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Ethical Literature Review

Dementia Ambient Care: Multi-Sensing Monitoring for Intelligent Remote Management and Decision Support

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Abstract (for dissemination)		Ambient assisted living technologies can provide assistance and support to vulnerable persons, including those who suffer from dementia and mild cognitive impairment. They might allow them the possibility of living at home for longer whilst maintaining their comfort and security. However, the introduction of AAL technologies also triggers serious ethical issues regarding their usage. This report is a systematic literature review of the on-going scholarly debate about these issues. More specifically, we look at the question of what are the ethical issues involved in the various stages of research and development, clinical experimentation, and clinical application of AAL technologies for people with dementia and related stakeholders? In the discussion we focus on: 1) values of the goals of AAL, 2) the balance between cost-effectiveness and quality assessment in R&D of AAL, 3) the question of responsibility of AAL, and finally 4) the complex question of informed consent for the usage of AAL.

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Executive Summary

The aim of this report is to present a systematic review of existing literature on the ethical aspects relevant to Dem@Care.

The Introduction presents global trends in population ageing and states the necessity of Ambient Assisted Living Technologies (AAL). We include works mostly relevant to AAL since the technologies used (e.g. continuous monitoring) and the ethical issues arising are similar with the ones that Dem@Care aims to employ for diagnosis and assessment of dementia at home. The literature for AAL is also much more extensive.

A question is addressed regarding the ethical issues involved in the various stages of research and development, clinical experimentation, and clinical application of AAL technologies for people with dementia and related stakeholders.

Methodology section presents the information source and the process for the collection of this information while the Results concentrates on ethical issues, challenges and opportunities in the case of various stakeholders (e.g. PwD, caregivers, MDs, clinicians, software/hardware engineers, designers, technicians) during the R&D, design, clinical trials and clinical applications processes.

Other ethical challenges are addressed in the Discussion. These include the value of the goals of AAL, the justifiable balance of cost-effectiveness and a quality-centred R&D procedure, the various levels of responsibilities for the AAL, and the complex issue of informed consent from PwD using AAL.

In Appendix A1 a table with Ethical Issues Mentioned in the Literature can be found. A figure in Appendix A2 shows the Chronological development of the scholarly debate, while a list of relevant articles from Data Base research is available in Appendix A3

Abbreviations and Acronyms

AAL	Ambient Assisted Living
AmI	Ambient Intelligence
PwD	Person(s) with Dementia
AD	Alzheimer's Disease
ICT	Information and Communication Technology
RF	Radio-Frequency
MD	Medical Doctor
R&D	Research & Development

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1 Introduction

1.1 Ageing of the World Population

An estimation of contemporary demographics emphasizes that developed societies are seeing an increasing number of elderly people in their populations. Due to increased life-expectancies and a falling birth rate, the age distribution in developed countries is gradually shifting towards older populations. Even though the population on our planet is still increasing overall, the birth rate in various countries has decreased to such a level that it has become impossible for them to maintain the size of their population.

One of the first nations confronted with this trend was Japan. Its demographics already demonstrate a high proportion of over-60 year olds, a result of repeated baby booms after the World War 2. While in 1950, Japan's population pyramid was a standard size, by 2010 23% of its population was older than 60 years old, and within the next 40 years, this number is predicted to almost double to 39% [1]. Europe is going through a similar process. Whilst in 1960, an average ratio of three young people to one elderly person existed, it is predicted that there will be more than two elderly people to one young person by 2060. The country with the highest median age, of 36, was Sweden, during most part of the 20th century. This leadership was overtaken in the 1990s by Italy. It is expected that in the next 30 years, Germany will become oldest country in Europe, which will then be superseded by Latvia and Romania by the year 2040, at which time, Sweden will have become one of the countries with the lowest median age. By 2060, the average population proportion of the "oldest-old" elderly persons, aged over 80, in Europe will be about 10%, compared to the 1–2% at the beginning of the 20th century [2].

From the World Population Prospects of the United Nations figures, revised in 2006, it is obvious that none of the countries in the world will avoid the consequences of the ageing population, in the following 50 years. By 2050, all developed countries, together with Latin America, the Caribbean, and most of Asia including China, are expected to have a median age of around 40 years. Most African countries will still have a median age of 30 years by 2050 compared to 25 at the moment [3].

1.2 Emergence of Ambient Assisted Living Technologies

These facts about a growing elderly proportion of the population necessitate a better and more effective health care system and technologies. One of the most common co-morbidities of elderly people is dementia, which is diagnosed by a set of progressive symptoms (*aphasia* – loss of language function, *apraxia* – loss of the ability to perform intentional movements,

agnosia – loss of the ability to recognize objects, and problems with abstract thinking and complex behaviour). The most common form of dementia is Alzheimer's disease (AD). In the early stages, a person with dementia (PwD) needs memory support, regular daily activities and social contacts. In the mild stage of the disease, special medication and medical care becomes necessary. This care and management continues and is progressively more demanding as the disease progresses until it reaches the most severe stages. The care and management is therefore multi-faceted, with special efforts aimed at prevention, enablement and treatment. The extensiveness of the disease means that there are a variety of claims that need to be recognised and which can often only be fulfilled at significant economical, personal, organisational, social and managerial sacrifices. An important disquieting fact regarding dementia is its prevalence amongst growing numbers of elderly people, which leads to ever-increasing societal costs required to manage it.

Using the latest technology, ambient assisted living (AAL) technologies try to provide PwD with the means to actively live their daily lives, protect their dignity, feel safe, maintain their capacities, sustain their integration with their communities, and help their care-givers in monitoring and preventing avoidable complications in consecutive treatment. Its major goal is the support and provision of necessary data for effective care and management at a more affordable cost than that at present. Despite the high hopes invested in AAL technologies, its research is still at an early stage. Very few clinical trials have been completed so far and there are still many research projects underway.[1]

While Dem@Care also aims at diagnosis and assessment employing technologies at home, in this report we include works mostly relevant to AAL since the technologies used (e.g. continuous monitoring) and the ethical issues arising are similar and there is much more extensive literature for AAL.

It has to be mentioned that the ethical analysis is supported by actual EU legislation[2], national legislation[3] and also by the Helsinki Declaration, accepted by all the EU states.[4]

1.3 Research Question

[1] Among these are namely *Easyline+* (with its EDUCATID – *e*thically *d*riven, *u*ser-*c*entered *a*pproach *t*o *i*nterface *d*evelopment)[6], *MINAmI* (FP6 European Union Research Project), *MIMOSA*, *UAS-SCOTTY*, and *SWEET-HOME* project.

[2] The most cited document in this topic is the European Data Protection legislation (directive 95/46/EC), mentioned by [7]. The Directive 2000/31/EC of the European Parliament and of the Council (8 June 2000) on certain legal aspects of information society services, electronic commerce is also mentioned also by [7].

[3] Such as the German Constitutional Court in Census Act Case about the right of the individual to self-determination mentioned by [7], or the Dutch Exceptional Medical Expenses Act for the right to nursing home care (AWBZ in Dutch; EMEA) [8].

[4] Accessible from http://whqlibdoc.who.int/euro/1994-97/EUR_ICP_CEH_212.pdf

Responsible development of AAL technologies demands substantial analysis of the ethical issues, which might occur during research and development, as well as during clinical trials and any further clinical application [4, 5]. During these various stages of development, different claims and interests emerge from different stakeholders. Therefore, the question we would like to address with this analysis of the available literature is: what are the ethical issues involved in the various stages of research and development, clinical experimentation, and clinical application of AAL technologies for people with dementia and related stakeholders?

2 Methodology

For the literature review we used the following available medical and computer science publication databases: Web of Science (Web of Knowledge), SpringerLink, and Scirus (Elsevier). The search was undertaken using a combination of the terms *"ambient intelligence" AND "ethic"*. The search was adjusted according to the manuals of the particular database searches and filters (using wildcards, regular expressions, etc.), which varied.

After the initial search, the articles were sorted, according to their relevance to Dem@Care and this deliverable objective, based on their title and short abstract. The selected articles, for the literature review, were restricted to the languages of English and German. Potentially relevant articles, judged by their titles, were excluded if the abstracts were not available. Articles focusing on very general and broad topics of *technology* and *ethics* not directly connected to the issue of AAL technologies, smart homes, elderly persons, etc. were excluded as well. The search in the aforementioned databases (Web of Science, SpringerLink and Scirus) gave 300 results, of which 42 articles were ranked as relevant, based on their titles and the content of their abstracts. Seven of these articles were duplicates leaving us with 35 sources.

3 Results

According to the literature, the term Assisted Technologies can be used for anything, which assists persons with their disabilities.[9] One of the categories of assistive technologies is ambient intelligence, which involves intelligent, pervasive and ubiquitous computing. While the pervasive attribute usually means an information and communication technology (ICT) "everywhere, for everyone, at all times", the attribute ubiquitous – the term introduced originally by Weiser in [10] – covers the invisibility and disappearance-into-background of the technology[11], and partly also its uncontrollability [7]. One of the attributes of these ICT is their integration into everyday objects [7]. Ambient intelligence can be defined [11] as a technology which

> "*... refers to the presence of a digital environment that is sensitive, adaptive and responsive to the presence of people. Within a home environment, ambient intelligence will improve the quality of life of people by creating the desired atmosphere and functionality via intelligent, personalized inter-connected systems and services. Ambient intelligence can be characterized by the following basic elements: ubiquity, transparency, and intelligence. Ubiquity refers to a situation in which we are surrounded by a multitude of interconnected embedded systems.*"

Hoffmann calls the usage of ambient intelligence for actual help in everyday-tasks a welfare technology [12]. Its aim is to provide better and more specific care, reduce risks and therefore increase safety, making it possible for the vulnerable to increase their ability to cope and self-determination, as well as to stay at home for longer before being institutionalized [12].

However, the usage of ambient technologies in the case of PwD raises certain ethical issues. These are here presented from the point of view of the stakeholders: the PwD, caregivers (nurses, proxies), (medical) researchers and clinicians (MDs), (software/hardware) engineers, designers, and technicians. For all these stakeholders we have listed the most important ethical issues that occur in three different stages of the technology: research and development, clinical trials, and clinical application. The complete set of ethical issues mentioned in the literature is presented in Table 1. Figure 2 in Appendix A2 charts the chronological development of the scholarly debate. Appendix A3 lists the results of the database search marked as relevant articles.

3.1 Persons with Dementia

Research and development: Francis points out that a new technology might be rejected and abandoned by its possible users, when they have not been directly involved in the research and development process from the very beginning [9]. Persons with mild cognitive impairment have special needs and requirements, which may not be immediately apparent to the developers and researchers. These need to be understood when developing and designing an assisted technology. Fairclough in [13] recommends the use of a 'titration' approach, developed by Wilson and Russel, which employs subjective self-reports to standardize the various experiences of participants, for a more objective and scientific evaluation. Moreover, Francis in [9] also proposes the recommendations of the TASC (The Autism Simplex Collection, 1998) project, which involves using visual communication tools for less-verbal users during the interview questions, thus helping to introduce these participants actively into the process of R&D, without recourse to using abstract and complicated concepts.

Clinical trials: During the clinical trial period, the vulnerability of PwD could raise certain questions regarding informed consent. The hi-tech nature of the AAL technology may make it difficult for the PwD to fully understand what their consent is being sought for. Also, the ambient functioning of the AAL technology in the private home of the PwD may mean that additional informed consent would be needed from co-habitants. Moreover, the PwD could become dependent on the AAL technology to such an extent that it reduces their autonomy and could infringe the validity of their informed consent [12]. Furthermore, one of the major fears of the participants (PwD), when dealing with ambient technologies, is the possible lack of control (e.g. what to do if there is a false alarm and how can the falsity of the alarm be confirmed?)[8], which they would have to cope with, when employing these assisted tools.[10] One of the major positives of ambient assisted technologies for PwD is their ability to prevent certain harms (i.e. accidental falls), which can reduce anxiety [12]. However, Kosta in [7] emphasises the fear about the laboratorization of the home and his aspect is supported support by van Hoof in [8] when he uses the expression of the "medicalization of home" by the introduction of new technologies. During clinical trials, certain users reported fears about these technologies having a 'life of their own'. There is a risk that users might find the technologies obtrusive [10]. The researchers should bear in mind that a person with mild physical or cognitive impairment would prefer using voice commands to touchscreen control of the devices [10]. Also, Duquenoy points out in [11] that during a trial the participants have to be protected against information overload. Not following these recommendations could result in unnecessary resistance and anxiety from the participants[9].

Clinical application: Almost every publication emphasises the benefits of ageing at home instead of in an institution: i.e. more privacy, integrity and dignity. This is directly in line with Dem@Care main objectives, which aim to provide support mainly at home settings. However, certain authors are sceptical whether the actual autonomy of the PwD is really increased through AAL technologies. After all, enhanced dependence on ICT might result in greater inactivity instead of real independence [6, 10, 12]. Moreover, dependence on technology should automatically incorporate a certain amount of trust [7] and confidentiality in these systems, despite potential problems e.g. regular false alarm warnings, incorrect notifications

or even failures of the technology [8]. In addition, sensors, battery-driven devices, and external devices should not cause problems for the mobility of their users [14], either when worn or when installed in their homes. This relates mostly to Dem@Care WP3 and WP4 being responsible for gathering through various sensors and analysing the monitoring data. Although ageing at home could have a positive impact on PwD, especially when counter-balancing the negative aspects of institutionalization (especially in the case of couples, who are used to living together and have done so autonomously and privately for decades)[8], the use of assisted technology may also bring the danger of embarrassment [15] caused by their diagnosis as a PwD, which may then be followed by a feeling of stigmatization caused by the need to use an AAL system at home [8]. This is of significant importance for Dem@Care since diagnosis and assessment are part of the objectives. Partners are aware and are working with organizations against stigmatization and related social phenomena. AAL technologies evoked resistance in certain persons with mild cognitive impairment because of their "handicapped-look" design.[9] Assisted technologies could raise security issues due to risks of surveillance [7]. Hofmann, discussing general (positive) surveillance during monitoring, asks whether normal daily activities can even be satisfactorily defined for welfare technologies at all? [12]. Kosta asks whether the use of AAL technologies promote social exclusion, rather than inclusion. Francis points out that the use of technology for persons with autism/Asperger's syndrome, to enable them to communicate better and therefore seemingly promote their social inclusion, can actually enforce their social exclusion by causing more intense anxiety in specific situations [9]. The literature calls such social exclusion caused by technology between users of ICT and non-users, the digital divide, which, according to Francis, could be comparable to the situation of persons excluded from the ICT design cycles [9,12]. Francis also mentions that according to Katz, the prevalence of technology for certain people can cause a feeling of alienation [9].

3.2 Caregivers (nurses, proxies)

Research and development: The basic interest for caregivers in the development of AAL lies in the possibility of continuous monitoring of PwD [14]. An important question here is whether AAL mainly benefits PwD or the caregivers [12]. Hofmann points out that whilst many papers mention benefits for PwD, empirical evidence from documented studies that would substantiate these claims is missing [12].

Clinical trials: According to Fairclough, during clinical trials, the caregivers can, together with the PwD, benefit from the so-called reciprocal accountability regarding the AAL technologies, the 'open-source' relationship between them and the technology in general. This mainly means that the user has, in fact, the right to know what data are collected about him or her; to have access to that data if required; to have to give his or her implicit/explicit prior consent; and finally, to have, at least, some benefit from the system that requires that the data be collected [13].

Clinical application: Caregivers, especially proxies, tend to welcome allowing PwD to remain at home, and so, oppose the institutionalization of these persons, e.g. help couples to live their lives together for longer at home, even with a mild-dementia diagnosis. However, Hofmann questions in [12] who is responsible and liable for any possible misuse of the technology in the home setting, both ethically and legally? He also stresses the possible risk of the problems that excessive automation can bring to patient, due to lack of direct contact with a human caregiver. Values such as hope, coping, vulnerability, dignity, meaningfulness or proximity, are essential core aspects of care-giving activity [12] and cannot be yet meaningfully exchanged with technologies.

3.3 (Medical) Researchers and Clinicians (MDs)

Research and development: The interest clinicians and medical researchers have in AAL is basically the same as that of the caregivers, namely, the continuous monitoring of the PwD. Nevertheless, Duquenoy in [11] emphasizes the more holistic approach taken by the clinicians and medical researchers in assuring that the real challenges and opportunities provided by assisted technology are met. This view can be extremely beneficial for all the stakeholders, especially during the research and development process. With a holistic and human-centred approach, all the processes of introducing and maintaining the ambient assistive technologies could be made more stress-less, goal-orientated and successful, while also avoiding the dangers of technical/technology-based and economic biases.

Clinical trials: During the clinical trials, an important aspect for medical researchers and the Dem@Care project is the meaningfulness of the gathered data, both from a scientific and a medical point of view, in order to be able to translate it into a valid knowledge. These data have to be prioritized, according to their relevance, importance and urgency [14]. With tracking technology, the reduction of fear and insecurity, and an increase in safety has been documented [12]. These findings should always be promoted by clinicians during the trials.

Clinical application: The clinical application of the AAL technologies should incorporate two considerations: a) a human-centred approach (instead of a technology-centred approach) [7], which implies, for example, that not only the health- and security-orientation of an ambient system be considered but also, that the satisfaction of the need for comfort of the PwD and of their special needs as persons living in their homes be taken into account, etc., and b) a consideration of whether a PwD really needs Assisted Technology [12].

3.4 (Software/Hardware) Engineers

Research and development: It is imperative for engineers and designers of AAL technologies to involve persons with mild cognitive impairment in the customization and co-design of these assisted technologies [9]. In addition, all the literature mentions the necessity of providing strong data security, as stipulated by both international and national legislation. Kumar in [15] stresses the importance of protection against Denial of Service (DoS) attacks on the whole system because of their potentially tragic consequences and harm. Moreover, the Quality of Service (QoS) should be evaluated together with the security of the system.. However, the installation of assisted technologies should not reduce the mobility of their users [14]. This also holds for implantable sensors, which should not overheat and harm their user [14]. During the research and development [17] engineers should be aware or be warned by other stakeholders about certain tasks, which are not suitable for ICT solutions (e.g. either physical service: lifting, turning, monitoring; or caring and emotional labour: conversations, social interactions, sympathy, emotional support, etc.). The danger regarding AAL technologies as "quick and easy fixes" to the grave psycho-social and societal problems is still present [12]. Moreover, the development of technologies for the elderly is seen by researchers as a low-prestige endeavour (compared to technologies for certain set of health-care domain, e.g. diabetic insulin pumps, artificial cardiac pacemakers, wearable EEG systems, or wearable dialysis machines, etc.)[12], although their need is dramatically increasing. It must also be considered during R&D, that the longevity of these technologies mean that they must be developed with the possibility of extending and integrating their use, compatible with other future systems and sensors [14].

Clinical trials: The consideration of indispensable third parties, without any direct health responsibilities (electricity-, heating-, gas-providers, etc.) for the application of assisted technologies, from the clinical trials stage onwards, must crucially be made [8,12]. An unexpected power-cut or loss of internet connection of the ISP could have tragic consequences in a smart home and for a PwD using wearable life- and health-logging sensors. The need for more intensive testing of assisted ambient technologies has been expressed [12]. Compared to the testing of drugs in healthcare, the regulation of ambient technologies seems to be lax [12]. In principle there are three possible venues of testing: a) *in-situ* (in the real environment of the user), b) *in-vivo* (in laboratories), and c) *in sitro/in-simu* (in a simulated environment, reproducing the users' home environment). Dem@Care objective is to develop and test the technologies in all these kind of settings. Against this background Portet in [10] points out that there are very few instances of *in-situ* testing. He also remarks that although the *in-vivo* tests are more affordable and possibly more objective, in comparison, the *in-situ* tests provide more realistic data, although at a higher cost and possibly with an observers' subjective bias. It has been indicated [12] that the principle of proportionality, known from the legal system, should be applied during the application of welfare technology.[5] For

[5] Hofmann defines welfare technology as a heterogeneous group of technologies which are „*supposed to give better and more focused care, reduced risk and increased safety, increased coping and self-determination,*

example, the tracking system should not impose physical restrictions or mobility surveillance on its user by blocking him in his or her activities but rather, should apply less obtrusive subjective barriers, with labels, mirror doors, RF[6]-coded access points, etc. However, the benefit of these alternatives might also be questioned [12]. In Dem@Care, this important aspect that will be taken under consideration by WP8 (Pilots, Evaluation and Clinical Validation) for the planning of the trials.

Clinical application: During the clinical application, a demand is placed on the engineers to deal with the issue of data protection, involving its secure storage for a requisite amount of time, and its subsequent secure removal [7, 13]. The bandwidth necessary for transferring medical data is a scarce resource and therefore, a bandwidth prioritization should be applied [16]. Moreover, the assisted technology should be easy to learn for future users. Also, it should be, as much as possible, error-free [10]. Nevertheless, the engineers of ambient assisted solutions should bear in mind the differences between the life-cycle of a device (technology), and the life-cycle of the healthcare service providing it, as they are usually not identical [7].

3.5 Designers

Research and development: For the designers, the literature, in general, emphasizes the designed-for-all smart homes approach. However, according to Portet, this may be inappropriate for PwD because of their specific needs based on their pathologies.[10] However, he emphasizes that "*no smart home application is going to be successful if the intended users are not included in the design*."[10]. It is imperative to focus on safety design –security by design [7], which maintains privacy [10] and user-friendliness [11,14]. As stated before, the active involvement of PwD into the process of design along the lines of the user-centred Participatory Design Approach is necessary for the overall usability and success of the product and service [9]. This approach is also referred to in the literature as "proactive design" [16].

3.6 Technicians

Clinical trials: Technicians are the mediators between the technology, the PwD, and their homes. Their approach to the installation and un-installation of the technological equipment must be very sensitive to avoid producing extra harm and anxiety for the PwD. Van Hoof

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make it possible to stay at home longer, avoid harm (from falling, fire, robbery), make more just resource allocation, and to promote technology development, commercialization and growth."[12]

[6] Radio-frequency.

mentions the complaint of one of the participants of their research about the drill holes left behind by technicians in their home [8]. In Dem@Care, WP8 will ensure all these activities will be performed without causing disturbances to the PwD.

Clinical application: Naturally the remark above about sensitivity holds for the application stage as well. Furthermore, during a regular maintenance/check-up activity, technicians should consider the special status of PwD, for example by minimizing repeated departure-and-returns to the easily confused patient's home. Because of the possible memory impairment of the PwD, technicians should work in pairs, in order to maintain a constant presence and connection with the PwD residents, to avoid losing continuity in contact and recognizable access with the persons during their work, and to be able to listen and repeatedly explain to the PwD and answer their questions [8]. In this case, the indispensability of third parties should be incorporated as well [12].

As is apparent from Table 1 in Appendix A1, not all of the ethical opportunities and challenges listed have been elaborated upon (especially the most general ones, evident in many other paradigms). Some of the challenges are applicable to various stakeholders during more than one stage of the process of development of the ambient assisted technology, therefore, when possible, they were applied in the Table 1 where needed, for a better overview and further usage.

4 Discussion

In the scholarly debate to date privacy and security issues are major concerns in relation to AAL technologies for PwD. It is also clear, however, from an emerging number of articles and projects linked with the use of AAL technologies for persons suffering from mild cognitive impairments, that PwD have persistent mobility issues and need support for their everyday living at home, which can be provided by ambient assistive technologies.

Besides the privacy and security issues, which are currently dominating the ethical debate, there are also other serious ethical challenges, which the researchers, designers, clinicians and other users of ambient intelligence should consider as important aspects of the development of these technologies. These could be summarized and will be discussed under the following headings: 1) value of the goals of AAL technologies, 2) the balance between cost-effectiveness and quality assessment in R&D, 3) issues of responsibility, and 4) the complex question of informed consent. Since these issues have not received attention yet in the scholarly debate, we focus on them in our discussion.

4.1 The value of the goals of AAL technologies

Many of the reviewed articles somewhat presumptuously predict or accept the benefits (e.g. better-, 24-hour non-stop care, longer staying at home for PwD, cheaper solution than nursing home, maintaining independence and autonomy of PwD, etc.) of using AAL technologies in various healthcare situations, including that of dementia. However, very few articles critically question this presumption. Moreover, there is the question of who will primarily benefit from the application of AAL, in the case of PwD. This is especially pertinent if we consider the seriously limited means by which assistive technologies can be assessed and their effects proved. Hofmann predicts that the usage of assistive technologies (which he calls "welfare technologies") will benefit the care-givers more than those in need of care.[12] This criticism raises serious questions about the justification of the benefits of using AAL for the vulnerable group of users, especially when it does turn out that the biggest share of the benefits are for the third parties whilst those in need of care bear the brunt in terms of risks and harms of usage.

The pathologies linked with dementia are varied and are currently the objects of scientific research, investigating their biological nature, as well other (phenomenological, behavioural, etc.) aspects. The collection of data within the home-settings of the PwD is very challenging for researchers. The chance to collect such data can assist researchers in their work, as well as open up the horizons for establishing better scientific foundations for more sensitive diagnosis and treatment or management. Although the clinicians' aims of better treatment and solutions for patients diagnosed with dementia, can encompass and be fulfilled by the collection of scientifically and medically relevant data using AAL, the presence and intrusive nature of the

AAL technologies, with their possibly harmful effects, raises serious ethical issues regarding the introduction of AAL technologies for this purpose.

The perspective of better diagnostic techniques could be a valid justification for the introduction of AAL to PwD. However, this benefit, as such, may be disproportionate to the serious potential harms and risks thus posed to this very vulnerable segment of the population. Similarly, the application of sensor-systems, mainly for research data collection could also go against the principle of proportionality, in the case of ambient technologies. One of the major fears of a PwD is of falling down, as reported by Hofmann [12] and van Hoof [8]. However, even the most advanced and complex ambient technology would miss this goal, if this service could be provided by a system that was more lightweight, simpler, cheaper and easier-to-use. The sensor-full smart-home does not provide greater help in preventing or assuaging the fear of falling down in PwD than a much simpler one-button danger-reporting piece of equipment. Ambient intelligence should provide much more than being just another solution for reporting complications for PwD. The obtrusiveness of ambient intelligence demands proportional benefits.

Another question raised by Hofmann [12], asks who will define, and on what basis, what constitutes the average everyday normal activity for a person with dementia? Different users can have different needs, behavioural expressions and habits. Therefore, the goals of the AAL should be defined alongside the provision of a high level of customization and adaptability of the system, and the avoidance of actively forcing the elderly population suffering with dementia into performing activities required by the assistive technologies.

Also, in a future scenario, where ambient technologies are widespread and widely accepted, the topic of the refusal of assistance from AAL technologies by a person with dementia or mild cognitive impairment has to be considered. Despite the variety of culturally influenced decisions, likely between different countries, the beneficence and value of AAL technologies for a wider society and for individuals would still need further analysis.

Although the value of the goals is, in general, tangible and could be justified, extra attention should be given to the possible harms and risks for the vulnerable PwD. The goals of AAL are mostly defined, according to the literature, as developing a technology, which gives assistance and support to vulnerable persons, allowing them to continue their lives for a longer time at home whilst maintaining their comfort and security. However, due to a lack of sufficient empirical evidence, the feasibility of achieving these goals is still very much an open question.

4.2 Balance between cost-effectiveness and quality assessment

According to Picking [6], a correct balance between the cost-effectiveness, time-consumption and the assessment of the quality of feedback from the participants of ambient technologies during the R&D procedure should be made. This balance needs to be emphasised because feedback methodologies, which vary in cost, are differently optimized and so, can provide

different results from participant feedback for the R&D process. These differences, though slight, may be crucial and could cause serious issues later on during the final introduction of the AAL technologies to a wider group of PwD. So, the quality of the feedback methodology directly affects the quality of the feedback from the PwD participants. Therefore, the introduction of the PwD into the R&D process is vital, the quality of the feedback itself will be considered essential for the whole project of the use of ambient intelligence for PwD. In Dem@Care project, this will be investigated in WP6: Client-side interaction.

Hofmann's observation is relevant, when he compares the complexity and profundity of the testing of pharmacological drugs and their introduction into the healthcare system, with the relative lack of rigorous testing and regulation when it comes to medical devices in healthcare.[12] Although the methodologies of these two medical interventions are different, their very nature overlaps, in the sense that they both aim to help those who are vulnerable and suffering with their health (e.g. direct and indirect benefits). Therefore, one must stress that the testing of AAL technologies should be taken as seriously as the testing of new drugs (because of direct and indirect risks and harms).

Ambient technologies by their nature should remain unseen and hidden from the user, reacting interactively to the needs of its users. However, users reported their issues with false alarms, which are, because of the sensitivity of the ambient technology, somehow inevitable [8]. Therefore, extra efforts should be made during the R&D, to ensure that the technology fulfils the attribute of "ambient", while also providing a system that allows the reporting false alarms by the users themselves. The case of PwD raises an extra issue here due to their cognitive condition, but this should not disqualify them from a certain amount of control and feedback-providing of the applied AAL technology.

R&D therefore should, on the one hand, actively involve, the actual PwD as participants, as they will later be the end-users of the technology. On the other hand, their vulnerability imposes serious requirements on the quality and quantity of data collected during the R&D procedure. This requirement is also valid for the testing period of the clinical trials. Therefore, a balance between the approach of the researchers to the PwD, as well as the assessment of the quality of gained data from the PwD should be provided. This will very likely ensure a better applicability of the AAL technology in the final clinical application period.

4.3 Issues of Responsibility

A further issue is responsibility for ambient assisted living technologies. Although modern hospitals, care and nursing homes currently use a plenitude of various technologies, for which partial responsibilities are held by various stakeholders (engineers, designers, etc.), there is usually a 'safety net' of human care-givers (nurses, clinicians, proxies) present in case of any malfunction of the technology. AAL technologies by their nature try to reach a level where such assistance should not be needed thus enabling users to live at home longer. Moreover, assistive technologies are not present in the clinical settings but rather, in the private homes of PwD. These facts introduce a need for a much higher level of safety and reliability in the

AAL technologies, than in technologies used in hospitals and nursing homes. For example: the technology in the hospitals and nursing homes are always connected to a caring person, while an impersonal contact and a misunderstanding with a technology at home can cause extra harm for the PwD, instead of required support.

It would be ethically unacceptable and also barely justifiable that in case of fault or malfunction, the responsibility is allotted to the 'system' and not to somebody, who designed, engineered, or applied it. Therefore there is a serious need of guidelines for the R&D of the AAL technologies, where the liability and accountability of a developed technology is preserved thorough the whole process of application and usage of the AAL technology by the actual PwD.

4.4 Complexity of informed consent in the case of PwD using AAL

Informed consent for the application of any treatment and technology in healthcare is considered to be crucial. However, PwD with their possible mild cognitive impairment and memory issues pose a serious challenge regarding informed consent. Therefore, as any care-giver, clinician, or technician, as stated before, is obliged to repeatedly explain to the PwD what they are doing with and for them, it would seem inevitable that the concept of 'rolling informed consent' be introduced. Rolling informed consent involves the necessity of repeatedly providing information whenever requested and asking for consent for actual treatment, while also maintaining the possibility of opting-out or withdrawing from treatment. In practice, however, rolling informed consent could cause issues for the care-givers and clinicians, regarding considerations of its validity and its being time-consuming, which would then prolong the whole treatment process. The rolling informed consent does not result in the case of PwD in a single-event legal act but rather, is a continuous consideration of the choices, which the vulnerable person in need makes. Naturally, care-givers can find the concept of rolling informed consent burdensome and an impediment to their work. However, maintaining rolling informed consent is ethically desirable from the view point of the principle of respect for persons. This principle is broadly accepted as pivotal in research and healthcare settings in general, especially so when dealing with vulnerable persons [4].

5 Conclusion

Ambient assistive technologies are said to provide assistance and support to vulnerable persons, especially those who suffer from dementia and mild cognitive impairment; allowing them the possibility of living at home for longer whilst maintaining their comfort and security. However, the introduction of AAL technologies also poses serious ethical challenges regarding their usage, development and application, in relation to the PwD. The ethical challenges focussed in the literature to date, are mostly issues of safety, security and privacy.

Without questioning the relevance of these topics, other ethical challenges need to be addressed as well. They involve the value of the goals of AAL, the justifiable balance of cost-effectiveness and a quality-centred R&D procedure, the various levels of responsibilities for the AAL, and the complex issue of informed consent from PwD using AAL. Moreover, there is a need for a better-founded, more specific and more inclusive R&D process. In addition, claims about the benefits of AAL technologies for PwD will have to be better substantiated by empirical evidence obtained from the application of AAL itself. Finally, the vulnerability and cognitive impairments of PwD pose challenges for all the stakeholders during the various steps of the development of AAL technologies.

All the above mentioned challenges will be considered in Dem@Care to ensure that R&D, clinical trials and the final application are in accordance with the highest ethical standards.

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A APPENDICES

A.1. Ethical Issues Mentioned in the Literature.

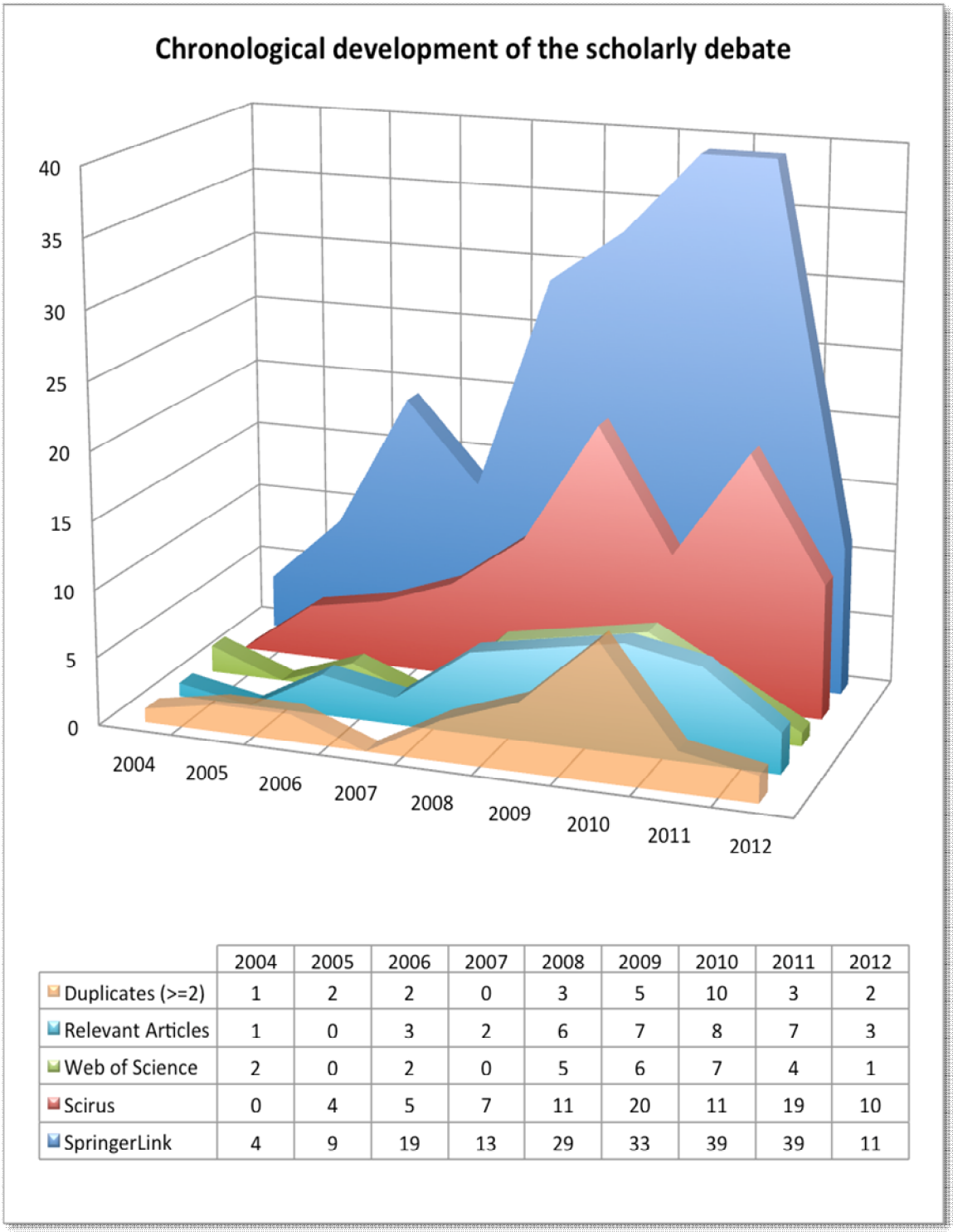
Table 1: Ethical Issues Mentioned in the Literature

	Research & Development	Clinical Trials	Clinical Application
Patient with Dementia (PwD)	• Abandonment (lack of user R&D) • Self-Reports (Titration approach) • Not only informed consent but interviews (simple sentences TASC)	• Informed Consent • Control • Prevent harm (e.g. fall accidents) • Laboratorization of living environment/Medicalization of home • Ambient technology has a "life on his own" • Voice > LCD • Information overload • Resistance • Anxiety	• Privacy • Integrity • Dignity • Ageing at place • Autonomy (decrease/increase?) – Enhanced dependence on ICT -> inactivity/Independence • Daily activity -> inactivity • Confidentiality • Trust • Honesty • Mobility • Embarrassed/stigmatization • Feel safety/reduce insecurity • Against institutionalization (especially couples) • Fear of failure errors (95% would still use it) • Information overload • Resistance • Handicapped-look • Surveillance-risks • Social exclusion/e-Inclusion (digital divide) • Discomfort • Anxiety • Alienation (Katz) • Binary distinction

			• Home = territory/domesticity
Caregivers (nurses, proxies)	• Continuous monitoring • Social exclusion/e-Inclusion • Who will gain? Patients or proxies/carers?	• Reciprocal accountability	• Against institutionalization (ageing at place) • Misuse – who's responsibility? • (in)efficient? • Reciprocal accountability
(Medical) Researchers and Clinicians (MDs)	• Continuous monitoring • Holistic approach	• Meaningful data collection (scientific/medical) • Prioritization of medical data • Laboratorization of living environment • Medicalization of home • Reduce insecurity	• Human-centred approach • What is a normal daily activity? • Is the person really in need of Ambient Technology?
(Software/ Hardware) Engineers	• Customization • Data security • Mobility • Implantable biosensors overheat • ICT "quick fix" – tasks not suitable for ICT • Low-prestige ICT development • DoS attacks, hacks • QoS • Cost-benefit ratio • Integration/compatibility with various sensors	• Customization • Indispensability of 3rd parties • Laboratorization of living environment • Medicalization of home • Lax testing of Ambient technologies (compared to drugs) • Very few testing in actual homes (*in situ*) • What is a normal daily activity? • Tracking for safety, not with physical restrictions • Principle of proportionality	• Indispensability of 3rd parties • Data protection • Bandwidth prioritization • Easy to learn • Error-free • Life-cycle of device (technology) ≠ lifecycle service • Principle of proportionality • System providing health, security, comfort
Designers	• Design-for-all approach • Privacy "by design" • User-friendly design • Involvement of PwD into design (Participatory Design Approach) • Proactive design	• Prevent harm (e.g. fall accidents) • Discomfort (e.g. battery)	• Easy to use • Handicapped-look
Technicians		• Sensitive installation of devices into homes of PwD	• Indispensability of 3rd parties • Special approach during system maintenance in homes of PwD

A.2. Chronological development of the scholarly debate.

Figure 2: Chronological Development of the Scholarly Debate



	2004	2005	2006	2007	2008	2009	2010	2011	2012
Duplicates (>=2)	1	2	2	0	3	5	10	3	2
Relevant Articles	1	0	3	2	6	7	8	7	3
Web of Science	2	0	2	0	5	6	7	4	1
Scirus	0	4	5	7	11	20	11	19	10
SpringerLink	4	9	19	13	29	33	39	39	11

A.3. List of Relevant Articles from the DB Search

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