

Increasing Family Involvement in Elderly Care

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Abstract. This paper describes the design and field trial of the *Dynamic Collage*, a system which aims support extended family members to take part in the care for an elderly person in a light way manner by sending photos to a digital frame in the elderly home. We evaluated the dynamic collage in a field trial of 4-6 weeks with two families, yielding positive results. Photo-sharing was seen as a valuable contribution by the elderly person and all family members, it provided narrative support for visitors of the elderly and it led to an increased awareness of caregiving behavior and increased cohesion in the family. The study shows there is an opportunity to include Awareness Systems and Persuasive Technology within a participation ecology, which could be beneficial for health care.

Keywords: Persuasive Technology, Awareness System, Health Care.

1 Introduction

Because of reforms in Dutch healthcare which aim for more self-care and a receding government, informal caregiving has become a key theme. Increasingly, adult children or other relatives will have to provide elderly care. Not surprisingly, healthcare institutes have expressed interest in exploring ways of including informal care for residents in these institutes [1,2,3,4]

In cooperation with three healthcare institutes we have set up a case study directed at designing an application that improves relationships between professionals and family of residents. Because of this wide open problem definition, we used 1-10-100 [5] as a method for involving stakeholders in the design process. We used provocative prototypes to collect information and gain a better understanding of the context. We found that in many cases, some family members were highly involved with the care for their partner, mother or father, but most were at a distance. Also, this distance became larger over time.

Therefore, we wished to design an application that might restore the interest and involvement of family members at a distance. The resulting Dynamic Collage [DC] shared many characteristics with Social Awareness systems [6] such as the digital family portrait [7], Astra [8], the social health display [9] and the whereabouts clock [10]. It also exploits principles of persuasive technology [18]. In this paper, we discuss development and design of DC, and show evaluation results. The results suggest

that DC influences family behavior positively. After discussing the design and evaluation we discuss the relations between the DC and existing work more explicitly.

2 Design Case

2.1 1:10:100; Three Independent, Concurrent Design Cycles

To make sure the design solution would fit the expectations and the (unarticulated) needs of the clients, we used the 1:10:100 method to include them in the design process actively.

1:10:100 promotes ‘radical innovation’, and allows flexibility throughout the design project by completing the project in three complete, independent, concurrent cycles with an increasing time span. Each cycle consisted of user-centered design steps, determining requirements, creating design solutions and testing the design solutions. The development oriented triangulation framework [12] was used to ensure balance of research within the iterations.

In each design cycle, we presented provocative design solutions to the clients in a quality review board (QRB), in which framing and settling a more specific focus for the next cycle could take place. The outcome of the first QRB led to a focus on improving communication in informal care participants, while the second QRB resulted in a distinction of primary and secondary caregivers, and the identification of an opportunity to include the secondary caregivers (mostly socially or physically remote, passive family members) in the care process [13].

Next we studied the diversity of ways in which family members can take part in family care. It became clear that there is a wide array of things family members can do that have a positive effect on the well-being of a resident in a care home. Family members can provide practical caregiving like cleaning, administering medicine or taking care of laundry, but they can also deliver social-emotional care through paying a visit, taking someone out for a walk or trip, making a phone call or simply “being there” for a person by being physically near¹.

We created a framework (figure 1), identifying four phases that influence decision making in informal care participation. First, the personal background, awareness, emotions and personality traits play a role in caregiving: we called this background. Second, family members had to make a decision for an visit or other form of contact. Thirdly, a contact moment took place in one form or the other. Finally, family members made an evaluation or reflection took place.

In a co-creation session, we invited participants to identify and qualify the different connections between the phases. Participants recognized the phases and could provide many stories sketching the connections between the different phases. In the end, the actions in each phase turned out to result in consequences for the others, depicted

¹ Many definitions for informal caregiving (or the Dutch equivalent ‘mantelzorg’) exist. For this study, ‘Informal caregiving’ will be considered in its most broad sense, and can in light of the DFC be considered as ‘visiting the elder person’.

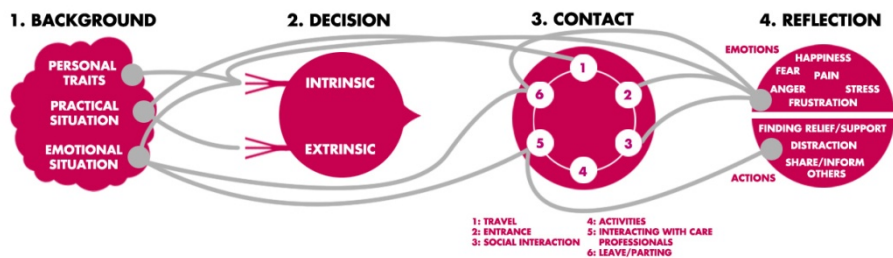


Fig. 1. Framing of the caregiving process and its internal and external relations divided in different steps; Before (condition), During (contact) and After (reflection)

as the gray lines connecting the four separate phases (figure 1); all phases are heavily intertwined. Discussing the framework enabled us to identify the most important motivators for taking part in informal caregiving, including existing problems and opportunities for improvement. We found the presence of strong social ties and social cohesion as a family to be a major motivation for deciding to take part in informal care, and improving cohesion became a core target for the final design.

2.2 Theories for Behavioral Change

The first two cycles of 1-10-100 led to a desire of understanding possibilities to change behavior of relatives surrounding a care dependant elderly person. To gain a quick understanding of theories of behavioral change, we consulted two psychologists. This led to a quick identification of the most important theories in the field and an idea of how they could apply to our work. According to [14], four mainstream theories on behavioral change are the TransTheoretical Model (TTM) [15], the Health Belief Model (HBM)[16],The Social Cognitive Theory (SCT) [17] and the Theory of Planned Behavior (TPH) [18]. All of these theories focus on a context of a personal and big behavioral change. These changes can be triggered by events with a huge impact.

Family relations were dwindling in the families we consulted, so few individual high impact triggers to change behavior exist. Latent guilt, loyalty and shortage of attention and time play a dominant role in these families. These are all elements that fit within the motivation and ability dimensions of Fogg's Behavior Model (BFM) [19]; Lack of motivation spawns from feelings of emotional distance and/or social rejection within the family, whereas physical distance and lack of available time are characteristic for one's disability to join.

Because big impact triggers do not seem feasible in an environment where both motivational and ability issues are apparent, we have chosen for interactions that can be ignored or require very little attention; the individual user experience should blend in their daily lives. This is in line with Fogg's suggestion for a modest approach

towards behavior change in general [11]. Instead of trying to design for radical behavior change in regards to participation in the care process, a focus was put on the smaller issues of improving the motivational and ability problems mentioned earlier.

2.3 Final Design Solution: the Dynamic Collage (DC)

The Dynamic Collage is a system where a digital photo frame in the home environment of a care dependent elder person shows a family portrait which is composed of separate pictures sent by family members (figure 2).



Fig. 2. The DC prototype in context of its surroundings

The composition of the joined portrait is based on data gathered by the system: members who have participated by visiting will be more visually prominent in the composition: those pictures have a larger size and are positioned closer to the elder. When members don't show involvement, their part of the composition will suffer in size and opacity (figure 3).

Family members can update their part of the portrait only in the event of a trigger: occurring when someone is around the vulnerable elder person (for example someone visiting). The result is a composition made from snapshots of 'mundane' moments, all taken at the specific time of a trigger, rather than the most interesting or precious events in people's lives. After sending the photos, the new composition will be visible on the photo frame of the resident, as well as on the mobile phones of the users.

We had 4 goals in mind for the design:

1. Disclosure of informal caregiving behavior to the extended family.
2. Lightweight involvement through contextual photos
3. Supporting commitment and interaction
4. Strengthening social (group)ties

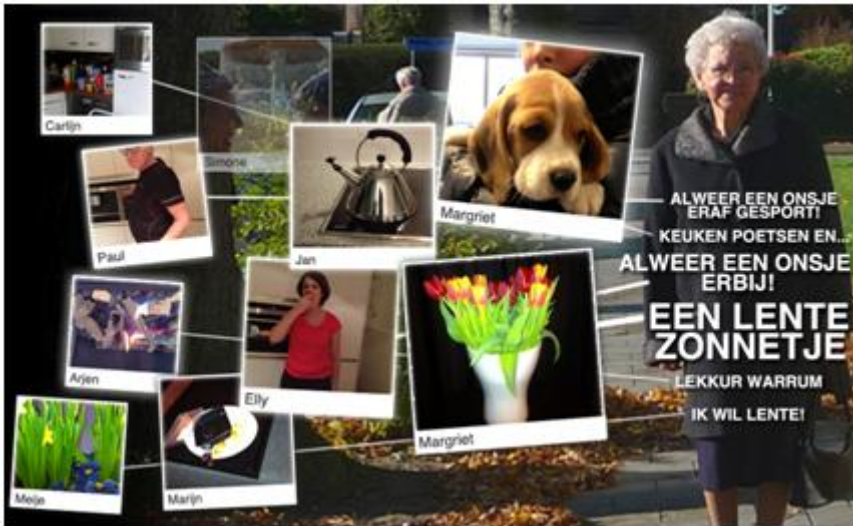


Fig. 3. The composition on the tablet computer. One of the pictures is faded as a result of lacking participation.

3 Field Trial

3.1 Setup

A field trial, using a Wizard of Oz setup [20], was performed to evaluate the effectiveness of the dynamic collage. We wanted insight in changing participation patterns and involvement of the extended family in the care process.

Two test groups took part in the trial. The first group was a family surrounding an 87 year old woman in a nursing home. The eleven participants included all of her four adult children, three of their partners, and all four adult grandchildren. This test group used the dynamic collage for six weeks. The second group was a family surrounding an 88 year old woman who was still living at her own house. This family had sixteen participants, including adult children, adult grand children and their partners. This second test group ran for four weeks.

The families worked with a prototype of the system on a tablet computer. It showed the dynamic collage which was created by the researcher, acting as a Wizard of Oz, behind the scenes. Visiting family members would announce their visit to the wizard, who would inform the family members with a kind reminder to send a picture, which were in turn converted in a dynamic collage during the visit. This setup ran without major problems [13].

We held weekly semi-structured interviews with different participants of each group. We used these interviews to check if participants had been following instructions, and gather their experiences and opinions about the themes involved in the design. In particular we asked participants about the usability of the system,

awareness, disclosure, lightweight involvement, and possible unforeseen effects. We held face-to-face interviews with the adult children (4 in both test groups) in the first week and near the end of the trial. We held interviews by telephone with the more distant relatives (grandchildren) in the remaining weeks of the trial.

4 Field Trial Results

(Group) Awareness. Results from the trial suggest the dynamic collage contributed to awareness of the informal caregiving behavior. A notable finding was that, in particular, the family members who participated less in informal care evaluated this awareness positively. The trial showed that family members who considered themselves to be more (socially) distant were now able to predict and see patterns in the informal caregiving behavior of others. When asked about their experience of caregiving awareness, one of our participants, a grandchild in the first group remarked: *“I suddenly realized holy shit, M. is going there 4 times a week”*, showing that the amount of time invested by other family members had sunk in.

More surprisingly, the dynamic collage allowed family members to recognize abnormalities in the weekly routine. The partner of one of the daughters in test group 1 explained *“patterns become visible; I could see that it's Monday: Oh, then I guess this and this person will be there again”*. The awareness of irregularities resulted in information that would otherwise not reach them, as was plain when one of the more active caregivers in group 1 fell ill; *“I found out about things I would never have known about otherwise, like when M was ill”*. While the group dealt with this particular illness adequately, it is likely that such an awareness of caregiving behavior can contribute to keeping the family closer together as a functional group in other cases.

Lightweight Photo Sharing as Narrative Support. Users showed particular effort in making their photos meaningful. This is in line with previous work by Romero et al. [8] that shows how much people value personally targeted effort. The system was designed with the intent to create awareness of people's lives by encouraging sharing photos of 'everyday moments'. However, the trial showed that participant sent photos with a functional goal in mind: helping the visitor in his or her social interaction with the elderly person by having something to talk about. We were surprised how much photos were created and used as a narrative support for the visiting family caregiver.

Biemans and van Dijk [21] reported similar results and suggested the everyday events are of less value for the elderly because, due to the generation gap, they no longer play a part in these everyday lives and therefore have trouble understanding the pictures. The trial in this paper shows that this holds true for sharing towards family members of the same age group as well. This suggests that sharing mundane, everyday events is seen as less valuable even when such photos can be understood by the receiving party. In both studies, the digital photo frame resulted in opportunities for 'food for talk'.

During the design we wondered whether sending photos could be seen as valuable contributions to caregiving. Arguably, a mismatch in invested effort and 'reward' could result in more strained relations, which would be counterproductive to the goal

of uniting and connecting the family. Remarkably, the family members from both test groups who were visiting reported the functional use of photo sharing as very helpful and valuable.

This also meant that contributions to our system were less lightweight than intended: because people wanted to make a meaningful contribution (instead of sending a ‘random’ photo) the act of updating one’s picture became a task of some effort. This made the photo itself valuable to both the receiver and the sender. Because of this participants complained about the short turnaround time of the photos: “I think it’s somewhat of a waste to put a lot of effort into [making] a picture when it could be replaced the very next day”.

Social Connectedness, Group Attraction. Photo sharing also led to an increased sense of connectedness among some of its users. When interviewed, one of the grandchildren mentioned quite literally that the regular sending of photos meant that “the family was now more connected”.

The forced, specific timeframe to send photo updates gave all sent photos a ‘time-stamp’ as common attribute. For example, when someone was visiting eight o’clock in the evening, all sent photos would be of an evening atmosphere. This awareness of being involved in the same activities contributed to a sense of unity; “It was really nice to see all the pictures coming in when everyone was having dinner, it was like we’re having dinner together”.

Changing Family Behaviors. The system succeeded in giving the secondary family caregivers a way ‘in’ for the care process: although actual visits remained low in number, secondary caregivers contributed with photos which were valued by the elderly person and the primary caregiver. However, we hoped the system would also inspire less active family members to increase their involvement by interaction more with the elderly person outside of the system and this was not achieved. Arguably, such changes in communication patterns within a family need time to settle, but the users did not expect the system to encourage more involvement outside of the system; they reported that the threshold to engage in ways of communication was simply too high.

5 Conclusions

In this paper we discussed the user-centered design and field trial of the dynamic collage, a system that seduces more distant family members to take part in the caregiving process of an elderly person by sending photos to a digital frame at the elderly residence during a visit of another elderly member. These photos turned out to provide food for talk for the visitor and elderly, creating a sense of community and awareness of caregiving in the family that was valued by our participants. The system shares characteristics with Awareness Systems [6] and Persuasive Technology [11] embedded in what Gerard Fisher calls a Participation Ecology [22]. Participation Ecologies are socio-technological systems which support a rich set of smaller and bigger contributions in a joint ‘barn raising project’. Participation Ecologies arise in

open source communities and other co-creative online systems, such as Wikipedia and Scratch. The Dynamic Collage is a step in this direction. The Dynamic Collage supports multiple roles and contributions and it makes sure these contributions can come together in an innovative, meaningful and positive way.

Because of this, our design efforts move beyond seminal Awareness Systems such as the Digital Family Portrait [7], the Whereabouts Clock [10] Social Health Displays [9]. These examples are information centric awareness systems. Awareness is provided through a display of automatically captured data. The dynamic collage, in contrast, supports awareness as a collateral benefit from a communication centric system. Family members are allowed co-create the dynamic collage, and experience the result - and the benefits for the elderly person and her visitor - as a joint achievement. The idea of participation ecologies provides a useful lens for our efforts to achieve Persuasion as well. For many family members paying a regular visit to the elderly person is, in terms of Fogg's behavior model [19], too demanding on both the axes motivation and ability. We facilitated those family members with a) a trigger to b) a rather undemanding task in terms of motivation and ability (sending a photo). But we did not replace the demanding task with an easier one. In our participation ecology the 'easy tasks' become a visible and valuable contribution to the full process. Both types of users valued this. Visiting family members felt supported and seen, and non-visiting family members appreciated the opportunity to make a contribution.

Clearly, a participation ecology with only two roles may not be particularly rich enough to be sustainable in the long run. Although usage patterns in the field trial stabilized, participants commented on photo-sharing as an activity which they did not imagine doing for a much longer time. Enriching the dynamic collage so that more roles, types of triggers, and types of activities are supported is key. Therefore, we are currently looking further into the field of persuasive interfaces [11], investigating integration with traditional social media infrastructures [23] and searching evaluative measures which can help us to get a sharper eye on relation to motivational goals, persuasion and long-term user experience.

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