Elderly People’s Perceptions about Care and the Use of Assistive Technology Services (ATS)

Christina Harrefors

Luleå University of Technology
Elderly Peoples’ Perceptions about Care and the Use of Assistive Technology Services (ATS)

Christina Harrefors

Luleå University of Technology
Department of Health Science
Division of Nursing
# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>4</td>
</tr>
<tr>
<td>ORIGINAL PAPERS</td>
<td>5</td>
</tr>
<tr>
<td>PREFACE</td>
<td>6</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>7</td>
</tr>
<tr>
<td>Care of the elderly – a historical view</td>
<td>8</td>
</tr>
<tr>
<td>The home – a place to be cared for</td>
<td>10</td>
</tr>
<tr>
<td>Basic concepts in quality care</td>
<td>11</td>
</tr>
<tr>
<td>Information technology in care of the elderly</td>
<td>13</td>
</tr>
<tr>
<td>THE AIM OF THE LICENTIATE THESIS</td>
<td>16</td>
</tr>
<tr>
<td>METHODOLOGICAL DESIGN</td>
<td>17</td>
</tr>
<tr>
<td>Participants and procedure</td>
<td>17</td>
</tr>
<tr>
<td>Interviews</td>
<td>18</td>
</tr>
<tr>
<td>Data analysis</td>
<td>19</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>20</td>
</tr>
<tr>
<td>FINDINGS</td>
<td>22</td>
</tr>
<tr>
<td>Best care</td>
<td>22</td>
</tr>
<tr>
<td>Assistive Technical Services in care at home</td>
<td>24</td>
</tr>
<tr>
<td>Integrated findings in Paper I and Paper II</td>
<td>27</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td>31</td>
</tr>
<tr>
<td>Methodological considerations</td>
<td>35</td>
</tr>
<tr>
<td>Conclusion</td>
<td>36</td>
</tr>
<tr>
<td>SUMMARY IN SWEDISH – SVENSK SAMMANFATTNING</td>
<td>38</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENT</td>
<td>40</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>41</td>
</tr>
</tbody>
</table>
Elderly Peoples’ Perceptions about Care and the Use of Assistive Technology Services (ATS)

Christina Harrefors, Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå Sweden.

ABSTRACT

Values associated with the care of the elderly have changed and developed during the last decades due to socio-political changes. Dignity is a basic concept for quality care regardless of how and where care is given. Assistive Technology Services (ATS) are used to promote quality care and support for care-dependent elderly living at home. Previous research has described quality care and the use of ATS in care; however, as values change over time it is necessary to illuminate values in care.

The overall aim of this licentiate thesis was to describe elderly peoples’ perceptions about care and the use of ATS if care is needed in the future. Qualitative research interviews were conducted with twelve healthy elderly couples living in their own homes. All participants were 70 years of age or older and received no professional care or social support. Open, individual, semi-structured interviews were conducted and analysis was supported by written vignettes describing three levels of care needs. A qualitative content analysis was used to analyze the interviews.

This study shows that regardless of the health scenario presented ranging from required care while remaining in the home with a healthy partner to total dependence for care without a partner in the home; participants strived to maintain the self and desired dignified care at the end of life. As the health scenarios were changed they discussed new solutions to achieve the goals of individuality and dignity. The best care was related to their home and their relationship to the partner and later on the best care was perceived as being in a nursing home with well educated nursing staff. Participants hoped that nursing competence included a basic nursing competence as well as respect, compassion and ability to closeness. The risk of losing one’s individuality and becoming anonymous without meaningful relationships was a pervading concern amongst participants.

There were also a broad range of perceptions regarding the use of ATS in care. ATS was seen as either an asset or a threat depending on care needs and abilities. The use of ATS was viewed positively by participants of the study since it would enable them to continue a normal life even if they had some disabilities. The trust they experienced in their relationship with their partner was a firm foundation for learning and handling new technology. Hesitation in their abilities to use ATS increased if they lacked a partner and their cognitive impairment increased. Hesitation turned to fear and revulsion against the use of ATS if they were dependent for their care and they did not have a partner at home to assist them.

These findings highlight elderly peoples’ values about quality care and the use of ATS in care and should be taken into consideration when planning care of the elderly, and implementing new technology related to their care.

Keywords: perceptions, values, care of the elderly, Assistive Technology Services (ATS), care at home, dignity, control, qualitative content analysis
ORIGINAL PAPERS

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


Papers have been reprinted with the kind permission of the journals.
Preface

For as long as I can remember, I have had an interest in ethical questions related to my work as a registered nurse (RN). My interest increased after I started to work at a haematological ward where severely ill people were treated. There were a lot of technical devices used in the care of the patients, i.e. drip counters/cassettes that automatically deliver the proper dose of drugs. If correctly programmed, RNs can be sure that the device provides the proper dose at the correct time. When these technical devices were first introduced, many RNs felt unsafe using them instead of the traditional, continuous observation techniques; however, as RNs became more familiar with the technology and realized its benefits, it was really appreciated. How RNs valued the drip counters/cassettes changed over time, and patients and their relatives also appreciated the devices. This technical device represented independence, freedom, and safety. The ability to leave the ward for a while with the knowledge that if something went wrong, the machine would sound an alarm and help was not far away was liberating.

Later in my career, I started to work as a nurse consultant in residential eldercare. It was common that the elderly at the institutions and those who lived at home had a special alarm that alerted nursing staff in the event that something went wrong or they needed other assistance. Sometimes they fell on the floor, became sick or just wanted something. They could press the button and through a telephone line get in touch with nursing staff. These technical devices became connected with values of safety and trust. I also noticed that spending extra time chatting with the old person following their nursing care left them extremely satisfied and thankful; and was expressed with laughter, cries, or a hug. These moments allowed for story telling and getting to know each other, but unfortunately did not occur very often due to time constraints.

These experiences made me interested in the value foundation in care of the elderly and inspired me to conduct research about elderly peoples’ values in connection to their care in general and the use of Assistive Technology Services (ATS) specifically. My interest was also based on the rapid development of ATS in care of the elderly, and a trend in Sweden towards private home care versus institutional care for the elderly.
INTRODUCTION
In this thesis, I describe values associated with quality care and the use of Assistive
Technology Services (ATS) in care of the elderly with a focus on care in Sweden. Literature
on this subject discusses three concepts: eldercare, elderly care, and care of the elderly.
Eldercare and elderly care describe elderly people living in nursing homes, institutions,
residential care, or sheltered homes. This thesis investigates elderly people living at home,
and therefore focuses on the concept of care of the elderly. It may also be useful to define
some common concepts connected with care including values, ethics, and morals. Values are
beliefs or ideals held by individuals or groups’ concerning what is good, right, desirable, or
important in an idea, object, or action (White & Wooten, 1986). Ethics are concepts and
standards held by individuals or groups concerning the values surrounding the rightness and
wrongness of modes of conduct in human behaviour, and the result of human behaviour
actions (White & Wooten, 1986). Morals refer to practical activities against someone or
something. In everyday language, ethics and morals are synonyms; however, in the western
tradition, ethics are a theoretical reflection over human actions (Fagerberg et al., 1984, p. 11).

There are few studies regarding the values of care of the elderly from the public and
individual perspective. In society, values associated with care are expressed in the policies,
laws, and principles regulating public healthcare. Perceptions, attitudes, concepts, and views
are often used to describe peoples’ values regarding care, including the people receiving care
and the people giving care. According to White & Wooten’s (1986) definition of values, there
are different ways to express values imbedded in the concept, care of the elderly. This thesis
will examine an overarching question:

What values are imbedded in healthy elderly peoples’ perceptions
of quality care and the use of ATS in eldercare?
Care of the elderly – a historical view

In this thesis, I have chosen to describe how the concept of care of the elderly has developed in Sweden. Political, economical, and cultural changes have impacted our values regarding care over time. The concept, care of the elderly, is a phenomenon for which content has changed and developed during the last one hundred years. A report by The National Board of Health and Welfare (1991) states that the welfare system in each country has its roots in the social and cultural tradition. For example, Sweden’s officially regulated system has developed from the cultural context. This means that values, norms, laws, habits, and religious perceptions prescribe the framework for care and nursing (Odén, 1998). Throughout the 19th century, the development of care of the elderly changed its focus. Treatment of the elderly as a group has shifted with treatment of the individual person, at least from a theoretical perspective. This is reflected in laws and policies which include ethical principles such as autonomy, integrity, and dignity (Gaunt & Lantz, 1996).

Between 100 and 150 years ago, the home as a place played an important role as a social foundation. The household was not a private sphere, but rather a social construction where teaching, practices of religion, care for frail and ill elderly, and care for children were an obligation for the family. The family was the base for all care and it was an unspoken rule that the family took care of its elderly. Women, especially, had the responsibility to guide members of the family from the cradle to the grave (Broomé & Jonsson, 1994; Elstad & Hamran, 2006). This ideal from northern Norway and Sweden was similar to many other countries during this time. The elderly people’s living conditions where depended on the extended family. The extended family construction, several generations living together in the same home, was common in many parts of the world; however, demographic changes and modernism changed the extended family prerequisites (Kertzer, 1995). In the early 1900s, there was a change from an extended family care system to a public-based care system for the elderly in Sweden. During the first two decades of the 1900s, there were new regulations as well as new ways of organizing care of the elderly. The duty to care for the weak in society remained a value throughout the development in the public care system (Odén 1998 p. 45). A 1918 law stated that each municipality had to provide “old peoples’ homes” (älderdomshem). The institutions were intended to be as “home-like” as possible with elderly, fairly healthy people in residence. People living in these homes were no longer referred to as poor people (fattighjon), but rather as pensioners or poor relief takers (Åman, 1976).
Qvarsell (1991, p. 143) states that authors Ivar-Lo Johansson (1901-1990) and Ellen Key (1849-1926) were critical of “old peoples’ homes,” believing that these “homes” could satisfy material needs at best, but could never convey the feeling of home. Both authors claimed that old and ill people had a right to live in their own home; a concept that we presently refer to as old people’s integrity. Moving elderly people from their own home’s to “old peoples’ homes” had negative consequences such as loss of autonomy, identity, and dignity (Gaunt & Lantz, 1996; Rosén, 2004). Arguing for this idea in the media, authors Johansson and Key created public opinion for quality care of the elderly; their thoughts that all people have the right to their own home became more or less an official policy for the care of the elderly (Edebalk, 1990; Gaunt & Lantz, 1996). The values associated with quality care of the elderly have shifted from living at home with extended family towards institutional care and back to the private home again.

Care of the elderly was no longer a responsibility for relatives, but became the responsibility of the municipality (Edebalk, 1990; Odén, 1998; Rosén, 2004). This radical change in care occurred in 1992 in the form of the Elderly Reform Bill (Ädelreformen) and stated that the responsibility for elderly care was a main task for municipalities. Furthermore, this bill became a fundamental condition for the municipalities to provide primary care and care at home for elderly people. Swedish laws regulating public healthcare state that all care should be administered with respect and dignity (SFS, 1982:763). The Swedish Parliamentary Priority Commission (Ministry of Health- and Social Affairs, 2001) based their work on three ethical principles: 1) the principle of human dignity which means that regardless of circumstances, there is a right to be treated with dignity; 2) the principle of need and solidarity which means that the most care resources should be given to the person in most need of care, i.e. children, people with dementia, and people with difficulties communicating; and 3) the cost-efficiency principle which means one should strive to find a balance between costs and effect, related to improved health and quality of life. According to these principles, age should not be a criterion for receiving good healthcare in Sweden. Furthermore, it advocates for an individual’s right to be valued for their very existence.
The home – a place to be cared for

The home is a unique place. It contains a specific combination of material and symbolic attributes with strict boundaries between the official and the private. The concept of home overlaps with the concept of family and is valued as special, often connected with feelings of closeness and safety. The home is a place to develop close and deep relationships. It is an arena for life. Unfortunately, it can also be a place associated with violence and abuse. The home impacts our individual identity, is a place we long for and dream about (Bowlby et al., 1997; Moore, 2000; Borg, 2005; Lantz, 2007). Daily routines and the details of home can be a way to manifest that life is normal especially as people age and suffer from illnesses (Thomas, 1986; Öhlander, 1991). Living at home can strengthen the mind of a person with dementia where routines and security are well established (Öhlander, 1999). In a study (Borg, 2005) discussing the prerequisites for what makes a home a home, the findings show that simply having a home is important in recovering from an illness. The experiences of home have also been described as a dialectic process where informants described their thoughts and feelings about home during the time they had been away (Case, 1996). Case (1996) argues that there is evidence that the dialectic process promotes the concept of home. The two main themes of routine and loneliness create a picture of the home (Case, 1996). The concept of home can be described from a sociological, psychological, physical, and philosophical viewpoint. As a person’s age, relationship status, and illness changes, the way in which the home is valued may also change over time (Leith, 2006).

Administrating nursing care at home provides many benefits for people needing care. Self-determination plays a central role when receiving care at home. Specific demands are placed on nursing staff when a severely ill person receives care at home because the home has specific cultural rules regarding autonomy (Borell & Johansson, 2005). The person who receives care at home has more possibilities to make decisions for themself as compared to the person being cared for at a nursing home (Sandman, 2007). Furthermore, when care is administered at home, nursing staff has the opportunity to see the person as an individual with his or her own routines in an environment that is familiar to the person needing care (Karlsson, 2005).
Basic concepts in quality care

The health care policy in Sweden states that care should be based on a humanistic view of the individual, where each person is seen as unique and of equal value. Values of quality care are closely related to dignity, a way to be treated as worthy. Within the humanistic view, the concept of dignity is a primary value (Beyleveld & Brownsword, 2001) and an important aspect of ethical care. The word “dignity” is derived from two Latin words: “dignitas” meaning merit and “dignus” meaning worthy (Collins, 1991). Kant’s (1948) view of dignity is that it is an intrinsic, unconditional, and incomparable worth or worthiness and should not be compared with things that have economic value. Human dignity is an absolute dignity and is given to each individual through nature and cannot be taken away (Edlund, 2002). There are different approaches to understand the idea or the concept of dignity. Maiti & Trorey (2004) emphasize that dignity is a multidimensional, subjective, and relative concept.

Nordenfelt (2004) discusses the concept of dignity by distinguishing between its intrinsic and contingent value, and by describing four concepts. The first concept, dignity of Menschenwürde, means that we all have, to the same degree, an intrinsic dignity because we are human. It is specifically a human value. We have this value and we are equal. The dignity of Menschenwürde cannot be taken from the human being as long as they live. Besides, it is a duty for all of us to respect these rights. The second concept is dignity as merit which means that people have a special dignity based on certain roles or office, or because they have earned merit through their actions. The dignities of merit can come and go and people can be promoted and demoted. People can have an informal fame and a high reputation for a period of time and then it can be lost. The third concept, dignity as moral status, is dignity related to people’s moral status emerging from their actions and omissions and from what kind of people they are. Dignity of moral status is dimensional. Status can vary from extremely high to extremely low position and therefore it may come and go. Dignity as moral status has some features in common with dignity as merit, but dignity as moral status is dependent on the thoughts and deeds of the subject. The fourth and final concept of dignity is dignity of identity. Dignity of identity is not dependent on the subject’s merits or by their formal or informal moral status. This is the dignity that we attach to ourselves as integrated and autonomous persons. It includes the person’s history and the person’s future with all the relationships to other human beings. This kind of dignity can be taken away by external events, by the acts of other people, as well as by injury, illness, or old age (Nordenfelt, 2004).
Dignity seems to be a salient concern among healthy older people. In a study where the participants were asked to describe how they viewed dignity, they emphasized dignity of identity, human rights, and autonomy (Woolhead et al., 2004). The same results were described by patients in the hospital setting where dignity was perceived as privacy, autonomy, independence, control, and respect. In general, older people agreed that admission to the hospital represented loss of dignity. The most frightening images were loss of control and loss of independence (Maititi & Trorey, 2004). Patients, relatives, and professionals in palliative care viewed dignity as being a human, having control, relationships, belonging and maintaining the individual self (Enes Duartes, 2003).

It is unanimous amongst health care professionals that another highly emphasized value of quality in nursing care is the maintenance of integrity, especially in long-term care (Andersson, 1994; Kihlgren & Thorsén, 1996; Randers & Mattiasson, 2000; Randers & Mattiasson, 2004; Franklin et al., 2006; Franklin, 2007). Integrity is defined as a state of wholeness (Irurita & Williams, 2001). It gives the individual a sense of being in control of their life and having a private self which is unique and whole (Kihlgren & Thorsén, 1996). Respectful care and treatment makes it possible to maintain integrity (Andersson, 1994; Irurita & Williams, 2001). Integrity as a concept is bound to the individual’s existence regardless of the situation and must always be respected. Furthermore, it means the opportunity to be alone or together with others; and that individual needs, desires, and habits are satisfied (Andersson, 1994; Kihlgren & Thorsén, 1996). Patient participation in decision-making in nursing care is regarded as a prerequisite for quality clinical practice in regards to the person's autonomy and integrity. Nursing staff have a professional responsibility to act in a way that allows patients to participate and make decisions according to their own values, according to their different preferences (Florin et al., 2008).

Respect for autonomy is a core element in quality care (van Thiel & van Delden, 2001) and closely connected to integrity (Bischofberger, 1990; Andersson, 1994; Randers & Mattiasson, 2004). Autonomy is often liberally interpreted with a focus on independence (Wetle, 1991; van Thiel & van Delden, 2001) and can be understood as the individual’s interest in making significant decisions regarding his or her life. Randers & Mattiasson (2004) discuss how the concept of respect for the patient strengthens their autonomy, even if the autonomy varies depending on the context. Autonomy and dignity appear to presuppose one another and can not be separated if older adult patient’s dignity is to be maintained. Values like autonomy and
dignity are highly emphasized as factors that are promoted by independent living for elderly in long-term care (Boisaubin et al., 2007). Autonomy is best maintained when a patient makes their own decisions and remains independent. The loss of independence is often equivalent to losing everything. And, if a patient is incapable of making their own decision, they desire that their close relatives, a spouse, or their children advocate and make decisions for them (Boisaubin et al., 2007).

Human beings are mutually interdependent upon one another. We are what we are because of the context we belong to. Different needs, wishes, and expectations are designed through the collective way of living. The ethical demand, according to Lögstrup (1956/1997, pp. 18-48), means that human interdependence is reciprocal. As humans, we are each other’s world and destiny. Life is a gift and consequently, there is an obligation to take care of our own life as well as the lives of others. We have the power and responsibility to take care of one another constructively or destructively. This ethical demand is unspoken, quiet, and radical. The challenge is that as humans we have to interpret the ethical demand in a community with other demands (Lögstrup, 1956/1997, pp. 18-48). Providing quality care to someone who is suffering from illness and dependent on care is a reciprocal process.

**Information Technology in care of the elderly**

There are a large number of concepts and definitions describing information technology in care. In this thesis, I use the concept of *Assistive Technology Services (ATS)* which refers to support for people with disabilities and their caregivers to help, select, acquire, or use adaptive devices (http://www.rehabtool.com/at.html). Another concept frequently used in this thesis is *Information and Communication Technology (ICT)* which, broadly defined, enables people to communicate, gather communication, and interact with distant services faster, easier, excessable and without the limits of time and space (Campell et al., 1999). When ATS is used in this thesis it refers to technology services in eldercare based on ICT.

Western cultures place a high value on technological development and are generally confident that its use can help solve many human problems. Technological development and innovations have been revolutionary, almost like a paradigm shift. It has quickly and absolutely transformed medical practice (Denton, 1993). Collste (1998) describes how technology extends and substitutes human action. Technology is useful because it makes it
easier and faster to achieve different goals. According to Bynum (1998), ICT revolutionized information, forever and significantly changing many aspects of life with affects on community life, family life, and human relationships. The use of ICT has influenced and reformed many working areas, including medicine and nursing care. However, perceptions regarding the use of technology have varied in the history of care. On the one hand, it has been linked to advances in medicine and nursing care, and on the other hand, there have been many concerns about losses to the quality of care. One major concern has been the association of technology with the philosophical mechanistic paradigm which conceptualises humans as components and parts and contradicts a humanistic paradigm (Sandelowski, 2000). Different ways of using ICT have been reported as beneficial for users, whether users are patients, relatives, or healthcare professionals (Östlund, 1995; Whitten et al., 1997; Jenkins & Mc Sweeney, 2001; Sävenstedt et al., 2003; Vincent et al., 2006; Torp et al., 2008). Development of advanced technology in healthcare has been viewed positively; however, it continues to pose problems in regards to the ethical principles of healthcare (Rauhala & Topo, 2003; Dittmar et al., 2004). There is a duality described by health personnel using ICT among elderly people with large caring needs. This duality includes a feeling of fear of inhumane care and makes health personnel resistant to its introduction (Sävenstedt et al., 2006).

The use of ICT applications in care and treatment of people with chronic health problems have facilitated the development of more home-based care. Living at home is highly valued by individuals in need of care. The use of ATS in the home has increased and it has become more common when care is given at home (Soar & Seo, 2007). The development of advanced technology for use in homecare has implications for both the recipients of care and their families. The home turns into a working place for professional staff and reduces privacy for the person receiving care (Røback & Herzog, 2003). The perception of the home where a person receives medical care is in sharp contrast to the perception of the private home as a place for close family relationships (Gardner, 2000). For people dependent on ATS for their survival (Lindahl et al., 2005), the new technology has been described as the technique becomes a part of the home. For people suffering from cognitive impairments who want to continue living at home, the use of pervasive computing technology allows for independence and security (Magnusson et al., 2004; Cahill et al., 2007; Soar & Seo, 2007). Torp et. al (2008) report that the use of ICT has the potential to promote health for elderly spousal caregivers. These studies confirm that the value associated with the use of ICT in care has
changed since its introduction in the early 1950s. Cost reduction is another important consequence of implementing ICT among elderly suffering from mental diseases (Menon et al., 2001; Magnusson & Hansson, 2005; Vincent et al., 2006; Kwang-Hyun et al., 2008). Although dependency on advanced technology for care at home may be considered a burden, it also represents independence and autonomy (Lindahl et al., 2003). Use of advanced technology in care at home is related to feelings of safety and openness, but also with fear and insecurity about the future. Technology is viewed as a way to promote quality humane care both from the caregiver’s and caretaker’s perspective; however, others believe the use of technology could result in poor and inhuman care (Sävenstedt et al., 2006).

Implementing ICT systems in elderly care is an increasing concern. ICT systems should support and satisfy the needs of different groups connected to care, such as users on different organizational levels, the elderly, and their relatives. As a result, there are value conflicts that need to be discussed and negotiated related to the use of ICT in elderly care (Hedström, 2007). The author claims that values are related to an individual, and values guide peoples’ actions. Hedström (2004) also discusses using ICT as a tool for providing quality care of the elderly, especially when media reports incongruities in care of the elderly. There is an expectation from society that ICT in care gives possible solutions to different types of problems. ICT has been positively valued and given unexpected outcomes. Different needs and expectations from different members in the field of care of the elderly might be pervaded with difficulties depending of how needs, expectations, and solutions are implemented and discussed. New technology in care has consequences for its users and it might be difficult to foresee the consequences. When Collste (1998) discusses ethical aspects of technology, he states that new technology often satisfies certain demands and needs from different members in society, which is a condition for successful implementation. After a while, unintentional and undesirable consequences may appear. Society often becomes dependent of the new technology, and as a result it can be difficult to change to a new system. As technological systems influence human life and well-being in different ways, he argues that it is the task for ethicists to reflect over the consequences (Collste, 1998). In retrospect, the development of technology to this point can be seen as something necessary and hopefully beneficial. According to Molin et al. (2007), there are still major concerns about whether the use of ICT is beneficial or if it replaces the human touch, especially for users suffering from cognitive impairments without close relatives who can represent and advocate for them.
THE AIM OF THE LICENTIATE THESIS
The overall aim of this licentiate thesis was to describe healthy elderly peoples’ perceptions about care and the use of Assistive Technology Services (ATS) if in need of care in the future.

The specific aims for the papers are:

Paper I to describe elderly peoples’ perceptions of how they want to be cared for, from a perspective of being in need of assistance with personal care, in the future.

Paper II to describe healthy, elderly peoples’ perceptions of using Assistive Technology Services (ATS) when in need of assistance with care.
METHODOLOGICAL DESIGN
A qualitative method with interviews was used to describe perceptions about care and the use of ATS among healthy elderly persons. Qualitative studies seek to explore, describe, and answer questions such as what, how, and why; and can be used when strict descriptions of a phenomenon are desired (Sandelowski, 2004). Interviews are a way to understand phenomena, as well as an established technique in the qualitative research tradition (Patton, 2002; Kvale, 2007). A technique with vignettes was used to facilitate interviews about the participant’s perceptions. Vignettes are a technique used to help the participant achieve an enactment in the scenarios discussed, to get in touch with their feelings, and elicit their perceptions and ideas about a phenomenon (cf. Drew 1993). To select the sample population for the interviews, a strategy to achieve variation among the informants was used to cover different experiences of the phenomenon studied (cf. Sandelowski, 1995).

Participants and procedure
The two papers included in this thesis were conducted with 12 healthy elderly couples from six different locations in northern Sweden, representing three villages and three cities (Table 1). Being healthy in this thesis means that the participants could have different medical diagnosis but not in need of professional assistance at home. The participants were recruited from two of the most established organizations for pensioners. The author visited member meetings, made a presentation about the study, and invited individuals to participate. At the end of the meetings, individuals had the opportunity to express their interest and received written information about the study. Approximately one week following the meeting, the researcher contacted each couple to arrange an interview. The inclusion criteria for participants were: 1) 70 years of age or older; 2) living in couplehood at the same address for at least five years; and 3) receiving no social services at the time of the interview. All 12 couples were married except for one couple, who were co-habitants. The length of relationships varied between 16 and 58 years (Mean = 46.8, Median = 50.5). The youngest participant was 70 years old and the oldest was 83 years old (Mean = 74.8). None of the participants used any kind of technical support, such as an alarm or assistive device.
Table 1. Socio-demographic characteristics of the elderly participants (N=23).

<table>
<thead>
<tr>
<th>Variables</th>
<th>N = 23</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living today</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private house</td>
<td>17</td>
<td>74</td>
</tr>
<tr>
<td>Terrace house</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>Cooperative flat/apartment</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>Flat with right of tenancy</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td><strong>Distance to primary health care centre</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 20 km</td>
<td>19</td>
<td>82.4</td>
</tr>
<tr>
<td>21 – 40 km</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>41 – 60 km</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td><strong>Distance to hospital</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 50 km</td>
<td>14</td>
<td>60.8</td>
</tr>
<tr>
<td>51 – 100 km</td>
<td>5</td>
<td>21.8</td>
</tr>
<tr>
<td>101 – 150 km</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td><strong>Living environment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>14</td>
<td>60.8</td>
</tr>
<tr>
<td>Village</td>
<td>9</td>
<td>39.2</td>
</tr>
</tbody>
</table>

**Interviews**

Open, individual tape-recorded interviews, based on vignettes, were conducted with the 24 participants in their home. The interviews were the basis for both papers I and II. In the process of interviewing, one interview was excluded due to technical problems with the tape recorder. Health scenarios were designed to create a picture of situations where the participant was in need of care. Scenarios were step-wise with increasing health complications and care needs. The first scenario was “little need of care, healthy partner at home” and was presented as a situation “where you are doing fine, but cannot take care of your personal hygiene”. The second scenario was “dependent on care, healthy partner at home” and was presented as a situation “with several bodily dysfunctions, and totally dependent on care from others”. The third scenario was “dependent on care, no partner at home” and was presented as a situation “with several bodily dysfunctions, and totally dependent on care from others” (Table 2). The three scenarios were presented to each participant as affecting themselves and then from the perspective of affecting their partner. There were two parts to each interview; the first part concerned the concept of “quality care” and the second concerned “assistive technology services”. The scenarios were written down separately, one scenario on each piece of paper. In the interviews, scenarios were presented one after the other from least to most severe, followed by questions (Table 2). For each scenario, the interviewer encouraged the
participants to narrate freely about their perceptions using follow-up questions when necessary. During the interviews, the concept of ATS was used in a broad sense. Examples of different technology services were presented ranging from simple technical aids for daily living to assistive technology for security, communication, and remote consultation. The interviews, between 30-60 minutes, were conducted with each participant individually and transcribed verbatim. Notations of non-verbal expressions such as silence, cries, laughter, and body movements were made directly after the interview. The interviews were very rich and the participants well articulated. It was determined that to do justice to the content in the text, the text was divided into two parts, two analyses and two publications.

<table>
<thead>
<tr>
<th>Different scenarios</th>
<th>Perspective</th>
<th>Main questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st scenario: little need of care, healthy partner</td>
<td>Own</td>
<td>What are your perceptions of the best care in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS for remote consultation and health examination in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS in this situation?</td>
</tr>
<tr>
<td>2nd scenario: dependent on care, healthy partner</td>
<td>Own</td>
<td>What are your perceptions of the best care in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS for remote consultation and health examination in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS in this situation?</td>
</tr>
<tr>
<td>3rd scenario: dependent on care, no partner at home</td>
<td>Own</td>
<td>What are your perceptions of the best care in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS for remote consultation and health examination in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS in this situation?</td>
</tr>
<tr>
<td>1st scenario: little need of care, healthy partner</td>
<td>Partner’s</td>
<td>What are your partner’s perceptions of the best care in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your partner’s perceptions of using ATS for remote consultation and health examination in this situation?</td>
</tr>
<tr>
<td>2nd scenario: dependent on care, healthy partner</td>
<td>Partner’s</td>
<td>What are your partner’s perceptions of the best care in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your partner’s perceptions of using ATS for remote consultation and health examination in this situation?</td>
</tr>
<tr>
<td>3rd scenario: dependent on care, no partner at home</td>
<td>Partner’s</td>
<td>What are your partner’s perceptions of the best care in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your partner’s perceptions of using ATS for remote consultation and health examination in this situation?</td>
</tr>
</tbody>
</table>

**Data analysis**

The collected data from 12 healthy elderly couples were analysed in two separate analyses. The data concerned with “quality care” were analyzed and discussed in paper I, and the data concerning the use of ATS was analyzed and discussed in paper II. To analyze the interviews,
A qualitative content analysis inspired by Downe-Wamboldt (1992) was used. After the transcription, the text was read and reviewed in order to acquire an overall impression of the content. Then, the text was divided into meaning units corresponding to the aim. All text from the interviews was included in the analysis. Meaning units were condensed, coded, and initially grouped according to the person’s own perceptions about themselves and then their perceptions about their partner. Gradually, it was recognized that the two perspectives had the same dimensions of content and the two perspectives merged into one. This process was similar for both paper I and II. The step-by-step grouping of content into more abstract levels resulted in seven sub-categories that formed three categories and an over-arching theme (Table 3) in paper I. In paper II, the content resulted in 10 subcategories, three categories and an over-arching theme (Figure 1). Together with my supervisors, we discussed the analysis until an agreement was reached.

The interviews had two foci and two perspectives. First, the participants were asked to describe the best care (paper I) and then the use of ATS in care (paper II). When reviewing the interviews, it was obvious that the participants answered the questions from both a perspective of what was the best care and the use of ATS in care. The two perspectives included their own perceptions and what they believed were the partner’s perceptions about care. We analysed the interviews according to the aim. All answers related to the best care were coded the best care. And vice verse, all questions concerning the use of ATS in care and the answers related to those questions were coded as the use of ATS. After finalising the two papers, a new analysis was made focusing on an interpretation of what values are imbedded in the participant’s perceptions in the integrated results of the two papers.

**Ethical considerations**

Ethical aspects were discussed and considered throughout all stages of the research process. Participation in the study was voluntary which was clearly expressed when recruiting participants and they could choose if they wanted to participate or not. They could withdraw their participation in the study at any time, without explanation and consequence. And, participants were assured that results would be presented anonymously. After participants had decided to participate, I scheduled an interview, and was invited to visit their home. The location of the interview, an environment familiar to the participant, resulted in a calm, comfortable atmosphere for participants to reflect freely about their perceptions regarding the
topic. Participants stated that they were grateful to discuss and share their opinions. After the interview was complete, participants were informed that if they had any concerns resulting from the interview, they were welcome to contact me. None of the participants expressed any need for further contact after the interviews were completed.

A researcher must be aware that an interview is not a discussion amongst professional equals, and therefore the researcher defines and controls the situation. In qualitative research, the risk of exploitation must be taken in consideration since studies show that the psychological distance between the investigator and participant declines as the study progresses (Polit & Beck, 2008, p. 145). Researchers should strive to minimize all types of harm and discomfort for the participants (cf. Polit & Beck, 2008).
FINDINGS

Best care

When participants were asked to describe their perception about how they wanted to be cared for (Paper I), they clearly expressed a desire to stay at home as long as possible (Table 3). However, a prerequisite for being cared for at home was their partner’s willingness and ability to provide help and support. Participants stated that a long-standing trustful relationship over many years between themselves and their partners was the foundation for security and advocacy when health problems occurred. This was clearly expressed when discussing their own perceptions as well as when reflecting on their partner’s perceptions. All participants stated it was extremely desirable to support one another when care was needed. In the event that their partner could not provide assistance with practical care matters, they relied on one another for mental support. A second important prerequisite for being cared for at home was that they receive professional assistance and technical devices when bodily functions started declining.

Table 3. Elderly peoples’ perceptions of how they want to be cared for (paper I).

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Categories</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home, as long as my partner and I can support each other</td>
<td>At home as long as possible</td>
<td></td>
</tr>
<tr>
<td>Getting medical care and service at home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a limit how much we can take care of each other</td>
<td>Professional care at nursing home when advanced care is needed</td>
<td>Maintaining the self and being cared for with dignity to the end</td>
</tr>
<tr>
<td>Not at home when lonely and severely ill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to be dependent on the nursing staff.</td>
<td>Fear of being abandoned</td>
<td></td>
</tr>
<tr>
<td>Trapped in myself without friends.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frightful of being lonely and totally dependent on care.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As the scenarios changed they wanted to receive professional care at nursing home when advanced care is needed (Table 3). Both male and female participants stated that they wanted to be in a place where elderly people could receive care. One of the main reasons for leaving their private home and entering a nursing facility was that there was a limit to how well the healthy partner could take care and support the ailing partner who was dependent on the partner’s care of the ill spouse. All participants described how they did not want their partner to be a nurse for them, because it could be demanding to nurse a severely ill partner. They did
not want to be a burden for their partner. All participants expressed that if they were ill, their partner had the right to a good, independent life on their own, and being a nursemaid to their ailing partner could have negative consequences both for the caring partner and for their relationship. The home and the marital relationship were described in varying positive ways and that they had to leave the home if becoming totally dependent on care. Participants believed that there was a limit to the amount of care they could receive at home especially if the partner was no longer at home with them. Living alone, dependent on care could result in loneliness and insecurity. Instead, they expressed the need to move to a nursing home. The nursing home, with well-trained nursing staff, could provide the security that no longer existed at home if the participant was alone and totally dependent on care. Living in a nursing home where nursing staff could meet their health needs day and night, seemed to be a place to feel secure.

The fear of being abandoned seemed to be a great concern when the participants reflected on being totally dependent on care and no partner at home (Table 3). Different kinds of feelings and fears were raised concerning life at a nursing home. Participants expressed that there were no other choices to living in a nursing home; and being alone and severely ill could be a horrible situation. The loneliness and dependence on strangers for their care was perceived as terrible, and participants worried about whether or not they could manage loneliness, isolation, and dependence on care. Being abandoned could lead to feelings of being trapped, especially without close relatives or nursing staff nearby. Furthermore, relationships with others including neighbours and friends could diminish if they were unable to take care of themselves. This situation could be terribly lonely. All participants were concerned about what would happen to them if they were totally dependent on care and had no partner at home. All of the participants both answered the questions and also raised new questions of what will happen in the future.

The participants stated that the best care involved maintaining the self and being cared for with dignity to the end (Table 3). Regardless of the circumstances, it seemed that the participant’s desire to be treated as an individual and maintain the sense of self was extremely important, especially when dependent on care and suffering from an illness; even if they did not desire living in a nursing home, they realized that it was the best solution. Participants wanted to be taken care of by nursing staff with basic competence in nursing who have respect and compassion and can provide closeness.
Assistive Technology Services in care at home

One aspect of the participant’s perceptions about the use of ATS (Paper II) was that ATS provide an opportunity (Figure 1). This perception was significant when the first scenario, “little need of care, healthy partner at home” was presented. There were overwhelmingly positive responses towards using ATS and other technical devices for remote consultations and health examinations. All statements with regards to this topic were quickly and spontaneously answered. The participants stated that ATS were an additional way to communicate with people in the outside world. Remote consultations at home could be peaceful and quiet as compared to visiting a healthcare centre, where it can be stressful. ATS could provide increased safety, and facilitate living at home longer than if they did not have access to ATS. These positive benefits to using ATS were described by participants as “terrific,” “wonderful,” and “super.”

Figure 1. The relationship between scenarios, sub-categories, categories, and themes of elderly’s perceptions of the use of Assistive Technology Services (paper II).
Participants expressed positive perceptions of how ATS could provide an opportunity to stay at home for a longer time which could enhance their quality of life. It was important for all participants to stay at home even if they became ill and dependent. The home was highly valued, especially as the participants grew older. As a result, the use of ATS could be necessary for them to realize the dream of remaining at home. The use of ATS at home could also provide increased safety by allowing for remote consultations; which was perceived as more beneficial than leaving home and receiving the same consultations elsewhere. Participants also described the use of ATS as a means to get in touch with nursing staff quickly since there was always someone monitoring the device remotely who they could be in touch with. Moreover, ATS was viewed as a way to communicate with friends and relatives.
Another aspect of using ATS was expressed as the consequences of using ATS are hard to anticipate (Figure 1). As the scenario changed from “little need of care, healthy partner at home” to “dependent on care, with a healthy partner at home,” all participants discussed perspectives, advantages, and disadvantages of using ATS. They became more resistant about the use of ATS as they perceived needs for care increased. Participants realized that using ATS was a necessity if they were care dependent and severely ill. Many participants stated that the development of ATS was remarkable and use of ATS in care was unavoidable.

Another consequence of using ATS was that it could make work easier for nursing staff. All participants expressed that nursing staff have a difficult, demanding job; and using ATS could allow nursing staff to spend more time with the patient.

There were positive and negative consequences of using ATS in care at home with regards to partner relationship. If used with their partner, ATS was manageable. Although, they were concerned that using ATS could become a burden for the partner. This was of special concern if one of the partners was dependent on care. If the healthy partner was very old, using ATS could be too much responsibility. Participants also mentioned age as a hindrance for learning how to use ATS. The participants were concerned that they may not have sound enough judgement if they were suffering from cognitive impairments; this type of situation made it seem difficult to learn how to use ATS.

As the scenario changed from “dependent on care, with a healthy partner at home” to “dependent on care and no partner at home,” positive perceptions regarding the use of ATS changed to strong feelings of fear of ATS when completely dependent on care (Figure 1). Related to feelings of fear and resistance they raised questions like “what, when, how and why”. As was the case with the other scenarios, the participants’ reactions regarding the scenario had different aspects. One opinion was that ATS could never replace human encounters, no matter how effective and useful. In that situation, the overwhelming conviction was that being touched by another person could never be replaced. There were feelings of fear connected to dependency on care, living alone, and dependency on ATS. Total dependence on ATS was another aspect that seemed terrifying for participants. During this discussion, participants stated that closeness to nursing staff was important.

The last scenario, “dependent on care and no partner at home,” were associated with feelings of threat, fear, and a feeling of being violated and neglected by the official healthcare system.
This scenario represented a threat to personal integrity. Participants did not want someone else to get information about their private life even if there was nothing to be ashamed of. In their opinion, their private sphere, their way of living, had to be respected.

The use of ATS was perceived as an asset or threat depending on care needs and abilities. The discrepancy between an asset or a threat was related to physical needs, cognitive impairments, and a healthy partner living a home. All participants described dependency on care as difficult but that the use of ATS could support them at home and provide a feeling of security. A healthy partner in the home influenced perceptions about the use of ATS. The healthy partner’s ability to act as a spokesperson for their ailing partner was extremely appreciated, and was mentioned by participants in all of the scenarios. ATS was viewed as a threat if there was not a healthy partner at home, especially when a person was dependent on care. Use of ATS was perceived as something horrible when lonely, dependent and suffering from cognitive impairments since ATS could never replace human encounters.

**Integrated findings in Paper I and Paper II**

After completion of the two manuscripts, it was realised that it was possible to make an integrated interpretation of what values are imbedded in the participant’s perceptions.

**Values about the home**

Regardless of whether participants were discussing the best care in general or ATS supported care, they were convinced that the best place to receive care was the home. Values associated with the home were closely connected to the values associated with couplehood. Participant couples believed that as long as they were together there were no problems too difficult to handle. The partner relationship, based on many years together, and having knowledge of each other, made them strong and they could face many different challenges. Participant couples were convinced that together they could meet the demands of learning how to use new technical devices and develop skills to manage the situation. If one partner was not entirely capable due to illness or aging, it was perceived that the other partner could compensate and be able to take charge on their behalf and decide what was best for the unhealthy partner. The home is a highly valued environment especially when occupied jointly with the partner.
Concerns about how the couplehood could be a base for care in the home was expressed in scenarios where one of the partners became more dependent on care. Specific concerns were raised related to the partner’s ability to provide adequate care to the other partner in regards to age and health. The burden associated with extensive care needs may limit the partner’s ability to lead a good life. Many of the participants stated that they could not demand that their partner become the informal caregiver. The partner was seen as playing a vital role in maintaining the home as a home, and therefore it is important to care for each other.

Feelings of trust and safety were associated with couplehood, whereas living in a scenario without the support of a partner was associated with feelings of fear, threat, insecurity, sadness, and loneliness. The home could turn into an undesirable place to receive care without the safety of couplehood, the support of their partner, or with diminishing ability to care for oneself. It seemed horrible to be forced to stay alone at home with reduced mental capacity and a reduced ability to take care of oneself properly. The value of the home as the best place to receive care changed as the health scenarios changed. If health deteriorated and the dependency for care became greater or an individual was living without their partner, the home’s value decreased and participants started to consider institutional eldercare as a viable option.

Values about the use of ATS in care

Values associated with the use of ATS in care were closely connected to the ability of being in control of the care situation (Figure 2). ATS as a tool to facilitate care was perceived as an asset as long as the couples were in control of their care situation. Since participants had limited or no exposure with the use of ATS, their answers reflected a “wait and see” approach. On the one hand, they were fascinated by the possibilities of having access to assistive devices that could facilitate care at home. On the other hand, it was possible to detect fear that they would not be able to handle the new devices due to lack of experience and their age. The fear could be easily overcome if the couple’s relationship was intact. There was also a sense that the technical development of assistive devices and the use of ATS in care was something that they had to accept, whether they liked it or not. The use of ATS was viewed as an unavoidable development in a society where ICT in general was connected to advances and development.
The negative values associated with the use of ATS in care were connected to the lack of control in the care situation. If there was less control over care, focus shifted towards being seen as an individual, especially when the partner could no longer advocate for their dignity. This lack of control as a result of ATS was associated with fears of detachment from the basic needs of closeness, human touch, and individuality. Technical devices for care, such as ATS were associated with negative values and were linked to inhumane care that conceptualised humans as components and parts.

![Diagram](image)

**Figure 2.** The relationship between control and feelings of not being worthy or having dignity.

**Values about dependency**

The state of dependence of becoming ill was perceived as undesirable. However, dependency on others for care seemed a surmountable situation if one was functioning at full mental capacity and had a healthy partner at home. All participants were aware that aging and illness were factors that impacted their independence. When perceiving the scenario, “dependent on care and no partner at home,” dependency on others was connected to feelings of fear, threat, insecurity, sadness, and loneliness. The aforementioned feelings were associated with a situation which involved: i) leaving the home; ii) losing their partner; and iii) a diminished mental capacity. Uncertain feelings of the future were also of concern. However, the main concern seemed to be the loss of control over one’s own life and loss of their identity. The value associated with supportive services in their home thus became meaningless. The
alternative in this situation was to become dependent and rely on care from well-educated nursing staff in a residential care setting. Although this was perceived as the last alternative, participants trusted that trained nursing staff would have the ability to support their identity, protect them, and cater to their needs of physical and emotional closeness.

Values about dignity
When participants were presented with the first scenario, “little need of care, healthy partner at home,” they expressed feelings of worth and dignity from people around them (Figure 3). Values associated with dignity were closely connected to maintaining identity, and being surrounded by people who knew their life story and that they trusted. These values became more evident in the discussions with participants as scenarios changed from having a supportive partner with them at home to becoming dependent on care and losing control in their lives. Dignity was associated with care by someone who could be their advocate and compensate for their reduced abilities. It was ideal if they had someone who would show interest in their life history, cater to their needs, be close and touch them, and compensate for their inability to create and retain relationships. Regardless of other factors, dignity is highly valued, and has greater importance when other values like autonomy and independence are reduced.

Figure 3. Dignity through human encounters are valued as important in all categories
DISCUSSION
The integrated findings of papers I and II showed that participants changed their values regarding the home as the best place for care and the use of ATS depending on their level of care dependence and support from their partner. The participant’s core values about the home changed as circumstances related to a sense of self, the partner’s health and ability to stand by their side changed. The participant’s perceptions of the importance of the home and use of ATS when in need of care were expressed with strong conviction.

The home was valuable to participants, representing a place where relationships with their partner, children, and friends could be maintained. The home also represented them as a person and living at home facilitated being considered as someone, as well as providing an identity (c.f. Bowlby et al., 1997; Moore, 2000; Lantz, 2007). These three publications have the same message about the home; they describe the home from a symbolic perspective where both relationships to others and different activities are developed and give a person an identity. This is supported by McGarry (2009) which describes the elderly as key recipients of care at home. The author presented an ethnographic approach to explore the nature of the care relationship within the home setting. The findings indicate that when the elderly were in their home surrounded by their artefacts nurses saw them as individuals. The concept of the home signifies at least two different aspects: the physical room where people live; and an abstraction or notion of identity and belonging (Groger, 1995; Wreder, 2008). Another study (Zingmark et al., 1995) describes the home as a place where there is a tie to deep relationships and their development, as well as an association to things, activities, and places. This description of the home was confirmed by the participants in our study; things, relatives, and friends in their nearest neighbourhood were important for maintaining the home as a home. The home environment, as both a physical entity and a meaningful context for everyday life, has significant implications for how old age is experienced (Kontos, 1998). The home is described as an invaluable resource for elderly as they adjust to physical decline that occurs with aging, as well as a resource for sustaining independence and a sense of personal identity.

Meaningful human relationships are a crucial part of the self. Baumeister & Leary (1995) stress that the need to belong to someone is one of the most fundamental human motivations, and underlies many emotions, actions, and decisions throughout life. Belongingness can be understood as people seek to have close intimate relationships with each other. As people develop social and intimate relationships, it influences the sense of self. According to
Eriksson & Eriksson (2004), relating to others is an ongoing process throughout life and experiences from childhood impact personality for the rest of one’s life. Reciprocity and symmetry in close relationships are qualities that allow relationships to grow and are balanced between independence, dependence, and interdependence (Hinde & Stevenson-Hinde, 1997; Rönning, 2002). Reliability is a basis for interpersonal trust (Rotenberg, 1994). Trust in oneself and in other persons is built on experiences from the interactions with others. All the participants in this study expressed that trust was a status that had developed during several years together and was a stable foundation in their relationship. In many of the participants’ statements, they used the term “we,” and expressed feelings of strength and capability in their couplehood, able to handle new and difficult challenges like illness and aging. Skerrett (2003) discusses the concept “we” which means that when couples build awareness around how to talk and relate to each other when ill, it is a resource to promote healing. When couples incorporate the sense of “we,” it confers important properties that promote both individual and couple resilience (Skerrett, 1998). Hellström et. al (2009) describe how working together in couplehood can strengthen the person who is suffering from cognitive impairment.

The possibility to exert control over one’s own life is a fundamental need. This possibility means that one is able to take command over everyday situations. There is a feeling of power associated with exerting control. Those who have power are also able to have control (Syme, 1989). In the current studies, the participant’s feelings of fear of being care dependent and exposed to ATS are interpreted as connected to losing control. When shifting scenarios in the interviews they also changed their values about how to be cared for and the use of ATS. Thus, it can be inferred that control and independence are highly valued regardless of which scenario the participants discussed. Calnan et al. (2006) reports that independence is highly valued, and as dependence on others increases, individuals struggle to maintain control over their lives for as long as possible. When the participants in this study reflected on the different scenarios, maintaining control seemed to be an important factor for how they could handle unexpected, difficult, and changing situations. Control was associated with mental control, ability to self determine, and when the own ability is failing the partners capacity represented control. Participant’s central concern was a lack of control; they hesitated if the home was the best place to be cared for and advanced using of ATS. The idea of no control at all was associated with fears of abandonment, worthlessness, indignity (Figure 2). Other major concerns included a future where individuals had cognitive impairments, no close
relatives, reduced capacity for self-determination, and worries about how to be treated with
dignity from the public healthcare system.

Dignity is interpreted as a central concern and value to the participants in these studies (Figure 3). From the participant’s perspective, dignity was maintained and achieved through personal identity, independence, and human encounters. The participants in this study viewed the concept of dignity in a similar way as Nordenfeldt, Woolhed et. al, Calnan et. al and Tadd & Bayers (2004; 2004; 2006; 2006). The participants emphasized that independence, having control over their own lives, and maintaining their mental capacity was important for preserving dignity. The home and a healthy partner by their side were factors that strengthened their feelings of autonomy and consequently, their dignity. The participants expressed that they could have feelings of self-respect and dignity of their own identity if they were living at home with limited assistance needs, a healthy partner in residence, and no cognitive impairments.

All of Nordenfelt’s (2004) concepts of dignity including dignity as an identity, dignity as a moral status, dignity as merit, and dignity as menschenwürde were represented in the interviews with the participant’s in this study. The statements were interpreted at different levels by the participants, use of ATS in a situation when limited care was needed was related to dignity, it supported their need for independence, and it was interpreted as a possibility to perceive use of ATS as providing an opportunity (Figure 3). When the scenario changed to more dependence on care and more isolation due to illness and cognitive impairments, their concerns about dignity were even more salient. This included both how to be treated with dignity, and how to maintain dignity. Participants expressed that not being remembered, and having a reduced ability to develop and maintain relationships with familiar people as neighbours and friends were ways to lose their dignity. These findings are similar to what Nordenfeldt (2004) describe where an individual loses dignity as an identity due to illness and aging.

Furthermore, participants expressed fear when considering what would happen to them if they were totally care dependent and living alone, regardless of whether it was in one’s private home or in an institution. This was interpreted as losing dignity as a moral status and loss of dignity as a merit. A study by Matiti & Torey (2004) describes that entering the hospital was associated with fear of losing dignity. Fears included being naked, invasion of personal space,
loss of self-control, and loss of independence. Privacy, independence, confidentiality, and making choices are among other factors important for maintaining control and preserving dignity (Maititi & Trorey, 2004). For all the participants in this thesis, all their questions, quotations, and discussions related to being totally care dependent and living alone represented fear. In an event being dependent and having a feeling of fear of being abandoned, their concerns seemed related to not being treated with dignity, not even having the intrinsic absolute menschenwürde (cf. Nordenfelt 2004).

Regardless of external conditions, it was obvious that human encounters were helpful in overcoming fears of not being treated with dignity. Participants referred to their social situations with their partner, relatives, and friends, as well as having a role in society. A real threat to the participant’s identity could be needing healthcare regularly. The lack of privacy, suffering from an illness, and poor communication could result in feelings of abandonment (Figure 3). The lack of privacy results in embarrassment, shame, and humiliation and may diminish an older person’s dignity (Calnan et al., 2006). This is similar to what the participants in this study expressed. The more care dependent the scenario became, the more focused participant’s became on being treated with dignity, and maintaining dignity while aging and had a reduced ability to care for themselves.

Preserving dignity means protection against danger and implies some kind of action (Anderberg et al., 2007) and may not be considered a concept. Anderberg et al. (2007) presents five attributes when discussing how to promote the preservation of dignity of older people in care of the elderly: individualized care; control restored; respect; advocacy; and sensitive listening. In a similar way most of the same factors have also been described by Walsh & Kowanko (2002). Findings show that respect, privacy, control, advocacy, choice, and time are important to maintain dignity (Walsh & Kowanko, 2002). The participants in this study expressed that when totally care dependent and living alone, human encounters could never be replaced by the use of advanced ATS, and living at home was not a good alternative to be in a nursing home. In this situation, they wished to be seen by the nursing staff and that nursing staff must have the ability and responsibility to create human encounters with the participants. This is similar to findings in a study by Westin & Danielsson (2007) where residents in eldercare described the feeling of being somebody is to be seen, confirmed, respected and affected. Human encounters have positive outcomes including being a part of a community.
METHODOLOGICAL CONSIDERATIONS

Study I focused on the perceptions of how elderly people want to be cared for, and study II focused on elderly peoples’ perceptions of using ATS when in need of care. The results of all qualitative studies have to be judged from their context (Patton, 2002). In order to create a similar interview context for all participants, we used a vignette describing three different scenarios that were presented in a similar way. A specific problem related to the design of the query of perceptions and the context is the design of the vignettes. It is obvious that the content and presentation of the vignettes may influence the participants’ perceptions and we may have got different answers with vignettes designed differently. However, the design of the vignettes was carefully made based on documented knowledge on how different ATS have been used with success in care of elderly. In addition, we think that the structured method of using vignettes assisted in creating uniformity in the interview situation (c.f. Drew, 1993; Sävenstedt et al., 2006).

The participants were selected to insure variation in living conditions and experiences, and despite this strategy it is possible that the results might have been different with a different sample. Additionally, the interviews reflect the perceptions of the participants at the time of the interviews. It is possible that perceptions will change over time, as participants grow older their personal health changes, and their experiences using ATS in care change. It is always the reader’s responsibility to assess whether or not the results are transferable to another context. I have tried to clearly describe the context and the methodological process used in the studies of this thesis, which should help facilitate the possibility of transferability of the results (cf. Graneheim & Lundman, 2004; Elo & Kyngäs, 2007; Polit & Beck, 2008).

When the studies were conducted, I had some concerns about how my pre-understanding about quality care and the use of ATS in care would impact the participants’ answers, and how the results were interpreted. I tried to be as open-minded as possible and avoid influencing the participants and interpretations throughout the whole process.

I paid close attention credibility, dependability, and transferability to increase trustworthiness in this qualitative study. Credibility is an especially important aspect of trustworthiness (Patton, 2002) and is achieved to the extent that results, interpretations, and data collection engender confidence (Elo & Kyngäs, 2007). According to Patton (2002), credibility is associated with how well the focus for the research is connected to how data and the analysis
process gets along with that focus. Dependability concerns how the data changes over time during the analysis process; this can be reached by having open-minded dialogue in the team (Patton, 2002). Trustworthiness of these studies was achieved by using rigour in all parts of the studies, from planning, data collection, analysis, and results compilation. All steps were checked and discussed with respect to credibility and dependability by all the authors of the manuscripts until a general consensus was reached.

CONCLUSION
Values associated with care of the elderly have changed a lot since the mid 1900s. The focus has shifted from viewing the elderly as a group towards viewing each person’s individual needs. This change is reflected in healthy elderly peoples’ perceptions about care and also in official healthcare policies. Contemporary research about values describing quality care emphasise the importance of treating each person with dignity and respect. The core value in care with dignity is that each person, regardless of who he or she is, has a value of their own and the right to be cared for according to their individual needs. Values about caring interventions and how care is administered depends on the context and the resources available. The context of care of the elderly will change over time and there are many challenges in the future as a result of decreasing resources, increasing numbers of elderly, and different ways of organizing care. Considering the anticipated changes of the caring context, it is important to take into consideration the elderly peoples’ perceptions of quality care, including their perceptions of using new technical services.

The results from this study confirm that being in an environment with opportunity for human encounters and human touch is important when needing care. The conclusions of this thesis are:

- Basic values about how to be cared for remain; however, if the social context changes, the values about how quality care should be administered will also likely change
- The home is highly valued as a place to live as long as control and close relationships are a part of daily life
- As the development of information technology continues, the development of new technical services in the care of the elderly must be user-driven and must be based on elderly peoples’ values of what constitutes the best care
Maintaining dignity, autonomy, and self-determination is a large task in the care of the elderly, and therefore it is necessary to continuously evaluate the consequences of using ATS in care from the perspective of dignity.
Äldre personers föreställning om vård och användande av Assistive Technology Services (ATS).


Värderingar inom god vård av äldre har förändrats och utvecklats under det senaste århundradet i takt med sociopolitiska förändringar. God vård handlar om värdig vård där grundläggande begrepp som vårdighet utgör basen för hur vården skall utformas. Vårdighet innebär att människan har en absolut värdighet och oberoende på vilket sätt eller var vården ges bör detta vara ett signum för vården. Vård av äldre på institution har alltmer ersatts av vård i hemmet. Detta underlättas till stor del av att ATS alltmer används för att stödja och underlätta boende i hemmet. Forskning som beskriver värderingar om god vård finns men eftersom värderingarna förändras över tid är det av stort värde att kontinuerligt kartlägga dessa värderingar.

Det övergripande syftet med denna licentiatuppsats var att beskriva äldre personers föreställningar om god vård och användande av ATS i händelse av vård.

Licentiatuppsatsen består av två delstudier, delstudie I vars syfte var att beskriva äldre personers föreställning av god vård och delstudie II, vars syfte var att beskriva äldre personers föreställning om användande av ATS i vård. I studierna ingår tolv par. Kriterier för att kunna delta i studierna var att alla deltagarna var > 70 år, etablerad pensionär, sammanboende i minst 5 år och inte någon form av teknisk support som exempelvis alarm eller annat beviljat bistånd. Den yngsta var 70 år och den äldste deltagaren var 83 år. Kvalitativa individuella forskningsintervjuer har använts som datainsamlingsmetod. För att få fram deltagarnas föreställningar om god vård och användande av ATS användes en vinjett med olika scenarier som alltmer komplicerades. Frågorna ställdes utifrån två olika perspektiv, eget perspektiv och partnerns perspektiv. Deltagarna ombads reflekttera över dessa scenarier och besvara de frågor
som följd. Intervjuerna spelades in på band och skrevs därefter ut ordagrant. Utifrån syftet användes en kvalitativ tematisk innehållsanalys för att analysera intervjuerna.


Föreställningar om användande av ATS visade på stor variation beroende på egen förmåga och behovet av vård. Vid ett ringa behov av vård värderades användande av ATS som en tillgång. Samtliga deltagare beskrev många positiva effekter med den nya teknologin, exempelvis kunde det innebära att man kunde bo kvar hemma betydligt längre och även känna trygghet eftersom användande av ATS innebär att man kände sig trygg. Med ett alltmer ökat beroende av vård uttrycktes osäkerhet om vilka konsekvenser användande av ATS kunde medföra. Även här nämndes partners närvaro som en viktig förutsättning för att man skulle kunna båda lära sig men även kunna känna tillit till ATS. Totalt beroende av vård och ingen partner i hemmet uppfattades användande av ATS som ett hot. Att i en sådan situation använda ATS för vård i hemmet väckte både rädsla och förtvivlan. Det fanns en genomgående överensstämmelse om att användande av ATS aldrig kan ersätta det mänskliga mötet.

Ensamhet, isolering and osäkerhet var uttryck som ovanhängande när föreställningarna om god vård och ATS diskuteras. Speciellt när behovet av vård var totalt och ingen partner längre fanns i hemmet. I de situationerna var deltagarnas behov av att bli sedd och berörd det som var det allra viktigaste. Att bli behandlad med vårdighet poängterades ofta, en önskan om att vårdpersonalen förutom tekniskt kunnande även har kunskap som medkänsla och respekt. 39
ACKNOWLEDGEMENTS

This licentiate thesis was carried out at the Division of Nursing, Department of Health Science, Luleå University of Technology. I wish to express my sincere gratitude to all whom have helped and supported me in different ways throughout this process of learning and writing.

My sincere thanks to:

- The elderly couples who generously participated in this study. Thank you for sharing your thoughts and perceptions with me. This work was possible because of you;

- My main supervisor, Professor Karin Axelsson, Division of Nursing, Department of Health Science, Luleå University of Technology. Thank you for providing guidance in the field of research by sharing your extensive knowledge, for constantly asking good and subtle questions, and for your invaluable support and engagement. Thank you for always "being there" via telephone, mail, marratech, or meetings. Thank you for giving me the opportunity to do this research, for all the serious discussions, and the good laughs;

- My second supervisor, Dr. Stefan Sävenstedt, Division of Nursing, Department of Health Science, Luleå University of Technology. Thank you for always being reflective and supportive of my work, offering good advice, and never being in a hurry. You have always been available to me and generously shared your knowledge about qualitative research. I appreciate that you were always wise, sensible, and humorous;

- Colleagues, doctoral students, and friends at the Department of Health Science and the Research School for Music, Media, and Technology (MMT), Luleå University of Technology. Thank you for your support, friendship, constructive criticism, and discussions. Special thanks to Birgitta, Britt-Marie, and Lisbeth for being good supporters and real friends;

- Kelley Gundale for giving comments, time and excellent editing services;

- The staff at the Luleå University Library for your fantastic service, especially Anders Brännström; and

- Last, but certainly not least, my beloved children Gustav, Josefin, and Frida, and my dearest husband Dag. I am so proud of you, you are my life. Thank you for all the time, support, love, and hope, especially during times of illness and feelings of “not making it”.

Thank you!
References:


Andersson, M. (1994) *Integritet som begrepp och principl. En studie av ett vårdetiskt ideal i utveckling (Integrity as a concept and as a principle in health care ethics; Abstract in English)* Åbo Academi University. Åbo, Finland.


Leith, K. (2006) Home is where the heart is ... or is it? *Journal of Aging Studies* 20: 317-333.


Abstract:
Many countries encounter a demographic change where the number of elderly people will increase. As a result, the number of very old people needing care, services and medical assistance will increase. Care in the private home is often described as providing the best alternative for many elderly people.

The aim of this study was to describe elderly people’s perceptions of how they wanted to be cared for, from a perspective of becoming in need of assistance with personal care, in the future.

Twelve couples of healthy elderly people living in a couple hood participated in an interview study. They were all 70 years and older and received no kind of professional care or social support. Open individual semi-structured interviews were conducted with the support of written vignettes. The vignettes were formed as scenarios that described three levels of caring needs where the elderly people would become ill. A qualitative content analysis was used to analyze the interviews.

The findings were interpreted in one main theme: maintaining the self and being cared for with dignity to the end. The theme was built from three categories: At home as long as possible, Professional care at nursing home when advanced care is needed and Fear of being abandoned. The categories reflect the perception that when minimum help was needed, care and support by the partner and nursing staff were preferred. As the scenarios changed to being totally dependent on care, they preferred care in a nursing home. There was a pervading concern of the risk of not being seen as an individual person and becoming a nobody with no meaningful relations.

Thus, there must be a singular goal to support old people, in all stages of their lives, through the recognition and affirmation of self, and providing care with dignity to the end.

Key words: self concept, dignity, elderly care, homecare, dependency, perceptions, qualitative study
INTRODUCTION

Many European countries as well as other countries in the western world will encounter a demographic change in the coming years. The growth in the number of older people is so dramatic that it has been described as a silent revolution [1]. Parallel to this development, there will be an increase in home-based care and in the number of old persons above 60 years, who will require provided care in their private homes. Our perception about “the home” as a place for privacy is in sharp contrast to “the home” as a place of work for health care staff where people get medical care and services [2].

Being healthy and well functioning is something that people strive for, but in cases of being ill and dependent of care, either being young or old, acutely or chronically ill, people wish and demand to meet qualified nursing and medical competence. To promote good care among persons living in nursing homes, different ways of interpreting respect for autonomy has been described among nursing staff [3]. When caring, a respectful behaviour is necessary in intimate situations like assistance with personal hygiene. Being treated with respect and seen as a unique person has been described as the most important indicator of promoting good long term care, among caregivers and elderly people getting palliative care [4, 5]. In a similar manner has good care for elderly people with dementia been described [6]. Developing good care is dependent on the nursing staffs’ ability to create good relationships [7].

Freedom and independence are in the modern western culture seen as a goal of the human person with the right to make own decisions. Thus in a situation being dependent of care can these highly ranked values result in a feeling of uselessness and worthlessness [8, p. 112]. Freedom and independence can at the same moment, mean something positive and something negative. When striving to be independent, there is a risk of becoming more isolated and lonely. To be dependent on others in daily life often means dependency on someone or something. As long as one is healthy, strong and able to take care of the own life, it seems strange and difficult to understand what it means to be dependent on others, especially when it comes to the basics such as, eating by one’s self, putting clothes on and handling the intimate hygiene. Aging means probably both morbidity and disability, and as a consequence, more dependency on others than usual [9]. Strandberg et al. [10] describe the patient’s aspects of dependence on care like a struggle for the existence from two dimensions, where the patient wants to show oneself to be worthy of receiving care, on the one hand because of the fear of being abandoned and on the other hand to be able to protect the self as a valuable human being.
Table 1. Socio-demographic characteristics of the elderly people (N=23).

<table>
<thead>
<tr>
<th>Variables</th>
<th>N = 23</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living today</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private house</td>
<td>17</td>
<td>74</td>
</tr>
<tr>
<td>Terrace house</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>Cooperative flat/apartment</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>Flat with right of tenancy</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td><strong>Distance to primary health care center</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 20 km</td>
<td>19</td>
<td>82.4</td>
</tr>
<tr>
<td>21 – 40 km</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>41 – 60 km</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td><strong>Distance to hospital</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 50 km</td>
<td>14</td>
<td>60.8</td>
</tr>
<tr>
<td>51 – 100 km</td>
<td>5</td>
<td>21.8</td>
</tr>
<tr>
<td>101 – 150 km</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td><strong>Living environment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>14</td>
<td>60.8</td>
</tr>
<tr>
<td>Village</td>
<td>9</td>
<td>39.2</td>
</tr>
</tbody>
</table>

**Data collection**

Open individual tape recorded interviews, based on vignettes were made with the 24 participants in the participants’ home. However, one interview was excluded due to technical problems with the tape recorder. The vignettes were formed as short written scenarios [cf. 15, 16]. The scenarios were designed to provide a picture of situations where the participant was in need of care and where the situation was stepwise and becoming more complicated. First step was “little need of care, healthy partner at home” and was presented as a situation “where you are doing fine but can’t take care of personal hygiene”. Second step “dependent of care, healthy partner at home” was presented as a situation “with several bodily dysfunctions and totally dependent of care from others”. The last step was “dependent of care, no partner at home” and was presented as a situation “with several bodily dysfunctions and totally dependent of care from others”. These three steps were presented at first from their own and then their partner’s perspective. In the interviews, these scenarios were presented one after the other, followed by questions as: *What is the best care for you/your partner in this situation?* For each step the interviewer encouraged the participants to narrate freely about their perceptions using follow-up questions when necessary. The interviews, which lasted between 30-60 minutes, were conducted with each participant individually and
Table 1. Socio-demographic characteristics of the elderly people (N=23).

<table>
<thead>
<tr>
<th>Variables</th>
<th>N = 23</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living today</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private house</td>
<td>17</td>
<td>74</td>
</tr>
<tr>
<td>Terrace house</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>Cooperative flat/apartment</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>Flat with right of tenancy</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td><strong>Distance to primary health care center</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 20 km</td>
<td>19</td>
<td>82.4</td>
</tr>
<tr>
<td>21 – 40 km</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td>41 – 60 km</td>
<td>2</td>
<td>8.8</td>
</tr>
<tr>
<td><strong>Distance to hospital</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 – 50 km</td>
<td>14</td>
<td>60.8</td>
</tr>
<tr>
<td>51 – 100 km</td>
<td>5</td>
<td>21.8</td>
</tr>
<tr>
<td>101 – 150 km</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td><strong>Living environment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>14</td>
<td>60.8</td>
</tr>
<tr>
<td>Village</td>
<td>9</td>
<td>39.2</td>
</tr>
</tbody>
</table>

**Data collection**

Open individual tape recorded interviews, based on vignettes were made with the 24 participants in the participants’ home. However, one interview was excluded due to technical problems with the tape recorder. The vignettes were formed as short written scenarios [cf. 15, 16]. The scenarios were designed to provide a picture of situations where the participant was in need of care and where the situation was stepwise and becoming more complicated. First step was “little need of care, healthy partner at home” and was presented as a situation “where you are doing fine but can’t take care of personal hygiene”. Second step “dependent of care, healthy partner at home” was presented as a situation “with several bodily dysfunctions and totally dependent of care from others”. The last step was “dependent of care, no partner at home” and was presented as a situation “with several bodily dysfunctions and totally dependent of care from others”. These three steps were presented at first from their own and then their partner’s perspective. In the interviews, these scenarios were presented one after the other, followed by questions as: *What is the best care for you/your partner in this situation?* For each step the interviewer encouraged the participants to narrate freely about their perceptions using follow-up questions when necessary. The interviews, which lasted between 30-60 minutes, were conducted with each participant individually and
transcribed verbatim. Notations of nonverbal expressions, such as silence, cries, laughter and bodily movements, were made directly after the interview.

**Ethics**
The interviews were made in an environment which was well known for the participants and after the interview there was also time for reflection. The participants were all independent and could choose if they wanted to participate. They were informed that they could at any time break off from the study without any consequences.

**Data analysis**
The interviews were analyzed in a step by step process using qualitative content analysis [cf. 17, 18]. The text was read and listened to first to acquire a first impression of the content. Thereafter, all the text was used in the analysis and divided into meaning-units corresponding to the aim. Those meaning units were condensed, and at first grouped from the person’s own perceptions and the partner’s perception. Gradually, it was realised that the two perspectives had the same dimensions of content and the two perspectives were merged into one. The step by step grouping of content into more abstract levels resulted in seven sub-categories, that formed three categories and an overarching theme (Table 2). All three authors followed and discussed the analysis process until an agreement was reached.
RESULTS

The results are presented beginning with the categories, sub-categories and after that the overarching theme.

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Categories</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>At home, as long as my partner and I can support each other</td>
<td>At home as long as possible</td>
<td></td>
</tr>
<tr>
<td>Getting medical care and service at home</td>
<td></td>
<td>Maintaining the self and being cared for with dignity to the end</td>
</tr>
<tr>
<td>There is a limit for how much we can take care of each other</td>
<td>Professional care at nursing home when advanced care is needed</td>
<td></td>
</tr>
<tr>
<td>Not at home when lonely and severely ill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to be dependent on the nursing staff</td>
<td>Fear of being abandoned</td>
<td></td>
</tr>
<tr>
<td>Trapped in myself without friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frightful of being lonely and totally dependent on care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

At home as long as possible

In a perspective of being in need of limited help with personal hygiene and otherwise doing fine, all participants had a perception that the best care was provided in the private home with different kinds of support.

At home as long as my partner and I can support each other

All participants spontaneously talked about their partner when they were asked to describe the best care, in case of loss of bodily function and in need of assistance. Both men and women emphasised the importance of living together with their partner as long as possible. As long as they were together, they felt more secure and they could support and advocate for each other when problems occur. Even if they could not help they could at least hold each other’s hand. "My partner is able to help me; I really think he is able when it only comes to minor health problems, a minor health problem or handicap. In those situations I think the best solution is that my partner assists". The feeling that they, as a team, were much stronger than as two separate persons is based on an experience of a long trustful relation that provided a sense of security. In situations with limited need of care assistance, they were convinced that together,
they could manage any situation and find a solution. Their feeling of being a good team was expressed in different ways by several of the participants, i.e. “we are strong, we are close”. Few of the participants talked about their children and when they did it was with respect for their independent lives. No one ever mentioned them as a presumptive carer.

Getting medical care and service at home
All men and women expressed wanting to stay at home as long as possible, even if a home care assistant was needed. It was apparent that the thought of having professional assistance in the home was easier to accept for more men than women. They expressed that the best must be to stay at home with some sort of help from social worker, nurse or someone who came and helped them to get a shower and manage their personal hygiene, “In those situations maybe it is possible that he can get assistance, from the district nurse or the home care assistants”. Both men and women could also consider the use of assistive technology as a possible way of compensating for the loss of bodily function. One man was quite sure that if his partner was in good mental health, she would prefer to stay at home and receive help from someone with nursing competence.

Professional care at nursing home when advanced care is needed
As the scenarios changed to a situation of lost bodily function and need of advanced care, the possibility of leaving their home for a nursing home or some sort of institutional care became important for the participants. The participants’ perception of what kind of institutional care they thought of was vague. Both men and women mentioned hospital, primary health care centres and nursing homes as a place where elderly people could get care and other elderly people were living. In the presentations of the results, the concept of nursing home is used when institutional care was described.

There is a limit for how much we can take care of each other
When scenarios with more advanced care were presented, men as well as women expressed a wish that their partner could be freed from an obligation to take care of the other. Behind this wish seemed to be a consideration of their relation with each other. They wanted their partner to have a good life on their own and not to take on a role of being a nurse. They saw their partner as an independent person who needed an independent life. “I don’t want a situation where he is compelled to care for me all day around, when he all the time takes care of me, I don’t want that, he has to be able to live his own life”. The consideration of being a burden
for the partner was mostly expressed by the women. They considered the partner so old and weak, that it was impossible to act as nursing staff. To care for the person might destroy the partner’s health and that was absolutely wrong. More men than women expressed hesitation to take care of their partner due to their own health; it could make them feel insecure if more advanced care was provided by a partner with little experiences. All of them perceived that there was a narrow limit when the need for care would become overwhelming and they could not manage to provide care any longer.

_Not at home when lonely and severely ill_

Most of the participants were convinced that when they would become severely ill it was necessary to move to a nursing home. To live at home in such situation could result in loneliness and also a feeling of insecurity. Even if many of the interviewees felt that the best was to be at home as long as possible, there seemed to be a limit where the security of the home became less important than the insecurity of being severely ill. “You have to move to an institution at an earlier stage if you don’t have a healthy person living with you, if you understand how I mean. It could work but for the safety there could be so much of anxiety and feeling of unsafe if you not are able to get out of your bed before you get assistance”. In a situation of being severely ill, the nursing home would provide more security. To know when the insecurity of illness would become stronger than the security of the home was regarded as difficult to anticipate.

Many of the participants expressed the importance of being cared for by well trained nursing staff who were competent to see their need of care, and also were able to provide it all time around day and night. “I think you should be at some nursing home, you never know what will happen if you are dependent of care all day around and lonely, it could be tragic. I like having people around me and then being alone and besides be in mourning and new people all the time coming in the home no, I prefer to be taken care of at a nursing home all day around”. Both men and women expressed the importance of getting professional care from professional staff, since they perceived that the partner could never replace nursing staff and give professional care.

_Fear of being abandoned_

Perceiving a situation of being in need of extensive care and living at a nursing home was connected to many different kinds of feelings and fears.
Difficult to be dependent on the nursing staff
One fear was to be alone when dependent of care from strangers. Both men and women perceived the situation of being alone and severely ill, to be a horrible situation. Some of the participants regarded the dependence on institutional care as something terrible. “I don’t know what the worst is but if you are at good mental health and realise you are totally dependent of care it seems so horrible then it must be better to be lost of mental capacity, the awareness about needing help with absolutely everything I think that would be terrible”. Many participants felt that they would never manage being alone; waiting for some staff to come for helping. They wondered what would happen if the time passes and no one came.

Trapped in myself without friends
There was a fear of being isolated, in being without the partner and friends, and having to spend many hours alone waiting for someone. With no one close, it is easy to feel abandoned. “It is not good to be isolated to loose all relations it is not good if you are a couple than you have someone to talk to but I hesitate I don’t think it’s good to stay at home for ever, after a while the friends disappear if you are sick, they don’t have the strength to meet all this, they disappear that’s what I think”. One woman told a story about a neighbour who lived alone and became ill. In the first month, the neighbours visited him often, but after a while they did not come to visit him any longer. All participants expressed a fear of being trapped in themselves, with loss of human relations and facing terrible loneliness.

Frightful of being lonely and totally dependent on care
Thinking about being lonely and dependent of care made many of the participants silent, someone cried, and another hoped this never would happen. Some of them stopped talking; another one whispered that they had never even thought or talked about this with the partner. Many of them formulated questions such as “What could I do to help my partner then? What would happen then?” and “What can I do to manage this?” A few participants talked about what they heard about examples of bad care in the Medias. They were upset and felt strongly about what a shame it is for a rich country to not be able to take care of the elderly. They were worried about what would happen to themselves, but also expressed worries about their partner. The most difficult scenario seemed to be loss of bodily function and in need of help with everything, but still be in good mental health. “I hope I will die before it happens it is difficult if you have a clear mind and realise that you are completely dependent, it is much better to be demented, I think it would be very difficult”.

55
Maintaining the self and being cared for with dignity to the end
An over arching theme for best geriatric care was interpreted, which concerned maintaining the self and being cared for with dignity. The desire to be treated as a unique person and to maintain the self was important, no matter the illness, state of mental health or living situation. It seemed that as this becomes even more important, the more in need of care and the more vulnerable the elderly became. An outmost threat was the thought that they could not express their needs and how, when and in which way they would need care and assistance, when they were among strangers who did not know them and their life story.

There was a paradox in their reflections about their trust in other people. They wanted to be taken cared of, but they did not want to hand over their life to unknown nursing staff who may fail to treat them with dignity. Being treated without dignity meant not being seen as a unique person and not being able to relate to persons they knew. Thinking about this scenario made them both indignant and angry. They realised that they were thrown into the existing health care system where there are few other alternatives in case of being dependent of care. Maintaining their self meant among other things, to be able to live in their private home together with family members as long as possible. When in need of extensive care, it seamed important to be cared for by somebody who could assist them in maintaining their self, somebody who could recognise their spiritual, psychological and physical needs.

DISCUSSION
The aim of this study was to describe elderly people’s perceptions of how they wanted to be cared for, from a perspective of becoming in need of assistance with personal care, in the future. The main theme was interpreted as; maintaining the self and being cared for with dignity to the end.

Whatever the circumstances were, there was an agreement on the importance of being treated with respect and dignity. Especially in situations with bodily and intellectual impairments; when being alone and without support from a healthy partner, relatives or friends. The results indicate that the perceived possibility of maintaining their self was closely connected to how they were cared for. Perception of identity and self is formed in a social interaction with other people [19, 20] and one aspect of social interaction is care. According to van Manen [21], reciprocal care is something that most people have experienced from close relations. The human care involves someone to belong to and someone who can confirm that you are an
important, loved and a very special person.

The participants in the couplehood expressed worries regarding what would happen if their partner could not care for them any longer. If they ended up in a caring situation where nobody would know them and nobody would be able to confirm their self in a meaningful interaction. Care as a worry presupposes a way of being and van Manen [21] discuss it from a phenomenological, philosophical and ethical view. Viewing care as a worry is an interaction process and that parallels the findings of this study. The more caring needs, the more important the relation with the partner became and the relation seemed to be a guarantee for being treated well. Without a partner, there was no perception of trust and only fear, loneliness and anguish. Savikko et al. [22] confirmed in their study that loneliness is a realistic and real threat for older people and the most common subjective causes were illness, death of a spouse and lack of friends. Atchley [23, p. 89] as well as Baumeister and Twenge [24] describe that losing a partner is in many ways stressful, a threat to the identity and could cause many reactions, i.e. anxiety, depression and isolation.

Another aspect of the importance of social interaction among older people is that passing through all changes in life gives another perspective of the meaning in life and makes a person able to accept that lifetime has passed, face mortality, and the presence of death [25, 26]. When people become increasingly aware that they gradually approach the end of life, it becomes more important to appreciate close social relations. They seem to be aware of making the right choices, give priority to goals like feeling satisfied, and for most people, such goals are connected to social relationships with highly familiar and emotionally close social partners [27].

An interesting part of the results is the absence of children in the older people’s perception of care. Their thoughts revolved mainly around the partner’s role as a prerequisite for receiving care at home. It is possible that this reflects values in contemporary family life in Scandinavia where children are an important part of the family but not expected to take care of their parents when they get old and in need of care. This is in sharp contrast with other parts of the world like East Asia were it is more or less an obligation for children to take care of the elderly [28, 29]. When economic circumstances are improved together with a possibility for higher education of female children the attitudes towards institutional care among elderly are also changed [30].

All participants were aware that the circumstances would change as they get older and their relationship to the home, altered. The concept of home can be described from several points,
sociologic, psychological, physical and philosophic. The meaning is complex and will probably change as people’s circumstances will change [31]. Our homes mean for most of us something very special, “houses are assumed to become homes because they provide and become the environment within which family relationships – close, private, and intimate – are located” [32, p. 334]. The participants in this study focused on an understanding of home as a place where they could maintain a relation with their partner. Even if professional carers and technical devices would be a part of their home, it would still be their home. The partner is almost mentioned as a part of the home, the partner and the home was the basis for maintaining the self. This way of describing the home parallels the psychological point where the symbolic and representative nature of home is in focus, a place where people can develop bonds with certain places, to enter meaningful relationships with these places and incorporate them as a part of their self-identity [33]. Some of the participants also perceived that it was like being trapped in their home and without a relation with a partner. Moore [33] and Price [34] describe that the home means a wide set of associations and meanings, where on one hand, it can represent both a place for domesticity, privacy and comfort, and on the other it could be a prison and a place full of obligations.

At-homeness is described with several dimensions such as a feeling of being in the body, in the room and in contact with health care, [35-37]. They [35-37] describe at-homeness as being in the present, contact with others and a feeling of meaning and affinity with others. At-homeness is more described as a concept which is not always associated to the physical home but connected with a spiritual experience. For the participants in this study, at-homeness was connected to being seen and cared for by someone who knew them well. The absence of at-homeness was related to not being seen and cared for by anybody. The most frightening scenarios for the participants was not being known or understood by anybody who knew their life story. The importance of being known and knowing someone’s life story has been described as a way to enhance the options for a carer to get a deeper understanding of each individual [6, 38]. There was a paradox in the participants’ perception of professional health care as provided by nursing staff. On the one hand, they were doubtful that the professionals would be interested to know their life story and see them as individual persons, and on the other hand they knew that if they were in need of extensive care, the best care was provided at nursing home. This paradox made them hover between trust and distrust.

Being treated with dignity presupposes that the nursing staff is educated and has knowledge about the history of the person. To maintain and retain integrity, everyone must be seen as a
unique individual. Randers and Mattiasson [39] state that when nursing staff treat the patient with autonomy, the integrity is protected and as a consequence of this their dignity is maintained. The same authors [40] also showed that respecting elderly people’s social self would reduce feelings of loneliness, isolation and seclusion. If the nursing staff not is able to meet the patient’s needs and desires, the patient could feel violated if their person/self is ignored [41]. Nordenfelt [42] argues, when talking about elderly and dignity, besides a collective dignity of merit, we have good reason for paying attention for the special vulnerability of the elderly.

Lögstrup [43, pp. 18-28] talks about the human interdependence where we are reciprocally dependent of each other; which means that we have the power to take care of the others life either constructively or destructively. The ethical demand, taking good care of each other, and showing respect and dignity, was something which all participants were familiar with from their long relation with the partner. Providing good care to someone who is suffering from illness and dependent of care is something reciprocal. If the health care staff has a good understanding of the reciprocal aspect of care, they have a possibility to acquire competence and a deeper understanding about the life story of the person in need of care. Competence and understanding will in turn enhance the ability of the health care staff in providing good care.

Methodological considerations

The study focused on the perceptions of how elderly people want to be cared for. Each interview situation is unique and the context influences the content of the interview [cf. 14]. In order to create a similar interview context for all participants, we used a vignette describing three different scenarios that were presented in a similar way to all. Perceptions are easily influenced by the context; however we think that the structured way of using vignettes was a guarantee for uniformity of the interview situation.

The nature of qualitative inquiry is that the results are difficult to generalise and have to be judged from a specific context. However, the participants were selected in a way to ensure variation in living situation and it is likely that their perceptions represent a Scandinavian context. Another aspect of context is that the interviews reflect the perceptions the participants had at the time of the interviews. It is possible that perceptions will alter over time as they get older and their personal health changes. Despite these limitations we think that the perceptions of good care among those healthy elderly persons that participated in the study provide an important contribution to the understanding of how elderly persons with
large caring needs, want to be cared for.

Trustworthiness of the study was supported by using rigour in all part of the analysis process where all steps were checked by all the authors. The researchers collaborated in every step of the study until a general agreement was reached.

**Conclusion**

The overall theme in the results emphasized the importance of being able to maintain the self and being cared for with dignity to the end. The perception of maintaining the self was closely related to maintaining relations. All participants in this study had long marital relation. However, among persons in younger generations in Sweden it is more common to have several long relations during a lifetime. It is likely that the next generation of older people cannot rely on their partner in the same way when maintaining their self and planners of care must take this into consideration. Nursing staff must be aware of possible changes in older peoples’ family situations and be able to provide care that promotes the self with dignity even when relations between family members are changing. It is imperative that politicians and decision makers give this aspect of elderly care serious attention and explore various options to deliver the best care, as perceived by the elderly.
REFERENCES

31. Leith K. Home is where the heart is ... or is it? J Aging Stud 2006; 20: 317-33.
Perceptions of using Assistive Technology Services when being in need of care

Interviews with Healthy Elderly People

Christina Harrefors, R.N.T.; M.N.Sc., Ph.D. Student
E-mail: christina.harrefors@ltu.se

Karin Axelsson, R.N.T.; Dr. M.Sc., Professor, Dean
E-mail: karin.axelsson@ltu.se

Stefan Sävenstedt, R.N.T.; Dr. M.Sc., Senior Lecturer
E-mail: stefan.savenstedt@ltu.se

Department of Health Science, Luleå University of Technology, Luleå, Sweden

Correspondence:
Christina Harrefors
Department of Health Science
Luleå University of Technology
SE-97187 Luleå
Sweden
E-mail: christina.harrefors@ltu.se
Abstract

Background: Assistive technology services (ATS) in nursing care have increased in the last decades and the care of elderly has moved from nursing institutions to the private home. There are studies describing elderly people’s attitudes to ATS in care, but most of these studies are about healthy and moderately ill patients. Few studies have highlighted the perceptions of the severely ill and totally dependent on care.

Aim: The aim of this study is to describe healthy elderly people’s perceptions of using ATS when being in need of assistance with care in the future.

Method: Twelve healthy couples, aged over 70 years old from northern Sweden were interviewed about their perceptions of using ATS in case of being in need of assistance with personal care. Open, individual semi-structured interviews supported by written vignettes describing three levels of caring needs were used. A qualitative content analysis was used to analyze the interviews.

Findings: The findings were interpreted as one main theme with three categories: Asset or threat depends on caring needs and abilities: ATS provide an opportunity; the consequences of using ATS are hard to anticipate and fear of ATS when completely dependent on care.

Conclusions: The results highlight that ATS in care is appreciated as long as one is in good physical and mental health. When life changes are accompanied by reduced mental and physical abilities, trust, human presence and security became increasingly important values, especially when ATS is used in care at home as well as in human interactions.

Key words: Trust, presence, ATS, homecare, dependency, perceptions, qualitative study

Summary statement:
What is already known about this topic?

- The development of more advanced assistive technology services (ATS) in care has increased over the last decades.
- More elderly care is performed at home, which enhances the development of ATS.
- The use of ATS in care of elderly at home has been evaluated by many researchers as something positive from the perspective of patients, relatives and nursing staff, even as resistance to its increased use has also been noted.

What this paper adds

- Being old, living alone and totally dependent on care, the use of advanced ATS in care is perceived as both a threat and a possibility.
- The boundary between trust and mistrust in ATS is a subtle distinction by each person and this depends on their perceived physical and mental abilities.
- Independence is perceived as a highly appreciated value when healthy, but when totally dependent on care, values like trust, security and human presence become increasingly dominant.

Implications for practice and/or policy

- Trust and security in the care of elderly who are severely ill, dependent on care and living at home should be a hallmark in using ATS to ensure good care.
- Human presence is an important dimension when receiving nursing care and must be considered when developing concepts for ATS.
Introduction

The home as a place for receiving nursing care is in a glaring contrast to the perception of the private home as a place for close family relations and privacy (Gardner 2000). While technology may be considered a burden, it also presents the possibility to maintain the autonomy of people living at home who are dependent on a ventilator, as described by Lindahl and colleagues (2003). The same authors (Lindahl et al. 2005) have described that being dependent on advanced technological applications for survival means that the technique also becomes part of the home. Technology brought into the homes not only safety and openness, but also fear and insecurity about the future.

The use of assistive technology services (ATS) has increased and it has become more common when care is given at home (Soar & Seo 2007). In a review of patients’ aspects of satisfaction with telemedicine it was found that most of them were ‘overall satisfied’ (Williams et al. 2001). In another review, telenursing care has been appreciated by the elderly living at home (Arnaert & Delesie 2001). Even among family carers the use of ATS in the care of elderly relatives has been evaluated as useful tools (Sävenstedt et al. 2003). In a pilot study of informal carers’ the use of ATS was seen having potential to contribute to health promotion in the care of a frail elderly relative (Torp et al. 2008). In a review, Roback and Herzog (2003) discuss how the use of different technologies in care at home has implications for the recipients of care and their families as the home turns into a place of work for professional staff and options for privacy are reduced. Technology as a promoter for good and human care was supported both from carers and caretakers; on the other hand, technology could result in poor and inhuman care (Sävenstedt et al. 2006).
The care of the elderly people is an important topic that has been discussed and developed in to the pursuit of providing both independence and cost-effectiveness (Magnusson & Hansson 2005; Kwang-Hyun et al. 2008). Although some studies have found that elderly peoples’ perceptions of the use of contemporary technologies are positive (Jenkins & McSweeny 2001; Vincent et al. 2006; Cahill et al. 2007), the development of more advanced ATS used in caring activities will pose new problems that have to be addressed according to the values of healthcare and established ethical principles (Rauhala & Topo 2003; Dittmar et al. 2004).

The increased use of ATS in care of the elderly at home needs to be followed by studies focused on the perspective of being severely ill and totally dependent on care.

The aim
The aim of this study is to describe healthy elderly people’s perceptions of using assistive technology services (ATS) when being in need of assistance with care.

Method
Design and data collection
The study was conducted in 2006 in Northern Sweden. Twelve couples were recruited from three villages and three cities. The recruitment of participants was made with the assistance of two established organizations for pensioners who facilitated member meetings and couples from these places accepted to participate. The inclusion criteria were: living in couplehood at the same address for at least 5 years, more than 70 years old, no professional work and receiving no kind of professional care at the time of the interview. The length of their relationship varied between 16 and 58 years (Mean=46.8, Median=50.5). The youngest was 70 years old and the oldest 83 years old (Mean = 74.8) (Table 1). Most of them lived in
private houses (Table 2). All couples were married except for one couple, who were cohabitants. No one had any kind of technical support such as alarm or assistive devices.

Table 1. Socio-demographics like age, education and professional experience of the participants (N=23).

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age 70-74</th>
<th>Age 75-79</th>
<th>Age 80-84</th>
<th>Education</th>
<th>Professional experience last 10 years</th>
<th>Manual</th>
<th>Administrative work</th>
<th>Technical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>8</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>8</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Men</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 2. Socio-demographic characteristics of the participants living situation.

<table>
<thead>
<tr>
<th>Living today</th>
<th>N=23</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private house</td>
<td>19</td>
</tr>
<tr>
<td>Cooperative flat/apartment</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Living environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>City</td>
</tr>
<tr>
<td>Village</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Distance to hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 50 km</td>
</tr>
<tr>
<td>51 – 100 km</td>
</tr>
<tr>
<td>101 – 150 km</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Distance to primary health care centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 20 km</td>
</tr>
<tr>
<td>21 – 40 km</td>
</tr>
<tr>
<td>41 – 60 km</td>
</tr>
</tbody>
</table>
The interviews were made with 24 participants in their home and were conducted by the first author. Each interview was an open individual tape recorded interview and based on vignettes. Because of technical problems one interview was excluded. The vignettes were presented both verbally and as short written scenarios (cf. Drew 1993; Sävenstedt et al. 2006). The scenarios were designed to provide different situations which were stepwise increasingly complicated. There were main questions in each scenario; at first the interviewed person’s perspective and then the partner’s perspective (Table 3). The interviews consisted of two parts, one about good care and the other on which this study is based.

Table 3. Content of the different scenarios presented to the participants as the basis for the interview.

<table>
<thead>
<tr>
<th>Different scenarios</th>
<th>Perspectives</th>
<th>Main questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st scenario, little need of care, healthy partner</td>
<td>Own</td>
<td>What are your perceptions of using ATS to remote consultation and health examination, in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS, in this situation?</td>
</tr>
<tr>
<td>2nd scenario, dependent on care, healthy partner</td>
<td>Own</td>
<td>What are your perceptions of using ATS to remote consultation and health examination, in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS, in this situation?</td>
</tr>
<tr>
<td>3rd scenario, dependent, no partner at home</td>
<td>Own</td>
<td>What are yours perceptions of using ATS to remote consultation and health examination, in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your perceptions of using ATS, in this situation?</td>
</tr>
<tr>
<td>1st scenario, little need of care, healthy partner</td>
<td>Partner’s</td>
<td>What are your partner’s perceptions of using ATS to remote consultation and health examination, in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your partner’s perceptions of using ATS, in this situation?</td>
</tr>
<tr>
<td>2nd scenario, dependent on care, healthy partner</td>
<td>Partner’s</td>
<td>What are your partner’s perceptions of using ATS to remote consultation and health examination, in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your partner’s perceptions of using ATS, in this situation?</td>
</tr>
<tr>
<td>3rd scenario, dependent, no partner at home</td>
<td>Partner’s</td>
<td>What are your partner’s perceptions of using ATS to remote consultation and health examination, in this situation?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What are your partner’s perceptions of using ATS, in this situation?</td>
</tr>
</tbody>
</table>

During the interviews, the concept of ATS was used in a broad sense. Example of different technology services were presented ranging from simple technical aids for daily living to...
assistive technology for security, communication and remote consultation. The interviews lasted between 30-60 minutes and were transcribed verbatim.

**Ethics**

The first author visited member meetings for pensioners and gave the group a short verbal presentation of the planned project. Written information was available for those who were interested to participate; which included information that they could withdraw their participation at any time without giving any explanations. The persons included in the study gave their informed consent about participation. All the participants were familiar with the environment in which the interviews were conducted. Identifying data were avoided during the interview, and if there was any they were removed while transcribing the interviews.

**Data analysis**

A qualitative content analysis inspired by Downe-Wamboldt (1992) and Sandelowski (2000) was made on the text about using ATS. To acquire a first impression of the content the whole text was read and listened to. Next, the text was divided into meaning-units. The meaning units were condensed, coded and initially grouped from the person’s own perspective and then the partner’s perspective. Gradually, it was realised that the two perspectives had the same dimensions of content and the two perspectives were merged into one. During the analysis process, the codes and sub-categories were discussed by all three authors until an agreement was reached.
Findings

The step-by-step grouping of content into more abstract levels resulted in ten sub-categories, which formed three categories and an overarching theme. The relation between scenarios, sub-categories, categories and theme is illustrated in Figure 1.

ATS provide an opportunity

The category includes the positive perceptions of using ATS for remote consultations, health examinations and other different technical devices when in need of help. The positive
perceptions were connected, among others, to the possibility of having an additional way to communicate with nursing staff and the network of friends. It was also connected to the possibility of staying at home for a longer time. All statements in this category were pronounced quickly and spontaneously and mostly related to the scenario “Little need of care, healthy partner at home”.

ATS beneficial for consultations at home

When the participants were asked to describe their perceptions of using ATS for consultations and health examinations in case of loss of bodily function and in need of assistance, they all talked about it in a very positive way. Superlatives like terrific, fantastic and great were used to describe their thoughts: “I could consider examinations and medical consultations at home...almost any kind...I think that would be...not peculiar at all...it would be great...it would be very valuable....” Men as well as women expressed that routine health examinations at home would suit them very well because a visit to the healthcare centre was connected to anxiety and inconvenience. There was a benefit if they could perform the consultation peacefully and quietly at home instead: “It would be great because when you are visiting the physician the blood pressure can be raised before you are there...it sounds really great.”

ATS provide an opportunity to stay at home

Another positive perception was the possibility that support through ATS would make it possible to live at home for a longer time and through a manner that enhances well-being and quality of life. Men in particular, stressed that they had nothing against the use of technical devices, as it was regarded as part of development. They expressed that they really would make use of the opportunity. Technical devices could be a necessity when suffering from
illness and still wanting to live at home. It could provide an alternative for placement at a
nursing home. “I am happy to use the technical devices since it is something...I have to
accept that... technology is something I like... if it is  possible to invent devices that will assist
me to stay home longer ... life would improve in many ways....” Many of the participants
discussed their perception of home as something that changed meaning when they got older.
The home was much more appreciated when getting older; they mentioned that to live at
home was very important and much more stimulating compared to being at a nursing home.
“You can live together with the person you love ... living in an institution where nobody has
time for you...it is not good ....” The descriptions about the partners in this study were all
characterized by respect, closeness and trust.

ATS provide increased safety
Another positive aspect of using ATS was the possibility of becoming more secure at home
through the regular monitoring of health. A requirement was that ATS consultations provided
the same quality of assessments as if it was done at the healthcare centre or the hospital.
When dependent on care and in need of help, the interviewees expressed that they wanted to
have someone to communicate with. “It is not much different then to talk with the nurse on
the phone ... the difference is that  you can see each other ... it provides safety since you have
to assume that the persons dealing with the technical devices are serious ... I assume that the
nursing staff in any case are ...[serious].” Many of them expressed that they felt safer with
technical devices at home compared to being placed at a nursing home. They perceived that
with the help from ATS, there was a possibility to get in touch with the nursing staff quickly,
or someone who was always present. Another aspect of safety when being dependent on care
was the risk to lose the communication with their network of friends and relatives. The
opportunity of remote communication via ATS could assist them in maintaining
communication and enhance their sense of safety. “Of course if I fell down they would discover that ... otherwise I had to lie on the floor for ever and nobody would help me.”

**The consequences of using ATS are hard to anticipate**

As the scenarios changed and covered the aspect of being dependent on care, with a healthy partner at home it was obvious that all participants were reasoning from various perspectives on the benefits of different solutions for care and the use of ATS. Many of the responses were dialectically formulated, such as “from one point ... but from another ...”, reflecting that they could perceive that there were both benefits and disadvantages with the different solutions.

**ATS is here to stay**

Although all the participants could perceive that assistive technical devices for care was something good and even a necessity, their attitudes seemed to change as the perceived needs of care increased. They became more resistive when perceiving a situation with illness and dependence on the assistance of ATS in their homes. This increased resistance was to some extent compensated by a feeling that ATS has come to stay and there is no use in ignoring such a development. There was also a possibility that technical devices could help promote their well-being and comfort. They realised that being ill or severely ill is a difficult and vulnerable condition and if they opted to stay at home they might have to accept things that were unthinkable when being healthy. “It is not always that these things are introduced voluntarily ... you have to accept ... you are unable to care for yourself and if you don’t get support from those that care for you, obviously you have to accept.” This kind of view was especially expressed by the women in the study.

**ATS can support nursing staff**


Participants were also concerned over the needs of nursing staff. They realised that nursing care of the elderly is a tough and demanding job and if technical devices could make life easier for the nursing staff, then it is good to use them: “If the technical devices can assist the nursing staff I think it is worth while using them ... you have to consider the benefit of all involved, even the nursing staff....” One of the participants expressed that one of the benefits of technical devices is that they are never in a bad mood and do not differentiate between people, which can make care more equal. Another observation was that if the use of ATS could make the care more efficient, then the nursing staff would have more time to spend with the patient. “If the introduction of ATS contributes to reduce the cost for healthcare there would be room for increasing the number of nursing staff ... the perfect solution would be access to both nursing staff and assistive technical devices if I need caring support.” Another aspect was the possibility that if the care burden for nursing staff was reduced, they might be more patient, which could then improve the level of care and benefit both the person who is ill and their family members.

ATS impact on my relationship with my partner

During the interviews, the participants often mentioned that the partner was their closest person, even if all of them had children. They never talked about the children as a presumptive carer. When talking about their partner’s perceptions, for men in particular, it was obvious that they wanted to assist their partner. Together, they could face and handle new technical devices especially if they both were in reasonably good physical and mental health. At the same time, there was a concern that the use of technical devices could develop into a burden for their partner. “I would accept it ... but the question is ... what it will mean for our relationship... it is very demanding for our partner if one of us becomes very overloaded with caring burdens.” If the use of new technical devices was a prerequisite to stay at home, there
was also a risk that the partner could be “overloaded” with demands. Everyone mentioned that their partner was old and not always healthy, which must also be considered. Without their partner, it would not work to use ATS; but when partners are together, new technical devices were not something to worry about as they could help and support each other.

ATS requires me to be in control

Suffering from cognitive impairments was something that really concerned all the participants. Losing cognitive abilities and not having sound judgment was a difficult scenario to perceive as anything could happen. One’s life situation could change quickly and they could easily be unable to handle technical devices. “I am really not against it ... no it would be a good thing provided I could learn how to manage them ... and then it depends on if I am still cognitively in my full senses.” Being dependent on care, or being alone may make it very hard to learn and manage ATS. Others also admit that their fear and resistance against the use of ATS probably had to do with their lack of knowledge about the new technology. One aspect was that they felt that they were too old to start using ATS since it might be difficult to learn new things now. To be able to handle new technical devices they perceived that they had to learn how to use them well in time before they became unhealthy.

Fear of ATS when completely dependent on care

Perceptions related to fear were connected to the participants’ perceptions of using ATS when being faced with the scenario of being “dependent on care and no partner at home”. It was obvious that when considering this scenario a lot of strong feelings were expressed. Thoughts related to this scenario were formulated with questions as what, when, how and why. It was obvious that their statements about using ATS in this situation in different ways were expressions of fear and resistance.
Advanced ATS can never replace human encounters

The participants had an overwhelming conviction that regardless of how effective and useful technical devices are, they can never replace human relations: “I really don’t like the idea of substituting people with technical devices … they have to support enough resources to provide … human encounters.” The possibility of being physically touched by another person could never be replaced. When dependent on care and no partner available, the perception of having remote consultations via advanced ATS seemed terrifying. The possibility of interacting with other people, having the possibility to see and hear people talking, laughing and doing things around them was expressed as something very important. Even if the participants still would accept the use of ATS when severely ill, they pointed out the necessity of human presence in care and of physical touch: “I feel that the human hand ... is very important... when you are not able to care for your self ... many have confirmed that to be able to physically touch each other is very important, more important than you first realise ...”

Unsafe when completely dependent on ATS

The scenario of being dependent on care, living alone and dependent on the use of ATS seemed to be connected with fears — the fear of not being seen as a unique person with specific needs. Being alone and dependent most of the time on remote communications, especially when living in isolated areas, was a terrifying thought: “But... it is just this thing of being alone... it depends on how ill you are… to leave an old person that is more than 85 years of age alone... and the nursing staff is in another village... that is difficult.” In this scenario, the perception is that access to professional, well-educated nursing staff had high priority. Even if they perceived life at nursing homes to be tremendously boring, they agree that it would be much more secure. No matter how effective ATS were, there was always an
uncertainty and a risk that something will go wrong in all systems: “You know ... something can fail ... and if that is not observed ... what will happen then ... you can never rely on technical devices 100 percent ... it just is like that.”

**Advanced use of ATS is a threat to my private sphere**

Being exposed to ATS without having the control was described like being violated and neglected by the official healthcare system and the society. This was perceived as a threat to one’s personal integrity. “But what nightmares, then you are remotely controlled night and day ... it sounds terrible ... I mean you cannot do anything without... you don’t have any integrity then.” Several participants regarded with fear the situation where someone unknown could watch and invade the most private sphere of their lives. There were also several thoughts about what would happen with the information about one’s private life and peculiarities. While it was easy for participants to understand the economic and organisational arguments for developing the official healthcare system for the elderly with the use of ATS, they also emphasized that it was important to care for the elderly with respect.

**Asset or threat depends on caring needs and abilities**

On the basis of the different categories, elderly people’s perceptions of using ATS when in need of assistance with care may be interpreted in the theme, “Asset or threat depends on caring needs and abilities.” The asset ATS was connected to hope and trust, while its threat was connected to mistrust and loss of control. The assets were described in situations when the interviewees or their partners had control and could be a part of making decisions. Threat and mistrust seemed very closely connected, was associated with the use of technical devices when dependent on care and being alone without a partner. There were expressions of great
fear when mistrusting their own ability of control over the use of ATS. Trust gradually turned into mistrust as scenarios of increased illness and decreased family support were presented.

Important aspects on how and by whom ATS was used were associated with the possibility of creating human presence, trust and security in the caring situation. The lack of human touch, mistrust and the violation of their integrity were the concerns over using ATS at home, as well as being unsure that someone could advocate for them. The main thread in the participant’s perceptions was that the use of ATS could replace human encounters.

Discussion

The perspective of this study was influenced by a keen interest in elderly people’s perceptions of using ATS from the aspect of being in need of assistance with care in the future. The main theme was interpreted as ‘Asset or threat’ depends on caring needs and abilities.

Trust is a central in understanding a person’s development and maturity. From an early age it is the goal of each person to develop a fundamental trust. Building trust is an ongoing process throughout life and experiences from childhood impact personality for the rest of one’s life (Erikson & Erikson 2004). Trust in one’s self and in other persons is built on experiences from the interactions with others. The foundation of trust is rooted in formative experiences, a sense of security that develops in early nurturing relationships (Rotenberg 1994). The participants perceived ATS as an asset when caring needs were limited, the partner still healthy and when they were living in couplehood. In circumstances where they still perceived that they could make choices and decisions on their own, they also had trust in themselves. Mistrust in using ATS was related to increased illness, cognitive impairments and decreased family support, causing a growing mistrust in themselves.
Older adults’ perceptions of “smart home” technologies were described as overwhelmingly positive and also with concerns that technological devices could replace human interaction and in a way violate their private sphere (Demiris et al. 2004). Similar results may be found in reports where participants, before implementing videophones in care, expressed fears about the invasion of their privacy (Arnaert et al. 2007). The participants’ perceptions about ATS in care seem to be more related to the context in which ATS is introduced and used than the technology itself. The partner’s ability is a guarantee for trust and hope for the participant, the partner is trust.

Trust in care situations reflects abstract positive expectations that partners can count on being cared for by each other, as well as being responsive to different needs. Trust in intimate relationships emphasizes that its foundations are collared by the seminal experiences, which lead to different stages of interdependence (Holmes & Rempel 1989). According to Cutrona (1996) the interpersonal relation can be a resource in times of stress by providing social support. The partner’s supportiveness and motivation to support are central to the beneficial effects for the relationship, such as stability and quality. Common experiences from many years together indicate that participants really knew each other. They expressed a strong wish to stand up for each other, even in times of overwhelming challenges such as becoming ill and dependent on care; the relationship also meant trust in care situations.

Their main concerns about being dependent on nursing staff were expressed in concepts like trust versus mistrust and human presence versus absence. The more vulnerable the person, the more important the nursing staff’s professional competence became. Well-trained nursing
staff was raised as an important requirement. There was a strong wish expressed that nursing staff should consider their uniqueness as persons and would protect their privacy.

The importance of trust in caring relationships is described by several authors and in different care situations. Radwin and Alster (1999) describe how caring relations can build trust and hope; it is important parts when oncology patients described a sense of well-being. The participants in their study experienced hovering between the two extremes of fear and trust. Svedberg et al. (2003) describe when being treated in a friendly and compassionate manner by nursing staff the development of trust in caring relations increase and is a sign of the their competence. Similar results are also described by elderly clients in their relations with home care nurses (Trojan & Yonge 1993). Trust is the first step in a process where the clients could interact with the nursing staff. Reflecting over the last scenario of being totally dependent on care and living alone, all of them expressed a fear of losing control and not being treated like the person that they are. Participants inquired about who was going to protect and represent them on the basis of the knowledge about the specific person they are.

Another aspect of relational trust is that elderly people with failing personal resources are more likely to experience a condition of psychological frailty (Rockwood 2005; Strandberg & Pitkälä 2007), which can be associated with increased social isolation. Being totally dependent on care can result in feelings such as fear and threat (Rockwood et al. 2004). With declining physical and mental health, the participants’ trust in the use of ATS seemed to decrease—especially without a supportive partner.

The perception among the participants was that individualized care connected with security and trust was difficult to achieve with only the help of ATS, especially when being totally
dependent on care. Buber (1958), states that an interaction with tenderness, human presence and awareness ought to be a common ground in relation with the other. Technical devices, regardless of which form they are used, are still only devices and can hardly be developed to replace human relations. Using ATS in care situations without considering a fruitful personal relation will lead to lack of human presence. The feelings of fear, insecurity and threats found in the study are interpreted as fear of loss of identity and personality. Although perceiving the loss of both cognitive and physiological abilities, they still wanted to be treated with warmth and closeness. The use of advanced ATS could in the worst scenarios mean that the participant would be reduced to a thing, with relational coldness, detachment and instrumentality (cf. Buber 1958). Our interpretation of the interviews is that human encounters are fundamental. In situations where the partner no longer is available and their own abilities are reduced, the participants wished that nursing staff should be close, listening, and touching, which becomes a substitute and another way of maintaining human presence.

When discussing the possible consequences of using ATS in care, it is emphasized that even with great advances in the development of technical services, it can mean a new kind of “spatial vulnerability” in nursing and threaten the presence in caring relations (Sandelowski 2002 p. 66). A central value in nursing care is trust in the care relationship (Lowenberg 1994). Rotter (1971) has defined trust in care as an expectancy, pronounced or written by another; something one can rely on. Promises in nursing care may be explicit but are often implicit and not communicated directly. Kitwood (1997) points to the necessity of being present and meeting the person in his or her uniqueness; especially in interaction to people with dementia. The ability to be present is a personal gift and means a way of being that underlies all true relationships. Presence is often described as a core element in nursing care. Presence is both
physical “being there” and psychological “being with” the patient with the purpose to see and meet caring needs.

The study focused on elderly people’s perceptions of using ATS when being in need of care. To create a similar interview context for all participants, vignettes describing three different scenarios were used. A structured way of presenting the scenarios guaranteed uniformity in each interview situation. It is difficult to generalize the results of a qualitative inquiry and therefore it needs to be judged from the specific context in which it has been conducted. Participants were selected in a way that ensures variation in living situations, and it is likely that their perceptions represent the current Scandinavian context. Perceptions change owing to the living situation and experiences; it is possible that increased age and reduced health will alter perceptions among the persons interviewed. Despite these limitations our conviction is that perceptions on the use of ATS are a valuable contribution in planning and organising the care of elderly people at home.

The trustworthiness of the study was ensured by using rigour in the various aspects of analysis, where all the steps were checked by the authors. The researchers collaborated in each step of the study until a general agreement was reached.

**Conclusion**

Perceptions about technical services will change while human needs remain unchanged. As the perceptions on ATS among the elderly will probably change over time, it is important to follow and describe them, especially in times when new technical services are rapidly being developed and are likely to be introduced in the care of the elderly. Implementation of new technical services must consider the constant control and evaluation of the quality of services,
with focus on the most vulnerable elderly people’s perspective and their basic needs. Fundamental human values like trust, security and presence remain the same over time, and must be considered when planning the use of technical devices in nursing care, particularly among the elderly.
References


