

FINAL AUTHOR VERSION

# Family Carebook: A Case Study on Designing Peace of Mind for Family Caregivers

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**Abstract.** Family caregivers often are key to aging-in-place. They not only help with everyday activities and needs, but also tend to be a valuable part of the senior's social network. Many family carers however experience a hard time combining care activities with their busy job and family life. At the same time, they indicate they feel insufficiently aware of the actual situation and needs of the senior, which results in worries and inefficiencies in care. Present communication systems appear to be inadequate in addressing these information needs of family carers. Towards improving awareness of family carers, and ultimately enabling peace of mind, new design directions need to be explored. This paper presents a design exploration in which an interactive communication concept was developed. The focus was on supporting the family carer. A working prototype was studied in the field. The findings from the case study suggest that both functional awareness and peace of mind need to be considered towards creating new communication services for a sustainable family care setting.

**Keywords:** Design exploration, peace of mind, aging-in-place, family care.

## 1 Introduction

The number of senior citizens in western societies is expected to increase dramatically in the next decades. Seniors often prefer to live independently in a familiar setting as long as possible. Family carers play a central role in supporting seniors when they need help living on their own. Often family carers combine family care with a paid job (71% in The Netherlands [SER, 2007]), which results in busy schedules. To provide the right care at the right time, caregivers need to be aware

of the actual needs of seniors. Interviews conducted in this study do however indicate that the current level of awareness is insufficient.

ICT systems that provide awareness of the actual situation of the senior could potentially support family carers in providing care at the right moment and provide peace of mind. A wide range of systems with the aim of assisting seniors and their carers has already been developed. Sensors are increasingly being used in the homes of seniors to detect for example presence, the key application appears to be monitoring and alarming. Albeit valuable, present systems do however not properly address the needs of carers in terms of providing peace of mind.

To better understand how awareness systems can be used to enable peace of mind for family carers, a design exploration was conducted. The specific needs of the family carer are mapped and design directions are explored. The present paper describes the design steps that resulted in a prototype awareness display for family carers and the findings from a field trial. The case study serves as an example of how awareness systems could be designed to improve both functional awareness and peace of mind.

## 2 Related work

The use of ICT to support family carers has been studied before. A key example is Digital Family Portrait (DFP), which was designed to provide awareness and peace of mind to extended family members through showing trends in a person's daily life [7]. DFP is based on the assumption that peace of mind can be provided by monitoring day-to-day activities. Icons show information about information categories over time. DFP visualizes plain aggregated sensor data. A field trial showed that the DFP ambient display was appreciated as a way to learn about the life of a distant family member. The information shown on the prototype was based on user reports rather than real sensors. One might argue that the information displayed by DFP cannot be collected using sensors alone. Research is needed to find ways to collect the required information.

Similar to DFP, CareNet Display [2] presents information on the elder's condition. Users can zoom out from detailed information on events to a 5-day trend view. Whereas DFP could only be used as a source of information, CareNet Display enables carers to coordinate care tasks. A field trial showed that local carers experienced lower stress levels [2]. The exit-interviews did however indicate that the system lacked a 'human touch': the sensor data did provide a quantitative view, whereas carers felt the need to know qualitative view.

The ASTRA project [5] focused on *sharing* to increase family connectedness. Human-human communication was used to detect the needs and state of a caretaker. A mobile device was used to share information on the go. Whereas information sharing seems to be a proper way to enable social communication, it is unclear if people are willing and able to share information regarding care needs in a similar

way. In exploring design directions, sharing could be considered as a mechanism to exchange information regarding care.

The challenge of combining user input with sensor data has been studied in the Daily Activities Diarist (DAD) project [6]. The DAD application was used to journal activities of daily life. Seniors were asked to correct the activities detected by the system, eventually enabling the system to automatically recognize daily activities. The journal was found to have a positive effect on social connectedness, and was used as a peripheral social awareness cue [6]. Since DAD provides only a description of activities rather than a subjective view, one might expect DAD not only to reassure carers, but also to raise new questions.

The ContextContacts [4] and FamilyAware [8] projects focused on sharing context information using mobile phones. Both systems could potentially be used to support a group of carers to coordinate care tasks and determine availability. Whereas ContextContacts was limited to sharing location information, FamilyAware did include the option to communicate. Even though these systems could be used to increase awareness of presence and availability, none of the systems aimed to increase awareness of actual care needs.

To conclude, the use of communication devices and sensor systems to support family care has been explored extensively. Several projects focus on communication, resulting in improved social connections, while other projects emphasize the use of sensors to automatically detect the present state or patterns in time. Based on explorations with family carers, we do however expect that combination of monitoring *and* communication will outperform existing systems in terms of peace of mind and awareness. The present paper presents the findings from a case study in which the needs of family carers were studied, and a hybrid communication and monitoring system was developed. A working prototype was deployed in the field, in order to collect data on user experiences in a realistic setting. The paper concludes with the findings, discussion and suggestions for future work.

### 3 User research

To better understand the current family care situation, and to understand how family carers could be supported using ICT systems, a contextmapping study was conducted. The study was conducted according to the method described by Sleeswijk Visser et al. [9]. A group session with four participants and semi-structured interviews with four family carers were set up. The participants were sensitized using a booklet, and then participated in a generative session. The recordings from the session and the materials made by participants were analyzed, and used as a start for the design phase.

The analysis of the generative session was based on the grounded theory, where the potential indicators of a phenomenon are discovered during the analyses [3]. The sessions were transcribed. Interesting quotes regarding current situation, information need, worries, and wishes for the future, were selected. To translate the-

se quotes into interpreted facts, statement cards were used; cards that include a quote from the research and an interpretation of this quote. All of the statements were grouped into clusters according to their topic. The clusters were categorized into a framework to explore their relations.

**Current situation:** To describe the current family care situation, the quotes from the generative session were visualized using a mindmap. A number of topics described in related literature reappear in these clusters. Clusters 3 and 5 do provide new insights. Cluster 3 ('Together you know more') relates to the need for communication to get a grip on the situation and finding confirmation. Cluster 5 ('Keep an eye on the situation') represents the need for up-to-date information. The family carer can be worried at any moment of the day. Having up-to-date information available can not only support the family carer in planning and coordination, but can also provide peace of mind. Table 1 shows the clusters resulting from the study that characterize the current family care situation.

**Table 1.** Key clusters characterizing the present care situation.

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
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| <p><b>(1) Personalized care:</b> care activities are linked to the needs of an individual, therefore the information needs of the caregivers vary per casus and in time.</p> <p><b>(2) Caring is done together:</b> seniors are generally supported by multiple family caregivers who collaborate in providing care.</p> <p><b>(3) Together you know more:</b> towards understanding the actual care needs, caregivers need to communicate the pieces of information they collect.</p> <p><b>(4) Include the senior:</b> input from the senior is valuable in building awareness.</p> <p><b>(5) Keep an eye on the situation:</b> peace of mind is improved by updates from people visiting the senior.</p> |
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**Worries:** Family carers get worried when things go wrong. Minor issues are often regarded as the start of bigger problems. Especially when caregivers have to judge issues from a distant location, minor issues can result in huge worries. Family carers can be worried at any place and at any time. Information is needed to take away the worries. Table 2 shows the clusters characterizing the worries.

**Table 2.** Overview of worries as described by the participating family carers.

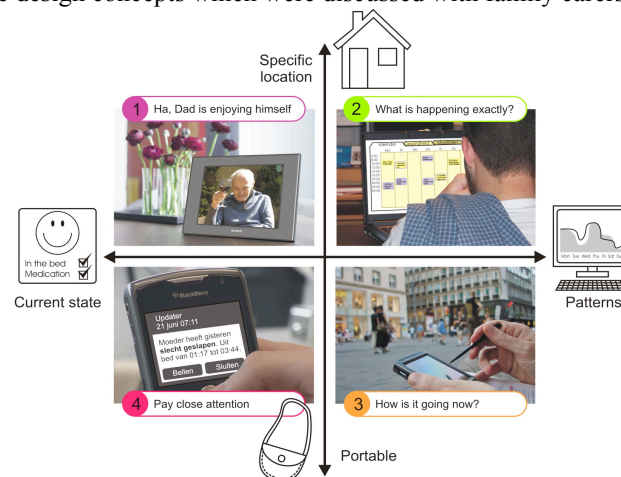
|                                                                                                                                                                                                                                                                                                                                                                                  |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p><b>(1) Love and belonging needs,</b> including emotional state and loneliness</p> <p><b>(2) Safety needs,</b> including state of the home, incidents, safety, and financial needs</p> <p><b>(3) Physiological needs,</b> including worries about nutrition (moments of eating, preparing food), medicine, sleep (amount, moments), daily care and acute physical problems</p> |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

**Awareness/information needs:** The participating family carers expressed the need to be better aware of the actual needs of the elder. This information need originates from their personal bond, which results in a feeling of responsibility.

**Peace of mind:** Lack of awareness of the situation results in worries, and consequently in a lack of peace of mind. The participating family carers expressed that need to feel up-to-date in order to feel peace of mind.

## 4 Design

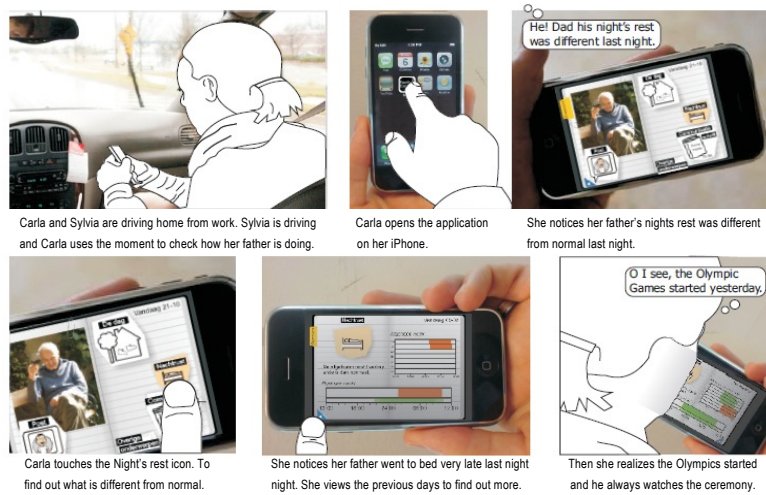
As a first design step, design directions were identified based on the related studies. The literature showed previous systems can be categorized in 4 clusters according to two main design dimensions: (1) at home vs. mobile (when and how to communicate), and (2) current state vs. patterns in time (how to present sensor data). For each cluster, a provocative concept was developed. Figure 3 shows the provocative design concepts which were discussed with family carers.



**Fig. 3.** Provocative design concepts were developed to trigger family carers to reflect upon their needs and the role of ICT.

The carers expressed a clear preference for a portable ambient concept. This allows the carer to check how the elder is doing any place any time. Their main interest is in the current state of the senior to see how the senior is doing at the moment if they need to pay more attention to the situation or if it is going as normal. When the situation of the senior has changed they would like to be able to see patterns. As opposed to earlier work, it was decided to focus on creating peace of mind rather than improving efficiency.

The final concept is labeled *Family Carebook*. The concept combines message-based communication, to support the social awareness, and monitoring based on sensors. The storyboard on the next page (figure 4) describes the product-user interaction in context and over time. The application is designed for a touch screen smart phone, which enables family carers to access status information any place any time (more details will be given in sections 5).



**Fig.4.** Storyboard explaining the book metaphor interaction

## 5 Evaluation

To find out to what extent the Family Carebook contributes to the awareness and peace of mind of family carers, and to better understand the user experience, a working prototype was built. An explorative field trial was conducted in which target users could experience the concept. Two participant couples were recruited based on age and care situation. Each couple consisted of an independently living senior (age >80), and a family member or friend who regularly helps the senior.

**Prototype.** An iPhone application was developed for the carers. The prototype combines message-based communication, to support the social awareness, and monitoring based on sensors to provide awareness of the senior's night's rest, medication and presence. A pressure sensor was placed in the senior's bed, an infrared sensor was placed in the living room and the medication box was placed on a reed sensor to detect when it was lifted. The senior was provided with a touch screen for sending messages and viewing the sensor data.

**Test set up.** The field trial consisted of three parts.

*Part 1 (3 days): baseline.* The participants were given a booklet with assignments. The booklet was used to measure the perceived awareness level and perceived peace of mind before using the Family Carebook. Information on sleeping and medication activities was collected and used as input for the prototype.

*Part 2 (5 days): prototype testing.* The photo frame display and the sensors were placed in the house of the senior. The family carer was provided with the iPhone with the Family Carebook app. The supervisor explained the product use to the

participants. Assignments to look at the information and send a message were given for the first two days; the assignments helped the participants to become familiar with the prototype. After two days they could use it in their own way.

*Part 3: exit interviews.* An exit interview was conducted at the end of the trial.

## 6 Findings

Even though the field trial is limited in size and duration, the qualitative feedback can be used as an ‘explorative’ validation of the design choices. Participants were generally positive about their experiences with the Family Carebook, both in terms of peace of mind and of awareness. During the 8 days of the trial, the family carers kept on using the Family Carebook. The application had become part of their daily rituals. One caregiver would for example send a message to his mother every morning in order to keep up communication and to check if everything is fine. All participants would have liked to keep using the system and would have liked to introduce it to family members living further away.

**Peace of mind.** Whereas both couples experienced only few worries at the time of the field trial, the participating family carers did anticipate a future situation in which they would have worries. Family Carebook was considered to be a valuable addition to existing communication mechanisms. The value of the system was illustrated by the following situation: The weather was terrible outside and the family carer knew that his mother was away from her home. Without the system, the family carer would use the phone several times to check if his mother would be home safe. Using the Family Carebook, he noticed when she arrived home, he was soothed and he sent a message to ask how her evening was.

**Awareness.** Both participating caregivers used the Family Carebook as an additional source of information. They indicated that the Family Carebook would be especially useful for children who live at a distance from their independently living parent. The need for information was found to be different for couple B as compared to couple A. Family carer B was interested to know detailed information about the current situation. He would prefer to know more when there was little activity since this would lead to concerns; the senior could be away from home, be sitting in a chair enjoying a TV show or might have fallen down and not be capable of getting up. Therefore the sensor data resulted in extra communication (through the system or by phone). Family carer A, on the other hand, was happy with the data available through the system.

**Privacy.** The seniors accepted the lack of privacy caused by the sensors, since they valued the peace of mind provided by the system. Also the fact that they themselves could see what was being monitored made them part of the system, rather than being a passive subject. The messaging function also helped include the senior and provided a clear use the system. One senior often checked the Family Carebook to see how it captured her daily routines.

## 7. Conclusions

This paper presented a case study of a communication tool targeted at family carers of an independently living senior. A mobile phone application was developed which was aimed at supporting awareness and promoting peace of mind through sharing practical information combined with social communication.

Even though the field trial is limited in size and duration, the qualitative feedback can be used as an 'explorative' validation of the design choices. Participants did report improved peace of mind, which does suggest that a monitoring and communication tool can be used not only to improve efficiency and increase connectedness, but also to improve peace of mind.

A key limitation of the present system was found to be the 1-to-1 communication setting. Many seniors are supported by a group of caregivers, which would require group communication mechanisms. These group communication mechanisms will be studied in a next design iteration.

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