

Next of Kin

Supporting Family Members Taking Care of the Elderly

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Abstract—Family members may in a significant manner contribute to the care of the elderly. The paper discusses, on the basis of a field study, the involvement of family members in the care of elderly living independently in their own homes. It argues that it is prudent to include family members when designing pervasive healthcare for the home of the elderly. That is, it may be fruitful to include them as a category to be designed for as well as a group to be included in the participatory design process.

Keywords: *Pervasive healthcare, home, elderly, family, participatory design*

I. INTRODUCTION

In this article, an attempt is made to achieve a better understanding of how family members may actively contribute to the performance and coordination of the care of older adults living independently in their own homes. Whereas a number of previous studies have focused on providing family members with awareness of the activities of senior adults [e.g. 1, 2-4] the interest here is to explore how family members actively engage in the practicalities pertaining to the care of elderly [an interest partly shared with e.g. 5, 6]. What is implied here is that relatives may play a significant role in the care of elderly and that this has implications for the design of assistive technologies.

The arguments are based on a qualitative study conducted in the home of older adults living in sheltered senior housing, which is arguably an excellent location for studying the relationship between the elderly, their close relatives and the professional caregivers. The elderly may be assisted in their homes by their relatives as well as by professional caregivers. Furthermore, relatives often engage in the coordination of care with professional caregivers.

The question is this: How may we include the family members of elderly as a category to be designed for as well as a group to be included in the design process? This is the challenge that we will try to outline below. We will proceed as follows: First we will describe how relatives are part of the care of elderly. Secondly, we will reflect on this state of affairs in regard to the design of technologies for assisted living. Finally, we shall point to questions for further research.

II. METHODS

This paper is based on fieldwork focused on the involvement of family members in the care of elderly living alone and independently in their own homes. One of the settings studied was sheltered senior housing in a municipality some 100 km from the City of Copenhagen. A combination of observation and interviews was used. The fieldwork also included collecting (e.g. taking photographs of) artifacts used by the actors involved.

III. ON THE ROLE OF CLOSE RELATIVES IN THE CARE OF SENIOR ADULTS: THE CASE OF MARIE

A growing social concern in the Denmark and elsewhere is the support of aging adults in a manner that allows them to continue an (quasi) independent lifestyle in their own homes, rather than moving to some sort of institutional care. As we grow older, our body generally weakens and ordinary as well as extraordinary activities may become a challenge in terms of locomotion and cognition, hence elderly may be in need of assistance [2]. As indicated above, family members may provide care for the elderly in a significant manner. We will now turn to an example of this, viz. the case of Marie.

Marie is 92 years old when we meet her. She uses a wheelchair due to partial paralysis in her left side - the effects of a stroke that she suffered some ten years ago. Due to her physical condition she requires comprehensive care, day and night, including help with getting dressed, getting a bath and generally getting around. She lives alone in her own home in a senior residential area in a countryside municipality (see figure 1.). She has regular as well as support on call from caregivers employed by the municipality. In addition to the professional care that Marie receives her daughter Elaine who lives some 100 km away, helps out in a substantial manner.

For instance, Marie had out-clinic cataract surgery on both her eyes recently and in connection with this procedure, her daughter Elaine appropriated the wheelchair friendly transportation back and forth between the clinic and the home. That is, Elaine made the arrangements with a local cab company. After the surgery a nurse gave Marie some eye drops and told her to administer them two times a day for two weeks.

However, Marie frequently forgets to take her medicine and consequently Elaine had to make sure that the professional caregivers who frequented Marie's home on a regular basis received and understood this message. Elaine called them and gave them instructions regarding the eye drops. In this instance the performance of surgery on an elderly person and the subsequent related care required the involvement of not only professionals but family members as well.



Figure 1. A home in a sheltered residential area for the elderly.

In general, there are a number of tasks that the professional caregivers employed by Marie's municipality do not perform as it is not part of their job description. As a matter of principle, the local caregivers, for example, do not perform tasks perceived as directly related to participation in social events such as Christmas or birthdays. Consequently, when Marie is invited to social events such as a birthday, it is Elaine or another relative that must prepare her wardrobe i.e. iron the clothes, etc. Furthermore, on the day of such an event Elaine or another family members has to remind the local caregivers to dress her mother in the clothes prepared for the event, otherwise they may easily forget to do so. Marie does not remember such things herself.

Furthermore, Marie most often spends Christmas Eve at Elaine's house, some 100 km away in the city. She has done so for the past 10 years. Such a trip involves family members organizing transportation in a special wheelchair friendly taxibus. Moreover, it also involves notifying the caregivers with the municipality, so Marie can receive professional care as she travels out of her own municipality and spends the holidays at her daughter's house. The latter notification is handled by Marie's home municipality, her daughter merely has to call them up on the phone to make sure that they have been notified and that they are coming on the right dates.

Finally, Marie's local caregivers do *not* handle maintenance work (again, this is not part of their job description). Included in the category of maintenance work is for example the replacement of a broken light bulb. Consequently, if a light bulb needs to be replaced, this requires the help of friends or relatives - as Marie is not physically able to perform such a task herself (she is in a wheelchair after all). What Marie used to do

is to call the local electrician and have him send an apprentice over to replace the bulb. However, she cannot manage to perform this kind of phone calls any more, and may simply sit in the dark until a family member or a friend discovers that the bulb is broken and replaces it for her. In this manner the daughter for instance is involved in the care of Marie if not on a daily basis then on a weekly basis.

Note that the family members may be said to provide care to the elderly in a way that complement, rather than supplement, the care provided by the professional caregivers. That is, there seems to be something akin to a division of labour in place where the relatives handle the type of tasks (e.g. tasks related to social events or light maintenance work) that the professional caregivers for various reasons do not handle. In this manner the role of the relatives as caregivers for the elderly are partly constituted as complementary to the role of the professional caregivers.

Furthermore, in addition to task performance *per se* (e.g. ironing and replacing light bulbs) family members also assist the elderly in contact with the professional caregivers. That is, the family members play an active role in the coordination of the care of the elderly (e.g. administering eye drops, calling caregivers in regard to wardrobe, etc.). An issue worth mentioning in this context is that it is an ensemble of perpetually 'changing faces' that provides the professional care that for example Marie receives. That is, the professional caregivers may, even within the same profession, consist of many different individuals with different approaches and personalities.acerbating this issue is the fact that the turnover of employees working as caregivers, in for example Marie's municipality is high. This prompts additional coordination work as routines and practices are hard to establish with an ever-changing ensemble of actors.

This is of course only one case, one example, of how the care of an elderly person may rely on the involvement of next of kin. However, it may provide us with an opportunity to reflect on how we may design technologies for assisted living that pays heed to the role of next of kin.

IV. TOWARDS DESIGN

According to Mynatt and associates [2, p.333] part of the solution to the challenge of supporting 'aging in place', is to promote awareness among family members of senior adults' day-to-day activities. The concrete suggestion that Mynatt and associates make is to provide *peace of mind* through 'digital family portraits' that may provide qualitative visualizations of an adult's daily life. Mynatt and associates designed a family household object, that is, a digital portrait frame populated with iconic imagery that summarize the last 28 days of the elderly, with the aim of providing a means for family to remaining aware of a distant elders day-to-day activities.

Although this approach may be part of the solution, there are a number of practices which awareness support alone does not address. Obviously it does not support the level of practical involvement from family members that we have, for instance, seen in the case concerning Marie. That is, there is far more to

taking care of Marie, from a family member's point of view, than simply being aware of how she is doing by looking at for instance icons appearing on a picture frame. This is evident from the descriptions above.¹

Perhaps we could suggest that in addition to supporting awareness from a distance, there must be support of the direct involvement of the family members. As indicated above, this involvement takes the form of task performance as well as coordinative efforts or articulation work.

What does articulation work entail? According to Strauss, articulation work is a kind of supra-type work in any division of labour, done by the various actors concerning the meshing and integration of interdependent cooperative work tasks [7, p.8].

Something worth noticing is that Strauss uses the term 'division of labour'. Perhaps we should take this notion of labour to heart when describing and analysing the efforts of some family members in regard to older adults. It is not be paid labour - it may in fact be the *labour of love* - none the less labour it is. Many family members are far more than mere spectators to the lives of their elderly kin. More to the point, there is a *de facto* division of labour between professional caregivers and family members. Where the professionals, simply put, handle what may be dubbed ordinary tasks (e.g. personal care and food preparation, and etc) and the family members handle what is outside the job description of the professionals, what is deemed extra ordinary (e.g. social events and light maintenance). Strauss' point is that 'in any division of labour' there is articulation work - indeed that is part of what we have described in the case concerning Marie. Recall, for example, how Elaine had to call the caregivers in regard to the eye drops and the wardrobe for the birthday. How do we support such articulation work involving professional caregivers and family members (as well as the elderly themselves)?

On the face of it, it seems as if all we designers have to do is for example to make it easier for adult children to coordinate the care and take care of their aging parents. This may be so, although there are a few complications to consider.

Autonomy and dignity

Based on a literature survey, Lindley and associates convincingly argue that older people show a strong resistance to being cosseted by their children later in life [8]. Older people, sometimes irrespective of their evident physical and mental state of decline, can view the efforts of their children as compromising their personal autonomy and dignity. They may even resist family assistance for this very reason [6].

The importance of autonomy to older people and their reluctance to feel as though they are dependent on family members, is demonstrated in the study by Spitze and Gallant [6]. In a focus group interview a group of elderly were keen to emphasise their independence and it was difficult for the

researchers to get them to talk about how they receive help from their family (Spitze and Gallant, p.394):

(M: Can you tell us in what way do members of your family help you take care of yourself?)

(#s 1, 5, 9, women all together): No

(M: Does anyone in your life make it easier for you to take care of yourselves?)

(#s 14, 37, 47, women): No, definitely not.

One of the recurring themes that Gallant and Spitze take up is the elderly's sense of their adult children being overprotective (see also Lindley et al. 2008). Some elderly withholds information from their offspring to avoid what is perceived as intrusion, while others simply tell their children that they are intruding [6].

This state of affairs may prompt us as designers to reflect on how we may help adult children help their aging parents without compromising the personal autonomy and dignity of the latter. For example, how may we support the likes of Marie and her daughter in a manner that is sensitive to this issue?

A first step towards addressing the themes and issue presented above in the context of design could be to point to a relevant approach or method. We shall suggest that the tradition of Participatory Design may prove a tenable approach.

Participatory design of technology for assisted living

The Scandinavian tradition of Participatory Design may be said to be based on two interrelated lines of arguments: a democratic and a process one [9]. We will begin with the former and in turn consider the latter, and discuss how each line of argument is relevant for our endeavour.

The democratic line of argument states that the stakeholders are entitled to have a direct influence on their daily lives including the technology that is involved. It states that compromises have to be reached, that professional designers are not neutral and that the different stakeholders have to safeguard their own interests. In line with this argument Ballegaard and associates have argued for the recognition of a patient or citizen perspective to rival the perspective of the professional healthcare workers and caregivers in the technology design process [10]. The idea is to prevent the professional healthcare workers and ITC professionals from monopolising the design process. We could adopt this view and point out that a citizen's perspective in the context of developing technologies for assisted living must include not only the elderly but their active relatives as well.

We will now turn to *the process argument* that holds that as ICT gets more interwoven with our practices at work and at home, firsthand knowledge and familiarity with these practices are a vital resource in design. That is, one of the key contributions of participatory design is to mobilise the actors of

¹ I imagine that Mynatt and associates would agree.

a given practice and make them active partners in a collaborative design process. In this manner, knowledge and experience within a given domain may be made available as a resource in the design process. Consequently, in the context of the development of technologies for assisted living it may be prudent to involve the users, i.e. the elderly and the active family members. For example, the elderly and their children could be involved in problem identification in realistic settings i.e. in the home of the elderly. Furthermore, the users could be involved in workshops where physical mock-ups and simulations of use where in play. Finally, we could involve the users in the evaluations of proposed solutions based on prototypes.

What we are implying, then, is that we may involve next of kin as a category to be designed for as well as a group to be included in the design process by relying on the methods of Participatory Design.

V. CONCLUSION

The design of healthcare technologies for assisted living most often do not include the perspective of the family members, and on the rare occasions that it does family members may be cast in the role of somewhat passive onlookers that must be provided with awareness and *peace of mind* [see e.g. 2]. In this paper, we shift focus to the role of family members as active and involved caregivers, this view focuses primarily on the regular activities of family members, their task accomplishment, and the coordination of care with professional caregivers and hereby present an important view or perspective to be included in regard to the design of technologies for assisted living.

A question further research, then, is this: When designing technology for the home of the elderly, what could it entail to include family members as a category to be designed for as well as a group to be included in the participatory design process?

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