Design Implications to Systems Supporting Informal Caregivers' Daily Life

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Abstract. This paper is about studying informal caregivers to understand their exhausting life. Our aim is to define design requirements for any kind of information and communication technology to support them. Based on ethnographic studies we gathered information about our users' needs, possibilities, constraints, and challenges. After a brief introduction to the related research on current technology solutions we introduce our methodology. Then we present two of our user cases in detail. We point out areas in which we can really provide technology support for our users. We also describe what qualities and features the technology should have to meet these requirements. We summarize our findings before we conclude the paper.

Keywords: User interfaces, ethnography and field work, interaction design, informal caregivers.

1 Introduction

Informal caregivers provide 80% of all care in the European Union. They are at a higher risk for both psychical and physical morbidity [5] [7]. Caring at home results in heavy physical, psychological, or emotional burden. These "hidden patients" [11] have an increased risk of mortality compared to their non-caring counterparts.

The daily life of informal caregivers is characterized as interplay between routine work, spontaneous interruptions mainly caused by care receiver, and lack of time. Activities of a normal day are usually pre-defined. Certain care needs to be carried out on a daily base by the caregiver or someone external like home care or physiotherapist. Because everything is determined by the needs of the care receiver, the course of the day is heteronomous. Heteronomy is caused besides the routine care processes, on the one hand, by the care receiver, especially when urgent help is needed or some kind of activity wanted that is out of the daily routine. On the other hand, it is caused by external service providers especially when they do not deliver their services on time. Delays have negative impact on the time resources of caregivers. The lack of time leads to social exclusion. They cannot meet their friends, spend time with others they like, or do something what

they like. Very often they are not even able to leave their home because of their care responsibilities. This makes keeping contact with other family members or friends almost impossible. The level of burden increases when informal caregivers still have a job, are old, or have a health condition.

Within the project TOPIC[1] we apply ethnographic methods like participatory observations, in-depth interviews, cultural probes to understand the life situation of several informal caregivers [1]. Additionally, we study different technological solutions available on the market to find the right match for carers' requirements. Most of the technological solutions provided nowadays aim to support professional care and to solve single problems in care processes. We think about integrated platforms and improvements of interaction interfaces to technologies, their handiness and easy use to make them attractive and acceptable for elderly informal caregivers. In this paper, we want to illustrate life situations of two caregivers and how we analyze their needs and requirements to technological solutions. We believe that it is the only way to meet their requirements and provide them a real help to overcome the challenge of care giving and having a life of their own.

In the next section we briefly present the related research on current technology solutions for informal caregivers. After introducing our methodology we describe two of the caregivers we studied in our project to underline their requirements to technology by showing their daily care situation. We also describe what qualities and features the technology should have to meet these requirements. We summarize our findings before we conclude the paper.

2   Related Research

Some studies claim that technological solutions must offer high usability and short response times by being well designed and easily understandable [2] [8]. Additionally, they have to provide different interaction modalities like speech recognition, large screen displays, handwriting recognition with support on touch screens to adapt the system to a specific user group who has certain usability and functional needs [4]. Dynamic profiling enables the specification of a user group's preferred functions and interaction styles. Especially for elderly people who are not used to deal with information and communication technology, the system might provide a guide with voice and/or text prompts for navigation and for orientation like offering the possibility to see which parts of the system the user already visited [2] [8].

Video-based learning is very useful for informal caregivers who cannot leave their homes due to their care responsibilities [2]. With such a support like courses on first-aid instructions or languages they can define the point of time and the length of the learning sessions in which they can attend a course.

Communication through video can be seen as an important enhancement to telephony, not only in a work context. In ambient environments video-based communication can ease smooth exchange among informal caregivers [8]. Besides friends and other family members [8] [10] informal caregivers regularly need to communicate with professionals like therapists, general practitioners, or hospice staff [10]. Being an additional asset video communication increases the security perceived by caregivers and reduces their isolation and anxiety.

Shared calendars and whiteboards are used usually for communication at work or at work-related environments [4] [3]. Calendars represent work and make work that is carried out or only planned visible to others. At the same time, they are reminders of work [9]. Interestingly calendars mirror the balance achieved (or never kept) between occupational work and care work, and the time spent for recreation and recovery. Besides providing work awareness, calendars support task coordination between different persons in care context. An overview can be provided for the primary caregiver, showing who among the other potential caregivers (e.g., other family members) is available at a certain point of time. If they are also willing to provide care, a message sent by the caregiver can easily trigger asking for help [3] [4].

An online address book with data of all relevant local services was claimed for several solutions – especially when more than one person is caring for a particular family member [4] [10]. The possibility of participating in an "online discussion" group is normally very much needed considering the health and care situation of informal caregivers [8].

Two requirements are very important to all technological solutions provided for informal caregivers: Users need a platform which integrates all offered services in one [3] so that they have easy access and ambient integration. The second requirement is privacy [6]. It is about their home and their private environment including often very sensitive data.

3   Methodology

To understand the life situation and identify the needs of informal caregivers we have employed a user centered design approach supported by ethnographically informed studies within the TOPIC project.

For the pre-study, we were working with 10 informal (1 male, 9 female) caregivers in different situations: Five informal caregivers are caring for their spouse, three of them for their parent and two for their child. Two informal caregivers are not living in the same household as the care receiver. Our youngest informal caregiver is 55 and the oldest is 80 years old – the average age is about 64 years. Two informal caregivers are still working, but will retire within the next two years.

While working with these 10 informal caregivers, we were using different methodological tools: We started the contact with the informal caregivers with an interview about their situation at their homes. Then we arranged 3 to 4 more appointments at their home to conduct participatory observation during their

daily routines. At one of these appointments we also brought a box with cultural probes with us and handed over to the informal caregiver: We gave them an introduction and asked them to use the probes for two weeks. During all these appointments we also talked a lot with them and also with their care receivers if possible. At the end of the observations we arranged an additional appointment for an in-depth interview, where we wanted to clarify things we didn't understand so far and asked the informal caregivers about their opinion to some of our design ideas.

The cultural probes consisted of 1 diary, 1 actimoClock (to visualize the kind of work they have to do during the day), emoticon stickers (for the diary and the actimoClock) (Figure 1), picture cards (different photos of care situations where they had to describe their associated feelings), a polaroid camera to take photos for documentation, and a social map. Additionally, the box included two kinds of questionnaires the informal caregivers had to fill in – one about the care in which we wanted to gather some (sociodemographic) information about the informal caregiver, the care receiver, and the care situation, and the Zarit Burden questionnaire [12] to get to know the stage of their burden.

In the following we want to present our two cases: Ms. Kreativ (creative) and Mr. Sorgsam (caring). After a short description of the persons we want to illustrate their requirements and try to discuss possible technologies that are, we think, useful to meet these requirements.
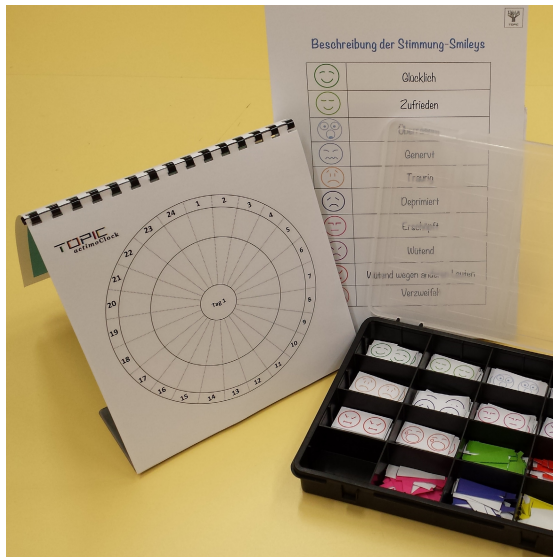
Fig. 1. Cultural probes we used in TOPIC: actimoClock, emoticons, box with stickers

4   The Case: Ms. Kreativ

Ms. Kreativ[2] is 56 years old and retired since two months. She cares for her mother who is living in the same household for more than two years now. Ms. Kreativ is feeling burdened in caring for her mother, not because of her own health situation but also because she and her mother have always disagreements and fights over almost everything. She is interested in knitting, reading, baking, and doing handicrafts (Figure 2). She needs these activities to relax and recover. From time to time she goes to the fitness center although it is hard for her to overcome hers weaker self. Ms. Kreativ is suffering from Crohn's disease and has high blood pressure.

Fig. 2. The Advent calendar made out of toilette paper rolls by Ms. Kreativ

Ms. Kreativ is not married and has a daughter who already moved out and is living together with her boyfriend in another district of the city. They meet each other from time to time: They go shopping, go to a coffee shop for a chat, or meet at home. Ms. Kreativ also has a brother and a nephew with a little son. The nephew helps once in a while with driving Ms. Kreativ's mother to the doctor. Ms. Kreativ's father died when she was a child. She suffers from his early death and often thinks of him. Now and then Ms. Kreativ meets her friends or colleagues in a coffee shop. She likes it a lot, but after retirement she has not enough money to spend for going out.

Ms. Kreativ doesn't feel well very often. She does not want that her mother is aware of her sadness or depression. She doesn't want to talk to her mother about her problems. She says that she needs to talk to somebody to feel better. Many of her friends are still working and therefore do not always have time for her – especially during the day. She cannot invite her friends to visit her because when her mother is around which is always the case, she cannot talk about her problems. And meeting in a coffee shop is too expensive for her. With *a (text, audio, or video) chat system* she could easily find some of her friends who are

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

online at that particular moment and available to talk. Sometimes it would be enough for her to see that someone she knows is there. The awareness about the presence of such a friend can be implemented with *an ambient system*, like *a colored cube* changing its color when somebody is available to contact.

Besides keeping contact to her friends and being aware of their presence even without actively communicating with them, Ms. Kreativ can also use the chat system to contact professionals, like nurses, psychologist, to ask her urgent questions or to get support from them to deal with her (mental) problems. She also wants to participate in *self-help groups over video communication*. Unfortunately she cannot join their face-to-face meetings that are normally held evenings when she has to prepare dinner and care for her mother. If she is connected online, she can attend the group meetings from home.

Ms. Kreativ's mother is 74 years old and had a stroke some years ago. She suffers from diabetes and therefore has to inject insulin on a regular basis. She is overweight and in danger of falling. She forgets many things (e.g., PIN code of the bank account) and it happens from time to time that she is not able to find the way back home when she is outside. Then she calls Ms. Kreativ for help. Once Ms. Kreativ's mother went for a walk just around the house block, fell down, and couldn't stand up. Luckily she was able to reach her *mobile phone* and call for help.

Ms. Kreativ's mother likes being mobile and going out, but she is doing this less and less often because she is feeling insecure. Locating her mother when she is outside can solve this problem and provide the security both need. A system capturing the *GPS coordinates of the mobile phone* of Ms. Kreativ's mother can keep track of her location if needed. In case of an emergency, e.g., if Ms. Kreativ's mother is lost, she can look for her, either go and pick her up or guide her home over the phone.

Another solution is a kind of *Smart Watch*, which Ms. Kreativ's mother has to wear when she is outside. Beside locating her geographic position, a Smart Watch can connect both by means of a video communication. For instance, when Ms. Kreativ's mother falls and is not able to reach her mobile phone, she easily can call her daughter by using the watch and tell her what is going on.

Since her retirement, Ms. Kreativ feels often bored and is afraid of letting herself go. She is thinking about attending some courses at the community college. She is interested in improving her English and computer skills. But she is not sure if she is able to pay for these courses with the less money she gets monthly for her retirement. So it would be a good solution for her, if some other informal caregivers who have good English skills can offer a kind of *an online course*. This means, that all interested people arrange an appointment where they can meet online via a video communication tool. So nobody has to leave home and their care receiver, and can improve their (English) skills.

5 The Case: Mr. Sorgsam

Mr. Sorgsam[3] is a 65-years-old retired electrician, who provides care to his 68-years-old partner. He has been caring for her for more than two years. Besides the interest in plants and electronics he had health conditions including surgery because of heavy smoking. He tries to take care of himself by spending 3 weeks a year for recovery, partly covered by his health insurance, partly self-covered.
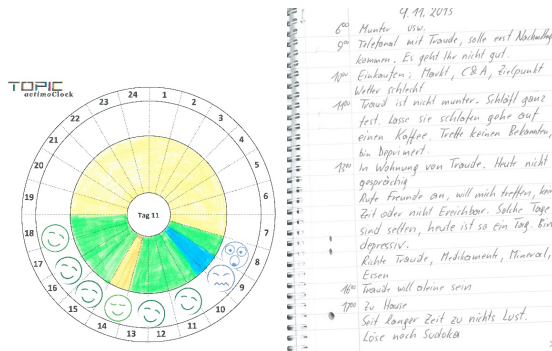
Fig. 3. The actimoClock filled by Mr. Sorgsam showing his (care) activities and his mood around the clock and a diary entry showing his daily schedule. Besides shopping one can read how concerned he was about his partner.

Mr. Sorgsam has a partner since 40 years, two sons with her and a grandchild. Unfortunately he does not meet his sons enough. They do not answer his contact requests via phone or SMS, or sometimes only with a relatively long delay. Even one of the sons lives very close to his mother's apartment, he does not visit her. Not meeting his sons makes Mr. Sorgsam very often sad and desperate.

Mr. Sorgsam lives in 30-45 min distance to his spouse. Besides accompanying and taking care after his partner (Figure 3), he has friends who he meets regularly, mostly in his favorite coffee shop. He does not share the care situation of his partner with all his friends, but only with a few. Anytime he spends the time without his partner he feels strange, because he constantly thinks of her and her well-being and wonders whether everything is all right with her at that moment.

One of the most important issues for Mr. Sorgsam is to be sure that his spouse is well and nothing is wrong in her environment. His concerns are well-explained: Mr. Sorgsam's partner suffers from chronic obstructive pulmonary disease (COPD), asthma, chronic bronchitis, arthritis, rheumatism, and osteoporosis. Hence, she is at a high risk of falling and getting seriously injured. Due to her health condition and not sharing the home with her, Mr. Sorgsam wants

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

to be informed about her situation and wellness the whole time. Technology can help in this matter:

- A *bidirectional video communication channel* can potentially help to maintain contact with her spouse when he is away. He can contact her, talk to her, hear her voice, ask her whether she needs something. His spouse lies in bed the most of the time and watches TV. Even during the night the TV is on. He has also a big display that he does not use because he is not interested in watching TV. Equipped with the right additional technology these both TV screens can be monitors of the video connection between both of them. So, Mr. Sorgsam would feel much better if he could observe and talk to his partner via this video channel.
- Besides the general status of his partner, Mr. Sorgsam is very alarmed about possibilities for accidents or problems of her health condition like difficulties in breathing. Her lung disease impacted by the weather conditions and humidity can cause serious troubles for her which alarms Mr. Sorgsam. If she is not close to the telephone she cannot call his spouse or answer the phone when she is called. This happens sometimes when she is not in her bed. With *a monitoring system based on several sensors* Mr. Sorgsam can be made aware of her health situation and her environment any time as needed. In this context it is very important to think about configuration of such a monitoring system by her spouse and by him. Especially it must be possible to switch off the system and notify Mr. Sorgsam that the system is shut down by her and there is no need for concern because everything is fine. Furthermore we have to answer the question when the system needs to be switched on again and by whom. What happens if she has something and that is why she cannot turn on the device? Is there any possibility to configure regular short term activation of the system to make a single image or a short clip to inform Mr. Sorgsam that she is doing fine? How would be the notification mechanism for him at the background without disturbing him or making him nervous while waiting until he gets the next message? How can he be sure that the system is running correctly?

Mr. Sorgsam cannot always spend time with her spouse because sometimes her health condition does not allow that. These are the times when he wants to talk to someone else, either one of his friends or someone who professionally can help him. *A chat system* can make this possible: He does not need to go to the coffee shop, he can stay at home and talk to a friend.

Mr. Sorgsam needs additional technical support in managing care: Home care service is scheduled on a daily base. Unfortunately the supporters very often do not arrive at the scheduled time. Mr. Sorgsam needs to know when they will really be in the flat of his spouse in order to meet them or talk to them and clarify certain care activities or arrange additional ones like going to a pharmacy or buying something for her. This would help reduce stress and save time. A telephone call is unfortunately with the home care support personnel not possible. *A distributed time schedule system* could help to enable these temporal

arrangements. With an additional feature for messaging the system would make his communication with home care service people possible, independent of their arrival time.

Mr. Sorgsam is very keen on recording the changes of the health situation of his spouse and of himself. *A health care recording system* for non-professional use scan help him to keep track of such changes, e.g., by noting the blood pressure, temperature, medicine she takes, problems she has in breathing or moving, etc. He also wants to know how his and her health situation is progressing.

Mr. Sorgsam writes down regularly the money he spends for her spouse because she wants to know the exact payments related to her income. This activity can surely be easily supported by *a book-keeping application.*

6   Some Results and Conclusions

The paper presents some ideas based on the analysis of our findings in our ethnographic case study: First of all, we could describe why certain technologies are needed for informal care, like (text, audio, video) chat systems, ambient systems like colored cubes, self-help groups over video communication, mobile phones, GPS coordinates, Smart Watches, online courses, bidirectional video communication channels, monitoring systems based on several sensors, distributed time schedule systems, health care recording system for non-professional use, book-keeping systems. The integration of these different systems at one platform is important to provide a single point of access to all services implemented. This means usually a central storage of data. A distributed means of data management can be done by replication mechanisms, without increasing the response time and the effort for its maintenance. Through different peripheral devices or ambient solutions the data retrieval must be fast, adapted to the specific domestic environment, and easy to trigger.

The location of the devices plays a crucial role in their effectiveness and acceptance by their users. Some must be in a common area; some tend to be used privately. Portability at home and surrounding enable users mobility and flexibility which is crucial for informal caregivers.

Robustness and fault tolerance of the systems need to fulfill the safety related critical requirements of the care setting, especially when the system sends alarm signals in case of falls or emergencies. The software should allow interruptions, e.g., when an emergency occurs, and allow resuming without any problems, when the emergency is over.

The platform and its services should offer multiuser access, especially for other family members or professionals involved. It should also offer the possibility to adapt the user interface to the different needs like bigger font, guiding with voice, etc. Next to that, the platform and its services should provide a multimodal interaction like video, audio, text, speech recognition.

Monitoring services like camera surveillance systems or GPS tracking are very useful but should offer the possibility to be turned off. Since it should always be considered that the care receiver, who will be monitored, can be still mature and decide whether s/he wants to be monitored or not.

Not only because of the average age of informal caregivers (58 in Austria) but also of the care receiver (78 in Austria), the usability should fit for all ages. Tablets and smartphones are not the only systems that fit best our users' requirements and abilities. We have to think about other innovative embedded solutions like sensors, tangibles, or wearable systems.

Our future work in TOPIC will focus on designing, developing, and evaluating different types of systems for our users. Our special attention will be usability, integrity, robustness, reliability, privacy, and configurability of such systems.

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