the people who provide elders with care and offer guidelines for designers of coordinated care technologies.

Introduction

Chances are that in your lifetime, you will both provide care for an elder and be cared for as an elder. Many people who are not professional caregivers are involved in caring for an elder, particularly when the elder lives at her own home and not in a care facility. The lives of these people are affected by the potentially demanding responsibilities involved in that care.

We present results of a user study that initially focused on developing information systems to reduce stress for caregivers and concerned family members of elders. Although we expected to find several people who provided care and had concern for the elder, a surprising result was the broad range of people involved in the care and the extent to which caring for the elder severely affected the personal lives of the concerned individuals. We observed uneven distribution of responsibility, miscommunication, misunderstanding, distrust, unmet care needs, and negative impact on careers and personal needs. These issues were largely due to problems of coordinating the elder's care.

Technology has the potential to help people coordinate the activities involved in caring for elders. However, despite the breadth and depth of this area, research in caring for elders has not yet been thoroughly analyzed from the point of view of the entire care community. Current research has typically investigated how technology from robots [1] to smart phones [2] can assist elders in their daily activities and how monitoring devices such as digital picture frames [3] can provide information to a geographically distant family member. Addressing specific issues in eldercare rather than addressing the issues of caring as a whole limits the impact of these technologies in real-world deployments.

We believe this issue of coordinating the care of elders who live at home is a problem that has not yet been thoroughly explored or defined. Our primary contribution in this paper is to define the problem space, identify the types of challenges it presents, and based on our user studies of people involved in caring for elders and a prototype technology, present guidelines for designers of coordinated care technologies. Our work extends a suggestion of Tad Hirsch et al.¹ [4] and focuses on using technology to aid the elder's entire care community. To distinguish this space from the broader research issues of computer-supported cooperative work (CSCW), we call it

¹ As part of the ELDER project, Hirsch et al. [4] suggest that “opportunities exist for communication and technology products and applications to enhance communication between stakeholders—elders, friends and family members, doctors and nurses.”

computer-supported coordinated care (CSCC) and propose that it is a meaningful focus for the pervasive computing, CSCW, and human-computer interaction (HCI) communities.

While some aspects of CSCC are very similar to existing CSCW work², CSCC instead focuses on a *person* rather than a shared objective such as “keeping a person healthy.” This shift in focus has implications for supporting technology because issues such as emotion, trust, and privacy become foremost in importance. Though one of the objectives of the community is to keep the person healthy, it must also consider the person’s mental and emotional states and overall well being. In many circumstances, the community is dealing with a person who is slowly losing their independence.

User Studies

Our initial task was to explore the space of caring for an elder, which we did by conducting a series of interviews. More specifically, we had to determine who was involved in the care, what types of care were needed, and what types of care were being provided. Within the care communities, or *support networks*, we wanted to determine the methods and content of communications. We further explored CSCC from multiple perspectives within the support network by addressing:

- roles within networks,
- communication structures within networks (means and players),
- types of information shared,
- importance of that information, and
- comfort in sharing that information.

We applied what we learned about CSCC by building a prototype, the CareNet Display³, and deploying it with a number of support networks in an in-situ study. Analysis of the data from the initial interviews and subsequent prototype deployment helped us define the space of CSCC, identify its characteristics, and provide guidelines for the design of CSCC systems.

Methods: Interviews

In March-May 2003 we conducted a series of interviews with elders and the people who care for them. We used semi-structured interviews and a three-week phone diary study to uncover current practices, needs, and privacy concerns of the stakeholder groups. The data consisted of questionnaires, audio recordings, and investigator notes. All participants⁴ were recruited by the research team, who gave talks at local geriatric care meetings, placed posters in senior centers, and worked with eldercare domain experts. Participants were 3 elders (aged 83–93), 4 concerned family members (aged 51–65), 3 familial caregivers (51–80), 3 professional caregivers (aged 31–70), and 3 geriatric care managers (aged 46–50).

Interviews ran 60–90 minutes and were conducted in a variety of locations based on the participant’s preference: our offices, the participant’s home, a senior center, or over the phone (for non-local participants). Three of the four concerned family members participated in the follow-up phone diary study to further explore their daily care-related activities.

² One such similarity is to activity theory which describes cooperation as “a *collaborative activity*, with one objective, but distributed onto several actors, each performing one or more *actions* according to the overall and shared objective of the work” [5].

³ See sidebar at end of document for a summary of the CareNet Display

⁴ Pseudonyms are used throughout the paper to protect the participants’ identities.

Methods: In-situ Deployment

In Fall 2003 we built and deployed a prototype, the CareNet Display, to investigate how sensor-based pervasive technologies might address the needs of support networks. The CareNet Display is an interactive, ambient picture frame, loosely based on the Digital Family Portrait [3]. The CareNet Display provides local network members with frequent intraday updates on the elder's calendar and several aspects of her condition including meals, medications, outings, activities, and mood.

We conducted an in-situ study of the CareNet Display to see what would happen when we introduced a CSCC technology into the support network. Displays were deployed for three weeks at a time in the homes of members from four support networks; two or three members from each of the networks participated. All participants, including the elders, were interviewed before and after the three-week deployment. All participants, except the elders, completed mid- and post-study questionnaires⁵. Participants were 4 elders (aged 80-91) and 9 members of the four different support networks (aged 44-60).

Members of the research team collected the data about the elders by speaking to the elders and/or their caregivers several times each day by phone. The evaluators then updated the displays remotely with a web-based tool. We expect that sensors would replace the role of the evaluators in the final version of the CareNet Display.

Results

Our analyses of both studies focused on exploring information systems to help the people who provide an elder with care, while respecting the concerns of the elder. In-line with this goal, we discovered several common themes that help shape the CSCC perspective. Within this discussion, we have interspersed the results of the two studies and offer examples from several support networks. We use the results discussed in this section to later formulate the characteristics of CSCC.

Support networks. One of the common themes observed is that elders who live at home have rich support networks of people who provide them with care. These support networks include people of varying ages and computer skills. They provide care ranging from basic activities of daily living to social support. They consist of family members, friends, and often neighbors. Paid help such as professional caregivers, pharmacists, housecleaners, and doctors may be involved (because doctors were not interviewed, they are not included in our analysis). We call the individuals who participate *network members*. Network members may live with the elder, in other states, or even in other countries. Local members provide the majority of care.

The complexity of support networks varies. For example, 91-year-old Grace, who lives alone, has a support network of more than 20 members. Her two daughters and a close family friend provide the majority of her care. Several other family and friends also provide social support, home maintenance, and may occasionally fill-in for other members when they are unavailable. Grace also has a weekly housecleaner and on-call handyman. When she has been particularly ill, professional caregivers have temporarily joined her network. Another elder, Rita, lives alone and has a support network of 10 members. Rita's primary support comes from two of her four children and a part-time professional caregiver (see Figure 1).

⁵ Other network members who lived in the same household as the "official" study participants also completed the mid- and post-study questionnaires.

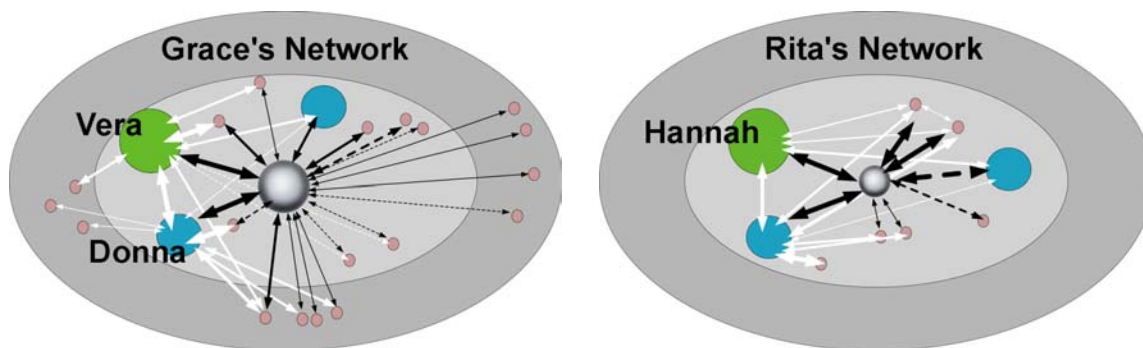


Figure 1. Support network diagrams for elders Grace and Rita. The circle representing the elder is in the center of each diagram. Other circles represent network members—green/large circles represent members who have made drastic life changes to care for the elder; blue/medium circles represent members who make significant contributions to the elder's care; and pink/small circles represent members who have peripheral involvement in the elder's care. The size of the elder's circle reflects the amount of care she is able to provide for herself. The distance between outer circles and the elder represents the distances between their physical locations. The inner light-grey oval contains members who live within reasonable driving distance and the outer dark-grey oval represents members who live much further away. Lines show communication flow, with thickness representing volume. Solid lines represent family relations—dashed for unrelated members. Black lines represent communications between the elder and other network members. White lines represent communications about the elder, but not directly with the elder. These diagrams show that network structures vary, but local members provide the majority of care.

Network members often have significantly different roles when it comes to the care of the elder, and consequently their roles have different impacts on their own lives. We separated network members into three categories that describe how providing care impacts the members' own lives: (1) those who make *drastic life changes* to support the elder, (2) those who make *significant contributions* to care for the elder, and (3) those who have *peripheral involvement* in the elder's care.

We found that each network has one member who drastically changed her own life to care for the elder. These changes include quitting jobs and ignoring social activities such as hobbies and travel. For example, Rita's daughter Hannah works a part-time job with flexible hours. Though she likes bike riding, hiking, and participating in her book club, she often cannot do these activities because she must be available to help Rita. Grace's daughter, Vera, mentioned that she has "had to put her life on hold to care for [Grace]." Like Hannah, Vera works a part-time job with flexible hours. She has turned down job offers she otherwise would have taken because they did not allow for enough flexibility with her schedule. She also seldom takes vacations. The members who have made drastic life changes to support the elder are critical members of the network; their sudden absence would have a strong, negative impact on the elder's care.

The second category of network members includes those who make significant, regular contributions to the care of the elder, but have not had to make drastic changes to their own lives to provide care. For example, these members' lives have certainly been affected by the role of providing care, but they have not had to quit their jobs; their primary focus is still their own daily lives. The third category is that of the peripherally involved member, often characterized by sporadic social or home maintenance-type interactions with the elder. For these members, caring for the elders has had minor impact on their own lives, but the interactions with these members still hold meaning for the elder.

Network members are often unclear about the amount of care each member provides for the elder. In general, the *drastic life changes* members and the elder have an accurate understanding about the participation of each member in the network, while the *significant contributions* members tend to believe that drastic life change members and significant contribution members contribute to the care "about equally." CSCC systems can increase the awareness of the participation level of all members. Regarding the CareNet Display's feature of

sharing information among network members, one participant claimed, “[We] all benefit with this system of sharing the responsibility.”

Disseminating information. It is not surprising that the primary forms of communication for support networks are phone calls and face-to-face conversations. In most support networks, at least one or two members also use email. Despite its advantages, email cannot currently be used as a primary form of communication because so many other members do not use it. Often the person who is responsible for disseminating the majority of information (e.g., Hannah and Vera), wished the other members used email. The reasons for not using email had less to do with age and more to do with whether or not they already used email in their daily work lives.

Because of the difficulties involved in communicating with network members, several members are not informed about the elder’s current condition. Instead, only a select few who talk with or see each other frequently know about the most recent occurrences. Several support networks have developed systems that keep important information in a place that is known and accessible to local network members in the event of an emergency. For example, Vera helps Grace maintain a tote bag full of the important information a doctor or emergency medical technician might need; this bag is kept near the front door of Grace’s house. Hannah has a similar file prepared for Rita.

In most cases, the CareNet Display deployment resulted in increases in communications between network members and the elder. These increases centered on information gathered about the elder that was shared with display users. For example, having the display gave one peripherally involved member details about the elder’s day-to-day life that he never knew about before; he enjoyed learning about these details and was able to speak with the elder about meaningful events from her daily routine. As a result, he became more involved in her care.

Another finding was that sharing information through the CareNet Display alleviated the dissemination task previously done by certain network members. For example, the number of communications one participant had with the elder’s primary caregiver decreased during the deployment. Through the display, the participant was able to get information about how often and where the elder was getting out of the house and who needed to drive her to appointments; this information eliminated the need for some phone conversations. Both parties welcomed the decrease in phone call frequency.

Evolving needs of elders and network members. Several network members mentioned the problem of keeping everyone “on the same page.” By this, they were either referring to discussions about deciding what the elder needs or problems of coordinating eldercare requirements, including keeping network members informed of important aspects about the elder.

A common issue that network members expressed was that other members had an unclear understanding of the type of care that is both needed and given. For example, Vera mentioned that when something happens to Grace, the *significant contribution* members do not really understand how much care Grace requires. Recently when Grace was ill, Vera temporarily moved in with Grace to ensure she did not develop respiratory problems—something for which Grace is at risk. Several network members did not think Vera needed to take such drastic measures. Vera felt they did not understand the seriousness of the situation and ignored her explanations, despite the fact that she is a registered nurse who specializes in geriatrics.

Problems may also occur when the elder resists additional help. For example, Rita has mild dementia. Her son has called to remind her to take her medication and waited on the phone while she claimed to ingest it, only to learn later that she did not. Rita has also told network members that she ate a “proper breakfast,” when she only had a cup of coffee. Other network members are concerned about this, as a cup of coffee is not an acceptable breakfast for a diabetic like Rita. Unfortunately, Rita is unaware that she does not reliably communicate to the other members about significant events such as medication and breakfast. These unreliable reports have created issues when the network tried to get Rita more help. Rita does not understand why she needs it, claiming she “is not a baby.”

Care requirements for elders change over time. Some are predictable, such as the well-understood progressions of diseases and conditions. Others are unpredictable, brought on by sudden changes such as a fall, stroke, or virus. Such events can immediately change the needs and dynamics of the support network. In Rita's case, her dementia impacts her ability to care for herself. Consequently, her children are becoming more insistent about her having around-the-clock care. Rita recently agreed to a 2 hour per day professional caregiver. Her network hopes to move Rita to a two-bedroom apartment where the second bedroom could be occupied by a live-in caregiver.

Though we observed few, if any changes in care needs during the 3-week deployments of the technology, the display was designed to be flexible enough to accommodate such requirements. For example, the type of information being monitored about the elder could change as needed. Most participants mentioned during their interviews that they anticipated their information needs would change overtime.

The Characteristics of CSCC

Based in part on the evidence collected in our studies, we determined that these support networks have a strong need for help with coordinating the activities of the elder's care. In doing so, we defined the characteristics of CSCC. These three characteristics help distinguish CSCC from the more broad research issues of CSCW and provide a scope within which researchers can focus their efforts.

C1: The focus of the network is a person. While our work builds on aspects of CSCW, it focuses on a *person* rather than a shared objective or activity. Because a person, and not a shared objective like "keeping a person healthy" is the focus of the network, issues of emotion, trust, and privacy are primary. What is right for the elder from a health perspective is not necessarily what is right for the elder emotionally.

A further complication is the dual role of the elder as both the focus of the network *and* a network member. Decisions about what type of care she can provide for herself are made by the network. For example, can the elder still bathe herself? Several elders may be reluctant to admit the need for help with such personal tasks, even when they need it. Rita, for example, does not realize that she cannot reliably report information such as whether or not she took her medication or had a proper breakfast.

C2: The organizational structure of the network varies from network to network, and over time within one network. The relationships and coordination with network members are loosely coupled and often channeled through the member at the center or a designated member. No assumptions can be made that all network members know each other, that any member will take on any amount of responsibility, that all members skills are the same, that all members share the same motivation to care for the elder, or that all members have the same access to the elder and the healthcare concerns.

Networks are created in an ad-hoc fashion, largely based on opportunity. For example, on one occasion when Grace was sick and no one else was available, her daughter Donna's tenant—who is usually involved at a peripheral level—stayed overnight with her. Each support network creates its own structure that may be forced to change as the members of the network or needs and priorities of the elder change. Because there is no formal structure or organization for the related activities and members, the issue is not so much collaboration or cooperation as it is *coordination* of the activities related to the care of an elder.

C3: Caring is a background, yet critical, activity. The network interactions and activities related to caring for the elder are often secondary to the primary work and play of network members. A goal of CSCC is to help the elder remain independent, while other network members maintain their day-to-day lives as a primary activity. CSCC systems that distribute responsibility could help some of the members who have made drastic life changes get some time back for themselves. For example, Rita's son only checks email one day a week and does

not check voicemail in the evening, despite the fact that his sister Hannah uses these methods to communicate with him about Rita. It is not that he does not care about his mother, but rather that he can rely on Hannah to monitor Rita's immediate needs. While he is able to maintain his day-to-day life as a primary activity, Hannah is not able to do the same for hers.

CSCC Design Guidelines: Caring for Elders

A variety of CSCC systems could help the members of an elder's support network. Based on the results of our user studies, we offer a set of design guidelines to help inform the development of successful CSCC systems. While these guidelines are not necessarily unique to CSCC, they are particularly important in the domain of caring for an elder.

1. Privacy for all members of the support network is a crucial aspect of CSCC systems.

CSCC systems should respect the privacy of the elder and other network members. For example, as a result of providing updates about the elder, the CareNet Display also shared and archived information about other network members (e.g., Vera is driving Grace to Monday's appointment with Dr. Smith). It was important for us to involve these network members in our design and evaluation to ensure they were comfortable with such information being included.

2. CSCC systems should strive to reduce cognitive load by augmenting current tasks rather than creating new ones, or using the user's peripheral (or ambient) awareness.

Similar to awareness and instant messaging in CSCW, the attention to care activities is often peripheral to other tasks. CSCC solutions should attempt to reduce cognitive load. They should fit into current practices of network members. Augmenting peoples' existing practices will be more successful when taking advantage of existing technologies such as phones and televisions. Taking advantage of the user's periphery may also be appropriate, for example, with the use of ambient displays. An ambient display form factor was successfully used by the CareNet Display.

3. To minimize issues of trust and reliability of reporting, CSCC systems should employ redundancy in sensing, data collection, and sharing when appropriate.

Currently, one or more network members, often the elder or primary caregiver, collect any data shared about the elder. Network members often consider information reported by elders to be unreliable, usually due to issues of cognitive decline or embarrassment. High levels of stress and lack of time are common issues for primary caregivers and contribute to inconsistencies with or omissions of critical data being shared. Results from the CareNet deployment suggest that data collected by a reliable third party (e.g., a pervasive computing system) can solve such problems. For example, a participant of one elder's network was surprised to see that her mother had a glass of wine with every dinner—this is something her mother never mentioned. Though the participant has no intention of confronting her mother with this issue, she was happy to know about it so that she could alert relevant medical personnel in the event of an emergency.

Why Should the Pervasive Computing Community Care?

Many opportunities exist for pervasive computing solutions to be employed in successful CSCC systems. One such opportunity is data collection.

Network members need timely and reliable information to provide an elder with care. For example, which medications has Mom taken today? Does Mom need a ride to her doctor appointment? Who is fixing the broken lock on Mom's gate? Pervasive computing technologies, such as sensors in the environment, could become data collectors for the network. Assuming the sensors are sufficiently reliable, they could either augment or replace current data collection

tasks. Recent advances in wireless sensor network technologies have resulted in drastic improvements in sensor size, cost, power usage, and variety. The latest generation of UC Berkeley sensor motes [6] is about the size of a US quarter and can report environmental conditions such as temperature, light, vibration, motion, and pressure for months at a time before needing a new battery. The wireless reporting and ad-hoc routing make these platforms ideal for incremental deployment in existing homes. As wireless sensor networks move into mainstream production, they will greatly enhance the quality and quantity of data that can be generated automatically and unobtrusively.

Related Work

Much of the research in the area of caring for elders could be used by CSCC systems. We present the most relevant work in eldercare applications.

There continue to be numerous research efforts in the area of eldercare. Several projects aim to help elders maintain their independence, predominantly in the home environment. These efforts aim to directly assist elders, their caregivers, or their family members. For example, ethnographic research conducted by Intel on households living with cognitive decline highlights the value of support networks to elder wellbeing [7]. Mann and Helal [2] are working on applications involving elders using smart phones to control their environment. The Digital Family Portraits project [3] envisions a digital picture frame, augmented with information about an elder, being used by geographically distant extended family members. The Nursebot project [1] uses a robot at a retirement community to remind elders about routine activities and guide them through their environments.

Other recent efforts are creating “smart homes” (homes instrumented with a variety of sensors and/or actuators) to help elders “age in place⁶.” For example, the Smart Medical Home at the University of Rochester includes prototype systems such as an interactive medical advisor. Other well-known homes include Georgia Tech’s Aware Home, and MIT’s House_n. A similar project focusing on existing homes is Honeywell’s Independent LifeStyle Assistant™.

The technology being developed for these homes could be used by CSCC systems to provide updates and communicate needs to the support network. For example, sensors in smart homes could report that the elder has taken morning medication; household maintenance needs could also be communicated to the network.

Already mentioned was the ELDer Project [4] that made observations that are directly relevant to CSCC. For example, they point out that “the goals of healthcare change as patients age.” They also claim “opportunities exist for communication and technology products and applications to enhance communication between stakeholders—elders, friends and family members, doctors and nurses.” Although this suggests helping the support network, they did not create any technology to support this idea, nor carry out any studies to validate it. Our studies confirm the importance of the support network and use the results to establish the CSCC perspective.

Conclusions

Future work in the area of CSCC could go in a variety of directions. For example, actual sensors could be deployed in-situ to gauge reactions to and acceptance of such new technologies, and form factors other than ambient, interactive picture frames could be explored⁷. We considered additional guidelines formulated from our analysis that could not be empirically validated because of the limitations of our 3-week deployments of the CareNet Display:

⁶ “Aging in place” refers to the postponement of the transition to a care facility.

⁷ Results from our CareNet deployment indicate that network members probably want an unobtrusive technology to use at home, such as the ambient, interactive picture frame and another, more mobile form factor, such as a phone service or website.

- Attempts should be made to lessen the impact of the elder's changing needs and priorities on members of the support network;
- CSCC systems should be proactive about the predictable changes in needs and priorities (e.g., the progression of well known conditions); and
- CSCC systems should monitor the health of the support network; e.g., looking for vacated roles, uneven distribution of responsibility, or necessary but unavailable skills.

We recommend long-term field studies to confirm our additional design guidelines. In addition, we suspect the CSCC approach could be broadened to address other groups of people who require regular care.

The need for technologies to help care for elders is growing as the size of our aging population increases. Accordingly, the role and needs of the support network will also grow. An increasing number of people in these support networks, including the elder, will benefit from technology that helps target coordination activities. These coordination activities are required to provide proper care for the elder while allowing the other network members to maintain their day-to-day lives.

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CareNet Display Sidebar



Figure 2. CareNet Display prototype. The user can click on any icon surrounding the photo of the elder to get detailed information about an event. The icons represent: meals, medications, outings, activities, mood, falls, and a calendar.

The CareNet Display is our initial application in the space of Computer-Supported Coordinated Care. It extends the idea of the Digital Family Portrait designed by Elizabeth Mynatt et al. [3]. Similar to the Digital Family Portrait, the CareNet Display is an interactive, ambient picture frame that augments a digital photograph of an elder with information about his/her daily life. However, instead of targeting distant family members to provide them with peace of mind, the CareNet Display targets local members of an elder's support network to help them with issues of coordinating care activities and disseminating information. This change in target user results in providing different types of information and levels of detail than the Digital Family Portrait. The photo (see Figure 2 at left) is surrounded with icons of specific events about the elder: meals, medications, outings, activities, mood, falls, and his/her calendar. To get details, the user touches an icon, which replaces the photo of the elder with details of that event. The display is automatically updated as events occur throughout the day.

The actual prototype uses a touch-screen tablet PC housed in a custom-built beech wood frame.