Privacy Perceptions in Ambient Assisted Living

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Abstract: Ambient Assisted Living (AAL) Technologies may help address the challenges that the ageing populations pose on the health care systems by supporting older adults in ageing-in-place, improving independence, and quality of care. Technology acceptance by the potential users and particularly privacy concerns are decisive obstacles to the widespread use of AAL. In order to examine privacy perceptions in detail, 86 participants (50% older than 50 years) evaluated AAL technologies and privacy concerns in a questionnaire approach. Additionally, with Maximum Difference Scaling the importance of AAL system characteristics to privacy perceptions by the users was investigated. Overall, the attitude towards AAL is positive, privacy concerns regarding the misuse of data, feeling of surveillance, and obtrusiveness of the technology are prevalent but not tremendous. Who has access to the data is by far the most important characteristic of an AAL system for the users' privacy. Prominence of the system, sensor location, and sensor types are least important. The results contribute an important understanding of how AAL technologies need to be designed to respect users privacy.

1 BACKGROUND

Ambient Assisted Living (AAL) technologies support older adults in 'ageing-in-place' (Peek et al., 2014). AAL shows the potential to help counteract the dramatic challenges that the ageing population poses on the health care systems. With improving the quality of health care and independence of older adults, health care costs, costs for institutionalisation, and the need for nursing personnel can be reduced (Yusif et al., 2016; Blackman et al., 2016). At the same time, most older adults desire to age in place and live as long as possible independently, in dignity, and with a high quality of life. Staying at home contributes to lasting well-being, independence, social participation, and healthy ageing (Mortenson et al., 2016).

For AAL, no universal and clear-cut definition exits (Blackman et al., 2016). AAL could best be translated as 'age-appropriate assistance systems for a healthy and independent life' (Strese et al., 2010). Under this umbrella term, concepts, products, services, and technologies are included that aim at enabling people with specific demands, e.g. people with disabilities or older adults, at all stages of their lives to live in their preferred environment longer and increase quality of life (Strese et al., 2010).

One tremendous challenge for healthcare systems as well as for caring families and relatives is the high proportion of people with dementia (Livingston et al., 2017). In Germany, 10% of people aged over 65 years suffered from dementia in 2016 (Deutsche Alzheimer Gesellschaft e.V., 2016). Family caregivers report a high level of care strain and show a high probability for depression (Jennings et al., 2016). AAL technologies can assist and monitor older adults in different stages of dementia and thereby improve quality of life, reduce care needs, and support caregivers (besides reducing active care effort also in feeling assured of the safety of the patient) (Dupuy et al., 2017). Examples are the monitoring of daily activities of living (e.g., getting up, meal preparation, and physical hygiene), applications for safety (e.g., automatic lighting when going to the bathroom at night, door sensors, and stoves that automatically switch off), for social participation (e.g., video telephone, information about social events), for health monitoring (e.g., monitoring of vital parameters, medication intake), and wayfinding (e.g., GPS tracking, orientation assistance) (Dupuy et al., 2017).

1.1 Technology Acceptance

Despite their promising potential and the ever-increasing range of products, the demand for and diffusion of AAL technologies is unexpectedly low (Hallewell Haslwanter and Fitzpatrick, 2016). The

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acceptance by potential users is a key factor for the use and diffusion of new technologies, but can also constitute a decisive barrier if the needs, desires, and individual demands of users are not understood (Legris et al., 2003; Ziefle and Wilkowska, 2010). The target group of AAL – older adults – is an important factor for acceptance. Age-related changes in the cognitive, psychomotor, and perceptive abilities of older adults may lead to difficulties in handling new technologies and the great individual differences in these ageing processes make older adults a very heterogeneous user group (Jakobs et al., 2008). In addition, generation-specific experiences with technology influence technology acceptance (Sackmann and Winkler, 2013). In general, a high willingness to use new technology can be observed with older adults, but new technologies are often adopted slower than in other age groups (Heart and Kalderon, 2013).

Many benefits and barriers for the acceptance of AAL technologies by the users have been identified in previous research (Peek et al., 2014). One decisive barrier are privacy concerns (Yusif et al., 2016). AAL technologies do naturally invade the home of users. The home is not only a roof over one's head, but a multi-faceted, valuable, and intimate place of living and retreat, which is of great relevance especially for the elderly (Mortenson et al., 2016). In addition, the use of various sensors as well as the analysis and transmission of sensitive and intimate data, on which many AAL technologies are based on, evoke privacy concerns.

1.2 Privacy Concerns in AAL

Privacy concerns arise when the actual level of privacy does not equal the desired level of privacy (Li, 2014). The desire for privacy depends largely on the context and the individual attitudes (Nissenbaum, 2010; Bergström, 2015). Many definitions of privacy put *informational privacy* into focus, the control over personal information (Westin, 1967). But in the context of AAL, other dimensions of privacy are also relevant (Courtney, 2008). AAL technologies may invade the *physical privacy* (limitation of access to the physical self), *social privacy* (control over social contacts, interaction, and communication), and *psychological privacy* (limitation of access to thoughts, feelings, and intimate information) (Burgoon, 1982). At the same time, AAL technologies digitise the access to the informational, physical, social, and psychological self and analyse and transmit data, so that information privacy becomes a possible part of the other privacy dimensions, expanding the audience and persistence of this information (Koops et al., 2017).

In AAL, privacy concerns often regard the feeling of permanent surveillance, fear of access to and about misuse of personal information by third parties, but also about the invasion of personal space, obtrusiveness, technical disturbances, and stigmatising design of the technologies (Kirchbuchner et al., 2015; Peek et al., 2014; Boise et al., 2013; Wilkowska and Ziefle, 2012). Privacy concerns are influenced by the perceived sensitivity of the collected information: Medical information, especially information about mental illnesses, are perceived as very sensitive (Valdez and Ziefle, 2018; Anderson and Agarwal, 2011), again increasing privacy concerns regarding AAL.

On the other hand, AAL technologies show great potential to support older adults and reduce the burden of family caregivers. For the decision whether to accept AAL technologies, privacy concerns and other barriers need to be weighted against the usefulness of the technology in the individual context (Courtney, 2008; Schomakers et al., 2018). Thus, privacy concerns may be overridden by the benefits and usefulness of the technology. For example, Boise and colleagues found in their study that users are very willing to be monitored as the usefulness surpasses privacy concerns (Boise et al., 2013).

Multiple user studies have identified privacy concerns as major barrier to AAL acceptance (Peek et al., 2014). But the question arises, what characteristics of the technology evoke these concerns and how AAL systems should be designed to protect the users' privacy. In a theoretical framework for personal health information disclosure management, Rashid and colleagues identify the intimacy of information (*what*), the data receiver (*who*), and the time granularity and complexity of the information (*how*) as important factors for information privacy in smart home healthcare (Rashid et al., 2007). Regarding the '*what*', also the activity sensitivity and type of sensors are important (Garg et al., 2014; Himmel and Ziefle, 2016). For AAL technologies, additionally the placement of the sensors in the different rooms of the living space (*where*) needs to be considered (Kirchbuchner et al., 2015; Himmel and Ziefle, 2016). As privacy is essentially based on control, control over the technology – e.g., being able to switch functions off – is another important condition for the perception of privacy (van Heek et al., 2017).

1.3 Focus and Aim of the Study

The aim of this research is to understand privacy concerns in AAL and to empirically study how the characteristics of AAL technologies and systems influence privacy perceptions. What, how, who, where,

and specific characteristics of the AAL system are important for the privacy perception of the users, but which of it is the most important? This study adds on to previous studies that have identified important concerns and system attributes that influence privacy perceptions. In qualitative studies and questionnaires using traditional rating scales, all these characteristics evolve as important. In this study, concerns and system characteristics regarding privacy are weighted in comparison to another to discern the most important factors. Using a Maximum Difference Scaling (MaxDiff) approach, the discrimination between the factors is in focus to answer the question which system characteristics are most important.

2 METHODOLOGICAL APPROACH

To examine privacy concerns and how system characteristics affect the perception of privacy by the users, a questionnaire approach with Maximum Difference Scaling (MaxDiff) tasks was chosen. Beforehand, three focus group sessions were conducted as prestudy, in which the participants discussed barriers and benefits of AAL in general, as well as their concerns regarding privacy in AAL settings in detail (for details see (Schomakers and Ziefle, 2019)). Based on their statements and the preliminary literature study, the questionnaire items were chosen.

2.1 The Questionnaire

The questionnaire consisted of four parts. In the first part, demographic data (age, gender, education level) and experiences with caring (4 items, e.g., "I experienced that a close relative was in need for care") were assessed. The second part started with introducing AAL to the participants. A range of technologies tailored for older adults living alone with dementia – including smart oven, medication reminders, location tracking, and emergency detection – were introduced with short descriptions and visualisations. The explanation ended with the information that different sensors are used for AAL technology (with examples), that the data may be accessed by different stakeholders (with examples), and in different modalities, e.g., only in emergency or as daily summary. After reading the technology description, the participants evaluated the benefits and usefulness of AAL technologies on a semantic differential scale (items in Figure 2). In the third part of the questionnaire, the participants evaluated five concerns regarding privacy when using AAL (items in cf. Figure 3). All items were evaluated on 6-point scales. The last part of the questionnaire consisted of the MaxDiff tasks. In an introduction, the task of choosing the most and the least important was explained in detail. In the next section, the MaxDiff tasks are presented.

2.2 Maximum Difference Scaling

Maximum Difference Scaling, also referred to as 'best worst scaling', is a method to obtain preference scores for multiple attributes. In contrast to rating scales, it shows greater discrimination among the items and their relative importance (Sawtooth, 2008). That is, when asking participants, what is important to them regarding privacy in AAL, all items are somehow important. In MaxDiff, the participants have to choose the most and least important items out of a set of attributes. Also, response-biases, like e.g., the acquiescence bias, extreme responding, or social desirability, are eliminated while ratio-scaled results are obtained. Especially for AAL MaxDiff is interesting, as the task to choose best and worst out of a few items is easier to use for participants than e.g., the ranking of multiple items or a choice-based conjoint were participants have to consider several attributes with differing levels (Sawtooth, 2008). Thus, the cognitive effort for answering is lower and the method is suitable for older participants.

In total, nine system characteristics were evaluated for their importance for the participant's privacy when using an AAL system (cf. Table 1). For this questionnaire, the comprehensibility and ease of use for the participants was foreground. Therefore, the attributes were presented in simple language. Also, we used examples and symbols for better comprehensibility of the attributes. An experimental design was chosen, in which the participants were presented with four system characteristics each time (cf. Figure 1) and six of these choice tasks were conducted in order not to fatigue the participants. Six different questionnaire versions were produced. All in all, the frequency and positional balance of the experimental design was optimal (each item appeared 16 times and appeared four times as first and four times as last in the presented list). The orthogonality of the design was not optimal, but satisfactory (each items was paired with the other items between five and seven times).

2.3 The Statistical Analysis

The MaxDiff is analysed using hierarchical Bayes estimation to compute individual-level weights (multinomial logit). The resulting probabilities range from

Table 1: Instructions of the technology characteristics in the questionnaire for the MaxDiff tasks.

factor	instruction in the questionnaire
data recipients	 who can view the data
automatic decisions	whether emergency calls can be made **automatically** by the system
data granularity	 how data can be accessed (e.g. live data, summaries only)
controllability	 options to switch the system or functions off
monitored activities	which activities are monitored (e.g., falls, position, medication)
prominence	prominence of the system
sensor types	 which types of sensors are used
sensor location	 where sensors are installed
reliability	reliability of the technology (e.g., no false alarms)

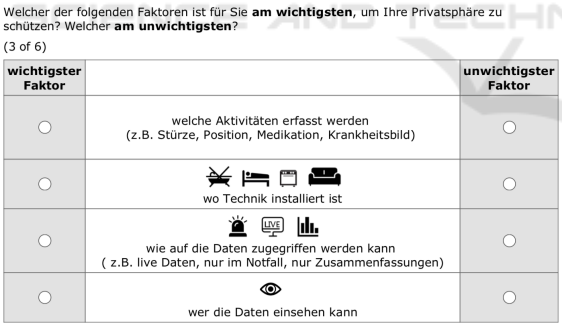

Figure 1: Examplary MaxDiff tasks with ”most important” option to the left and ”least important” option to the right.

1 to 100 and are ratio-scaled. Thus, an item with a score of 20 is twice as preferred as an item with a score of 10. Still, these relevance scores are relative as they result in a comparison to the other attributes. No absolute evaluation of their importance results from the MaxDiff analysis. Additionally, the results of the counts analysis are reported, which present the proportion that an item was chosen best, or worst, respectively, when it was included in the presented set of items (Orme, 2009).

3 THE SAMPLE

The questionnaire was distributed online and in paper-and-pencil form to the participants, who were recruited with a snowball sampling from the authors' social contacts as well as online discussion forums for older adults with dementia and their informal caregivers. The aim of this sampling method was to reach a wide range of participants with experience with care and dementia and from different sociodemographic groups. A scenario-based approach was used to account for the sample of users not living with dementia. 125 participants started the questionnaire, of which n = 86 (68.8%) completed it. The participants were between 19 and 88 years old ($M = 46.75, SD = 20.3$), with 50% older than 50 years, and 58.8% women. All levels of education were present in the sample (compulsory basic secondary schooling: 4%, secondary education: 13%, apprenticeship: 26%, university entrance diploma: 50%, university degree: 6%; no diploma: 1%). All participants are from Germany or Austria. Regarding the participants experiences with elderly care, 20.9% have already nursed an elderly relative, 92% of the participants have experienced that a close relative was in need for care, and 73.2% state that they have experienced “how dementia affects the lives of the patients and their relatives”.

4 RESULTS

4.1 General Evaluation

In Figure 2, the mean evaluations of the benefits and use intentions are depicted. In general, the system was evaluated positively. AAL technologies are perceived as useful ($M = 0.50, SD = 0.55, min = -1, max = 1$), beneficial ($M = 0.42, SD = 0.52$), relieving ($M = 0.44, SD = 0.51$), and comfortable ($M = 0.29, SD = 0.51$). The only attribute that the participants do not agree to is that the system ‘brings them closer to people’ ($M = -0.06, SD = 0.58$). In line with the positive benefit evaluation, the use intention is generally high ($M = 0.38, SD = .44, min = -1, max = 1$). 84.8% of the participants reported a (rather) positive attitude towards the potential use of an AAL system in case of dementia.

4.2 Privacy Concerns

The participants rated five concerns regarding their privacy, that have been mentioned in preliminary focus group sessions. Misuse of data is the most prevalent concern for the participants 3, but is only rather

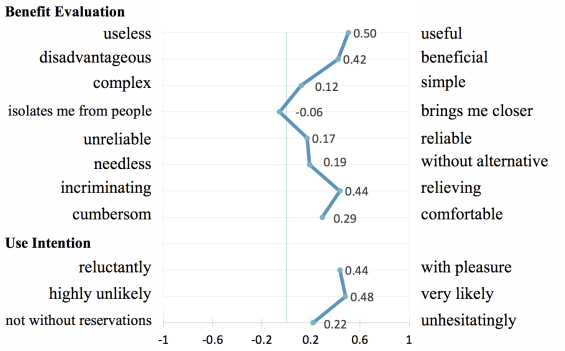

Figure 2: Benefit evaluation and use intention, n = 86.

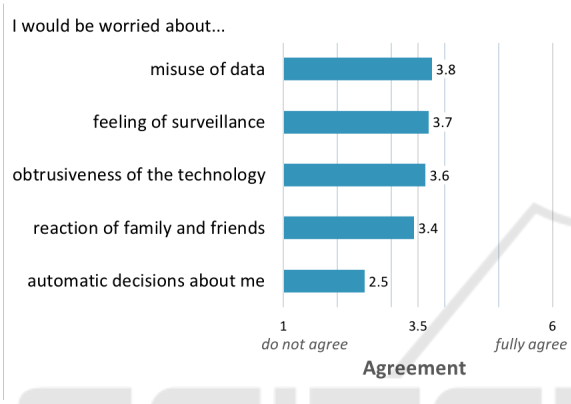

Figure 3: Mean rating of the concerns, n = 86.

agreed on ($M = 3.76, SD = 1.4, min = 1, max = 6$). Feelings of surveillance ($M = 3.7, SD = 1.3$) and obtrusiveness of the technology ($M = 3.64, SD = 1.3$) are additional concerns, that the participants rather agree on. That they are worried about reaction of family and friends is slightly denied ($M = 3.43, SD = 1.3$). Concerns about automatic decisions that the system makes about the users are rejected ($M = 2.51, SD = 1.2$). The perception of privacy concerns is moderately correlated with the disposition to value privacy ($r = .57, p < .01$), but not to the other user factors.

4.3 MaxDiff

In MaxDiff tasks, the participants were presented with four out of nine system characteristics and evaluated which is the most and which is the least important for their privacy when using an AAL system. Figure 4 shows the resulting relevance scores from the hierarchical Bayes analysis.

By far the most important system characteristic for ones privacy is who has access to the data (data recipient: 21.0). Least important is the prominence of the technology (1.3) followed by the sensor location (4.8) and the sensor types (7.1). The results indicate that the control over the data recipients (21.0) is three times as important as are the type of sensors used (7.1). What is monitored by these sensors (monitored activities: 13.4) is than again almost double as important as the type of sensor itself.

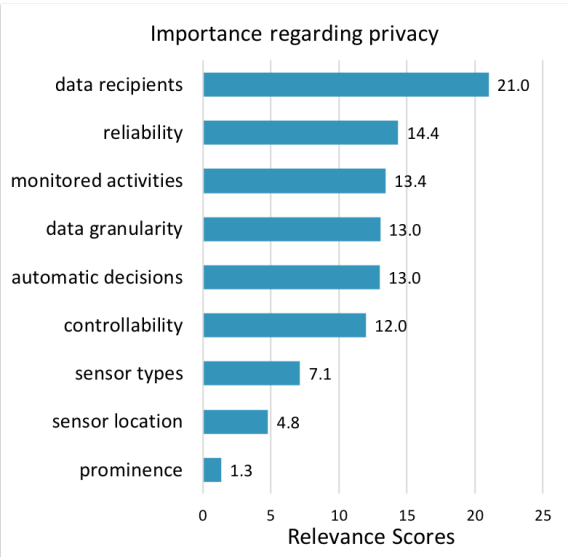

Figure 4: Relevance of the system characteristics for the users' privacy, n = 86.

Reliability, monitored activities, data granularity, automatic decisions, and controllability are on average quite similarly important to the participants. Examining the counts analysis (cf., Figure 5), we see that here the participants strongly differ in their evaluation. These medium important five attributes are almost as often selected as least important as they are selected as most important.

The count analysis mirrors the results of the hierarchical Bayes analysis: especially prominence has been often (66% of times shown) selected as least important. Who has access to the data (data recipients) was more than half of the times selected as most important, again stressing its relevance.

5 DISCUSSION & CONCLUSION

Privacy concerns represent one decisive obstacle to the acceptance of AAL technologies by the potential users, and correspondingly, to their widespread use (Peek et al., 2014; Yusif et al., 2016). In this study, privacy concerns regarding AAL technologies were examined in detail. In focus lies the research question how characteristics of AAL technologies and systems influence privacy perceptions. The relevance of these characteristics is weighted using a Maximum Difference Scaling (MaxDiff) approach. For that, 86 partic-

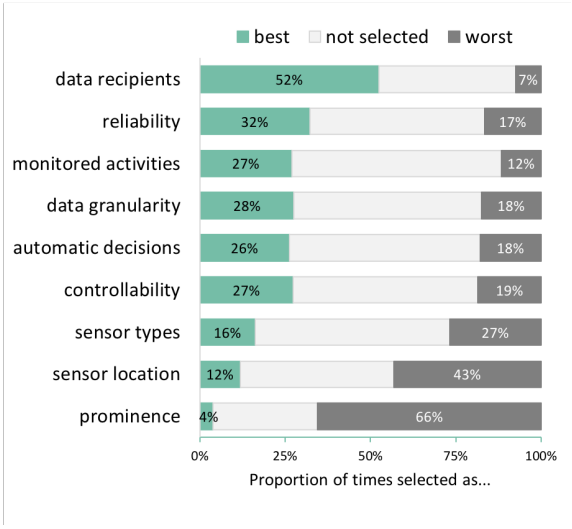

Figure 5: Proportion of characteristics being selected as best, worst, or not selected from the times shown, n = 86.

ipants of all age groups evaluated AAL technologies in a paper-and-pencil or online questionnaire.

The most prevalent privacy concern is the misuse of data, but also concerns about feelings of surveillance and obtrusiveness of the technology exist. The only concern that is clearly denied by the participants is that they worry about automatic decisions the AAL technologies make about them.

The results of the MaxDiff analysis show clearly that the data recipient (who has access to the data) is the most important system characteristic regarding privacy. Users want to decide who they entrust their data. Additional important influences constitute the sensitivity of the data which is monitored and accessed (monitored activities, data granularity), thus corresponding to the concern of data misuse. But also the obtrusiveness within the home environment (reliability), psychological privacy (automatic decisions), and control over the system as a whole are important, revealing that a sole focus on informational privacy is too limiting regarding AAL.

The core element of privacy is control. Users want to decide on their own *what* data is analysed and to *whom* it is transmitted and *how*. Therefore, they should be given the choice to whom data and emergency calls are transmitted as well as in what granularity and which data. As users trade off the usefulness of a technology and also of single functions with the perceived (privacy) barriers – the privacy calculus – it is important to provide them with control over the technology so that they can choose which functions to use in what way. Particularly, it has been shown that the need for technological support is an important counterweight to concerns (Peek et al., 2014). This suggests that 'modular' AAL systems should be developed, in which functions may be switched off until the user decides that this function is now needed. In this case, the increased need for the technology and the corresponding higher usefulness would after some time override privacy concerns when ageing processes advance. Modular AAL technologies show the additional advantage that the users can get used to the technology and the interaction with it before ageing process increase difficulties in interacting with and learning of new devices.

Our results indicate to another important aspect: privacy perceptions are individual. User diversity adds another layer of complexity for the acceptance of AAL. More research is needed to identify user groups that show similar attitudes towards AAL, e.g., similar privacy preferences, perception of usefulness, need for technology, abilities in interacting with technologies. Technology should be developed that is adapted to the specific needs of each user groups. Here again, modular AAL systems can be a useful approach. Users should be able to pick those functions and interaction options they prefer.

That the data recipient has the strongest influence on the privacy perception is only the first step to comprehend privacy attitudes in AAL. Next, it is important to examine which data recipients are most accepted, and the same for the levels of the other important system attributes, e.g., which monitored activities are accepted, which data granularity is accepted. Here, the question arises, whether these can be examined separately or whether they should again be examined in combination with each other, e.g., in conjoint approaches. Maybe, the accepted level of data granularity differ dependent on the data recipient and what activities are monitored. Conjoint analysis would offer the opportunity to study a limited number of attributes in cohesion, illustrating the trade-offs between these factors. Correspondingly, the result would be more realistic and thus valid in contrast to approaches evaluating each attribute in separation.

Moreover, also privacy perception should not be examined only separately, but the trade-offs between usefulness, need for technology, and privacy concerns are important (Peek et al., 2014). For example, it could be that the data recipient which is seen as most critical can contribute the most effective help in emergency. The user may still decide to disclose the data to this recipient because the usefulness of the data disclosure outweighs the privacy concerns. These trade-offs and the privacy calculus is important in explaining user decisions and behaviours.

Despite the interesting insights into privacy preferences by potential users of AAL, some methodolog-

ical limitations have to be considered when discussing our results. The sample was quite small, especially to examine influences of user factors on the attitudes and perceptions. With a larger sample, cluster analysis approaches could provide more insights into user group specific preferences for privacy. That the sample included people of all ages can at the same time be seen as strength and weakness. On the one hand, it allowed for the analysis of age effects, but on the other hand, AAL technologies are targeted to older adults and their specific needs so that evaluations by younger adults are of limited relevance and validity. Solely *empathising with* the situation and needs of older adults is not the same as *being* in this situation.

A drawback of the questionnaire approach is the missing hands-on experience with the presented technologies. In spite of all attempts to provide a most comprehensible technology presentation, the participants had only limited information about the AAL technologies and no option to ask questions.

The questionnaire was distributed in Germany, correspondingly providing only a German view on privacy perceptions. Previous studies have shown that attitudes towards AAL as well as privacy perceptions are culturally biased (Alagöz et al., 2011; Krasnova and Veltri, 2010). On social network sites, Germans have been shown to expect more damage and perceive higher risks for their privacy than Americans (Krasnova and Veltri, 2010). In contrast, in a comparison of the attitudes towards AAL between Turkish, Polish, and German participants, Germans showed the lowest level of concern (Alagöz et al., 2011). Demographic developments challenge not only the German health care system and society, correspondingly AAL technology acceptance should be studied in other cultures as well.

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