



Listening to the ones who care: exploring the perceptions of informal caregivers towards ambient assisted living applications

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Abstract

Ambient assisted living (AAL) technologies have received increased attention from government, industry and research. Informal caregivers will be directly affected by the use of these technologies and are likely to be key influencers in the adoption decision of older adults. However, so far the informal caregivers' perceptions, concerns and needs have been mostly overlooked in AAL research. To address these shortcomings, two studies were conducted. Study I consisted of 20 in-depth interviews with informal caregivers to investigate their perception of various AAL applications. In Study II these findings were validated with regard to our own prototype application called SONOPA. The second study included couples of informal caregivers and care receivers to compare both user groups. Although informal caregivers had a more positive attitude than care receivers and appreciated the opportunities of AAL technologies (e.g., increased safety, peace of mind); they also had several concern such as invading the care receiver's privacy, the lack of human touch, and the care receiver's technology experience. To address these concerns, informal caregivers should be more involved when developing AAL applications.

Keywords Ambient assisted living · Smart homes · Technology acceptance · Caregiver · User-centered design

1 Introduction

The burden on family caregivers of older adults is ever increasing. With the demographic pressure rising, many European governments have reformed their long-term care (LTC) policies towards more 'aging in place'. This means the decentralization of care to regional and local levels, a shift from intramural care to more care at home, and more reliance on informal caregivers (Pavolini and Ranci 2008). While older adults are likely to embrace the idea of aging in their trusted home environment and receiving care by one of their kin (Eckert et al. 2004), it is unsure how informal caregivers will cope with the increased workload.

In the Netherlands, informal care is defined as "Long-term care that is provided beyond a caregiving profession to a person with care needs by one or more members from the close social environment, as such that care provision

directly results from the social relationship" (House of Representatives of the Netherlands 2001, p. 7). Tasks performed by informal caregivers include domestic support (e.g., groceries, prepare meals, cleaning); psychosocial support (e.g., administration, doctor visits, social activities, emotional support) and, usually to a lesser degree, personal care (e.g., bathing, dressing, feeding) and basic medical care (e.g., monitor medication intake, surgical dressing) (Timmermans 2003). With LTC policies changing, informal caregivers might have to take up more formal care tasks (i.e., personal care, basic medical care) in the near future. Caring for a frail older adult can have negative consequences for the caregiver's physical health and mental well-being (Pinquart and Sörensen 2003; Schulz and Beach 1999). Other undesirable consequences include a reduced participation in the labor market and an increased risk for financial dependence (Colombo et al. 2011; Mosca et al. 2016).

Informal caregivers are typically female and spouses, children or children-in-law, with the majority aged between 45 and 65 years (Colombo et al. 2011; Huber et al. 2009; Riedel and Kraus 2011). While the demand for informal care is increasing, it is expected that the number of informal caregivers declines over the next years due to changing family structures, a growing participation of women in

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the labor market and a later retirement age (Colombo et al. 2011). These authors predict that to maintain the current ratio of informal caregivers to care recipients, some countries would need a 20–30% increase in informal caregivers. Policies that aim to support informal caregivers (e.g. cash benefits, flexible work arrangements, respite care) are still in an early stage, and there are significant differences between countries regarding the availability, extent and quality of support (Courtin et al. 2014). Moreover, a recent study showed that people might not be willing to take on more care tasks, especially with regard to personal and medical care (Hoefman et al. 2017). It is therefore questionable, whether continuous and high quality care can be provided under the demographic transition and the new care reforms.

To address these challenges, state-of-the-art technologies that support independent living and active aging, introduced as ‘Ambient assisted living’ (AAL) technologies, have received increased attention from the government, industry and research. AAL is envisioned as a potential solution to the challenges of the aging population while maintaining a high quality of care. The promises of AAL include saving LTC costs, improving the quality of care, unburdening family caregivers, and increasing the independence and overall quality of life of older adults (Broek et al. 2010). Over the last decades the European Union has provided a substantial proportion of funding to stimulate research initiatives, development and market exploitation of innovative technologies for ageing well, such as the ‘Active and Assisted Living Programme’ (AAL JP) or the ‘European Innovation Partnership on Active and Healthy Ageing’ (EIP AHA) (Gehem and Sánchez Díaz 2013, p. 40). While the policy enthusiasm for AAL is undeniable high, at this stage it is unclear how these technologies will be received by older adults and their caregivers. Previous studies have shown that there are several barriers towards the acceptance of AAL among older adults and their caregivers (Cardinaux et al. 2011; Hwang et al. 2012; Novek et al. 2000; Peek et al. 2014). It is therefore worrisome that the AAL field is still technology-driven rather than user-driven (Queirós et al. 2015) and lacks a profound understanding of how and why users might accept or reject AAL technologies (Liu et al. 2016; Peek et al. 2014). These insight are crucial to guide developers of AAL to create applications that fit the user’s needs and in turn increase the likelihood of future acceptance by the intended user groups.

Especially one of the secondary user groups, i.e. the informal caregivers, have not receive enough attention in AAL research. This is surprising, as informal caregivers play a vital role in the care of older adults and are therefore directly affected by the use of assistive technologies such as AAL. AAL applications could relieve some of the informal caregivers’ task pressure and provide them with peace of mind. On the contrary, informal caregivers might also feel

threatened by these technologies, as they could take over some of their tasks and make them feel less needed. It is also unclear whether informal caregivers will entrust a technology with the care of their love ones. For the future success of AAL technologies, it is therefore crucial to consider the perceptions and needs of the informal caregivers. This is also confirmed by Chen et al. (2013) and Schorch et al. (2016) who call for more understanding of informal caregivers’ physical, social and emotional needs when designing care technologies.

The current work seeks to explore the perceptions and needs of informal caregivers with regard to AAL technologies and examines if and how these perceptions differ from the care receivers’ perceptions. The first study¹ explored the perceptions and needs of informal caregivers towards various AAL applications. In a second follow-up study these findings were validated with regard to our own AAL prototype application called SONOPA. To get more detailed insights on how informal caregivers differ in their perceptions from care receivers, and which role informal caregivers play in care-related decision making, both user groups were involved in this follow-up study.

Both studies were carried out in the Netherlands. Recently, the Dutch government introduced a major transition to the LTC system together with substantial saving targets. Centrally funded care is now limited to people with heavy care needs, who require permanent supervision or residential care. Intramural care is shifted towards more care at home, meaning more reliance on informal care and higher expectations of self-management and autonomy among care receivers. As the former LTC system included a rather generous coverage for LTC services (Carrera et al. 2013) and less reliance on informal care (Riedel and Kraus 2011), the new reforms have led to a great deal of social unrest (Kroneman et al. 2016). These circumstances make the Dutch informal caregivers a rather interesting population to explore attitudes, expectations and needs towards AAL technologies.

2 Related work

2.1 Ambient assisted living

Ambient assisted living is still a relatively new and emerging field, and there is neither a precise nor commonly accepted definition in the literature. However, after considering different attempts for describing and defining AAL, we found some common ground:

¹ The initial results of our study were presented during AmI 2017 (Jaschinski and Ben Allouch 2017).

1. **Complies with the principles of ambient intelligence:** AAL solutions build on the principle of ambient intelligence (AmI) (Aarts and Encarnação 2006) by developing a new generation of assistive technologies which are embedded (i.e., non-invasive and unobtrusively integrated into the environment); context-aware (i.e., recognize the user and the situational context); personalized (i.e., tailored to the specific needs of the individual user); adaptive (i.e., responsive to the user through learning); and anticipatory (i.e., anticipating the user's needs and desires without conscious mediation) (Acampora et al. 2013; Blackman et al. 2016; Broek et al. 2010; Queirós et al. 2015; Rashidi and Mihailidis 2013). In AAL, ambient intelligence is used to create supportive environments that provide all-encompassing, non-invasive, and pro-active assistance to the user. As Blackman et al. (2016, p. 57) state: "AAL is the result of a progression from individual devices assisting with one task or activity of daily living (ADL) to ambient systems in which the assistance or support completely encompasses the living area and the person".
2. **Comprises various state-of-the-art ICT-based technologies and advanced computational techniques:** AAL includes a broad range of advanced technologies with a strong emphasis on smart home technology, mobile and wearable sensors, and assistive robotics (Rashidi and Mihailidis 2013). The technologies are combined with advanced computational techniques, including activity recognition, behavioral pattern discovery, anomaly detection, context modeling, location and identity identification, planning, and decision support (Acampora et al. 2013; Rashidi and Mihailidis 2013). All components of the AAL environment are interconnected and communicate with each other. The embedded sensors collect information about the environment and the user (*sensing*); computational techniques are used to aggregate, analyze and interpret this information and decide on the appropriate action (*reasoning*), and various types of actuators, intelligent interfaces and assistive devices facilitate action and interaction with the user (*acting*) (Broek et al. 2010; Queirós et al. 2015)
3. **Aims to maintain older adults independence and enhance their general quality of life while also supporting their caregivers:** The vision of AAL is to provide older adults with secure and supportive environments (Blackman et al. 2016; Cardinaux et al. 2011), maintain and improve their physical and mental health (Blackman et al. 2016; Broek et al. 2010; Peek et al. 2014; Rashidi and Mihailidis 2013), and foster social involvement and active participation in the society (Blackman et al. 2016; Broek et al. 2010; Queirós et al. 2015). The goal is to preserve the older adults' independence (Blackman et al. 2016; Broek et al. 2010;

Cardinaux et al. 2011; Peek et al. 2014; Rashidi and Mihailidis 2013) and overall quality of life (Blackman et al. 2016; Broek et al. 2010; Cardinaux et al. 2011). A secondary target group of AAL technologies are informal and formal caregivers (Broek et al. 2010; Chan et al. 2009; Queirós et al. 2015; Rashidi and Mihailidis 2013). AAL technologies aim to reduce the burden on caregivers (Pollack 2005; Rashidi and Mihailidis 2013), provide peace of mind (Mynatt et al. 2001), help them to manage and coordinate care tasks (Bossen et al. 2013; Broek et al. 2010; Consolvo et al. 2004), and facilitate remote communication and social connectedness between caregivers and older adults (Broek et al. 2010; Cornejo et al. 2013). This vision underlines the development toward assistive solutions that target more than one area of 'successful aging' and offer all-encompassing support for older adults and their caregivers.

Based on these finding, we propose the following definition for AAL: "State-of-the art ICT-based solutions that comply with the principles of ambient intelligence, to build intelligent environments that provide all-encompassing, non-invasive and pro-active support to older adults, with the ultimate goal to maintain their independence, enhance their overall quality of life, and support their caregivers."

2.2 Acceptance of AAL

HCI Researchers have shown increased interest in the relationship between technology and the aging population. Vines et al. (2015) found that by 2012, 162 papers have been published in Human-Computer Interaction venues (ACM SIGCHI) that had a primary focus on the relationship of older adults and technology. A majority of these papers have been published after 2006. Several interesting research projects have been launched, such as University of Missouri's 'Aging in Place' project (Rantz et al. 2005), Georgia Tech's 'Aware Home' (Abowd et al. 2002), or Fraunhofer IPA's assistive robot 'Care-o-bot' (Graf et al. 2004). While the interest in technology for the aging population is rising, a recent systematic review concludes that the predominate focus in the field is still on the technology rather than the user (Queirós et al. 2015).

Nevertheless, the body of user-centered studies in AAL is slowly growing, and several researchers have explored user perceptions of AAL applications (Demiris et al. 2004; Melenhorst et al. 2004; Smarr et al. 2014; Steele et al. 2009; van Hoof et al. 2011). Demiris et al. (2004) explored older adults' perceptions of various smart home applications. While added safety, health benefits and assistance with daily activities were perceived as predominant advantages of such technologies, concerns were expressed about privacy, the reduced human touch, and the usability of the technology.

Steele et al. (2009) investigated older adults' attitude towards wireless sensor network technologies and suggested that independence was the strongest driver for acceptance, while cost was the most prevalent barrier. Interestingly, they also suggested that privacy might not be a major concern to older adults. Smarr et al. (2014) found that older adults preferred robot assistance for domestic tasks such as chores, manipulating objects and information management, while human assistance was preferred for personal care and leisure activities.

However, the majority of user studies in AAL have a pre-dominant focus on the attitudes and needs of older adults and overlook the perceptions of informal caregivers. Informal caregivers play a vital role in the care of older adults and are therefore directly affected by the use of assistive technologies, such as AAL systems (Chen et al. 2013). They also have an important influence on care-related decision making (Bass and Noelker 1987; Byrne et al. 2009) and the selection and appropriation of assistive devices (Greenhalgh et al. 2013). Furthermore, AAL studies with older adults suggest that older adults take their family's needs and opinions into account, when making care-related decisions (Courtney et al. 2008; Lorenzen-Huber et al. 2011). Despite their likely role in the older adult's decision to adopt AAL, informal caregivers are either underrepresented or not included in most AAL studies. In the limited cases that informal caregivers are part of the user sample, data are often grouped together with the older adults' data, making it difficult to identify the perceptions belonging to the informal caregivers.

There are several exceptions when the informal caregiver is considered as the primary user. The Digital Family Portret project (Rowan and Mynatt 2005) examined an ambient display that provides awareness of older adults' daily activities with the aim to increase the peace of mind of distant family members. The design of the ambient display relied on the need analyses of both, older adults and their adult children, and was evaluated with participants from both user groups in the subsequent field trials. The field trial showed that the Digital Family Portret increased the peace of mind of the family member, while increasing the older adult's feeling of safety. Moreover, the older adult reported to feel less lonely. A similar technology was introduced by (Consolvo et al. 2004). The CareNet Display targets the different members of the care network with the aim to support and coordinate care activities. Through an ambient display, information about the older adult's activities (e.g. meals, medication, visits) is displayed. The CareNet Display was tested among four older adults and nine informal caregivers during a three week in-situ deployment. Results showed that the technology supported the carers in the communication and coordination of care tasks, provided peace of mind, and raised the general awareness of each caregiver's contribution. It

also helped less involved caregivers to learn more about the older adults activities, which in turn lead to better conversations with the older adult. Ambience, usability and control were important design requirements resulting from the field trials. The CareCooor system (Bossen et al. 2013) aims to facilitate coordination and planning of care tasks and provides information about scheduling, completion of care tasks, swapping or cancellation of tasks, new tasks, and a feature for exchanging messages. The two pilot evaluations with informal caregivers and professional caregivers showed that participants valued the possibilities for coordination support and communication. Critical comments among the professional caregivers included that CareCooor was not appropriate for urgent tasks that require immediate attention, and that the system is only useful if all involved caregivers know how to use it. The informal caregivers' feedback was mainly about the usability of the interface. Other AAL studies which actively involve informal caregivers are mainly centered around people with dementia (e.g., Hwang et al. 2012; Rialle et al. 2008). Again, these studies usually consider the informal caregiver as the main user or as the main decision maker and natural spokesperson for the care receivers' needs due to their cognitive impairment.

We argue that informal caregivers should be involved in acceptance studies, even when they are not the primary users, and even when applications do not specifically target people with dementia. These informal caregivers will still be affected by the use of AAL technology, and it is likely that they will be involved in the decision making process concerning the adoption decision. Looking at popular theories from behavioral sciences and the technology acceptance field, the need for including informal caregivers becomes even more apparent. Theory of Planned Behavior (Ajzen 1991), Domestication Theory (Silverstone and Haddon 1996), Social Cognitive Theory (Bandura 2004) as well as Diffusion of Innovation Theory (Rogers 2003), all stress the importance of the social environment in the process of accepting a new technology. Luijckx et al. (2015) investigated the influence of family members on the acceptance of different technologies such as computers, laptops, tablets, mobile phones, electric bikes and personal alarms. They conclude that "the acceptance of technology by older adults, in the sense of purchasing and using devices, is not an individual matter; it is influenced by spouses, children and grandchildren" (p. 15479). They argue that family members should be included when implementing technologies for older adults. Although the focus of that study was not strictly on assistive technologies, it still underlines the need to involve informal caregivers in AAL studies. As influential stakeholders and secondary users, their needs should be taken into account when developing AAL technologies.

3 Study I: informal caregivers' perceptions towards AAL applications

With the objective to explore the informal caregivers' attitudes, concerns and needs towards AAL, we conducted semi-structured interviews with 20 Dutch informal caregivers. This qualitative approach allowed us to get an in-depth understanding of the informal caregivers' perception of AAL technologies.

3.1 Participants

The participants were sampled in the Eastern part of the Netherlands via snowball sampling. To be included in the sample, informal caregivers had to provide informal care for at least 3 month and caregiving had to directly result from a close social relationship (House of Representatives of the Netherlands 2001, p. 7; Timmermans 2003).

Our sample was a good representation of the typical informal caregiver population with a large proportion of female participants ($n = 18$) and with almost all ($n = 19$) participants from the 45–65 age group ($M = 53.3$, $SD = 6.91$). Most of the participants were working part-time ($n = 14$) or full-time ($n = 3$), next to their caregiving responsibilities. The large majority provided care to one or two family members, either parents ($n = 17$), in-laws ($n = 1$) or siblings ($n = 1$). Only two participants cared for a person outside their family circle (e.g., friend, neighbor). More than half of the participants ($n = 11$) had been an informal caregiver for at least 10 years. When asked about their time investment, nine participants indicated to spend less than 3 h a week on caregiving tasks, five participants spent 3–7 h a week, and only three participants spent 8 h or more a week on informal caregiving. All caregivers reported to provide some form of psychosocial support (e.g., administration, doctor visits, social activities, emotional support), and most of them ($n = 19$) also helped with domestic tasks (e.g., groceries, prepare meals, cleaning). Only three respondents were involved with personal care (e.g., bathing, dressing, feeding) and basic medical care (e.g., monitor medication intake). When asked about their overall ICT experience, all participants had experience with mainstream ICT such as pc, laptop, smart phone or tablet, and most of them ($n = 14$) used these tools on a daily basis. This level of ICT skills is representative for the Dutch population in this age group (Statistics Netherlands 2017).

3.2 Materials

Application domains of AAL technologies are very broad, as they aim to provide all-encompassing support in all areas of the older adult's life. For the purpose of this study, we

focused on applications for mobility and safety. Mobility and safety are important aspects for shaping the older adults' level of independence and overall quality of life (Gabriel and Bowling 2004; Rubenstein 2006). With older age, problems in these areas increase. Common restrictions which affect the mobility include balance control, reduced perception of touch and vibration, reduced walking speed, gait disorders, strengths deficits, and lower reaction time (Rogers et al. 2003) Those restrictions also increase the likelihood of falls, which is one of the most prevalent safety risks for older adults. Falls can lead to anxiety, inactivity, further mobility restrictions, premature nursing home placement, or even death (Rubenstein 2006). The objective of this first study was not to evaluate a specific AAL application but rather to explore the general perception of AAL among informal caregivers. This is in line with the vision of AAL which is about all-encompassing supportive environments rather than a single device. Therefore, we used several different AAL applications that could aid the care receiver's mobility and safety as examples in this study.

For the field of safety different types of sensors were shown to the participants. Each example contained a short textual description and a visual. Visual sensors (cameras) and ambient sensors were used as the first two examples. It was explained that these sensors can monitor the older adults' activities and detect falls or unusual behavior such as abnormal sleep behavior. As a third example we used wearable sensors. It was explained that these sensors could be implanted, body-worn or be integrated in a garment to continuously measure the older adult's vital signs. The accompanied visual depicted ultrathin sensor technology that is directly applied on the skin, similar to Webb et al. (2013). For the mobility field we showed a smart wheelchair with an autonomous break system, wayfinding support and speech recognition (Lankenau 2001); a smart wheeled walker with an autonomous break system and wayfinding support, and an adaptive kitchen with moveable cupboards and countertops. As a fourth example we used an assistive robot. It was explained that the robot could help with different (instrumental) activities of daily living ((I)ADL). The accompanied picture showed TU Eindhoven's robot AMIGO fetching an object from the drawer. To provide additional context on how these AAL tools could be aid the care receiver in real life, two user scenarios, one focusing on safety and one focusing on mobility, were created.

3.3 Procedure and data analyses

The interviews were conducted in the participants' own home environment to create a comfortable interview situation. Each session started with some general information about the purpose of the study, the interview procedure and the consent for recording. The interview started with several

question about the context of informal care such as daily care routine, workload and motivation to provide informal care. We also included some question about the care receiver's mobility and safety issues. After that, the participant viewed the AAL examples together with the scenarios and were probed to reflect on their perceptions and attitudes regarding AAL.

Each session lasted about 60–90 min and was recorded and transcribed verbatim for subsequent analyses. All transcripts were carefully analyzed to identify common concepts and themes. When coding the data we applied a mixed-method approach, meaning that some of our themes were based on prior knowledge from literature (deductive approach), and some themes emerged directly from the participants' narratives (inductive approach) (Ryan and Bernard 2003). We performed several rounds of coding to compare new codes to previous assigned codes, to make sure the identified themes remained valid and to derive the final set of themes.

3.4 Results

3.4.1 Context informal care

When asked about their motivation of providing care 12 informal caregivers reported it to be pleasant and rewarding: "It's a wonderful job [...]. I really enjoy it. But I have a darling mother-in law so that makes it easy" (participant 4, in-law, female). Nine participants perceived care as a 'matter of course': "This is what you do, you don't think about it" (participant 2, daughter). This was often connected to a feeling of reciprocity: "I think it is normal, being a daughter. In the past, my mother cared for me, now I care for my mother" (participant 5, daughter). Four informal caregivers also felt some degree of obligation provide support: "It's what you supposed to do. It's your mother and you care for her" (participant 13, daughter). This obligation was sometimes routed in the care-receivers' wish to age in their own home environment. Finally, less frequently mentioned drivers were the caregiver's own peace of mind ($n=2$) and altruism ($n=1$).

The most common problem the participants experienced as informal caregivers was workload. More than half ($n=11$) of the participants reported to sometimes feel overburdened, especially in combination with their other responsibilities: "If you work four days a week and you have one day off, it is quite stressful" (participant 17, daughter). Five participants also felt emotionally challenged: "At the moment it is really hard. It's not so much the time you invest but the psychological burden to see your father further deteriorate" (participant 19, daughter) Three participants mentioned that they encounter resistance on the part of the care receiver in accepting their support: "I sometimes do things for her with good intentions, but she perceives it as taking

away her agency" (participant 2, daughter). Other problems which were revealed by individual caregivers included lack of support (participant 19, daughter), communication between caregivers and bureaucracy (participant 9, daughter), physical burden and financial burden (participant 7, daughter), and confidence in one's own abilities (participant 10, daughter). Five participants reported to experience no problems with regard to providing care: "No not really, because we are several people and tasks are divided. One does this and the other does that" (participant 13, daughter).

In accordance with our expectations, almost all informal caregivers ($n=18$) were closely involved in care-related decision making. According to their comments, informal caregivers regularly check on potential safety risks and new care needs: "Once in a while I want to sit with her in the car to see if it is still safe. And if I feel it isn't safe anymore, then I will discuss this with her" (participant 8, daughter). Subsequently, they are often the ones who initiate the appropriate measures to address these issues. However, the degree of social influence differed. Some informal caregivers pointed out to provide carefully phrased suggestions, while others had a strong advisory role. A few informal caregivers even made decisions without consulting the care receiver first: "As soon as needed, we bought a wheeled walker [...] although she did not want one in the beginning. You just buy the thing and put it there" (participant 1, son).

3.4.2 Current strategies to cope with safety and mobility issues

The safety and accessibility of the care receiver's home environment was an important topic for informal caregivers ($n=17$). Reasons for concern included potential falls or accidents ($n=14$), burglary ($n=12$) and other home safety issues like gas leaks or fire ($n=3$). To address these safety issues, informal caregivers reported about several adaptations and assistive technologies in the care receiver's home. Those adaptations included grab bars, threshold ramps, a shower seat, a hoist and an adapted bed. Some of the more technological solutions included a hospital bed, a stair lift, a key lock box, and a doorbell signaler. Although most of the solutions were rather low-tech, two participants had experience with more advanced solutions in the care receiver's home, such as temperature sensors and stove sensors (participant 19, daughter) and even cameras for monitoring (participant 6, friend, female). In case of an emergency, it was important to the participants that the care receiver could immediately reach out for help. Therefore, thirteen care receivers had a push alarm system: "Now I know [...] if something is wrong, she can push the button and one of us will be alarmed" (participant 5, daughter). Two informal caregivers even indicated that the care receivers had a tablet for

check-ins with the professional care service (participant 1, son; participant 14, neighbor, female).

The care receiver's mobility and transport were also important to the caregiver. Informal caregivers ($n = 12$) emphasized that they want the care receiver to go outdoors, engage in activities, and stay in touch with social contacts to avoid social isolation: "I think it's important that she gets outside now and then and that she has her social contacts" (participant 3, daughter and sister). The majority of informal caregivers ($n = 18$) indicated that the care receiver uses walking aids such as cane, wheeled walker, wheelchair or mobility scooter to support their mobility. In addition, many informal caregivers assisted with transport. This was contributed by the fact that accessibility and transport options were often limited, or that participants worried about traffic accidents: "Then I sit here with an anxious feeling while she is away with the car. Well, then I rather drive her myself" (participant 4, in-law, female).

Although informal caregivers provided assistance on many levels, they tried to preserve the care receiver's independence and autonomy ($n = 12$): "I think it's important that she can do her own thing for as long as possible" (participant 2, daughter).

3.4.3 General evaluation of AAL

The majority of participants ($n = 13$) had a positive overall attitude towards AAL. They appreciated the different possibilities for support and thought of AAL technologies as a positive development for the future of caregiving: "Well, I think first of all it is fantastic that a lot of stuff is being developed" (participant 3, daughter and sister). In contrast, four of the interviewed participants were rather skeptical towards AAL: "I think it's a scary idea" (participant 6, friend) or "I can't really picture it to be honest" (participant 12, daughter). In their view, such technologies were a last resort and they would rather try to manage the necessary care by themselves: "I don't hope it will come to this [...], and then I still think that we as her children would manage most of it" (participant 17, daughter). The remaining three caregivers had a mixed view of AAL technologies with some positive and some negative perceptions. Although, most informal caregivers had a strong influence on care decisions, the majority ($n = 15$) emphasized that using an AAL technology would strongly depend on the wishes of the care receiver, and they would not use these tools without their consent: "You have to honor their wishes. Do they want this or not?" (participant 10, daughter).

Comparing the different applications that were used as an example in this study, the smart wheeled walker was positively perceived by most participants ($n = 17$), followed by the ambient sensors ($n = 13$) and the adaptive kitchen ($n = 12$). The participants especially liked that these tools

could support the care receiver's mobility, prevent and signalize accidents and therefore provide some peace of mind to them as caregivers. In contrast, most participants had a negative attitude towards the assistive robot ($n = 16$), followed by the wearable and visual sensors ($n = 8$). The participants complained that these tools lack the human touch and invade the care receiver's privacy. It should be noted that only seven participants commented specifically on the smart wheelchair, making it hard to compare these evaluations. Table 1 provides an overview of these overall evaluations. The next section discusses the specific drivers and barriers of AAL acceptance in more detail.

3.4.4 Drivers of AAL acceptance

Safety. Safety was identified as a strong driver towards AAL technology acceptance. Almost all participants ($n = 19$) perceived that AAL technologies could contribute to the safety of the care receiver. They appreciated that the various sensors could immediately trigger an alarm in case of emergency and therefore falls or other accidents would not remain unnoticed by the caregiver: "Essentially, you minimize the chance that somebody lies on the floor for one or two hours or maybe days" (participant 1, son). They liked that they could keep an eye on the care receiver's safety from distance and provide immediate help when needed: "You can see that the person is safe and doesn't do anything stupid" (participant 2, daughter). With regard to the adaptive kitchen, participants pointed out that hazardous situations could be prevented, e.g. climbing on a stool to reach the upper cupboard. The smart wheeled walker and the smart wheelchair were regarded as a tool to prevent dangerous situations and accidents outside the home, as becomes clear in this statement: "Especially the wheelchair and I-walker could prevent a lot of accidents [...] Simply, because it is hard for older people to react quickly" (participant 3, daughter and sister).

Peace of mind. Another strong driver that is closely related to safety was peace of mind. The majority of the participants ($n = 15$) emphasized that AAL technologies could increase their own peace of mind as well as the care receiver's peace of mind: "Yes, I think it can contribute to peace of mind for all parties" (participant 3, daughter and sister). The caregivers pointed out that the presence of sensors could help them worry less about the care receiver's well-being: "You know that if they fall you get an alarm. That's very comforting" (participant 9, daughter) and also relieve some of their responsibility "That you don't have to feel guilty if something should happen" (participant 10, daughter). Interestingly, several participants ($n = 7$) were concerned that having all the sensor data could also have the opposite effect and cause more worries. As one participant stated: "Sometimes, I think it is better that I don't know how she gets through the day. Because some stuff I don't want to

Table 1 Overview of the general evaluation of AAL applications among informal caregivers

Participant	Overall attitude	Ambient sensors	Visual sensors	Wearable sensors	Smart wheelchair	Smart walker	Adapted kitchen	Assistive robot
1	±	+	+	+	n/a	+	±	-
2	+	+	-	-	±	+	n/a	+
3	+	+	+	+	+	+	+	-
4	+	+	+	+	n/a	+	+	-
5	+	+	+	-	n/a	+	+	-
6	-	±	+	-	n/a	-	+	-
7	+	+	+	-	±	+	n/a	-
8	+	-	-	-	+	+	+	-
9	+	-	+	+	-	+	+	-
10	±	+	-	+	n/a	+	+	-
11	+	+	+	+	-	+	+	-
12	-	+	-	+	n/a	-	n/a	-
13	-	-	-	n/a	n/a	+	+	-
14	+	+	+	n/a	n/a	+	n/a	n/a
15	+	-	-	+	-	+	n/a	-
16	±	+	-	-	n/a	+	+	-
17	-	n/a	-	-	n/a	+	+	-
18	+	+	+	+	n/a	+	n/a	-
19	+	n/a	±	n/a	n/a	+	n/a	n/a
20	+	+	±	-	n/a	n/a	+	+

+ positive evaluation, ± mixed evaluation; - negative evaluation, n/a no answer

see. Stuff that would scare me” (participant 8, daughter). In line with this concern the majority of participants ($n = 14$) preferred to have the sensor data managed by a professional care center and then be alarmed in case of emergency.

Mobility and support with daily activities. An additional 15 participants acknowledged that the presented AAL tools could increase the care receiver’s mobility and support them with their daily activities. They pointed out that tools like the smart wheeled walker could encourage the care receiver to go more outdoors, walk small distances, and increase the overall mobility radius: “And you help her with long distances. Now she is still able to do this, but when she can’t anymore in the future this is very useful” (participant 5, daughter). They also acknowledge that the adaptive kitchen and the assistive robot could compensate for the care receiver’s physical limitations, e.g. getting dizzy when bending down to reach for objects, and help them with housework and personal care.

Independence. More than half of the participants ($n = 11$) mentioned the care receiver’s independence as an important benefit of AAL, as becomes clear in this statement: “I am advocate of staying independent for as long as possible; and if you use these technologies then you stay independent” (participant 20, son). According to the informal caregivers, staying independent would preserve the care receiver’s sense of freedom and self-worth. They also acknowledged

that AAL technologies could enable the care receiver to stay in the familiar home environment for as long as possible: “Staying in your own environment is very important to my mother” (participant 18, daughter). However, there were some critical voices towards keeping the care receiver home at all costs: “Just let this guy go to an nursing home, please” (comment on the user scenario, participant 17, daughter). Three informal caregivers indicated to prefer a care home over AAL technologies when the health condition of the care receiver would change.

Support with caregiving tasks. Support with caregiving tasks was recognized as another driver of AAL technologies. Several participants ($n = 8$) pointed out that AAL technologies could support them in some of their usual caregiving task. For example, one participant stated with regard to the smart wheeled walker: “I would not have to drive her to the hair dresser anymore because she could do that herself” (participant 2, daughter). Participants recognized AAL tools would enable them to provide more care from distance, perform tasks more efficiently and ultimately relieve some of their workload, meaning that they have more personal time: “You have a little bit more freedom. You don’t have to stay home or find somebody else if you are away for the weekend” (participant 5, daughter).

Absence of social provision. A contextual driver of AAL technology acceptance was the absence of social provision.

Several participants (n = 6) stated AAL solutions were most suitable to older adults without a social support system or with family members living at some distance: “If I would live at distance [...] then all the stuff that you have as an example here, yes, I think it could give some peace of mind” (participant 3, daughter and sister).

Finally, a few caregivers mentioned *social connectedness* (n = 4) and *health benefits* (n = 3) as other advantages of AAL technologies.

3.4.5 Barriers towards AAL acceptance

Privacy and intrusiveness. Privacy and intrusiveness formed strong barriers towards AAL technology acceptance. Almost all participants (n = 18) were concerned that AAL technologies could invade the care receiver’s privacy. This was especially true for the visual sensors but also for the wearable and ambient sensors. Some informal caregivers stated that they would feel like a spy, and that they would not want to have all kinds of information about the care receiver: “A bit like Big Brother is watching you. That’s the feeling I get” (participant 8, daughter). Likewise, some participants also thought that the care receivers themselves would not appreciate it to be monitored by them as caregivers. They also feared that care receivers might not always be fully aware that they are being monitored. While some participants regarded the care receiver’s privacy as a priority, others believed the safety benefits to outweigh the privacy concerns (n = 6): “In that phase safety is more important” (participant 13, daughter). Some caregivers stated that instead of feeling safe, the care receiver might feel uneasy about the sensors: “Sensors under the skin measuring heartbeat and respiration – well that would get my heart rate up if everything is being monitored” (participant 20, son). Other critical comments about the intrusiveness of the wearable sensors included “a bit like an alien” (participant 8, daughter), “I would feel like a robot myself” (participant 2, daughter) and “animals are also tagged” (participant 6, friend, female).

Lack of human touch. Another strong barrier towards AAL technology acceptance was the lack of human touch. The great majority of participants (n = 17) had some concerns that AAL technologies could reduce the human touch in care. The participants stated that contact, warmth and empathy are crucial to the care receivers and that technology could not offer these qualities. Participants were especially critical towards the assistive robot in that regard: “You want someone with you to hold your hand and hug you from time to time. Well good luck with that robot” (participant 4, in-law, female). Another concern was that technologies might create more distance between care givers and care receivers and therefore increase social isolation: “Knowing they have those things at home, you might visit your mother or father less often to check on them” (participant 4, in-law, female).

The majority of caregivers emphasized that technology could not and should not replace human care: “You can have the greatest devices. But people will rather be bathed one time less and have a chat, than being in a lonely home with all these technologies.” (participant 5, daughter) Or as participant 19 stated: “I think technology can be a supporting tool, but the humans should stay in control”. Interestingly, one of the few male informal caregivers (participant 20, son) actually preferred an assistive robot over a human caregiver for his father as well as for himself in the future. He argued, that often female professional caregivers carry out intimate tasks, such as bathing. The same participant stated that the professional caregivers should not be responsible for the care receiver’s social involvement: “People always emphasize the human touch [...], but I think, go visit clubs to get in touch with others. This should not depend on the caregivers”.

Unfelt need for support. The unfelt need for support was another significant barrier towards AAL technology acceptance. Before even exposing participants to the AAL technology examples, they were asked if they would like any support in their caregiving tasks. The majority (n = 17) indicated that they would not need any support in their current situation. This can be explained by the fact that most of the participants shared their responsibilities with other family members, and some already had support from professional care services. This unfelt need was also reflected by most participants (n = 17), when evaluating the AAL technology examples. Several participants (n = 9) stated that the care receiver was still independent and healthy enough and would not need a specific AAL tool at the moment. Then again, other participants (n = 4) pointed out that the care receiver would be too restricted to benefit from a specific AAL tool, as becomes clear in this statement about the smart wheeled walker: “This would not be suitable for my mother because she rarely moves outside the house anymore” (participant 16, daughter). Some informal caregivers (n = 5) felt there was no need for a specific AAL tool because they lived nearby and could provide the necessary care themselves or with the support from a professional caregiver. Others (n = 6) stated to be satisfied with their current assistive tool e.g., push alarm system.

Technology experience. Another barrier towards AAL technology acceptance was technology experience. More than half of the caregivers (n = 11) were worried that the care receiver might lack the necessary experience and skills to be comfortable using AAL technologies. The participants emphasized that the care receivers have not grown up with technology and therefore might not be open towards AAL technologies: “She would not want that. Because she is from another generation and is not at all used to technology” (participant 2, daughter). The care receivers might even be scared of tools like an assistive robot: “A robot is scary to people” (participant 1, son). Also, care receivers might have

difficulties handling AAL tools: “If my mother gets a kitchen like that, all the buttons would drive her crazy” (participant 17, daughter). A few caregivers (n = 2) were also worried about their own technology skills. However, most participants were convinced that technology experience would not be a barrier for them as the next generation of care receivers. Nevertheless, it was emphasized that usability is an important requirement for AAL technologies (n = 4).

Reliability and trust. Reliability and trust formed another barrier towards AAL technology acceptance. Half of the informal caregivers (n = 10) had doubts about the reliability of AAL technologies. Several participants indicated that one could not completely trust AAL technologies because they might not work all the time: “It’s technology so it can break down, you can’t completely trust those” (participant 5, daughter). For example, one participant worried about potential accidents when the electronic breaks of the smart wheeled walker would malfunction. This lack of trust was often grounded in previous negative experience with care-related ICT tools. Therefore, several caregivers (n = 5) emphasized that they would like to be able to test and experience an AAL tool before using it.

Resistance to change. Resistance to change was another barrier mentioned by the informal caregivers. Several participants pointed out (n = 7) that the care receivers are not comfortable with new and unfamiliar situations and therefore, might be apprehensive towards AAL technologies: “I doubt that people that age can handle such major changes” (participant 3, daughter and sister). Participants pointed out that AAL technologies that are based on familiar tools, e.g., adaptive kitchen, will be more acceptable than the more unfamiliar tools, e.g., assistive robot.

Contextual limitations. Additional barriers towards AAL technology acceptance were contextual limitations. Some informal caregivers (n = 7) stated that the care receiver’s living environment could be problematic for some of the AAL tools. As one participants pointed out: “It is all very narrow, so if a robot would need to get through, then I see a problem” (participant 20, son). One caregiver also found the smart wheeled walker and the intelligent wheelchair less appealing for the care receiver because they lived outside the city center with everything far away.

Financial costs. Financial costs was also a barrier concerning AAL technologies. A few informal caregivers (n = 5) were concerned about the potential costs of AAL technologies: “I think immediately: gosh this costs a lot of money. This is not affordable for the average older adult [...]” (participant 9, daughter). Therefore, some participants demanded that AAL technologies must not be too expensive so that the less well-off older adults could afford them.

Pride. Finally, pride was another barrier towards AAL technology acceptance mentioned by a few informal caregivers (n = 2). The participants stated that the care receiver had

already trouble to accept support and therefore would also be hesitant towards supporting tools such as AAL technologies.

4 Study II: evaluation of SONOPA

To validate the results from the first study with our own prototype application called SONOPA and to get a clearer picture of the potential differences between the informal caregivers’ and older adults’ perceptions, a second study was conducted. We also wanted to gain more insights into the decision dynamics and the social influence of informal caregivers in the process of care-related decision making.

4.1 Participants

In total, nine Dutch informal caregivers and eight care receivers participated in the second study (n = 17). Participants were conveniently sampled via snowball sampling. To be included in the sample, informal caregivers had to provide informal care for at least 3 months, and caregiving had to directly result from a close social relationship (House of Representatives of the Netherlands 2001, p. 7; Timmermans 2003). Care receivers had to be 65 years or over, live independently, and receive informal care for at least 3 month, to be considered for inclusion. The final sample consisted of seven ‘couples’ of informal caregivers and their respective care receivers. One of these couples included two informal caregivers providing joint care for their neighbor as the care receiver. In addition, one informal caregiver and one care receiver were interviewed without also interviewing their respective care receiver and informal caregiver. Table 2 gives a detailed overview of the background information of the sampled participants.

4.2 SONOPA

For the second study, our own AAL prototype application called SONOPA was tested (<http://www.smartsigns.nl/en/sonopa/>). SONOPA aims to empower older adults to age in their own home environment, while staying active, safe and socially connected. The SONOPA system consists of four major components (see Fig. 1).

1. A *sensing infrastructure* with low resolution visual sensors (30 × 30 pixels) (Camilli and Kleihorst 2011) and passive infrared sensors (PIR) to detect the care receiver’s location and monitor activities.
2. A simplified *social network environment* that offers different social interaction components, like message system, activities and interest groups, video calls and real-time chat.

Table 2 Overview background information participants

Informal caregiver (IC) ^a	Gender	Age	Relationship with CR	Working situation	IC tasks	IC frequency	ICT experience
1	Female	47	Daughter	Part-time	ds, ps	Several times a week	High
2	Female	50	Daughter	Housewife	ds, ps	Several times a week	Medium
3a	Male	61	Neighbor	Full-time	ds, ps	Several times a week	High
3b	Female	61	Neighbor	Housewife	ds, ps	Several times a week	Medium
4	Female	52	In-law	Entrepreneur	ds, ps, mc	Several time a day	High
5	Female	72	Spouse	Retired	ds, ps, pc, mc	Full-time	Low
6	Female	46	Daughter	Part-time	ds, ps	Several times a week	High
7	Female	46	Daughter	Housewife	ds,ps, pc	Once a day	High
8	Female	42	In-law	Part-time	ds, ps	Several times a week	High
Care receiver (CR) ^a	Gender	Age	Distance IC	Living situation	Professional care	ICT experience	Care ICT use
1	Female	82	Same town	Alone, fh	No	Medium	Push alarm
2	Female	84	Neighboring town	Alone, fh	No	Low	No
3	Female	81	Neighbors	Alone, fh	No	High	Several aids for visual impairment
4	Female	80	Same premises	Alone, fh	Yes: pc, dc	High	No
5	Male	71	Live together	With spouse, fh	Yes: pc, mc	Low	Push alarm
6	Female	79	Same town	Alone, fh	Yes, dc	Low	No
7	Female	86	Same neighborhood	Alone, fh	Yes	Low	Push alarm
9	Female	84	Same town and neighboring town	Alone, sf	Yes, pc, dc	Low	Push alarm

^aEqual participant numbers refer to the respective informal caregiver/care receiver

ds domestic support, *ps* psychosocial support, *pc* personal care, *mc* medical care, *fh* family home, *sf* senior flat

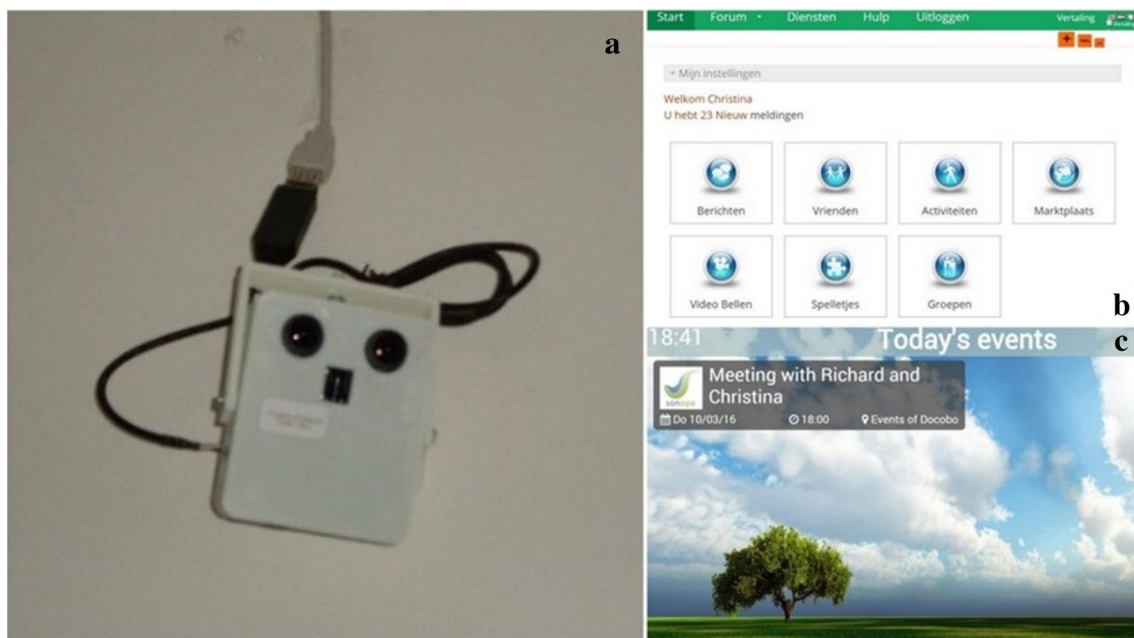


Fig. 1 Components of the SONOPA system: **a** visual sensor, **b** social network environment **c** intelligent user-interface with agenda information

3. The *controller* that receives and analyses the sensor data and social network data with advanced activity recognition and match-making algorithms.
4. An *intelligent user-interface* that is linked to a web application and offers information and recommendations to the care receiver, using input from the care receiver's activity data, the care receiver's social network activity, and an online agenda. Informal caregivers can also push information to the user-interface. The intelligent user interface is set up as a cloud-based solution that runs on a tablet or a smart TV.

4.3 Procedure and data analyses

Similar to the first study, the interviews were conducted in the participants' own home environment to create an open and comfortable interview situation. Informal caregivers and care receivers were interviewed apart from each other with the exception of two older adults, who preferred to be interviewed together with their care receiver (CR 7 and CR 5). This already gives an indication of the important role of informal caregivers with regard to care-related topics. In addition IC 3a and 3b were interviewed together, as they were taking care of the same care receiver.

Each session started with some general information about the purpose of the study, the interview procedure, the consent for recording, and a short demographic questionnaire. After the introduction, the interview continued with some general question regarding the care receiver's current and preferred living situation for the future, the current care context, and the experience with (care-related) ICT technologies. In the second part of the interview, participants were introduced to the SONOPA system via visuals and a detailed verbal description of all subcomponents and their main functionality. In addition, participants viewed a short demo video showing a potential user scenario for SONOPA (https://www.youtube.com/watch?v=WIOZ_Nh6_To). Following the demo video, participants were probed to reflect on their perceptions and attitudes regarding SONOPA and AAL in general.

The sessions lasted about 60–90 min and were recorded and transcribed verbatim for subsequent analyses. All transcripts were thoroughly analyzed to identify common concepts and themes. This time our approach to data analyses was mainly deductive, using the themes from the first study. Several rounds of coding were performed before deriving the final set of themes.

4.4 Results

4.4.1 Informal caregiver's perception

Informal caregivers in the current study were more skeptical than in the first study. Only four informal caregivers (IC

3a, 3b, 7, 8) had had an overall positive attitude towards the presented technology and AAL in general, and three of them indicated to want to use these technologies in their current care situation. The other informal caregivers had mixed attitudes towards SONOPA, although all but one could imagine to use some form of AAL in the future, when the health of their care receiver would deteriorate. Again the movement sensors were perceived as more acceptable than the visual sensors.

Seven of the eight drivers towards AAL acceptance that were found in the first study could be validated in the second study: safety (n=8), peace of mind (n=7), support with caregiving tasks (n=6), social connectedness (n=5), absence of social provision (n=5), mobility and support with daily activities (n=3), and independence (n=3). Health benefits were not mentioned as a driver by the informal caregivers in the current study. Similar to the first study, enhancing the care receiver's *safety* and providing *peace of mind* to the caregivers themselves as well as the care receiver was perceived as the main advantage of SONOPA. However, there was again some ambiguity around the issue of peace of mind, meaning that the system was also considered as a potential stress factor (n=6): "On the one hand, it can be less pressure. That you know it is safe, you know, that if she goes out and goes astray then we know that. But if you get an overkill of information, then that can also causes a lot of pressure I think (IC 1)". *Support with caregiver tasks* was also recognized as an important advantage of SONOPA. This support included the possibility for coordination between the (informal) care-network, less need for face-to-face visits, saving time, relieving workload and the possibility for agenda management: "I think something like this may be able to relieve the workload of the informal caregiver. The caregiver does not have to visit to check-in. He can check- in on him or her [the care receiver]in a different way" (IC 4). *Absence of social provision* and *social connectedness* were more prevalent drivers, in comparison with the first study. More than half of the participants appreciated that AAL technologies like SONOPA could stimulate the social connectedness of their care-receiver: "She certainly misses the contact with friends. Maybe this [SONOPA]can support her with that" [IC 8]. In contrast, *mobility and support with daily activities* and *independence* were less prevalent drivers, in comparison with the first study.

With regard to the barriers towards acceptance, seven of the nine barriers were validated in the current study: privacy and intrusiveness (n=7), unfelt need for support (n=6), technology experience (n=6), reliability and trust (n=3), cost (n=2), and lack of human touch (n=1). Contextual limitations and resistance to change were not mentioned as a barrier towards acceptance in the second study. Similar to the first study *privacy and intrusiveness* were perceived as the most important barriers towards the acceptance of

SONOPA. Caregivers were concerned about intruding the lives of their care receiver when using SONOPA: “I think, as an informal caregiver, I would still feel awkward if I saw this and would interfere with it. Because who am I to tell her that she must move around” (IC 2) Another important barrier was the *unfelt need for support*. Most informal caregivers indicated that in their current situation, they would not need a technology like SONOPA: “With my mother’s state at the moment, I think, I don’t need that yet”. (IC 1). Furthermore, informal caregivers were worried about the *technology experience* of their care receiver: “That is a technology that she cannot master” (IC 6). Another barrier concerned the *reliability* of the technology. One-third of the informal caregivers had doubts about the reliable functioning of AAL technologies: “technology can break” (IC 6). Like in the first study, *pride* and *financial costs* were less prevalent barriers. Surprisingly, only one informal caregiver had concerns about the *lack of human touch* and that SONOPA could create more distance between care givers and care receivers. In the first study *lack of human touch* was one of the most important barriers. This could be explained by the fact that SONOPA encompasses several features for social connectedness and mutual social awareness.

4.4.2 Care receiver’s perception

Only two care receivers had an overall positive attitude towards SONOPA and AAL in general (CR 2, 3). One of these care receivers (CR3) already had lots of experience with digital aids due to her visual impairment. However, both participant did not feel the need to use a system like SONOPA at the moment but rather in the future, when their need for support would increase. Three care receivers had mixed attitudes towards the presented system (CR 5, 6, 9). These three participants could not imagine to use SONOPA at the moment but might be willing to use it sometime in the future. The other three care receivers were rather negative towards SONOPA and AAL in general and could not imagine to use these technologies (CR 1, 4, 7).

Similar to the caregivers, *peace of mind* (n = 4) and *safety* (n = 3) were the most prevalent benefits of SONOPA among the care receivers. Care receivers felt that the system could give them and their family members peace of mind and make them feel safer in their home: “A feeling that someone is looking after me” (CR 2). Another benefit mentioned by CR 2 and CR 3 was that a system like SONOPA could help them to age *independently* in their home environment. Two care receivers also indicated that SONOPA would be beneficial for people with *less social provision*: “I think that if people do not have the same ‘human possibilities’ in the sense of family that is involved... Yes, I can imagine that [...] they could be supported by this” [CR 1]. CR 3 liked SONOPA’s feature for *social connectedness*. The same participant

also thought that SONOPA could help caregivers to detect changes in someone’s *health* status early on. *Support with caregiver tasks* and *mobility and support with daily activities* was not mentioned as a benefit by the care receivers.

The most prevalent barrier among care receivers was the *unfelt need for support* (n = 8). Even the participants who had a positive attitude towards AAL, indicated to feel no need to use the system in their current situation. The second most prevalent barrier towards acceptance was *privacy and intrusiveness* (n = 7). Participants indicated that they felt uneasy about being constantly monitored and were afraid there care receivers would take too much control about their personal life: “If you have a sweet tooth, which I have... That they know: oh, my mother has eaten candy again. That’s nobody’s business.” (CR 3). Five care receivers were worried about their *technology experience* and wondered if they would be able to interact with SONOPA: “because my cognition keeps deteriorating and I will get less and less access to this” (CR 1). *Pride* was also a barrier that became apparent among two care receivers. *Contextual limitations, resistance to change, reliability, financial costs, and lack of human touch* were not mentioned by the care receivers in the current study.

4.4.3 Main similarities and differences between informal caregivers and care receivers

Comparing the results of the two participant groups, informal caregivers were more positive towards SONOPA than the care receivers. Almost half of the informal caregivers (n = 4) had a positive attitude towards the system, and almost all of them could imagine to use the system in their current situation (n = 3) or in the future (n = 5). In contrast, care receivers were more skeptical towards SONOPA, and only two of them had a positive attitude. Nobody could imagine to use the system in their current situation, and three care receivers did not want to use the system at all. Informal caregivers were still very critical towards the presented system, and privacy and intrusiveness, unfelt need for support, and the care receiver’s technology experience were the most prevalent barriers towards acceptance. Care receiver’s perceived the same barriers, although the unfelt need for support was more prevalent among the care receivers. Overall, informal caregivers mentioned some barriers that were not mentioned by the care receivers, such as reliability, financial costs and lack of human touch. Safety, peace of mind and support with caregiving tasks were perceived as the most important benefits of SONOPA by the informal caregivers. While safety and peace of mind was also recognized as a benefit by half of the care receivers, support for caregiving tasks was not mentioned by this participant group.

Overall, we can conclude that the majority of the care receivers did not see much value in a system like SONOPA

in their current situation. In contrast, most informal caregivers recognized the opportunities of a technology like SONOPA but were hesitant to use it because of the implied risks such as privacy invasion or the care receiver's lack of technology experience.

4.4.4 Influence of informal caregivers in decision-making

During the interviews we also wanted to learn more about the informal caregivers influence on care-related decision making. Similar to the first study, it became clear that the informal caregivers play an important role in care-related decisions. Informal caregivers are often the one's initiating the discussion about care measurements and also have a strong advisory role. Some informal caregivers might even take the decision for the care receiver: "They can be so stubborn at this age. Then I say well, mom, you cannot do those things anymore, so you have to" (IC 2). However, most 'couples' of informal caregivers and care receivers indicated that they would take care-related decisions together: "I think I would make an overview of the advantages and disadvantages and then together with my mother-in-law decide what do with it" (IC 4). Often more than one informal caregivers is involved in this decision making process: "It is not a decision made by me or my mother alone, that sort of things we decide together." (IC 7). Several care receiver's indicated to consider to use SONOPA, if their informal caregivers would ask them to: "Then we would discuss that, and if they really think that this is also easier for them then I would agree (CR4)."

5 Discussion and conclusion

The perception of the user is crucial to the successful implementation of AAL technologies. This paper highlights the perspective of an often underrepresented target group: the informal caregivers. The first study explored the perception and needs of 20 informal caregivers towards various AAL applications via semi-structured interviews. In a second study, these findings were validated with regard to our own prototype application called SONOPA. To investigate how informal caregivers differ in their perceptions from care receivers, 9 informal caregivers as well as 8 older adults were involved in this follow-up study. The results of these studies revealed several drivers and barriers, that are likely to influence the decision to accept or reject AAL technologies in the future. These aspect should be taken into account in the development and implementation of AAL.

In accordance with our expectations (Bass and Noelker 1987; Byrne et al. 2009; Greenhalgh et al. 2013), almost all informal caregivers in our sample were closely involved in care-related decisions. They were often the ones initiating

discussions about care-related issues, and their influence varied from careful phrased suggestion, to a strong advisory role, to making decisions for the care receiver. Several care receivers in our second study indicated that they would use AAL, if their informal caregivers would advise them to do so. This underlines the importance of involving more informal caregivers in AAL research and development.

The majority of informal caregivers in our first study had a positive overall opinion about AAL and only four participants were highly critical towards AAL. However, there were some differences between AAL applications. While the smart wheeled walker was most acceptable, informal caregivers were most skeptical towards the assistive robot. This could be explained by the fact that a wheeled walker is a familiar assistive tool, that was already used by most care receivers. The robot instead, is much more unfamiliar. The statements of the informal caregivers also revealed that the assistive robot is viewed as a replacement of their human care, while the wheeled walker is regarded as a supplement for support. Informal caregivers in the second study were a bit more skeptical than in the first study. Only half of them had an overall positive attitude towards SONOPA and only three of them indicated to want to use these technologies in their current care situation. The other informal caregivers had mixed attitudes. This could be explained by the fact that the SONOPA system included visuals sensors, which were also negatively perceived in the first study. For the future of AAL technologies, ambient sensors such as PIR sensors seem more promising as they are more likely to be accepted. The care receivers in our second study were even more skeptical towards SONOPA. Only two of them had an overall positive attitude. Most of them did not see much value in a system like SONOPA, as they were satisfied with their current care provision.

Safety was perceived as a major advantage of AAL technologies among informal caregivers in both studies. This is similar to previous studies among older adults (Demiris et al. 2004; Mahmood et al. 2008; van Hoof et al. 2011) and the perception of care receivers in our own study. The informal caregivers appreciated that AAL technologies could prevent accidents and immediately alert them in case of emergency. Clearly, the safety and well-being of the care receiver is a number one priority to caregivers. That is also reflected by the fact that more than half of the informal caregivers already used a push alarm system with the care receiver.

Peace of mind was another strong driver of AAL acceptance. Informal caregivers from both studies reported that AAL technologies would help them to check-in with the care receivers, feel less worried about their well-being and also take away some of their responsibility. Peace of mind was also an essential benefit for informal caregivers in the Digital Family Portrait studies and the CareNet Display project (Consolvo et al. 2004; Rowan and Mynatt

2005). As Bossen et al. (2013) suggest, family caregivers are emotionally invested in the care process and find it difficult to reach peace of mind. Therefore, they appreciate technologies which give them regular and detailed updates about the care receiver's well-being. The informal caregiver's peace of mind was also an important benefit to the care receiver.

Other, although less prevalent, drivers were the increased independence of the care receiver, mobility and support with daily activities, support with caregiving tasks, absence of social provision and social connectedness. All of these drivers were discussed by informal caregivers from both studies. The prevalence however differed across studies and seems to be dependent on the technology in question.

Privacy and intrusiveness was an important barrier for informal caregivers. The participants from both studies felt uncomfortable to 'spy' on the care receiver and have intimate information at their disposal. While results concerning privacy and intrusiveness are somewhat mixed with regard to older adults in previous studies (Beringer et al. 2011; Mahmood et al. 2008; Steele et al. 2009; van Hoof et al. 2011), the care receivers in the current study clearly felt uneasy about being monitored and were afraid their care receivers would take too much control about their personal life. To counter this feeling, AAL tools could grant care receivers control over what data points are shared and with whom, as suggested by Consolvo et al. (2004). However, too much control can also lead to a loss of safety. Hence, it is important for developers of AAL tools to find a careful balance between privacy and safety. Moreover, our study revealed that the AmI principles of embeddedness and seamless integration were not acceptable for some informal caregivers, when it comes to integrating sensors seamlessly on or within the body of the care receiver. Wearables which are embedded in textiles seem therefore more promising for the future of AAL.

Surprisingly, although informal caregivers reported on several problems with providing care, such as workload and the emotional burden, the majority indicated that they would not need any support in their current situation. This unfelt need for support was a strong barrier towards AAL acceptance in both studies and among both user groups. Klerk et al. (2015) found that informal caregivers often need support, but might be too ashamed or proud to ask for help. Therefore, developers should closely involve caregivers (not just older adults) during the design process of AAL tools and allow them to experience prototypes in everyday life. This user-centered approach could aid the caregivers' understanding of the benefits of AAL technologies over traditional assistive tools. Moreover, with the recent reforms of the European care systems and the resulting pressure on informal caregivers, it is likely that their need for support will increase in the near future.

Informal caregivers from both studies were worried about the technology experience of their care receivers. The participants emphasized that the care receivers have not grown up with technology and therefore might not be skilled enough or even willing to try to interact with AAL technologies. This was confirmed by the older adults in our second study, who were indeed worried about their technology skills. However, most informal caregivers were convinced that technology experience would not be a barrier for them as the next generation of care receivers. Nevertheless, the interaction with AAL technologies should be simple and easy to learn, with interfaces that are intuitive and clearly structured. Special training programs should be designed along with the AAL technologies to improve the care receiver's confidence in their skills.

Participants from the first study, expressed the strong concern that AAL technologies could reduce the human touch in care and create a distance between them and the care receivers. Schorch et al. (2016) suggest that experienced caregivers often view themselves as care-experts have difficulties entrusting the care tasks to somebody else. This seems especially true for technologies which are often perceived as 'cold' in contrast with 'warm human care' (Pols and Moser 2009). To combat this barrier, AAL developers should emphasize that AAL technologies could also improve the relationship between caregiver and care receiver by providing mutual social awareness, providing input for meaningful conversations and relieving task pressure so there is more time for psychosocial support (Consolvo et al. 2004; Cornejo et al. 2013; Lorenzen Huber et al. 2012). The SONOPA system provides several features that foster social connectedness and provide mutual social awareness between informal caregivers and their care receivers. In consequence, lack of human touch was only mentioned by a single informal caregiver and by none of the care receivers.

The results of these two studies should not be considered without taking into account several limitations. First, the results are based on two national samples. This could have affected the generalizability of our results. Second, visuals, use scenarios and videos provide a somewhat limited view on the advantages and disadvantages of AAL technologies. However, the focus of this study was to access drivers and barriers in a pre-adoption phase, rather than investigating actual usage. Despite its limitations, this study offers several interesting avenues for future research. First, given the fact that care tasks and the (subjective) task pressure can be highly diverse, future studies should compare different groups of informal caregivers [see caregiver roles by Consolvo et al. (2004) and other contextual factors: culture, age, personal innovativeness] and explore how these factors affect the perception of AAL technologies. Second, the two male informal caregivers in our studies were fairly positive towards AAL technologies. Although informal caregivers

are typical female, it would be interesting to focus more on the male perspective in future research. Third, we believe that our in-depths findings can be leveraged for quantitative approaches to further investigate the influence of the identified drivers and barriers towards AAL acceptance. Fourth, considering that our results describe perceptions in a pre-adoption phase, it would be interesting to investigate if and how the meaning of the found drivers and barriers change in a later acceptance stage when technologies are integrated in the everyday care practices.

Awaiting future research to address these issues, the current study provides interesting insights into a user group that is often overlooked: the informal caregivers. Our findings show that although informal caregivers recognize the opportunities of AAL technologies, they also have various concerns when it comes to AAL technologies. Considering, that our finding show that informal caregivers have a strong social influence on the care receivers' opinions and subsequently could have a positively influence on the decision to adopt AAL technologies, their attitudes, concerns and needs deserve more attention in the AAL community. We strongly suggest to designers and developers of AAL, that informal caregivers should be involved during the development and testing, even when they are not intended as primary users.

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