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**Telecare of frail elderly -
reflections and experiences
among
health personnel and family members**

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ABSTRACT

Telecare has been an approach to care that, internationally, has experienced a generally rapid development during the last ten years. There are many examples of successful pilot projects where ICT applications have been used in the care of elderly: for improved remote consultation with health professionals, to improve the communication and support of the elderly person's social network, and as intelligent sensors intended to improve the safety of the elderly person. Despite these successes, implementation has been slow. This research project was set up to provide additional knowledge on some of the important questions regarding quality and implementation aspects of the use of ICT application on the care of frail elderly persons.

The overall aim of the research project is to illuminate reasoning and experiences of using applications of telecare for frail elderly persons.

The research project comprised five studies that were conducted using qualitative research methods. Four of them were carried out within the framework of three telecare projects. Different qualitative research approaches such as content analysis, phenomenological hermeneutics and conversational and discourse analysis were used, in accordance with the research questions of each study.

The experiences revealed in the findings of the studies indicate that it is possible to have communication of good quality via videoconferencing with frail elderly persons, even those that have mild or mid-level dementia, provided the conditions are right. Technical limitations of the videoconferencing media in transferring communication cues and the limitations on what the camera can expose place special demands on those communicating with the frail elderly and on the general setting. On the other hand, these limitations on the context of interaction in some situations also seem to be an advantage for demented elderly persons and contribute to increased attention. One example of meaningful remote communication with frail elderly persons was family members' videophone conversations with their demented relatives when they were placed in nursing homes or homes for respite services. This communication gave new possibilities of being involved in caring for, and of maintaining a relationship with, their demented relative. An introduction of teleconsultations in the care of frail elderly persons will, according to the experiences recorded, affect the professional role and the practical spheres of involved health professionals. The perceptions and experiences of participating health personnel indicate that in order for ICT applications to become valuable assets in the care of frail elderly persons they have to be part of a care alternative that is viewed by all concerned as the best alternative, as a whole, for all affected parties.

Further research is needed in order to confirm or refute the findings of this thesis and in order to further broaden our understanding of the use of ICT applications in the care of frail elderly persons. This could facilitate a development of ICT applications suitable for the care of frail elderly persons and their introduction into regular care activities, to the benefit of both the frail elderly persons and their carers.

Key words: Telecare, frail elderly, nurse-patient interaction, quality of care, professional roles, videoconferencing, ethical reasoning, perception of care

ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

- I** Sävenstedt S., Sandman PO., Zingmark K. The duality of Information and Communication Technology (ICT): Health personnel's reasoning regarding the use of ICT in the care of frail elderly. Manuscript submitted for publication
- II** Sävenstedt S., Bucht G., Norberg L., Sandman PO (2002) Nurse-doctor Interaction in teleconsultations between a hospital and a geriatric nursing home. *Journal of Telemedicine and Telecare* 8, 11-18
- III** Sävenstedt S., Brulin C., Sandman PO. (2003) Family members' narrated experiences of communicating via video-phone with patients with dementia staying at a nursing home. *Journal of Telemedicine and Telecare* 9, 216-220
- IV** Sävenstedt S., Zingmark K., Sandman PO.(2004) Being present in a distant room. A study of the qualitative aspects of teleconsultations with elderly people in a nursing home. *Journal of Qualitative Health Research* 14, 1-12
- V** Sävenstedt S., Zingmark K., Hydén L-C., Brulin C. Establishing joint attention in remote talks with the elderly about health. A study of nurses' conversation with elderly persons in teleconsultations. Manuscript submitted for publication.

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TERMINOLOGY

There are several definitions of the concepts presented below and the explanations presented correspond to the ways I have used them in this thesis.

Telemedicine: Medical care provided at a distance via the use of interactive communication based on Information and Communication Technology. This includes activities such as diagnosis, consultation and treatments as well as education and transfer of medical data. Telemedicine was historically the first terminology used to describe medical activities at a distance.

Telecare: Is a wider and more recent concept than telemedicine and includes not only medical consultations, treatments and educational activities but also care activities provided by other professionals than medical doctors.

Telehealth: The concept of telehealth reflects a further broadening of the concepts of telemedicine /telecare to also include health information and activities accessible at a distance to the general public.

E-health: The concept of e-health is the most recent concept and it is strongly connected to the use and development of the Internet. The concept reflects the development whereby the health consumer has in different ways an almost unlimited access to interactive health information and consultations via the Internet.

Telepresence: The experience of presence at a remote site via the use of information and communication technologies and virtual reality.

Gerontechnology: Interdisciplinary field of research and application involving gerontology and technology. One goal of gerontechnology is to use technology to prevent, delay, or compensate for the perceptual, cognitive, and physical declines of ageing.

Frail elderly: Defined as older adults or aged individuals who are lacking in general strength and are unusually susceptible to disease or to other infirmity. The concept is in this thesis used to reflect the group of elderly in need of care either through home service or through group dwellings or nursing homes.

INTRODUCTION

The interest in research on the use of modern Information and Communication Technology (ICT) applications for frail elderly persons arose from my own involvement as a project manager in different telehealth projects. The projects had a special focus on facilitating care activities with elderly persons and a focus on home-based care. My initial interest in participating in the projects was based more on my experiences of managing projects and participating in different kinds of development work than on a special interest in ICT applications. As time passed and I gained more experience of the difficulties, constraints and the potential of telecare applications for the elderly I realised that this was an area where only limited studies had been made. My realisation was supported by Starkhammar and Dahlenborg (2002) who had reached similar conclusions with their findings. At the same time, I learned through experience that telecare is an area of health care that is value laden and where many people, both professionals and elderly persons, expressed strong attitudes both for and against. These were values and attitudes that I felt were, most of the time, not based on documented knowledge and experience but more on a general attitude towards the use of ICT in the care of the very old, and a general resistance towards change. One obvious reason for the lack of knowledge and experience of ICT applications in the care of frail elderly persons is that it is quite a new phenomenon. It has until now, in most health care institutions in Sweden and most other countries, only existed within limited project activities and has not been introduced as an ordinary strategy in the implementation of health care. The experience from these telecare projects for the elderly indicates that there is great potential to develop telecare concepts that can contribute to the care of frail elderly persons. However, there is also a need to further study telecare applications for the frail elderly in order to identify limitations, benefits, and ethical implications.

An important reason for my interest in telecare for frail elderly persons is that it, to my understanding, has a potential to make a contribution in the great challenge of the health care for the frail elderly. The demographic development in Sweden, as well as in many other Western countries, is such that a growing number of elderly persons means a parallel increase in the need for social- and health care (The National Board of Health and Welfare, 1997). There have been developments in modern health care whereby complicated health problems among the elderly above 85 years of age can now be treated successfully and at the same time the number of beds in hospital based care has decreased. This development has created an increased interest in home-based care (The National Board of Health and Welfare, 1997).

An increased number of the very old will also mean an increased number of demented elderly persons. The prevalence of dementia among elderly persons aged 85 in Scandinavia is today about 30% (Aevarsson and Skoog, 1997). This structural change means that the professional health care system enters into the private home with demands on family members to participate, as well as a potential for individualised care with improved quality of life (The National Board of Health and Welfare, 1999). Advanced home based care will need the support of qualified health personnel, and remote communication with the assistance of ICT has the potential to facilitate that support (Ministry of Health and Social Affairs, 2002).

Rationale for the study

The first reported uses of telemedicine occurred in the late 1950s and early 1960s. Even though almost 50 years have passed there has been a relatively slow introduction of telemedicine in general. There are a variety of factors contributing to this slowness, such as reimbursement problems, licensing requirements and inadequate telecommunication networks. An important barrier is the dearth of evaluation data about the effects of telemedicine (Yellowlees *et al.*, 2003). The number of published research articles in the area of telemedicine has rapidly increased during the second half of the 1990s. A majority of those studies have assessed the accuracy of diagnostic decisions or the effects of telemedicine services (Taylor, 1998). As in many other areas of medical technology, telemedicine was first developed for highly specialist medical applications such as intensive care, and the introduction of the technology into basic care situations for the elderly is quite recent. This situation is also reflected in the limited number of published research articles related to the telecare of frail elderly persons. The great demand for medical and social care of the elderly in most developed countries, and the costs involved, could motivate a drive for telecare applications for this target group. One barrier to this development is the perceived negative attitude among elderly persons towards the use of modern technology. Levy *et al.* (2003) found in a pioneering study of the attitudes of elderly people towards telecare technology that "tele-receptive" individuals tended to be under 80 and among those who had an urge to stay at home for as long as possible.

Another barrier to telecare applications for the elderly is a perceived loss of interaction qualities. Miller (2003) argues that even though there are those who believe that telemedicine will alter doctor-patient relations, there is no consensus as to whether it enhances or damages the therapeutic relationship or the traditional practice of medicine.

He concludes in his review of research on doctor-patient communication in telepsychiatry that further research is necessary if the nature and content of the communication process is to be fully understood. Quality of care is closely linked to the quality of the care relationship and the quality of the communication process (Arnold and Boggs, 1995) and it is therefore also important to understand the communication process in telecare applications.

Considering both the perceived potential and the perceived barriers in using ICT applications in the care of frail elderly persons, as well as the limited research conducted in the area, there was a need for further research. The studies conducted within this thesis address both issues related to the introduction of ICT application in the care of frail elderly persons, as well as issues related to quality aspects of telecare.

BACKGROUND

The caring network of frail elderly persons

Interactions with significant others can be described as social networks. Seikkula (1996) claims that the phenomenon of social networks is a concept that helps us to understand a system of interactions that is important in a specific situation. The social network of frail elderly persons is a description of their social identity in their network of significant others who can assist and interact in caring and other important aspects of their lives. The frail elderly person acts in different sub-groups, such as the immediate family, relatives, friends and professional careers, and the links between the different groups are important (cf. Seikkula, 1996). Tornstam (1994) concludes that a given elderly person's social network is not as small as anticipated but that the very old are often socially isolated. Many of the very old have faced the loss of significant others in the social network and have difficulties in establishing new relations. (Tornstam, 1988). Waerness (1999) claims that modern society creates people that are free and used to choosing with whom they want to relate. At the same time this situation creates a risk of increased isolation for those who have difficulties in relating, as some of the oldest elderly persons do.

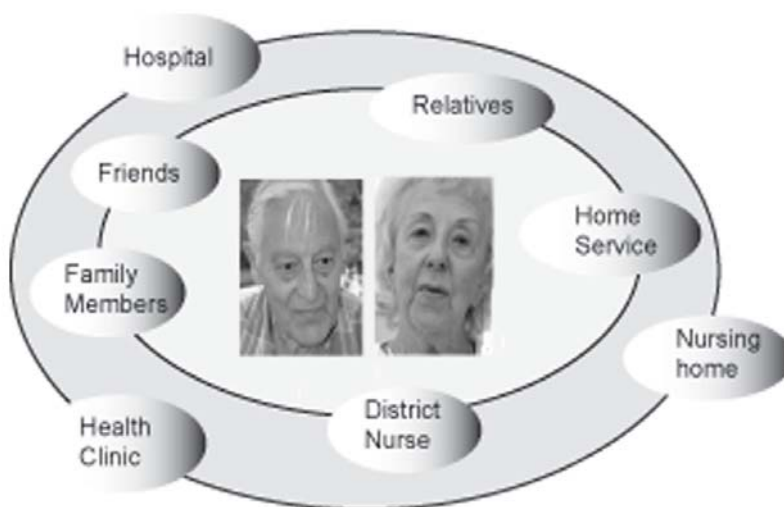


Figure 1. The frail elderly person's network, with careers and significant others

An important part of the frail elderly persons' social network is family members. Spouses are the most common informal carer and, together with children, they perform three times the amount of care work compared to professional carers (Tornstam 1994). The importance of the social network of frail elderly persons and their carer spouses was studied by, among others, Sällström (1994). She found that carer spouses with small networks tended to have a negative view of themselves in relation to others while spouses with large social networks view themselves, in relation to others, in an equally positive and negative way. They also regarded the content and quality of the relationships with family and non-family to be predominately positive. Lundh (1999) showed in a study of family carers that many experience a number of aspects as stressful, both with the care relationship and the physically demanding nature of their role. Almqvist, Grafström and Winblad (1997) studied family members' strategies of coping with these stressful situations and showed that a mixed strategy of emotion based acceptance and seeking information, and social support in the network was an effective choice of strategy.

Even though the informal carers carry out the main part of the care work for the frail elderly, the professional carer plays an important role in the network of most frail elderly persons. This role is demanding and complex and requires general geriatric knowledge as well as specific knowledge about the individual elderly person (Marcusson, Blennow, Skoog and Wallin, 1995).

Even if many frail elderly persons have faced the loss of significant others in their social network and have difficulties in maintaining relations there is a possible potential that ICT applications can facilitate remote communication and relations with persons that are important in the care of elderly persons in their homes (cf. Arnaert and Delesie, 2001) and for social interactions. This could include social interactions through remote communication with close family members, relatives and significant others.

Caring relations and communication with frail elderly persons

Caring for frail elderly persons can be understood in terms of the care relationship that exists between the professional carer and the elderly person (Waerness, 1999). For health professionals, a care relationship differs from social relationships in that connections and bonding are purposeful and directed by the professional. The professional takes the primary responsibility for maintaining the boundaries and guiding the relationship, and the quality of the

care relationship is directly linked to the quality of the communication process (Arnold and Boggs, 1995).

Thomson (1994) made a review of interpersonal communication in health care. She found that most of the research was carried out by nurse researchers and that research on communication in medical journals was much less common. Generally the research indicated a lack of time spent on communication in health care encounters, as well as a lack of emphasis on relational factors during this communication. There was a frequent lack of care provider interest in communication or communication skills and health care providers typically maintained control of interactions.

There is a long tradition of research into the communication process between health personnel and patients. One example of quantitative research on how communication between doctors and patients is carried out in different situations has been carried out by Roter. Her research has, among other things, showed that interpersonal skills among health personnel can be taught, and measured in order to improve the quality of care (Roter and Hall, 1992 pp. 111-130). Caris-Verhallen has, in a series of papers, studied, among other things, the aspect of training to improve nurses' communication with the elderly using a similar research approach (Caris-Verhallen, 2000). The development of qualitative methods for studying medical discussions stemmed from attempts to understand the communication process in its context (Silverman, 2001). Mishler (1984) argues that health personnel's conversations with patients can only be understood in its full complexity through an analysis of its overall and sequential structure. He has demonstrated, among other things, the importance of the conflict between the different standpoints of the doctors and the patients. The doctor stands for the "voice of medicine" representing the medical profession's knowledge of medical and technical issues and the patients communicate with the "voice of the world of life" representing their experiences from their day to day life. The "voice of medicine" tries to dominate the communication in order to make efficient medical decisions.

Research on the communication process between health personnel and elderly persons has been carried out by several researchers. One example is studies of the effect of training on the communication process with the elderly, and some researchers have showed that socio-emotional interaction with the elderly improved after structured training (cf. Hansebo and Khilgren, 2002). Elderly people with dementia often have difficulty with both receptive and expressive language (cf. Potkins, 2003), and this complicates the communication process and the care relationship. Ryan, MacLean and Orange (1994) have studied the strategies health personnel use to accommodate to the communication ability of demented elderly persons. They found that many health personnel had a tendency

to underestimate the communication ability of the demented elderly person, which was shown in the use of an over-simplified language.

Remote communication with the assistance of ICT applications is different from face-to-face communication. One difference is that videoconference media lacks the richness and intimacy of face-to-face encounters (Cukor and Baer, 1994). It could consequently be assumed that videoconferencing techniques add additional interaction and communicative problems, especially with frail elderly and demented persons.

Caring needs among frail elderly persons

In this thesis the concept of the frail elderly is used to describe the group of elderly persons who are generally lacking in strength, and who are unusually susceptible to disease or to other infirmity. Another way of describing the frail elderly is that they are the group of elderly persons in need of regular care, either through home service or through group dwellings or nursing homes. The group of frail elderly persons is characterised by often having multiple medical problems as well as different kinds of impairments, creating an often complex pattern of care needs (Larsson and Rundgren, 2003).

One of these multiple problems that is closely associated with care needs among frail elderly persons is dementia. The prevalence of dementia in a Scandinavian population of elderly persons of 85 years of age is about 30 percent (%) (cf. Aevarsson and Skoog, 1997). About fifty percent (50%) of elderly persons with dementia reside in nursing homes, where they constitute the majority of the residents. The number of elderly persons with mild, mid-level and severe dementia is estimated to be 130 000 in Sweden and will rise to 150 000 by the year 2010 (The National Board of Health and Welfare, 2000).

Kitwood (1997) stated that an elderly person with dementia should be seen as a social actor with special needs. The person with dementia has needs that are not exclusive to him/herself but which it is necessary to consider in encounters and relationships with significant others. From this perspective there is a focus on the individual and dementia related behaviours are seen as compensations for losses of functions, and as a way of communicating with the environment (Johansson *et al.*, 1999). Dementia can be understood as an existential problem that affects both the life of the impaired elderly person and his/her family (Zingmark, 2000, 2002). The frail elderly person's care needs have to be considered when the use of ICT applications is planned. Questions as to what

ways the ICT applications can support the specific needs of the frail elderly person should be asked.

Presence in caring

Presence is an important concept for all professionals, such as nurses, doctors and counsellors, who care for people through the medium of skilful human interaction (Karl, 1992). The concept reflects quality aspects of the interaction and is, as a phenomenon, socially constructed in the relationship between the professional health personnel and the patient. Berger and Luckman (1968 pp. 28-29) state that our most important experience of others takes place in the face-to-face situation, which is the prototypical case of social interaction. Only here is the other's subjectivity emphatically close and it become progressively anonymous the further away they are from each other.

Gilje (1992) made an analysis of the concept of presence in nursing and found that there were several common perceptions. The first common perception is presence as being, and according to Buber (1958) philosophically understood as being, dependent upon the relationship between the "I" and the "Thou". Reality is "being in-between" and characterised by mutuality and "presentness". A second simplified way of understanding presence is as a contextual definition as being in one place and not in another. A third perception of presence is "closeness", meaning nearness in time, space, quantity and resemblance. Closeness has psychological, emotional and spiritual realms. The fourth perception relates presence to "having existence or influence in the present" where the focus of the definitions falls on the words existence and influence. The fifth perception relates presence to transcendental experience or a presence of a higher being. Presence has also been associated with caring as a definition, and non-caring situations as absence of presence and emotional distance by the nurse. The most consistent definition of presence in the literature is "being with" (Gilje, 1992).

Fredriksson (1999) made a review of qualitative research on an ontological and theoretical understanding of presence, touch and listening in care conversations. He found that there are two modes of relating in care conversations: a relation with high inter-subjectivity and another with low inter-subjectivity. The situation with high inter-subjectivity was characterised as "being with" and the situation with low inter-subjectivity as "being there". One aspect of this thesis has been to understand whether care relations with frail elderly persons facilitated by ICT applications can maintain a care conversation that is characterised by high inter-subjectivity, and as "being there".

Presence in virtual reality

Communication with ICT applications such as videoconferencing requires a level of presence. Presence production in virtual realities such as videoconferencing is a complex, multidimensional perception and a developing area of research prompted by the fast development of ICT (Ijsselsteijn and Riva, 2003).

Enlund (2000) proposes a model describing factors that determine the sense of presence and reality in virtual environments. He claims that there are three main factors that determine the sense of presence and reality among the participants in a virtual reality service. One is the sensory environment, which is related to the technical qualities of the media such as interactivity and the vividness. The second factor is the individual preconditions among the participants relating to their emotional state, motivation and associative context. The third factor is the content characteristics such as plot and story and dramaturgy. The most important factor of the three is the content characteristics.

Lombard and Ditton (1997) talked about physical- and social presence in virtual realities in a similar way to that in which Fredriksson (1999) describes nursing presence. Physical presence corresponds with "being there" and social presence as "being with". In the intersection of the two is co-presence, described as a sense of being together in a shared space. According to Lombard and Ditton (1997) videoconferencing is a medium with the potential for co-presence.

Riva and Mantovani (2000) proposed a cultural concept of virtual presence as a construction where the experience of presence and telepresence is not so much dependent on the technical quality or the reality of the virtual environment as on the capacity to produce a context where the actors can communicate and interact. Ijsselsteijn and Riva (2003) conclude that research on presence has to reach beyond a search for realism and fidelity only and ask questions concerning the purpose and the context of use. Questions like: how does the context appear where the frail elderly participant experiences co-presence with others and what are the symbolic references that allow the participants to orient and coordinate themselves? These questions about the context of interaction could include the aspects of shared knowledge of each other's present and past activities, as well as shared artefacts and environments (cf. Riva and Mantovani, 2000).

The understanding of virtual presence as a social construct indicates that the conditions for co-presence with frail elderly persons in a context of caring with the assistance of ICT could be very different from conditions for experiencing co-presence with other groups of carers.

Caring and technology

Frail elderly persons are, in the twenty-first-century, cared for in an environment that often relies on different forms of technology and it is a challenge to create an environment of personal care in the context of the often sophisticated health care technologies (cf. Schoenhofer, 2001). ICT applications are examples of recent developments in health care technology. Health personnel of different categories often have, according to my own practical experiences when implementing telecare projects, a value-laden relationship to the use of ICT. Even though they can recognise that medical technology has played an important role in the advancement of medical treatment and care their relationship with technology seems troubled. In the 1970s there was a view among nursing scholars that depicted caring and technology as in opposition to each other. It positioned nursing as a female culture at odds with masculine technology, and linked nursing to nature, nurturing and caring and technology to maleness/power and control over nature (Sandelowski, 2000 p. 9).

One way of looking at the technological applications that are used in the care of frail elderly persons is to look at them as something that is socially constructed in the interaction between health personnel, manufacturers and specialists. The choices and the uses of technology have been influenced by manifestations and experiences of technology through processes such as supplying resources, participation in the use of technology, political support etc. (cf. Barnard, 2002).

A common view in our society is that technological objects are seen as value free or neutral and acquire value or non-neutrality only by virtue of how human beings use or abuse them. However, on closer inspection it is obvious that there are built in social, moral and political values (Nissenbaum, 2000). Values concerning technology can be viewed from two perspectives, one where values form the development of technology and the other where technology forms values (Winner 1986, Freeberg, 1999). Stanly Reiser (1978) has studied the history of medical technology and showed how it has, besides contributing to important improvements in medical treatment and diagnostics, contributed to an unintended effect where the attention of the doctor has been diverted more from the patient in favour of the objective data produced by technology. Barnard (2001) describes dehumanisation as the loss of identity and community through objectification or denial of human attributes. He argues that it must be possible to make use of the advantages of technology at the same time as it is balanced against the struggle for a humane and caring world. Non-conformity to the development of techniques makes nursing unresponsive to the predominant agenda of technological health care.

One way of describing the influence and importance of technology is to look at how it's used in a particular context. The "power" of the technical object is from this perspective mediated by social interactions and cultural constraints (Sandelowski, 2000). Well functioning telemedical equipment could, from the doctors' perspective, be seen as a valuable tool to facilitate remote consultations and medical treatments of patients not possible to treat by other means (Tsuchiya, 1998). It could also be seen, from the perspective of health personnel not motivated to learn to use equipment, as a disturbing technical object symbolising all the forces that want to dehumanise health care and make it more efficient without increasing the number of staff members.

Technical devices do not only receive their "power" from the context and the interactions with users, they can in some situations also be seen as having a built in power and in that way become actors in a social process (Sandelowski, 2000). It can for example be argued that guns in themselves increase the likelihood of killing simply by virtue of their presence. Computers and IT technology are often seen as symbols of development just by their presence.

Don Ihde (1991) describes the phenomenology of the relationship between humans and machines as four different kinds of relations. The first is embodiment relations, where the technical devices extend the senses; in perfect embodiment relations devices withdraw from notice to such an extent that they become almost transparent. One example might be the contact lens, that could be experienced as a part of the body and where most of the time the user is not conscious of its presence. In the second relation, called the hermeneutic relation, the technology not only transforms reality by what the instrument permits us to know of it, but the information produced is in itself an altered representation of reality. Knowledge is not obtained from the senses directly but from interpretive readings of data, such as a ECG printout. A third relation Ihde calls the alterity relation. In this relation the machine is experienced as a "quasi other" where the user experiences the technical equipment as having a will of its own. The computer is a good example of a love/hate relationship where the computer can be depicted as either friendly and helpful or as an irrational monster that is impossible to manage and understand. The fourth relation, background human/technology relations entails relations among machines, rather than with them *per se*. By this relation Ihde refers to the fact that in many of our environments and workplaces there are a lot of technology managing important functions but which goes unnoticed until a breakdown occurs. There are ventilation systems, security systems, heating systems and communication systems that are so integrated into our environment that they have become a natural part of our habitat. It seems to me that all four relationships to technology are present in care situations.

According to Sandelowski (2000) there is also a cultural aspect to technology. Most western people see technology as a force for cultural change, so that the use of technology alters the way we think about reality and the world and our role in it. She claims that feminist critics of technology have observed how resistant to change existing gender norms and expectations are. Technology changes but cultural assumptions and values are often hidden in new technologies.

She gives as an example that traditional social relations between physicians and patients and physicians and nurses were incorporated into computerised information systems intended to convey objective information and to empower patients.

The use of telehealth technology for clinical practice supports the relational components of care through interaction, and in the best cases provides care to those who otherwise would not benefit from the same level of service (Wright *et al.*, 2000). Wright *et al.* (2000) argues that the use of telehealth can be seen in at least two ways. One perspective is that it can provide access to care support in an interaction that in many ways resemble the "face-to-face" interaction. It can also be the experience of care receivers that remote consultations give a greater sense of privacy compared with traditional home-visits. The other perspective is that remote consultations where the care receiver never personally meets the care giver "face to face" can be experienced as alienating and dehumanised compared to the "face-to face" encounters where the caregiver knows their world. Sandelowski (2001) argues that technologies are what they are by virtue of the meanings they have and the meanings they hold for us. Any technology has a double life. In one sense they are limited by virtue of their "thingness"; that is there are limits to what their hardware can do. On the other hand, a technology is limitless by virtue of everything we can read into it and design it to be.

Frail elderly and ICT applications

Frail elderly people in Sweden have a life-long experience of technical changes and it could be claimed that they are among those that are the most experienced users of technical devices in society. However, it seems if as their interest for new technical devices, such as ICT applications, becomes less with increasing age even though it doesn't reflect a general negative understanding of technical development. Their perspective on life seems to affect the interest in new techniques (Österlund, 1999).

One aspect for the frail elderly of the use of different technical applications is to develop an optimal technological environment for them. This aspect is included in the concept of gerontechnology which according to Fosard *et al.* (2000) is an interdisciplinary field of research and application involving gerontology and technology. Bouman (2001) identifies four types of important technological support. One type is that which enhances human options, such as is accomplished by telephone, radio and TV, e-mail and transportation.

A second technological support is one that prevents potential losses in the physical and biological environment. A third compensates for declining capacities and a fourth supports caregivers. This fourth aspect is included in the concept of telecare, which is defined as a wider concept than telemedicine and, besides medical treatment and diagnosis, also includes care activities (cf. Ministry of Health and Social Affairs, 2002)

A governmental report (Ministry of Health and Social Affairs, 2002) reviewed the experiences of telemedicine and telecare in Sweden. They found that telecare was tested with good results in many situations and applications of health care but there were also many constraints in the introduction of telecare. Their recommendation was that the largest potential for telecare in the health care of frail elderly persons lay in: stimulating the accessibility of medical care for the elderly through teleconsultations, improving the utilisation of resources such as personnel and introducing the concept of telecare in the basic education of health personnel. A survey of telemedical activities in Swedish health care was carried out by SPRI 1997 (Holm-Sjögren, Sandberg & Schwieler, 1996). They identified over 100 telemedical activities most of which were activities to facilitate communication between different hospital units and between primary health centres and hospitals. A small number of activities focusing on home-based activities and basic care of elderly persons were identified. Alexander (1995) described a similar development in Australia to that found in Sweden. One important constraint in the introduction of home based telecare in Sweden has been the distribution of a technical network for transferring videoconferencing of good quality to private homes at a reasonable price (Ministry of Health and Social Affairs, 2002).

Specific ICT applications for frail elderly persons have been developed in many different areas. Telecare applications using videoconferencing technology have been tried in different ways. One example is that many countries have successfully developed telecare consultations and support by health professionals of frail elderly persons in their homes (Whitten *et al.*, 1998; Stroetmann *et al.*, 1999; Arnaert and Delesie, 2001; Demiris *et al.*, 2003). Ensumi *et al.* 2003 reported on a videophone network among the elderly that appeared to be helpful for peer-supported relationships and videophone networks to support informal caregivers have been developed in Sweden (Magnusson *et al.*, 2001). Geriatric consultations between professionals have been tried in different ways. Hui and Woo (2002) have reported on telemedicine as a feasible means of medical consultations for nursing homes and the Geriatric Centre at Umeå University Hospital has successfully developed a system for discharge planning of frail elderly persons with all involved connected through videoconferencing (Carelink, 2004).

There also exist ICT applications developed in order to increase security for frail elderly persons. One example is electronic devices that allow improved security through remote monitoring of those who have difficulties of finding their directions due to cognitive impairments, and applications that draw attention to, or disconnect, dangerous house hold appliances not in use (Tang and Venables, 2000; Banerjee et al. 2003; Mathie et al. 2004). These are examples of areas where ICT applications are used in the care of frail elderly persons today. However, the development in both gerontechnology and telecare seems to be rapid, and new ICT applications and methods for using them are constantly being developed.

The aims of the study

The thesis focuses on two areas of the use of ICT applications in the care of frail elderly persons. One area is the quality aspects of remote communication via the videoconferencing medium and the other is aspects of introducing ICT applications. The different studies that are part of the thesis are conducted within the framework of telemedical projects focusing on the elderly and implemented in the counties of Norrbotten and Västerbotten during a timeframe covering 1999 to 2003. The data that it was possible to gather from those projects became a natural limitation to, and framework of, the studies.

The overall aim of the research project is to illuminate reasoning and experiences of using applications of telecare for frail elderly persons.

The specific aims of the five papers were:

Paper I. To illuminate health personnel's reasoning about the use of Information Communication Technology (ICT) applications in the care of frail elderly persons.

Paper II. To elucidate both the interactions between a doctor and registered nurses, and the problems and tasks dealt with in ward rounds, carried out as teleconsultations between a university clinic for geriatric medicine and a nursing home for the elderly.

Paper III. To illuminate family members' experiences of communicating via videophones with elderly patients with dementia who are staying at a home for temporary relief care or living at a nursing home.

Paper IV. To elucidate qualities in communication in the professional encounters between nurses and nursing staff and elderly persons in a context of teleconsultations.

Paper V. To describe how dialogue and interaction are accomplished in teleconsultations between nurses and elderly persons assisted by staff members, and how problems are handled that emerge from the fact that the communication is conducted through videoconferencing techniques.

METHODOLOGY

The research project comprised five studies that were conducted using qualitative research methods. Four of them were carried out within the framework of three telecare projects (II, III, IV, and V) implemented in Northern Sweden. Different qualitative research approaches, such as content analysis, phenomenological hermeneutics and conversational and discourse analysis were used in accordance with the research questions of each study.

Settings

The settings in all the papers in this thesis were chosen based on their specific focus on the care of frail elderly persons. In Paper I the settings of homes service and nursing homes with no experience of telecare or using ICT applications were chosen since they were suitable for illuminating perceptions among health personnel with limited experience of these applications.

Paper II was based on a telecare project that was implemented during a time frame of 16 months (1999-2000) in a nursing home with two wards containing about 25 – 30 frail elderly persons. The two wards at the nursing home were connected with a 384 kbits./s. bandwidth connection via desktop videoconferencing equipment to a doctor at the clinic for geriatric medicine. The goal of the telecare project was to replace traditional ward rounds consultations by the doctor with regular remote teleconsultation. The setting in paper III was a telecare project where family members could communicate via videophones with their elderly relatives placed at a nursing home for relief service or an ordinary nursing home. Most of the family members had an analogue videophone in their homes with low bandwidth and a few tested a broad band digital videophone. In the setting of paper IV and V, 18 residents of a small nursing home were given the possibility of remote consultation, via a broadband videoconferencing unit, with registered nurses based about 12 km away. The videoconferencing units were used for consultations between nursing staff members and registered nurses, and between registered nurses and elderly persons with the assistance of nursing staff. The reasons for performing teleconsultations with the residents varied from situations where the nurses wanted to follow up the general health situation of the elderly person, to the following up of known, specific health issues.

Table1. *Data collections, participants and methods for analysis*

Paper No	Participants	Data collection	Method of analysis	Status
I	10 health personnel	Reflective interviews	Content analysis	Manuscript
II	5 nurses 1 doctor	Narrative interviews, 15 video recorded teleconsultations	Interaction analysis and content analysis	Published
III	7 family members	Narrative interviews	Content analysis	Published
IV	7 nurses nursing staff members	Narrative interviews	Phenomenological hermeneutic analysis	Published
V	2 nurses, 7 nursing staff 6 elders	22 Video recorded teleconsultations	Discourse analysis	Submitted

Subjects

A total of 30 informants, including seven family members, one doctor, seven nurses and 15 enrolled nurses, contributed their experiences through interviews. In papers I, III and IV a convenient sample of interviewees was used while in paper II interviews were carried out with all the participants, a doctor and five nurses, participating in a telemedical project with regular teleconsultations between a doctor at a university clinic for geriatric medicine and nurses at a nursing home for the elderly. In Paper I ten health personnel with work experience from both home service and nursing homes but with limited experience from using ICT applications were selected for interviews. Seven family members, both spouses and sons/daughters, communicating with their demented relatives via videophones were selected in Paper III with the inclusion criteria that they had had more than three months of regular experiences from interacting via the videophone and were willing to participate. In paper IV seven staff members working in nursing homes and with experiences from teleconsultations with frail elderly persons were interviewed.

Subjects participating in video recordings (II and V) included both staff members and elderly persons. In Paper II, the participants were the same doctor and nurses that acted as informants in the interviews. In Paper V, eleven elderly residents, three nurses and four assistant nurses participated in the recordings. Among the participating elderly persons, most were assessed to have some degree of dementia in a screening using the Mini Mental State Examination (MMSE) (Folstein *et al.*, 1975).

Data collection

The main approach to collecting data in all five studies of this thesis was based on a qualitative method of data collection. These comprised both narrative and reflective interviews and video recorded interactions. In one of the studies (II) statistical data about the consultations, such as medical problems and treatments, and variables of the interaction were also collected as a complement.

Interviews

In papers I, II, III and IV methods for qualitative open narrative interviews were used to collect data (see table 1). All interviews were audio recorded and transcribed verbatim.

Narrative interviews

Narrative interviews with narrative dialogues as a means of investigating peoples' experience were carried out with the informants, namely 12 health personnel working at nursing homes and seven family members (see table1), in paper II, III and IV. All interviews were carried out as individual interviews, by myself and in Swedish, and transcribed into text. The interviews lasted about 40-90 minutes and were carried out as open interviews focusing on the aims of the different studies (cf. Kvale, 1997). The informants were asked to narrate their experiences through open, broad questions such as: "Could you please tell me about your conversations with your relative via the videophone?"

In some of the interviews, two different strategies for re-experiencing specific events (cf. Drew, 1993) were used to facilitate the narration of the interviewees and their connection with their life world experiences. The first of these strategies was used in paper III where the informants, when they were interviewed for a second time, reviewed recorded video-phone communication sessions in which they had participated before the interviews.

The second strategy was to present a recorded sequence before the interviews (V). In this case the interview session started by showing a montage consisting of a five-minute long video recording of five selected consultation sessions with elderly persons who were assisted by nursing staff members. Each session was about one minute long and they were selected to provide a variety of participants and mental capacity among the elderly.

Reflective interviews

Reflective interviews were carried out in paper I with ten health personnel. The interviews, that were conducted in the Swedish language, were preceded by showing a presentation of the most common applications of ICT for elderly persons developed thus far. The presentation had, in this situation, the purpose of familiarising the interviewees with available ICT applications, since all of them had only limited experience of using ICT applications in the care of frail elderly persons. The presentation was about five minutes long and consisted of a computer presentation with still pictures and commentary. The presentation contained demonstrations of "smart house applications" i.e. intelligent electronic devices in the home that can prevent accidents, different sensors for monitoring the movements of elderly persons and applications of communication through videoconferencing. After the presentation the interviewees were asked to reflect about their perceptions of the use of the presented ICT applications in relation to their own working experiences. The interviews were conducted with broad, open questions such as: "Please tell me what your feelings are when you look at the presentation" as well as more specific questions like: "What are your thoughts when you think about the specific ICT application?"

Video recordings of interactions

Video recordings of videoconference consultation sessions were made for both paper II and paper V. The number of video-recorded sessions was 15 in paper II and 22 in paper V. In both studies the video recordings were made via the videoconferencing unit of the consulting doctor or nurse, which gave one selected perspective of the consultations. The video recorded consultation session varied in length between 7 and over 30 minutes. The recordings showed the image and sounds as they appeared on the screens of the videoconference unit showing either the nurse (II) or the elderly person and assisting staff member (V) as the main image and the consulting doctor (II) and nurse (V) as a smaller image ("Picture in Picture function"). The consulting doctor and the nurses controlled the video recording equipment.

This perspective was selected based on a judgement that it was the most practical system for making the recording system work and for reducing technical problems. In one of the studies (II) technical failures interrupted the video recordings so that five out of 20 possible consultation sessions were unavailable. In paper V, two out of a possible 24 consultation sessions were left out. All the conversations in the video recorded consultation sessions were transcribed verbatim into text.

Analysis

The methods of analysis in the five papers corresponded with the aim of the papers and the different ways of collecting data. The different analysis methods can be grouped into two main approaches for analysis: methods for analysing qualitative interview data (c.f. Kvale, 1997) (I, II, III, and IV); and methods for analysing institutional communication and interaction in papers I and V (c.f. Hydén and Mishler, 1999).

Analysis of interview data

Two approaches for analysing interview data were used, one approach for qualitative content analysis and one for a phenomenological hermeneutic analysis. The phenomenological hermeneutic approach was chosen in paper IV in order to get a deeper understanding of the meaning of the lived experience (cf. Lindseth and Norberg, 2004). The content analysis approach was chosen in the other studies (I, II, and III) in order to focus on both the manifest and abstracted latent content (cf. Graneheim and Lundman, 2003).

The content analysis was performed in different steps as an inductive process. The first step was to read through the transcribed interviews in order to get an overall understanding of the content. There then followed a step where the details of the content, identified as meaning units relating to the aims of the studies, were identified. The identified meaning units were thereafter condensed and grouped according to similarity of content as categories (I). Thereafter, the meaning of each group was abstracted and further interpreted into sub-themes and themes (II and III). The concept of themes was considered to be the thread of underlying meaning (cf. Coffey and Atkinson 1996, Graneheim and Lundman, 2003). This was an inductive analysis process, not as linear as described above, that involved going back and forth and reassessing the data material several times.

In paper IV a method of phenomenological hermeneutic analysis inspired by Ricoeur (1976) was used. The method provides an opportunity to combine the philosophy of the meaning of lived experiences with a hermeneutic interpretation of a transcribed interview text. The transcribed narration was seen as an autonomous text that expressed its own meaning and that could be studied as a way of interpreting lived experiences concerning the phenomenon in focus (cf. Lindseth and Norberg, 2004).

The process of interpreting the text was carried out in steps according to the approach outlined by Lindseth and Norberg (2004). The first step was to read the texts of the transcribed interviews several times to get a naïve understanding of the text as a whole. This first interpretation was then validated or rejected by the subsequent structural analysis. In the structural analysis the meaning units of the text were interpreted into themes at the same time as the text was viewed as objectively as possible. In the final step of the comprehensive understanding, the main themes, themes and sub-themes were further interpreted in relation to the research question and the context of the study,

Analysis of video recordings

The analysis of the video recorded consultations (II and V) was carried out with two methods of interaction analysis.

In paper II, 15 video recorded teleconsultations between a doctor and nurses at the nursing home studied were analysed with an adapted method for interaction analysis inspired by the Roter Interaction Analysis System (RIAS) (Roter 1989) in order to analyse the interaction between the nurses and the doctor. The video sessions were first viewed a number of times to gain an initial understanding of the verbal interaction. Based on this, main classes of interaction were identified. Under each main class, categories and sub-categories were developed. Only verbal categories referring to information transfer and problem solving were considered. Each video recorded session was then reviewed twice to validate the identified categories, and minor adjustments of the categories were made as required. The identified and validated categories were thereafter used to analyse their frequency in the video recorded interaction.

In paper V the data were analysed with a qualitative method inspired by conversation and discourse analysis, in which the structures of the communication can be studied through detailed analysis of sequences of dialogue (Drew and Heritage, 1992; Silverman, 2001).

The video-recorded consultations were transcribed using an adapted and simplified version of Goodwin's transcription system (Goodwin, 1981) that covered both verbal and non-verbal aspects of the conversation (Baggens, 2002; Hydén and Peolsson, 2002). Three non-verbal aspects of communication were specified in the transcription in separate columns for each participant (N=nurse, E = elderly resident, SM= staff member). The aspects were linked to the verbal elements and were:

1. Gaze, when the participants looked straight into the screen
2. Other nonverbal aspects, including shifts in bodily position and physical actions
3. Camera projection of participants

Ethical considerations

All the five studies in this thesis were planned in such a way that the possible benefits of performing them were judged to be greater than the risks involved for the participants. This was a special consideration in the studies where it was anticipated that it could be difficult for elderly participants with dementia to give their informed consent to participation.

All informants were, when they were asked to give their informed consent, informed both verbally and in writing about the aim of the studies and the methods for data collection. They were also assured of confidentiality and informed that they could refuse participation and could withdraw at any time without any effect on their treatment, care or working conditions. The Ethical Research Committee, Umeå University, approved the written plans of the studies before the data collection began.

In studies where elderly persons with dementia in any way participated (III, IV and V) their relatives were approached both verbally and in writing in order for them to give their consent to participation. Special consideration was given to video recorded data during the process of collection and analysis in order to ensure confidentiality and respect the private lives of the participants.

FINDINGS

The findings of the five different studies included in this dissertation are presented under two headings: **Quality of remote communication with frail elderly persons** and **Reflections and experiences among health personnel**.

Quality of remote communication with frail elderly persons

Several of the studies (III, IV and V) focused on aspects of the quality of remote communication with frail elderly persons via videoconferencing technology. This was assessed both through the experiences of family members and the experiences of health personnel. The results are presented in two headings: Maintaining a relation through remote communication and The difference of remote communication.

Maintaining a relation through remote communication

Aspects of the qualities of family members' communication via videophone as a means of maintaining a relationship with their frail elderly relatives were illuminated in study II. Their experiences of maintaining a relationship were interpreted and abstracted into a theme, *to see makes me involved*. The theme illuminates how the family members' videophone conversations gave new possibilities of being involved in care for and of maintaining a relationship with their demented relative. The specific aspects of being involved in the care of their demented relatives were illuminated in sub-themes.

The sub-theme, *to see is to maintain communication and freedom*, deals with the family members' experience that videophone communication was an additional possibility for maintaining contact when the relative was placed in a nursing home. For the family members, that meant freedom to choose the best time for calls and the freedom to stay at home. The sub-theme, *to see makes me part of caring*, described the videophone as a tool for helping family members to limit their bad conscience. The care relationship with their relative was important and often connected to a bad conscience about different aspects of that relationship. Some interviewees also experienced close contact with staff members who frequently assisted their relatives in the videophone conversations. The sub-theme, *to see is to be able to interpret the current well-being*,

emphasised the importance of being able to see their relative on the videophone and being able to determine his or her well-being.

The last sub-theme, *to see is to confirm our relationship* highlights, despite their relative's limitations in communication ability, the importance of receiving feedback concerning their relative's interest in participating in the remote communication. It seemed as if the image made it possible to interpret their feelings.

The difference of remote communication

The quality aspects of remote communication with frail elderly persons were often compared with the experiences of "face-to-face" communication and the differences assessed. The face to face communication was preferable in most situations but there were also situations where the difference contributed to advantages. The results of the analysis of interviews and recorded consultation sessions in the studies (III, IV, and V) dealt with aspects of differences.

In paper III the phenomenon of communicating with frail elderly persons in the context of remote consultations with nurses was interpreted in a critical, comprehensive sense. In this interpretation the qualitative experience of the remote communication has a spatial aspect that seemed important and connected to the ability to perceive individuals placed in a room, and a certain context, visually. The experience of virtually being in the room and context of the person with whom one is communicating seems to have varied between two extremes. At the one extreme there was no experiencing of a virtual transfer from one room to the other; at the other extreme, there was an experience of being in the other room. The process was perceived to be not "either/or" but changing over time and promoted by different aspects, such as feeling safe in the situation, familiarity, transparency in communication, and the meaningfulness of the content of the communication. The experience of presence with the person with whom one was communicating seemed also connected to inter-subjective feelings of closeness and connection on an emotional level. The communication ability of the elderly person, together with the ability of the assisting staff member to facilitate the communication, was also important.

One interesting aspect of the remote communication with frail elderly persons was the level of attention among the elderly experienced by the interviewed health personnel. The meaning of their experiences was interpreted in the sub-theme; *being attentive* (V). In this sub-theme the experienced high level of attention of the elderly person could not be fully attributed to the novelty of

the situation, but was also attributed to the very specific situation of the remote communication.

This situation was characterised by having the full attention of the other participants both through the videoconferencing medium and by the assisting staff member. The sub-theme in study III, *to see can be focused, relaxed but demanding*, describes to some extent a similar experience among family members. The frail elderly person seemed focused in the video-phone interactions, although only for a short time. One of the family members in this study found that he had his best moments of interaction with his demented relative via the remote communication. This was attributed to the fact that the interaction could take place at times that were convenient for both and also that there was nothing in the context of interaction that was disturbing for the elderly relative. The level of attention among the communicating elderly person was also assessed with a different approach in the analysis of the recorded consultations sessions in study V. In 16 of the 22 recorded dialogues (the dialogues where the participants could establish a level of connection with the elderly) the residents were focusing their eyes on the screen in about 92% of the communication turns. The focusing on the screen (interpreted as gazing at the nurse) was interpreted as a high level of attention from the frail elderly person.

Another aspect of the differences in remote communication was that the joint attention was affected by the fact that the viewers in the videoconference-mediated communication were limited to the visual impressions that were shown by the camera (V). The interpretation was that the projection used also had an effect on attention. In the projection of the extreme close-ups, not only the general context of the setting was excluded but also the resident as a physical person. On the other hand, the limited camera view created in the most frequently used upper body projection seemed to support the attention of the resident. In that projection it was as if the exclusion of unnecessary contextual information and the focus on the nurse and her facial expressions helped to maintain the resident's attention.

An important aspect of the possibility of experiencing presence and achieving joint attention with the elderly person in remote communication was the support of a staff member. This was interpreted in the sub-theme, *being connected in the triad* (V). The triad of participants i.e. the remote communicator and the frail elderly person assisted by a staff member, had a special meaning for the connection. The assisting staff member was often experienced as having an intermediate role in the communication with the elderly person. The staff members' ability to facilitate the contact seemed especially important for elderly persons with more severe cognitive impairment. The sub-theme in study III, *to see is to be dependent on staff members*, illuminates another side of the

importance of the triad. Family members were dependent on the assistance of staff members but they felt that it was difficult for some of the staff members to understand how important the videophone calls were for them. This together with dependency contributed to a frustration among some of the family members.

A special aspect of the difference between "face-to-face" communications and remote communication mediated by videoconferencing was how joint attention was established and maintained in the triad of participants. The findings (V) indicate that the interactional context of videoconference with frail elderly persons created special conditions. In order to create a joint attention, the participants often had to verbally confirm and reconfirm that contact had been established. The triad of participants played a special part in maintaining the joint attention through compensating for the contextual aspect of the medium's limitations and the demented elderly person's communication problems. "Dialogues about the communication" and passages of social talk took place when the nurse or the staff member wanted to re-establish and maintain joint attention.

Reflections and experiences among health personnel

Two of the studies (I and II) were planned to study health personnel's reflections and experiences of introducing assistive ICT applications in the care of frail elderly persons. Paper I deals with health personnel's reflections about using ICT applications and the interviews in paper II deal with health personnel's experiences of introducing telemedical consultations between a geriatric specialist and nurses at a nursing home.

Reflections

Health personnel's reflections about implementing ICT applications in the care of frail elderly persons were interpreted in a theme, *ICT as a promoter of both humane and inhumane care*.

The theme captures health personnel's overarching duality towards the use of ICT in the care of the frail elderly, a duality that concerns the very essence of caring. This duality made many of the health personnel take on a defensive attitude. There was a paradox in their reflections since the same attributes of ICT that could promote a humane care also was seen as a risk and induced a general fear of a propelled development towards a dehumanised care.

Promotion of a humane care using ICT was in their reflections related to a sense that it could provide new opportunities of providing a care that recognized the intrinsic values of the individual person. This meant providing such things as increased freedom, less dependency, and increased security for the elderly person. On the other hand there was also a general fear that the introduction of ICT would propel development towards a dehumanised care of the elderly where the focus was on efficiency and remote control

Many of the interviewees believed that the fears of introducing ICT could be handled if the health personnel and the management of the care organisations were conscious of their own basis of grounded values and the risks involved.

This overarching duality in attitudes towards the use of ICT applications in the care of frail elderly persons was formed by a duality in their thoughts about many specific aspects. Some of these aspects were related to consequences from a caring perspective and others were related to consequences from the perspective of being a career.

Specific aspects of the sensed consequences from a caring perspective were described in three sub-categories. The sub-category, *genuineness and superficiality* illuminates that good quality care for the elderly was linked to the possibility of genuineness in relations and social interaction with the elderly. The apprehension was that ICT applications could facilitate genuineness in relations through an increased possibility of having a ongoing dialogue, especially with those elderly living isolated in their homes. Superficiality was connected to a general fear that the use of ICT applications would contribute to a caring situation for frail elderly where the closeness and intimacy of face-to-face communication was reduced and replaced by a remote form of communication characterised by superficiality in the personal relationship.

The sub-category, *freedom and captivity*, describes freedom for the elderly persons as connected to the possibility of being able to choose an independent living in their private homes. Captivity was related to the perception that ICT becomes a problem if it is used in such a way that it delays placement in nursing homes for those elderly people with a poor sense of personal security. The choice of moving to a nursing home must always be there for those elderly persons who do not have a basic sense of security and are in need of the sense of community that nursing homes can offer.

In the sub-category, *dignity and unworthiness*, was dignity associated with the understanding that the use of ICT applications could facilitate assistance according to the frail elderly person's individual needs. There was a sense that ICT applications could provide an increased level of independency and reduction

in confinement for elderly person with dementia. The understanding was that there was a thin line between the dignity in assisting an elderly person according to her/his needs and the unworthiness of remote control turned into remote surveillance.

Valued good and bad consequences for the health personnel were illuminated in the sub-categories *involvement and dissociation* and *aids and threats*. They anticipated that ICT applications both could facilitate an involvement with elderly in situations where it otherwise was difficult to maintain and also be of benefit in many other situations. Bad consequences were related to the risk of dissociating your self from the elderly person and a sensed threat that ICT would change existing conditions for their work.

Aspects of introducing ICT applications

Aspects of introducing ICT applications from the perspective of health personnel were illuminated in the findings of paper II. The content analysis of interviews with a doctor and five nurses were abstracted into two themes that related to the structure of work and the need for mutual trust.

One theme, *teleconsultations have improved the structure of work*, describes how the structure of work and professional roles for both the doctor and the nurses have been affected by the teleconsultations. This theme also contains the sub-themes *in the teleconsultations, the doctor depends more on structured, reliable information from the nurses than during traditional ward rounds*, and *the nurse is a link between the patient and the doctor*, which describe slightly new and adjusted roles for both the doctor and the nurses. The doctor takes on the more accentuated role of the remote expert who makes the decisions based on the information provided by the nurses. The nurses, on their hand, become a link between the frail elderly person and the doctor, and they have to provide well structured medical information in order for the doctor to make proper decisions. A consequence is illuminated in the sub-theme, *teleconsultations required more preparation than traditional ward rounds*. In order to provide well structured information the nurses have to make preparations in advance and use available aids such as still pictures. The nurses experienced that the role of making good presentations of medical problems to the doctor, and the doctor's role of performing remote medical assessments in the videoconference medium, meant a partial change in their roles compared to traditional ways of working.

A second theme, *mutual trust is important to our interaction*, describes aspects of trust between health personnel. One aspect was described in the sub-theme *the doctor has to be able to trust the nurses in order to be able to make medical decisions based on information provided by them*. Another aspect

was described in the sub-theme *the nurses need the support of the doctor in order to feel secure in making decisions*. The teleconsultations seemed to accentuate the need for the doctor to have trust in the nurses and their way of presenting medical problems. The nurses also needed to feel the support and trust of the doctor in order to feel secure that the medical situation of the frail elderly person could be handled by them.

DISCUSSION

The history of telemedicine and telecare has been filled with enthusiasts who have held strong beliefs that ICT applications could make a major impact on health care. One of the greatest enthusiasts is the Australian psychiatrist Pete Yellowlees who forecast that e-health will revolutionise health care (Yellowlees, 2000). In a Swedish Governmental report it states that even though it is possible to list many advantages of telemedicine there are also problems and obstacles (Ministry of Health and Social Affairs, 2002). The studies in this report dealt with quality aspects and the experiences of using videoconferencing technology in the care of frail elderly persons. It also studied perceptions among health personnel of using ICT applications for the same target group. These are aspects that could be of importance when considering introducing ICT applications that are both acceptable for health personnel and also serve the purposes of care of the frail elderly.

The major findings of this thesis indicate that it is possible to have meaningful interactions via videoconferencing with frail elderly persons provided that certain preconditions are met. There are also indications that the limitations of videoconferencing in transferring communications cues could in some situations be of an advantage for the demented elderly. The findings also indicate that an introduction of ICT applications will affect the structure of work and the roles of health personnel. It has also been shown that health personnel with limited experiences of using ICT have a duality in their perceptions of using ICT applications in the care of frail elderly persons that makes them defensive towards an introduction.

Quality of remote communication with frail elderly persons

An important finding in the studies was that the experiences of the interviewees showed that it is possible to have a communication of good quality

via videophones with frail elderly persons, even those that have mild or mid-level dementia, provided the conditions are right. In paper V it was found that the possibility of creating a connection with the elderly and a feeling of presence in the remote communication was connected to the presence of certain aspects of communication, such as feeling safe in the situation, familiarity, transparency in the communication, and the meaningfulness of the content of the communication.

Familiarity was both connected to the context of interaction with environment and people and to the ICT application. Zingmark (2000) found in a study of care aspects considered as dimensions of good quality of life among people with Alzheimer's disease at a nursing home that familiarity was important. In her study familiarity meant sharing everyday life in a sense of nearness and encountering a sense of belonging. Another aspect of familiarity is the familiarity of the use of technology and what Walters (1995) described as a phenomenon where technological devices become so familiar that they become phenomenologically transparent to the user, who is not always aware of their existence.

Ijsselsteijn and Riva (2003) introduced the concept of virtual co-presence which is a situation occurring in the intersection between physical presence, i.e. being physically present in a mediated space, and social presence, i.e. a feeling of being together. Co-presence can, in their opinion, occur in videoconferencing. Establishing joint attention with the frail elderly person via videoconferencing (Paper V) and a sense of presence (Paper IV) could be labelled co-presence. The concept of virtual co-presence is a social construct where technical transparency is only one factor. Riva and Mantovani (2000) proposed a cultural concept of virtual presence as a construction where the experience of presence is not so much dependent on the technical quality or the reality of the virtual environment, as on the capacity to produce a context where the actors can communicate and interact. Ijsselsteijn and Riva (2003) conclude that research on presence has to reach beyond a search for realism and fidelity only and ask questions concerning the purpose and the context of use. The shared context that promotes experiences of co-presence with frail elderly persons must be composed of symbolic references specific to the participants that make them able to orient and coordinate themselves. It includes familiarity with the other's present and past activities as well as shared artefacts and environments (cf. Riva and Mantovani, 2000). This means that the conditions that promote virtual co-presence with frail elderly persons might be quite different from the conditions that promote co-presence with young people.

The most consistent definition of presence in nursing literature is "being with" (Gilje, 1992) and such situations are characterised by a high level of inter-

subjectivity (Fredriksson, 1999). Nursing presence interpreted as being with a frail elderly person with a high level of inter-subjectivity would in the vocabulary of Ijsselsteijn and Riva be labelled social presence in the context of care. Videoconferencing as well as shared virtual realities (VR) can provide a mix of physical and social components and it seems likely that as technology increasingly conveys non-verbal communication cues, such as gaze direction or postures, the likelihood of achieving nursing presence will increase (cf. Ijsselsteijn and Riva 2003). This indicates a link between the concepts of nursing presence and virtual co-presence in ICT mediated interactions.

Findings in three of the papers (III, IV and V) indicated that the videophone encounters could create increased attentiveness among the frail elderly with cognitive impairments and sometimes make them focused on the communication. The attentiveness was attributed to the special context of interaction and the special sensory environment of the videophone encounter. A possible explanation for the increased attentiveness of the frail elderly could partly be attributed to the special attention given by the health personnel in the videophone encounter. Normann, Asplund and Norberg (1998) have, in a study among carers in nursing homes, shown that episodes of lucidity in people with severe dementia took place when the carers were using a person centred communication and acting closely with the patients. Situations that Dewing (1999) characterised as person-centred care and that Zingmark *et.al.* (1993) described as "being one with an important other in a calm atmosphere that creates the feeling of being at home". A person-centred care that Hansebo & Kihlgren (2002) showed was dependent on the carer's ability to take into account their own as well as the elderly person's life experience and mood for the day.

Another explanation for the attention could be the frail elderly person's relationship to the mediated environment of the videoconference. Ijsselsteijn and Riva (2003) points out that in videoconferencing-mediated situations multisensory stimulation arises from both the physical environment as well as the mediated virtual environment. The fact that we feel presence in either one of them depends on what becomes the dominant perception at any one time.

Based on the findings of the study it can be hypothesised that a limited view (with limited sensory stimulations, peripheral distraction and limited demand for global attention on the image on the videoconferencing screens) was conducive and created increased attention among the frail elderly. This conclusion is supported by findings by Mapstone *et al.* (2001). They studied the allocation of attention among elderly persons with and without Alzheimer's disease and found that both groups had more difficulty in maintaining attention and central eye

positions than young persons when faced with the task of looking at a dynamic stimulus that required global attention.

Reflections and experiences among health personnel.

The finding of paper I indicates that health personnel had a duality in their perceptions about using ICT applications in the care of frail elderly persons. This was due both to the anticipated consequences for frail elderly persons and to the consequences for them themselves. One of the major concerns of the health personnel was that ICT applications would contribute to a dehumanised care where the focus of health personnel would be diverted from the relationship with the frail elderly person to the information produced by the technology. This fear has some grounding in the history of medical technology. Stanly Reiser (1978) has shown that medical technology has been beneficial for the care of the patient in many ways, but also contributed to an unintended effect of diverting the interest of the doctor from the patient towards the data produced of the technology. However, perceptions and values about technology applications are not only grounded in the history of care, they are also related to the "power" of the technology. Sandelowski (2000) argues that the technology gets its "power" from the perspective of the context it is used in and how the social interactions of health personnel and cultural constraints mediate conceptions about it. An example of this phenomenon were the findings in paper III that indicated that family members viewed the videophones as a means to become involved in the care of their frail relatives. At the same time the family members had some problems convincing staff members to assist since not all of them were convinced about the benefits of the technology.

Waerness (1999) argues that in order to discuss the practical care of frail elderly persons it is important to include both the perspective of the care receiver and the perspective of the health personnel. The practical care is performed in an interaction between the staff member and the frail elderly person, and their relationship must be in focus. The findings in paper I indicated that health personnel experienced a fear that remote communication would contribute to care relations with less closeness in the relationship. None of the findings in this study indicated that problems with the closeness of relationships necessarily have to occur, but since this is an important factor in the quality of the care of frail elderly persons, this aspect should be considered when introducing new ICT applications.

Findings in study II indicated that remote consultations between a geriatric specialist and nurses at a nursing home affected the way nurses had to structure

their work, and also the professional roles of both the doctor and the nurses. Kvarnström (1998) argues that health systems encourage both cooperation between different professions and team work. At the same time there is a competition between each profession that works against the spirit of team work.

She points out that nurses tend to be responsible for technical devices used close to the patient in emergency care and that this tends to take them away from other care activities. In the world of teleconsultations this could mean that the nurses' role as a middleperson and interpreter of the health needs of the frail elderly could be accentuated. The role of the doctor could be diverted towards the role of a remote consultant with limited contact with the frail elderly. It seems important to consider changes in professional roles and practical spheres when introducing ICT applications in the care of frail elderly persons. Changes and competition between professional groups and practical spheres should not only be seen as a problem but could also be a way of developing the professions (cf. Johansson, 1998).

The consequences of introducing ICT applications to the care of frail elderly persons can, from an ethical stand, point be discussed using the theoretical model for valuing ICT technology in health care developed by Collste (1993, pp.162-171). He argues that an analysis of the consequences of a new technology has to be based on a philosophical standpoint, that a new technical application is right if it, when compared with the alternatives, gives in total the best solution for those who are concerned. Criteria for what is a good solution should be based on the satisfaction of the wellbeing of the individual. Wellbeing should be interpreted as the satisfaction of human needs and the satisfaction of individuals rights, such as the right to integrity, and the right to be treated according to the principle of equality

The care of frail elderly persons is always carried out in an interaction and relationship with a family member, a professional staff member, or a significant other. The care process requires a network of persons who are concerned and a care alternative (cf. Sällström, 1994). An ICT application is the best alternative if it contributes to the best solutions for all concerned. Even if the model gives room for considering the wellbeing of all participants in the care process the main focus must be on the situation of the frail elderly person.

There are limited studies made that can illuminate the effects of using ICT application in the care of the frail elderly. The findings in paper III showed that remote videophone communication with frail elderly relatives could make family members more involved in care. Heyn Billipp (2001) showed that interactive computer communication with vulnerable elderly persons, together with regular

training by nurses or a significant other, greatly improved self esteem when compared to a control group. Chan et al. (2001) showed that acceptability was good for medical services provided by a community assessment geriatric team to frail elderly persons at a nursing home and their nursing staff, and there was an increase in the level of services provided. Even if the findings of these studies indicate that remote communication can cater to some of the social and caring needs of the frail elderly person there are also many indicators that physical closeness is important in the interaction

(cf. Hansebo and Kihlgren, 2002; Zingmark, Sandman, Norberg, 2002) as well as physical touch (Routasalo, 1999). Barnard (2001) argues that it must be possible to make use of the advantages that technology can provide at the same time as striving for a humane and caring world where the quality of relationships is in focus. This balance seems very important when analysing the consequences of introducing ICT applications in the care of frail elderly persons.

Conclusions

This study is based on qualitative data from a limited number of telecare projects implemented in relation to the care of frail elderly persons at nursing homes. Many of the findings can most likely be generalised to other similar contexts in a foreseen expansion of telecare in home based care, even though it is important to confirm or refute them in new studies. The experiences revealed in the studies indicate that:

- It is possible to have a communication of good quality via videoconferencing with frail elderly persons, even those that have mild or mid-level dementia, provided the conditions are right.
- Technical limitations of the videoconferencing media in transferring communication cues, and the limitations to what the camera can expose create special demands on those communicating with the frail elderly and of the general setting. On the other hand these limitations, in the context of interaction in some situations, also seem to be an advantage for the demented elderly and contribute to increased attention.
- An introduction of teleconsultations in the care of frail elderly persons will affect the professional role and the practical spheres of involved health professionals.
- The perceptions and experiences of participating health personnel indicate that in order for ICT applications to become valuable assets in the care of the frail elderly they have to be part of a care alternative that is viewed by all concerned as the alternative that, as a whole, provides the best alternative for those concerned.
- Further research is needed in order to confirm or refute the findings of this thesis and in order to further broaden our understanding of the use of ICT applications in the care of frail elderly persons. This could facilitate a development of ICT applications suitable for care of the frail elderly, and their introduction into regular care activities of benefit to both the frail elderly and their carers.

METHODOLOGICAL CONSIDERATIONS

Human interactions are complex and the studies were planned so as to use different qualitative research approaches in order to get a broader understanding of the use of ICT applications in care situations with frail elderly persons. One problem in choosing research methodologies was that studies focusing on remote communication with frail elderly persons are very few, and there are limited experiences to compare with. Even though we have tried to utilise the experiences of other similar areas of research the situation has an air of trial and error.

The trustworthiness of the findings in this study is, according to qualitative research tradition, related to such concepts as credibility and transferability (Patton 1987, Polit & Hungler, 1999). Credibility relates to how well collected data and research methodology address the research questions (Patton, 1987). In qualitative research it is often of interest to choose a number of participants with such a variety of backgrounds so that the focus of interest can be covered (Kvale, 1997 pp. 95-97). An important problem in this research project has been the limitation of possible participants to those participating in a few telecare projects for frail elderly persons available for the research. It is possible that if we had had the option of selecting participants from a wider variety of contexts that I would have discovered other and different aspects of the use of ICT applications in the care of the frail elderly . Additional research will clarify that issue.

In some of the studies (III and V) we have used video recordings of virtual interactions as presentations, as a way to facilitate the narration of the interviewees and their connection with their life experiences. The intention was that the vignettes would facilitate for the interviewees to get immediate access to what their emotions, thoughts and perceptions were in connection to the phenomenon and bring them into the present (cf. Drew, 1994). The way the vignettes were used has similarities with the technique to use psycho dramatic re-enactment as a way to keep the interviewees grounded in the context of their experiences (Drew, 1994). The vignette became a way to facilitate a narration about a phenomenon of communicating with frail elderly via videoconferencing and to keep in touch with the phenomenological perspective of the life experience. This perspective is the immediate emotions, thoughts and perceptions as opposed to the intellectual description of the phenomenon (cf. Lindseth and Norberg, 2004).

A presentation describing common ICT applications used in the care of the frail elderly (I) was used in a different way. In this case the presentation became a technique for focussing on perceptions of ICT applications that the interviewees

had limited experience of. This use of presentations resembles methodologies commonly used in research on attitudes and values (cf. Selec and Philips, 2003). I believe that the different ways of using presentations have contributed to improving the quality of the interview data and, subsequently, the credibility of the studies involved.

The research discourse in the area of telecare of the elderly is still very new and undeveloped and the theoretical framework for the research was, to some extent, borrowed from other areas of research and discourses such as gerontechnology and presence production. It is possible that, due to the immaturity of the discourse, I have left out important aspects and theoretical considerations. Further research will contribute to developing the discourse. Many of the relevant questions that we have posed in the research project were not known to us when we entered the project, even though the main focus of the research was established. The research project has been a process that developed and matured over time. Many aspects and questions that turned up in the research process could not be answered due to lack of time, resources and the need to focus.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Televård, vård på distans med hjälp av modern Informations och Kommunikations Teknik (IKT), har från ett internationellt perspektiv haft en snabb utveckling under de senaste tio åren. Det finns många exempel på framgångsrika försöksprojekt inom vård och omsorg av äldre, både i Sverige och internationellt. Exempel är projekt där IKT har använts för att möjliggöra distanskonsultationer mellan hälsovårdspersonal och äldre, för att underlätta kommunikation och stöd av äldre genom det sociala nätverket samt olika former av intelligenta elektroniska hjälpmedel som underlättar för äldre genom att ge ökat oberoende och säkerhet. Även om försöksverksamheterna i många fall varit framgångsrika så har det visat sig svårt att ta steget till att använda erfarenheterna i reguljär vårdverksamhet. Det här forskningsprojektet planerades för att ge ny kunskap om viktiga aspekter på vårdkvalitet och hur ett införande av IKT påverkar vården av äldre med stort vårdbehov.

Syftet med forskningsprojektet var att belysa föreställningar om och erfarenheter av att använda tillämpningar av televård i vården av de äldre med stort vårdbehov.

Forskningsprojektet består av fem olika delstudier som genomfördes med kvalitativa forskningsmetoder. Fyra av studierna baseras på data som samlats in inom ramen för tre försöksprojekt med televård för äldre. För att kunna svara på frågeställningarna i de olika studierna så användes olika kvalitativa forskningsmetoder som kvalitativ innehållsanalys, fenomenologisk hermeneutik och konversions- och diskursanalys.

Resultatet av studierna visar att det är möjligt att via videokonferens genomföra en kommunikation av god kvalitet med äldre med stort vårdbehov, även med dem som hade lätt och medelsvår demenssjukdom. För att kunna kommunicera med god kvalitet med äldre med stort vårdbehov så måste vissa förutsättningar finnas. En förutsättning är att de äldre känner igen sig, en annan är att de känner trygghet, en tredje är ett intresse av ämnet och en fjärde är att det inte finns några tekniska störningar. De tekniska begränsningarna av videokonferensmediet då det gäller att överföra icke verbala kommunikationssignaler och begränsningar i vad en kamera kan exponera ställer speciella krav på dem som kommunicerar med äldre med stort vårdbehov och på den miljö där kommunikation sker. Å andra sidan så verkar det som om identifierade begränsningar i videokonferensmediet som medium för kommunikation i vissa situationer kan genom att bidra till ökad uppmärksamhet vara till fördel för den äldre med demenssjukdom.

Ett exempel på meningsfull distanskommunikation med äldre med demenssjukdom var närståendes kommunikation via bildtelefon med anhöriga när de var placerade på äldreboende eller befanns sig i avlastningsvård. Den kommunikationen gav nya möjligheter för närstående att vara involverade i vården och att upprätthålla en relation med sin dementa anhörige.

En introduktion av telekonsultationer i vården av äldre med stort vårdbehov kommer enligt de erfarenheter som belyses i studierna att påverka både den professionella rollen och innehållet i arbetet för de yrkesgrupper som blir berörda. Enligt erfarenheter och de föreställningar, som kommit fram i studierna, om införande av IKT i vården av äldre så måste IKT för att bli ett accepterat och framgångsrikt hjälpmedel vara del av de arbetsmetoder som i ett helhetsperspektiv betraktas som de bästa alternativen för alla inblandade parter, inklusive personalen.

För att bekräfta eller förkasta resultaten i denna avhandling är det viktigt med mer forskning om televård för äldre med stort vårdbehov. Forskning är även viktigt för att kunna vidga kunskapen om tillämpningar för målgruppen. En sådan forskning skulle underlätta utvecklingen av anpassade IKT tillämpningar för målgruppen och introduktion i reguljär vård och omsorg. Detta skulle gagna både anhöriga och äldre.

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