Challenges and Opportunities for Collaboration Technologies for Chronic Care Management

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Abstract

In this paper, we explain how our research on applications for chronic care domain problems has uncovered challenges and opportunities in the design and development of collaborative applications. Specifically, we discuss projects focused on care of the elderly, children with special needs, and individuals with diabetes.

Background and Motivation

Growing awareness of the changing world demographic and increasing proportion of older population is leading to a blossom of computing applications that support healthcare. These applications span a spectrum from the more traditional support of medical professionals in acute care centers, such as hospitals, to the growing attention to supporting individuals suffering from long-term chronic ailments at their homes. Acute healthcare centers have long become an important area of study from the perspective of cooperation and inspired in-depth investigations in the field of Computer Supported Cooperative Work [27]. On the other hand, the appreciation of the chronic care environments as an inherently collaborative activity, while growing, is still nascent [8, 13, 25].

Over the past several years, each of us has engaged in research agendas focused on elder care, care for children with specials needs, or support of individuals with diabetes respectively. This work has covered a large spectrum of human-computer interaction research, from exploratory, ethnographic work to deployment and evaluation of full systems. These research projects were not initially motivated by the ideas about collaborative work. However, through the investigations, each set of researchers independently reached the same conclusion: chronic care is an inherently collaborative effort and applications that support it need to reflect its intricate cooperative nature. Both individuals providing care and those receiving it face significant challenges in coordinating care, sharing information, and communicating within a sometimes very large network of caregivers. Furthermore, although these caregivers usually each share a common goal of providing the best care possible, they often have other different and sometimes conflicting goals and priorities.

Our research in the design of applications for a variety of chronic care environments has uncovered both challenges and opportunities for collaborative applications for chronic care management. We focused these projects on supporting familial caregivers of the elderly and aging in place, professional and informal caregivers of children with autism, and professional and self-care for patients with diabetes. Through this examination of chronic care, we have formulated two research questions:

- How do the underlying technologies of existing chronic care applications need to change to support usage by a group of people?
- How do the practices, approaches, and theories in CSCW need to be adjusted to transition from work practices into such areas as home technologies and, specifically, chronic care at home?

In this paper, we describe the conditions on which we have focused to provide the reader with sufficient background in the domain problems. We also describe the similarities of the chronic care management problem across these conditions. We then describe the networks of caregivers, including the patient or student in the center, for each of these conditions again with an eye towards the commonalities that can provide some indication of parallel system needs. We then recount the technologies developed by us and by others for addressing some of the problems within these domains. Finally, we conclude with a discussion of the design considerations for technologies to support chronic care and how the group of caregivers supporting these students and patients directly and particularly influences these considerations.

The Problem Domains

In this section, we present findings from our formative work in three domains of chronic conditions: pervasive development disorders in young children, care for elderly individuals, and diabetes management. Much of this has come from interviews with domain experts, caregivers currently treating individuals with chronic conditions, and the patients themselves. We have also gathered information from participant observation and through a search of relevant literature to these domains.

Pervasive Development Disorder

Pervasive Development Disorder (PDD), also known as Autism Spectrum Disorder (ASD), is a cognitive impairment that characterized by deficiencies in communication, social interaction, and creative or imaginative play [3]. This spectrum includes sub-categories: Autistic Disorder (Autism), Asperger's Syndrome, Pervasive Development Disorder Not Otherwise Specified (PDD-NOS), and Rett's Disorder. Individuals with PDD, particularly those with autism, the focus of most of our work, may exhibit stereotypical, self-stimulatory behaviors, such as rocking, hand flapping, or vocalizations. Autism is the most common of the Pervasive Development Disorders, affecting an estimated 1.5 million Americans today, and growing at the astonishingly rapid rate of 10 to 17 percent annually. Autism is typically diagnosed between the ages of two and six, although other variations on the ASD spectrum can sometimes be diagnosed a little earlier or later than that range.

Although there exists a set of known ways autism manifests itself in individuals, it is a highly variable and individual disorder, making each case unique. Individuals who are diagnosed on the spectrum can have large variations in their degree of functioning. Higher functioning individuals may be able to achieve high levels of independence, and in fact, until recently, many very high functioning individuals with Asperger's went undiagnosed and were sometimes simply perceived as "odd" due to their deficiencies. Lower functioning individuals may never achieve true independence. The variation seen in individual patients is not limited to the severity of their conditions. The disorder manifests itself extremely differently within each person, and in fact, may even present differently in the same person over time. The anecdotal comment echoed by practitioners and family members alike is "If you've seen one child with autism, you've seen one child with autism."

Evidence in the behavioral, educational, and social sciences indicates that early diagnosis and intervention can be essential to achieving greater independence, an ultimate goal of PDD care activities [29]. As echoed in descriptions of other language acquisition disorders, such as deafness, children who do not achieve some level of language and communication functioning by the time they start school can be severely limited in their future abilities to interact with other people in the world [15]. Thus, caregivers can be in a race against time to try to find the treatment that will work for their children. However, there are many interventions that may or may not work for any particular child, and these interventions are often applied simultaneously by a variety of professionals and other caregivers. The types of treatments employed include pharmacological interventions, special diets, holistic approaches such as occupational therapy and sensory integration, behavioral therapies such as applied behavior analysis or functional behavior analysis, and symptom-specific treatments such as speech or language therapy. Heflin and Simpson provide an overview of the types of therapies available for children with autism [14].

Aging

Rapid aging of the world's population has resulted in unprecedented attention to the issues associated with health and care for aging individuals. The unfortunate, but inevitable, consequence of growing old is the increasing risk of developing physical, emotional, or cognitive ailments. In their mild form, these ailments may affect individuals' quality of life and their ability to participate in regular daily activities. For example, climbing stairs, getting in and out of the house, or driving may become prohibiting in advanced years. In a more severe form, such ailments may lead to a complete disruption of one's lifestyle and put individuals in need of continuous medical attention. Studies show that two thirds of Americans over 62 have at least one chronic disease; heart disease, diabetes, and respiratory problems are the top chronic ailments of this age group [21]. At the same time, aging individuals often experience signs of cognitive decline, which in more severe cases takes the form of dementia, a brain disorder that impacts persons' ability to carry daily tasks. According to the Alzheimer's Disease Education and Referral Center [1], 4.5 million Americans suffer from Alzheimer's Disease, the most common form of dementia. In addition, an elder's emotional state can be affected greatly by loneliness, loss of a spouse, loss of a child, and other changes to their social structure including those resulting from loss of activities outside the home or from loss of friends.

Aging is a lifelong process that progresses along a spectrum of decline towards the end of life. Diagnosis of a particular type of decline usually includes assessment of an individual as being some level below average functioning. While there exist general standards regarding such averages (usually assessed via Activities of Daily Living scales), establishing individualized baselines can be essential for a better diagnosis and treatment process [24]. Like PDD, aging and its associated decline are exhibited along a spectrum with varying degrees of functionality. Although there are some defining symptoms that help to place an elder within the Alzheimer's diagnostic population, dementia, etc., aging affects each individual uniquely and personally.

The goal of care for aging individuals is to maintain independence as long as possible. Again, like in development delays, when considering cognitive decline, early attention is essential in helping the elders cope with aging: in preserving physical and mental health as well as in early recognition of developing disorders and diseases. Strategies exist for preventing some of this decline. These include cognitive exercises, for example provided by Dakim's [m]Power™ Cognitive Fitness System [2], rehearsals and reminiscence therapy can help to maintain the memories of the past and one's identity, or therapy and social interventions to help combat loneliness and emotional fragility. A variety of interventions are available for maintaining physical and mental health: mild physical exercise and a careful diet rich on essential vitamins can help individuals remain strong physically. An organization of physical space for aging individuals can play an important role in their ability to remain independent. Interior design that reduces risk of tripping and falls, simple organizational tools such as pillboxes and post-it notes with reminders can help individuals go about their daily activities. In more severe cases of decline, a variety of pharmaceutical solutions are available for both physical and cognitive ailments. In all these interventions, however, motivation of the aging individual is one of the critical success factors. Engaging elders in self-care can be one of the most challenging aspects of elder care.

Diabetes Management over a Lifetime

Diabetes mellitus is one of the most costly and common chronic illnesses among the elderly. There are 20.8 million people in the United States, or 7% of the population, who have diabetes [6]. Diabetes is a disease that affects a body's ability to either produce (type 1) or use insulin (type 2). Insulin is an important hormone responsible for converting sugars, starches and other foods into energy necessary for daily life. Without insulin, the sugar accommodates and affects internal organs, slowly leading to a variety of complicated diseases including blindness, end-stage renal disease, stroke, and coronary artery disease. One of the dangers of diabetes is the lack of clear symptoms, which leads to such diagnosis rate. According to the American Diabetes Association, 6.2 million people are unaware that they have the disease.

Diabetes is defined as a progressive and as a spectrum disease, one of the main challenges being a great variability of individual cases. The extent of insulin production or consumption in the body varies greatly, rendering each case unique. While there exist general guidelines regarding symptoms, or reason for aggravation of conditions, each individual diagnosed in diabetes needs to become a detective, carefully monitoring their conditions and learning how their bodies react to different foods, medications and physical activity [23].

The main purpose of treatment and care in cases of diabetes is to keep blood sugar level consistent and within the desired range. Deviations in both directions are dangerous and can be lethal. Similarly to the two previously discussed cases of PDDs and aging, early detection and intervention, are crucial to avoiding complications typical for diabetes. While there are a large variety of available medications, it is essential that they be complimented by alterations to one's lifestyle. Restricted consumption of carbohydrates and sugars and regular exercise are critical to maintaining consistent blood sugar levels. One of the main challenges of diabetes care is devising an optimal treatment plan that addresses each particular instance of the disease. Great individual variability of symptoms and reactions prevents healthcare professionals from developing exact rules for diabetes management or from finding a perfect combination of medications. Each case needs to be carefully considered and each affected individual needs a unique combination of medications and lifestyle changes.

Discussion of Conditions

The three sets of conditions discussed in this paper have important differences; however, they also have striking similarities, typical, perhaps, to other chronic conditions as well. In all cases, early detection is crucial to achieving the desired result of a higher level of independence. This can be either from the caregivers, as is the case for the aging adults or children with autism, or from increasing reliance on medication, as is the case for individuals with diabetes. All cases lack a known cause or single definitive cure. Instead, they require long-term commitment to a variety of interventions that help to manage symptoms, rather than cure the condition. In all cases, great individual variability presents the need to carefully tune an intervention to the needs of a particular individual. Such tuning can only be achieved by careful observation of successes of each attempted intervention. These similarities in conditions lead to a number of common traits in the organization of care for the aging individuals, children with autism, or individuals with diabetes.

Care Network

The caregiver networks of children with autism, the elderly, and individuals with diabetes have many similarities and some key differences. Each of these conditions can be quite complex, unique in each case as described in the previous section or be further complicated by other ailments. Because of this complexity an individual often receives care from and consults with a wide variety of specialists. Additionally, family and friends often participate in the care, to a degree demanded by the severity of one's conditions and ranging from occasional calls to daily assistance in all essential activities. In all of these cases along a wide spectrum of independence, however, individual caregivers can participate in the care at varying levels depending on their relationship and responsibilities. In this section, we describe the caregiver networks present in each of these cases and then conclude with a discussion of the similarities and differences in each of the problem domains.

Groups of Adults Caring for an Individual: the Autism Case Study

As previously discussed, a primary concern of those focused on caring for children with autism (CWA) is to provide early interventions in the hope of increasing later independence. This goal usually translates into multiple types of care provided by different people, but all are centered on the child (see Figure 1). Care tends to be directed by someone whom we describe as the "primary caregiver." This person may be a parent, and often is, but it may also be a guardian or someone who lacks any legal responsibility for the child at all, for example an official from a foster care center, or a concerned teacher from a school or family services. If the child is high functioning, he/she may also have some involvement in making treatment decisions; however, this case is extremely rare, especially for very young children.

CWA often spend the traditional 35 to 40 hours per week at school and an additional 20 to 40 hours per week in external therapies with a variety of specialists (speech therapists, occupational therapists, physicians, etc.) and with teachers, para-professional classroom aides, baby-sitters, friends, and family members. Although many of these individuals are co-located (in a school or in a home), there are numerous challenges to their communication about an individual child's care: lack of time for discussion, lack of documentation, lack of a common background, and in the case of non-co-located individuals, lack of access to one another. Often there is a reliance on the primary caregiver to relay information obtained from other caregivers. Sending information through the primary caregiver can result in incomplete or inaccurate information between the occurrence itself and the transferred information. To avoid some of the problems of forgotten or inaccurate information, some caregiver networks use the practice of writing notes in a journal carried in a backpack by the CWA. Finally, other caregiver networks make use of forms and scoring sheets to detail important data from the child's experiences.

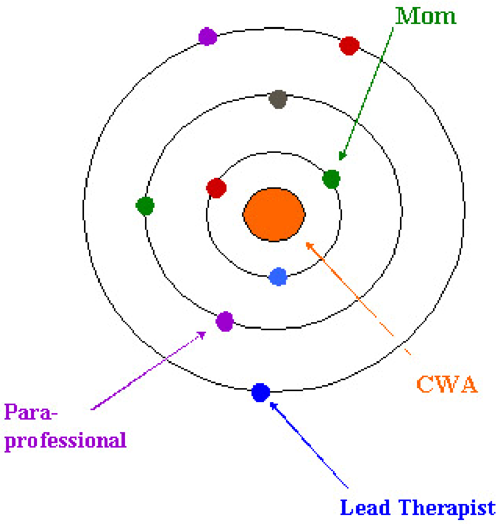

Figure1: An example of the caregiver network centered around one child with autism (CWA)

Meticulous records, however noted, require large amounts of effort on the part of the caregivers. Recording details from experiences with a child can take more time and effort than is available for busy caregivers. Echoing Grudin's challenges for groupware [11], a secondary concern in this case stems from the burden of data collection falling on individuals who often do not benefit directly from the access to it, such as teachers gathering data for use by a behavior specialist. Similar to these concerns about the benefit of data collection, caregivers have concerns regarding control of this data, reflection of themselves and their competence to the outside world, and the social affordances of keeping various types of records [12]. The CWA himself, may also have concerns about the type of recording and communication done about his care, if not now, then as he ages and becomes more independent, aware, and able to make decisions for himself.

Planning for the Next Generation to Care for You: The ElderCare Case Study

One of the main goals of the elder care is securing continuous independence and high functioning of the older adults. The number and types of caregivers can vary greatly from patient to patient but they generally include the patient him/herself, professionals, adult children, and other friends and family members.. Professionals often include a primary care physician who ideally has established a relationship with the patient prior to any severe decline. Specialists are then sometimes recommended by this primary care physician or by others in the care network, depending on available medical plans. Family and friends tend to organize themselves through appropriate roles. There can be a central individual, in most cases an adult daughter, but sometimes other family or friends or even workers at a public institution. The other caregivers then coordinate their care through this primary caregiver, similar to the networks witnessed in the autism case study. Oftentimes, the individuals make arrangements for the care they receive as they age. Even if informally, elders often participate in the care they will receive towards the end of their lives. This participation, however, may decrease as aging progresses.

Elder patients spend a vastly varied amount of time and money on their care, depending on the particular challenges. Both the amount of time and money required, however, tend to expand over time, eventually resulting in long time expanses in hospital or hospice with extensive pharmacological bills. Thus, in preparation for this time, most caregivers and patients will seek advice and treatment from a large number of individuals, each of whom may supply different interventions. These professionals are frequently located in different offices and may not know one another. Furthermore, usually only one or a small number of informal caregivers actually interact with these professionals. While in a hospital or hospice, a unified health record can help the professionals to keep the communication lines open. Even if this record were available at all times and to all professionals involved in the care, family and friends still have to rely on communication to filter through the network, resulting in similar misinformation problems as seen in the autism case study.

Managing Your Own Diabetes with Help from Others: The Diabetes Case Study

The main target of diabetes care is achieving a strict control over blood sugar, maintaining it at a consistent level within the desired range. Patients with diabetes are often very involved in their own care, excepting in those cases in which independence is greatly reduced by another disorder. Despite personal involvement in the care, however, diabetes patients still have to rely on a large network of other caregivers including an endocrinologist, a general physician, a nurse, and a dietician. The communication with all these specialists varies in frequency, issues discussed, goals, and purposes, and nearly always centers through a primary caregiver, in this case nearly always the patient him/herself.

The patient's endocrinologist, or often general physicians, is responsible for selecting appropriate treatment. Because devising a perfect treatment is not possible, it is usually refined through multiple cycles of trial and error – a treatment would be prescribed for 3 or 6 months, depending on the severity of the case, and then adjusted based on the outcome. Nurses are responsible for education and the majority of day-to-day questions. Communication with nurses is usually more frequent and spontaneous and many clinics provide on-call nursing assistance for individuals with diabetes. Additional caregivers include dieticians, who help develop personalized diet plans or specialists who monitor for typical diabetes complications, such as foot or eye disorders. However, individuals with diabetes, especially type 2, rarely develop the condition in isolation, and thus each individual is likely to see a number of other specialists. Many of the difficulties with selecting a treatment are due to the conflicts between treatments for different ailments. For example, the best medication for diabetes may not be appropriate due to liver malfunctions.

In the best case scenario, individuals enroll into certified diabetes education courses upon diagnosis. This not only allows them to take charge of their health, but also introduces them to a well-organized caregiver network. In the centers where these courses are provided, the nurses, the dieticians, and the physicians already know each other and have come up with ways to work together and appreciate each other. More commonly, though, there is a great disconnect between the individual and each of these supporting nodes in the network and between the nodes themselves. On one hand, the most difficult task for an individual with diabetes is to communicate to the specialist their current state of health or factors that impact it, for example recent diet and exercise routine or medication adherence. Common means to facilitate such exchange include journals for daily blood sugar records, meal diaries, or 24 hour diet recall. At the same time, disagreements and miscommunication between the caregivers are common. For example, dieticians may disapprove doctors' choice to increase medication, instead of insisting on restricted diet.

Technological Support for Chronic Care Management

Chronic care management is a complex set of domain problems that could benefit from a variety of computing and technological support. Attempts by caregivers to record the right information at the right level required for chronic care represents a weighty capture and access problem in ubiquitous computing. The sheer amount of information collected for diagnostic and monitoring of chronic conditions create an impressive data storage, management, and mining problem. The struggles experienced by caregivers attempting to communicate with one another demonstrate a compelling need for rich communication at a distance and the ability to communicate through and with shared artifacts both physically and digitally. Finally, allowing patients to monitor and to access their own health details using increasingly complex medical devices represents significant human factors and assistive technologies problems. In this section, we describe the technologies created by our research projects as well as those created by others for each of the three case studies discussed in this paper.

Supporting Record Keeping for Children with Autism

Although a number of technological advances have been made in developing systems for children with autism (CWA) to use themselves, the focus of our research projects has been on creating technologies to support the care of these children. Collecting and analyzing evidence of widely varied symptoms for diagnosis, treatment, and monitoring of CWA is a major part of this care process. Thus, we have developed three major systems for supporting record keeping for CWA:

- Abaris, a capture and access application to support therapists in a specific, controlled therapeutic intervention [18];
- CareLog, a capture and access application to support caregivers in documenting incidents of interest outside of expected instances [13]; and
- Walden Monitor, a combination wearable and Tablet PC based system that combines two existing paper-based data-collection instruments for timed data collection in the natural environment of a classroom [32].

Capture and access technologies are particularly applicable to the monitoring, diagnosis, and intervention treatments of behavioral and learning disabilities in children. Behavior and learning data are pieces of information that can be captured, measured, mined, and analyzed over time. Furthermore, the members of care teams are particularly motivated to do these activities, which may or may not be the case in traditional capture and access scenarios, such as meetings and classrooms. Capture and access applications created as a part of a cyclical system of diagnosis and treatment are also an interesting and special case wherein, the data captured in the past, once accessed and analyzed, affects the treatment plan and often the data to be captured in the future.

Discrete Trial Training therapy is a current best practice intervention for children with autism in which teams of therapists administer intensive, one-on-one teaching of basic skills. Abaris supports this practice by using recognition technologies to index into videos of therapy sessions via an access interface that allows for the collaborative discussion of the progress of the child. By allowing for easy indexing into videos, teams of therapists can use the videos to use video evidence to go back and review how the child is doing, look for inaccuracies, and easily show problem areas to other therapists for evaluation [13, 18].

CareLog is a mobile capture and access application for recording behavioral data in informal settings. CareLog also takes advantage of the Experience Buffers architecture [12], a collection of capture services in the environment that are always on and available but only archive when explicitly requested. Otherwise, the information captured is deleted after a short period of time (*e.g.* fifteen minutes). This system allows caregivers to capture information in informal and unplanned settings while maintaining some of the social norms surrounding recording in that environment. CareLog's advantage over other data collection techniques is that it can provide caregivers with video evidence of incidence that can be easily shared in a manner that is more informative and less work than traditional forms of data collection, such as writing down observations or narrative descriptions post-incident.

In some schools, paper-based data-collection instruments, such as the Child Behavior Observation System (CBOS) and the Pla-Chek (pronounced PLAY-check) serve to add some form and structure to data collection in the natural environment. These data are also gathered using CBOS, in which a research assistant enters the classroom with a handheld video camera and records the child for five minutes. Another researcher watches the video and codes the variables on a spreadsheet similar to Pla-Chek. The teacher tabulates the data and includes it in written reports. We have created a prototype called the Walden Monitor (named after the school we studied), which served to streamline many of these processes by indexing the manually collected data into a video recording captured from the point of view of the caregiver using a head-mounted camera and a tablet PC [32]. The Walden Monitor aims to ease some of the burden in data capture and analysis and provides an easy way for researchers to capture this data and share it with others.

Other researchers have looked into how technology can help individuals with autism, but mostly in developing applications for use by the individuals themselves, rather than by their caregivers. These devices include Simone Says, a system using voice recognition technology to teach and analyze language skills [20]. The Discrete Trial Trainer [31] is a commercial software application that attempts to replace the therapist in Discrete Trial Training Therapy by administering similar therapy and education through the computer. While Simone Says and DTT are both applications used by the individuals themselves, they can both help ease some of the burden on caregivers by allowing a computer to administer therapy, leaving the caregiver more time to deal with other issues in care. Researchers have also looked at how storytelling with virtual peers can be used to teach social skills to children with autism in a setting they are comfortable with [30], while others have looked at how images of people can be exaggerated to help individuals understand subtle emotional cues [17]. These types of socially based applications can be used in conjunction with caregivers to provide a more rich education in social skills, which again leaves the caregivers with more time for other, more pressing issues.

Supporting Monitoring and Communication in Eldercare

There are a number of opportunities for computing technology to enhance elder care. Most of the applications follow one of the few directions we discuss below.

A majority of commercially available applications for disease management target clinical monitoring of aging individuals by certified nurses or other healthcare practitioners. These applications, such as Phillips Motiva [26] or Health Hero Network [4], and many others are including a variety of sensing and self-report techniques to allow nurses keep an eye on their older patients remotely. Occasionally these applications also allow family members of the patients to access collected information through web portals. However, the main purpose of such applications is to allow health professionals to make informed judgments regarding medical treatments or to prevent emergencies and complications.

The second class of applications include those that use similar capture techniques to allow adult children maintain awareness of their aging parents' health. By denying the casual daily contact that naturally occurs when families are co-located, the geographic distance between extended family members makes casual, lightweight observation or "keeping an eye out" for family members impossible. The Digital Family Portrait [28] reconnects family members by providing a qualitative sense of a distant relative's well-being while striking a reasonable balance between privacy and the need for information. Like a traditional portrait, it is designed to be hung on the wall or propped on a mantle, at the same time utilizing the dynamic frame to reflect activities and context of the aging person. In a similar manner, a CareNet display, designed by the researchers at Intel communicates to collocated caregivers a selection of information about an elder's health and habits [7]. Wizard of Oz deployment of the prototype of this application with one household demonstrated improved care and increased participation of peripheral caregivers, in addition to the primary one. However, it also showed that elders desired higher level of control over what information is being shared and with whom.

The final class of applications focus on providing health and assistance to the aging individuals themselves. The Cook's Collage and Memory Mirror applications, developed at Georgia Tech, are designed to assist individuals with simple and repetitive tasks that often escape one's memory. While the Cook's collage is providing assistance in remembering recent steps taken while cooking, the Memory Mirror reminds individuals their last interaction with small items that are frequently lost or forgotten, such as medication bottles, or keys. The Memory Mirror system uses RFID (radio frequency identification) technology which is available yet expensive today. Each household item (e.g. medicine bottles, food containers) has a RFID tag on the bottom, and the designated storage area (e.g. medicine cabinet, key tray) has a RFID reader on the top.

Ongoing research continues to investigate issues regarding elder care. New applications monitor individuals' cognitive abilities as demonstrated in game playing and allow noticing deviations early on [16]. Extensive ethnographic work conducted by the researchers of the Intel's Proactive Health group identified a number of concerns that seniors have. These fall along three main categories, including social and identity, such as feelings of loneliness helplessness to change it, cognitive, including embarrassment about forgetting things like people's names, or physical, such as fear of falls.

The majority of elder care applications discussed above tend to support a particular link within the care network, focusing either on the clinical caregivers, the family members or the elders themselves. A relatively unexplored direction that we advocate in this paper is development of applications that specifically focus on fostering communication and information exchange between the various nodes of the network. A notable example of providing information to all the parties involved in the care, including the elders themselves are applications developed by Elite Care [9]. At Oatfield Estates, run by Elite Care, concerned caregivers outside of the facility and the patient him/herself can check on signs of health through a web interface. There are two goals to the monitoring technology in place: "The first is [for] residents who want biofeedback and cues to prolong their independence. The second is [for] staff who want ways to identify health problems early and objective quality control." This class of applications can serve as a facilitator between the caregivers providing different views on the health information that reflect differences in goals and priorities.

Supporting Individual Management of Diabetes with Support from Other Caregivers

Computing technologies for diabetes management tend to follow a similar pattern and address individual nodes in the care network, rather than focus on fostering interaction and exchange between them.

There exist a large number of emerging computing applications that target enhanced diabetes self-care. Because affected individuals usually serve as primary caregivers, they are often considered the most important link in the care network. These applications include various methods for storing relevant records, such as meal diaries and records of blood sugar, or provide access to important knowledge bases, such as nutritional libraries that help to look up nutritional values of various foods. Oftentimes these tools are available on mobile devices, such as PDAs or cell phones. While these applications provide valuable information, their actual benefit is not well-understood and their usage and impact may be quite intricate. For example, Frost and Smith [10] found that even when given an opportunity to take pictures of their meals, individuals tend to maintain relatively skewed view of their diets. Thus, while taking a picture of a healthy lunch, individuals failed to notice things that were pointed by others during collective reflection, such as cans of coke in a trashcan. Similarly, deployment of the Continuous Health Awareness Program (CHAP) by Mamykina et al. [22] illustrated a number of shortcuts and biases individuals may fall into while reviewing their retrospective records.

CHAP application, jointly developed by Siemens Corporate Research, Georgia Tech and Columbia University, attempts to serve as a comprehensive tool for retrospective diabetes analysis and utilizes a combination of clinical and lifestyle monitoring techniques. The system includes an advanced clinical monitoring device, GlucoWatch G2 Biographer, which takes a non-invasive reading of blood sugar every 10 minutes, making daily trends visible. CHAP also includes a combination of sensors and self-report tools that allow individuals to keep track of activities, composition of meals, and emotional state. All of this data is then aggregated and presented visually back to the individual on a daily basis. Deployment of CHAP as a technology probe highlighted particular strategies adopted by individuals when analyzing these retrospective records.

Similarly, there exists a large variety of technologies for supporting clinical overseeing of patients with diabetes by healthcare professionals. Such technologies, however, tend to focus on more precise methods of monitoring blood sugar, rather than on allowing clinicians to gain deeper insight on the factors affecting blood sugar. Most commonly, clinicians still rely on traditional tools, such as paper meal diaries or 24-hour diet recall. At the same time, gaps in communication and shared understanding are common even for clinicians responsible for a single diabetes patient [19].

There exist several notable attempts to utilize computing technology to foster communication between diabetes caregivers. For example, MyFoodPhone [5] allows individuals to use a camera phone to take pictures of their meals and send them to their dietician or a fitness specialist. Such exchange can facilitate interaction and lead to a deeper understanding between the parties. However, these tools may also lead to a quick information overload of clinical professionals. Further analysis is required for development of successful boundary objects that foster communication, while allowing each actor accomplish their unique goals.

Cooperative Technologies for Chronic Care Management

Technologies designed by our research groups and by others have begun to explore how we can better capture and share information amongst patients and caregivers across three varied chronic care domains. These technologies are still seriously lacking, however, in that they were designed to support only subsets of the care provided. More work is needed to design bridging technologies that can support the overlap and conflict between varied interventions and data collection strategies in these situations. In this conclusion we reflect on challenges that we identified in our own work and observed in the work of others and opportunities for furthering technologies for chronic care.

Challenges

The care of individuals with chronic conditions as a collaborative problem presents several unique challenges for researchers to address. Teams of caregivers and educators are often diverse, coming from different backgrounds and may not be technologically savvy. Additionally, they are rarely co-located, and do not see each other on a regular basis, if at all. For example, in our studies of children with autism, it was not uncommon for a child to see a behavior therapist, an occupational therapist, and a speech therapist all on the same day, with no way for them to have access to each other's records, although sharing would often be beneficial. Low-tech solutions have included passing paper records with the child or parent, however, these records often do not capture the appropriate data needed by each of the individuals and can be too much of a burden for many involved. Technologies that can automatically collect and share data, such as capture and access applications we have tried with children with autism, can help support these types of interactions [13].

For individuals with diabetes, awareness of successes and limitations of past management strategies, such as diet, exercise or medication is the crucial factor in devising future approaches. Often, this awareness depends on the patients' memory, their ability to observe relevant correlations and to communicate them to healthcare professionals. Automated capture of relevant activities and blood sugar levels can inform individuals' and their caregivers' reasoning regarding the desired alterations to the medical regimen and lifestyle.

In addition to these challenges amongst teams of caregivers, coordination between individuals inherently includes issues regarding privacy, security, and legislative control. For example, in the United States, patients are protected under the Health Insurance Portability and Accountability Act (HIPAA) and students are protected under the Family Educational Rights and Privacy Act (FERPA). These regulations ensure that medical data and educational data, respectively, must be kept private and protected from malevolence, and software designed to share and discuss this data must ensure that data is not misused. The design of applications that can follow these laws will also help to address any concerns raised by the individuals receiving the care or caregivers close to that individual. In the design of DFP, for example, we chose to provide remote caregivers more abstract data about activity levels rather than more invasive information such as live video feeds. The CareLog system, designed to support functional behavior assessment of children with developmental disabilities, used selective archiving of camera recordings in the environment to balance the desire to catch relevant behavioral episodes retroactively against privacy and information overload concerns of continual recording throughout the school day [13].

Strategic decisions for health and education should be based on evidence from everyday life. While we as humans are good at detecting and interpreting the meaning of any given situation, we are not good at detecting trends over longer time periods. As a result, strategic decisions are often overly influenced by immediate phenomena or imperfect memory of events over the recent past. Because care is often done by teams with little collocated, synchronous interaction, there is a real need to share rich details of experience, but often little time to create those descriptions. We saw this problem in our study of children with autism, both for specific therapies (e.g., discrete trial training) [18] and planning of Individual Education Plans (IEPs).

Opportunities

Our experience shows that there are opportunities for collaborative technology to support the needs of the caregiver network. There is a possibility of advancing both practical care and the research about that care if we can document and visualize the progress for these individuals. If new technologies can improve the amount and quality of data collection for these individuals, it can help to open lines of communication amongst groups of caregivers and patients. These new lines of communication may even be able to help build communities of trust, in which caregivers and subjects of care all feel comfortable sharing in the collaborative work processes. We can also provide a large dataset for other science, medicine, or education researchers to use in searching for patterns in chronic conditions. We can also use this opportunity to deploy and evaluate new collaborative technologies in settings in which high levels of motivation for improving care will likely encourage earlier adoption, as we have already seen in our own projects.

Central to this opportunity is the consideration of rich data, such as video and audio, as part of an individual health or education record. Our limited experience shows the value of this rich data when it can be mined effectively. For chronic conditions in which behavioral evidence is important (e.g., performance on activities of daily living for an aging person, or self-stimulating behaviors for a child with autism), these richer data types are just as important as blood glucose measurements for a diabetic.

With such willing participants, we may also be able to evaluate some of the challenges inherent to groupware. For example, Grudin [11] describes a challenge to adoption of groupware applications when individuals doing much of the work are not the same as those receiving much of the benefit. Similarly, caregivers collecting data are often not the ones analyzing it. The diverse nature of caregiver networks also allows us to explore groupware applications among multiple parts of the CSCW Time/Space grid. We have begun to evaluate Abaris, a tool for supporting a team of co-located, synchronous individuals who are evaluating the progress of a child with special needs. There are also situations where we have asynchronous times and locations, such as passing information between one healthcare provider to another. We can also use exploration of these domain problems as an opportunity to try some of the existing evaluation techniques for groupware as well as to evaluate the underlying technologies of the tools we've developed (i.e. activity monitoring or capture and access).

Conclusion

Based on our own experiences and our review of relevant literature, we have presented a case to encourage researchers to focus more deeply on the issue of technologies to support the coordination of care of individuals with chronic conditions. Though there are many challenges in designing technologies for cooperative care, there are also many opportunities. Since there is such a great need for something to help caregivers organize their communication structure and help to reduce redundancy in data collection, there will be no shortage of willing participants or problems that need solving. Through our experiences in developing technologies for children with developmental disabilities, the elderly, and individuals with diabetes, we have already found commonalities amongst these conditions. We suspect there are similar challenges with other chronic conditions such as cancer, visual or hearing impairments, and other cognitive disabilities in adults. The key to designing useful applications for these types of people will involve an extensive understanding of each domain problem and creative approaches to solving the communication needs amongst the patients and their caregivers.

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