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Ambient Intelligence in Home Care in the Netherlands

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Ambient Intelligence in Home Care in the Netherlands ¹

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Abstract

The largest age group in the Netherlands is aging and when they are in need of home care, there will

not be enough people to take care of them in the current healthcare system. One solution could be

found in Ambient Intelligence, for it could aid in maintaining independency and postpone the time

that people have to go to a nursing home. Furthermore, it could make the job of the caretakers

easier. There are pros and cons to use Ambient Intelligence in this delicate matter that will be

discussed in this paper. Furthermore, the implications of employing Ambient Intelligence strategies

in home care situations will be considered. The conclusions of a recent study by the Rathenau

Institute will be used as the red thread, critically looked at and taken into consideration for the

recommendations of how to implement Ambient Intelligence in home care.

Keywords: Ambient Intelligence, Technology Assessment, home care, user-centred design, well-

being.

JEL codes: I11, I18, O33

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Introduction

Ambient Intelligence

Ambient Intelligence (AmI) is a conceptual vision about a future world in which ICT is used to create a user-friendly and intelligent support of personal interaction (Chiarugi, et al., 2006). Through the use of embedding technology in different objects and electronic devices, a wide range of possibilities is created. The AmI technology represents a system which is implemented in an environment, and is aware of the different parts of the system as well as of its user. It aims for natural interaction of the user with the system, where people are empowered through a context aware environment that is sensitive, adaptive and responsive to their needs, habits, gestures and emotions (Chiarugi, et al., 2006), thus creating intelligent environments. A simple example of this could be when sensors on the body measuring vital signs such and based on this giving personal recommendations for an exercise schedule. According to Aarts and Marzano (Aarts & Marzano, 2003) there can be five different layers distinguished in which an environment can be intelligent. The first layer is 'embedded' in which the equipment is incorporated in the environment in such a way that the person hardly realizes this, and can communicate with it in a natural way, also referred to as social embedding. The second layer is 'context aware', in which the technology links properties of the person to properties of the environment. The third layer is 'personalized', in this stage there is a personal profile which allows the equipment to be tailored to the needs of the user. The fourth layer is 'adaptive'; here the technology automatically reacts on the changing circumstances. The last, fifth layer, is defined as 'anticipatory' in which the technology reacts on environmental factors to prevent any kind of problem (Aarts & Marzano, 2003, p. 14).

Hensel, Demiris & Courtney (2006) proposed a framework that distinguishes eight dimensions of obtrusiveness that users may experience: physical, usability, privacy, function, human interaction, self-concept, routine and sustainability. Meulendijk et al. (2011) mapped the dimensions identified by Hensel, Demiris & Courtney (2006) to the five layers proposed by Aarts & Marzano (2003). Figure 1 shows the degree to which obtrusiveness is an issue in each of the five layers, based on the literature study by Meulendijk et al. (2011).

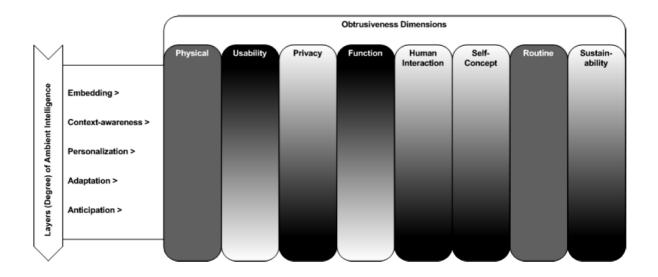


Figure 1 The impact of obtrusiveness in each of the five layers. A lighter shade of grey indicates a less prominent obtrusiveness issue, while a darker shade signifies a more heavily represented one.

The dimensions and their obtrusiveness were interpreted as follows:

- "1. Physical dimension; the physical presence of sensors and equipment is present from the first layer, but does not increase in later ones;
- 2. Usability dimension; usability issues may occur in the first layers, but gradually diminish as technology becomes more intelligent and needs less operation;
- 3. Privacy dimension; privacy infringement may not be a significant issue at first, but worsens when applications begin to gather more data from environments and users;
- 4. Function dimension; especially in the first layers users may expect too much from devices, but when applications become more capable this will decrease and people will put more trust in them;
- 5. Human Interaction dimension; as devices become more capable and intelligent, human caregivers become unnecessary. Consequently, relationships with carers and family may lose intensity;
- 6. Self-Concept dimension; when ambient intelligent domotics become more capable, users may feel more dependent. Their sense of self-concept and confidence may diminish;
- 7. Routine dimension; in the first layers, users may have to accommodate requirements of domotics in their daily activities, and perceive that as obtrusive. In layer phases, domotics may perform so many actions that users may experience this as interfering with their routines; and
- 8. Sustainability; when costs increase, it may become more difficult to maintain domotics. Additionally, if users' conditions deteriorate to such extents that domotics can no longer assist them, they may have to give up tools they've grown used to."

(Meulendijk, van de Wijngaert, Brinkkemper, & Leenstra, 2011)

They state that the usability aspect decreases in obtrusiveness as the technology needs less operation from the user side. This may be true when everything goes according to plan, but when

something goes wrong it might be harder to recover from this for the user, as the user is not familiar to interact with the system.

Concerning the privacy dimension, at all five levels of intelligence user profiles play a key role. A user profile is a personal data record, which not only identifies the individual, but also facilitates file linkage and the exchange of information amongst databanks (Schuurman, El-Hadidy, Krom, & Walhout, 2009). These profiles add to the matter of privacy sensitivity, especially when more data is stored in them.

In the dimension function they raise the concern that the user might expect too much. For this reason it is important to have an interaction style with the product that fits the intelligence of the product. When one can naturally talk to interact with the system, it is likely that the expectations the user has for the understanding of the system are high as well.

The point raised at human interaction is worrisome; the caregiver should never be totally replaced with a computerized system. When there has not been a caregiver in first instance, it might not be a problem, but the user should not be comprised in social contact. The way of interacting with the caregiver will be different, though not lost.

As for sustainability, it is expected that there will constantly be developments in technology, and products can easily get outdated. Yet it is not expected that the existing product decreases in functionality. When software updates can be easily done in the system, and sensors are based on a plug-and-play system, the sustainability can be increased.

The most suitable way to provide for an AmI system in healthcare would be through the insurance company. In this way the system will not be wasted after one person will stop using it, but can be given to another person after all the equipment is cleaned and checked. Whether this is attainable depends on the healthcare system.

Healthcare in the Netherlands

In the Netherlands it is obligatory to have a health insurance. An insurance company must accept someone applying for basic health insurance, but they are allowed to deny someone who applies for additional insurances, and when someone is older than 65 they have the right to charge higher monthly fees (Rijksoverheid, Wat is een aanvullende zorgverzekering en ben ik verplicht er een af te sluiten?). This is one of the reasons people have fears that the data collected by Ambient Intelligence systems can get in the hands of insurance companies.

The use of Electronic Medical Records (EMC) is being discussed in the Netherlands. Electronic Medical Records contain information about the medical history and medication use of patients. Doctors and specialists in the Netherlands could consult this file. This would decrease the mistakes that are made in prescriptions of medication, and improve the care that can be given to the patient (Rijksoverheid, Electronisch Patienten Dossier (EPD)). In 2009, the government had voted in favour of the law that would regulate EMC, but in April 2011 the higher parliament has denied these laws. The main reason is the privacy and protection of the patients, which was regarded as not sufficient in the proposed law. They are now looking into a way to change the proposed law, such that these requirements will be fulfilled, and are investing in research on how to solve these privacy problems. For Ambient Intelligence to be implemented efficiently, these EMC's are crucial. Without these, a system is not complete, which can be very dangerous for the patients involved.

Health care in the Netherlands is increasingly organized on the basis of 'care chains'; a patient who is referred by his/her general practitioner (GP) to a specialist in a hospital, for example, typically enters a chain, made up of a series of connected health care processes, from admission and diagnosis to treatment and rehabilitation (Schuurman, El-Hadidy, Krom, & Walhout, 2009).

In 2010 the Netherlands had circa 2.54 million people older than 65 years (approximately 15% of the total population); this number is expected to rise to 3.36 million in 2020, while the age groups of 0-20 years and 25-60 years will decrease in number (Verweij, Sanderse, & de Beer, 2009). These demographics raise concern for the home care and nursing homes in the Netherlands. It is a fact that there will be more people in need of care, and less people to provide this. In home care there is an increasing need to provide more care with the same amount of staff. The number of people that need care is increasing, while the number of people who provide this care is decreasing.

Because of this it is expected that in 2025 an urgent shortage of labour force will be developed (Mutsaers, 2008). This shortage is mainly caused by the rise of the costs within healthcare in combination with the "greying" society and the growing amount of people with chronic diseases (Scheepbouwer, 2006). With an unchanged healthcare policy almost a quarter of the Dutch labour force has to be active in the healthcare sector (Tsiachristas, Notenboom, Goudriaan, & Groot, 2009).

Currently used solutions try to make the home care more efficient, which lead to tight schedules that allow for less social time with the patient. Another trend that can be seen in the Netherlands is that more work of home nurses is taken over by cleaning personnel, which are obviously trained differently than home nurses. This has the consequence that there is not just one nurse helping the patient, but multiple people with all different areas in which they work. Besides that, the personnel of one company helping one person are often changing, to maintain an efficient schedule. This has a

negative effect on the bond the patient has with the person helping. When having insecurities, they might have to share this with a nurse that is unfamiliar to them.

One way to create a labour-decreasing effect is when the patient can take on a more active role in its own care process. The patient takes the role of both consumer and co-producer of care, where the professional acts more as a coach. Toffler (1980) referred to this as prosumption. He argued that prosumption was predominant in pre-industrial societies. This was followed by marketization that drove a wedge into society, which separated these two functions; producers and consumers (Toffler, 1980, p. 266). In the case of prosumption in healthcare, the patient has a big responsibility in the choices that he/she makes in his/her own care process (den Breejen, 2009). The question is whether the patient is adept to make these kinds of decisions.

Self-management can increase the independence of the patients. Self-management entails that not only doctors but also patients have an important role to fulfil in the daily care for their condition (Holman & Loring, 2000). That care does not only include monitoring of symptoms and based on this adapting medication and self-care measures, but also being able to deal with the way in which the disease affects daily life (Dorn, Heymans, van Dijk, Francke, Wolters, & de Leeuw, 2007, p. 12).

Another way to attain a decrease in labour can be found in prevention, since less illness will lead to less demand for care. Investing in prevention of frequently occurring diseases like dementia, obesity and heart and vascular diseases will be most logical (RVZ, 2006).

A common division of prevention is towards primary, secondary and tertiary prevention. Primary prevention includes activities that prevent that a certain health problems, illnesses or accident does not develop. The target group for primary prevention are healthy people. Secondary prevention is aimed at people that are sick, and those who have an increased risk or have a genetic predisposition. The aim here is to detect the disease in an early stage so that the disease does not progress or can be cured faster. Tertiary prevention is often already regarded as care, where complications and decline of the health because of the disease occurs. The aim here is to increase the independence of those who are already diagnosed (den Breejen, 2009).

Healthcare is prone to *Baumol's disease* (Schut, 2003). This is because of the fact that personal services and the effort that is put into the work is an important part of the service and determines for a large part the quality of the service (den Breejen, 2009). A way to maintain this kind of quality in Ambient Intelligence services for healthcare will be a challenge, yet a necessity.

Ambient Intelligence in Healthcare

The application of AmI technologies in the field of health as a whole is still under-researched, and besides a lack of visionary documents on AmI and health, there is a lack of studies addressing the interdependencies between new technologies and the healthcare ecosystem (Friedewald & Da Costa, Science and Technology Roadmapping:Ambient Intelligence in Everyday Life, 2003). Most likely the current healthcare system would have to undergo a lot of changes. The study of Chiarugi et al. (2006) identifies the following trends in healthcare:

"Important trends in modern healthcare include citizen mobility and the consequent move towards shared or integrated care where an individual's healthcare is the responsibility of a team of professionals in a geographically extended healthcare system. In this new scenario, the possibility of consulting and collecting clinical information from different points is becoming a common need for citizens and physicians. Moreover, the increase in the life expectance has produced an older population that may need continuous assistance especially in cases of serious or chronically ill people that wish to live independently. A clear benefit is obtained when high quality of care can be delivered outside the hospital premises allowing people at risk or patients with proved health problems to continue their usual life at their homes and work places. Remotely delivered care for prevention or follow-up situations is becoming increasingly feasible, through sophisticated eHealth services facilitated by intelligent environmental and biomedical sensors, portable monitoring devices, handheld or wearable technologies, the Internet and wireless broadband communications."

(Chiarugi, et al., 2006)

From this can be seen that there is a need for a central system with information of patients in order to provide good care. Even more important for the caregivers, is to be able to provide good care outside the hospital, reaching more people. There are four main domains in which Ambient Intelligence could assist in healthcare: prevention, cure, care and health management and administration. This can be done in several manners such as monitoring, providing information and consultation. Every aspect has their specific requirements and needs, in order to be able to provide the best aid possible for the user. Likewise, different technologies are needed, and the implementation of it may vary.

The domain of prevention aims on the prevention of diseases, which includes continuous monitoring of health and health related behaviour, promotion of healthy lifestyle and related advice, alerts against eating dangerous products and prediction of diseases (Savidis, et al., 2001) (ITEA, 2004) (Riva, 2003) (Cabrera Giraldez & Rodriguez Casal, 2005). Prevention is an area in which a lot of actors are involved: the general public, specific social categories with a tendency towards health problems, practitioners, specialists, but also government agencies, pharmaceutical industries etc. (Friedewald & Da Costa, Science and Technology Roadmapping:Ambient Intelligence in Everyday Life, 2003).

The domain of cure aims at the cure of diseases, especially directed towards short-term recovery. Cure starts from diagnosis and continues as a treatment at any time and any place (Friedewald, Vildjiounaite, Punie, & Wright, 2005). This should be achieved by ad hoc networks of medical equipment and information sharing between doctors. For some cases, a continuous monitoring of vital signals is needed (Riva, 2003) (Savidis, et al., 2001). The activities in the cure domain are mostly undertaken by medical and paramedical staff. Overcoming the limitations of time and place, increasing personalisation and the drive towards more efficiency are the main drivers that impact this field (Friedewald & Da Costa, Science and Technology Roadmapping:Ambient Intelligence in Everyday Life, 2003).

Care, which is a long-term activity directed towards the recovery process of patients and towards the support of everyday life functions of people in need of long-term attention, such as the elderly, handicapped or chronically ill (Friedewald, Vildjiounaite, Punie, & Wright, 2005). Care implies continuous monitoring to support autonomous or semiautonomous life and to make the caretaking process easier. There are several ways in which this is attained, first by embedded intelligence capable of tracking activities, detecting anomalies and giving advice inoffensively and, second by socalled assisting technology such as hearing aids, prostheses and implants (Morganti & Riva, 2005) (Cabrera Giraldez & Rodriguez Casal, 2005) (Riva, 2003). Care is a collection of more long-term activities directed towards the recovery process of patients and towards the support of everyday life functions of people in need of long-term attention, such as elderly, handicapped or chronically ill people (Friedewald & Da Costa, Science and Technology Roadmapping:Ambient Intelligence in Everyday Life, 2003). Caretaking activities are mainly provided by (professional) nurses, activity companions but also by (non-professional) family members and friends. Drivers such as raising efficiency levels and reducing costs, and objectives such as enabling personal and social autonomy have a large impact upon these activities (Friedewald & Da Costa, Science and Technology Roadmapping: Ambient Intelligence in Everyday Life, 2003).

There are different technologies needed to fulfil the different tasks in the different domains. Technologies such as Microsystems and electronics play an important role in an Ambient Intelligence environment. Therefore, the development of Ambient Intelligence in healthcare is largely determined by advances made in chip design, packaging density, miniaturisation of components, component and functional integration, embedded computing, as well as in such new areas as nanotechnologies (Friedewald & Da Costa, 2003). For over 30 years this development has followed Moore's law, which means that the number of transistors on a chip roughly doubles every two years (Intel, 2005). Besides chips there are other technologies that are of importance for AmI in healthcare, of which ITEA has created a foresight analysis using a Technology Roadmap and an Embedded

Systems Roadmap. In the table below, the different technological aspects are categorized and divided by the time they are expected to be developed, which was formed by the Rathenau Institute (Schuurman, El-Hadidy, Krom, & Walhout, 2009).

Broadband network infrastructure and network services				
Technologies	Short term 0-5 years (2010- 2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020-2025)	
Interoperability across heterogeneous networks 'Smart' ad hoc context-based networks Growing broadband	Automatic suitability for use in various networks Automatic adaptation of equipment to network (limited functions) Cable xDSL < 50Mbit to	Automatic interoperability across heterogeneous networks Automatic adaptation of equipment to network Optical fibre; 100 Mbit/s	Seamless network interoperability Smart ad hoc context-based networks (e.g. user profiles, interoperability) Optical access	
Universal Internet protocols (IPs)		ethernet to home services. Whether IPv6 is rolled ore, but it is not yet supported by		
Fully distributed environment	operators. Limited web access for and to sensors and actuators Main applications: monitoring and warning	Limited standardization of M2M services	Extensive electronic M2M services Web-based services in sensors and actuators in all equipment, using standard formats and protocols	
Transparent access to distributed data (individual sensors, actuator data or derived data) in local networks	Transparent access to individual sensors in a building	Secure external access Data combination becomes easier	Standardized methods of adding domain knowledge to sensor data and thus educing information and knowledge ('smart sensors')	
Digital sensors and actuators				
Technologies	Short term 0-5 years (2010- 2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years	
	2013)	(2013-2020)	(2020-2025)	
Intelligent battery management	Increased granularity and more efficient use of energy in sensors	New power sources, e.g. fuel cells	(2020-2025)	
	Increased granularity and more efficient use of energy	New power sources, e.g. fuel	Movement interpretation, intelligence, deduction of people's activities by the combination of information; introduction of application-specific knowledge	
management Sensors and	Increased granularity and more efficient use of energy in sensors Individual sensors on the body Domain-specific: • Heart rate • Blood pressure	New power sources, e.g. fuel cells Portable incident monitoring system Warning generator,	Movement interpretation, intelligence, deduction of people's activities by the combination of information; introduction of application-	

Technologies	Short term 0-5 years (2010- 2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020- 2025)	
Speech/sound/ movement/ gesture (for application control)	Spoken commands (specific and limited multi-setting and context) Direction monitoring on the basis of movement (games) or sensors in clothing.	Improved comprehension of natural language, speaker- independence Interpretation of gestures	Full comprehension of natural language, related to semantic interpretation, understanding of content, some emotions Facial gestures for application control	
Intelligent situational aware adaptive technologies (with sensors and profiles)				
Technologies	Short term 0-5 years (2010- 2015)	Medium term 5-10 years (2015-2020)	Long term 10-15 years (2020-2025)	
User profiles	Profiles within enclosed environments	Dynamic and roaming profiles for various environments	Situational aware man- machine interfaces with sensors, profiles and limited emotions	
Intelligent, situational aware man-machine interfaces with sensors and profiles	Detection of presence of individuals/groups, location functionality	Situational aware with sensors and profiles (multiple diverse environments)	Learning-enabled user interfaces (with limited understanding of human behaviour)	
Learning user interfaces	Learning user interfaces (adaptable menus, single user, simple collaboration)	Learning user interfaces (multiple diverse environments)	Understanding of user behaviour	
Security	Basic plus start of multi- environment for privacy and security	Multi-environment for privacy and security aspects extended with trust etc.	Technology for complete security support	

Multimodal interfaces

Based on ITEA Technology Roadmap and Embedded Systems Roadmap (Schuurman, El-Hadidy, Krom, & Walhout, 2009)

As can be seen from the table, the ITEA is quite optimistic about the development of Aml and expects to reach a high level of intelligence in 2025. In this case, mankind would not be waiting for technology to develop, but for society to be ready for it. Furthermore, having the technology ready does not imply having the right design yet. To come to a good design user involvement should be there from the first design, to know which aspects are of high importance for the user, and which should not have a priority. For instance speech recognition is still very hard, especially context aware ones. Nowadays, the speech recognition will only work properly in a quiet room when the person is talking close to the microphone. The intelligence of the system is aimed and promoted really high, namely natural interaction, and any performance lower than that would not count for natural interaction and context awareness anymore. It can be questioned whether this is really the most important aspect. It could be advocated that the emphasis should be on aiding people in crucial situations, rather than on how they interact with the system. Other aspects may be more important for the system to be accepted by the user, such as safety of their personal data. Either way, still a lot of development is needed to come to solutions for home and health care, and to make this

development the products need to be tested on a large scale. However, there is a lot of commotion as to whether Ambient Intelligent is in a stage where it can be implemented in society. Basic premises for Ambient Intelligence are denied by the government, such as Electronic Medical Records. This makes it hard for Ambient Intelligence in healthcare to make leaps in development. The main reason for this is the safety of personal data of patients, combined with the fact that health insurance companies might find ways to know about personal data and act accordingly.

More social issues are that providers of healthcare might know more than the patients want them to know, through the automatically measured and sent data. On top of this, also the impacts on existing social bonds are worrisome, making the reliance on the technological systems even higher.

Even though there are concerns, the increase of use of technology is inevitable. The Electronic Medical Records are heavily discussed in the Netherlands, these records contain the medical history of patients which can be accessed everywhere in the Netherlands by doctors, to improve upon the care they can give. Although people have to give their consent to the use of these files, sensitive data will be available in an on-line system, which does not have the solid protection yet needed to deal with threats like hacking. Many of the patients are not aware of the threats of this, yet others do not want any of their data on-line, but most importantly, people want to feel like they will have the best care when they need it. Especially the younger generation is used to have technology all around, and is more aware of the benefits and threats than the older working class. Questions of what is required to implement AmI healthcare systems in society will be discussed in the next section, using the Technology Assessment of the Rathenau Institute as a guideline.

Analysis

Technology Assessment of Rathenau Institute

Schuurman et al. (2009) have written a technology assessment report about the use of Ambient Intelligence in healthcare. The report considers current developments in Ambient Intelligence in healthcare, and assesses it through scenarios. The concepts and products are an example of Ambient Intelligence that can be used in healthcare situations (Schuurman, El-Hadidy, Krom, & Walhout, 2009). The term technology assessment might be argued, since only a few concepts are considered in this report, and it assesses *a design* in which the technology is used rather than the technology itself. A lot of their outcomes should be seen in this light, since a poor design does not make for a poor technology. Normally a sequence of iterations is needed in the design process to accomplish a holistic design, which implements Ambient Intelligence in home care in an appropriate way. Even

though, through the scenarios used in the analysis, important aspects are brought to light that are of high importance for the development of Ambient Intelligence in healthcare.

The first implementation discussed represents a product in the area of prevention on the intelligence level "embedding", being monitoring the location of a patient using a patch. It is used in this case to prevent a demented patient from making walks at night, outside the institution. In the future scenario a My Daily Assistant is considered, which helps people with dementia remembering things in going on in life such as appointment, medication regimen and alerts family members in case of an emergency. With sensors in skin patches, data about blood sugar level is recorded.

The second product is in the area of care on the level of context awareness. In this case the heart rhythms are monitored of a patient that suffered a heart attack, the heart rate is fed back to the patient, and abnormalities are giving an alert. The data is also sent to the caregivers, who will interpret the data when the patient has a check-up.

Thirdly a concept in paediatric physiotherapy on the level of personalization was considered in a more hypothetical approach. The concept is called The Little Acrobat, which is a device that you attach to your belt, which is programmed to monitor your activities and encourage you to change the way you behave in your own surroundings (Schuurman, El-Hadidy, Krom, & Walhout, 2009). The patient wears a number of sensors attached to the skin or hidden in clothing. These measure body fat, muscle tension and muscle activity, record palpitations and perform regular EEGs. The device also tells what sort of food is advised to eat. In the scenario is hypothesized that on the insistence of the European Commission, all products have to have a unique radio-frequency ID chip. All the user has to do is scan the label of anything he/she is thinking of eating or drinking.

A fourth analysis is done on follow-up care for cancer patients on the intelligence level of adaptation called My Life Manager. The My Life Manager monitors nutrition, stress, fatigue and her activity pattern. It provides personalized advice on what the user should do, given her present capabilities.

The last case reviewed in this report by the Rathenau Institute is in the domain of sport. The intelligence level of the implementation would be anticipation. In this scenario a SmartTracksuit, into which a range of ultra-light instruments are incorporated, constantly feeding data back to a mobile field lab is considered. The instrumentation and lab together form a wireless Body Area Network. One of the additional items is the SmartSportmonitor, with a vest for home use to measure the build-up and reduction of stress.

Conclusions of the Technology Assessment of the Rathenau Institute commented

In the next section, the conclusions from the assessment of the Rathenau Institute (Schuurman, El-Hadidy, Krom, & Walhout, 2009) are discussed. The following concerns were voiced:

- 1. Use of technology will lead to the replacement of people or social bonds
- 2. Independent life, causing social isolation.
- 3. Active role of the patients, need support
- 4. Collected data can be used against the user
- 5. User might not have the same goal as the caretaker
- 6. Covering of the insurance company
- 7. Hard for the patient to relate with the technology.
- 8. Recorded memories by the system, if out of context and missing links is meaningless
- 9. Not accepting the technology
- 10. Dependency on the technology
- 11. Interpretation of the data

Social interaction

A concern that keeps returning is that the use of technology will lead to the replacement of people or social contacts. There seems to be a contradiction, on the one hand they argue that there is a need to find a solution to provide care with less people, and on the other hand they do not want to replace the care that is currently being given by caregivers.

"It is our conclusion that, to a considerable degree, health care provision is and must remain the work of people."

- (Schuurman, El-Hadidy, Krom, & Walhout, 2009)

Naturally personal care is preferred over technology, but as they acknowledge themselves, in the future most probably the Netherlands will not have this kind of human resource, unless it experiences an import of guest workers. Some aspects are not suitable to be executed by technology alone, but therefore it should not be rejected as a whole. The reality is that in the future there might not be enough people to take care of those in need of assistance at home. In this perspective one should look at the opportunities the technology provides. The technology is not a substitute for the experts, but it might allow for easing the daily care regimen in such a way that a lay person is able to help in this rather than a home nurse. Furthermore, communities could be formed in which people

can take care of each other and join forces. People with the same medical condition could exchange information on how they deal with their activities of daily living. Often people develop simple tricks to cope with a disability, which can be very valuable for people who are new to this disability.

One of the remarks was that the social interaction with family members changed upon using the Ambient Intelligence technology. Having no message sent from the device to a family member should not be interpreted as "I don't need you now". Furthermore, having a technology between two persons does not mean that other forms of communication are excluded. People report to feel as if they are a burden on their children, and use the technology as a way not to impose on them. Yet they feel that when less aid is needed, they will receive less attention as well. But instead of asking if one can help with for instance medication, they could invite for another more fun and bonding activity to do with them.

The drive to be able to have an independent life does not mean that the patient should do everything alone, living in social isolation. After installing an Aml healthcare system, there will be changes for the caretakers as well as for the patient. Both need to be guided during this change. If family is taking care for the patient, they should not feel useless after having technology installed. The need is just shifted from needing practical help to social contact. When social deprivation is a pitfall, it could be included in the system to cope with this. It can be questioned whether the communication of the device should be limited to the vital signs, or rather encompass a broader aspect such as well-being, which takes into account to need for social interaction. Monitoring the social contact with the family, and letting the family know how they are doing. Furthermore, it says something about society of today, when for instance visiting ones mother is only done when it is strictly necessary. In the Netherlands there is a culture of "putting" elderly in the elderly home, but this was not always the case. Families would stick together and living in the same house with three generations was very common. This change has an effect on the rhythms within the whole society.

The role of the patient and caregivers and their responsibilities

AmI in home care asks and active role of the patient, but the patients need support in how to deal with self-care. It is clear that guidance in this is needed, an assessment whether the patient is capable of doing of fulfilling this active role is needed as well. When depressed, this can be an impossible task for the patient.

Furthermore, the user might not have the same goal as the caretaker. Where the user might want to have an overview on their process, the caretaker might want to change the behaviour of the patient.

When implementing this technology, caretakers and care receivers should have a conversation on what is expected from one another. In this way, misunderstandings can be prevented and a compromise can be made. The purpose of the Ambient Intelligence systems seems to be designed from the interest of the caregiver, rather than for the user. The systems should aid in the self-empowerment of the user, and not take over for the user. Having responsibility and ownership can help people in staying mentally fit and maintaining their independency actively (Langer & Rodin, 1976).

Monitoring

Although the technology is embedded, and the user does not have to realise it is there, a certain awareness of the user is important to avoid surprises. One way of providing the user with insights is to have weekly reports. Besides the fact that they will know what is monitored, they can be stimulated to have good reports, promoting a healthy lifestyle. This holds especially when peak moments in the data can be coupled with certain activities or habits.

The user should be well informed about what data is recorded and what it is used for. There should be a negotiation rather than a standardised protocol of the relation the caretaker has with the patient and how the recorded data is treated. Furthermore, the user should be able to come back on their prior agreement, if they feel it imposes on their privacy, another consultation should be held to come to a solution rather than rejecting the technology as a whole.

The user should be the one in control. In current scenarios, it seems like the technology is in control of the user. The collected data can be used against the user. For example, unhealthy or risky behaviour can lead to insurance companies denying paying for treatment. Another concern is that the data is not used like it should be. An example of this was that the GP used the logged data to know the couple returned home a day earlier from their holiday and decided to make a visit. Just because caretakers know quite a lot of facts, they should not deny normal social conduct.

Funding

Covering of the insurance company is important for the technology to be available to the mass. Being dependent on them also gives them the power to choose what to fund under what condition. They might for instance ask for personal monitoring data in return for a full coverage. This is a part that should be legislated, in order to protect the patient and create a fair system.

Acceptance of the AmI system

Not everybody might accept technology in the form of AmI as an aid. In fact, not everybody may be suited to use it. The fear of new technology is not recent, there used to be a lot of fear of electricity and the first light bulb. But gradually this technology has been adopted into daily living. Because the changes that are made using the AmI technology today are quite invasive of nature, acceptation of it cannot be expected instantly. New generations grew up with technology all around them, but we have to keep in mind that the development in technology has been exponential and that for older generations, what might be obvious to us, can be hard to grasp. Therefore it would be good for the adoption of AmI in daily life could be gradual. Implementing the technology in an early stage could help the user get acquainted with it, by letting them for instance be able to monitor a family in a playful way. This way they can understand what kind of data will be recorded, and familiarize with the technology.

Dependence on the system

The researchers fear that people would grow dependent on the technology. Where in most cases it was a problem whether the user would accept the recommendations of a device, here it seems to be the case that people over depend on the technology. In such a degree that personal contact is decreased with both the professional caretaker as the family. A personalized healthcare in which the user is central, as AmI in healthcare is defined, should not allow for this. The technology should be implemented as an aid to manage but not as a replacement of the current care. The system should also advise the user where to consult the caregiver. It should aid in both maintaining the user's independence as maintaining the social bonds and control of the people involved. Furthermore, it is important that the system aids in making measurements the old fashioned way, to prevent panic when a part of the system is not working. People should not forget the knowledge they have in the traditional way of making assessments about their own health. A way to accomplish this is to ask the user once in a while to verify the measurement of the system with a traditional measurement. Thus, it also depends on the design of the system. A well designed system allows the user to understand why certain behaviour is recommended, and provides insights in the user's process. One should never forget how they used to cope. Rather learn new ways to cope, empowering the user. Dependence from caretakers on the system should also be taken seriously. When the caretaker does not invest anymore to make his own diagnosis, care could be seriously compromised, and too much responsibility could be given to the technological intervention. A new protocol should be made in which it is clear what the responsibility is of the caretaker. This protocol should be a national implemented protocol, in cooperation with specialists. The AmI system should serve as an aid in and not as a full replacement of the current healthcare system.

When interpreting the data, it is wise to verify this with the patient. Sensitivity of the caretaker is needed here, to prevent embarrassment of the patient. When it is not necessary to analyse each spike in the data, this should be avoided.

Dementia

Another point raised was that as dementia developed into a more severe state, it became harder for the patient to relate with the technology. Dementia is still a very hard case to cope with using technology. The aim here should be to postpone the time that they need to go to a nursing home. Because at a certain point it is not realistic anymore to expect a proactive attitude from a patient, which is needed to keep living at home using an Aml healthcare system. Regular check-up is needed for patients with dementia to see whether they can still cope alone. When the user cannot make sense anymore of the recorded memories by the system, which is out of context, missing links and therefore meaningless, the system will not be useful anymore. The frustration of the user in a already tough situation should be avoided, and before this point is reached a new solution should be found for the patient.

The report did not only voice concerns, the following opportunities were identified by the study of the Rathenau Institute (Schuurman, El-Hadidy, Krom, & Walhout, 2009):

- 1. Help keeping track of items or their process
- 2. Postpone the time when one needs to go to nursing home
- 3. Clarify needs of patients
- 4. Psychosocial support
- 5. Help managing medication
- 6. Support healthy lifestyle
- 7. Support maintenance of balance

Although previously a decrease in social contacts was a concern, there are opportunities found to provide the patient with psychosocial support through on-line contacts. An E-buddy is an example of this. Within the safety net of the healthcare system, people could get into contact with people who

had or have the same illness or disease. This can be of great importance in coping with the circumstances, and increase the active attitude of the patient.

Furthermore, the needs of the patients can be clarified through monitoring and questionnaires. This can help the caregiver to tailor the care given to the patient in an efficient way.

The AmI is very suitable to help patients keep track of their process and progress. This can support the patient in keeping up with their regimen, especially when they see the effects of doing so and not following it. The same counts for the support it can give in living a healthy lifestyle and making decisions concerning food.

In sports a personalized schedule can be recommended according to the user's reaction to the different approaches of training. It gives insight on when rest is needed and what is the best way to come to a peak performance.

Requirements for Ambient Intelligence in Healthcare

A lot of developments in Ambient Intelligence have taken place, and a lot of interesting research is done on how to interact with them. The use of Ambient Intelligence determines the requirements for it, and although the vision of general Ambient Intelligence is worthwhile, the specific application in healthcare might strive for other factors. Nehmer et al. (2006) formulated requirements for the software engineering of Ambient Intelligence in their study towards living assistance systems:

- "a. *Robustness*. The system must be extremely robust against all kinds of misuse and errors. Wrong inputs must not lead to a system malfunction or crash.
- b. Availability. The system must do its job even in the presence of hardware component crashes, shortage of hardware resources such as storage or communication bandwidth, and other exceptional conditions.
- c. Extensibility. The system must support its extension by new components at runtime, e.g., sensors to measure specific vital functions or actuators for active assistance, in order to adapt the system to changing disabilities over time.
- d. *Safety*. The system should do exactly the job it was designed for. This requires precise system specifications and a guided design process including verification and validation steps, which assures that the specifications are met. Faulty system components and exceptions must never result in system misbehaviour.
- e. *Security*. A living assistance system, although continuously monitoring persons, must guarantee a well defined degree of privacy for the persons under observation. The privacy rules must be precisely formulated and verified.

- f. *Timeliness*. Although living assistance systems are not considered hard real time systems, some of their services, such as the emergency treatment, have to be carried out in time. Long propagation delays after the detection of an emergency are not tolerable.
- g. Resource Efficiency. The available resources, i.e., processing power, memory, communication bandwidth and energy, have to be utilized as efficiently as possible in order to allow (i) an affordable price of the systems and (ii) the realization of highly integrated, autonomous sensor nodes with a high endurance, which is of particular interest if the sensor nodes have to be mobile.
- h. *Natural, Anticipatory Human-Computer Interaction*. Living assistance systems have to provide human interfaces for three groups of people: the assisted persons, the medical personnel, and the maintenance personnel. Each of these groups has different requirements for interacting with the system. The human interface for the handicapped and elderly persons must be based on voice, gesture, and visual animation, and avoid any kind of particular skills. Multimodal interaction paradigms that combine several modes are a powerful approach to enhance usability. Anticipatory interfaces, which proactively contact persons in certain situations, are considered mandatory.

The service interface for medical personnel should allow to input/output medical data such as critical situation indicators and behavioural patterns of the persons under observation in a domain-specific notation, avoiding any specific IT knowledge.

i. Adaptivity. The systems are able to adapt themselves at runtime. Adaptivity on different levels and scales is considered one outstanding characteristic of living assistance systems. To support this, the systems must monitor themselves, i.e., continuously check critical system conditions such as resource bottlenecks, exceptions raised by components indicating upcoming crashes, low battery."

(Nehmer, Karshmer, Becker, & Lamm, 2006)

When going through these points, there are some interesting requirements formulated. However, some small changes in the formulation could help in the user-friendliness. For instance for the robustness of the system, it is expected to be able to cope with "all kinds of misuse", by not crashing. Of course it is important that the system does not crash, but a different approach could be to guide the user towards correct usage. The design requirements are of main importance for a product to be accepted by the user. Furthermore, the properties of the system should also be appropriate for the user. Therefore, the automation of health care services depends upon patients having the competences needed to operate intelligent health care equipment (Schuurman, El-Hadidy, Krom, & Walhout, 2009). As Ambient Intelligence aims to have natural interaction between the user and the system, one could claim this to be a perfect application area. However, one could also look at possibilities to aid the user in operating the system. Natural interaction and the absence of a tactile interaction could bring about more problems than benefits for some people.

Although system requirements should be able to be fulfilled before even thinking of implementing such a system in situations where lives depend on it, user and usability requirements should be formulated as well, in order to come to a holistic system in the end.

Stakeholders

To have a holistic design, the different stakeholders that are involved in the implementation should be taken into account when forming the requirements of the system. There are several stakeholders, first of all the user, which will use the system in a wide array of conditions in order to maintain their health and have support from the system in accomplishing this. Then there are the caretakers, who involve the specialists, the home nurses, but also the family of the user. Their main goal is to be able to monitor the user in for instance the progress of a treatment, the adherence to their medication regimen etc.

Then there is another category of stakeholders for which the interest lays in a different field. Insurance companies would like to prevent high costs that are made in unnecessary mistakes, besides that, they might want to learn from the data to predict the costs and means needed in order to provide for their customer's needs. A fear is that the technology will be used to put pressure on the client for instance by asking more money for the insurance if one does not use the technology. Producers of the Ambient Intelligence equipment have a commercial take in this. They want to deliver good products and services in order to have a lot of clients buying their products. Furthermore, they want to be able to develop their products to maintain the consumer chain.

Maybe this one is not an official stakeholder, but nonetheless should be taken into account; the potential hacker. Their goals may vary, but sure is that the user will not benefit from this. The safety of the user and its data is a major concern, and if this safety cannot be provided, one should be hesitant of implementing such a system.

Safety of the data

One issue in the Ambient Intelligent technology is the security. There are fears because the production of the chips and other technological components is outsourced in for instance China, and we do not know enough about their vulnerability to hacking or leaking.

Since we do not want to bother the user with a lot of processes within the system, these are placed in the background. However, it is important that there is a control in where the data is going, and action should be taken if data streams are intercepted by the system itself. There is a need for monitoring the monitoring system. The most important question is who will be responsible for monitoring this. Logically this would be the producer of the system. When there are complications they will know where the vulnerable places are in the system. Via an update of the software initiated by the producer of the Ambient Intelligent system as well, protecting all of their clients at once rather than one by one and having the responsibility with the user. In this specific application this cannot be asked from the user.

A lot of concern is expressed on how the insurance companies will handle the data (Schuurman, El-Hadidy, Krom, & Walhout, Ambient Intelligence. Toekomst van de zorg of zorg van de toekomst, 2007). To comment on this, the current insurance system in the Netherlands is far from perfect. There are too many providers, providing packages that cannot be compared with one another, with small print limitations to their coverage. Having centralised healthcare, the way the Netherlands had before privatising, would have many benefits. First of all, there would be a lot more transparency for both the user and the government. There would be less need to fear for abuse of data by the insurance companies since they are serving the state. An example could be taken in the Scandinavian healthcare system.

More problematic could be when the data is in the hands of a hacker, who might capture data to sell to commercial companies, or even worse, edit the data. This could result in disasters for the health of the user or in spam at your front door of companies trying to sell you medication, diets, equipments, the list is endless. So yes, the technology used should encrypt the data very well and protect it against these threats. As the means of the hacker will evolve, there should be an adaptive functionality of the technology used in Ambient Intelligence as well. The least it should have is awareness of third parties watching, with the adequate response to it.

Furthermore, this stresses the importance of not solely relying on the system. Abnormalities detected by the system should always be verified with an independent measurement.

Specificity of the system

A pitfall of the current implementations is the lack of a holistic approach. The needs of the user go beyond the specifics of the condition of their disease. In well-being aspects like social contact plays a major part. The feel that the current proposed designs give is that the user can do without or less

help of other people. Even though this empowers the user to be independent, this might be rather a wish of the society than of the user. The responsibility for having social contact should not lay within a technology, yet there is a major transition in the life of those people who choose to use these systems, and guidance in this change is appropriate. The need for contact with family changes from a necessity to cope with the daily activities to a need for mental well-being, and the responsibility is now with the user to express this need.

Phase of implementation

If the aim is for the user to maintain its independency, it is important to implement these systems before they are depending. Once they become dependent, social roles within the family will change. Furthermore it is important that the use of the system is in their routine and that they understand the feedback and main workings of the technology. When the patient is in a new stage of experiencing disabilities or difficulties, this would not be the ideal point in time to introduce a new technology, which is not only new but even takes effort to grasp for most of the people in the younger generation. Although the technology could be unobtrusive, one likes to know what goes on in their house and what personal information is gathered and who has access to this.

Promises of Ambient Intelligence revisited

The basic premise of Ambient Intelligence is that the technology disappears into the background. One of the main principles in design is that the user should feel in control. If the technology has disappeared, and cannot be called into the foreground, this requirement seems impossible to attain. However, if the technology can be called into the foreground providing the user with insight in what is going on in the system, this would empower the user. Yet there might be other complications with such an approach, according to Crutzen (2006) invisible and visible representations and interpretations of actions will influence the way human actors will and can act in the future, making an off/on switch for this technology an inappropriate instrument to make the invisible visible again or vice versa. It will cause an irritating flickering and more likely stabilise the invisible and visible as excluding positions (Crutzen, 2006). But maybe it is not necessary to hide everything in the background; domesticated artificial products are taken for granted, when they are thought of as a natural part of our daily life or when they become a part of our routines (Punie, 2003). Taken these two findings into consideration, it might be a better solution to incorporate the system into a daily routine than to make the system invisible running in the background.

Being able to naturally communicate with the technology, which is one of the other premises, raises the bar for the technology tremendously. Once a technology can understand for instance a simple spoken phrase, the expectations of the user rise to a level that the system has a human like understanding of the input they give. Since we are still far away from these kinds of algorithms, the interaction with the system should correspond with the level of understanding of the system, comparing it to the human mind rather than last year's cutting edge technology.

More important is that the system can couple the different measurements, and make sense of this. For instance, when GPS data is telling that the user is in the Himalaya's, it should take this into account when measuring breathing rhythms. Or coupling stress levels with the patient's condition. These kinds of features are more important when AmI is applied in healthcare.

AmI aims that people are empowered through a context aware environment that is sensitive, adaptive and responsive to their needs, habits, gestures and emotions. Especially emotions will be hard to respond to. It takes a lot of learning of the system before it can react to this specific person. When being sad, sometimes you need to deal with the issues and think things over. In other times one might want to change their mood, sometimes with the presence of other people, sometimes alone. The way humans deal with emotions has a lot of variance, and not everything has to be accounted for by a technological system. However, when the emotions are on the border with depression, aid is more than welcome. But for the most part, as emotions go, to facilitate options would suffice, rather than having the system choosing one. In this way the user is really empowered, and not living simply by a system's choice.

Discussion

From this literature research can be concluded that it is a necessity to look for a solution to provide care to more people with less staff. These solutions should be ready to be implemented on a full scale not even on such a very long term, just a decade from now. Therefore the importance of having the right main focus in the development of technologies that could offer a solution for this problem is crucial. What the Rathenau Institute has shown, is that there is not enough emphasis on the social context of the patient. A major pitfall that they indicate is that personal care is interchanged with technological systems. Even though this scenario is not favourable, when in need of help, at least the care could be provided with the amount of people available. The system should never be marketed as a replacement of social structures, but a way should be found to incorporate another form of social interaction that can fulfil at least part of the social need the patient has. An example could be

contact with people in a similar situation in which people can share their knowledge on how they cope with certain obstacles in life. Another important aspect is to maintain a strong bond between family members, in such a way that emergency cases are not the only time when they will see each other. The Ambient Intelligence system should try to provide in this, and maybe monitor this as well as a part of the patient's well-being.

What could be seen from the Technology Assessment report from the Rathenau Institute is that the design process has revolved more around the caregiver than the patient, who is the actual user. The fact that the caregivers will have an easier job seemed to have a higher priority than how the user feels about this. As a result of this, the user does not feel in control in the currently presented solutions, and feels like they do not really have a choice. It is important to include the prospect user in the design process, and to get in touch with their needs, insecurities and obstacles. Because there will be a lot of variance in this, it would be good if the system has a certain flexibility and functionalities can easily be added. A way to ease the patients into the system could be a gradual approach. A direct link between how much they use the sensors and comply with the recommendations of the system and how much they benefit in terms of health could persuade the user to use it more and realise the purpose of doing so. In this case the user has the freedom to choose what to start with, and can start using the system in a comfortable manner. Data sharing is something that can still feel very much intrusive. Therefore it might be good for the user to actively send the data in the starting period, to realise which data is sent and why it is useful when this part in the process is automatic. A mistake that is often made is that when people do not understand the technology they will also not understand the concept. However, this part is of great importance for the acceptance of the system. It would be sensible if a clear instruction of what the system they use does is on paper in the house. In this way they can read it again if they wish to or have insecurities, or discuss it with (grand)children. A holistic design approach is needed to come to a design for AmI in healthcare which is accepted by its user which both promotes the well-being of the user as helps society to care for its patients and elderly.

As for the fears of the technology, they are justified; on this moment there still is vulnerability in both the hardware as the data streams that would be automatically sent and no safety guarantee can be given concerning the personal data. In the future the question will be if people are willing to go on this path of data exchange to gain in health support. When looking at the behaviour of the current youth, it seems that for a large part of the population the user should be protected against itself for giving permissions to record data too easily and accepting agreements just to benefit from a service. Legislation should prevent abuse of the collected data by for instance health insurance companies, and technological developments are needed to make the technology in itself more safe.

Furthermore, there should not be a ten page contract to sign with legal terms on what they are giving away, and when making a decision, a patient should have the freedom to come back to it and discuss a new approach with the caregivers. This flexibility will give the patients a reassurance that when it is not suiting their wishes they can change their mind, and aid in the process of accepting the technology.

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