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E-HEALTH AND INFORMATION- AND COMMUNICATION TECHNOLOGY (ICT) AS SUPPORT SYSTEMS FOR OLDER FAMILY CAREGIVERS IN RURAL AREAS

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ABSTRACT

The overall objective of the thesis was to investigate how older family caregivers in rural areas experienced participation in an e-health based caregiver support system. Participants were 95 caregivers allocated to intervention group (n=63) and control group (n=32). The thesis had a mixed method design and is based on four original articles (I-IV). Data was collected through web-camera interviews (I-III), telephone interviews (II,IV) and questionnaires (II,IV) after 1.5 years of using e-health support. Quantitative data was analyzed using comparative statistics, multiple linear regression and logistic regression. Qualitative data was analyzed with content analysis. **Article I** showed that the caregivers, despite lacking experience from using computers, were able to adopt the new technology, with help from support nurses and family. Caregivers felt e-health helped them to regain social inclusion. **Article II** had a comparative design, comparing e-health support with conventional caregiver support. Caregivers using e-health were more satisfied with their support and found it to be available, flexible and helping them enhance caregiver competence. Control group caregivers were less satisfied with support and experienced unmet needs. **Article III** showed that e-health can reduce caregivers' feelings of isolation. Two themes were created, *Expanding the concept of place* and *Developing networks*. **Article IV** revealed that caregivers used e-health frequently, experienced benefits from using it and had become more independent. Support nurses were disappointed about the decrease in contact with caregivers, and also acknowledged a need for developing the professional nursing role while working with e-health. Conclusions drawn from the findings were that participants experienced benefits from e-health support and it helped them become more independent. Swedish municipalities are obliged to provide caregiver support, the findings from the study are valid to conclude that e-health support are as good as, or even more effective, than conventional support for older family caregivers in rural areas.

Keywords: caregiver support, e-health, family caregivers, ICT, isolation, rural health, web-camera interviews

Svensk titel:

E-HÄLSA OCH INFORMATIONS- OCH KOMMUNIKATIONSTEKNOLOGI (IKT) SOM STÖDSYSTEM FÖR ÄLDRE ANHÖRIGVÅRDARE I GLESBYGD.

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SVENSK SAMMANFATTNING

Det övergripande syftet vara att undersöka hur äldre anhörigvårdare på landsbygden upplevde att få anhörigstöd via en e-hälsa-tjänst. Avhandlingen hade en mixed method design och bestod av fyra originalarbeten (I-IV). Deltagare i studien var 95 personer, boendes i gles- och landsbygdsområden, som i det egna hemmet vårdade en make eller maka med kronisk sjukdom. Deltagarna var fördelade på interventionsgrupp (n=63) och kontrollgrupp (n=32). Datainsamling skedde efter 1.5 års användning av e-anhhörigstödet, genom web-kamera intervjuer (I-III), telefonintervjuer (II,IV) och frågeformulär (II,IV). Kvantitativa data analyserades genom komparativ statistik, multipel linjär regression och logistisk regression. Kvalitativa data analyserades med innehållsanalys. **Artikel I** visade att anhörigvårdarna, även om de inte hade någon vana av datorer sedan tidigare, kunde lära sig och bli användare av den teknik och utrustning som ingick i e-anhörigstödet, när de fick hjälp och stöd av anhörigstödjare eller andra. Anhörigvårdarna upplevde att e-anhörigstödet hjälpte dem att återfå social delaktighet. **Artikel II** hade en komparativ design och jämförde e-anhörigstöd med traditionellt anhörigstöd. De som använde e-anhörigstödet var nöjda med stödet i högre utsträckning än de som fick traditionellt stöd. E-anhörigstödet upplevdes som tillgänglig, flexibelt samt bidrog till att de utvecklade sin kompetens i vårdandet. Kontrollgruppen var mindre nöjd med sitt stöd samt upplevde att de hade behov som inte tillgodoseddes av stödet. **Artikel III** visade att e-anhörigstöd kan minska anhörigvårdares upplevelse av isolering, dels genom att de upplevde en känsla av att vara på andra platser fast de rent fysiskt befann sig i hemmet, dels genom att de utvecklade sociala nätverk. **Artikel IV** visade att anhörigvårdarna ofta använde e-anhörigstödet och att de upplevde nytta av att använda det. De blev också mer självständiga vilket ledde till färre kontakter med anhörigstödspersonalen. Personalen kände viss besvikelse över att kontakterna med anhöriga minskade och uttryckte att den professionella omvårdnads-rollen behöver utvecklas när e-hälsa införs och tillämpas i vård- och omsorgsarbete. Slutsatser som drogs från fynden i avhandlingen var att anhörigvårdarna hade stor nytta av att använda e-anhörigstöd samt att det hjälpte dem att bli mer självständiga, vilket reducerade deras behov av kontakt med kommunernas anhörigstöd. Sveriges kommuner har en skyldighet enligt lag att tillhandahålla anhörigstöd, med stöd av fynden från den här studien kan man dra slutsatsen att e-anhörigstöd kan fungera lika bra som, ibland till och med effektivare än, traditionellt anhörigstöd.

Nyckelord: anhörigstöd, e-hälsa, informations- och kommunikationsteknologi, IKT, isolering, glesbygd, web-kamera intervjuer.

TABLE OF CONTENTS

LIST OF ARTICLES

This thesis is mainly based on the following two articles, herein referred to by their Roman numerals:

Article I	Blusi M., Asplund K., & Jong M. (2013). Older family carers in rural areas: experiences from using caregiver support services based on Information and Communication Technology (ICT). *European Journal of Ageing, 10* (3), 191-199. doi: 10.1007/s10433-013-0260-1
Article II	Blusi M., Dalin R., & Jong M. (2014). The benefits of e-health support for older family caregivers in rural areas. *Journal of Telemedicine and Telecare, 20*(2), 63-69. doi: 10.1177/1357633x13519901
Article III	Blusi M., Kristiansen L., & Jong M. Internet based caregiver support counteracts isolation among older spouse caregivers in rural areas. Accepted September 2014.
Article IV	Blusi M., Dalin R., Kristiansen L., & Jong, M. Utilization of e-health caregiver support among older family caregivers in rural Sweden. Submitted September 2014.

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PREFACE

My interest in caregiver support and spousal caregiving in rural areas originate from the early 2000's when I worked as a nurse in the palliative care unit at the oncology department at a regional hospital. Information, education and support to the closest family, most often the spouse of the patient, was an important part of everyday work. A common desire among patients was to remain in their home and end their days there. A significant part of the geographic area being serviced by the hospital consisted of rural areas, with long distance to the hospital. In the rural areas there were no advanced home care teams which could tend to the sometimes rather advanced medical needs of the patients, or handle the medical devices the patients needed in their home to get the proper palliative care.

To enable the care needed to be given in the homes of patients, spouses needed to take on some medical responsibility. Back up from nurses closer to home was also required. Collaboration with rural nurses, working at nursing homes, was established. The rural nurses were very keen on going out of their way and make the effort to provide the nursing services palliative patients needed in order to remain in their homes and avoid unnecessary traveling. During this time I had the privilege of meeting patients, spouses and rural nurses, in their own surroundings, training them in some of the medical tasks they needed to learn. I was impressed with their willingness to learn new, advanced and sometimes uncomfortable tasks. Despite the nurses sometimes worrying about taking responsibility for these new tasks, their positive attitude of "anything is possible" was always shining through. Most patients were over 65 years old, and had severe dysfunctions. Their spouses not only dared to challenge the responsibilities of advanced caregiving, they also had an admirable attitude, focusing on remaining functions and abilities to make the most out of every day.

In 2007 I had the opportunity to pursue my interest for nursing research. When local authorities in mid- and northern Sweden were asked to participate in a project testing if computers and internet could be used to provide caregiver support in rural areas, I was offered to participate in designing and evaluating the project. Target group of the intervention was old persons providing long term care for a spouse at home. Recalling my previous experiences of seeing nurses and spouses in rural areas, in salutogenic spirit challenging the norms of care-organizing in order to enhance quality in daily life, I found it very appealing to see if computers and internet could be tools used to support old spouse caregivers and help them enhance quality in caring and daily life. I have always been fond of trying new ways and methods, as long as they are intended to improve the quality of whatever is subject to change. Communicating with old people in their homes through computers was definitely outside the norms of eldercare in our area. Turning down participation in this kind of project was never an option.

INTRODUCTION

Due to the changing demographic structure of the population in many countries, the proportion as well as the number of older people with care needs has rapidly increased, and will continue to do so (European Commission 2009, Hoffmann & Rodrigues 2010). This development brings an increased demand for long-term care services, which will be a challenge as current supply is considered to be insufficient and inadequate in terms of meeting current and especially future needs for long-term care (European Commission 2009). Family caregivers play a strategic role in providing long term care and throughout Europe enhanced caregiver support has been introduced (Kröger 2003, Winqvist 2010). The situation where informal caregivers currently are assuming the major part of the provision of care is unsustainable, partly due to the impact on the caregivers' health and social lives. Formal services can help informal caregivers, but few use them. The main reason is that caregivers do not have enough time to make use of these services and they have little information on them. Moreover, many caregivers are dissatisfied with the services available. Such dissatisfaction may be due to limited availability, waiting lists and associated costs (Carretero *et al.* 2012).

Demographic challenges

Population ageing is taking place in almost every country in the world. The 10 countries with the highest proportion of citizens over 60 years old in 2011 were all in the developed world. By 2050 the picture will change as the most rapid aging is taking place primarily in relatively newly industrialized countries. The country with the highest proportion of older citizens is Japan. The United Nations predicts that in 2050 there will be 42 countries with higher proportion of 60+ populations than Japan (31%) has now. The equivalent number for Sweden is 25% (United Nations Population Division 2011). Over the last 20 years in Sweden, there has been a trend of decreased public health care resources for the older, and the publicly funded care sector is facing difficulties in meeting the needs of the people (Johansson 2007, Johansson *et al.* 2003).

On one hand, modern medicine and healthier lifestyles have increased longevity and also made old age healthier. On the other hand, due to increased life expectancy, older adults are more likely to suffer chronic illnesses and also consume more care services (Bloom *et al.* 2011). The demographic development challenges the health and social care systems globally as it will put rising pressure on public expenditure for formal care service (European Commission 2009, Johansson 2007). Other challenges are aging among health professionals along with difficulties recruiting new work force to health professions (Keating 2008). The prognosis for Sweden is a deficit of 100 000 health care professionals by 2030 (Håfström & Fransson 2013).

Family caregiving

In Sweden nearly 70 per cent of care for older persons living in their own homes is provided by family caregivers such as spouses, relatives or friends (Larsson 2006, National Board of Health and Welfare 2009). In Europe as a whole, approximately 80 percent of care hours for older people are provided by family caregivers (Hoffmann & Rodrigues 2010, Marin *et al.* 2009). Family caregivers are taking on a greater responsibility and providing a larger part of the care due to a diversity of reasons. More older people are choosing to stay in their own home and there is also a reduced accessibility to nursing homes due to financial cut-backs in the public care sector (Johansson 2007, Johansson *et al.* 2003), creating an increased need for family caregiving (Bergmark *et al.* 2000). In many cases when home-help service is received, family members still carry out most of the caring tasks (Larsson 2006, National Board of Health and Welfare 2009, Sand 2005, Szebehely 2006). Many older people live together with a spouse who needs help and care in order to manage ever-day life (Larsson 2006, McConaghy & Caltabiano 2005, National Board of Health and Welfare 2009, National Board of Health and Welfare 2012).

A caregiver is anyone who looks after a family member, partner or friend who needs help due to illness, frailty or disability. The care they give is unpaid. Measuring the prevalence of family caregiving is difficult as there is no official statistics available. Family caregivers are found in all age groups. In Sweden every fifth person is a family caregiver, which equals 1.3 million persons (National Board of Health and Welfare 2012). Equivalent numbers for other countries are 65.7 million family caregivers in the United States and 6.5 million in the United Kingdom (Carers UK 2014, National Alliance for Caregiving and AARP 2009). Among family caregivers age 65 years and older it is most common to provide care for a spouse (National Board of Health and Welfare 2012). An earlier Swedish study described that 3% of the population between 55 and 84 years old fits the definition of family caregivers as they provide care to a co-living person on a daily basis or at least several times a week. Most of the care givers were between 74 and 84 years old (Szebehely 2006). Taking on the role as family caregiver is rarely a choice made deliberately, it usually develops over time (Family Caregiver Alliance 2014, Johansson 2007). Many older spouse caregivers are tied to their home by their caring duty. They may not want to, or are afraid of, leaving the home and the cared for spouse alone (Johansson 2007, Sand 2007).

The role of spouse caregivers

Being caregiver to a spouse is often a task performed 24 hours a day, seven days a week. Besides giving general practical help such as cooking, cleaning and laundry, they provide social stimulation and assist with personal care, hygiene and dressing (National Board of Health and Welfare 2012). A person with chronic disease may be ill for many years. Spousal caregiving can also include monitoring chronic and sometimes acute, medical conditions. The progression of various conditions can lead to needs like feeding tubes, urinary catheters, daily injections or oxygen treatment. In institutional care such care is performed by nurses, but when caring for an old spouse at home, these sorts of nursing tasks are often tended to by the spouse caregiver (Family Caregiver Alliance 2014). When caring for a spouse with chronic disease, performing nursing interventions can be a major part of caregivers' everyday life (Jeppsson-Grassman 2003). In situations where the care receiver is unable to fulfill his or her needs regarding nutrition, elimination, bathing or mobility, help provided by spouse caregivers can be viewed as replacement for self-care (Orem 2001). From this perspective there are similarities between the work carried out by spouse caregivers and the work carried out by professional nurses.

Health and quality of life

Being a family caregiver often takes its toll on health. The more extensive the care, the more does it have a negative effect on the quality of life for the caregiver. At the same time, most family caregivers are pleased with being caregivers, as it gives them satisfaction to care for their loved one (National Board of Health and Welfare 2012). Constantly being on duty, often with need for constant presence at home, leads to many caregivers experiencing negative health effects, such as sleep disturbances, stress, social isolation, feelings of loneliness, burdensome responsibility and depression (Ekwall *et al.* 2004, Hoffmann & Rodrigues 2010, McConaghy & Caltabiano 2005, Sand 2005). Loneliness is a significant factor when it comes to quality of life for older people. Both experiences of loneliness and absence of social networks have a negative influence on quality of life (Ekwall *et al.* 2004). Other factors influencing quality of life for older family caregivers are burden and caregiver satisfaction (Andren & Elmstahl 2005). The high risk for health problems within this group is well documented in previous research, however, simultaneously with the negative effects results from psychosocial interventions have shown significant positive effects on family caregivers' experiences of satisfaction with caring (Andren & Elmstahl 2005). Spouse caregivers provide more care than other categories of family caregivers and also report higher levels of psychological distress, greater financial burden, and lower levels of psychological well-being (Pinquart & Sörensen 2011). Services provided within the healthcare sector have traditionally been analyzed and measured using objective measures of health, such as mortality (death) and morbidity (prevalence of illness). In recent years, the importance of including subjective perceptions of health has become increasingly recognized (Bowling 2005).

Support for family caregivers

Throughout Europe enhanced caregiver support has been introduced (Kröger 2003, Winqvist 2010). Information, educational programs, support groups, personal counseling and respite services are among the types of support most frequently offered (Jegermalm 2003, Johansson 2007, Larsson 2006). Despite the expansion of interventions and support forms available, there is still a need for further development and to design new and more effective ways of supporting older family caregivers (Schulz 2001). Social, psychological and educational interventions are some of the best strategies for informal caregivers to manage the pressure of care (Zarit 2002). However, the way in which support is offered does not always match the varying individual needs, which often applies for standardized care activities and programs, thereby being viewed as non-flexible and non-personalized (Clare 2002, Lauriks *et al.* 2007).

Caregiver support in the Swedish context

In 2009, the Swedish Parliament passed a new law stating that: "Municipalities are obliged to offer support to persons caring for people with chronic illnesses, elderly people, or people with functional disabilities" (Swedish Social Services Act 2009). The legal text does not state recommendations on how the legislation should be implemented, and gives extensive freedom to the municipalities regarding how and what kind of support to provide (Johansson *et al.* 2011). Large amounts of resources have been invested in developing and improving support to older family caregivers. As a result the great majority of local municipalities in Sweden provide a diversity of support for this target group. Some of this support is aimed directly at caregivers, for example feel good activities, individual counseling, support groups and education. Other services, such as day care, home care services or respite care in the form of institutional care are indirect support for caregivers (Winqvist 2010).

In most municipalities there is at least one, often several persons working with caregiver support and support services are commonly organized as support centers. They are working to develop, inform and offer various forms of support to family caregivers (Swedish National Family Care Competence Centre 2013). Support workers may have various education and professional background and there is no uniform title. Examples of competence among staff at the local support centers, are social workers, physical therapists, assistant nurses, registered nurses, and also specialists from the fields of public health-, psychiatry- and dementia nursing. In this thesis we call caregiver-support professionals ‘support nurses', as they work with counseling family caregivers on nursing issues or issues which are related to the caregivers performing nursing duties in their homes.

Use of Information and Communication Technologies (ICT) in the support of family caregivers

ICT-services can contribute to improve the flexibility of caregiver support, and is promoted as an important factor in meeting future care needs. ICT-services have the potential to help family caregivers increase their quality of life, ease their burden, stay healthier and improve social inclusion as well as improving the quality of care provision (European Commission 2010a). The potential value of ICT in helping informal caregivers perform their tasks in the community has been recognized by research and policy contexts both in Europe and other parts of the world. Nevertheless, there is still limited availability and use of ICT-based services for informal caregivers. The CARICT-study (ICT for carers and other social actors: enhancing the sustainability of long-term care and social support), where 52 European ICT-based initiatives for caregivers were analyzed, concludes that new services enabled by ICT can support family caregivers more effectively and efficiently than conventional services (Carretero *et al.* 2012).

The use of ICT, as a tool for support to older people and family caregivers constantly increase (Powell *et al.* 2008, Schmidt *et al.* 2011). One of its most important characteristics is the ability to provide the help needed, when needed (Schmidt *et al.* 2011). A diversity of ICT-services is being used throughout Europe, including telecare (Jarrod & Yeandle 2009) online support groups, online training, telealarms and monitoring systems (Schmidt *et al.* 2011). Informational websites offer helpful information for family caregivers, and instrumental ICT-support such as mobile phones or videophones can be used to facilitate social contact and prevent isolation. However, previous research concludes that there is a need for even more flexible, personalized care and ways of support (Lauriks *et al.* 2007).

Older people and technology

People who are old today have lived through a time with many technological breakthroughs (Hagberg 2004). Through their life-course they have experienced a number of powerful technological objects that have emerged into everyday life and become embedded in routines and habits, such as the radio, washing machine, TV, refrigerator, telephone, mobile phone, computer and internet. Complex artefacts and systems have become common necessities (Larsson & Hagberg 2009). Older people themselves sometimes have a negative attitude towards learning and using new technology and a majority lack computer experience (Larsson *et al.* 2009). According to Magnusson et al. (Magnusson *et al.* 2004) initial resistance to learn new technology is put aside as older persons experience benefits and find technology useful. However, continuous support and encouragement during learning and getting started to use ICT seem to be essential for older family caregivers in order to fully benefit from ICT-based support (Magnusson *et al.* 2005a, Savolainen *et al.* 2008). A certain resistance about introducing ICT as an instrument in working with care for older people has also been seen among health care professionals (Magnusson *et al.* 2005a, Sävenstedt *et al.* 2003).

Aging in the rural context

In many rural areas the proportion of the population 65 years and older is larger than in the more densely populated areas (Goll 2010). Rural areas have a changing social infrastructure with depopulation and loss of local facilities such as shops, post office, public transportation, and health care centers. Health- and social care provision has traditionally been weaker in rural areas and the ongoing changes may result in older people in rural areas becoming even more vulnerable due to increased loss of essential services (Phillipson & Scharf 2005).

Family caregivers living in rural settings face specific challenges, including fewer physicians, less health- and education services, fewer available formal services, weather problems in winter, transportation difficulties, geographic distance and isolation (Family Caregiver Alliance, 2014). In rural areas it can also be difficult to access caregiver support. There is a danger that the demographic development will make it more difficult for authorities to provide good health- and care-services in rural areas in the future (Keating 2008, Senior 2005 2003, Statistics Sweden 2005). In the future it is likely that the use of different ICT tools in the support of family caregivers may become more prevalent, since it can be provided regardless of geographic location and distance (Schmidt *et al.* 2011).

There is a contrasting image of rural settings as supportive, and expressed concerns about the loss of young people moving to urban areas for better employment prospects (Keating 2008). Meeting care needs can be difficult as rural areas have fewer community based services. Employment costs for caring services are high as populations are small and scattered over larger areas with long distances between clients (Keating 2008). Respite services are sometimes not available at all, making it nearly impossible for family caregivers to get a break (Chappell *et al.* 2008). With children often living far away, and distant neighbors, practical assistance from friends and relatives is usually not readily available.

Definitions of rural

There is a lack of clarity concerning definitions of rural (Scharf *et al.* 2005, Swedish National Rural Development Agency, 2007}. Rural can be defined in a variety of ways and from different perspectives. One approach is to use situated definitions for rural, related to population size, density, distance from larger or urban centers and a relative lack of formal transportation, healthcare and other services (Canadian Institute for Health Information 2006, Hart *et al.* 2005). The European commission (2010b) is consistently using the OECD methodology (OECD 1994) to define rural areas, where a region is labeled as "Predominantly Rural region" if more than 50% of the population of the region is living in rural communes with less than 150 inhabitants per km^2. A comparable definition used in Sweden definition classifies municipalities with less than seven inhabitants per square kilometer as rural. In 2007 24% of Sweden's nine million inhabitants lived in rural areas according to the Swedish definition (Swedish National Rural Development Agency 2007). Another way to define rural is the socio-cultural approach, focusing on rural as a reflection of a set of attitudes, behaviors and beliefs. Stereotypes characterize rural people as having a slower, less pressured way of life, strong community feeling, close connections to the land and conservative, traditional values (Atkin 2003). While some live in idyllic settings, buffered from stress and social problems of urban areas, others face challenges of isolation, poverty, poor infrastructure and harsh climate (Keating 2008).

Ageing in place

Place has long been a consideration in research on health and social care (Poland *et al.* 2005). One motivating factor, contributing to why people become family caregivers, is the importance of place and the belief that the best thing for the cared for spouse is to remain in their own house, in familiar surroundings where they have their identity (Johansson 2007). Many older people have strong connection to their home and the area they live in (Abramsson & Niedomysl 2008). A majority of older people continue living in their own homes despite care needs and social deficiencies. Ageing in place has been the prevailing ideology in the care of older people many years and one of its intentions is to enable older persons to continue living in their own homes for as long as possible (Hagberg 2012, Larsson 2006). Besides constituting the foundation of housing-policies for older people (SOU 2003:91) the principle of ageing in place is also the obvious choice for many old couples when one of them become dependent on care in order to manage daily life.

The concept of place

Belonging to a place is an essential part of life. As people get older the number of places where they actually are becomes fewer and the place where one lives becomes even more important (Peace *et al.* 2006). According to Poland et al. (2005) place is often treated descriptively, as a locus for health and health-care activities. They also describe the emerging of a more multi-dimensional conception of place, where place is conceptualized as a set of situated social dynamics instead of just a physical setting. The most important places for older people are the home, the neighborhood and the area they live in. Belonging to a place implies or presupposes emotional attachment to that particular place (Hagberg 2012). Many older persons have lived in their home for a long time and wish to continue living there in the future (Abramsson & Niedomysl 2008). The significance of the home tends to increase with older age as a larger share of time is spent within the home. For some people the home becomes almost the only place where they spend their time (Keating 2008). The concept of place has traditionally been defined by its geographical location. The use of new communication technologies opens up for new and more complex spatial definitions. Where one is becomes an issue of which places one can connect to in real time. From this perspective, an older person who is physically tied to the home, can simultaneously live in a home where he or she can visit other places and be a virtual nomad in the world (Hagberg 2012).

THEORETICAL FRAMEWORK

Salutogenesis

When working with caregiver support I have found it suitable to have a salutogenic perspective. From my point of view the salutogenic perspective is a connecting thought in family caregiving as well as in providing caregiver support. The purpose of both situations is to help someone through challenges, with the goal to have a good life despite illness. The salutogenic approach focuses on factors that support human health and wellbeing rather than on factors that cause disease. Previous research has suggested salutogenesis to be worth implementing in practice much more than it is to date (Westlund & Sjöberg 2005). The word "salutogenesis" comes from the Latin “salus” (health) and the Greek “genesis” (origin). Salutogenesis is concerned with the relationship between health, stress and coping and embraces an interest in people’s possibilities despite the stresses they are exposed to and also takes an interest in how people use the resources they actually hold, even when these are extremely limited (Antonovsky 1987).

Illness, death and other losses are part of life and especially associated with aging. Thus, there is a variety of age- and disease related issues from which we cannot escape. It is interesting as well as necessary to inquire about how health can be maintained when individuals are exposed to the strains of life and aging (Riksdagen 2003). Among older people living in their own homes there are several individuals with chronic disease or who are subject to other chronic stressors. Chronic, progressive diseases expose old people to increasing loads {Westlund & Sjöberg 2005, Westlund & Sjöberg 2008). Caring for a spouse at home is often associated with high levels of stress and burden, leading to lower levels of health and wellbeing (Johansson 2007, Pinquart & Sörensen 2011).

Antonovsky's model rejects the "traditional" Western medicine dichotomy separating health and illness, treating them as two absolute conditions. Instead Antonovsky emphasized that we simultaneously can experience both health and illness. He described health as a continuum of more or less of health and illness, where every person finds him- or herself at a certain stage on that continuum. The position a person currently holds on this continuum depends on interactive processes between factors which represent burden (stressors) and protective factors (Generalized Resistance Resources) within the context of life experiences of the individual (Figure 1) (Antonovsky 1987).

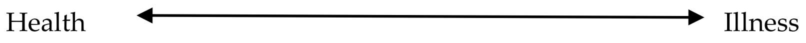

Figure 1. The continuum of health.

Sense of coherence

As illustrated above, salutogenesis concerns searching for the origins of health rather than the cause of disease. From this approach, Antonovsky put forward the concept of sense of coherence, SOC, which is a model for explaining why some individuals have the power and strength to endure difficulties and stay healthy while others do not. The answer he found was: A strong sense of coherence (Antonovsky 1987). SOC is strongly related to perceived health, especially mental health. It appears to be a health promoting resource, which strengthens resilience and develops a positive subjective state of health. A person with a strong SOC is more likely to feel less stress and tension, and to believe that he or she can meet demands (Westlund & Sjöberg 2008).

SOC consists of three components - comprehensibility, manageability, and meaningfulness. Each of the components are important by themselves, but they are especially valuable together. With a strong sense of coherence follows a high probability that the individual will find a strategy for maintaining health despite severe strains. Comprehensibility is the extent to which events are perceived as making logical sense, that they are ordered, consistent, and structured. Manageability is the extent to which a person feels they can cope. Meaningfulness is how much one feels that life makes sense, and challenges are worthy of commitment (Antonovsky 1987).

The concepts of E-health and ICT

In the articles of this thesis two terms, e-health and ICT, have been used to label the intervention. As there are several definitions available of the both terms, it feels essential to present the ways terms and concepts have been used in this thesis.

The intervention that was used and 'evaluated' through this thesis was the ACTION-service (Assisting Carers using Telematics Interventions to meet Older People's Needs), which is further described in the method section. The process of developing the ACTION-service is described in a thesis from 2005, entitled "Designing a responsive support service for family caregivers of frail older people using information and communication technology" (Magnusson 2005). In several articles published about ACTION it has then been referred to as ICT-based caregiver support (Hanson & Magnusson 2011, Magnusson & Hanson 2005, Magnusson *et al.* 2005, Torp *et al.* 2008). When the European Commission launched their strategy promoting the use of ICT for ageing well in Europe, ICT was further enhanced as the adequate term to use (European Commission 2010a). This is the reason why article I uses the concept ICT-based caregiver support (I).

Further into the work of this thesis searches in databases were expanded, and articles using the concept e-health became more frequent. In 2012 the Journal of Telemedicine and Telecare published an article analyzing trends for the use of the terms telemedicine, telehealth and e-health. Their analysis concluded that, even though telemedicine was currently the most popular term, e-health was predicted to be the most popular term within the next ten years (Fatehi & Wootton 2012). Based on this argument, it was relevant to transform my use of concept from ICT to e-health (II). Furthermore, the journal publishing article II suggested a change from ICT-based caregiver support to e-health based caregivers support, as they found the later terminology to be more accurate and up to date.

The term telemedicine literally means "healing at a distance" (Strehle 2006) and concerns using ICT to increase access to care and medical information, thereby improving patient outcomes (World Health Organization 2010). Providing distance-spanning health care, which is particularly valuable in rural areas, is in research described with various terminology and a study from 2007 found 104 peer-reviewed definitions of the word telemedicine (Sood 2007). To describe distance-spanning care by other professions than medical doctors the concept of *Telecare* developed. As the use of ICT in the health care sector expanded, comprehending a wider range of professions and applications, beyond those included in telemedicine and telecare, the term *Telehealth* was introduced. *E-health* is a broad concept without clear definition, which today often is used to describe all sorts of use of ICT in health care (Sävenstedt & Florin, 2013). According to the World Health Organisation, WHO (2014) "e-health is the transfer of health resources and health care by electronic means". WHO further describes e-health as "E-health provides a new method for using health resources - such as information, money, and medicines - and in time should help to improve efficient use of these resources. The Internet also provides a new medium for information dissemination, and for interaction and collaboration among institutions, health professionals, health providers and the public" (WHO 2014).

The definition of e-health used in this thesis refers to being internet based and directly involving patients or clients (Figure 2). Products, services and interventions within the concept of e-health can be provided in different ways, for different purposes. E-health can refer to systems: 1) directly or indirectly involving patients or clients, operated by clinicians such as doctors or nurses, or 2) intended to use for administrative or organizational purposes within the health care sector, for example exchange of information (Sävenstedt 2013, WHO 2014). E-health services can be internet based or non-internet based.

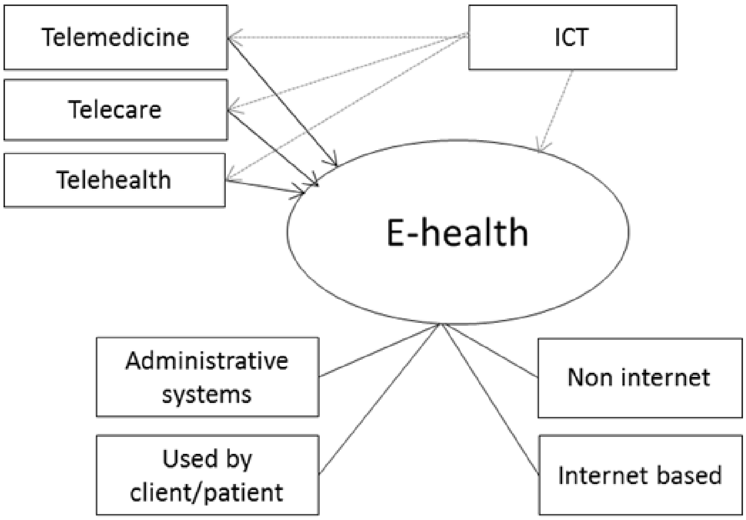

Figure 2. Conceptualization of terminology within the field of e-health, as interpreted and used in this thesis.

Alongside the terminology mentioned above, there are still more terms which are being used in research and literature to describe the phenomenon of using ICT in providing care and support for older people. Some of those concepts are networked technologies (Powell *et al.* 2008), telematics (Hanson & Magnusson 2011), IT (Hanson *et al.* 2002), picture telephone (Sandqvist 2010), socio-technical (Berg *et al.* 2003) and Technology-based (Carretero *et al.* 2012).

Stages of use of e-health

In the research made within the work of this thesis, older family caregivers in rural areas participated in an intervention study, where caregiver support was provided through an ICT-based e-health service. In order for e-health services to be successful it is essential that they are actually being used. In various e-health trials high attrition rates have been reported. As opposed to drug trials, where the intervention often is “prescribed”, studies involving e-health services are mostly dependent on the voluntariness of the participants. Participants have the option to discontinue usage very easily. This circumstance leads to loss of trial participants in any longitudinal study where the intervention is neither mandatory nor perceived as critical to the participants' well-being (Chiu & Eysenbach 2010).

The "stages of use" framework, developed by Chiu & Eysenbach (2010), explores usage behavior in four different phases when family caregivers adopt and use an e-health service. The framework is theory-driven and empirically tested (Chiu & Eysenbach 2010). It contributes to understanding why caregivers use or not use e-health interventions and also helps bring forward factors which affect the clinical outcomes. The framework includes a theoretical model which describes the four stages of use of e-health interventions (Figure 3).

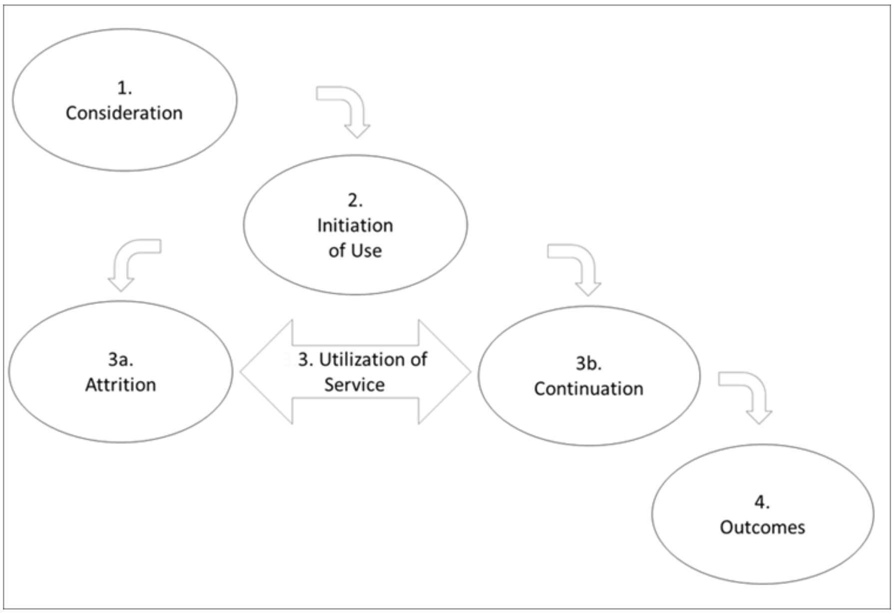

Figure 3. Stages of Use of e-health interventions (Chiu & Eysenbach 2010).

The four stages of use are:

1. *The Consideration Stage.*
   Based on information available about the intervention or service, caregivers decide whether they will use the service or not and act upon the decision. For example by signing a consent form or creating a user account.

2. *The Initiation Stage.*
   Caregivers start using the service and make their first login or first meaningful action. Factors likely to influence if participants will actually use the service or not, despite the initial agreement, are competing interests, change of interests, lack of previously present peer pressure, lack of time or simply forgetting about it.

3. *The Utilization Stage*
   Caregivers begin to actively use the service and actively engage in the intervention. In this stage users choose from one of two paths, attrition or continuation. The decision is influenced by experiences of usefulness of the technology, perceived needs or change in needs. Experiencing positive changes provide motivation for continuing use. If use is discontinued, the intervention is ended before completion.

4. *The Outcome Stage*
   Attaining a positive outcome is the ultimate goal of e—health interventions.

Drawing on the common problem of attrition and nonuse of e-health interventions, the stages of use framework was developed to highlight "the importance of conceptualizing e-health 'use' and 'adoption' as dynamic, continuous, longitudinal processes occurring in different stages, influenced by different factors to predict advancement to the next stage" (Chiu & Eysenbach 2010). Conceptualizing the attrition phenomenon in e-health service use were based on two theoretical models: the Behavioral Model of Health Service Utilization, BMHSU (Andersen, 1995) which is a frequently used theoretical model for predicting and explaining use of e-health services and the model for Unified Theory of Acceptance and use of Technology, UTAUT, which explains the intention to adopt or use information technology (Venkatesh *et al.* 2003).

In developing the framework, findings from empirical studies of ICT-mediated interventions for dementia family caregivers were used (Powell *et al.* 2008). The characteristics of participants in those studies are compatible with a majority of the participants in our study, which makes it relevant to apply the model to our context. Even though not all participants in our study were caregiver to a person with suffering from dementia, there are many similarities in their circumstances.

OBJECTIVE OF THESIS

In the rural areas of north Sweden, with a large proportion of older people, access to caregiver support services is limited. Availability is dependent on the capacity of the support service in each municipality. In some municipalities nurses serve as support nurses one day a week. With such small resources it is not possible to give support to a large number of family caregivers. The long distances are time consuming to travel and with the expected shortage of professionals in the care sector, there will be difficulties recruiting qualified staff, especially in rural areas. For older people living in rural areas to have proper access to the support services they are entitled to by Swedish law, it is essential to pursue new ways of providing support. Using the possibilities of ICT and e-health services to reach people in their homes open up for new opportunities to provide equal support to older family caregivers regardless of where they live.

The overall objective of the thesis was to explore the experiences of older family caregivers in rural areas receiving e-health based caregiver support. The thesis focuses on two main areas: 1) Description – in order to obtain a more holistic picture by studying caregivers’ experiences, 2) Evaluation- by exploring different perspectives on e-health based caregiver support and also in comparison with existent caregiver support.

AIMS OF THE STUDY

Specific aims of the four articles were:

Article I	To illuminate the meaning of ICT-based caregiver support as experienced by older family caregivers living in rural areas.
Article II	To compare the benefits of caregiver support between rural older family caregivers receiving e-health based support with caregivers receiving conventional non e-health based support.
Article III	To explore how e-health based caregiver support may influence the experience of isolation among older spouse caregivers in rural areas.
Article IV	To explore how caregivers used the different features included in the e-health caregiver support service and associations between benefits and frequency of use. A secondary aim was to explore support nurses′ perspective on the intervention.

METHODOLOGY

In this pragmatic intervention study, multiple forms of design were applied. In Article I a qualitative, descriptive design was used to obtain a starting point regarding older family caregivers’ experiences of receiving e-health based support in rural areas. The study in Article II had a comparative design, where family caregivers receiving caregiver support through e-health were compared to a control group receiving conventional forms of caregiver support. Article III was an exploratory study focusing on how e-health based caregiver support may influence caregivers’ experiences of isolation. In Article IV an exploratory approach was used to study how frequent caregivers used the support and if the support was useful. The perspective of support nurses was also included. An overview of design, subjects and methods for data collection and analysis is provided in Table 1.

Setting

The study took place in 15 different local municipalities, situated within three regional counties in north Sweden. The rural areas of north Sweden are among the most sparsely populated areas in the country. Like in the international context, also from a domestic Swedish perspective there are different ways to define what is rural. In general, rural areas are characterized by having few job opportunities and residents, but having plenty of geographical space. The interpretation of what could be classified as rural in each municipality was delegated to the support nurses who recruited the participants. They made their assessments based on the geographical location of the family caregiver's homes and the definitions used by the Swedish Rural Development Agency (Glesbygdsverket)[1] and the Swedish Agency for Economic and Regional Growth (Tillväxtverket)[2].

Northern Sweden is characterized by mountains and forests with sparsely located small villages and few towns. The proportion of the population 65 years and older, is larger than in more densely populated areas. There is an ongoing change in social infrastructure with depopulation and loss of local facilities such as health care centers, shops and public transportation. Public transportation is

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[1] Sparsely populated areas: more than 45 minutes ride by car to the nearest densely built-up area/town of more than 3000 inhabitants

[2] Rural areas: between 5 and 45 minutes ride by car to the nearest densely built-up area/town of more than 3000 inhabitants.

limited and public service, when available, is mostly located to towns, leading to long geographic distances for those living even more remotely. Winters are long, cold and rich in snow (November-April). During summertime daylight is nearly constant and it does not get dark at night.

Table 1. A schematic overview of the articles included in the thesis**.**

Article No	**Design**	**Subjects**	**Data collection**	**Method of analysis**
I	Qualitative	31 intervention group caregivers	Semi structured web-camera interviews	Content analysis (latent)
II	Mixed method	22 intervention group caregivers and 11 control group caregivers	Semi structured interviews via web-camera and telephone	Content analysis (latent)
		35 intervention group caregivers and 21 control group caregivers	Self reported Questionnaire - Care Effectiveness Scale (CES)	Linear regression, comparative statistics, mean group values
III	Qualitative	31 intervention group caregivers	Semi structured web-camera interviews	Content analysis (latent)
IV	Mixed method	42 intervention group caregivers and 23 control group caregivers	Questionnaires for frequency of use and perceived benefits	Descriptive statistics, multiple linear regression, logistic regression
		7 support nurses	Semi structured telephone interviews	Content analysis (manifest)

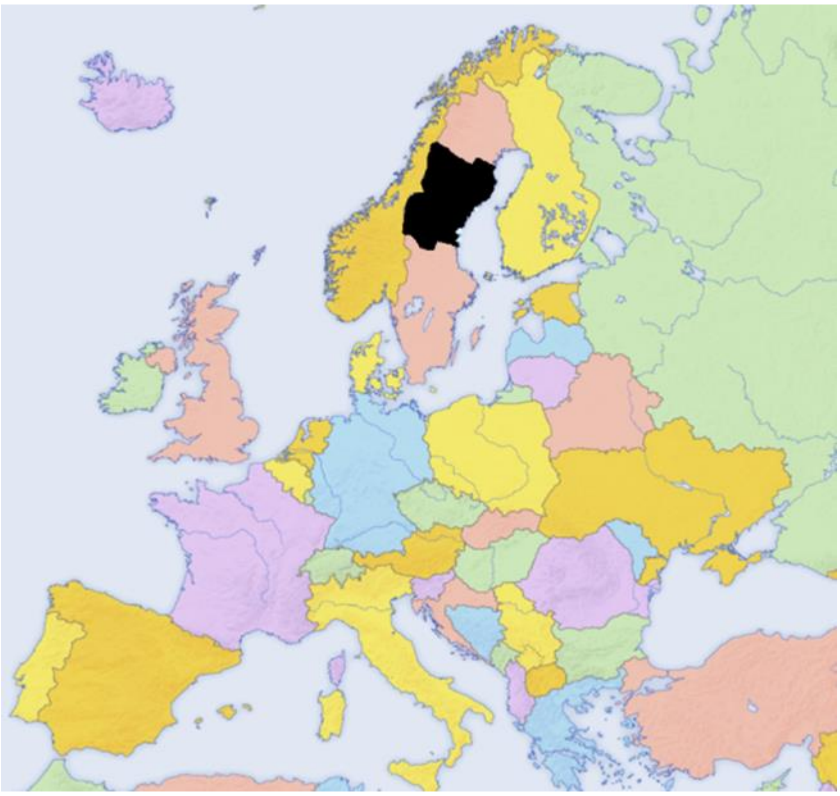

Figure 4. Map of Europe. The area in Sweden where the study took place is marked with dark contrast.

Participants and recruitment

Older family caregivers living in rural settings in the northern parts of Sweden were invited to participate in the intervention study. Inclusion criteria were to be at least 65 years of age, being primary family caregiver of a co-habiting spouse, being resident in a rural area and still living in their own home. Additional criterion were for the intervention group to have access to high speed internet from their home and for the control group to be participating in at least one of the support activities offered at their local caregiver support center.

Recruitment of participants was made by support nurses, working at caregiver support centers in the 15 municipalities. Participants were consecutively recruited as they came in contact with the caregiver support centers. After the intervention group was filled, caregivers were allocated to the control group. All of the participants but one had prior to inclusion in the study been in contact with the support service where he or she was recruited. One participant heard about the study from friends and made contact with the local support service and asked to be included in the study. Baseline characteristics of the participants are shown in Table 2.

Table 2. Baseline characteristics of study participants.

Variable	All Participants n=95	Intervention Group n=63	Control Group n=32
Caregiver age, mean (range)	74(65-85)	74(65-85)	75(65-84)
Care recipient age, mean (range)	76(65-97)	76(65-97)	77(65-89)
Gender of caregiver			
Women	65(68%)	45(71%)	20(62%)
Men	30(32%)	18(29%)	12(38%)
Care recipients with dementia	36(40%)	27(43%)	9(28%)
Care recipients with stroke	17(18%)	8(13%)	9(28%)
Care recipients with multiple diseases	25(26%)	19(30%)	6(19%)
Previous experience of using computer			
Much experience	3(3%)	2(3%)	1(3%)
Some experience	51(54%)	36(57%)	15(47%)
No experience	41(43%)	25(40%)	16(50%)
Level of education			
Primary school	54(57%)	30(47%)	26(81%)
Secondary school	26(27%)	23(37%)	2(5%)
Higher education	15(16%)	10(16%)	4(14%)

Articles I-III focused on the experiences of spouse caregivers. In article IV, support nurses were included as informants and their perspective on the caregivers' experiences of using e-health based support was added. Staff of support nurses at the local caregiver support centers, ahead referred to as nurses, were qualified professionals with various education and experiences from nursing, such as assistant nurses, registered nurses, district nurses or nurses specialized in geriatrics, psychiatry or dementia.

Participants in the intervention group received for a period of three years e-health based care giver support from the caregiver support center in their local municipality. They received e-health based caregiver support in accordance with the ACTION-service (Magnusson *et al.* 2005a) and were provided with computer, web camera and high speed internet in their homes. At the prospect of the study each municipality had a predetermined number of computers available for distribution to the family caregivers. Participants in the control group received support according to general availability in each municipality. There was no uniform range of support, and availability varied between municipalities. Examples of conventional types of caregiver support are individual counseling, information, education, emotional support, group meetings, café activities, financial support and respite care. Each municipality had a caregiver support center, providing caregiver support for family caregivers.

The intervention - The ACTION-service

ACTION (Assisting Carers using Telematics Interventions to meet Older People's Needs) is a service developed specifically for the older and their family caregivers in order to reduce isolation and loneliness and meet their needs of information, advice and support (Magnusson *et al.* 2005b). ACTION originates from an EU-supported (European Union) project and has over the years been further developed and modernized (Magnusson & Hanson 2005).

The intervention consisted of the ACTION-service including hardware and software; a computer, web camera and access to high speed internet. (Magnusson *et al.* 2005). The ACTION-service offers a combination of six multimedia components:

1. Web camera communication with peer caregivers, enabling face to face contact.
2. Web camera communication with support nurses, enabling meeting face to face with professional support staff while remaining in the own home.
3. Information- and education programs focusing on areas encountered in daily caring, including comprehensive education programs about medical conditions, coping strategies, relaxation, and physical- and cognitive training.
4. E-mail address.
5. Games, both for individual use on the computer and to play online with a partner.
6. Access to public internet.

Technical equipment was provided to family caregivers by each local authority at no cost to the caregiver during the period of the research project. Prior to start of the intervention, family caregivers were educated in using the technology. Training took place in groups at support centers, or in the home of the family caregivers, depending on the individual's possibilities to attend group activities, due to the caregiving situation as well as geographic distances and transportation abilities of the caregiver. The information- and educational programs covered areas such as caring in daily life, coping, relaxation, planning, respite care, claims and benefits. Specific areas regarding caring in daily life were incontinence, dementia, stroke, decubitus, end of life care and emergency situations. The idea of the internet-based secure social community was to enable safe and easily accessible contact with peer family caregivers as well as encouraging them to contact the call center via internet and web camera.

Each municipality set up a call center with professional caring staff, in order to facilitate for family caregivers to seek and receive support from health care professionals in their own municipality. The call centers consisted of support nurses employed by the local authorities for the purpose of providing various forms of caregiver support. Call centers were located at each municipality's conventional support-center and were accessible during office hours, which in these rural settings sometimes were limited, in some cases one day a week. To ensure caregivers having higher availability to professionals, call centers within the study collaborated in responding to family caregivers when the call center in their own municipality was closed.

Data collection

Data was collected using a mixed method design, including questionnaires (I, IV) and semi structured interviews (I-IV). The underlying logic of mixing methods was that quantitative data collected in the questionnaires, capturing trends and details of the topic under study (Creswell *et al.* 2004), would serve as a complement to the qualitative semi structured interviews. In the full study there were in total 95 participants; 63 participants in the intervention group and 32 in the control group. At follow up 1.5 years after start, in total 65 participants remained in the study, 42 in the intervention group and 23 in the control group. This represents a total dropout rate of 32% (n=30). The main causes for dropout were caregivers discontinued participating in the intervention due to care recipient moved to care facility, death of care recipient or caregiver became unable to care due to own illness. The study population during all data collection were the 65 remaining participants (II) or the remaining 42 participants in the intervention group (I, III, IV). Even though all data collection was made from the original group of persons, there is a variation in number of participants in each article. This variation is caused by internal drop out within each study, for example due to participants returning one questionnaire but not another. All questionnaires were sent to all participants. Selection of participants for interviews was made by randomization from the sample as a whole. Flow chart of participants, allocation and drop out are shown in Figure 5.

Semi structured interviews (I-IV)

Semi structured interviews (Denscombe 2010, Kvale 2008) were conducted with participants from the intervention group (I-III), the control group (II) and support nurses (IV). For all interviews, a topic guide was used and the interviewees were encouraged to speak freely about the topics. All interviews were audio recorded and transcribed word by word. Some of the interviewees spoke with heavy local accent and in those cases transcriptions were made in standard Swedish (Malterud 2009). Time for interview was scheduled ahead on a time set by the interviewee. Interviews with participants in the intervention group (I-III) were conducted at virtual face-to-face meetings over the internet, using web camera (further described below). Telephone interviews (Denscombe 2010) were carried out with participants in the control group (II) and with support nurses (IV).

Polilt & Beck (2011) suggest the use of semi structured interviews when researchers know what they want to ask about, but cannot predict what the answers will be. Instead of preparing specific questions, a written topic guide is prepared, which is a list of areas or questions to be covered with each respondent. The interviewer encourages participants to talk freely about the topics on the list. Using this technique, respondents can respond in their own words and provide as much detail as they wish, ensuring that researchers will obtain all the information required (Polit & Beck 2011). In preparing for this study I did not know how the participants would respond to the e-health based support, and could not predict answers. In order to capture their true experience, revealing both good and bad, semi structured interviews were considered the most fitting method.

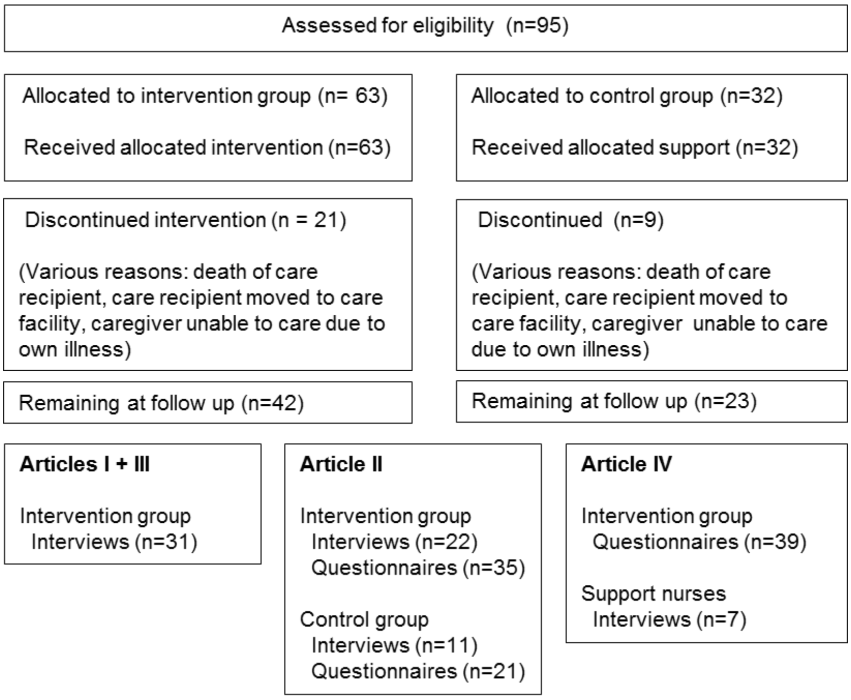

Figure 5. Flow chart of participants throughout the study.

Web camera interviews

Due to the large geographic area and as it was available through the intervention, interviews with participants in the intervention group were carried out as web camera interviews over the internet. The interviewer initiated the call from a computer using web camera, built-in microphone and speakers. Interviewees were in their homes, at an equally equipped computer. Prior to interviews, despite searches in databases, it was difficult to find references and guidelines about how to prepare for and conduct web camera interviews. In order to test the technology, and obtain some experience of web camera interviews prior to the 'real' interviews with the family caregivers, three pilot interviews were conducted with nurses from three different support centers. The purpose of the pilot interviews was to test the equipment and become familiar with the interview situation. Questions asked during pilot interviews were not connected to the questions later asked during telephone interviews with nurses (IV).

The pilot interviews revealed that conducting web camera interviews is quite different from face-to-face interviews in real life, IRL. Several details that usually does not influence interviews IRL becomes disturbing factors when having face-to-face interaction on web camera, for example improper lighting, messy backgrounds, noise from outside the room and certain patterns or colors of clothes. In an attempt to avoid unnecessary mishaps and promote quality during interviews, a strategy for the web camera interview procedure was developed (I). By following the strategy for each interview higher trustworthiness was achieved. The strategy included six steps. Here is a brief summary of the strategy. The full strategy is shown in article I.

1. Preparing the interviewee. Telephone contact with interviewees. General information about the interview. Giving them the opportunity to ask questions about the procedure.
2. Setting up the environment. Make sure the place you have selected is free from disturbances. Create a calm atmosphere in the area which is visible for the interviewee. Plan your clothing.
3. Before establishing connection. Test the technical equipment. Check lighting. Practice your position and looking at the camera.
4. Establishing on-line connection with interviewee. Make sure interviewee is comfortable before starting the interview. Check function of audio and video, small talk may be needed.
5. During interview. Speak clearly, look into the camera, avoid disturbing behavior.
6. End of interview. Tell interviewee that you will close the call. Shut down the connection.

Questionnaires

Demographic questionnaires were used to gather information about the participants. Example of data collected were gender, age, reasons for caregiving, and previous experiences from using computer. Quantitative data regarding caregivers' experiences of receiving support were collected using instruments relevant for the topics under each study (II, IV). There were also specific questions for each group. Participants in the intervention group were asked about using e-health support (II, IV) and participants in the control group were asked about what type of caregiver support they received (II), if they have a computer at home, how often and for what purpose they use their computer (IV).

The Care Effectiveness Scale (II)

The Care Effectiveness Scale, CES, is an instrument designed to use for family caregivers to evaluate support interventions by rating the assistance they have received. The instrument was developed by Archbold, Stewart and Miller (1995) and comprises 40 items, of which 30 explore the domains of preparedness (22 items), enrichment (8 items) and predictability (8 items). The scale uses a five-point response format on a Likert type scale graded from 1 (not at all) to 5 (a great deal). There is also a not-applicable-to-me response alternative, with the score 0. Three samples from the questions are: ”To what extent did the caregiver support”: (1) help you improve the quality of care you provide?, (2) help you feel more relaxed and (3) help you feel more prepared to handle the emotional needs of your spouse? In addition, the perceived overall benefits of support were measured by a single-item indicator on a Likert type scale from 0 (not at all useful) to 10 (extremely useful).

CES was chosen as instrument for exploring whether older family caregivers in rural areas could benefit from e-health based support (II). There were two main reasons for choosing the CES for our purpose. First, it had been previously used in evaluations of the ACTION-service (Magnusson *et al.* 2005). Secondly, as the questions in the instrument are formulated to rate the support received, regardless of type of support, it was applicable for both the intervention- and the control group, thereby being suitable for comparison between the groups.

Utilization of e-health based support (IV)

A study-specific questionnaire was developed with the purpose of surveying intervention group caregivers' use of ACTION, covering the areas of frequency and benefits, exploring how often the participants in the intervention group used the six components included in the ACTION-service and the degree of perceived benefits (IV). Frequency of use was measured by asking “How often do you use the component xx?” for each of the six components. A four-grade ordinal scale with response alternatives running from “on a daily basis” to “less than once a month” was used. There was also an “I don't know”- alternative available to capture if there were components which had not been used at all. Benefits were measured by 14 questions covering the areas of personal development, emotions and social participation. Response alternatives were on a four-grade Likert scale. There was also a “not applicable to me” response alternative to capture if participants had not used the e-health based support for this particular purpose. By allowing non-use as an option among the response alternatives, false negative values may be reduced.

Data Analysis

Qualitative Data Analysis (I-IV)

Analysis of qualitative data was performed using qualitative content analysis inspired by Graneheim and Lundman (2004) and Patton (2004). The exact procedure of analysis varies slightly between the different articles (I-IV), depending on the research questions. Content analysis includes interpretations of data, however the interpretations can vary in depth and level of abstraction (Graneheim & Lundman 2004). Manifest content analysis (IV) focus on the visible and obvious components of the text, describing what the text actually says. For a higher level of abstraction a latent approach is necessary (I,II,III), analyzing what the text talks about and interpreting the underlying meaning of the text (Downe-Wamboldt 1992).

The procedure of analysis may be designed in various ways, however there are some basic principles regarding the steps of the procedure, which were used in all articles of the thesis. In line with the ideas of Graneheim and Lundman (2004), the process of analysis started with reading through the text several times, to get a sense of the whole. During the process of analysis there was continuous reflection and discussion among the authors, and a movement back and forth between the whole and parts of the text. Meaning units, i.e. words, sentences or paragraphs related to the central meaning were sorted out and then condensed (I-IV). Condensation refers to shortening the meaning unit, while still preserving the core. The condensed unit was labelled with a code and sorted into categories (I-IV). Creating categories is considered a core feature of the analysis. Even though categories ought to be internally homogeneous and externally heterogeneous (Patton 2004) it is not always possible to achieve this division when analyzing texts dealing with experiences (Graneheim & Lundman 2004). A category is an expression of the manifest content (IV) of the text and answers the question ‘what?’ To expose the latent content (I,II,III) of the text yet another step is required, the formulating of themes. Themes answer the question ‘how?’ Quality in qualitative content analysis is defined by its trustworthiness, credibility and dependability (Graneheim & Lundman 2004).

Statistical data analysis (II, IV)

All quantitative data analysis were performed with a standard statistical package (SPSS Statistics 21). Prior to statistical calculations all data was checked for quality with respect to missing values. In both the CES (II) and the questionnaire for frequency and benefits (IV) there were internal missing values. For the CES, when a subject had missing responses to items within a scale, the average of the non-missing responses was calculated as the scale score for that respondent and hence imputated. For the other instruments a limit was set for how many internal missing values would be acceptable in order for the data to contribute to a meaningful analysis. If the limit was exceeded, meaning the respondent had more internal missing values than the limit allowed, the respondent was excluded from further analysis (IV). As different scales were used in different sections of the questionnaires, each scale had its own missing value limitation set in relevance with the unique characteristics of the scale.

Demographic data about the participants in the intervention- and control group were analyzed through descriptive statistics (II, IV). Substantial differences in distribution of two categorical variables, Care Recipient's dementia diagnosis and Caregiver's levels of education were found and they were judged to be possible confounders. To avoid error, the mean differences between groups were adjusted by using linear regression with Group, Dementia and Education as indicator variables. By using this method mean group differences were calculated controlling for the variables Dementia and Education (II). For analysis of CES (II) group means were calculated for the instrument (40 items) as a whole, its three dimensions (subscales) and for the Overall benefit item. The analysis of internal missing values showed the patterns of non-response to each item of the sub-scales, hence internal missing data did not cause errors in the results.

Caregivers' utilization of e-health based support (IV) was initially analyzed using descriptive statistics, where frequencies and means were calculated. Bivariate non-parametric correlations between the six different components and perceived benefits were analyzed, followed by multiple linear regression analysis. The linear regression showed low associations with the benefit dimensions for the variables Internet use and E-mail use. These variables also had the biggest variance inflation factors (VIF) showing multicollinearity in the regression equation. As this can be harmful to the correctness when calculating statistics these variables were excluded from the regression models. To describe associations between frequency of use of the different ACTION components and benefits as defined by items in the survey the output from the linear regression was analyzed. All surveys containing one or more missing answers were excluded from analyzes which reduced the number of cases. For method triangulation binary logistic regression analysis was performed, using dichotomized versions of the variables which were used in the linear model.

Ethical considerations

The study was approved by the Research Ethics Committee of the Medical Faculty at Umeå University, Sweden (Dnr 2010-187-31). Participants were guaranteed confidentiality and informed of their right to withdraw their participation at any time without giving a reason. They were also ensured, in writing, that withdrawal from the study would not exclude them from access to further support. Family caregivers were guaranteed that they would be allowed to keep technical equipment and have full access to services included in the intervention for the full project period, at no cost, if they decided to withdraw from the study. They were also informed about their right to return the equipment and totally withdraw from participation in the project if they for any reason did not want to continue in the project.

Methodological considerations

As support centers do not file data about their clients it was not possible to randomize participants to the intervention- and control groups. The number of participants was fairly large for this type of study, which gave trustworthiness and variation of experiences. Through the use of quotations and by consulting the tables in the qualitative parts of the articles (I-IV) it is possible to see data and follow an example of the process of analysis. These are essential aspects for judging the credibility of the study (Graneheim & Lundman, 2004).

FINDINGS

Based on the overall objective of the thesis, the findings can be divided into three fields: 1) A description of caregivers' experiences from receiving caregiver support, 2) Knowledge about how the participants used the e-health based caregiver support and the effects they experienced, and 3) A deeper understanding regarding the process of implementing e-health based caregiver support in rural areas, from the perspectives of spouse caregivers and support nurses. A brief summary of the findings from each of the articles included in the thesis are presented in Table 3.

Article I

The meaning of using e-health based caregiver support

The aim of the first article (I) was to illuminate the meaning of e-health based caregiver support, as experienced by older family caregivers living in rural areas. In this qualitative study semi structured web camera interviews were conducted with 31 intervention group participants. After analyzing data, using latent content analysis, two themes were formulated; *Adopting new technology with help from others* and *Regaining social inclusion.* Both themes were built from categories which gave a rich and detailed description of caregivers' experiences. A majority of the participants had no previous experience of using computers when they started to use ACTION. Through the caregiver support centers they received training on both using a computer and how to use the ACTION service.

Adopting new technology with help from others

At the beginning of the intervention there had been various technical problems. Nurses had been quick to solve problems and provide technical support when needed so from the participants view, technical problems had not been an obstacle for using ACTION. There was consensus among the participants that one must give priority to learning and actively use the technology, not just wait around for someone else to call or in other ways take the initiative. Just receiving support was not enough, actively using it was considered necessary in order to develop skills and experience benefits. This finding was later confirmed by analysis from another approach (IV).

Table 3. Summary of aims and findings of the four studies included in the thesis. IG = intervention group, CG = control group.

Article No	Aim	Type of data	Findings
I	Illuminate the meaning of e-health based caregiver support, as experienced by family caregivers	Qualitative	2 themes: Adopting new technology with help from others and Regaining social inclusion
II	Compare benefits of e-health based and traditionally provided caregiver support	Quantitative Qualitative	Intervention group had significantly higher score on caregiver effectiveness Intervention group found support to be available, flexible and enhancing caregiver competence Control group experienced unmet needs
III	Explore how e-health based caregiver support may influence caregivers' feelings of isolation	Qualitative	2 themes: Expanding the concept of place and Developing networks
IV	Investigate frequency of use and perceived benefits of e-health based caregiver support	Quantitative Qualitative	Most caregivers used e-health support on a daily or weekly basis. Information- and education programs had strongest positive association with benefits 3 categories: Caregivers' dedication, Caregivers resignation and Acknowledging a need to develop the professional nursing role

Support staff played an important role as educators but also for inspiring and encouraging caregivers to take on the challenge of learning new technology. Peer caregivers encouraged and helped each other in experimenting with the technology. Another source of motivation was receiving praise from others for being bold and modern. Motivation was also auto generated as participants experienced benefits from using the ACTION-service. During the process of adopting new technology participants experienced a journey of personal development. After having doubted their own abilities at the start they overcame the fear of technology. In the process of learning they were acknowledged as competent and courageous which lead to them growing as individuals, feeling increased self-confidence and increased self-esteem.

Regaining social inclusion

On a societal level active use of e-health support enabled participants to recapture their position in society. All interviewees expressed feelings of loneliness and isolation. These feelings originated from a combination of reasons: friends who had vanished, children living far away and difficulties leaving the spouse alone in the home. Their social exclusion had over the years been reinforced by the closing of public services in the area, such as pharmacy, bank and shops. Especially through the use of internet they regained access to bank, shops, pharmacy and other public services which had been long gone. While participating in the intervention they made new acquaintances among peer caregivers, whom they could actually meet "in their own home" through the use of web camera.

Using the internet also lead to participants strengthening their relationships with the cared for spouse as well as children and grandchildren living far away. Especially grandchildren came to play an important role, as they actively supported their grandmothers and grandfathers in using the new technology. Grandchildren taught the participants several features which were not directly included in the ACTION-service, but available on the internet. This new form of bonding between grandparents and grandchildren lead to a change in character of their relationship, to a deeper and more meaningful level. Before they 'became friends on the internet' relationships with grandchildren had been more sporadic.

Finally, using e-health support contributed to increased feelings of security. On demand accessibility and having the opportunity to face to face contact with other people when needed, both professional and others, was particularly important as participants lived in remote areas where they could not expect instant help from a physically present person. Security was also increased regarding the role as caregiver. A majority of the participants had cared for their spouse for several years and were self-taught. Through exchanging experiences with peers, having access to professionals and by using the information-and education programs, they found themselves to be acknowledged as competent caregivers.

Article II

Comparing benefits of e-health based and conventional caregiver support

The aim of article II was to investigate whether caregiver support provided as an e-health service (intervention group) could benefit older family caregivers in rural areas in comparison with conventional non-e-health based support (control group). Both groups found the caregiver support they received to be beneficial. When comparing how intervention- and control group caregivers rated the benefits of support, caregivers who received e-health based support were more satisfied with the support they received than caregivers who received conventional support. This difference in opinion was evident both in the quantitative result ($p<0.05$) and the findings of the qualitative part.

In the quantitative part of the study, where the Care Effectiveness Scale (CES) scale was used, the intervention group rated the benefits of support significantly higher than the control group in all dimensions measured; care effectiveness ($p<0.007$), preparedness ($p<0.008$), enrichment ($p<0.037$) predictability ($p<0.03$) and overall benefits ($p<0.002$) (Table 4). This indicated that participants in the intervention group to a greater extent than those in control group felt:

- Better prepared to care for their spouses and resolve problems related to care.
- More effective in using enrichment strategies to prevent or reduce strain.
- More in control of their situation and felt reduced stress.

During the interviews, the same topic guide was used for interviewing all participants regardless of group to find out what they thought about the caregiver support they received. After analyzing what the participants really talked about, the underlying meaning, a comprehensive theme was formulated: Flexibility and availability essential for meeting caregivers' needs (Table 5). Analysis revealed there was a clear discrepancy between the two groups regarding what was considered essential regarding the support.

Participants in the intervention group emphasized the value of e-health support as being flexible and available at all times, when a need occurred. They appreciated being able to design the support in accordance with individual needs, choosing suitable information and support activities matching their current needs and accessing it without leaving the home. Through the e-health based support they had developed their caring skills, learning from peer caregivers and health professionals. The subject put forward as being the most important thing regarding the caregiver support by participants in the control group was that they had unmet needs. For more details see Table 5.

Table 4. Group means and adjusted mean differences for the CES as analyzed with linear regression.

Scale/Dimension	Scale consistency		Intervention group mean (n = 35)	Control group mean (n = 21)	Regression analysis	
	Chronbach's alfa	N of items			Group mean difference[a]	p-value
Overall benefits[b]		1	6.54	3.43	2.98	0.002
Care effectiveness[c]	0.987	40	3.12	2.08	0.91	0.007
Preparedness[d]	0.976	22	3.10	2.15	0.91	0.008
Enrichment[e]	0.847	4	2.98	1.95	0.78	0.037
Predictability[f]	0.921	4	3.11	2.04	0.88	0.026

[a] Mean differences are adjusted by controlling for Dementia and Education.
[b] Scale range is from 0 to 10.
[c] Scale values are means of 40 items, each ranging from 1 to 5.
[d] Scale values are means of 22 items, each ranging from 1 to 5.
[e] Scale values are means of 4 items, each ranging from 1 to 5.
[f] Scale values are means of 4 items, each ranging from 1 to 5.

Table 5. Examples of subcategories, categories and theme from content analyses from both groups, and the comprehensive theme formulated after comparison (II).

Comprehensive Theme	FLEXIBILITY AND AVAILABILITY ESSENTIAL FOR MEETING CARERS NEEDS		
Group	*Intervention group*		*Control group*
Category	Flexibility	Availability	Unmet needs
Sub categories	Choosing suitable information	Always someone to ask	Wrong sort of support Limited availability Insufficient support
	Deciding the time of support	Accessible at odd hours	Organisations needs outrank carer's needs
	Matching support activities with current needs	On demand	

Caregiver support in the control group

Control group participants (n=21) received different types of support, depending on what was available in their municipality of residence (Figure 6). There were no uniform range of support services and availability varied between municipalities. The most common types of support were information (n=11) and group meetings (n=10). On average each control group caregiver participated in three different types of support during the first 18 months of the (range 1-6). Together the 21 control caregivers participated in a total of 69 different support activities during the first 18 months of the intervention study.

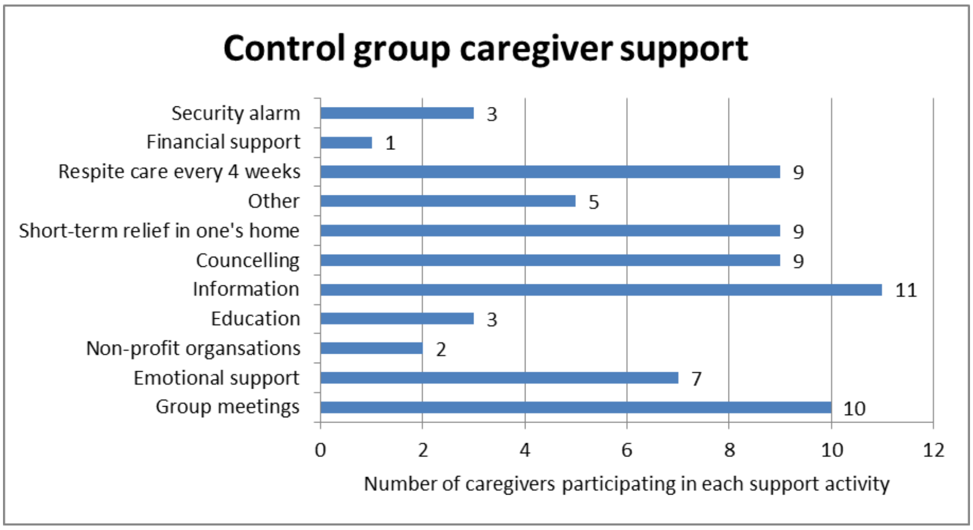

Figure 6. Types of caregiver support received by control group participants (n=21). Several of the activities were continuous and occurred on multiple occasions, e.g. group meetings, counselling and emotional support. Multiple occasion activities are counted for as one.

Article III

E-health support counteracts isolation

The aim of the study (III) was to explore how internet based caregiver support may influence the experience of isolation among older spouse caregivers in rural areas. The findings revealed that participants in the intervention group experienced internet to be a bridge to a life less isolated. Caring responsibilities made it difficult for participants to physically leave the house and they sometimes felt trapped. Through the use of internet they felt they were able to have a social life, both in and out of the home, even though physically remaining within the walls of the home. Two themes were formulated from the analysis; *Expanding the concept of place* and *Developing networks* (Table 6).

Table 6. Overview of the subthemes and themes created from the analysis (III).

Themes	EXPANDING THE CONCEPT OF PLACE	DEVELOPING NETWORKS
Sub-themes	Re-connecting with familiar places	Re-vitalizing of social and supportive connections
	Exploring new places	Re-connecting with the ill person
	New meaning to existing rooms in the home	Developing relationships with technology and objects

Expanding the concept of place constituted of three subthemes; *Reconnecting with familiar places, Exploring new places* and *New meaning to existing rooms in the home.* The subthemes described how participants could virtually leave the ordinary place in the house where they spent most of their time. They also described what they were doing on those virtual excursions. Popular activities were to read on-line newspapers from places where they used to live, thereby re-establishing emotional connections with familiar places and also being able to virtually visit those places. It gave a sense of still belonging. Internet also made it possible to make virtual excursion and explore new places. For example by using websites from places they wished to go, reading stories and looking at movies, pictures, satellite photographs. Place was not only referred to as being outside the home or far away. Existing rooms within the home gained new meaning, and were used both to include the cared for spouse in internet activities and as respite away from caregiving.

Developing new networks was formed by three subthemes; *Revitalizing of social and supportive connections, Reconnecting with the ill person* and *Developing relationships with technology and objects.* New social networks were formed, foremost with peer caregivers within the ACTION-network. Interaction with nurses and family members living far away came to play a different role than before. Using web camera for visual contact gave a feeling of actually being together. For some participants the relationship with the cared for spouse changed in a positive manner and came to a new start with added meaningfulness. Participants also described forming relationships with the computer and other significant objects in the house. It was quite common for participants to refer to the computer as 'he' during the interviews, and giving it status as a subject with human qualities.

Article IV

Utilization and benefits of e-health support

The primary aim of this study (IV) was to explore caregivers' utilization of e-health caregiver support, with specific interest in how frequent they used the various components included in the e-health support, and also to explore associations with perceived benefits. A secondary aim was to explore support nurses' perspective on the intervention.

The most frequently used component of the ACTION-service was general use of internet; 77 % of the participants used internet on a daily basis or several times a week. The second most frequently used component was E-mail, which was used with the same frequency by 69 % of the participants. The component used least frequent was web camera communication with nurses. Half of the participants, 50 %, used this component less than once a month (Figure 7). Among control group participants 41% had a computer at home and used the internet on a daily or weekly basis. None of them used the internet for activities or services related to their role as caregiver or found using the internet to be useful for caregiver purposes. Therefore, no further analyses were made on data from control group participants.

Using the ACTION-service support was considered beneficial by the participants. Information- and education programs had a significant positive association with the ACTION components included in the multiple linear regression model, when controlling for the other variables in the model, i.e. Webcam with peer carers, Webcam with support nurses, and Games. The association was highly significant with dependent variables Personal development ($p<0.002$), Social participation ($p<0.000$) and Emotions ($p<0.013$). When comparing the result of the multiple linear regression with the corresponding results from a binary logistic regression using dichotomized versions of the variables, results were similar. In the binary logistic regression Information- and education programs showed significant association with Personal development ($p<0.025$; OR=10) and Social participation ($p<0.029$; OR=14). The variable Emotions showed the strongest association with the independent variable Information- and education programs, but with a non-significant p-value (p=0,130) and OR=5. Details about the regression analysis are displayed in table 7.

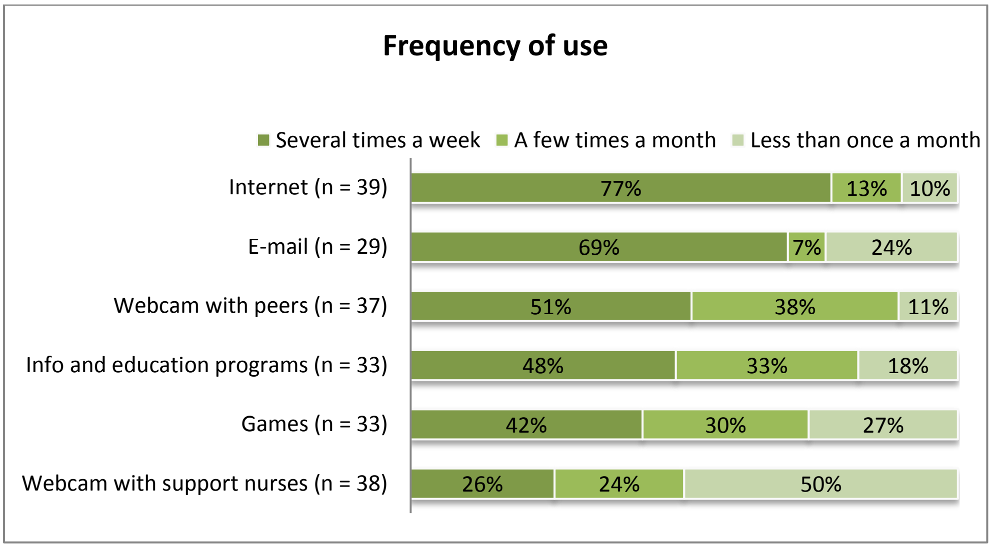

Figure 7. Frequencies of use for the six components included in the ACTION-service.

During interviews support nurses expressed that contact with participants with time had become increasingly sporadic. Three main approaches were found and three categories were created, *Caregivers' dedication*, *Caregivers' resignation* and *Acknowledging a need to develop the professional nursing role* (Table 8). The first two categories illustrate how nurses interpreted reasons for the decrease in contacts from the caregivers' point of view while the third category focuses on nurses' own situation.

Caregivers' dedication was created from the subcategories Commitment and Empowerment. Nurses either found the decline in frequency of contacts to be a sign of empowerment, indicating that caregivers had evolved as e-health users and thereby managed to fulfill a greater part of their needs on their own, or they felt that caregivers had resigned and ceased to use the ACTION-service. *Caregivers' resignation* constituted of the subcategories, Discouragement and Disengagement, and illustrates reasons why some nurses thought caregivers had given up and resigned from using the e-health service. Problems with the technology, insufficiencies and difficulties to get hold of caregivers for web-camera visits were mentioned as examples of obstructions. The final category, *Acknowledging a need to develop the professional nursing role,* concerned how providing caregiver support through e-health imposed new challenges in daily work routines. The category was created from the subcategories Attentiveness and Disappointment. On one hand the nurses were attentive to the demands of their new professional role, while on the other hand they were disappointed about having few contacts with the caregivers.

Table 7. Regressions of Frequencies of use and Benefits.

	Multiple linear regression				Binary logistic regression	
Benefit dimension Frequencies of use	Size of effect[1]	p-value[2]	Number in analysis	Explanatory power[3]	Odds ratio[4] (95 % CI)	p-value[5]
Personal development			n = 27	$R^2 = 0.459$		
Webcam with peer carers	- 0.05	0.799			5.7 (0.3; 122)	0.264
Webcam with support nurses	0.17	0.284			3.0 (0.2; 39)	0.403
Info and education programs	0.55	0.002			10.3 (1.3; 80)	0.025
Games	0.23	0.119			0.5 (0.3; 8)	0.620
Emotions			n = 26	$R^2 = 0.469$		
Webcam with peer carers	0.40	0.082			2.0 (0.1; 42)	0.642
Webcam with support nurses	0.12	0.535			3.5 (0.2; 69)	0.413
Info and education programs	0.57	0.013			5.1 (0.6; 41)	0.130
Games	0.24	0.169			5.1 (0.3; 99)	0.281
Social participation			n = 26	$R^2 = 0.599$		
Webcam with peer carers	0.29	0.089			0.9 (0.1; 15)	0.967
Webcam with support nurses	0.02	0.868			2.5 (0.1; 47)	0.533
Info and education programs	0.79	0.000			14.1 (1.3; 151)	0.029
Games	0.03	0.810			2.9 (0.2; 43)	0.438

[1] Mean change in the *Benefit* dimension variable for one unit increase of frequency of use, controlling for other model variables.

[2] P-value for testing Size of effect ≠ 0.

[3] Proportion of explained variation in *Benefit* variables.

[4] Ratio of odds for *More beneficial* given *Frequent use* and odds for *More beneficial* given *Infrequent use*.

[5] P-value for testing Odds ratio ≠ 1.

Table 8. Examples of codes, sub-categories and categories from content analysis of interviews with support nurses

Category	Care givers´ DEDICATION		Care givers´ RESIGNATION		Acknowledging a need to develop the professional nursing role	
Sub-category	Commitment	Empowerment	Discouragement	Disengagement	Attentiveness	Disappointment
Codes	Encouragement Determination Motivation	Independence Knowledge Self –esteem	Technical problems Insufficiency	Not connected Passivity	Sensitivity Adaptation	Few contacts Passiveness

DISCUSSION

The overall objective of the thesis was to investigate the experiences of older family caregivers in rural areas receiving e-health based caregiver support in their homes. The findings indicate that e-health based caregiver support can be a valuable tool for this target group as it contributes to improving their daily lives in various ways, not only related to the role as caregiver. To fully experience the benefits of e-health caregiver support there are three determining factors to consider. First of all family caregivers must be active and actually use the support (I). Secondly, they must use it on a regular basis (IV). Thirdly, caregivers need support and encouragement from someone they trust during learning to get started (I, IV). These findings are in line with previous research stating that the more frequent support is used, the greater the perceived benefits (Chiu & Eysenbach 2010). The importance of a trusting relationship and encouraging older people when they start using ICT has also been previously concluded (Chiu & Eysenbach 2010, Wälivaara *et al.* 2011). Older people's inclusion in the digital society has a positive impact on independence, autonomy, self-development and being more in charge of one's daily life (Olphert et al. 200, Green & Rossall 2013). These kinds of positive impact were also found in our study (I-IV). The way the caregivers were able to re-possess a position in society was not only a relaxation from caregiving, but also contributed to a feeling of inclusion in society, despite being isolated in the home (I, III). The idea to explore how the e-health support may influence experiences of isolation came during the analysis of data in article I, and lead to knowledge about how caregivers virtually can lead a life outside the home, while physically remaining inside the home (III).

Participants in the control group, who received conventional caregiver support, rated their support as beneficial but when asked to describe what they found to be important about the support received they emphasized having unmet needs (II). Overall they rated their support significantly lower than the intervention group. The major shortcomings of conventional support, as experienced by the participants in the study, were that it was standardized, not set up to meet their individual needs, and lacking in availability (II). These findings are not unique, and other research studies have brought up the issues of family caregivers still having unmet needs, despite receiving conventional caregiver support (Lauriks *et al.* 2007). After conducting a review of ICT-based services for unmet needs in people with dementia and their caregivers, Lauriks et. al (2007) concluded that ICT can be helpful in meeting unmet needs and also acknowledged a need for more flexible and individualized ICT-support.

Similar features to those included in the ACTION-service are freely available on the internet for anyone to use. Hypothetically several of the benefits appreciated by intervention group caregivers (I-IV) may be experienced by anyone using internet. This was one of the reasons for inquiring among control group caregivers to see if they used the internet, and in what way (IV). A third of them had a computer at home and used the internet on a daily basis or several times a week, however none of them used the internet for purposes related to their role as caregivers and did not experience the kind of benefits reported by the intervention group (II, IV). I found this outcome a bit surprising, nonetheless it may be a confirmation that older people, in order to fully benefit from e-health, need encouragement from nurses or another person they have a relationship with (Chiu & Eysenbach 2010, Savolainen *et al.* 2008, Wälivaara *et al*. 2011). When exploring associations between perceived benefits and the different components of the ACTION-service, the information-and education programs stood out as the one component of the e-health service which statistically could explain the perceived benefits of using the e-health service. Interestingly, the information- and education programs were specifically developed for the ACTION-service and not available for anyone on the internet (Magnusson *et al.* 2002, Magnusson 2005, ACTION Caring 2014). With these findings (IV) in mind one possible explanation may be that the ACTION-service contained features in an organized way, packaged as a concept, while on internet similar resources are scattered on different sites by different providers. This finding may indicate that a fourth factor, the 'packaging' of the service, needs to be considered when providing e-health caregiver support, however more research is needed before conclusions can be drawn.

E-health and nursing care

As a consequence of working with e-health, support nurses in this rural study acknowledged a need to develop the professional nursing role. Increased use of e-health leads to changes in the relationship between nurses and their patients or clients, where the relationship is likely to be more equal. (Sävenstedt & Florin 2013). When patients or clients become more independent in their relationship with the nurse, the role of the nurse transforms from being the expert to being more of a mentor supporting the patient (Berg *et al.* 2010). When interactions between nurses and their clients take place on the internet the client can be the one in charge of when and how they prefer to participate (Sävenstedt & Florin 2013).

When the participants learned to use the e-health service on their own they became more independent and frequency of contact with the support nurses decreased. (IV). At the time of follow up, 1.5 years after starting the intervention, web camera communication with support nurses was the least frequently used component of the ACTION-service. While some support nurses interpreted the decreasing frequency of communication as a sign that the participants had ceased to use the e-health support service. Other support nurses felt it was a desired development as the goal had been to empower participants and support their independence, but at the same time they were disappointed about having few contacts with the participating caregivers (IV). These findings are consistent with previous research exploring nurses' reflections on health promotion and empowerment related to older patients, showing that nurses were ambiguous, as increased patient participation made nurses feel as they lost professional control and their day became more unpredictable (Berg *et al.* 2010).

The empowerment felt by the spouse caregivers who used the e-health service enabled them to fulfill needs which had remained unmet previous to using the e-health support and they increased their competence as caregivers (I-IV). When educating and supporting the caregivers, the support nurses had helped the caregivers in their self-care, until they were able to manage independently. According to Orem's self-care deficit theory of nursing the goal of nursing is seen as helping 'the patient' to the highest possible independency in performing his or her self-care (Orem 2001, Kirkevold 2000). Models and theories of nursing generally focus on 'the patient' and are developed from the view of professional nursing with the registered nurse as care provider (Kirkevold 2000). According to Kirkevold (2000) Orems theory has the potential to work as a theory for care carried out by non-professionals, such as family caregivers. However, Orem puts her main interest in the work performed by professional nurse and contributes with few advices on how to put nursing into practice in situations where the main problem consists of suffering, sorrow, meaninglessness or other 'unsolvable' problems common in family caregiving. Family caregivers are mentioned in Orem's nursing theories as holding the role of 'other care providers' and she mentions that nurses shall be sensitive to the needs of family caregivers as well as support them (Orem 2001, Kirkevold 2000). Perhaps it is time for a nursing theory that target family caregivers as care providers, with guidelines on how to care from the perspective of family caregivers.

Salutogenesis

E-health support was used by the caregivers for activities focusing on abilities and improvement of situations of daily life (I-IV) which is in line with the salutogenic approach. Using the e-health support service positively affected several of domains of daily life for caregivers in the study, this is consistent with previous knowledge about using ICT for supporting family caregivers (European Commission 2010a, Schmidt *et al.* 2011). Participants emphasized the development of meaningful relationships, particularly with grandchildren and also with the person cared for (I). The caregivers were creative and used the ACTION-service to improve the situation of the care receiver as well (I). Salutogenesis embraces an interest in people's possibilities despite the stresses they are exposed to and also takes an interest in how people use the resources they actually hold, even when these are limited (Antonovsky 1987). From a salutogenic perspective both caregivers and support nurses focused on embracing the possibilities which became available through the e-health support service. Both nurses, when supporting the caregivers, and caregivers, when managing their own situation, seemed to use the e-health support service for working towards the health-end of Antonovskys (1987) continuum of health. The caregivers' abilities to find strategies for maintaining health despite severe strains indicate that they had, or developed, a strong sense of coherence during the intervention (Antonovsky 1987).

Stages of use

In Sweden internet use among persons aged over 65, living in rural areas, is rather low (Berner *et. al* 2014). From an international perspective Sweden has good internet connections with high accessibility to broadband, also in rural areas (Post and Telecom Authorities 2010). Among participants in this study, lack of experience from using computers was not an obstacle for learning to use and benefit from e-health services. When planning this intervention study we were aware that there would be challenges along the way. In retrospect I find it interesting to view the process of the intervention in the light of Chiu and Eysenbach's (2010) 'Stages-of-use' framework. In an attempt to provide a greater understanding I would like to illustrate how experiences from participants in our study corresponded with the stages in the framework. The following passages give descriptions of challenges encountered and re-use quotations from qualitative data in the articles as examples.

The first challenge was finding participants who were willing to learn to use computer and add a new experience to their daily life, and also make the decision to participate in the study. This represents the first stage, 'the Consideration Stage', in Chiu and Eysenbach's (2010) 'Stages-of-use' framework. As there were no lists of persons who fit the 'description' of older family caregiver, the recruiting process was dependent on caregivers themselves taking the first step and making contact with the support nurse or support center. The rural municipalities in the study have rather small populations and various limitations on resources regarding caregiver support services. In some municipalities caregiver support service was available one or two days a week, because the support nurse also had functions in other areas of nursing within the municipality, where he or she worked the rest of the week.

The next challenge was to get participants started, to motivate them to spend time on learning by doing and continue throughout the project. When the caregivers made their first login and started using the service they entered the 'Initiation Stage', during which there are many factors influencing whether caregivers will continue to use the e-health service or not (Chiu & Eysenbach 2010). Support nurses were considered as key actors in the process. At this step in the process providing continuous support, is essential (Chiu & Eysenbach 2010, Magnusson *et a.l* 2005, Savolainen *et al.* 2008) (IV).

Support nurses were actively encouraging participants to use the service (IV). Their role would be somewhat double, besides providing caregiver support, they would also provide technical- support and education on how to learn the technology and services involved (I, IV). The trusting relationship between support nurses and caregivers may have been essential at this stage. Having a trusting relationship is an important factor for successful outcome when supporting old persons using distance-spanning technology (Wälivaara *et al.* 2011). Support nurses in our study suspected that not being able to put enough time into guiding caregivers in learning to use the support may lead to caregivers resigning from using the e-health support (IV). Having too many work demands has been identified as being the number one barrier for nurses to use computers in their work (Eley *et al.* 2009).

> Nurse (IV): "I think it was important for them that I took a lot of contact in the beginning, helping them to get started, and tried to make sure they made a habit out of using the computer regularly. It is so easy to forget about something that's not in your everyday routines".
>
> Woman, 77 years (I), who had expected to get more out of the the ACTION-service: "The support nurse is supposed to come here and show me more, but it keeps being postponed and I have a hard time getting to it on my own."

As caregivers begin to actively use the e-health service and engage in the intervention they enter the 'Utilization Stage', which is the third stage of the framework. Experiencing positive changes provides motivation for continuing use (Chiu & Eysenbach 2010).

> Woman, 78 years (I): “If I didn’t have the computer I would never have been able to learn all this, living out here everything is too far away”.

> Man, 75 years (III): “One becomes very isolated in this situation. You loose contact with everything around you. Here in the computer I have a list of persons who know what it is like, and they want to talk to me. I don’t feel so lonely anymore”.

Most of the participants who remained in the study were, at the time of follow up 1.5 years after starting the intervention, at the utilization stage, or the final stage, ‘the Outcome Stage’, where they saw using the e-health service as a natural part of everyday life (I-IV). Like among older people in general (Larsson *et al.* 2009), a majority of the participants in the study had no previous experience from using computers. In spite of this they managed to learn and adopt the technology. This development is in consistency with conclusions from other research showing that when older people start experiencing benefits from using ICT, initial resistance is put aside (Magnusson *et al.* 2004, Savolainen *et al.* 2008). However it is important to keep in mind that initial frequent contacts and a trusting relationship with the nurse seem to be essential requirements to reach this stage (IV).

> Man, 81 years (I): “I don’t have to worry anymore about doing the wrong things. Not only do I feel competent, I know I am”.

> Woman, 76 (I): “I turn the computer on first thing in the morning. Then I can see who is ‘’home’’ or online as they call it. It’s such a great company. When the little symbol is lit and I know they (my grandchildren) are there, I don’t feel alone”.

> Man, 78 years (I): “I can now go to the bank, the chemist’s, and different shops for clothes and this and that, on the Internet. I never had such a selection before. For many years one place after the other has closed down. Now I can access all of this, from my home, when I have the time, without needing to arrange for a sitter for my spouse”.

> Nurse (IV): “They contact us if they run into trouble, otherwise they manage on their own now”.

Reflections from a rural perspective

From the findings of this study it can be concluded that e-health services are suitable for providing caregiver support in rural areas. E-health support enables caregivers to access the support they need, when they need it, without having to leave their home (I-IV). Provision of health services in rural areas faces challenges with a growing proportion of older people in the population, depopulation, where younger people move away as well as difficulties in recruiting staff to work in rural healthcare (Goll 2010, Keating 2008). This in turn leads to closing down of public services (Keating 2008). With the use of e-health support services caregivers in rural areas can access a wide variety of services through the internet, services that are no longer physically present in their community (I, III). Caregivers and nurses in the study (I, IV) agreed that using the ACTION-service empowered the caregivers, enabling them to tend to their own needs and managing their situations more independently, while needing less contact with the support nurses. This development ought to be desirable by rural municipalities. If caregivers are able to manage independently and maintain their needs for support through an e-health service, they can get appropriate caregiver support despite lack of support nurses physically present in their community, which may delay the need for professional nursing care, or a transfer of care recipients to nursing facilities. One of the three main objectives in the health strategy of the European Union is supporting new technologies as they can contribute to the efficiency and sustainability of health systems as well as improving access to safe, high quality healthcare. The health strategy specifically highlights how e-health can help provide medical services in rural areas, especially where there is a shortage of health workers (European Commission 2007).

Methodological considerations

A major strength of this study was the long term follow up, 1.5 years after start of intervention. We have not found any other study with such long perspective. Including a long term following up gave us the possibility to interpret the intervention as sustainable. In the latest revision of recommendations for caregiver support in Sweden, long term interventions are promoted as most useful (National Board of Health and Welfare 2012). During the recruitment phase of the study there was a somewhat skeptical attitude regarding if there would be enough individuals fitting the inclusion criteria who would want to try e-health based caregiver support. The previously mentioned negative attitudes present in society towards e-health -services for older people (Hanson & Magnusson 2011) seemed to be present both among the older people themselves, but also among nurses providing support services.

This study had a pragmatic comparative design, where we had the opportunity to follow one group of people receiving the intervention (the ACTION-service) and compare these with a group receiving conventional forms of caregiver support.

Due to this real world perspective where each municipality's unique possibilities needed to be accounted for, a randomized design was not an option. Pursuing comparative studies without randomization can be seen as a weakness of the study, but we still deem the results to be valid thanks to several steps made to compensate for this 'weakness'. Firstly; the long term follow-up and secondly the method triangulation with the mixed method design where findings from the quantitative data are supported also by the findings of qualitative interview data from both family caregivers as well as support nurses.

Organizing the intervention

In the original proposal for the study, the caregiver support center in one of the municipalities volunteered to act as call center for the entire group of users in the intervention group, regardless of which municipality the caregiver resided in. This offer was turned down by the directors of the other municipalities, as they deemed it unsuitable for their frail and vulnerable older citizens, to ask for advice from someone outside their own municipality. Thus the directors made the decision to have ACTION call centers in each of the participating municipalities. Findings showed that the participants did not agree with the directors on this matter. From the participants' point of view one of the most important factors was availability and to get hold of support nurses when needed. In fact, some participants preferred to contact the national ACTION center rather than their local support center, because it had higher availability (I). For some municipalities support nurses described that ACTION became somewhat of a burden on their resources. A possible explanation for this may be the fact that a number of municipalities choose to set up their own call centers instead of collaborating and sharing call center within the region. As nurses at call centers needed education about the ACTION-service and how to run it, this lead to more nurses needing education. One municipality choose to limit their number of participants in the intervention group to two caregivers and organized their call center in a way that two nurses shared the responsibility for their call center. In this case two staff members needed education about the ACTION-service to serve their two users.

Comparison of e-health support and conventional support

As the findings give the impression that e-health based support was perceived as better than conventional support it is essential to emphasize that there was no intention in the aim of the research to study if e-health based support were better than conventional support. The idea was to investigate if it could be as good as conventional forms of support, thereby possibly being suitable as an alternative or a complement to conventional support.

While preparing for, and setting up the organization for providing the ACTION-service in the rural areas engaged in this study, the common way of talking about provision of caregiver support among us who were part of the process (researchers, nurses, directors, caregivers) was to refer to caregivers as recipients of caregiver support and municipalities, nurses and support centers as providers of caregiver support. This way of talking may be an expression for an underlying view of the caregiver as a passive (receiving) whereas support centers are assumed to be active (i.e. providing, giving). Drawing on the findings of this thesis (I-IV) it is likely that caregiver support would benefit in a positive way if caregivers would be viewed upon as active partners rather than receiving support. Working in partnership with older people and their caregivers can help empower them in their caring situation at home (Hanson *et al.* 2011).

Web camera interviews

The strategy for web camera interviews served its purpose well and helped to improve quality of the interviews. The strategy was found to be helpful both when planning and setting up the interviews as well as during the interviews. During the initiating telephone call to the participant, when setting time for the actual web camera interview, participants were slightly unsure about how 'to behave' during the interview, I could use the guidelines in the strategy to advice about things to consider for a comfortable environment such as lighting, pattern of clothes and background. Furthermore, the guidelines were also useful for coaching participants regarding their visual environment at beginning of interviews, thereby contributing to create a more relaxed and comfortable interview situation. In my opinion, and also expressed by the participants, the visual contact enabled through web camera enhanced the interview situation in comparison with telephone interviews. A conclusion I can draw after having conducted several web camera interviews is that it is a method well suited for conducting interviews with older people about sensitive and personal topics.

Rural context influencing the research procedure

The intervention started as a joint project among 15 municipalities in Northern Sweden, mainly because there are not enough people in one, or even a few municipalities to conduct this form of project. The geographic area served by each support center was large and sparsely populated. Some days the support nurse only visited with 1 or 2 clients, due to time consuming long travels. Initially each municipality decided how many ACTION-computers they wanted to distribute to family caregivers in their municipality. In the practical reality for the participating rural nurses, where some of them work with caregiver support one or two days a week, it took about a year and a half to include all participants (determined by the decided number of computers at hand). In order to enhance study quality and feasibility, and out of respect for the caregivers, data collecting procedures were scheduled for each participant individually. Collection of data occurred for each individual after 18 months of using the ACTION-service, not to be mixed up with time of inclusion in the study or time for receiving the equipment. In some cases the participant had the computer for some months, in their home, before it was possible for the nurse to finish the education for the participant, so they could start using the service on their own. This scenario, typical for sparsely populated, large geographic areas, constitutes one of the many challenges for providing caregiver support as well as health care in rural areas. It is also one of the reasons why it is urgent to investigate and apply different solutions involving ICT and e-health services to enable equal support for older family caregivers living in rural areas (European Commission 2007).

CONCLUSIONS

The overall findings of this thesis shows that e-health based caregiver support provides a way for older family caregivers in rural areas to access and benefit from caregiver support adapted to their individual needs.

- The findings indicate that the most essential factors for caregiver support to be beneficial are that caregiver support is:

  Individual - in tune with caregivers' individual needs (what is the present need)
  Flexible - changes in accordance with caregivers' needs should be smooth (how it needs to change)
  Available - accessible at a time suitable for the caregiver (when needed)

  These factors were brought forward by the intervention group when explaining the experienced satisfaction with e-health support and by the control group when expressing dissatisfactions with conventional support.

- E-health based caregiver support can be considered a valid alternative for providing caregiver support for older family caregivers in rural areas. It may also be suitable as complement to conventional support.

- E-health based caregiver support is likely to give as satisfactory support as conventional support, for many caregivers it actually gives greater satisfaction and is more useful as they can adjust the content and time of provision to their own individual needs.

- E-health support contributes to ease feelings of loneliness and isolation and enables for older family caregivers in rural areas to maintain contact and relationships with relatives living far away.

- When receiving motivation and encouragement, older family caregivers with no or very little experience of using computers can learn to master new technology and become competent users of e-health based caregiver support and services.

- In order to experience benefits from e-health, it is essential for nurses to support and encourage the older caregivers through the different stages of use.

Implications for nursing practice

This thesis contributes with knowledge about essential factors on how to structure e-health caregiver support, which can be used in clinical settings.

1. When introducing e-health to older family caregivers it is essential to initially invest time to guide and encourage the older caregivers in using the e-health service. In the long run, well invested time will most likely lead to independent caregivers who need less of nurses' time, which is suitable in the predicted rural scenario with shortage of health care staff and large number of older people with care needs.

2. Be aware that e-health changes the professional role of nurses towards a more equal relationship with the older family caregivers. Preparing for the change may prevent disappointment and also help nurses appreciate that few contacts with caregivers can be a sign of a successful nursing.

3. For most components of the ACTION-service there are similar features freely available on internet. Nurses ought to learn to be aware of the broad range of services available to the public. These services may be used for the purpose of advising and educating older family caregivers, making them aware of and benefit from these resources.

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