

CCCiC 2014

Proceedings of the **ACM CSCW Workshop** on **Collaboration and Coordination** **in the Context of Informal Care**

15th February 2014
Baltimore, Maryland (USA)

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ISSN 1021-73643

Institut für Gestaltungs und Wirkungsforschung, Nr. 18, February 2014.

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www.media.tuwien.ac.at

Preface

This volume presents the proceedings of the workshop “Collaboration and Coordination in the Context of Informal Care” (CCCiC 2014), held in Baltimore, USA, on the 15th February 2014, as part of the 17th ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW 2014). The proceedings list the papers accepted for presentation in the workshop and the abstract of the opening keynote.

CCCiC 2014 is the first edition of a series of workshops organised by the academic members of TOPIC (The Online Platform for Informal Carers), a European project that aims to advance the understanding of the daily practices of informal carers and to design information and communication technologies to lower their burden, funded by the AAL (Ambient Assisted Living) Joint Program.

Studies on issues of informal care suggest that further research in the area is needed to better understand its demands and to figure out more effective ways for technologies to support people who deal with them. These studies recurrently stress that care work is often demanding and that the results of these demands are different types of burden (e.g. psychological, physical, and emotional), which can be higher or lower depending on variables like the age, gender, and type of illness of the person receiving care.

Therefore, the workshop invited contributions on issues of design and development of systems to support coordination and foster communication and

collaboration between informal carers and their friends, family members, and health professionals, aiming at relieving the aforementioned burdens stemming from informal care activities. This includes but is not limited to systems such as: *integrated social support platforms* to serve all relevant aspects of carers’ needs through adequate products and services; *accessible (mobile, tactile) ICT* applications to automate tasks of general caregiving when suitable; and *social media for social support*, such as online communities with special focus on social support for the elderly.

Acknowledging the relevance of understanding the users’ context to be able to design up-to-date, useful and usable solutions, the workshop focused on research following *user-centred and participatory design approaches*, valuing the development of *sustainable technologies* and taking into account relevant *ethical issues* in terms of the use of ICTs for informal care.

The contributions featured in the proceedings have been **peer-reviewed** by the members of the workshop Program Committee and selected on the basis of their quality, compliance with the workshop theme, and the extent (and diversity) of their backgrounds in design. They express points of view of researchers from both academia and industry and provide relevant insights in the design and development of technologies for informal care.

CCCiC 2014 Organisers

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Workshop Papers

Enabling Care Provider Organizations to Make Use of Informal Resources: Visualizing Social Context

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CCCIC'14, February 15, 2014, Baltimore, Maryland, USA.

<http://cccic2014.wordpress.com>

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ISSN 1021-73643

Abstract

This is a position paper for the CSCW 2014 Workshop "Collaboration and Coordination in the Context of Informal Care." It describes the early stages of design work intended to allow care provider organizations to make use of (identify, recruit, coordinate, manage) informal resources (family members, friends, NGOs, community groups, etc.) to support their clients. The approach is to combine a broad range of data drawn from various sources to provide a holistic visualization of clients and their social contexts, so that care providers can orchestrate the use of both formal and informal resources. While this project focuses on care provider organizations, such visualizations could also be useful to individuals delivering care on their own.

Author Keywords

Informal care; visualization; social context; electronic medical records; health care; social services;

ACM Classification Keywords

H.5.2. Information interfaces and presentation (e.g., HCI): User interfaces.

Introduction

The approach to health and social care in much of the world is often problem-oriented. A mother becomes ill and goes to the doctor; an elderly person, disoriented and found wandering in the street, is aided by a mental health specialist; a child suffers abuse and is assisted by child protection workers. Problems occur; care providers react.

Over the last two decades various agencies have been exploring a new paradigm for delivering health and social care [4]. Though operating under various rubrics – coordinated care, patient-centered medical homes, community health teams, integrated care – these approaches all share a longer term, more proactive stance: care is delivered by teams; problems are identified early when prevention is less costly; and solutions are designed and managed so that they work in the larger context of a client's life.

An important aspect of this approach to care delivery is that it depends not just on formal resources (i.e. government and institutions), but also on informal resources such as family members, friends, and community groups and services. Examples of problems that might be addressed in such ways include

- Identifying local after-school activities for an 'at risk' teenager
- Recruiting someone to accompany an elder to an appointment with a physician, and to assist them in adhering to their medication regimes
- Coordinating volunteers to pay regular visits to someone who is unable to easily leave their home
- Finding a neighborhood Food Shelf to supplement government-provided assistance

Using both formal and informal resources to support those in need of care and services has advantages for both care provider organizations and individuals. On the organizational side, it allows for more complete support, and by tapping into volunteers stretches the organization's budget. On the client's side, it has the potential to create new ties with family, friends and community organizations that can better meet the individual's needs, and that can outlast the relationship with the care provider organization.

However, much of the information needed to provide this kind of support is not easily gleaned from current record keeping systems. In part it is because most records are narrowly focused on clients, and do not systematically represent knowledge about a clients' social contexts – their household, family, friends and community. Even where such information exists, it is generally produced and consumed by different people in different institutions using different systems. To support the shift to the more holistic, coordinated care paradigm, the systems, data, and ways in which data is represented will need to change.

The focus of this work is on how to portray the complex, entwined data that make up a client's social context so as to assist care workers charged with delivering care under this new paradigm. With reference to the workshop, note that such representations can also be used to support caregivers unaffiliated with care provider organizations. Few caregivers have a comprehensive knowledge of the resources available in their community; and many lack full knowledge of the social connections – and thus possible sources of support – of those for whom they are caring.

This paper is divided into three sections. First, it characterizes the domain of coordinated care delivery. Second, it describes the design rationale and rough prototypes that resulted from studying the domain. Third, it reports on a initial user study.

The Coordinated Care Domain

This characterization of the domain is based on interviews with subject matter experts (SMEs), resources to which the SMEs directed us, and visits to two coordinated care organizations that included conversations with managers and care workers. These studies, and subsequent analyses, were informal and *ad hoc*. Due to situational constraints, no photos or recordings were made; field notes were kept when possible, but were not comprehensive. The aim of this work was *not* to provide a definitive portrait of the domain, but to enable design prototypes to address realistic challenges that made sense to domain workers, and that could subsequently provide lay the ground for mutual discussion.

Themes

A number of themes recurred. One was that being reactive is expensive. A common story-type featured a person with a chronic disease like diabetes who is in and out of a hospital, his or her immediate problems being treated but not the underlying condition.

A second theme was that often the constraints of a client's situation disrupt the organizationally mandated ways of addressing a condition: *"It's hard to treat diabetes if you can't take care of your insulin, if you can't get your syringes, if you can't get to the pharmacy, if you don't have transportation, or if you can't keep track of those things"* [1]. Members of one

Community Health Team discussed the need to have a fine-grained understanding of their clients' situations. Does the client have a working car to get to a pharmacy? Does she have a working refrigerator in which to store her insulin? Is there a household member with substance abuse problems who might steal her needles? These needs may not be evident; many clients are embarrassed and are reluctant to volunteer such information – it may only emerge through talk.

A third theme was that many problems are systemic. Allergies may be due to mildew in substandard housing; moving, rather than pills, may be the solution. Loss of employment may lead to substance abuse and thence to domestic violence: employment counseling or Alcoholics Anonymous may be more effective than anger management classes. Overall, it's vital to understand the systems in which a problem is embedded, and the dynamics and details of the systems' contexts.

A fourth theme is that collaboration within multi-disciplinary teams (MDTs) is central to coordinated care, and thus it is important to understand the nature and needs of MDTs. First, members of MDTs are diverse – from care navigators who understand government programs and eligibility, to behavioral specialists, to medical personnel. Second, decision-making is team-based: *'Collaboration is an intrinsic part of everything,'* as one of the SMEs said. Care teams develop care plans and regularly meet to monitor their clients' progress; care organizations also have larger meetings to develop solutions to unusual problems. Third, a consequence of having a team supporting a client is that each team has many clients to keep track of. Fourth, the collaborative approach includes the clients: they, and often their

family, need to 'buy in' to an approach. Sometimes, as one informant said, this may mean that the first problem to be tackled isn't the most urgent one, but the one that the client feels able to address. Small successes early are important. This means that on-going conversation between a client and members of his or her care team is crucial.

The Design Rationale and Prototype

The understandings gained from the domain investigation were translated into a design rationale for guiding the development of prototypes. Three guidelines from the rationale follow:

- **Broadly accessible.** MDT members are diverse. The visualization must not be discipline-specific.
- **Glanceable.** MDTs have many clients: they need to rapidly make sense of a client's situation, and be reminded of clients they've worked with before.
- **Systemic analysis support.** The visualization should help its users understand the systemic nature of problems so that solutions devised by the MDT are compatible with the clients' situations.

The development of the social context visualization began with a type of diagram called a genogram [2]. Genograms emerged in the mid-1980's as hand-drawn diagrams for representing families, and were adopted in areas of social work such as family therapy [2][3]. Genograms resemble family trees with complex symbolic annotations, and provide information about family members' problems and relationships. Thus, the genogram shown in Figure 1 shows a divorced couple (Bob and Sue) with 2 children, and the couple's siblings and parents. It also shows emotional links between people (using various line types), and challenges like mental illness, substance abuse (shown via shading),

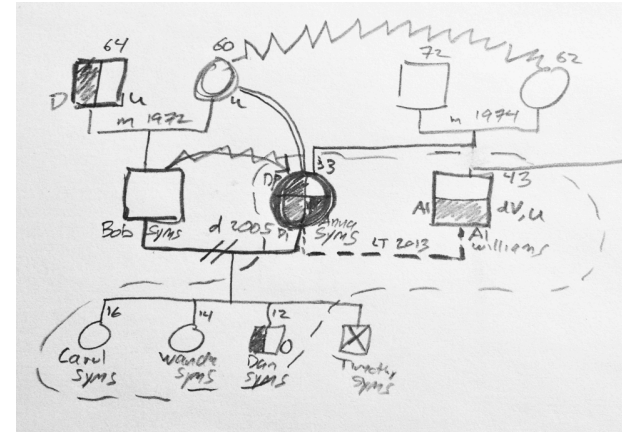


Figure 1. A hand-drawn diagram, known as a genogram, used in areas of social work such as family therapy [2][3].

and obesity, diabetes and smoking (via notations like O, D and S).

Genograms have pros and cons. They were a good place to start because they capture many types of data in a person-centric representation. Also, in line with the *systemic analysis support* guideline, they were developed by a discipline concerned with problems rooted in the dynamics of families and that viewed problems as the outcomes of systems of behavior. At the same time, genograms were not ideal. They began as hand-drawn sketches, not as interactive diagrams. They were used for on-the-fly analysis, rather than as a persistent record. And they had developed an arcane symbology, useful for family analysts, but less accessible to others. Adaptation was needed.

The design rationale guided the development of a series of social context visualization (SCV) prototypes (e.g., Figure 2). To make the SCV *broadly accessible*,

the genogram was simplified by (i) adopting a conventional family tree structure, (ii) grouping the 15 types of emotional links into 2 (positive and negative), (iii) using pictures/icons for people, and (iv) providing layers of annotations that could be toggled on and off. Tooltips (see Figure 2b) were used to reveal the specifics of emotional links, details about marital relationships, and to describe the challenge and strength icons associated with people.

The conventional family tree and simplification of the genogram's visual conventions were also intended to make the SCV *glanceable*, as were the use of photos and layers. The intent was that a care worker be able to quickly see who was in the household, expand it to the family, and get a sense of the magnitude of problems. Thus, in Figure 2, one can quickly see who is in the household (2a), and by toggling layers (2b) see that there is hostility due to the divorce, and that the

patient and her cohabiter have quite a few challenges.

Systemic analysis was supported by the use of the family tree structure, and challenge/strength icons attached to tree nodes. Family therapists have a sophisticated understanding of family dynamics – e.g., that dysfunctional emotional relations can repeat across generations. While most MDT members lack a family therapy background, it seemed likely that their tacit understandings of social arrangements and family dynamics would assist them in making sense of family relationships and their problems.

One other aim of the visualization is to support looking for solutions not just in government programs and services, but also in a client's family and community. This is touched on by the inclusion of indicators of people's strengths – here indications that they have successfully dealt with problems like smoking or obesity

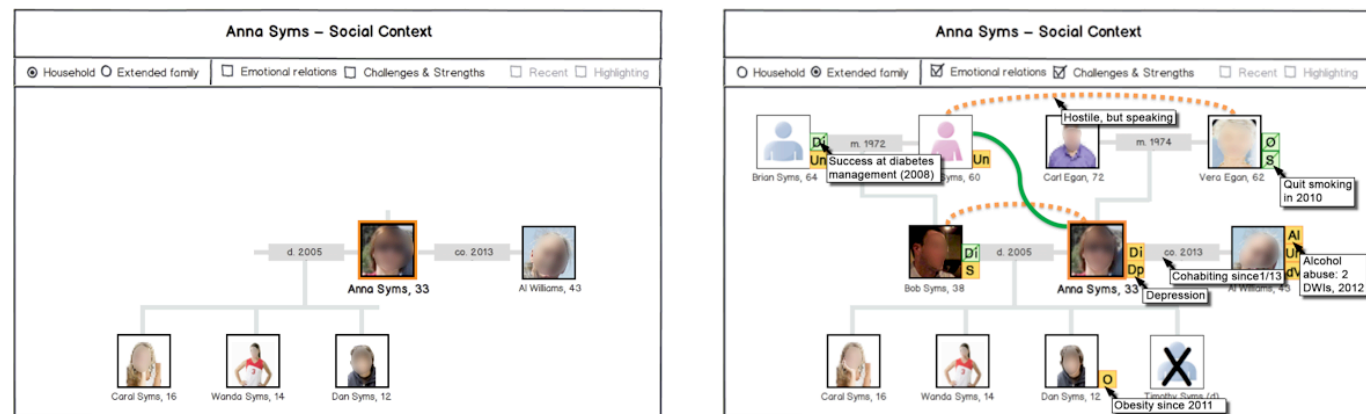


Figure 2. Two views of the Social Context Visualization: (a) The client and (only) their household. (b) The client plus their extended family with emotional relations (orange/dotted negative, green/solid positive) between family members, and challenges (orange squares), strengths (green squares) of individuals. Tooltips are used to reveal the details of relationships and challenge/strength annotations – in actual operation only one tooltip shown at a time, although here multiple tooltips are shown for expository purposes.

– that might enable them to serve as resources for others, but requires further development.

An Initial Evaluation

After several rounds of prototyping, a simple evaluation was carried out. Two instances of an interactive SCV were developed, one for client 1, and a second (Figure 2) for client 2. Clicking changed scope and revealed layers; hovering displayed tooltips.

First, evaluators were shown the first SCV, informed that they were seeing a new type of client record, and asked to discover how to use it and to describe client 1's situation. Next the clients were shown the second SCV and asked to role-play a care worker preparing to meet with client 2. In both cases evaluators were asked to think out loud; at the end of each case, there was a period of open-ended discussion.

The 8 evaluators, 3 women and 5 men, were recruited from among our colleagues; 2 had exposure to social work, one as a long time volunteer care worker, and the other via coursework. Colleagues were recruited both because it was convenient and because ultimately the SCV is intended to be used by a wide range of people, some of whom will lack training in medical and social work. Sessions lasted about 45 minutes; audio and screen recordings were captured with permission. One person ran the session; a second took notes.

The evaluation resulted in several observations. First, evaluators had no difficulty understanding the visualization, learning how to manipulate it, and making sense of its content. While evaluators turned up various bugs in the design (e.g., no indication of the directionality of emotional relations), they were able to

use it to get a sense of the client and her family. For instance, one commented that "*the boxes* [the orange boxes that indicate challenges] *give me a good indication of where the heavy stuff is*" and "*the more green boxes* [strengths] *I see, the more resilient the family is.*" He also speculated that the emotional relations spanning the two sides of the family indicated that it had been close before the divorce disrupted it.

Second, it was clear that evaluators were adept at bringing their knowledge of families and interpersonal dynamics to bear when interpreting the visualization. For instance, in the case of Anna Syms (Figure 2b), one suggested that her depression might be due to the upcoming tenth anniversary of her youngest son's death, and another that it was due to her divorce. Many were concerned about Anna's relationship with AI, her cohabiter: Would his presence pose a financial burden? Would his alcohol abuse make him a danger to her children? And so on. All of these comments go beyond the information provided in the SCV – but they are still useful in helping the care worker determine how to approach the upcoming conversation with Anna.

A third issue had to do with the absence of information. Evaluators often based their reasoning on the absence of information. Anna's depression may be situational (i.e. due to the loss of a child), since neither parent was flagged as having had depression. At the same time, most realized that negative information could either mean "no" or "don't know." Making this distinction explicit – perhaps flagging "don't know" instances – could be useful, both in making sense of the situation and in soliciting information to 'fill in the blanks.' More troublesome to many was the absence of emotional relations – e.g., between Anna and her

children. This is due to a convention, inherited from genograms, of only labeling unusual emotional relations; strong bonds between parents and children are assumed, unless otherwise marked. None of the evaluators (including those with a social work background) understood this. Yet, labeling *all* emotional relations adds a lot of complexity to the SCV; an alternative might be to only show negative relations.

A fourth observation is that in trying to make sense of a situation, evaluators were often concerned with when things started, how long they happened, and what had happened recently. The SCV mostly presented information with dates, which evaluators would mentally subtract to determine durations; it would be straightforward to calculate this for them. "*A good social worker thinks in time*", said one evaluator with experience in social work. When asked if a timeline might be a more suitable form of visualization, he commented that he would rather stay with the family tree diagram. Timelines are fine for post mortems, he said, but the family tree diagram shows you where the resources are – what might be drawn upon to address a client's problem. He also passionately argued for including non-family members in the diagram, because it expands the range of social resources that are available.

Conclusion

While the focus of this work is on supporting care provider teams in organizations, this type of visualization could be useful to any caregiver. Similarly,

the questions being pursued are of general import as well. How can a visualization enable caregivers to tap local resources? How can it serve to guide conversation with the client? How can it serve to help care workers bring their knowledge of the world to bear, so that they can devise solutions that are likely to work in the context of their clients' very complex lives?

As noted, this work is in its early stages. As of this writing, iterative prototyping continues. Further work will include adding friends and other community resources to the visualization, and eliciting feedback on the visualizations from SMEs and caregivers. In the spring of 2014, we will be deploying a working prototype of the system in a context involving the delivery of social and health care to elders. Over time the intent is to deploy prototypes to other social and health care contexts, and gradually develop a useful and robust visualization.

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RelaxedCare: A Quiet Assistant for Informal Caregivers

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Abstract

“How is my mom doing right now?” Answering this question in a quick, clear way without the need of calling or stopping by could relieve a lot of stress from informal caregivers. The “RelaxedCare System” aims to develop a solution built upon an existing AAL platform, using a multi-level pattern recognition approach to detect the current state of an assisted person, and then to communicate the state in a pervasive and unobtrusive way (i.e. lava lamp, smartphone widget, picture frame) to the caregiver. User organisations, researchers, designers and companies are working closely together to create a highly accepted, well-designed, functional and market-oriented “AAL-System in a Box” which is focused on easing the tasks of informal caregivers and thus alleviating stress.

Author Keywords

Ambient Assisted Living; Behaviour Pattern Recognition; Pervasive User Interfaces; User Involved Design Process; Ethics; Informal Caregivers; Older Adults; Elderly; Assisted Persons.

ACM Classification Keywords

H.5.2 [User Interfaces]: Graphical user interfaces, Input Devices and strategies, Prototyping, user-centered design; H.3.4 [System and Software]: User profiles and alert services; I.5 [Pattern Recognition]

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ISSN 1021-73643

Introduction

A major part of caregiving is done at home and by informal caregivers. A representative study [31] of Austria in 2005 showed that 80% of the people in need of care receive their care by informal caregivers at home. More than 2/3 of these informal caregivers feel overburdened some or all the time. A way of keeping caregivers informed about the current status of an assisted person without visits or phone calls might be well-received by both, since repeated check-in calls may become a nuisance to both parties and, due to their quantity, the quality of the interactions may suffer. This idea of continuous status information for caregivers is already addressed by several different products which are available on the market. As discussed below, these products vary greatly in terms of cost and geographical availability, and have other limitations which our current project, RelaxedCare [35], aims to overcome. As ascertained during our requirements-gathering processes with end-users, persons in need of care and living alone generally do not want to be under supervision, nor to put a burden on their family members. Thus, a system that would help to maintain or even increase the autonomy of an assisted person while relieving stress from the informal caregiver could definitely bring enormous benefits for both sides. Informal Caregivers see a big potential in technology use. For example, a study from the "National Alliance for Caregiving in 2011" [13] showed that family caregivers expect the following benefits from technology use:

- saving time (77% believe they would benefit somewhat or a great deal)
- making caregiving easier logistically (76%)
- making the care recipient feel safer (75%)

- increasing feelings of being effective (74%)
- reducing stress (74%)

A system to aid caregivers in such a way must be capable of reacting in a fast and clear manner. To avoid becoming yet another burden on caregivers, it should unintrusively integrate into their everyday lives, working in the background, and delivering information in a way that does not distract the user's attention when not needed. While it is common sense to design the in-house sensor network as unobtrusively as possible (e.g. to be free of aesthetic concerns for the care-receiver), our special focus is on unobtrusiveness for the informal caregiver. Since the system under development is targeted at situations in which it is normal that the care receiver does not often require immediate support, caregiver-facing status indications should be pervasive and unobtrusive (i.e. not requiring ongoing attention or maintenance). However, although pervasiveness is required in general, the user interface must still be able to draw the attention of the caregiver in case of emergency (e.g. by emitting conspicuous audiovisual and/or haptic signals). Thus in summary, the system in development must be able to:

- Allow for unobtrusive and automatic monitoring of assisted people's condition, without interfering with their individual lives.
- Remove burden and interruptions for informal caregivers, reducing the need of additional caregivers.
- Allow for a constant but flexible relationship connection between the assisted person and their informal caregivers.

State Of The Art

As mentioned above, there are existing solutions which aim to provide informal caregivers with ongoing status updates of the people for whom they are caring. These products are quite different with regards to availability, functionality and cost. Most of them - such as BeClose [20], Lively [25], eNeighbor [37], PERs+ [29], Sonamba [39] and SimplyHome [38] - are only available in the US. QuietCare [32] seems to be available internationally, but we were unable to determine geographical availability for WellAWARE [12], GrandCare [19] and Rest Assured® [36]. One reason for this country restriction might be the fact that some systems (e.g. BeClose, Lively and Sonamba) are using built-in cellular connectivity to communicate with their data centers. Others, however, can use the existing internet connection infrastructure (GrandCare, QuietCare) or some combination of cellular and internet (WellAWARE, SimplyHome). Built-in cellular functionality apparently does not require an existing internet connection at the home of the assisted person, but may instead involve additional monthly costs (which, in the event that the assisted person already has an internet connection, should ideally not be necessary).

All of the aforementioned systems are using wireless motion sensors to detect activities of daily living of the assisted person. However, for extended information-gathering and behavior pattern recognition, additional sensors are used. Examples include the sleep quality or humidity sensors in WellAWARE, or toilet-usage and bed pressure sensors in eNeighbor. Rest Assured® appears to be the only product that also focuses on environmental sensors like smoke and carbon monoxide detectors for additional home security. A more detailed comparison of these systems is difficult - since these are

strictly commercial products with closed architectures, there are no detailed technical specifications available which describe the implementations or which wireless network standards are used. Additionally, it is not clear how the different sensor data are used to compute behavior patterns nor what statistical methods are used, since there are no research papers / publications available to detail these. Presumably, this information is proprietary.

On the caregiver side (whether formal or informal), these systems offer various modalities for receiving incoming notifications. Almost every system offers online access via a secure website / web portal - presumably hosted by the service provider / company. Additional modalities like phone calls, text messages (sms), email and iPhone / Android apps are also available for various products.

Based on the available information, the total costs of the systems themselves, the installation, and any ongoing subscriptions seem to vary a great deal. Most of the systems don't mention the required expenses at all, while others show specific one-time prices for the various parts (e.g. base station, sensors,...), installation costs and monthly fees. SimplyHome states a price range from \$27,95 per month to \$250 per month, depending on the customized solution for each case. Sonamba indicates two price bundles, one at a cost of \$199,99 once plus \$69 monthly, or the other at \$549,99 once plus \$39 monthly. Additional sensors can be purchased separately for a one-time investment.

Regarding the behaviour pattern recognition goals of RelaxedCare, we are aware of a fair amount of prior research work, but not of many existing commercial products which explicitly employ these ideas as such. One particular area which has already seen a great deal of attention is that of activity monitoring and identification

of activities of daily living. The path to measuring basic activity with common sensors has been fairly clear-cut for some time. For example, [7] gives an overview of the available technology and the considerations involved in using the resulting data for activity monitoring; [41] does an analysis of the reliability of several off-the-shelf devices; and [4] demonstrates a successful application of this, showing that triaxial accelerometer data, integrated over time slices, is highly correlated with energy expenditure (which is a standard measure of physical activity). Identifying activities of daily living at a more abstract level (e.g. bathing, eating, etc.) given only passive sensor data, on the other hand, is more complex, and is an area of active research. Due to the varying relationships between sensor data and actual activities this is a problem well-suited to machine learning approaches, but these require substantial amounts of data to solve. RelaxedCare will initially base its work on datasets provided by other researchers in the field e.g. [6, 40, 34] and – most notably – [23] to make it possible to start crafting and testing solutions to pattern recognition tasks such as activity tracking. Studies like [26, 2, 40, 33] also have shown great promise at detecting activities which are already familiar to the system; and [8, 42] offer attempts at activities which are never before seen.

Objective

With RelaxedCare, we will attempt to improve upon the aforementioned solutions in several ways. First, due to its open source middleware, RelaxedCare would allow outside developers and organizations to extend the platform, to add new sensors (even those employing new wireless standards), to create new pattern recognition modules employing the sensor data, etc. The openness of the middleware also allows it to be hosted by anyone, including care organizations, telecom providers, or even

the users themselves. This could be a benefit to privacy, as well as putting responsibility for the system into the hands of those who interact most closely with the users. Finally, another important development planned for RelaxedCare is the pervasive interface for caregivers, using daily objects like lamps, picture frames, plants, etc. to convey information, instead of requiring the use of foreign-seeming devices in the home or on the body.

From a design standpoint, a major goal of RelaxedCare is to offer a “system in a box” that contains the necessary components for an end-user pair, as depicted in Fig. 1. Here we use “System in a box” to convey the aim of developing a market-ready system, to be made available in a single box, which will be easy to install and entirely self-contained.

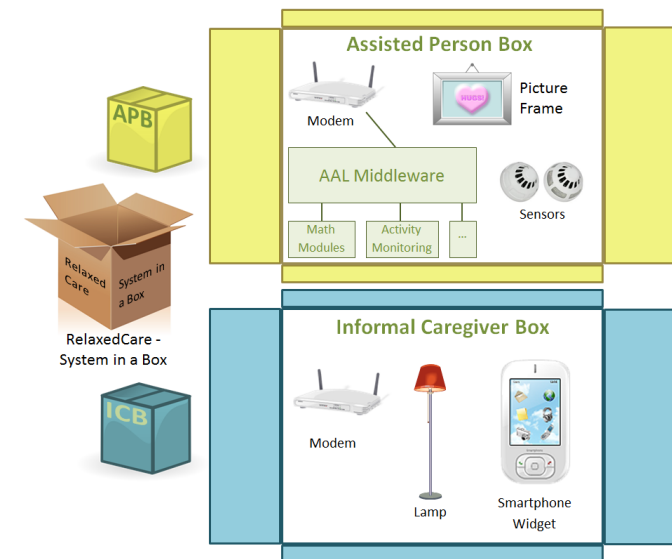


Figure 1: The figure shows the aim of delivering the RelaxedCare outcome as a “System in a box”. It consists of an “Assisted Person Box” (APB) and an “Informal Caregiver Box” (ICB), containing the different components for each end-user.

The system is interoperable with various AAL components, sensors and user interfaces and is thus easily adaptable to the person’s needs, to allow a high freedom of choice in user interaction. The added value of the RelaxedCare system relies on two major aspects:

- The system requires no effort from the user to collect data throughout the home. This approach guarantees large data sets (useful for developing pattern recognition solutions), improves the probability of generating accurate advice, and lowers the barriers to entry for older adults, who are often not highly motivated to use new technologies.
- RelaxedCare does not require an expert to interpret the output, and should thus be easy to use for everyone. This positive, user-centric experience will hopefully motivate users to continue using the system (and thus to continue enjoying its benefits).

All services will be based on existing AAL platforms - in particular, the HOMER [17] system, and also probably incorporating developments from the AALuis [28] project.

An additional aim of the project is to create a system which gives diverse service providers (e.g. telecom operators, social services and medical institutions) the opportunity to customize and then offer the system to its users, similarly to the way that personal emergency response systems are currently offered to users through various care organizations.

It is important to note, however, that RelaxedCare is not intended as an emergency device. As a research project, the goal of the RelaxedCare consortium is to explore the design, functionality, and technical possibilities of the system. For this reason, concerns such as reliability and availability are ones which would be addressed after our work is done, by those who might be bringing it to market as an actual, finished product.

To focus on this aim, the consortium includes all relevant stakeholders - and in particular, market-oriented end-user organizations and companies specialized on AAL Systems - in order to reach these goals. The system will be developed in a modular way to be able to adapt to different use-case scenarios, since the needs and wishes of older adults may be very diverse (e.g. different environments, living arrangements, privacy concerns, illnesses/handicaps, etc.). Informal caregivers may have diverse needs too, depending of the needs of the person whom they’re assisting, the distance between them, their preferred modes of communication, family and work constraints, etc.

To convey more concretely how a system addressing these needs should fit together, Fig. 2 illustrates the basic concept behind RelaxedCare.



Figure 2: RelaxedCare concept: Above, the assisted person is at home, where sensors (door, key, refrigerator etc.) are installed to monitor some of the person's activities; below, the informal caregiver is informed in different situations via various modes (smartphone, pictureframe, LED lamp) about the status of the assisted person.

Methodology

Involving the end-users throughout the project lifecycle is of utmost importance to develop a prototype which is not only functional, but which is both accepted by and beneficial to its users.

User Inspired Innovation Process

The RelaxedCare project applies the “user inspired innovation process” [11]. This process combines process

methodologies from the fields of creativity and perception [10], design thinking [5, 30], qualitative social research [3, 9, 16] and design research methods [22, 27], and innovation management including ecological, technological and economic issues [18]. This process enables the active involvement of knowledge and methods of different areas of academic research, design and industrial practice. With the combination of these various fields of expertise, the user-inspired innovation process aims at shifting the design process from design thinking, where normally team members get a briefing to create ideas corresponding to a defined topic, to a holistic-thinking process methodology. In everyday life, we do not get a briefing for the creation of new products. That is why the user-inspired innovation process starts with the focus on the ability to be open-minded and receptive to urgent, upcoming and future challenging questions of our society. Successful products of the future distinguish themselves through understanding and addressing end-users' motivations and values, holistic, closed production cycles and new service design offerings. Due to the fact that this process addresses all of the essential steps of a product development process, it has been chosen for this project not to offer a generally-accepted instruction manual, but to offer a guide for navigating through the complex process of holistic and innovative product development.

Research Approach

The overall goal of the end-user research process is to guarantee that the true end-users are being addressed throughout the whole course of the project. The end-users of RelaxedCare are split in two groups: elderly people living alone but needing regular (but not constant) assistance in certain situations, and their corresponding caregivers. The research process for the end-user

requirements engineering phase is designed as an unstandardized qualitative research study [16]. This was a comparative study broken into five phases (and employing seven methods in total).

Phase 1: Assumption Personas

This method was chosen to get a common understanding of both target groups (caregiver and elderly) among the team of project members of RelaxedCare. On the occasion of the first consortium meeting in June 2013, all project team members were invited to take part in an Assumption Personas workshop with the aim to create for each target group a male and a female Persona. The goal was to initiate an intensive discussion and to create material for reflection and guidance during the entire development process. After the full research study, the original Assumption Personas were compared with the findings for each user group, and several major changes had to be made. One of the major findings revealed by the methods was that the average age for caregivers and their assisted persons, originally assumed to be 30+ and 75+, had to be changed to 50+ and 80+, respectively. Concerning activities of daily living and preferred objects of everyday life, various similarities among the group of the caregiver and the group of the elderly could be identified. This process – first capturing individual team members' assumptions about our target groups, then learning from the users about where and how these assumptions were wrong – supported the goal of questioning and revising the teams mental models, and enabled fruitful discussions focused squarely on the real end-users of the product.

Phase 2: Questionnaire and Show and Tell Method

These methods were chosen to get structured impressions and insights into the everyday lives of people from both target groups and their preferences in product criteria.

Phase 3: Focus group discussion and Cultural Probes

These methods were chosen to be able to discuss the findings from phase 2 directly with the participants of both user groups, while at the same time preparing a Cultural Probes package to gain insights and vital pieces of information relating to the project scope.

Phase 4: Design Workshop

The Design Workshop was conducted in order to develop product criteria which are not only functional, but also follow an emotional and haptic approach. Using the creative potential of the participants, this workshop had the aim to start a conversation about possibilities of product criteria.

Phase 5: Contextual inquiry interview

Contextual inquiry interviews were used to get structured and tightly focused information on technological items already in use in everyday life, addressing especially the technological devices and motivations their usage in everyday routine within both user groups, as well as to get information about possible usage of technological devices for care situations.

These applied research methods were aimed at uncovering the relevant factors for assessing the users' needs in the early stages of the project. The findings from this study will inform the technical work and, through this, build a basis for the user-centric design and implementation of RelaxedCare.

Technological Approach

The technological core of the project is built upon existing, open AAL middleware platforms that have been successfully applied in other AAL projects like BEDMOND [24], NovaHome [21] and Companionable [1]. New modules for such an existing platform will be

developed, but not a new platform itself. The system will build a new “Model Abstraction & Interpretation Layer” where behavior pattern recognition modules can be connected, managed and adopted in a generic way. For estimating the assisted person’s mood and behaviour, the following modules will be integrated and used:

- Activity Monitoring: Basic activity-level tracking, as well as a set of localization and path-tracking methods have already been developed by the partners AIT Austrian Institute of Technology (AIT) and iHomeLab (IHL). The success of the location and path methods have also been successfully demonstrated during the evAAL competition in 2011 [14], where both approaches placed among the top three [15] (AIT used the HOMER platform, iHL was part of the ILOC Team). In comparison to the first-place winner, no body-attached items were used for the AIT system. RelaxedCare should also extend this activity tracking to a more abstract level, perhaps including awareness of certain basic activities of daily living.
- Social Interaction: Does the person regularly make voice / video communication with his or her relatives and friends? Sensors will also detect if the person leaves the house and/or has visitors in from time to time.
- Day-Night Monitoring: During night-time a sensor mat in front of the bed can detect when and how often the user gets out of bed. Whether or not the user is getting sufficient sleep could be of interest to caregivers, since it may have major impact on general well-being and mood, and could also be an indicator of other problems. Due to the movement

recognition, wandering at night can also be detected and reported as a potential risk to the informal caregiver.

- Indoor / Outdoor Monitoring: Later prototypes may incorporate GPS and mobile technology to extend the system outside of the home. For instance, how often, how much, and in which regions do the older adults tend to walk? A higher activity level can be considered another component of a good mood and healthy life style.

All the information modules’ data will be composed into a general estimate of the older adult’s mood, wellbeing, and behavior.

The consortium is aware of the ethical issues connected to the various kinds of data collection and behavior pattern recognition methods, and sees the security of and control over these data as an overriding priority.

To address anticipated privacy issues regarding the monitoring of the assisted person, the system will offer numerous “privacy customization” options. For example, the care-receiver has the freedom to actively decide which kind of information is sent to the caregiver, as well as the degree to or specificity with which these data are shared. This might be achieved by simply disabling certain sensors or sensor groups in some cases or, in others, leaving all sensors online but disabling certain transmission functionality. In the former case, this decision comes at the cost of the effectiveness of the whole system, since certain conditions will simply not be detectable when distinct sensors are turned off. This raises an interesting question, yet to be decided: should the user have the ability to shut down all sensors completely (the whole surveillance system) so that no information at all gets

processed by the system? If so, then even if an emergency occurs, the system would not be able to detect it and therefore could not send out the necessary request for help. This question needs to be addressed with further questionnaires to the target group.

Outlook

The project started in May 2013, since which time we have completed the user requirements and analysis phase, and are currently (as of January 2014) finishing the technical specifications. The first prototype (due July 2014) will be tested within lab trials, whereas the second (due November 2015) will undergo more extensive field trials in Austria and Switzerland.

At the end of the project the RelaxedCare system should:

- connect informal caregivers and assisted persons via new modes of interaction.
- help to reassure informal caregivers that the assisted person is doing fine, and that they'll be informed if the situation changes.
- help assisted persons to feel socially connected by reassuring them that their caregiver is there for them and aware of their situation.
- create well-designed and pervasive interfaces which are embraced by users, via a strong collaboration end-users and designers.
- develop new methods for AAL pattern recognition on different levels of abstraction.
- contribute to the AAL scientific community

Acknowledgment

The project RelaxedCare is co-funded by the AAL Joint Program and the national funding authorities and R&D programs in Austria (bmvit, program benefit, FFG), Switzerland, Slovenia and Spain.

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"Respite that fits our needs": Learning from a Day Care Service Defined by Spouse Caregivers to Design a Social Support Platform

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CCC'14, February 15, 2014, Baltimore, Maryland, USA.

<http://ccc2014.wordpress.com>

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ISSN 1021-73643

Abstract

This paper reports on a local day care service initiated by spouse caregivers: the Bright Spell. On the framework of the TOPIC project we are interested in the social support informal carers find in their daily life. On the basis of our observation of a journey at the Bright Spell and from interviews with three participants couples of this day care service, we propose and discuss several insights for the design of online social support applications.

Author Keywords

Social Support, Respite Care Service, Informal Caregivers, Socio-Technical Design

ACM Classification Keywords

K.4.2 Social Issues

Introduction

The current evolution of the western healthcare systems related to demographic pressure has made institutions, society and research more and more aware of the importance of the informal care provided by relatives of persons suffering from severe conditions

due to disease or ageing. The observed economic benefit of informal care could be seen as an opportunity in a context of expenses reduction. However, the physical and psychological costs of assuming the role of being an informal caregiver contradict such analysis. For instance in France, caregivers of patient suffering from Alzheimer's disease (AD) suffer more from depression than the general population [6]. It is obviously difficult for elderly informal carers to manage the informal care independently. Providing support to informal caregivers appears now as a necessity and as an opportunity to think how it can complement institutionalized healthcare services. But we are facing a situation where no method for lowering their burden has clearly emerged from nursing, psychology, or other disciplines, and where elderly in general have hard time or lack of interest to adapt and use ICT to help with many daily tasks. There is a clear trade-off between informal carers' needs of social support and today's potentials provided by new ICTs.

In this context, the AAL TOPIC (The Online Platform for Informal Caregivers) project [3] aims at designing accessible and useful solutions to alleviate stress and increase independency and efficiency of daily informal care giving tasks through information and communication technologies (ICT).

The project aims at developing an online social support platform which will address the interwoven needs of informal carers for informational, emotional and tangible support [5]. For so doing, we are currently conducting observations and interviews with an ethnographic perspective in the home of the informal caregivers we have recruited.. One important issue that we are looking for when conducting this study is where

do informal carers find support in their daily life? This will be our starting point for designing relevant and useful functions for the TOPIC platform.

This paper is related to a group of AD spouse caregivers we met during the recruitment phase of the French part of the TOPIC project. These family caregivers have initiated a bi-monthly day care service, called the Bright Spell, where they meet twice a month and support each other. We report on the effective social support practices we can find in this local solution partly run by the informal caregivers themselves: developing relationships with people sharing the same situation and specific needs, getting relief from the group, benefiting from the distributed watch over the ailing relatives, meeting each other outside their homes, all appear as sources of support. In line with the TOPIC project aims, we reflect upon which design requirements we can propose from the analysis of these effective social support practices.

After a description of the context and material of this exploratory study and the onset of the Bright Spell, we present the activities performed by the family caregivers in their respite care service. We then highlight the support they find in taking part to this service and present insights for the design of the TOPIC platform. We conclude by discussing the limits and perspectives of this study.

Approach and material

We got in touch with the Bright Spell during the recruitment phase of family caregivers for the TOPIC project. In September 2013, we have been invited to present the project purpose and aims on the occasion of a support group meeting dedicated to spouse

caregivers. Most of the interested participants were taking part to the Bright Spell and they asked us to meet them there. Since the study implies to welcome researchers at home to observe their daily life, the spouse caregivers wanted us to meet their ailing relatives at the Bright Spell before accepting to join our project. The Bright Spell is composed of 11 people: 5 couples and one spouse caregiver who has recently placed her husband in a AD care specialized unit. All but one of the caregivers are woman. One of the couple owns a dog that is also part of the group.

We have joined the Bright Spell two times, one morning and one afternoon, conducting observations of their activities. We were interested in the activities performed by family caregivers and their ailing relative during their stay at the day service. As three of the five couples have finally accepted to join the first phase of the TOPIC project, we were then able to conduct individual interviews to supplement our understanding about this respite care solution led by the informal caregivers themselves. In these interviews, we focused on the current support these caregivers benefit, especially by taking part to the Bright Spell. We also discussed their use of information and communication technologies. However none of them were currently involved in an online social support practice.

A respite care service initiated by informal caregivers

The Bright Spell started in June 2013. It is a respite day care service which has been initiated at the demand of four “young” AD spouse caregivers (aged 60+). They met while taking part in support group meetings organized by an healthcare network (called RÉGÉMA) dedicated to persons suffering from age

related pathologies and memory disorders, which is based in Troyes (North East of France). These four “young” spouse caregivers expressed their frustration regarding the available day care services. They thought they did not fit their situation (even if they manage to use them). In fact, some of them are just retired, and their ailing spouse is still mobile, so they find that the activities offered by existing day care service (mostly at retirement home) were not adapted. They were worried about their spouse being “alone” with older patients (80-90) with heavier conditions, and having difficulties to develop relationships with participants and having interests in the very quiet activities offered (e.g. painting, coloring pictures).

The idea of developing a new day care solution dedicated to spouse caregivers aged less than 70 emerged from the support group meetings and has benefited from the organizational support of the healthcare network. A place in one of the local retirement homes has been found with the help of the network coordinator. The agenda of the solution has been discussed following the idea to provide a lunch and respite time with and without the ailing relative during the day. Financial resources have also been collected through the RÉGÉMA funding network (e.g. insurance company, local foundations, public funds). These resources are used for foods and drinks, the participation of the retirement home employees, and handwork materials for afternoon activities. The informal caregivers also pay a fee.

A journey at the Bright Spell

The Bright Spell is organized twice a month on Monday at a local retirement home reception and dining room. The couples arrive nearby 10:00 am and start with a

coffee, waiting for each other to arrive. They are welcomed by two employees of the retirement home who help them to watch over their ailing spouse and for the activities. At the difference of classic day care services where family caregivers are supposed to leave their spouse for the day, here they stay for the day.

In the morning, they are used to stay at the big table and take news from each other. They discuss what they have done since their last meeting and the evolution of their respective spouse disease. Their ailing spouse are present and take part to these social activities their way, following the conversation of their spouses, drinking coffee, discussing with each other or commenting the behavior of the dog. At noon, they set the table and have a lunch altogether. The day we followed them during the morning the caregivers encouraged their ailing spouse to help with setting the table. The spouse caregivers wanted us to see that even if their spouses manage to keep up the appearances during social interactions, they have a lot of coordination and cognitive problems that require to assist them even for the most basic home duties ("You can imagine what we are living at home... ", as one of them told us).

During the afternoon, the family caregivers can take part to activities with or without their ailing spouse. The day we went visiting them, they had installed the table to do handwork (crafting flowered frames with flannel). This activity was proposed by one of the caregiver assisted. The two retirement home employees are present to provide help and support. The family caregivers had the opportunity to join this workshop or to go to a movie session ran by the retirement home entertainment service.

Three of the family caregivers have chosen to go to the movie session letting their spouse under the surveillance of the group. Before going to the retirement home movie room, they have waited half an hour discussing with another caregiver in sofas near the table. This last person explained she feels very tired these last days and finally preferred to have a nap on the sofa before taking part to the afternoon activity. The remaining two have chosen to take part to the handwork workshop to assist the employees in looking after the five participants' ailing spouses.

The journey ended around 16:30 when the movie session ended and its attendees came back to the reception room. They explained us they are used to leave at that time. In fact, they have noticed that when AD patients are less interested by the activities, they start walking around in the room. It means that it is time to finish the day at the Bright Spell. At 17:00, they were still discussing at the front door of the retirement home.

Identified sources of social support

We were interested in looking at the practical possibilities offered by the Bright Spell to understand the different sources of support for the informal caregivers. The interviews have helped us to get more knowledge about the day care service and to confirm our first analysis. We are now going to describe these sources of support: interacting with persons sharing the same situation; counting on the group to be able to run some activities with their ailing relatives; being able to run some activities outside their homes; sharing experiences and problems.

- Developing relationships with persons sharing a similar situation: Besides being a spouse of an AD patient, the informal caregivers emphasize the specificity of their situation as “young” family caregivers. They complain about their husband need for physical and outdoor activities that classical day care services scarcely organize. Among the other possible afternoon activities at the Bright Spell, they mention they appreciate to go outside for a walk when the weather allows it. They exchange news from session to session and they feel understood by the group. One of the family caregivers calls the members of the Bright Spell her “disease friends”.
- Respite with and without the ailing relatives: The distributed watch over provided by the group makes possible for family caregivers to enjoy respite with and without their ailing relatives.
- Doing things together outside the home: Even if some of them have to drive a long way to join the place (e.g. 40kms for one of the couple), they appreciate it so much that they are used to organize trips together between two sessions at the Bright Spell. For instance, the interviewees mentioned they have done picnics during summer; they went to the bowling and invited each other for dinner. They coordinated to join yoga and dance courses offered by other local respite care services. They are planning to join a journey to a historic town and to attend a painting exhibition at the end of November.
- Sharing experience and problems: The time shared at the Bright Spell is an opportunity to tell the daily problems they encounter in caring for their ailing relative to persons who can understand their situation. They provide advices to each other on how to deal with

the care they provide. If nobody has been confronted to a situation, they discuss to try finding possible solutions.

Insights for designing a social support application

The observation and analysis of the support provided to the family caregivers at the Bright Spell allowed us to identify four perspectives for the development of an online social support platform.

- Taking into account the participation of the care receiver: In line with reports on the numerous respite care initiatives [2], the Bright Spell illustrates that taking in charge the caregiver apart from her/his ailing relative may be a too narrow view on the ways of supporting him/her, especially when the caregiver is the spouse. It leads us to think about offering shared spaces for the caregiver and the care receiver.
- Taking into account the specificities of the caregiving situation: The fact that the family caregivers from the Bright Spell claim for their specific needs is illustrating that some dimensions are considered as important for sharing a similar situation: the pathology, the relationship with the care receiver (being a child, a spouse, a parent, ...), the age. This should be taken into account when defining users' profile of the social support platform.
- Finding the appropriate care service: Transferring the experience of the Bright Spell in digital applications would be a hard task, and is a clear example of a sociotechnical gap [1]: “[the] divide between what we know we must support socially and what we can support technically”. Ameliorating this gap could consist in providing ways to enhance the visibility

and ease the access to a service like the Bright Spell. Designing relevant information support to describe and search for such initiative can be an interesting feature of a social support platform. Besides, taking part to a same care service appeared as an entry point for social support exchange among users.

- Easing participation to collective activities: Collective activities are an important place for exchanging social support at the Bright Spell. Apart from an information and communication space, we then identify as an interesting feature to provide means to propose trips to other users for them to join.

Further work with the informal caregivers taking part into the TOPIC project is of course required to precise and develop these first insights.

Discussion

In order to design useful social support features to lower the burden of informal caregivers, we are interested in understanding the support the informal caregivers already receive, its origin, form and frequency. We find that the case of the Bright Spell deserves some analyses and discussions, especially on how the support which is found there could have a translation into the digital world. We wanted here to bootstrap the reflection on the insights we could find from such initiative.

The public of the Bright Spell, formed by AD spouse caregivers under 70 is much more focused than the intended end-users of the TOPIC platform (informal caregivers older than 50). Finding similar services for other pathologies and caregivers groups appear important to balance these initial findings. Besides, if respite care services have developed these last years

and show positive results, not all family caregivers wish to use them [4].

Acknowledgements

We thank all the participant of the Bright Spell and the RéGéMA healthcare network for welcoming our study. This work has been supported by European Union, ANR and national solidarity fund for autonomy through AAL program (project AALI 2012-TOPIC).

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Exploring Social Support Needs of Informal Caregivers

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CCCIC'14, February 15, 2014, Baltimore, Maryland, USA.

<http://cccic2014.wordpress.com>

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ISSN 1021-73643

Abstract

For the past number of years, research projects aiming at designing and developing technological solutions for informal caregivers have come out with different aids to support various aspects of the care process (e.g., to provide information about care procedures, to support caregivers with time management tools like reminders and calendars, etc.). However, relatively few projects have directly addressed the relevance of providing caregivers with different forms of social support, so that their daily life could be improved and their experience with informal care could be enhanced. This paper addresses how computer technologies can potentially meet social support needs of informal caregivers, by presenting a detailed account of a caregiving situation, analysing how computer technologies could fit to it, and identifying design implications.

Author Keywords

Informal care, caregivers, elderly, social support, on-line platform, user-centred design, ethnographic study, qualitative research

ACM Classification Keywords

H.5.2. User Interfaces: User-centred design; H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Studies on informal caregivers have recurrently highlighted that people who provide informal care are constantly submitted to demanding activities that might burn them out [1, 2]. The strains of informal care are even more accentuated among caregivers with affected health conditions, as some of these studies suggest.

For instance, Navaie-Waliser et al. [3] have investigated the characteristics, activities, and challenges of high-risk informal caregivers. For that, they have conducted telephone interviews with over a thousand informal caregivers in the USA. A relevant finding from the study was that 36% of caregivers were vulnerable (i.e., under some sort of delicate health conditions). According to the authors, these caregivers are more likely to have difficulties in providing care (especially high-intensity care) and their physical health suffers since they become a caregiver. Therefore, they might need different types of support to cope with the demands of informal care work, especially when they are more vulnerable. This is often the case of elderly people, who may need to care for someone.

As researchers progressively become more aware of such issues, different research studies have been proposed to investigate how technological solutions could support people who engage in informal care with their duties, so that the physical, emotional, and psychological burden stemming from care work could be reduced [1, 4, 5, 6, 7]. The outcomes from these projects have been technological solutions to support different aspects of the care process. However, relatively few projects have directly addressed the relevance of providing caregivers with different forms of social support (a noticeable exception is [4]).

This paper reports on preliminary results from the TOPIC¹ project, which sets out to explore different facets of the social support for informal caregivers. It provides a detailed description of a case of informal care featured in the project by the project team at the Vienna University of Technology and introduces different social support needs coming out from the case. No definite solutions are presented or tested in this paper. Instead, it introduces a series of issues and some implications for design to be further discussed.

The remainder of the paper is organized as follows: Section 2 summarizes the relevance of social support for people providing informal care and the different dimensions of the social support that the TOPIC project commits itself to explore. Section 3 details the user's context and everyday life of one of the informants participating in the first phase of this user-centred design (UCD) project that aims at designing an online platform for informal caregivers. Section 4 discusses possible technological developments that could support some of the issues observed in the data collected from the aforementioned participant and introduces some possible implications for design. Finally, Section 5 concludes the paper.

The Relevance of Social Support for Informal Caregivers

Existing research indicates that caregivers are often in need of social support and that they may benefit from the association with people who have had similar

¹ The Online Platform for Informal Caregivers (<http://www.topic-aal.eu>) is a European joint AAL project between 10 partners (3 from the academy, 4 from the industry, and 3 end user organisations) spread across Austria, Germany, and France.

experiences [8, 9]. Colvin et al. [10] explored the perceptions of caregivers using online social networks regarding advantages and disadvantages of online social support. Based on an anonymous web-based study featuring 63 users of social networks, the authors identified two major advantages: (1) attributes of computer-mediated communication (CMC) and (2) connectivity. The former include *anonymity*, which according to the participants makes it easier to relate to and reach non-judgmental people, and *asynchrony*, which allows for convenience and immediacy of information due to all-time presence. The latter is of particular importance to busy caregivers and includes ability to easily expand one's network, gain understanding, and reach necessary information. Notwithstanding the advantages identified, the study uncovered several disadvantages of online social support, with limitations of CMC (e.g., absence of physicality, intimacy, and tangible support) being the most prominent example. This study demonstrated that caregivers have the need of personalized CMC tools for online social support to meet their individual and ever-changing needs.

A plethora of empirical studies examined the role of social support in buffering and/or mediating the effect of stressors on caregivers' distress and demonstrated mixed, and sometimes unexpected, results [11]. Miller et al. [12] examined the replicability of models of social support and caregiver distress across 4 representative community-based caregiving studies with the goal of identifying areas of consistency in finding across the data sets. The study demonstrated that behaviour problems and caregiver's health are important contributors to caregiver's distress, but nevertheless showed that the pattern of relationship between social

support and distress were inconsistent. Interestingly, only one type of social support was associated with distress in the expected way: less emotional support was associated with higher levels of distress in 50% of the data sets.

Tixier and Lewkowicz developed *aloe-aidants.fr*, an application dedicated to online social support for family caregivers. The application was deployed and tested within the healthcare network *RéGéMA*. It allowed registered users to present themselves through personal pages, which they could use to connect with other users with the same interest and to share information and experience with their peers. However, although the application received positive feedbacks from initial users, the authors did not succeed in their goal of supporting an active online community.

Acknowledging the potential relevance of providing effective social support for informal caregivers, the TOPIC project sets out to investigate the everyday lives of representatives of this cohort of people in order to better understand the challenges and difficulties that they face day by day, as they provide care for the ones they look after. In particular, the project is interested in the needs associated with three different facets of social support that the literature suggests to be needed by informal caregiving: *informational* (flow of information, advices and opinions to help caregivers understand their problems), *tangible* (support in terms of goods or services for achieving daily tasks), and *emotional* (providing with the feelings of sympathy, empathy, friendship, and love) [13].

In order to pursue its aims, the project adopts a user-centred design (UCD) approach supported by ethnographically informed studies. Therefore, users are

involved during all the process, informing the design and providing feedback about how well the technological developments would meet their needs or fit in their everyday lives. Hence, before designing any device, application, or service, researchers of the project accessed the field and engaged in a pre-study to understand the users' context and everyday life.

In the scope of the TOPIC project in Austria, a total of ten participants were involved in the pre-study. These participants have engaged in all segments of the study, which included shadowing sessions, interviews, questionnaires, and focus groups. In this paper, we discuss the case of one of our users – Mr. Sorgsam² – whose life and caring situations aggregate several relevant characteristics observed across most of the informal caregivers we studied so far.

Currently, the data from the pre-study is being analysed to inform the design phase in which mock-ups will be produced and discussed with the participants before more elaborated prototypes are developed and submitted to usability tests. The technology partners of the project are the responsible for the development of the final platform.

The Case of Mr. Sorgsam: Emerging Needs

As our data analysis progresses, the need for social support becomes more evident. The findings strongly indicate that providing effective social support would alleviate the burden that caregivers often go through. This becomes evident across this section, which reports on the daily life of Mr. Sorgsam.

² Pseudonyms are used to assure confidentiality to the participants and imprint one of the strong characteristics of the person in question.

Mr. Sorgsam is a 65-year-old retired electrician, who has been caring for his 68-year-old partner for more than two years. He is very interested in plants and electronics. In terms of health, he is a heavy smoker and has gone through a bypass surgery on the vessels of both upper legs. His sight is slightly impaired and, therefore, he needs glasses when he reads. Every year he goes on a recovery leave for 3 weeks, although the health insurance financially covers it only every second year. His mental skills are good and he is constantly engaged in sport activities.

The family situation of Mr. Sorgsam is certainly interesting. He and his partner have been a couple for more than 40 years. They have two sons together and a grandchild, but they have never got married. They live in separate households, which are reachable in 30 to 45 minutes by public transport. Mr. Sorgsam's relationship with his sons is weak: he often tries to get in contact with them via phone or SMS, but they do not always answer his contact attempts, or do it with a few days of delay. One of the sons lives next to his mother's apartment, but visits her very rarely. Once in a while Mr. Sorgsam meets him in the street accidentally. The weak relationship with their sons makes him unhappy.

Mr. Sorgsam spends most of his time with his partner as some people important to him live nearby. His partner's neighbour is one of them: Mr. Sorgsam knows him very well because he has lived there for a long time. Besides the neighbour, there are some other good friends, who Mr. Sorgsam often meets in his favourite coffee shop. He cannot talk with all of them about his care situation, but there are some people with whom he can share enough.

Mr. Sorgsam tries to go to his favourite coffee shop as often as possible. From time to time he also goes out in the evening, e.g., to a cabaret. However, he acknowledges that enjoying being out is difficult as he is constantly thinking of his partner and wondering whether everything is all right with her.

The following subsections present multifarious information about (1) the care situation handled by Mr. Sorgsam, which includes details on the health conditions of his wife; (2) patterns of technology usage observed in his everyday life; and (3) daily routines undertaken by him. These data are introduced in an attempt to shed some light about the types of difficulties and needs that informal caregivers may be faced with.

Care Situation

Mr. Sorgsam's partner has cataract and light-sensitive eyes and, hence, wears glasses. She suffers from chronic obstructive pulmonary disease (COPD), which in her case manifests as asthma and chronic bronchitis. Furthermore, she suffers from rheumatism and osteoporosis, and she is hearing-impaired. Therefore, she is at a high risk of falling and getting seriously injured. Because of her COPD, she can hardly breathe. Her condition becomes more severe in autumn and winter due to the high air humidity. She also often complains that she feels cold.

She was a heavy smoker since her teenage years and stopped only two years ago. Her doctor has diagnosed that she needs external oxygen intake, but should avoid it as long as possible, because once she starts she will be always dependent upon it.

In terms of mobility, she can walk independently, but her breathing difficulties make it tiring and stressful.

She prefers to stay in her nursing bed, although the doctors say she should move as much as possible. She has a wheeled walker in case she wants to go outside.

She was close to death two years ago and had to spend 4 months in a hospital and 7 weeks in intensive care. At that time her weight lowered down to only 37 kilograms.

Similar to Mr. Sorgsam, she has nearly no contact with her sons and grandchild, which also makes her very sad. Mr. Sorgsam believes that the sons do not have any topics in common to discuss with her and that this is the reason why they do not call or visit. He also believes that it is better that his partner does not have contact with them, as she would be more upset if she knew more things about their lives.

She spends her days lying in the bed and watching TV; she leaves the TV on even during the night whilst she sleeps. She stands up mostly to go to the toilet. She owns a cell phone, which she uses only to call Mr. Sorgsam. Rarely, she goes to the park next nearby, always accompanied by Mr. Sorgsam. When she does so, she does not accept to stay outside more than three hours.

With regard to the care work, Mr. Sorgsam is the person responsible for cleaning his partner's apartment, washing her clothes, helping with the hygiene, cooking, shopping, and managing medication intake. He also covers financial, administrative, and organizational tasks for her. Moreover, he manages all doctors' appointments. He receives support from the professional caregivers who visit his partner twice a week (1 hour per visit). However, his partner accepts to be showered only by him and does not allow any other person to help. This sometimes can be a problem, especially when Mr. Sorgsam is away on his yearly 3-

week recovery leave, because he has to drive back home every weekend to shower her. Nevertheless, the external help that he receives comforts him, especially in cases when he is not able to visit his partner himself.

Technology Usage

Mr. Sorgsam is very familiar with technology. He is generally very interested in technology because of his professional background as an electrician. He owns a tablet and a laptop, which he uses to surf the Internet for up to 5 hours every day. He reads online news or searches for information about various topics, including caregiving (e.g., financial support, how to care, doctors, medicine info, etc.). Besides surfing, he uses his laptop to write a diary. He writes about his health, natural science, and other topics of his interest.

The first time we visited Mr. Sorgsam, he did not have a smartphone. He owned a plain cellular phone, and believed that it covered all his needs. Nevertheless, in the last visit, he was happy to show us his recently acquired smartphone. He got it for free when he extended his contract with the phone provider for some more years.

A relevant remark in terms of technology usage is that Mr. Sorgsam tries not to be always available. Therefore he occasionally turns off the sound of his phone, although he acknowledges that this creates problems when his partner or the professional caregiver going to her place on a specific day tries to reach him.

Mr. Sorgsam owns a flat panel TV that he received as a present from his son, but does not use it often. He claims that he is not interested in watching TV. Since he hardly ever does it, he keeps his TV covered by a plastic sheet in order to avoid dust.

Daily routine

Mr. Sorgsam gets up in the morning between 6 am and 7 am to start his morning routine: reading the newspaper and solving a Sudoku puzzle until 9 am, when he leaves to his partner's home.

If his partner calls him in the morning, he knows that something is wrong: she either does not feel good or does not want him to come for a visit. This event immediately affects Mr. Sorgsam's mood negatively and makes him concerned about her the whole day – he is never sure about what leads her to ask him not to come. He usually tries to take his mind off her by meeting friends. If for some reason there is no one to accompany him, he stays in bad mood the whole day.

In case everything is all right, he leaves his home either to go directly to her apartment or to buy groceries and medicines. Twice a week the professional help comes in the morning to her home. In most cases, Mr. Sorgsam is not present, though he wishes he could be there to talk with them and ask for some help with his chores (e.g., buying food or going to the pharmacy) so he does not have to do all on his own. However, he cannot do so as he is usually not there and is not allowed to have their phone number – he can only leave the information to the organization that employs them. Moreover, he cannot ask his partner to call him at the time when the professional caregivers arrive as she is usually sleeping when they are there or forgets to call him.

In the morning, Mr. Sorgsam also coordinates doctors' appointments for his partner or does his chores. He spends the lunchtime in the apartment of his partner, but cooks only for himself, as she does not eat lunch. Very rarely his partner asks him to go out and sit in the park in her neighbourhood. If this does not happen, he

goes for a walk alone or he meets his friends in a coffee shop.

In the evening, Mr. Sorgsam returns to his partner's apartment to prepare her a dinner. Most of the time he does not eat with her. After dinner, he drives back to his home, where he waits until 10 pm to prepare himself a dinner. He always calls his partner to check upon her and to inform that he arrived safely. These phone calls are very important for him because allows him to know that everything is OK with his partner.

Since he and his partner have separate finances, every night he calculates his daily expenses and marks them in a paper-based calendar. He also uses this calendar to organize his and his partner's appointments. Despite using the laptop on a daily basis, he refuses to use an electronic calendar for this purpose, because he is concerned with data loss (e.g., if for some reason the data disappears from the calendar) and with data access (e.g., if the devices he uses to access the calendar – for instance the laptop or his smart phone – does not work in a situation where he must check something on the calendar). Financial and time management take him half an hour each day.

At night, Mr. Sorgsam uses his laptop to surf the Internet, which he sometimes also does during the day at his partner's home.

Design Implications: How to Support Mr. Sorgsam

The user's context previously detailed suggests that Mr. Sorgsam needs something to:

- Be reassured that everything is all right with his partner when he cannot be around;

- Satisfy his communication needs when his friends are not available to meet and/or talk;
- Improve the communication between him and the home care service, especially with regard to coordination of visits and related activities, and
- Improve the organization and management of tasks by using a material calendar.

Although these issues refer to the needs of a single individual, our data suggests that they are recurrent among other caregivers who face a similar situation. In the following, we elaborate a few design implications we have identified, addressing the four issues presented above.

Improve communication with the partner

Taking account of the first issue previously introduced, it is feasible to think that improving the communication between Mr. Sorgsam and his wife can potentially improve his sense of security.

Living in different apartments and being mobile (e.g., meeting friends, going to supermarket, doctor, pharmacy, etc.) makes communication between them difficult. A *bidirectional video communication channel* can potentially help to maintain the contact when they cannot be physically together. Moreover, a *monitoring system based on several sensors* notifying him about any problems or accidents would be very relevant, as he is concerned that she may fall or stops breathing due to her COPD.

Nevertheless, it is worth pointing out that the system should be configurable and allows him to switch it off when he is with her. Also, the system should take into account issues of privacy and control, since Mr. Sorgsam's partner has clearly indicated that she does not always want him around. This is rather a challenge,

since giving her control over the system, so she could also disable it when she does not want Mr. Sorgsam to be watching over her could defeat the system purpose, i.e., notifying Mr. Sorgsam of an unexpected dangerous situation. We propose to address this challenge and further elaborate on it on the course of our project.

Improve communication with others

Improving communication with others addresses both the second and third issues enumerated at the beginning of this section. First, the life arrangements concerning Mr. Sorgsam and his partner (i.e. living in different households) do not allow them to have regular contact. In fact, sometimes Mr. Sorgsam's partner does not want to see him. In situations like this, he tries to meet some friends. Unfortunately, sometimes this is not possible. A possibility would be put him in contact with people in similar situations, even if they were unknown. It might be that talking with these people would make him feel better and not lonely. This is another question addressed in our research.

Improve management of caring

In terms of the forth issue introduced at the beginning of this section, there are several reasons why Mr. Sorgsam needs to manage his care activities. For instance, although home care service providers are scheduled on a daily base for a certain time of the day, they do not keep their visit time consistent. Sometimes they are late, sometimes – not very often – too early. Mr. Sorgsam needs to know when they would in fact arrive in her apartment in order to arrange additional care activities. This would help him save time and reduce stress. However, he cannot call them because he cannot have their cellular phone number. Thus, he needs to be notified when such professionals are on

their way and so he knows when they will arrive at her apartment.

It is also important to keep track of activities in the past and future for better care giving. As mentioned before, Mr. Sorgsam prefers a paper-based calendar where he can write on all the important appointments due to several reasons (e.g., risk of data loss or malfunction). He also uses post-its for important things to remind him. However, he acknowledges that it would be useful for him if he could integrate all the different paper-based calendars that he manages in an online calendar that would be accessible through different devices. It is feasible to think that a tangible artefact that would produce at the same time a physical entry of an event to a calendar (or piece of paper that could be attached to the calendar afterwards) and automatically duplicate it to an online calendar would be useful and appreciated. We plan to test such a solution in the TOPIC project and devise innovative solutions that can better support informal caregivers like Mr. Sorgsam.

Conclusions

In this paper we presented a comprehensive description of a real care situation and introduced a few ideas for technological developments to address the needs stemming from it. However, the findings and ideas on which we report here are not final. It is open for discussion, for instance, the extent to what the issues observed in the care situation herein described is representative of the different possible existing care situations and how effective the design solutions herein suggested would be in such a situation. Moreover, it is feasible to question which other issues of caregiving these design ideas can potentially support.

Acknowledgements

We would like to thank the Ambient Assisted Living Joint Program for financial support and the members of the TOPIC consortium for the insights and input in the project development.

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Internet and Parents with Children with Special Needs: A Meta-Analysis on PubMed Articles

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CCCIC'14, February 15, 2014, Baltimore, Maryland, USA.

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ISSN 1021-73643

Abstract

Internet is becoming one of the major information sources for parents who have children with rare and difficult illness and special needs. The past few years have observed substantial efforts from the researchers to understand how these parents use Internet to access health information for their children. Based on their findings, the researchers also offered some recommendations to enhance the effectiveness of these resources. Unfortunately, a major part of the Internet resources targeted to these parents is still suffering from the problems identified by the researchers. Considering this, we have decided to summarize all the efforts and suggestions provided by the researchers. This paper presents our preliminary results of meta-analysis of all the literature available in PubMed database that deal with Internet use by parents who have children with special needs. In addition to systematic collection of the scholarly articles, we have provided our own recommendations based on our expertise in online social network and community healthcare domain.

Author Keywords

Children with Special Needs; Parents; Internet; PubMed

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In 2008, Pew Research Center conducted a nationally representative telephone survey to understand how Americans use Internet for health purposes. They found that 61% of Americans use the Internet to find health information, and for 60% of them Internet had an impact in making health care decision.¹

Children with rare and difficult illness (e.g. a physical or an intellectual disability, autism, down syndrome, ADHD, cancer, etc.) or bad health conditions (e.g. obesity) need special care due to the uncertainty and emergency of their health conditions. According to US census, in 2010, 2.8 million (5.2%) school-aged children (aged 5 to 17) and 156 thousands (0.8%) small kids (aged below 5) had disability (here disability refers to having vision, hearing, cognitive, ambulatory, self-care, or independent living difficulty²). Parents who have children with special needs experience serious health concern for their children and invest their time, effort, money, and other resources, as much as they can do. For instance, De Rouck and Leys, after doing an extensive literature review in four electronic databases (Ovid Medline, PsycINFO, CINAHL and Sociological Abstracts), showed that parents of children admitted to a neonatal intensive care unit have high information need [1]. Internet is becoming a prominent source of information for parents with children with

special needs [2, 3]. Researchers also paid close attention to how these parents use the Internet (e.g. websites, online support communities, web 2.0, online social network, etc.) to access the information they need. For instance, Knapp et al., through a cross-sectional telephone survey, showed that, although three-quarters of the parents whose children have life-threatening illness consider the doctor as their primary source of information, 76% of them use Internet as an additional source [4].

Although the parents with children with special needs excessively use Internet now-a-days, the researchers found that, Internet resources are still suffering some fundamental issues [2, 3, 5-8] and most of the health-related websites are still not following the recommendations provided by the researchers. Observing this, we have decided to summarize all the scholarly findings and recommendations published to date in notable journals and conferences so that any future endeavor in this arena can be beneficial from our effort. We have also incorporated our own recommendations from our expertise in online social network and community health care area. In this paper, we are reporting our preliminary results mainly collected from scholarly articles available in PubMed database³.

Methods and Data Source

We performed a systematic keyword-based literature search in the PubMed database. We searched articles using the combination of keywords such as "Internet" "parent" "special care" and the different variations of these keywords (e.g. "eHealth", "rare disease",

¹ <http://www.pewinternet.org/Press-Releases/2009/The-Social-Life-of-Health-Information.aspx>

² <http://www.census.gov/prod/2011pubs/acsbr10-12.pdf>

³ <http://www.ncbi.nlm.nih.gov/pubmed>

"informal caregiver", "obesity", etc.). Our search considered all the articles published in the last 10 years in the "Humans" species domain. This keyword-based search resulted in 107 research articles. After going through all the abstracts, we have excluded a significant number of articles since those did not seem relevant to our search. We included any article which discussed the use of Internet by parents who have children with special needs. After filtering out the non-relevant articles, we also looked at other articles suggested by PubMed as similar to those articles. Finally, we have found 15 relevant articles. The findings reported in this paper are based on these 15 articles.

Results and Implications

After extensively analyzing all these relevant articles, we have identified some important findings and recommendations. Below we are pointing out the major findings and recommendations along with our own reflection.

Dominance of Women

Among parental Internet users, women are more likely to use Internet for their children as opposed to men, irrespective of whether their children has special needs [2-4] or not [9, 10]. For instance, Oprescu et al. showed that in an online support community where users are mainly parents of children of clubfoot disease, 86% of messages were posted by women and the rest 14% came from men [3].

Since men and women use Internet differently [11], we recommend that, an Internet resource for this type of parents should be designed keeping women's preference in mind. For instance, women have more trust on online communities as opposed to web portal

and social network as authenticate information provider [12]. Hence, we suggest that, more online communities should be created for these parents and those should be designed by giving priority of women's preference about Internet usage.

Inaccurate, Incomplete, and Unclear Information

People suffer from illness-related uncertainty as many health-related websites provide unclear, inaccurate, and incomplete information [13, 14]. Parents with children with special needs also experience the same problem [3, 6]. In addition, the parents, in several cases, are unable to distinguish between high quality and low quality information [2, 4, 6] and become perplexed to follow a particular health-related information.

To address this problem, we recommend that, health-related information should be written in plain, simple, and easy language so that even a layperson can comprehend the meaning very easily and act accordingly. Moreover, for the sensitive information, a trusted source (e.g. a specialized doctor, a reputed scholar in that domain, a well-known medical institute, etc.) must accompany the information. For example, sensitive health-information such as list of medications should be approved by specialized doctors to highlight the authenticity of the information. In case of non-sensitive information, a rating system by the existing user would be appropriate to differentiate between high and low quality information.

Experience-based Information

Researchers showed that parents prefer to learn the experience of other parents in similar situation [5]. However, it is non-trivial to encourage parents to share

their experience in the public domain. We recommend that, a reward-based system can be helpful in encouraging more parents to share their experience. For instance, a parent will be announced as parent of the month if their experience is “found helpful” or “liked” by a significant number of other parents. A model similar to yahoo answers and Facebook-like social network can be generalized in this regard.

Trusted Source of Information

Mackert et al. showed that parents with obese children usually do not trust the government as the health-related information provider [15]. On the contrary, university researchers are considered as the trusted source of information.

Considering this, we recommend that, the government should be very precise and accurate about the information they provide in Internet and their provided information should be endorsed by the reliable medical doctors or reputed and expert researchers.

Community-based Computer Center for Underserved Parents

Knapp et al. showed that older parents, less-educated and non-English speaking parents are unenthusiastic Internet users [2], sometimes due to lack of access to the computer and Internet. Hence the researchers gave importance on interventions to improve their computer and Internet literacy by designing community-based computer center [2, 16].

Based on our expertise on community informatics and community-based computer center, we also believe that, such interventions would be really helpful for the parents who have children with special needs.

Information Representation

Mackert et al. conducted a study on low health-literate, culturally diverse parents and showed that visual content, as opposed to simple text, could be helpful for the parents to grasp the important information for their obese children [12]. Richness in content is necessary but not sufficient; the presentation style is very important as well [4, 12].

Merely designing a website with proper content and fancy design might not be useful for the actual users if their need, preferences, and context are not considered. Hastings showed that, if we want to design an integrated child health information system, our central focus should be on the parents [17]. We believe that, the same finding is also applicable for designing a health related website for providing informal care. Since it is non-trivial to measure the right balance between text and audio-visual content, we recommend that, each health sites, before launching their final version on Internet, should perform an extensive user study involving the parents and refine the site design accordingly.

Publicly Available Search Engine for Diagnosis

Bouwman et al. discussed two cases which showed the necessity of publicly available Internet search engines as an effective diagnostic strategy in identifying rare diseases [18]. They also designed such a search engine dubbed as “Doctor’s Google.”

Although this is an excellent initiative if the parents can diagnose the rare disease using the search engine, we recommend that, the information should be used in a careful manner and parents should consult the doctor before taking an action.

Conclusions and Future Work

In this paper, we have reported the results of a meta-analysis on the literature systematically collected from PubMed database. In this ongoing research, our goal is to synthesize the contributions of the researchers who performed extensive research on how parents with children with special needs use the Internet. We also recommend some guidelines to make Internet more useful for these parents. These guidelines are as follows: (a) Online community for these parents should be more women-focused; (b) Avoid complex medical terms and use plain, simple and easy language to describe medical information; also the information should be endorsed by authentic sources such as a specialized doctor, a reputed scholar in that domain, or a well-known medical institute; (c) Encourage the parents to share their experience with other parents on similar situation; sites might introduce a reward-based system for the parents; (d) The health-related information provided by the government should be endorsed by the reliable medical doctors or reputed and expert university researchers to gain more trust from the parents; (e) More interventions are required to the underserved parents to use Internet; community-based computer center can be an example in this regard; (f) Information provided in the web should have a right balance between text content and audio-visual content; and (g) although publicly available search engine can be an excellent effort for diagnosis of diseases, parents should consult the doctor before taking an action based on the recommendation from that search engine.

In future, we want to explore some other relevant database such as ERIC, Ovid Medline, PsycINFO, CINAHL, Sociological Abstracts, and Social Services Abstracts. We also want to extend the domain for other

informal caregivers (e.g. children, friends) and patients (e.g. regular senior citizens, older adults with serious illness, etc.).

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Information Technology Tools For Long Distance Caregivers: A Needs Assessment

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CCCIC'14, February 15, 2014, Baltimore, Maryland, USA.

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ISSN 1021-73643

Abstract

Recent trends of population aging and globalization have required an increasing number of individuals to act as long distance caregivers (LDCs) to aging family members. Information technology solutions may ease the burden placed on LDCs by providing remote monitoring, easier access to information and increased communication. While some technology tools have been introduced, the information and technology needs of LDCs in particular are not well understood. Consequently, a needs assessment was performed by using video conferencing software to conduct semi-structured interviews with 10 LDCs. Interviews were enriched through the use of stimulus materials that included sample screen-shots for web and smart phone based health management. Responses were recorded, transcribed and then analyzed. Subjects indicated that information regarding medication adherence, calendaring, and cognitive health were most needed. In addition, all respondents estimated their usage of a LDC health management website as at least once per week, with half indicating a desire to access the website from a smartphone. These findings will be used to inform the design of a LDC health management website to promote the meaningful involvement of distant family members in the care of older adults.

Author Keywords

Informal Caregiver; Information Needs Assessment;
Data visualization; Smart home

ACM Classification Keywords

H.5.2. User-centered design; H.5.m. Information
interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

2011 marked a critical milestone for Americans; the first set of baby boomers reached the age of retirement. For the first time in the United States' history, the number of adults age 65 and older exceeded the number of children under the age of 5. By 2014, the percentage of the population age 65 and older will reach an all-time high of 14%; double the proportion that was seen in the 1940's [1]. As this process of "population aging" unfolds, the problems associated with caring for unprecedented numbers of older adults become increasingly apparent. Unparalleled demand will be placed not only upon the US healthcare system, but also, upon the millions of family members, friends, and neighbors that provide unpaid care to elderly loved ones. These individuals, often referred to as informal caregivers, form "the backbone for much of the care that is received by older adults in the United States"[2]. In an increasingly global society, geographic separation presents a significant challenge to many as they strive to provide care from afar. Challenges such as inadequate methods of communication, living in different time zones, and lack of familiarity with a loved one's surroundings may all combine to prevent a long distance loved one from providing care. Also, such separation often increases the burdens of time, cost, and emotional strain upon the caregiver [3]. In the

last few years, internet technologies have matured insomuch that they may prove to be viable options for providing support to long distance caregivers (LDCs). Such an approach however, remains largely unstudied.

As an initial step in the evaluation and development of information technology support tools geared towards LDCs, it is essential that we first understand the informational needs of this unique user group. While some researchers have investigated the information needs of caregivers in general, these studies were not focused specifically on caregivers that were geographically separated from their care recipients. Additionally, these studies have not assessed caregiver needs in the context of a "smart home". Some have focused on identifying information needs of caregivers for individuals with dementia[4, 5], while others have focused on providing appropriate information regarding how to care for other specific illnesses/conditions[6, 7]. One promising study, conducted by the National Alliance of Caregiving and United Healthcare [8], has investigated caregivers ranking of various health IT tools to support them in their care. This study however, obtained Likert-scale scores of importance rather than giving caregivers an opportunity to express needs, make suggestions, and offer feedback. The research outlined below is innovative, due to the fact that no studies have specifically looked at the information needs and technology preferences of LDCs by providing caregivers an opportunity to openly discuss their needs and preferences. Furthermore, our study is unique in that we are investigating information needs in the context of a smart home, in which many novel and important data streams are available as potential information sources. Investigating LDC needs from this perspective provides us with additional

information that will enable us to better understand the emerging needs of caregivers living in an increasingly “electronic” world.

Methods

A network of older adults living in “smart homes” throughout the Portland, Oregon region has been established as part of our existing cognitive health coaching platform. Older adults that participate in this health coaching platform are continuously monitored using various health tracking sensors. Areas of study include:

- **Medication adherence and reminding**
 - measured by a camera embedded pillbox
- **Socialization**
 - measured by phone, Skype and email monitors
- **Sleep quality**
 - measured using mattress pressure sensors
- **Cognitive health**
 - measured by cognitive computer games

Because the socialization module encourages the use of the telephone, email and Skype video calling, each older adult in the socialization intervention had previously chosen a remote partner with whom they would regularly communicate. These individuals in turn agreed to provide remote support to the older adults in our project. All remote partners lived in a different location than the older adult and were generally a close friend or family member. A group of 10 subjects was recruited from within this pool of “remote partners” as participants in our needs assessment. Due to the exploratory nature of this research, qualitative methods were chosen, with semi-

structured interviews serving as the primary method of data collection. Each participant was contacted initially via telephone and then later interviewed for approximately 45 minutes. Due to geographic separation between the subjects and the researchers and as all enrolled LDCs were familiar users of the Skype video conferencing software, interviews were conducted remotely through the use of this system. Initially, a short introduction was given in which the purpose of the study and each subject’s role was clearly

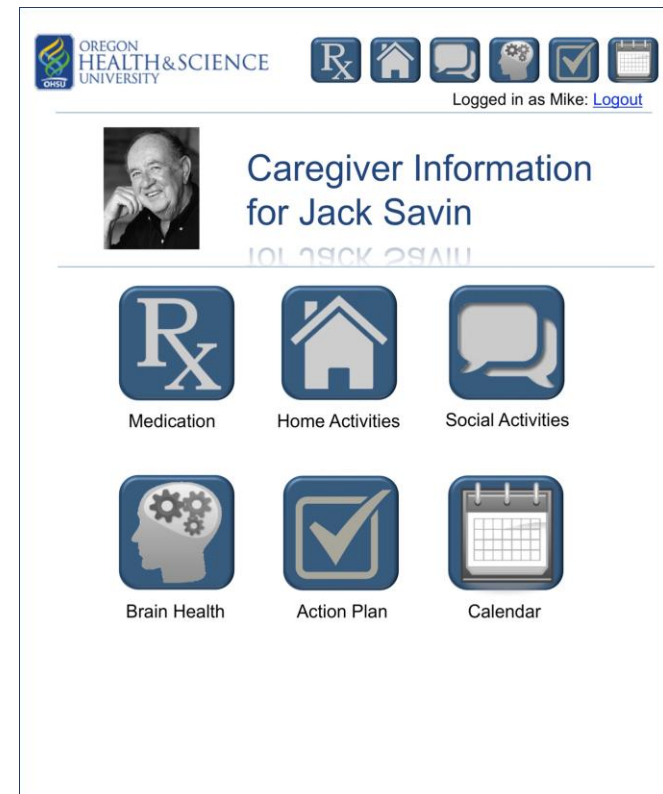


Figure 1: Screen shot of LDC website splash page mock up

explained. An emphasis was placed on the fact that subjects could ask questions or make suggestions at any time. Next, subjects were asked to introduce themselves and to describe some of the challenges that they had encountered as they strived to provide care from a distance. Respondents were then asked which types of information are most important to them as caregivers. Next, subjects were asked to identify ways in which technology might serve to ease some of the

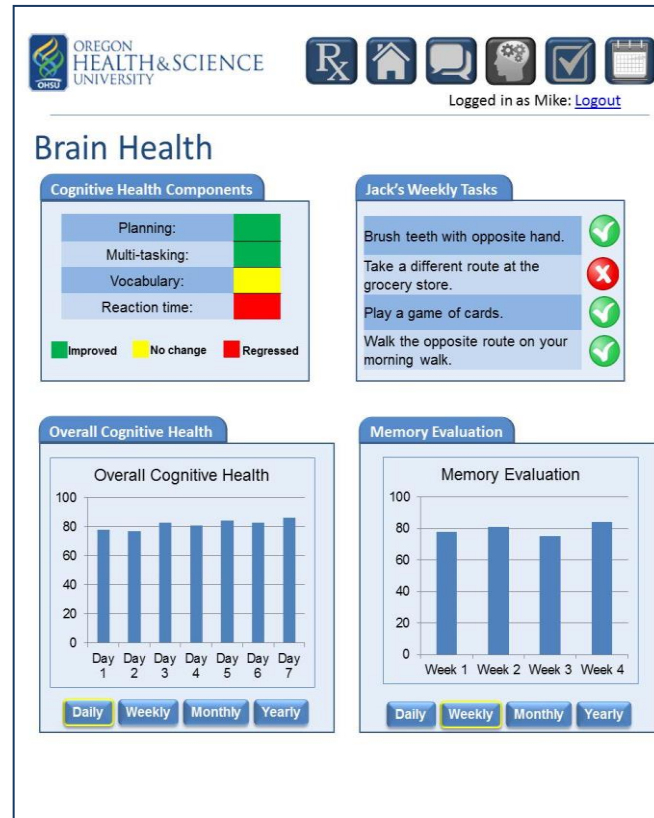


Figure 2: Screen shot of brain health page mock up

burdens encountered by LDCs. After respondents answered these questions, stimulus materials including sample screen-shots for web and smartphone based health management were displayed using Skype's "screen sharing" feature. These materials enriched discussion and provided subjects with a "real world" example of ways in which technology could help them to provide care. In particular, subjects were shown a mock-up website in which sensor data regarding medication adherence, socialization, calendaring, sleep quality, and cognitive health was presented using easily understood language and graphics. Tips and suggestions for how to help the older adult were also displayed within the mockup. After presenting the mockup, discussion was facilitated by the presentation of thoughtful questions designed to promote feedback about key areas of interest (e.g. estimates regarding level of usage, importance of mobile devices, design recommendations). Finally, each subject was asked for any additional comments or suggestions regarding site design and types of information available. Each interview was recorded, transcribed, and subsequently analyzed by grouping similar thoughts and concepts into appropriate themes and ideas.

Results

Of the 11 subjects that were initially recruited, 10 individuals were successfully contacted and interviewed, with one participant unable to proceed due to lack of a sufficiently reliable internet connection. Of these 10 individuals, 6 were female and 4 were male.

Expected Functionality

Video Calling – Nearly all of the individuals interviewed spoke about the benefits of using videoconferencing

software such as Skype to communicate with the older adult under their care. Four individuals spoke of the value of nonverbal communication that is not available over a regular telephone call. The participants' thoughts regarding this matter are well summarized by the comment "Now, instead of hearing how she's doing, I can see how she's doing. It's one thing to tell someone how you're doing but it's a little harder to look at someone and tell them that you're feeling good when you're not." In addition, one interviewee talked about the benefits of being able to show objects over video rather than simply describing them.

Calendaring – Six individuals indicated that a shared calendar would be useful to them in their caregiving responsibilities. Respondents were especially interested in being able to view upcoming doctors' appointments and any planned trips or outings. One person commented that "to [her] the calendar would not be at all useful because digital calendars are cumbersome". Another commented that "it might take a bit of switching going from a paper calendar to an electronic one but I think I can convince my mom to switch". Another reviewer commented that it would be useful for older adults to see a very high level version of the caregiver's calendar so that the older adults could be reminded of times that the LDC would not be available.

Medication Adherence – Four individuals indicated that information regarding medication adherence was very important to them. Respondents made comments such as "medications are a big concern" and "if you're not taking your medication, everything else would fall apart". One individual, however, said that medication information was the least important of all the types of information presented. He commented that this was

due to the fact that using images obtained from a camera embedded inside a pill box did not really indicate if the medication had actually been taken. In his words "they could take it out of the box but then not really take it".

Cognitive Health – Four interviewees suggested that data regarding cognitive health was very important to them. Two of these individuals indicated that this information would be especially interesting to them if it could be presented over a long period of time allowing the caregiver to track any problems. In the words of one subject, "as he gets older, I especially worry about his brain and memory".

Sleep – Three respondents spoke of the importance of knowing if and when an older adult was experiencing difficulty sleeping. Each of them expressed concern that inadequate sleep can then lead a large number to other problems/concerns. One interviewee described the utility of a system that would automatically alert her after her loved one had experienced multiple consecutive nights of poor sleep so that she could call and check on the older adult and then intervene if necessary.

Medical Records – Two LDCs asked about the possibility of being able to access the older adult's medical information and test results. They expressed a desire to be more informed and involved in the older adult's medical care because "sometimes if we don't go with him/her, then his/her story doesn't make sense".

Other Suggestions – Some respondents also suggested other types of information that would be useful to them as long distance caregivers. One caregiver suggested

the inclusion of "information about hobbies and interests". He went on to suggest a page in which the older adult could share pictures and information regarding hobbies with the caregiver. Another caregiver was interested in the possibility of including information regarding diet through the use of a "smart refrigerator to track if she needs milk and that sort of thing". One final suggestion was the ability to send an alert to the older adult. He commented that "Dad hasn't been drinking enough water lately. It would be really nice if there was some way to remind him with a beep or something."

Design Implications

Expected Usage – Every individual interviewed expressed optimism about their usage of the proposed system and felt that they would use it on a fairly regular basis. All participants indicated that they would likely use the system at least once per week with three participants indicating that they thought they would use the system "a couple times per week" and two respondents suggesting that they would use the system on a daily basis. Two individuals indicated that they would be much more willing to use the system regularly if "the system had the ability to alert me when there was something that needed my immediate attention". While not as valuable as actual usage data, these expected usage patterns provide valuable information regarding the overall flow and design of a caregiver website. Such high frequency of usage would suggest the need to design a "dashboard" that would allow the caregiver to quickly check an older adults condition without the need to click on each individual category. Also, as noted by two of our participants, an intelligent alerting system that drew the caregiver's attention to

potentially worrisome data would be ideal. If alerts are to be used however, the authors urge that a great deal of care to be taken so as to not inundate caregivers with "false alarms" as this is likely to lead to alert fatigue.

Smartphone Preferences – Of our sample, half of the respondents indicated that they would be likely to access the LDC website from a smartphone. This closely mirrors smartphone adoption data for the US population during the time that the interviews were performed. As such, we expect an increasing proportion of caregivers to request smartphone compatibility for a caregiver website. Of those that desired smartphone compatibility, many talked of the convenience and importance of having access to the system while traveling either to/from work or while on vacation. These participants described use cases in which a smartphone would be used while on the go but a traditional PC would still be the preferred choice if available (i.e. when at home). Such usage in which both a smartphone and a traditional PC are used interchangeably requires a consistent "look and feel", as well as similar functionalities and feature sets regardless of which device is used to access the site. In addition, due to respondents reporting high levels of expected usage, a mobile app is recommended in lieu of a smartphone compatible website. Such an approach allows caregivers to view historical data even when no data connection is available and allows for more sophisticated alerts to be displayed when necessary. Identified barriers to using a smartphone to access the LDC website were a small screen and relatively high costs of ownership and usage. However, we expect these concerns to fade somewhat as smartphone

manufacturers/providers continue to shift towards larger screen sizes and lower cost devices/services.

Data Sharing Preferences– A few caregivers expressed concern that due to the sensitive nature of health data, their older adult may not be willing to share all of the different types of information with them. Though this was not confirmed by discussing data sharing preferences with older adults in our study, we suggest that any such system provides a way in which older adults are able to control the visibility of the data collected.

Additional Thoughts

Overall Impressions - All 10 of the individuals interviewed expressed optimism and excitement regarding the proposed system. Comments such as "I think this is a great idea", "I think it's exciting", and "I think you're on the right track. This is going to be really helpful for people like me" were expressed. Though individuals suggested the improvements or changes that are detailed above, we were surprised by the fact that none of the participants thought that building a web site/app for LDCs was an overall bad idea. This may, however, be partly due to the participants' unwillingness to criticize the research team's work/ideas.

Unexpected Benefits – In addition to the expected benefits of being able to ease the burden of providing care from a distance and improve the involvement of LDCs in the care of their loved ones, a few other benefits of the proposed system were suggested. One caregiver talked about how the system would "help me not feel so guilty for living so far away". It was also

suggested that such a system would help older adults because "having us involved helps her to feel loved and valued". Even when an older adult already lives near family members, one individual suggested that "I can help my mom and uncle by alleviating some of their stress. If there's something going on I can let them know and have them go visit her". Finally, one caregiver spoke of the privilege of being able to care for his aging parents as they "experience this amazing process of the end of life" and suggested that a LDC website would allow him to do that more effectively.

Discussion

While our sample of 10 LDCs was insufficient to reach full saturation, many valuable themes emerged that will prove useful as we strive to provide long distance caregivers with new information technology tools. It was very encouraging to find that all 10 individuals interviewed suggested that building a LDC information website would generally be accepted positively. Equally encouraging were indications that this website may be used on a fairly regular basis. There is some concern however that these data are somewhat biased by the fact that interviewees may not have wanted to criticize the researcher's work. In addition, perceived usefulness and usage may not be accurate indicators of actual system usage and utility. While this study has indicated that information regarding medication adherence, shared calendaring and cognitive health are likely to be useful and valuable to individuals providing care from afar, the best methods for presenting these data to caregivers remains unexplored. In addition, while the ability to access an older adult's medical information and test results has been suggested as a useful feature, limitations regarding privacy of medical data may prove to be substantial hurdles. Another

suggestion regarding a caregiver's ability to provide reminders to an older adult should also be studied in the future. In conclusion, the authors feel confident that we have obtained sufficient preliminary data to

justify the development of a long distance caregiver website in order to conduct a field trial of such a system in the real world.

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Moving into a Senior Apartment: Opportunities and Hindrances in Rebuilding Social Relationships among Elderly

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CCCiC'14, February 15, 2014, Baltimore, Maryland, USA.

<http://cccic2014.wordpress.com>

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ISSN 1021-73643

Abstract

ICT research for the ageing society in support of physical, mental, and social wellbeing of elder people has recently gained much attention. We contribute to this discourse by investigating empirically into a specific issue: the shaping of relationships by elderly people who moved to a senior apartment and thus are forced to build up a “new” social environment for themselves. Our qualitative study shows aspects of elderly peoples’ communicative behavior which influences communication opportunities or hindrances in the new environment and the shaping of new relationships. Our findings stress a dominance of own conventions and values, perceived needs to find legitimations for certain activities, helping as a life motive and the fear of being a “social petitioner”.

Author Keywords

The elderly, shaping of relationships, senior apartment, wellbeing, independence, communication style, communication pattern, symmetry, legitimation, conventions, values, helping.

ACM Classification Keywords

H5.0. [Information Systems]: Information interfaces and presentation – General, H5.2 User Interfaces-User-centered design.

Introduction

How do elderly people talk to other people, about what and in which way? What are occasions for communication with other people and what are hindrances? There is a broad range of work in CSCW and HCI on supporting the elderly in maintaining relationships with their family members, friends, and with their wider social environment, such as supporting remote awareness or monitoring functionalities. Our qualitative study contributes to research on the specificities of communication and relationship “management” in later life stages in a field which has not been under explicit research until today: We examined living contexts of elder people who moved from their house into a senior apartment. In our research we found out slightly differing aspects to recent research results due to that certain living situation, which for these people means having to build up a “new home” and new relationships to neighbors and having to deal with the new community structures. In semi-structured interviews in three senior apartment environments we were able shed some light on related aspects of the shaping of relationships and on the handling of communication opportunities and contexts in the new environment. Our analysis identified the following communicative figures as being relevant for the elder persons’ shaping of relationships: The importance of one’s own conventions and values, legitimation as a strongly demanded motive of action and communication, helping as a live motive and the fear of being a “social petitioner”.

Related work

Enabling ICT to be able to help elderly people to stay as long as possible in their own home environments has become a growing research focus in CSCW over the last

few years. Different research foci approach this topic such as the provision of medical support by home care workers, e.g. [1] or the enforcement of social connections and emotional ties with family members or the wider community. Different themes have been elicited as having an impact on the use of ICTs, such as independence and reassurance, intimacy and asymmetry, reciprocity and roles in lived family and peer relationships [2]. As symmetry is seen to be more important in friendship and peer relationships, many elderly prefer to keep their former role as an active contributor to family life (in terms of e.g. emotional, economical, social support) and not being a family member who needs to be taken care for in a more passive role [3]. This is also connected to the desire to keep the feeling of self-worth and independence in the later life stages [4], [5]. In regard to ICT for bolstering peer and friendship relationships, research of [2] recommends to stress existing relationships which are emotionally meaningful to elderly people rather than focusing on initiating new ones. Resulting evidence suggests that, for many elderly people, few close friendships are more important for their wellbeing than a large social network.

Moving to senior apartments in later life stage

The rising phenomenon that many elderly people leave their familiar living environment in order to move into a senior apartment which becomes a new home environment for them, a home with all former requirements towards independence, self-worth, bodily, mental and social wellbeing gives a somewhat new perspective on their “management” of social relationships for their wellbeing. We examined the every-day life of elderly people who moved in such senior apartments with an emphasis on their handling

of social relationships and related media use in their “new” living environment. All of them moved in the apartments with similar expectations concerning the possibility of conducting their lives with more independence but also with the availability of support if one day needed. The apartments e.g. provide barrier-free architecture and individual services, such as care or meal service, as needed and wished. For many of these elderly people, the moving also meant settling into a new environment, having to initiate new relationships with neighbors and the community. This focus on “living at home” in a new environment has not been an explicit research focus in CSCW and HCI up to now. In regard to ICT support for non-family relationship “management”, such as initiating new friendships and connections in the new environment thus needs a closer look on related circumstances.

In our research we have come to certain incidents of what might be important when supporting elderly people in building up relationships within their new community environments. It is worth to reflect on questions of how elderly people talk to others and in what way and how this influences occasions for communication or related hindrances. In communication research we find approaches to systematize communication patterns, such as the metaphor of the “communicative household” by Luckmann [6], which denotes the entity of communicative repertoires or possible communicative courses of action of people in defined time and space frames which are marked by certain codes of interaction and communication. Transferred to communicative behavior of elderly people, communication research differentiates categories such as the background of the communication partner which

can particularly influence communication (e.g. generational cohort, institutional or familiar/ friendship communication situation) [7]. With increasing immobility actual encounters with the environment decrease which means that opportunities for free communication are reduced. Additionally, because of less confrontation with actual world affairs, more autobiographic parts in communication situations appear. Sometimes media reception even replaces interpersonal communication when immobility worsens.

The change in communication style is another aspect which has been stressed by communication researchers. [7] points at two aspects: the communicative behavior of elderly people is often marked by a high detailedness, and by attempts to demonstrate that they possess competencies of the middle generation in order to not be stigmatized with negative attributes of an old age [8].

Our work intends to contribute to a more detailed view upon related communicative aspects of elderly people who have moved to senior apartments for inspiring reflections on technology design.

Method and Sample

After a first orientation phase of discussing our project ideas with local care providers, doctors and housing companies, we started our empirical phase in 3 different living environments: two senior apartments and one retirement home, all distributed across different German regions.

At the first meeting with each of the 11 elderly households, studied we accomplished a semi-structured interview in their homes which lasted between 60-90

minutes of duration. From the 11 households we had three households with couples (one mother and son, respectively) and 8 single living persons, most of them widowed. We additionally accomplished interviews with 4 persons in leading care provider positions who work in the context of the senior homes. The interviews were recorded and transcribed.

Findings

In the following section we present our findings of communicative peculiarities we derived in our empirical study. We identified the following main communicative figures: importance of own conventions and values, legitimation as a strongly demanded motive of action and communication, helping as live motive and the fear of being a "social petitioner".

Conventions and values

Having a neat apartment and the act of cleaning was mentioned by most of the elderly. Another phenomenon was the claim of the most elderly to just watch intellectual television programs where some admitted to watch entertainment television programs just infrequently. Additional opinions regarded the agreement on not taking governmental support if not needed or not to complain about health problems. All these statements express some kind of conventions and values of defining how somebody should live to be socially accepted. In the interview situations, our interview partners all strived to communicate their own behavior and identity along the conventions and norms they valued. The question if they really live congruent to these conventions or if they just pretend to do so is not the point here. We found out that these conventions are the basis of every social contact and determine which behavior is socially accepted and

awaited. We even found cases where different opinions about conventions excluded people from being a potential social contact. This was e.g. confirmed by a woman who said that she isn't interested in a social relationship with the neighbors because they did not clean the corridor regularly.

Legitimation

Reflecting on our interviews, we found the dislike to try actively to gain social contacts. On the other hand many elderly would like more contacts but find themselves in the situation of joining a given group. We found many elderly attempting to give legitimation to connect socially. "I help the dementia patients, because somebody has to help them to count", was a statement of a woman who joined a group of dementia patients regularly to play games. On the one hand she gives a legitimation for playing games which normally is a children's duty and does not meet her conventions. On the other hand we find a legitimation for coming to groups which normally are only opened for the group of people living in the retirement home to which she does not belong.

Helping as a life motive

Many elderly interviewed pointed out that during their youth they lived in poverty, which was caused by the Second World War. It is often mentioned how they managed to come through this situation without institutional help which, from their point of view, stands in contrast to the situation of the youth today. Although they often had no institutional help, they helped each other in these hard times.

Today the elderly still help each other in daily life. One older woman who went to a retirement home twice a

week to pull elderly with their wheelchairs to group events said: „I`m fine, as long as I can help, I am happy.“

We also got evidence that it can be very frustrating for elderly if they can`t help anymore. We interviewed some women who were “helpers” and carers during their whole life (cared for their families, their children, their grandchildren, their elder neighbors, etc.). Due to physical infirmity by their age or by the lost of needs for their help they are confronted with a situation of being “useless”, which often lead to frustration and disorientation on their social role and identity.

Fear of being “social petitioners”

The elderly often try to help other persons for several reasons as pointed out before. Considering the point that most of the elderly managed hard times without any institutional help, this point is quite understandable. In today`s situation most of the elderly get professional care and are protected by a good social system. But many don`t want to act as petitioners. They always managed to solve problems themselves, so they still can do this today. Never having received help has made it difficult for some to accept help.

We interviewed a woman who lived and worked in Russia. She lost everything she worked for and finally came to Germany. She was very happy, but in the same moment frustrated about her situation. She pointed out that she could do so many good things for Germany if she were younger. She often mentioned the fact that she always worked for Russia and never got something back in return and that she never worked for Germany but gets so much.

Helping and accepting help are two very different points. We noticed this fact while interviewing a married couple. They often pointed out that they would like to have more contact to their neighbors. But in the same moment they clarify that they don`t really need contacts to others in order to have a fulfilled life. The point here is that they would have the feeling of being social petitioners if they displayed their desire for social encounters with their new neighbors too apparently.

Discussion

The establishment of a “new home” in a senior apartment is coupled to the need and wish to make social contacts in the new living environment. This process may be rather complicated for people in later life stages. In our interviews with elderly people who had moved to the new home environment, we identified several communicative patterns and figures which point at difficulties in establishing new contacts and which inspired our thinking on related technology support. First, people were uncertain about how other people (neighbors, local community members) “are”; what is important to them is to find a way of life compatible to their own. This incertitude about “the other” led people to a process of evaluating viewable external expressions of the other at the expense of one`s own norms and conventions. At the same time, own conventions and values were stressed and demonstrated in order to present a “socially competent” person. This strong adherence to own norms and conventions in most cases hindered establishing deeper contacts. The negative result was either regretted by the interview partners in retrospect or – in order to not being regarded as a “social petitioner” – was said to be not relevant. But in the context of the whole interview, we could often identify

discontent on the fact of not having made contacts and we “unmasked” related rhetorical figures. Related technology design would have to address and get over the uncertainty people have on the persons in their new living environment. A kind of “contact broker” in a senior apartment could give people the chance to learn things about other people beyond the external information they see. On the other hand it should provide mechanisms that help displaying competence and integrity of the own person, of the own identity. The high relevance for this requirement is shown by the numerous “legitimation figures” the people gave in the interviews for their activities. See the two examples where legitimations were given for playing and for visiting events in an old people’s home. So the question why the elderly need legitimations to initiate social contacts comes into the focus when thinking of ICT as a support for the establishment of new contacts. This finding is in line with the phenomenon of “helping other people as a life motive”: Helping in general seems to be a strong legitimation which could be reflected in ICT design for the support of establishment of contacts. Due to their life experiences to the elderly, mutual help and by this transporting their competences and identity seems to be an interesting anchor for community building.

This appears as an extremely strong motive for many elderly women who were “helpers” their entire lives. In higher age, when physical infirmity or the vanishing of needs for their help occur, there comes a kind of losing of important attributes of former social role and position of elderly in society. In some cases, they have no energy and no idea how to reposition or change their social roles to achieve new meaningful life contents. This stresses the need of ICT research

concerning qualitative enquiries for identifying meaningful motives in individual life histories and finding ways to connect them to social and community activities. In this regard one phenomenon has proven to be an important aspect: it is the fact that elderly people do not want to be seen as “social petitioners” when thinking about the establishment of new contacts. Thus, a related “contact broker” ICT system should support the sense of symmetrical “give and receive” shares in the new social encounters.

The interview situation (with us as unknown persons) may be seen similar to communication situations with people in the new environment. From the point of a critique of the interview method which we must review some parts of the interviews under the question of social expectancy. However, related communicative figures by the elderly people seem to be assignable to their general social contact behavior and thus, have relevance in the form in which they are displayed to us.

Conclusion

In our study on the establishment of contacts of elderly people in their new home environment in a senior apartment, we came across and uncovered several problems and related communicative patterns. Our findings differ to some extent from recent research on ICT to support relationships of elderly people to their families and friends. We have learnt that the presentation of the own identity – with aspects such as social role, integrity and competences – are crucial and often hindering elements in communication situations and community building processes of elderly people. When building technologies to support social contacts in the new living environment, e.g. in form of a “local contact broker”, all these aspects should be considered.

In further research we are going to investigate the field more deeply. We will especially reflect more deeply on the role of our research in the process of community building and on ways to involve other community actors (such as church groups).

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Collaborative Reflection to Empower Primary Caregivers

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CCCIC'14, February 15, 2014, Baltimore, Maryland, USA.

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ISSN 1021-73643

Abstract

Informal caregivers of children with autism need support to coordinate care across environments such as school and home. Communicative impairments make it difficult for the children themselves to report events of their day to a primary caregiver (e.g., a parent). So, the primary caregiver must make an effort to communicate with secondary caregivers, such as family members, educators, and clinicians. We define this process—of caregivers sharing information and knowledge over time to make ongoing decisions about behavioral intervention and care—collaborative reflection. We present two studies exploring approaches to supporting collaborative reflection, with the goal of empowering primary caregivers to better understand how to address their child's behaviors and care.

Author Keywords

Autism; special education; communication; information sharing.

ACM Classification Keywords

H.5.3 [Information Interfaces and Presentation]: Group and Organization Interfaces – Computer-supported collaborative work.

Collaborative Reflection to Empower Primary Caregivers

Collaborative Reflection

Long-term sharing of information and knowledge over time to make ongoing decisions about behavioral interventions

Primary Caregivers

Parents of children with autism, who need support to:

- stay informed about child's behaviors and care when they are not around
- understand how to address child's behaviors and care

Secondary Caregivers

In the home context: nanny, divorced parents, visiting family members.

In the school context: educators, therapists, behavioral specialists.

Study 1

Parent-driven use of wearable cameras to record behaviors and care

Study 2

School-driven use of a novel iPad-based system to record behaviors and care

Introduction

This paper focuses on caregivers of children with autism. Children with autism may require constant and consistent behavioral support and intervention. Maintaining consistency in behavioral intervention and reinforcement is particularly challenging across environments, *e.g.*, home and school. Primary caregivers (typically one or both parents) must therefore communicate and coordinate with secondary caregivers such as other family members and the educational, clinical, and behavioral staff at their child's school. Children with autism have communication impairments or may be completely nonverbal, so their lack of reporting makes it even more challenging for caregivers to stay informed about what happens with their child when they are not around.

This paper presents two approaches to helping primary caregivers of children with autism communicate and coordinate with secondary caregivers. Our focus is on empowering the primary caregivers to (1) stay informed about their child's behaviors and care, and (2) understand how to address their child's behaviors and care—both of which require coordination with other caregivers. First, by pooling information about a child's behaviors and care across environments, primary caregivers can stay informed about what goes on with their child throughout the day. Second, by seeking knowledge from professional caregivers (*i.e.*, behavioral specialists) they can understand how to address their child's behaviors and improve care. We call this process—of sharing information and knowledge over time in order to make ongoing decisions about behavioral interventions—collaborative reflection. In two studies, we explored approaches to supporting this process among caregivers of children with autism.

Study 1: Parent-driven use of wearable cameras to record behaviors and care

Drawing from Hutchinson et al.'s [1] use of technology probes with families in the home, we explored the use of two automatic cameras worn by children with autism. The still images captured by these cameras from the child's perspective were investigated as communication aids when reviewed by the child's primary caregiver.

Methods

Two automatic wearable cameras were used as probes: the SenseCam developed by Microsoft Research [2], and the Apple iPod Touch running a lifelogging app, LifeLapse (<http://lifelapse.com/>). We recruited five families with a child diagnosed on the autism spectrum. The primary caregiver in all the families was the child's mother, and was responsible for determining how and when to use the camera. The study began with an introduction to the camera, training to turn automatic image recording on and off, downloading the images onto a personal computer, and review and organize the downloaded images. Each week, the first author visited the families at their home for an interview along with observation of their home life and family interactions.

Results

The primary caregivers in our study were eager to use the cameras to learn what was happening when they were not with their child. The two primary caregivers with nonverbal children were the most motivated to use the camera, and gained the most new information from use of the camera—suggesting that lack of communication from their child leads to primary caregivers feeling, and being, less informed than if their child was able to share information with them.

"And then she went to her dad's. I was able to... show [her brother], and I'll share this with her dad too, that when they first get to his place that they're just kind of ignoring her. And then when they go out to a restaurant I noticed how much more they were looking at her and talking to her and stuff. And so just kind of like warn them not to... to think about that, to not ignore her."

"I know I've had this conversation with him before [about our daughter's safety]. And after I saw the pictures... I decided this is serious. I'm going to take care of the situation. ... I didn't bring [the pictures] up, but maybe I will. Let's see what happens. Let's see how long it takes for me to train him."

"I wanted to [use the camera] when we were going to the doctor's. Then I felt real uncomfortable and I didn't do it because I was going to have to ask them and... I didn't want to create any more tension than what we already had. ... Yeah I just turned it off because I was like, I don't feel like explaining."

Much of the information and knowledge transfer happened not only through the primary caregiver's review of images from their child's perspective, but collaborative reflection of what the images revealed. For example, one mother noticed that many images showed her daughter looking at sheet music. When she asked her daughter about these images, she discovered that her daughter enjoyed reading sheet music and wanted to have access to more of it. As a busy primary caregiver, the mother had likely not noticed this activity before, and with minimal communication her daughter had not been able to share it with her. It was only through a conversation about the images that this discovery was made.

● Two divorced mothers learned something from the images about their nonverbal child's activities while visiting their fathers (a secondary caregiver). Both mothers discussed how sharing the images with secondary caregivers would help them coordinate care.

● One primary caregiver wanted her daughter to wear the camera to one of many doctor's appointments so she could stay more informed about her medical care. However, she felt uncomfortable even asking for permission and removed the camera to avoid tension.

Even more tension exists between parents and schools. All of the primary caregivers in our study wanted their child to wear the camera at school, but this was not allowed. The authors avoided the significant barrier of seeking IRB approval for use of the cameras in schools as part of our study, yet one mother was so keen on it that she decided to ask for informal permission anyway. She was surprised to be turned down. Although photography was not allowed at her son's

school, she was accustomed to taking photographs as part of her role on the PTA (parent-teacher association). She was convinced that the principal would also approve of her using SenseCam, and was shocked when she was not granted this permission. Although to her SenseCam was no different from the camera she uses to take photographs for the PTA, the principal saw it as a threat likely due to its automatic capture which makes it impossible for others to know when a photograph is being taken. After this rejection, this mother became less likely to ask for permission. When she wanted to capture her son's extracurricular acting class, she chose to "sneak" it in without asking, and no one said anything to her about it.

Conclusions

The primary caregivers in this study were eager to have the use of a wearable camera to support their understanding of what happens when they are not with their child, and to coordinate care between caregivers in different settings (e.g., visiting a divorced father, seeing a doctor, going to school). Wearable cameras such as the probes in our study show promise for supporting collaborative reflection among caregivers, but only if the devices and their use are designed to avoid possible tensions among primary caregivers and secondary caregivers.

Study 2: School-driven use of a novel iPad system to record behaviors and care

To complement study 1, we used extensive fieldwork in schools for children with autism to investigate the flow of information from secondary caregivers in schools (e.g., educators, clinicians, behavioral specialists, personal aides) to primary caregivers in the home.

"Parents can see any data sheet they want. Some ask to see all data, and a lot ask for behavior data to show to a psychiatrist—helps with deciding on what meds parents will or will not give their kids. [Sharing data is] needed to make home life better."

"We have parent-teacher communication forms that have to be filled out every day. It's a ton of paper that's being wasted. Can we do this electronically? Teachers can sit down each day and say this is what has been covered. If you're looking for information on what's being done each and every day there should be somewhere you can go."

Methods

A research team of 12, led by the first author, conducted fieldwork including 58 person-hours of observation and 62 interviews. The team conducted fieldwork at seven special education programs over the course of one year. The sites were located in four states and provided services to children with autism and other special needs. During fieldwork, the team studied educators, clinicians (e.g., psychiatrists), therapeutic staff (e.g., speech, physical, occupational), and administrators.

Results

We found that maintaining communication and information sharing between school and home is a common and well-known issue. Much like the primary caregivers in our first study who wanted a more complete picture of the events of their child's day, the secondary caregivers in this study wanted information about what went on with a child in the home. To all caregivers, it was important to understand a child's behaviors and activities when they are not there to witness them, in order to be a more informed and empowered caregiver.

● School staff also struggled with sending information home to primary caregivers. A key problem clearly contributing to the challenges of communication and coordination between school and home was the lack of effective data management, as reported in [3]. Paper-based records of behavioral data in schools were challenging to manage and share. Manually creating, transferring, and sharing paper records was time consuming, and school staff had not found adequate ways to share these data with primary caregivers at home. Paper-based reports were an additional burden

on staff to create manually. Additionally, after staff would place them in students' backpacks to go home with them, staff would find the reports were never retrieved, making them aware that caregivers in the home were not reading them. Staff explicitly asked for electronic records for managing student data.

In particular, our participants asked for iPad-based recording and sharing of their students' behavioral data. In one school, staff members each had an iPad, and they used them for communicating with one another by email and taking notes during meetings. They reported evaluating several existing iPad apps, but when none of them fit their needs they continued using inadequate paper methods. We engaged staff at this school in participatory design of an iPad-based system to fit their information sharing needs. The system supports manually recording behavioral data based on existing paper-based practices, and introduces the ability to view multiple visualizations of aggregated data. In addition, the system enables teams to initiate communication based on their discoveries in these visualizations. Through data aggregation, sharing, and communication it supports collaborative reflection among school staff, as well as primary caregivers in the home.

Conclusions

Based on our formative fieldwork, participatory design process, and initial evaluations, we have found that iPad-based behavioral records have the potential to improve information sharing among school staff and primary caregivers at home. Our study suggests this approach has significant potential as a collaborative reflection tool for behavioral data recorded in the school setting.

Discussion

This paper explores the process of collaborative reflection among informal caregivers of children with autism. Our focus is on the challenges of a primary caregiver, who needs to stay informed about their child's behavior and care between environments—especially home and school. The communication impairments typical of children with autism make it especially challenging for a primary caregiver to learn what happens when they are not with their child. Using two studies, we investigated the use of several tools to improve information sharing and communication between home and school.

Our first study explored the parent-driven use of wearable cameras in the home, to help them coordinate care with secondary caregivers such as divorced fathers living in a different home, and other family members. Parents also had a strong desire to send their child to school and clinics wearing the camera in order to learn more about their child's care in those settings. Further research should explore the possibility of designing such cameras in a way that would be acceptable to those involved.

Our second study involved the participatory design of an novel iPad-based system for recording and sharing behavioral data within the school setting. We engaged a variety of staff within a school to design this system to replace their inadequate paper-based data management system. Our fieldwork and design work with this system suggests that there is significant potential for such a tool to improve the coordination of care within the school, as well as between school and home.

Our experiences with these systems show the promise of information and communication technologies to help caregivers of children with autism to keep each other informed and coordinate care. In particular, we are developing a theory of collaborative reflection to conceptualize how these caregivers work together over time to share information about behaviors and events, and make decisions about long-term behavioral treatment.

Author Background

Gabriela Marcu is a PhD candidate in the Human-Computer Interaction Institute at Carnegie Mellon University, advised by Anind Dey and Sara Kiesler. Her dissertation topic is the design, development, and real-world evaluation of a tool to support collaborative reflection—the long-term process of sharing and discussing data to make ongoing treatment decisions for behavioral intervention—among caregivers for children with special needs.

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Opening Keynote Abstract: Informal care - the important social aspect of health care

Mark Ackerman

People's health and illnesses are wrapped up in their everyday lives, sometimes becoming an overwhelming part of it. As such, health and illness necessarily include one's self, specialists, friends, and family members.

In the US, a medicalized view predominates in most of the discussions of healthcare. CSCW and HCI offer a useful counter-position, examining the entire social environment of a "patient".

In my talk, I will present an overview of my research group's studies of bone marrow transplant, GI illnesses, diabetes, depression, and other illnesses in field settings as varied as hospital wards, clinics, community outreach, and schools. This overview will be grounded in the theoretical positions in CSCW that my students and I have found helpful in constructing and analyzing this counter-position. I hope in doing so that I can propose some new, interesting research directions as well as how the micro-sociological theories we use might be extended to be even more helpful.

Speaker's short bio: Mark Ackerman is is the GH Mead Collegiate Professor of Human-Computer Interaction and a Professor in the School of Information and in the Department of Electrical Engineering and Computer Science at the University of Michigan, Ann Arbor. His major research area is Human-Computer Interaction (HCI), primarily Computer-Supported Cooperative Work (CSCW). He has published widely in HCI and CSCW, investigating collaborative information access in online knowledge communities, medical settings, expertise sharing, and most recently, pervasive environments. Mark is a member of the CHI Academy and an ACM Fellow.

Previously, Mark was a faculty member at the University of California, Irvine, and a research scientist at MIT's Laboratory for Computer Science (now CSAIL). Before becoming an academic, Mark led the development of the first home banking system, had three Billboard Top-10 games for the Atari 2600, and worked on the X Window System's first user-interface widget set. Mark has degrees from the University of Chicago, Ohio State, and MIT.

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CCCiC is especially grateful for the sponsorship of the following organisations. Their support made it possible to run the workshop smoothly through the provision of appropriate resources and infrastructure.

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