Information and Communication Technology-mediated support for working carers of older people

Stefan Andersson
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INFORMATION AND COMMUNICATION TECHNOLOGY-MEDIATED SUPPORT FOR WORKING CARERS OF OLDER PEOPLE

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Despite a growing awareness of the importance of support for carers who combine paid work with care of an older relative, so-called 'working carers', there remains a lack of empirical knowledge about more innovative ways to support this largest group of carers of older people. Information and Communication Technologies (ICTs) are becoming more readily available. As a result, ICTs have made it feasible to offer working carers more targeted forms of support. This thesis aimed to gain an understanding about support for working carers of older people via the use of ICT.

An integrative literature review was conducted to explore and evaluate the current evidence base concerning the use of ICT-mediated support for working carers (I). Content analysis of qualitative data was used to describe nursing and support staff's experiences of using web-based ICTs for information, e-learning and support of working carers (II). Content analysis was also used to describe working carers' experiences of having access to a web-based family care support network provided by the municipality (III). Descriptive statistical methods were used to analyse survey data which focused on the types of support received and how they were valued by working carers, with a focus on ICT support (IV).

Findings highlighted that ICT mediated support provided working carers with the means to manage their caring situation, via the provision of information, e-learning and education, in addition to practical assistance and emotional and/or physical respite from caregiving. In this way, working carers felt empowered in their caring situation by feeling more competent and prepared in their caring role and by strengthening their self-efficacy and positive self-appraisal of their situation. Carers were provided channels to share their frustrations and burdens via forums for emotional and social support between working carers, caring professionals, and other peer carers. This led to working carers feeling less burdened by their caregiving role and it helped promote their well-being. Further, carers were helped in some instances to balance work and care. As a result caregiving activities conflicting with work obligations were then lessened.

In contrast, when ICT mediated support was neither provided in a timely fashion or in accordance with individual carers' needs and preferences, then it was perceived by them to be unimportant. Cross-sectional data revealed that take-up of support services was low suggesting that unmet support needs may be inflated by work-care conflicts. For carers with lower digital skills, the additional time needed to learn to use ICTs was a further barrier.

Overall, ICT mediated support acted as a complementary form of support for working carers. Measures to overcome dis-empowering aspects of this innovative form of support are needed to avoid working carers' deprioritizing their own support needs and also to avoid possible digital exclusion from the current information society.
Abstract


Despite a growing awareness of the importance of support for carers who combine paid work with care of an older relative, so called ‘working carers’, there remains a lack of empirical knowledge about more innovative ways to support this largest group of carers of older people. Information and Communication Technologies (ICTs) are becoming more readily available. As a result, ICTs have made it feasible to offer working carers more targeted forms of support. This thesis aimed to gain an understanding about support for working carers of older people via the use of ICT.

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Keywords: Working carers, family carer support, information- and communication technology
To my family
To my family
**Abbreviations and terminology**

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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AGP</td>
<td>A good Place - a Swedish web-based family care support network</td>
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<tr>
<td>EU</td>
<td>European Union</td>
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<tr>
<td>GPS</td>
<td>Global Positioning System</td>
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<tr>
<td>ICT</td>
<td>Information and Communication Technology - provides access to information through telecommunications</td>
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<tr>
<td>Internet</td>
<td>A global wide area network that connects computer systems across the world</td>
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<td>NKA</td>
<td>Swedish Family Care Competence Centre</td>
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<tr>
<td>Online</td>
<td>Being connected to the Internet</td>
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<tr>
<td>SWEAH</td>
<td>The Swedish National Graduate School for Competitive Science on Ageing and Health</td>
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<tr>
<td>Web</td>
<td>World Wide Web - consisting of webpages that can be accessed using a web browser such as via a computer, smartphone and IPad</td>
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<tr>
<td>Web-based</td>
<td>ICT-mediated support that uses the web and Internet to provide carers online support such as information and education</td>
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Introduction

Approaching this research, I've previously worked as a gerontological, community-based nurse. In my clinical work, it was frequently brought to my attention that family members often took on different levels of caring responsibility for aged relatives and were in effect family carers. Due to the lack of overall integration between social and healthcare services, together with the municipalities' limited resources and the needs of increasing numbers of older people with advanced chronic conditions, family carers' involvement is evident, sometimes relied upon and often taken for granted. However, family carers particularly those carers who are caring for an extended period also require support themselves in order to practically be able to continue caring and to cope with emotional and physical challenges. In addition, while many family carers provide care for an older relative or significant other, they are also managing work and family responsibilities, thus being so-called, working carers (cf. Phillips, 2005; Kröger & Yeandle, 2014).

During my clinical work, I had not really considered the implication of carers combining family caregiving and paid work. During the course of applying for and becoming a doctoral student, within the frame of projects conducted by the Swedish Family Care Competence Centre and as a graduate student in the National Graduate School on Ageing and Health–SWEAH, I developed a growing awareness of the fact that the implications for carers themselves may be adverse and that support needs are not always being met. The question of how best to support family carers is increasingly being brought to the attention of policy makers, researchers and practitioners, both nationally and at European Union (EU) level (EFILWS, 2015). Special attention is given to working carers' situation, as it is acknowledged that working carers may prioritise being able to (or in fact are required to) combine both caregiving and paid work (EFILWS, 2015). While some aspects of such carer support may be policy related (e.g. paid leave, level of formal care in society), awareness has also been raised by the National Board of Health and Welfare Sweden (NBHWS, 2013a), suggesting that support for working carers requires joint efforts by healthcare and social service providers (i.e. formal support).
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care). However, there is currently a dearth of studies focusing on innovative forms of support to make this balance easier. As a result, family care support that can help to enable or facilitate such a combination for working carers who want to care for an older family member is the focus of this thesis.

The thesis focuses on different areas of support. First and foremost, in more recent years, various Information and Communication Technologies (ICTs) have been/are being developed and introduced as a potential way to deliver/offer support in order to respond family carers’ needs (Carretero, Stewart & Centeno, 2015). In fact, in a recent European summit on digital innovation for active and healthy ageing (2016), ICTs are identified as part of important digital innovations for health and social care providers looking for innovations to deliver care and treatment effectively at an affordable cost. Digital innovation is viewed as an important means to meet some of the challenges of demographic change and older people’s unmet needs and preferences. However, research on how these technologies specifically benefit working carers in the best way is seemingly sparse; thus, this thesis attempts to contribute by filling this gap in knowledge.
Background

Elder care in Sweden, longevity trends and role of family carers

The level of family caregiving of older people in society partly stems from the way in which care for older people is structured within the welfare state. Simply put, who is doing what and to what extent to meet older people’ needs that often arise from frailty, illness and/or disability, in order for them to manage their own everyday life. In Sweden, a Nordic welfare model has historically been and still remains the ‘modus operandi’; the official macro picture depicts formal services, opposed to families, which have a primary role in providing care for older people (Sundström, Malmberg & Johansson, 2006). This primary role stems from the principle of individuals becoming less dependent on their families to provide care, and families being less obligated to provide care i.e. de-familisation (Sundström et al., 2006; Gough et al., 2011). Nevertheless, on a micro level there is an overlap of roles, as many older people in Sweden either rely solely on their families (suggesting familisation), only on the state/municipality or a combination of both (Sundström et al., 2006; Szebehely & Trydegård, 2012). Overall, relatively few older people also rely on for-profit agencies and voluntary organisations (Jegermalm & Sundström, 2014).

In retrospect, looking back over the last few decades, community care policies and an emphasis on ‘ageing in place’, together with economic cutbacks have led to a reduction in the number of nursing home beds available (NBHWS, 2012). Increasingly, public home help services are targeted towards the most seriously ill older people living alone at home. As a consequence, these trends have also placed greater demands on family, even if there are no legislative demands for family members to provide care (e.g. unless you are married) (NBHWS, 2009). In other words, this trend has arguably contributed to a re-familisation i.e. going from de-familisation to a higher degree of familisation (Gough et al., 2011; Jolanki, Szebehely & Kauppinen, 2014). Thus, it can be argued that the government (state and municipality) expects...
individuals and families to take more responsibility for a higher portion of care for older people, which previously was collectively guaranteed (Walker, 2009).

Currently, the vast majority of care and support for older dependent people is informally provided by family carers alone or in co-operation with formal care providers (NBHWS, 2012; Jegermalm & Sundström, 2014). It is estimated that approximately 20 per cent (1.3 million) of the Swedish adult population provide help, care and support in varying degrees on a regular basis for a family member (parenthood for children not included) (NBHWS, 2012). The majority of family carers (71 per cent, 900,000) provide help, care and support for a family member, i.e. spouse, parent, relative or a friend, over 65-years-old. Almost half (48 per cent, 600,000) provide help, care and support for a family member over 80-years-old (NBHWS, 2014). Most family carers of older people are likely to combine caregiving and employment (NBHWS, 2012). It is estimated that 40 per cent of middle aged women and men between 45–66-years-old in Sweden are working carers i.e. combining working life with family care of a family member (of whom approx. 80 per cent are older people) (Szebehely, Ulmanen & Sand, 2014). Two-thirds provide care for an aged parent (NBHWS, 2012).

Longevity among Swedes is predicted to rise in the following decades. As living conditions and general health improve, people are being able to enjoy greater independence and to live longer. Between 2016 and 2060, the number of Swedes over the age of 65 years is expected to increase from 2 million (20 per cent) to 3.2 million (25 per cent) (Statistics Sweden, 2017). However, increased longevity also corresponds with an increased risk of frailty and developing age related chronic illnesses such as dementia and stroke. The demographic change, both in Sweden and in other EU Member States, is therefore also predicted to increase welfare costs, while the percentage of tax generating workers in the workforce is expected to decline (SPC & EC, 2014). Consequently, this demographic trend is therefore also expected to pose significant challenges for welfare systems to prioritise financial resources in health and social care services for older people. Working carers’ role in care provision for older people is likely to remain or increase (EFILWS, 2015; SPC & EC, 2014).

Family caregiving

Family caregiving often refers to the performance of supportive tasks for older people that they cannot do for themselves and what is normally viewed as beyond normal reciprocities between adults (Twigg & Atkin, 1994). Family caregiving comprising practical hands-on elements (i.e. what is visually being done) as well as less practical and more subtle elements that may all contribute
to the overall situation (Nolan, Grant & Keady, 1996). Practical hands-on elements can be described as involving instrumental, emotional, intellectual and economical aspects of care. Instrumental care includes practical care such as cleaning, cooking, doing the grocery shopping, gardening and transportation. It can also involve personal care such as help with dressing, hygiene and going to the bathroom (NBHWS, 2012). Emotional care can include listening, conversing, looking after, reassuring and reminding (NBHWS, 2012). Less visible aspects of practical care also involve intellectual care such as managerial care, i.e. informal orchestration of both formal services and informal assistance from other family members (Rosenthal et al., 2007) as well as financial help (NBHWS, 2012).

Less practical and more subtle aspects of caregiving include: anticipatory, preventive, supervisory, protective, preservative, reconstructive and reciprocal care (Nolan et al., 1996). During the course of caregiving, carers are known to anticipate their own and the cared-for person’s future needs, before and throughout the caring process (anticipatory care); moreover, they try to prevent potential emergency situations or crises from a distance, by monitoring to make sure that everything is okay with the cared for person (preventive care). Carers also supervise via subtle practical assistance to make sure everything is okay (supervisory care) and protect and maintain the cared-for person’s sense of ‘self’ (protective care). Additionally, it may involve preserving the cared-for person’s skills, abilities, interests, dignity, hope and sense of control (preservative care); reconstructing identity built on past histories and biographies (reconstructive care); and maintaining reciprocity, a sense of balance, interdependence and mutuality in the relationship (reciprocal care) (Ibid).

Family caregiving may also involve a complexity of aspects, including the process of becoming and being a caregiver (Nolan et al., 1996). For many family carers, caregiving is a satisfactory natural part of life based on family values and tradition (Lyonette & Yardley, 2003). At the heart of caregiving are relationships, and these are central to our understanding of family carers (Phillips & Martin-Matthews, 2008). It is well recognised that family caregiving can be founded on altruism and love. However, it might also occur as a result of external pressure arising from feelings of guilt, duty, responsibility and/or perceived lack of choice, which in turn may lead to increased levels of stress and negative consequences on well-being (Lyonette & Yardley, 2003). Ultimately, it may also result in negative consequences in terms of elder neglect and possibly also elder abuse (Érlingsson, Magnusson & Hanson, 2012).

In this thesis, family caregiving is conceptually viewed as being influenced by temporal processes, as described in the temporal model by Nolan and colleagues. Caring for an older family member often lasts for multiple years, and carers gradually undergo several temporal dimensions under which they 1) take on the role of a family carer, 2) ‘work through it’, providing care for
the older person and 3) ‘reaching the end and a new beginning’, eventually giving up the instrumental aspects of caregiving due to the older family member entering a nursing home or due to the death of the older family member and the adjustment process for the carer as s/he enters a new life situation (Nolan et. al., 1996; Nolan, Ingram & Watson, 2002; Nolan, Lundh, Grant & Keady, 2003). This is by no means a clear-cut linear process, as carers undergo phases of continuous negotiations defining the needs and preferences of themselves and those of their family member. Even when family carers seemingly have passed instrumental caregiving responsibility over to others, for instance when a parent or a spouse has moved to a nursing home, they are re-negotiating a new caregiving role. In this sense, family carers experience several multidimensional aspects of caring during their caregiving careers, which varies over time and from one individual family carer to another (Nolan et al., 1996).

**Working carers combining work and caregiving**

Becoming or being a working carer often means juggling, balancing or reconciling paid work and caregiving (Phillips, 2005; Kröger & Yeandle, 2014). To be able to combine work and care is what many working carers prefer to do (Eurofamcare, 2006; Eldh & Carlsson, 2011; EFILWS, 2015). For some, work is a sanctuary providing a break from a demanding caregiving situation (NBHWS, 2014). For others, it is rather a question of doing both in order to manage their financial situation. The implications of combining working life with care for a family member may have a negative impact on one’s career, personal economy and social life (NBHWS, 2014).

Carers attempting to combine work and care have three work related options: 1) to temporarily withdraw from work, 2) reduce working hours and 3) try to reconcile full time work and care (Sand, 2016). Seen in a life-course perspective, the drawback of the first and second options is loss of life income and loss of accumulated pension rights, which in the case of lengthy caring careers may be substantial (Ibid.) However, employment and caregiving are not necessarily conflicting responsibilities per se. In a Dutch study, parent-support had no impact on work hours, and work hours had no impact on parent-support per se. In other words, working did not reduce caregiving hours (van Putten et al., 2010). Nevertheless, in a survey conducted by the National Board of Health and Welfare Sweden, 10% of Swedish carers had reduced their working hours and five per cent had quit work completely as direct result of caring for their family member (NBHWS, 2012). In a Swedish study, working daughters and sons caring for a parent were equally likely to reduce their working hours or to quit their job. However, women experienced more mental and physical strain, had more difficulties finding time for leisure
activities, and felt that they were less able to focus fully on their work (Ulmanken, 2015).

Family carers’ engagement and role in caregiving is sometimes described in quantitative terms such as weekly hours or days per week. These terms may indicate the prevalence and intensity of care (see above), which can also have a direct influence on caregivers’ health and well-being. Family carers that provide extensive amount of care are reported to have lesser well-being and poorer health status (NBHWS, 2012, Erlingsson et al., 2012). However, quantitative measures of time spent caring may not be able to fully account for the breadth and depth of working carers’ caregiving situations and thus their individual preferences for support. For working carers, duration of caregiving in hours and days is most often in combination and sometimes in competition with other obligations such as work and family life.

Working carers in Sweden often care from a proximal distance due to their work situation and as a result of living separately from the older person (NBHWS, 2014). Being at proximal distance has been shown to create logistical challenges for working carers to perform hands-on care. Working carers are described as being particularly stressed by managerial care i.e. informal orchestration of both formal services and informal assistance from other family members (Rosenthal et al., 2007; Ulmanen, 2015). In a Swedish study, working carers are acknowledged as sometimes feeling forced to coordinate care for their older family members when formal managing and coordination of health and social care services is lacking (Werkelin Ahlin & Ölmübäck, 2014). This situation subsequently has a negative influence on working carers’ situation and contributes to stress, especially among women (Rosenthal et al., 2007). Other, more subtle, dimensions of care such as anticipation of care is acknowledged as particularly stressful when combining ongoing caregiving and working life, as it involves not knowing what is going on, and constantly worrying about the welfare of the cared-for person (Nolan et al., 1996; Beitman et al., 2004; Eldh & Carlsson, 2011).

While time and logistics can be an issue, it is also acknowledged that family carers may experience various stress (-ors) due to caregiving itself (i.e. primary stressors). These can be related to challenges in the situation, such as feeling unsupported, lacking knowledge and having to deal with challenging behaviours of the cared for person. In addition to these primary stressors, working carers may also experience additional challenges due to competing obligations at work (i.e. secondary stressors) that may adversely influence their stress levels and cause role strain (cf. Aneshensel, Pearlin, Mullan, Zarit & Whittlatch, 1995). Increased stress levels and strain in one’s roles are acknowledged to potentially have a negative impact on caregiving and working life (Gordon, Pruchno, Wilson-Genderson, Murphy & Rose, 2012).

It is suggested that once the caregiver role is taken on board then time spent on parents’ care and potential strain on one’s role is determined by personal beliefs and inner motives to provide care (such as reciprocity, family
tradition, guilt and obligation) rather than employment status or work hours (Dautzenberg et al., 2000). In a study by Erlingsson et al. (2012), such emotions were also found to be important on how carers perceived their caregiving situation and to what extent carers felt isolated in their situation, as opposed to experiencing mutuality, shared responsibility, control and ability. This continuum of perceptions had an impact on carers’ burden and low levels of well-being, which when negatively spiralled towards isolation had profound impact on carers’ perceived health status.

The ability to combine caregiving and work is regarded as important as it relates to working carers’ well-being and health (Bauer & Sousa-Poza, 2015). Although the majority of working carers may experience a sense of satisfaction in caring for an older family member (cf., Nolan et al., 2003), difficulties experienced in combining work and caregiving may potentially increase the risk for stress, burden and strain on working carers’ mental and physical health (Eldh & Carlsson, 2011; Bauer & Sousa-Poza, 2015;). If not supported working carers risk being exhausted (Eldh & Carlsson, 2011). Thus, the ability for working carers to continue working in parallel to caregiving (when choosing to) without reduced well-being and health may arguably be a fundamental aspect in working carers’ (successful) ageing (e.g. to avoid adverse health effects, loss of life income, early retirement) (EFILWS, 2015). It is acknowledged that working carers must be able to balance time for caregiving and for paid work (Eldh & Carlsson, 2011), reconcile caregiving and working roles, cope with the strain of multiple roles and achieve positive levels of preparedness in caregiving (cf. Wang, Shyu, Chen & Yang, 2011; Wang, Shyu, Tsai, Yang & Yao, 2013).

**Family carer support**

Support refers to key elements such as support being sufficiently individualised to meet the unique needs of the carer, matching what the carer is currently experiencing over changing temporal dimensions, and her/his prior knowledge and experiences of family caring (if any) (Nolan et al., 1996; Johansson, 2007). Carers in general are acknowledged to have a range of interconnected needs, which may require a variety of support (Twigg & Atkin, 1994). Support may involve being able to share with someone what is on one’s mind (Stoltz, Andersson & Willman, 2007) for social and emotional support, and counselling in order to cope with caregiving. Such support may involve individual meetings or caregiver support groups between working carers and care professionals, and other peer carers. Support may also involve being helped to increase ones capacity to care (Stoltz et al., 2007). Such support in caregiving may include information (e.g. about disease and available support), education and training (e.g. in care provision and self-
care), practical assistance (e.g. hands-on from people or ICTs) and various forms of respite (Lamura et al., 2008). With special attention paid to the work-life balance of caregiving and for paid work, the third area involves support for involving balancing dimensions of time, space and place (Phillips & Martin-Matthews, 2008; Eldh & Carlsson, 2011; EFILWS, 2015; Sand, 2016). Such support may involve being able to deal with logistical challenges of being tied up at work, that is, not being in close physical proximity (caregiving from a distance), or not being able to participate in face-to-face support meetings during office hours.

Support outcomes

Processes of support provision and carer outcomes in the thesis are consistent with aspects of empowerment. In its broadest form, empowerment refers to a dynamic process whereby individuals and groups, such as working carers, gain or increase choice and control over key aspects of their lives in order to maximise their quality of life (Zimmerman, 2000; Larkin & Milne, 2013). Empowerment entails both self-perceived capabilities in coping with various challenges (e.g. in caregiving) and the self-perceived ability to overcome obstacles (Barak, Boniel-Nissim & Suler, 2008). Its construct refers both to a value orientation and to the understanding of processes and consequences of efforts to exert control and influence over decisions that affect on psychological, organisational and community levels (Zimmerman, 2000).

From the view of support provision, empowerment in the thesis refers to empowering processes acknowledging partnership and temporal aspects of caregiving (Nolan et al., 1996; 2002; 2003). Such a value orientation may involve the critical aspect of empowering carers with choice and control on whether to take on a caring role or not and when to hand it over, or what aspects of caring to hand over, rather than health and social care and wider society simply assuming or taking for granted that working carers want to do so (cf. Nolan et al., 1996). Such choice may re-sculpture power relations between carers and welfare services (Larkin & Milne, 2013). It has been stressed that it is important that care professionals providing carer support recognise and respect the working carer as a co-expert regarding her/his caring situation. This means acknowledging the often detailed ‘first-hand’ knowledge that experienced family carers have of their older relative (Brown et al., 2001). Professionals need to work in partnership with carers to make the caregiving situation easier and ultimately make life better for both the frail older person and their family carer/s. This requires individually adjusted information, learning and advice over time, and support that focuses on instrumental, emotional and relational aspects of caregiving and that matches the phase of caregiving the individual carer is currently experiencing (Nolan et al., 2003). Support also involves a trusting, reciprocal relationship in which both parties share their knowledge and experiences with each other and learn from each
other in order to ensure as good a situation as possible for the older person and carer at home (Hanson et al., 2008).

On a psychological level, empowerment comprises aspects of competence and control (Zimmerman, 2000). Competence and control are conceptualised in carer outcomes such as achieving self-perception of caregiving mastery, caregiving self-efficacy, caregiving competence and caregiving preparedness, which are all conceptualised as doing caregiving well (Schumacher, Stewart & Archbold, 1998). Empowerment at this level is not to be viewed as an isolated scarce resource, which gets ‘used-up’ but rather expands resources longitudinally (Rapaport, 1987).

A predominant focus in family carer research over the years has also been on coping with and reducing stress and burden (Eurocarers, 2015). Indeed, reducing stress and burden receives attention in this thesis, as it is undoubtedly a major issue for working carers. However, it is also increasingly being recognised that it is the satisfactory elements of caring that help to sustain and empower those carers who wish to care, in their caring role (Nolan et al., 1996). Several satisfactory aspects of care are suggested e.g. being able to maintain reciprocal closeness, sustaining the autonomy of the cared-for person and maintaining a link with family history and traditions (Nolan et al., 1996; Eldh & Carlsson, 2011).

**Family carer support services**

In Sweden, as a result of ageing longevity trends, continued economic constraints combined with reduction in hospital beds and reduced number of nursing home beds (Gough et al., 2011), the situation of working carers is beginning to be brought to the attention of policy makers. There is increased emphasis on establishing services aimed at directly supporting working carers in their caregiving role (Hoffman & Rodrigues, 2010; Johansson, Long & Parker, 2011). An amendment in the Social Services Act in 2009 made it obligatory for the first time for municipalities to provide support for family carers. However, formal descriptions as to what constitutes such support remain vague (Johansson et al., 2011).

As a result of the relatively new Swedish legislation, the vast majority of municipalities now employ family care advisors or advocates to organise municipal family support units. These units offer and provide carer support such as, emotional support and advice (NBHWS, 2013; Winqvist, 2010). Anecdotal reports from these units imply under-usage by working carers. Possible explanations for this have been proposed, e.g. difficulties in providing carers with information regarding available support; working carers not identifying themselves as carers; working carers’ perceived lack of time and preferences for more flexible forms of support (Sand, 2010; 2016). A
cross national European survey (EUROFAMCARE) found that a cluster of non-cohabiting/working daughters had the lowest frequency of use of information, counselling, carer support groups, respite care, training and formal assessment of carers’ situation. Benefits of such services were also described as limited especially in countries such as Sweden that have extensive formal care service networks (Lamura et al., 2008). Other studies with a similar support focus indicate that most carers prefer (continued) services for the person they care for rather than support for themselves (Jegermalm & Sundström, 2013; NBHW, 2012). However, due to re-familiarisation and the fact that many older people rely heavily on their family carers (Sundström et al., 2006; Szebehely & Trydegård, 2012), such an option appears not to be available for all working carers. Further, none of these studies appear to have focused on such support provision via the use of ICTs.

Information and Communication Technologies (ICTs) mediated support

ICT is an umbrella term for technical means to handle information and communication and consists of information technology (IT) as well as broadcast media, telephony, and all types of audio and video processing and transmission (European-agency.org). ICTs are perceived to enable convenient, effective, low-cost and individually tailored support for family carers (Carretero et al., 2015). There is very little empirical literature that specifically addresses how ICT-mediated support can optimally be used to support working carers. Working carers’ perspectives are more or less entangled with those of older (retired) carers and hidden within studies. Nevertheless, there are several types of ICTs that may potentially be a means for supporting working carers: web-based ICTs, distance communication technologies, and tele-care and other assistive technologies.

Web-based ICTs are potential support sources for working carers’ online information and education (e.g. on topics related to being a family carer, diseases and illnesses, and health and social care services) and allowing one to network with peer carers and professionals for social and emotional support (Beauchamp et al., 2005; Kuhn et al., 2008; Mahoney et al., 2008; Schmidt et al., 2011; McKechnie et al., 2014). There have been policy initiatives at national level to fund development and use of web-based support services in municipalities1, which could provide carers with more flexible forms of support. Nevertheless, not all of these initiatives were formally evaluated during the project period.

1One such initiative was the Older People and Technology II programme 2010–2013 commissioned by the Swedish Institute of Assistive Technology.
Tele- and video technologies, tele-care and assistive technologies are commonly used within the interdisciplinary field of gerontechnology involving gerontology, the scientific study of aging, and technology (e.g. ICTs). Such ICTs are used to prevent, delay, or compensate for the perceptual, cognitive, and physical declines of aging (Fozard et al. 2000).

Distance communication technologies such as tele- and video technologies allow for communication and contact in real time over geographical distances, which promote communication between carers, older people and care professionals (Benefield & Beck, 2007).

Tele-care comprises of smart home concepts and tele-monitoring such as remote monitors, sensors, global positioning systems (GPS), alarms and pendants. Upon triggering, a call centre operative may respond and call on a family carer or other appropriate responder. Alternatively, carers may visit a service centre to view information on their own initiative (Mahoney et al., 2008). Such ICTs usually help to promote older people’s independence, well-being, safety and security, accessibility and social life (Chung, Demiris & Thompson, 2016). However, tele-care has been proposed to eliminate the need for constant presence and has potential to help with the reconciliation of care and work (Mahoney et al., 2008; Carretero et al., 2015).

Assistive technologies is an umbrella term for any device or system that allows care recipients (older person) to perform tasks they would otherwise be unable to do or that increases the ease and safety with which tasks can be performed (Stowe & Harding, 2010). Assistive devices such as cognitive aids and medical dispensers have the potential to assist carers with the practical aspects of caregiving (Chung et al., 2016).

**ICTs in caring practices**

Optimal partnerships in family care support rely on processes of care in which all parties perceive benefits (Nolan et al., 2003). It is vital therefore that research is not restricted to only focusing on ICT as a one-way medium of support transfer but also on how such ICTs (if any) can help promote working carers’ relationships and partnerships with the care recipient, care professionals and formal care organisations during different stages of their caring situation.

The development and introduction of new ICT-mediated support in family care support may require care professionals to alter/change their work methods. It is commonly accepted that technologies are value laden and that care professionals (e.g. nurses) may be reluctant and tend to act as gatekeepers regarding the use of ICTs that they do not feel are compatible and reconcilable with the goals of caring (c.f. Sandelowski, 1997, 2000; Whitten & Mackert, 2005). In a study by Sävenstedt, Sandman & Zingmark (2006), care staff for older people saw ICTs as promoting both inhumane and humane care. Sävenstedt et al. also proposed that such views need to be recognised and
discussed to be able to form the best possible caring (i.e. support) alternative. Magnusson et al. (2005) identified the issue of fear of replacing human contact among care professionals using an ICT service to support older people and their family carers. To the best of my knowledge, no studies have yet specifically included the perspective of care professionals in using web-based ICTs in working carer support.
Aims

The overall purpose of this thesis is to gain an understanding of support for working carers of older people via the use of ICT.

The specific aims for the studies were:

I. To explore the current ‘state of art’ in the field concerning the use of ICT-mediated support for working carers of older people.

II. To describe nursing and support staff’s experiences of using web-based ICTs for information, e-learning and support of working carers of older people.

III. To describe Swedish working carers’ experiences of having access to the web-based family care support network ‘A good place’, provided by the municipality to support adults caring for an older family member.

IV. To describe valued and received forms of support among Swedish working carers, with a focus on ICT-mediated support.

Rationale for the thesis

Working carers may experience challenges associated with providing care that negatively impact on their personal health, wellbeing and situation. Carer support is therefore needed to reduce negative impacts and promote satisfactory elements within carers’ situations for those working carers who wish to care for or who want to continue caring for their older relative. Currently, support offered by municipalities is not always available or optimally individualised to meet working carers’ unique situations (Sand, 2010; 2016). The availability of ICT-mediated support has made it feasible to offer working carers more targeted options for support, which have the potential to provide flexibility and accessibility upon need.

There is currently a dearth of empirical literature specifically addressing how ICT-mediated support can optimally be used to support working carers. Working carers’ perspectives are more or less entangled with those of older (retired) carers and hidden within studies. It is therefore necessary to explore and disentangle this perspective to provide much needed knowledge in this hitherto unexplored area of caregiver research.

Given working carers’ unique caring situations, attention should be given to how ICT-mediated support can (if at all) support working carers to feel empowered and to more easily manage with the challenges of caregiving as well as with the challenges and conflicts arising from combining paid work and care.

It is acknowledged that technologies such as ICTs may influence and alter caring processes. From a caring perspective, therefore, attention should also be given to how ICT-mediated support can (if at all) be utilised as caring tools to promote partnerships between working carers, care recipients, care professionals and formal care organisations during different stages of caring.

In summary, to further develop family care support, it is essential to further understand how ICT-mediated support for working carers can be optimally utilised.
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III. To describe Swedish working carers’ experiences of having access to the web-based family care support network ‘A good place’, provided by the municipality to support adults caring for an older family member.

IV. To describe valued and received forms of support among Swedish working carers, with a focus on ICT-mediated support.
Theoretical perspective

The theoretical perspective in this thesis emanates from caring science, which has its roots in human science. Caring science is based on a holistic view of knowledge in which the person, health, environment and caring are core epistemological concepts (Bergbom, 2012), guiding what knowledge is to be generated. The fundamental aim in caring science is to generate knowledge in order to promote health, well-being and to alleviate suffering (cf. Dahlberg & Segersten, 2010). Caring is not to be viewed as a phenomenon that is tied to a specific profession but rather refers to the process of intentions, activities, strategies and actions performed to promote such an aim (cf. Bergbom, 2012).

Within the caring epistemology of this thesis, the concept of ‘person’ (i.e. older persons or care recipients) also includes family members. Working carers’ situation acts as the specific focus. The older person is not per se a subject of but rather has an important contextual role as being the focus for working carers’ caregiving. Care professionals (i.e. family carer support professionals and other formal carers) in their support role of working carers and their families are included as part of the working carers’ context.

In the thesis, the caring process specifically refers to the process of family carers (i.e. those who wish to care) being supported in caregiving and thus becoming empowered in providing care over time. In this way it is an ongoing temporal caregiving process (Nolan et al., 1996; 2002; 2003).

Health is not only to be understood as an absence of ‘disease’ (e.g. caregiver burnout) but also a process where the person (working carer) can actualise and achieve vital goals in life, in what is considered as culturally normal life circumstances (Nordenfelt, 2004) e.g. combining paid work and care without it hindering one from actualising and achieving her/his vital goals. To generate knowledge about ICT-mediated support for working carers in caregiving and how (if at all) it may empower working carers’ in achieving such vital goals is a fundamental purpose in this thesis.

In order to achieve this purpose, focus is directed towards the environment in which working carers’ caregiving takes place such as the physical environment and the virtual via use of ICTs (cf. Bergbom, 2012).
thesis, environment can also be understood as a construct of circumstances in
the broader situation (context) in which working carers combine paid work
and care. Further, it also refers to the temporal caregiving process (Nolan et
al., 1996; 2002; 2003) in which caring and paid work activities take place over
the course of time.

The use of ICTs in working carer support is to be viewed from a caring
perspective. Information and communication are not theoretically of focus but
are rather viewed as an assumption for caring interaction (and relationship). I
position myself towards a humanities philosophy of technology (Barnard,
2001) where I accept the engineering of ICTs as opposed to focusing on it
(which is left for other science disciplines). The main focus is on support via
ICTs as viewed and experienced by working carers and carer support

Epistemology also refers to the theory of how knowledge per se is
produced based on what is “true” in the world. This in turn is intimately
related to ontological assumptions e.g. what kinds of entities and relations
there are in the world (Benton & Craib, 2011). The ontological foundation in
this thesis (and in caring science) is that humans (persons) are self-creators of
meaning within their life-worlds and thereby subjective experts on their own
life-situations. Epistemologically, this has placed the person at a mid-point in
research (cf. Dahlberg & Segersten, 2010).

Knowledge claims made in the thesis are based on studies using
qualitative, quantitative and mixed methods integrative review methodology.
This mix of methods can be regarded as complementary tools to generate
knowledge rather than incommensurable epistemological opposites. Based on
an ontology perspective, where working carers are subjective experts on their
own life-situations, I find this mix of methods compatible as they allow
participants in varying degrees to subjectivity express their experiences or
views (in interviews or in surveys). I have used a varied strategy to gather
data, which has been based on semi-structured interview guides, survey
questions and predefined strategy to collect secondary data (studies/articles for
reviews). By using this research strategy, I place myself within
constructionism, i.e. an assumption that knowledge is being constructed in
social processes rather than just being something “out there” waiting to be
discovered (Hacking & Hansson, 2000).

A concern that I have had during work with quantitative data is how
various constructs that are measured (for instance, from a scale index) may be
in conflict with caring epistemology as it may promote an atomistic
reductionist view rather than an holistic view on human beings (cf. Stoltz,
2007). However, these constructs and measures are used to shed further light
on working carers’ situation and provide details about both environment and
health aspects which can arguably be important aspects of the caring
epistemology.
Materials and Methods

Studies I, II, III and IV were conducted within the framework of the Swedish Family Care Competence Centre (NKA). Studies II and III were evaluation projects commissioned by the Swedish Institute of Assistive Technology within their Older People and Technology II programme 2010–2013. An overview of Studies I–IV is presented in table 1. Notably, due to the studies being project based and not following a straight path, the study conducted as number three is presented as study one in the thesis. In the following section, I will present design and focus, materials and participants, data collection and data analysis.

Table 1. Overview of Studies I–IV

<table>
<thead>
<tr>
<th>Study</th>
<th>Design and focus</th>
<th>Materials/ participants</th>
<th>Data collection (year)</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Integrative literature review (descriptive)</td>
<td>Published articles and reports (n=14) about carer support via ICTs</td>
<td>Database and ancestral search 2015–2016</td>
<td>Convergent qualitative synthesis</td>
</tr>
<tr>
<td>II</td>
<td>Qualitative descriptive</td>
<td>17 care professionals representing nursing and support staff in two Swedish municipalities</td>
<td>Single and group interviews 2012</td>
<td>Secondary analysis</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative descriptive</td>
<td>9 working carers in one Swedish municipality</td>
<td>Single telephone interviews 2014</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>IV</td>
<td>Cross-sectional descriptive (quantitative)</td>
<td>129 Swedish working carers</td>
<td>Web-survey/ Questionnaire 2016</td>
<td>Descriptive statistics Bivariate correlation</td>
</tr>
</tbody>
</table>
**Study I**

To explore and evaluate literature comprising the current ‘state of art’ concerning the use of ICT-mediated support for working carers of older people, an integrative review was conducted in accordance with the methodology presented by Whittemore and Knafl (2005). The review process included literature search, data evaluation, data analysis and presentation of findings. The study was not restricted to any specific ICT or area of use in order to scope the area widely. Literature searches for published articles and reports were conducted by using a set of relevant keywords in online databases: PubMed, CINAHL, Scopus, Social Services Abstracts, PsychInfo and Inspec. The search was complemented by manual ancestral searches in located articles.

Data evaluation followed pre-defined criteria for inclusion and exclusion, including information that made it possible to say that the study was about working carers. This included information such as number of participants in employment, measures and outcome variables in analysis, and findings relating to working carers’ situation. The final sample consisted of 14 published articles and reports using quantitative, qualitative or mixed methodologies. Information about quality appraisal, upon which conclusions can be drawn, was based upon quality assessment performed using the content validated and reliability tested Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011).

Data analysis was performed based on the steps of data reduction, data display, data comparison, conclusion drawing and verification (Whittemore & Knafl, 2005). Accordingly, data were coded, recorded, displayed and compared to discern patterns, relationships and categories, which were subsequently interpreted into a higher level of abstraction. To help guide the analysis process, the following question was posed: What does this study tell us about how (if at all) ICT-mediated support influences the situations of working carers?

**Study II**

Two separate datasets were used to describe care professionals (i.e. nursing and family care support staff’s) experiences of using the web-based ICTs called ‘Anhörigstödsportalen’ (the family care support portal) and ‘A good place’ (AGP)², respectively (referred to as web-based ICTs), in their work to support working family carers of older people. The web-based ICTs were used for working carers to readily access information, e-learning and personal support on an as need basis. The ICTs provide web pages, web portals and functions for e-messages, video streaming and telephone services. Both

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² ‘A good place’ was previously named ‘Gapet’ as used in the paper for Study I.
systems provide information and education on topics related to being a working carer. ‘AGP’ additionally features closed social networks for peer-to-peer support within contexts such as dementia and stroke. Both ICTs enable nursing staff to initially establish communication networks with working carers and other staff.

The total sample included seventeen care professionals, nine and eight respectively, from two municipality settings in Sweden. The sample represented various care professions including fifteen nursing staff, one occupational therapist and one recreational worker, all specially trained in family care support.

Data were collected in the same fashion in both settings, through group interviews (inspired by a focus group methodology) (Belzile & Öberg, 2012). A semi-structured interview guide was used to help guide dialogue as well as introduce topics of interests (Patton, 2002). The guide was structured around open-ended questions encouraging participants to speak freely about (perceived) benefits, opportunities and drawbacks (if any) of using web-based ICTs in their work with supporting working carers. The guide was also based around major topics of interest, namely, partnership working (Nolan et al., 2003), preparedness to care (Archbold et al., 1995), information, communication, personal support and support coordination (Schmidt et al., 2011). Interviews lasted between 70 and 110 minutes, were audio-recorded and transcribed verbatim.

Data from the two settings had previously been analysed manifestly and reported separately as required by the external fund holder (Andersson et al., 2013). The datasets were re-read and merged; thereafter, a secondary qualitative analysis was performed (Heaton, 2004; 2008) using qualitative content analysis (Graneheim & Lundman, 2004; Lundman & Graneheim, 2009).

Qualitative content analysis was used in both Studies II and III to inductively analyse data. Data (i.e. transcribed text) were condensed into meaning units (i.e. shortened without losing any core meaning) that were coded according to their content. Codes were then grouped and abstracted into categories describing the central message, and into themes describing interpreted latent meaning (Graneheim & Lundman, 2004; Lundman & Graneheim, 2009).

Study III
Nine working carers in one municipality that were caring for an older person were purposively recruited based on criteria that they received municipal family care support and had access to the web-based ‘AGP’ (see description in previous section). Varying situations regarding employment, life situation and intensity and length of the caregiving process were represented in the sample. Despite efforts to recruit male working carers, only women agreed to
Despite efforts to recruit male working carers, only women agreed to participate. Recruitment was assisted by the family care advisor who advertised the study via municipal websites, email or in person. Potential participants who were interested in participating were forwarded to SA for further contact. All of these potential participants were included in the study.

Data were collected using individual telephone interviews. As in Study I, a semi-structured pilot tested interview guide was used (Patton, 2002). The guide included questions concerning how (if at all) ‘A good place’ had influenced participants’: ability to balance care and work; relationship with the cared-for person; contact with other carers utilising ‘A good place’; relationships with support practitioners and other professionals; and preferences when seeking information or contacting professionals. As the interviews were telephone based, field notes were made during and after each interview to highlight and or (re)connect to aural observations made. These descriptions included participants’ intonations, hesitations and sighs. Interviews were audio-recorded and lasted between 30–55 minutes. Recordings and field notes were transcribed verbatim.

For a detailed description regarding the qualitative content analysis procedure, see under Study II.

**Study IV**

A sub sample of 129 working carers was drawn from a larger convenience sample (N=487) in an extensive survey about support for working carers of both older and younger care recipients. The survey included the perspectives of both present and previous working carers. Those eligible for participation in study IV were carers over 18 years of age, self-employed or in paid employment, and presently caring for a person aged 65 years of age or older. Based on the fact that role strain on carers may still continue after the older person has moved to a long term care facility (c.f. Nolan, 1996), no exclusions were made of such ‘prior’ carers. Furthermore, as fewer weekly caregiving hours may not fully comprise all non-instrumental dimensions of care and motives for preferring a particular support, no exclusion was made relative to weekly caregiving hours.

Data were collected via an open web survey that was advertised in a member bulletin and a webpage via the Swedish Dementia Association (Svenska Demensförbundet). As well, via an e-mail registry of delegates at the Swedish Carers Association’s (Anhörigas Riksförbund) annual carer conference, “Anhörigriksdag”.

The survey contained a selection of standard items for demographic information, items developed by the research team, and validated items and/or scales. The questionnaire had four main sections: demographic details to determine participant characteristics (N=10); family care situation to discern in what way, how much and to what extent caregiving took place and...
information about the cared for person (N=10); work-care conflicts (N=8), and valued and received forms of support (N=24).3

To discern the potential level of influence on the value of support, the 5-item validated work-care conflict scale (Pearlin et al., 1990; Aneshensel et al., 1995) was used. The scale comprised items examining worry about the care recipient and lack of energy while at work, disturbing telephone calls related to caring and losing too many workdays and feeling that the quality of one’s performed work is affected (Pearlin et al., 1990; Aneshensel et al., 1995). Scale items had a likert response format, with response options: totally disagree, partly disagree, partly agree and totally agree scored 1–4. High mean score on the scale represented high work-care-conflict. A translation-back translation procedure was conducted to translate the 5-item work-care conflict scale from English into Swedish. The scale had high reliability in the sample Cronbach’s $\alpha = .85$.

Altogether, views about support value comprised 10 items of ICT-mediated and 14 items of non ICT-mediated support. Items comprised a number of common support areas (e.g. information, emotional, social, peer, relief and respite and assistance with planning and coordination)4. Items on ICT-based support were developed based mainly on the findings in Studies I, II and III. Views of forms of support were operationalised into likert type responses regarding the degree to which participants viewed the various support forms as valuable or not. The response alternatives were: It would be very, quite, less or not useful to me and I don’t know. Participants were also asked if they receive or had received 12 support (if any) of which 3 support were ICT-mediated (see result section). The items were pilot tested with three working carers using a think-aloud approach (Drennan, 2002).

To communicate and compare areas of support and ICT-based and non ICT-based support within these areas, the 24 support items were categorised following a researcher triangulation protocol until consensus was reached. First, SA categorised the support based on findings from literature reviews. Second, support was categorised independently by a researcher expert in the field of carer support. Categories were then compared, discussed and tweaked. Thirdly, categories were then reviewed for comments by other members of the research team. The 24 forms of support were categorised into the following five areas: 1) health and social care management; 2) social, peer-to-peer and emotional support; 3) carer relief and respite, and independence of the care receiver; 4) financial support 5) and unspecified support (see table 2).

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3 The survey also contained the validated 15 item instrument Carers of Older People in Europe (COPE) querying about negative impact, positive value and quality of support in caregiving. Due to the extensive amount of data collected this data is not included in the fourth study. The data will be presented elsewhere.

4 The survey also contained 12 items of support at the workplace which are not included in the fourth study. The data will be presented elsewhere.
Table 2. Categorisation of support areas

<table>
<thead>
<tr>
<th>Support area for Health and Social Care Management</th>
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</thead>
<tbody>
<tr>
<td><strong>ICT forms</strong></td>
</tr>
<tr>
<td>• To have access to information via the web</td>
</tr>
<tr>
<td>• To be able to participate in meetings for care planning or doctors’ appointments at a distance via computers, tablets, smartphones and TV screens</td>
</tr>
<tr>
<td><strong>Non ICT forms</strong></td>
</tr>
<tr>
<td>• Help to have non ICT assistive aids introduced and adaptations made at the home of the care recipient</td>
</tr>
<tr>
<td>• To receive more assistance with planning and coordination of care/help/support</td>
</tr>
<tr>
<td>• To receive more help performing domestic tasks in caregiving, e.g. cleaning, gardening, shopping</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Support area for Relief and Respite Care, or Care Receiver Independence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICT forms</strong></td>
</tr>
<tr>
<td>To be introduced to available technical aids, such as alarms, sensors and equipment for communication</td>
</tr>
<tr>
<td>Use ICTs for remote prevention:</td>
</tr>
<tr>
<td>• To receive information, via different technology solutions, about whether the care recipient has used the stove, refrigerator, pill dispenser, toilet door or bed</td>
</tr>
<tr>
<td>• To be able to receive information about the location of the care recipient, or to be able locate where the care recipient is outside the home, e.g. via GPS</td>
</tr>
<tr>
<td>Use ICTs for safety monitoring:</td>
</tr>
<tr>
<td>• To be alerted in case of falls, or of use of windows and doors, via sensors and cameras in the home of the care recipient</td>
</tr>
<tr>
<td>• To be able to communicate with the care recipient from a distance via computers, tablets, smartphones and TV screens</td>
</tr>
<tr>
<td><strong>Non ICT forms</strong></td>
</tr>
<tr>
<td>• To get more relief in caregiving with help from other family members and friends</td>
</tr>
<tr>
<td>• To access information about where and how to get time for self, through respite care</td>
</tr>
<tr>
<td>• To be able to rest and have time for self through respite care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support area for Social, Peer-to-Peer and Emotional Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICT form</strong></td>
</tr>
<tr>
<td>• To be able to meet other caregivers via forums on the web to share experiences</td>
</tr>
<tr>
<td><strong>Non ICT forms</strong></td>
</tr>
<tr>
<td>• Emotional support- to be able to talk to someone about one’s situation’</td>
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<td>• To enjoy social support, e.g. caregiver support, caregiver groups</td>
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<td>• To be able to meet other caregivers onsite (face-to-face) in groups to share experiences</td>
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<td>• To get support from the family care support unit in the municipality</td>
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<tr>
<td>• To get information on how to get support as a caregiver</td>
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<td>• To access information about, or to get into contact with, the municipal family care support</td>
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<th>Financial Support</th>
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<td>• To receive financial reimbursement for caregiving</td>
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<th>Unspecified Support area</th>
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<td>• To be able to remain anonymous when meeting other carers</td>
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<tr>
<td>• To have the possibility to use technologies during work hours (e.g. alarms, cameras, video, GPS)</td>
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The analytic strategy comprised four different descriptive analyses:

First, descriptive statistics (e.g. frequencies, percentages, mean and standard deviation, median and inter quartile range) were used for demographic data, family care situation and work-care conflict. Mean and standard deviation were used when distribution of data was not particularly skewed, while median and inter quartile range were used for the opposite (Field, 2013).

Second, to examine what form of support the sample valued, frequencies and percentages were calculated for individual support. Likert response for very/quite valuable and less/not valuable were collapsed, hereinafter referred to as valuable and not valuable.

Third, frequencies and percentages were calculated for received support. To examine support received among those that valued support, selection of three ICT-based and eight non ICT-based support forms were compared for disparity between percentages of value and received support.

Lastly, to examine if there was an association between value of support and carer characteristic and work-care conflict, bivariate correlation was used. To correlate value of support treated as ordinal/continuous data with: 1) being a spouse/non-spouse and dementia/non-dementia carer (categorical data), bivariate point-biserial correlation was used and for 2) care-work conflict (ordinal/continuous), Spearman’s rho correlation was used. Alpha was set at p< 0.05 for each test. SPSS 23.0 was used for all statistical analyses.
Ethical considerations

The studies in this thesis have been planned and conducted in compliance with the ethical principles of the Helsinki-declaration (World Medical Association, 2013) and Swedish ethics legislation (SFS 2003:460). All studies adhere to ethical principles with regard to autonomy, beneficence, non-maleficence and justice throughout the process of planning, conducting and reporting phases of the research process. Studies that required formal ethical approval according to Swedish legislation have consequently undergone such a process.

Overall, in Studies II, III and IV, participants were informed about the study in writing either by electronic letter (II, III and IV) or via a designated site on the web (IV). Participants were given the opportunity to ask questions or raise concerns, were informed about the voluntary nature of their participation and of their rights to withdraw at any time without any repercussions to the care and/or support s/he received and/or that their older care recipient received. Participants were informed that individual responses would be kept confidential and about the potential usage of study data (i.e. publication and reports). Participants gave informed consent to participate in writing (Study II), by oral audio-recording (Study III) or by actively responding to a web-survey (or paper version n=4).

Specific ethical considerations: Study I

Study I, concerning an integrative review study was not the object of formal ethical committee approval as the sample consisted of articles and reports. However, an integrative review should comply with the same ethical principles as any other study. As such, ethical considerations had to be made during the process. One particular issue concerned collecting caregiver data from original studies using tele-care such as alarms and sensors, which first and foremost should benefit the older care recipient. Review of such studies demanded ethical considerations concerning the inherent trade-offs between privacy, safety, personal control and independence of the older care recipient under study (Hagen et al., 2004). It would have been unethical (and in
violation of the ethos of caring) to report benefits for working carers using an ICT to observe a care recipient if actual or potential adverse effects experienced by the care recipient were not also taken into consideration and reported on in the reviewed article or report. Therefore, when assessing the potential usefulness of ICTs for working carers’, although not a direct aim of Study I, issues of privacy, informed consent, autonomy, obtrusiveness, equal access, reduction in human touch, and usability among cared for persons were acknowledged and reflected upon (Magnusson & Hanson, 2003; Chung et al., 2016). Included studies reported such aspects to various degrees, and outcomes for care recipients were to the best of our knowledge not causing any degree of suffering.

**Specific ethical considerations: Study II**

Study II, concerning professional nursing staff’s experiences of ICT, was not the object of formal ethical committee approval in accordance with the Swedish Ethical Review Act (SFS 2003:460). A reason for this is that the participants were not regarded to be in an exposed and vulnerable position or deemed to be at risk of suffering adverse consequences from participation. However, approval to conduct the study was granted by the participating municipal authorities.

A potential problem arising from the organisations approving participation might be that participants in the role as employees might have felt duly obliged to participate. This might pose a problem when participants as individuals could potentially feel more exposed in group interviews. Due to the fact that there were participants in a project management position, project managers were interviewed separately in order to avoid potential problems arising from such a power relationship.

**Specific ethical considerations: Studies III and IV**

Study III, concerning working carers’ experiences of a web-based family care support network, was ethically reviewed by the South East ethics-committee Sweden (registration number: EPK 208-2014). Study IV was reviewed and approved by the Swedish regional ethics committee (dnr: 2016/8-31) (Notably, Study IV was confirmed by the ethics committee not to require formal approval but was nevertheless formally reviewed). In Study III, local approval to conduct the study was also granted by the participating municipal authorities. In Study IV, access to data was also granted and assisted by the two participating organisations.

As the studies: ensured (allowed) participants the right to withdraw at any time, and ensured that data and result would be dealt with in confidentiality, and did not involve physically and mentally obtrusive research methods participants were deemed to be at minimal risk as participants.
However, there might be a slight risk for an emotional impact due to talking about or answering questions concerning potentially emotional and burdensome aspects related to caregiving. As such, participants in Study III were informed that local authorities had agreed to offer emotional support as needed.

In both Study III and Study IV, efforts were made to provide participants with a choice to participate without feeling pressured to do so. The web-format in Study IV gave participants anonymity. In Study III, measures were taken to bypass the local family care advisor (assisting in recruitment of participants) to avoid situations whereby a potential power relationship existed. Potential participants who had indicated interest to participate in the study were directed to SA (the doctoral researcher) for direct communication.

In Study IV, the use of data was less than was actually surveyed e.g. workplace support. It can be argued that such an approach is a potential waste of respondents’ time and thus unethical. However, a decision was made to split the data and report on findings and recommendations in several papers due to the extent of the data, and given that the particular focus of this thesis is on ICT mediated support for working carers.
Results

In the following section, I will present the main results from each of the four studies, which contribute in their own right and in different ways to the overall aim of the thesis. A mild word of caution may be warranted here. Given that the studies are project based they do not necessarily follow a linear path. Some of the results are overlapping; therefore, the presentation of the results may comprise some unavoidable bumps and turns along the way.

Integrative results and current ‘state of the art’ concerning the use of ICT-mediated support for working carers of older people (I)

Study I specifically sought to answer how ICT-mediated support influences the situations of working carers. Using a scoping integrative review methodology to draw on both quantitative and qualitative data, 14 studies were identified. Four different areas of ICTs were identified to influence the situations of working carers: tele-care (n=6), web-based systems (n=7), assistive technology (devices) (n=1), and distance video communication technology (n=1). Working carers benefitted from ICT-mediated support forms that were both explicit i.e. specifically to facilitate work-caregiving balance (e.g. workplace support) and implicit i.e. to help cope with challenges arising from caregiving in general. Both these levels included support for information, education, problem solving, communication/interaction with peers, professionals and family members living at a distance, and assistance in caregiving. Further, support at both levels was also mediated via tele-care and assistive devices promoting older people’s independence, well-being or safety. All studies were assessed to have weaknesses, mostly due to small or biased samples, affecting the evidence base.

A thematic analysis of qualitative and quantitative data revealed seven themes relating to making work-life balance easier, reducing the burden of caregiving and promoting well-being: 1) burden, stress and depression; 2) peace of mind; 3) work interference, productivity, and participation; 4)
preparedness, self-efficacy and self-appraisal of the situation; 5) help seeking and wellness strategies; 6) help in caregiving; and 7) respite in caregiving. A detailed description of ICTs, interventions and support connected to carers’ outcomes is presented in paper IV, see attachment. An overview and summary of themes follow below.

With regards to the first theme relating to ‘burden, stress and depression’, analysis revealed that working carers utilising ICT-mediated support sometimes benefited from reduced symptoms of burden and depression. It should be noted that due to low power as a result of small samples, methods for statistical significance testing provided weak evidence of such effects. Web-based support, tele-care and assistive technologies helped to reduce stress, both in caregiving and in work. This was related to enhanced self-care of the older care recipient, being able to care remotely and being interrupted less often at work due to caregiving matters.

The second theme was that of ‘peace of mind’. Working carers were helped to experience a greater peace of mind. This was achieved by using tele-care (such as alarms and sensors) and distance communication technology which helped to alleviate stress associated with being away from the older person and worrying while at work about the well-being of the older person. Working carers were assisted when overseeing older people’s daily living at their convenience or via notifications and felt reassured that the older person was looked after at times when no one else was on-site. Peace of mind was also experienced from using video-technology for seeing and communicating with the older person online despite living close by.

The third theme was that of relating to ‘work interference, productivity, and participation’. Web-based support offered at work and use of tele-care used during work hours was indicated to benefit working carers by reducing caregiving responsibilities that interfered with work responsibilities while also feeling better supported at work. Such effects were sometimes related to accomplishing more at work, worrying less while at work, and missing fewer work days. A mix of quantitative and qualitative results showed that tele-care benefitted working carers by allowing them to balance caregiving and work responsibilities as well as enabling participation in employment and maintaining normal working hours.

The fourth theme related to ‘preparedness, self-efficacy and self-appraisal of carers’ situation’. Web-based support led to working carers feeling more prepared for the future and feeling more confident in handling caregiving demands (i.e. increasing their preparedness in caregiving). Working carers also increased their self-perceived ability and self-efficacy in meeting caregiving demands, thus, feeling more positive about their role (i.e. positive self-appraisal).

The fifth theme was related to ‘help seeking and wellness strategies’. Working carers were positively influenced in their help-seeking behaviour (e.g. seeking help from family, friends, the medical system, social services and
long-term care and in developing wellness strategies (e.g. becoming more involved in exercise and relaxation activities).

The sixth theme was related to ‘a help in caregiving’. ICT-mediated support brought flexibility and reduction of logistical challenges. It made combining employment and caregiving easier. By using tele-care, working carers felt more in control and were helped to oversee the caregiving situation, thus, promoting the independence of the care recipient. By using web-based interventions, working carers were supported in managing caregiving situations through gaining knowledge about aspects of caregiving (e.g. about diagnosis, action and management, planning, decision making, problem solving and dealing with challenging care partner behaviours).

The seventh and final theme related to ‘respite in caregiving’. All tele-care and assistive technologies contributed to working carers experiencing emotional and/or physical respite from caregiving. Emotional respite was connected to feeling calm, spending less time thinking about care, feeling reassured that the cared for person was looked after, having more time for work and leisure activities and being able to relax more and feel less tired from having uninterrupted sleep. Physical respite was connected to being “on call” and “on duty” less often and to having a more manageable window of response time or due to the older person becoming more independent. It decreased the amount of time spent doing caregiving.

However, analysis also highlighted problematic aspects such as over-reliance on ICT beyond its support capacity (e.g. wanting emergency alerts when there were not any) and situations where ICT-mediated support added to caring responsibility. Relative to support mediated by tele-care and using assistive devices, two main levels (low to high) were identified of working carer involvement in managing the ICT and responding to information generated. For higher level involvement, findings revealed ambiguous results regarding reduced respite as a consequence of added tasks and caregiving responsibility in already stressful lives. Also, functions such as alarms disturbed sleep among cohabiting working carers.

**Care professionals’ (support staff’s) experiences of using web-based ICTs to support working carers (II)**

Study II sought to answer the question of what were the (perceived) benefits, opportunities and drawbacks (if any) of using web-based ICTs AGP and ‘Anhörigstödspotalen’ to provide professional carer support to working carers of older people. The use of web-based ICTs in care professionals’ work was generally expressed as a positive and valuable complement to supporting working carers. Analysis of care professionals’ views and experiences generated three main themes.

The first theme concerning benefits revealed itself as being able to offer working carers a pathway or road (i.e. a way with entrance points or inroads)
for accessing support. The web-based ICTs provided alternative contact and access points, which had increased the number of contacts with working carers. Support was described as being less dependent on distance and time. Web-based ICTs were expressed as an alternative tool to work around issues of working carers’ emotional thresholds of seeking and receiving ‘support’. These were sometimes manifested as carers wanting access to the web-based ICT but not wanting support or as not wanting to be on display to others. The benefits for working carers’ autonomy, integrity and privacy were expressed in this regard.

The second theme revealed itself as ICTs being caring instruments in family care support. One aspect concerning benefits related to the ICTs providing effective and timesaving administrative tools for planning, managing and organising family care support services. One of the benefits described was freeing up time to support those family carers with most pressing needs. The ICTs were described as a means to inform on availability if needed, and it secured support access that was not restricted to working hours. The dissemination and encouragement of self-support resources, such as education and information, were described as enabling some working carers to manage their situation themselves. A second area concerned benefits for maintaining personal relationships with family carers. In this regard, the ICTs were described as having potential to facilitate individualised and personal digital communication with working carers. The ICTs were described as complementary tools to face-to-face meetings, which were still often needed in crisis or emergency situations. A third area related to being able to reach out earlier with timely support, which made it easier for staff to prevent rather than respond to crisis situations. The ICT was described as a means of connecting working carers to share experiences with other peer carers. It was described as an unobtrusive means to enable online support for working carers who were otherwise isolated and restricted to the home due to family dynamics. Views of benefits for working carers gaining control and autonomy in their caring situation was also described.

The final and third theme revealed itself as obstacles hindering access to ICT support. Participants described technical obstacles related to working carers’ digital literacy skills and insecurity. The value of supportive actions for education, training and showrooms to demonstrate and try new technologies were described. Obstacles also related to communication barriers when relying on text in communication, which was described as causing misinterpretation or not being suitable in sensitive matters and emergency situations. Communicating via text was also described as sometimes putting unwanted stress on working carers’ writing skills. Participants suggested other facilitating strategies such as including other ICTs as complements, thus, allowing working carers to communicate with others face-to-face i.e. via distance communication technology.
In the process of introducing ICTs to working carers, participants expressed the importance of needing to feel a sense of technical confidence in order to feel sufficiently secure to provide support to others. When working carers viewed the ICT with reluctance e.g. due to issues of security, integrity and privacy, this challenged participants to adjust their information in a way that would not scare carers or ‘put them off’. Participants also described an ethical balancing act when responding to some working carers’ reluctance or difficulties expressing their need for support. Not infringing on others’ integrity and privacy, and not prying into personal areas were described as important. To accept working carers’ individual needs and preferences of using the ICTs was also described as being important. The ICTs were viewed as support in themselves considering the flexibility they provided. Therefore, questions about working carers’ use of the service (e.g. to follow-up use among users) were sometimes few in order to respect their privacy.

Swedish working carers’ experiences of having access to web-based ICTs provided by the municipality (III)

A main research question in study III was what working carers themselves viewed as the benefits, opportunities and/or drawbacks of having access to the web-based ICT AGP, and how (if at all) the AGP had supported participants in their role of caring for an older family member. Findings consisted of three themes.

The first theme, ‘A support hub, connections to peers, personnel and knowledge’, described AGP as a useful, important and practical tool to connect and share personal experiences with peer carers, to connect with personnel and to receive support from family care advisors. The AGP was described as a place for emotional support, which made it easier to connect and share experiences and unburden oneself to other carers. Relating and sharing with others was described as helping participants to feel comforted, experience less isolation and solitude within their own caring situation, and consolation from learning that others have similar or worse situations when compared with their own. The participants described feeling relieved of frustrations, negative thoughts and fears connected with providing care (e.g. guilt, anxiety and inadequacy). The AGP was described as a knowledge bank and information source, which increased understanding and insight about participants’ current situation, thus allowing them to be more fully prepared and confident in handling current and future situations. Participants expressed being able to provide better support to the older person and becoming more confident in sharing information within the caregiving network as a result. Even when no new information was obtained, participants described a feeling of self-confidence in what they already knew. On the negative side, feeling pressured or forced to respond to peers’ postings was described as overwhelming and increased anxiety, especially when being reminded and
triggering memories of difficult episodes in one’s own situation or when being reminded of the frailty of their own cared-for family member.

A second theme, ‘Experiencing ICT support as relevant in changing life circumstances’, concerned issues of accessibility, usability and flexibility in support, and the correspondence of ICT support to carer’s situations in caregiving and in working life. The introduction of the web-based support early in the caregiving process increased effectiveness in helping carers cope with changing life circumstances, become a working carer and in the process to become more experienced over time. Later introduction of web-based support created a risk that the AGP would not correlate to carers’ own particular situation. The flexible access to support, thus, not being bound to office hours allowed for use at times best suited to one’s personal schedule and created an opportunity for greater participation and for seeking information which was perceived as helpful in staying informed and networking with others while prioritising caregiving and work. When information and peer-to-peer support did not correspond to changing life circumstances i.e. what was relevant (e.g. diagnosis, caregiver characteristics, how to address particular and personal problems), participants felt disconnected and found it not worthwhile using. It was mentioned that information and support needs change over time e.g. how it changed from the general to more specific, related to one situation. The web-based support needed to correspond to the caregiving situation (process) over time and respond to issues such as how to manage when the caring situation stretches over many years and how to deal with progressing frailty and disease. Participants described it as not being just a question of general information but also about knowing how to use it in practice. When such information was missing, the AGP was deemed to not correspond with changing life circumstances. As a result, participants turned to health and social care professionals. Uncertain response times from having to wait for replies could be experienced as stressful. Aspects of the caring situation, combined with work and family life being too time consuming and being able to prioritise time to use AGP were also factors that were described.

A third theme, which revealed itself as ‘upholding one’s personal firewall’, concerned issues of IT safety and security about using web-based support, keeping matters private to protect one’s integrity and of digital skills to feel comfortable in using AGP. Benefits included a sense of safety and security from using a forum exclusively for carers in similar circumstances that was locally managed by someone known to participants. It provided an alternative means of support and allowed one to remain anonymous (using an alias) and private which was beneficial for participants that avoided face-to-face group support e.g. when professional healthcare workers felt uneasy about meeting family carers of patients/clients and thus not being able to separate their professional and carer roles. Barriers were related to carers’ low levels of self-perceived digital skills, chatting and networking, and being restricted to
expressing oneself in writing (revealing communication skills and not allowing visual and auditory cues), which sometimes led to de-prioritising the communication aspect of the support. Participants also expressed that communicating via AGP sometimes amplified uninhibited discussion, at the risk of revealing too much personal information.

Working carers’ views of valuable support and support received (IV)

Research questions posed in Study IV were: 1) what ICT and non-ICT based forms of support are valued and received by working carers of older people, 2) to what extent are valued forms of support received, and 3) whether work commitments affected the provision of care and if work-care conflict was associated with the value of support.

Valued support

Several non ICT-mediated forms of support examined in Study IV are beyond the scope of the thesis[^5] and will therefore not be presented in detail here. Thus, an outline of the key findings regarding traditional forms of support will be given to help the reader situate the findings relating to ICT-mediated forms of support for working carers. However, most forms of support (see table 2) were viewed very/quite valuable (hereafter referred to as valued) by the majority of participants. Over sixty-per cent of the support (n=15) considered in the study was valued by between 50–80% of participants, with the remaining forty per cent of the support (n=9) valued by between 25–50%. Overall, non-ICT mediated modes of support were more highly valued. Eight of the 10 ICT-based forms of support were valued by less than half the participants, while only one of the 14 non-ICT based forms of support was valued by under half of the sample. Nevertheless, when compared within categorised support areas (see table 2), the ICT forms of support were complementary to other non ICT forms. Support (regardless of form) in the area of health and social care management averaged as the most valued support area, followed by social, peer and emotional support, and support for relief and respite for the carer or independence of the care recipient.

The majority generally valued information about various caregiving matters. For support in the area of health and social care management, having such information via web access stands out as the most valued form of support, including in the overall study (n=86, 77%). Although valued by

[^5]: Non ICT-mediated forms of support not reported include: Information (i.e. about support for the care recipient, various aspects related to the carer, respite and municipal support); assistance with planning and coordination; having non-ICT assistive aids introduced and adaptions made in the home of the care recipient; having more help performing domestic tasks in caregiving; emotional and social support; municipal support; relief from caring with the help of family and friends; and rest and time for self (e.g. via respite services).
fewer, a substantial number also valued being able to participate in meetings for care-planning or doctors’ appointments at a distance (n=54, 50%).

In the area of social, peer and emotional support, a majority valued being able to meet other caregivers (peers) onsite in groups to share experiences (n=58, 53.2%) and social support e.g. caregiver support (n=53, 50.4%). In addition, meeting carers via forums on the web to share experiences was valued by a substantial number of carers (n=52, 47.7%). A related ICT-mediated characteristic of support (unspecified support) was “meeting” other carers while being able to remain anonymous, which was valued by a quarter of the sample (n=28, 25.7%).

Of the ICT-based support in the area of relief and respite or independence of the care recipient, just under a half of the sample valued being introduced to available technical aids such as alarms, sensors and equipment for communication (n=52, 49.5%). Fewer valued being able to communicate with the cared-for person from a distance (n=43, 40.2%). About one-third of the sample valued being alerted about falls, opening of windows and doors via the use of sensors and cameras in the home of the cared-for person (n=37, 34.6%), being able to receive information about or being able to locate where the cared for person was outside the home e.g. via GPS (n=37, 34.6%), and to receive information if the cared for person used the stove, refrigerator, pill dispenser, toilet door or the bed via different technology-based solutions (n=34, 31.8%).

A related ICT-mediated characteristic of support not specific to any one support area was the possibility to use technologies during work hours, which was valued by over two fifths of the sample (n=45, 42.8%).

Support received and disparity between valuing and receiving support
Findings showed that receipt of support in the sample was low, and levels of disparity between value and receipt of support were substantial. Average disparity of ICT-mediated support was marginally larger compared to non ICT-mediated modes, 83.1% vs 76.6%. Of the three ICT-based supports examined for disparity (i.e. having ICTs such as alarms and sensors in the home of the care recipient, for networking with peer carers and having web-based access to information and education), disparity ranged from 63.5–93.0%.

 Associations between valued support and work-care conflict
The majority of participants (85%) were affected by their work-care situation. About one-third of participants had been unable to access support groups for information, education and carer networking during the day due to work, and two-fifths had not had time to use carer support sources due to their work and care commitments. The mean score for participants’ work-care conflict scale

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6 Disparity refers to the proportion of participants who valued a given form of support but did not receive that support. A high level of disparity is suggestive of unmet support needs.
was 2.3 (SD 0.85), close to the mid-point of the 1–4 scale. Among the most prevalent contributions to work-care conflict was psychological and physical strain arising from being worried about the older person while at work (n=72, 81.8%), having less energy for work (n=70, 77.8%), and stress related to logistical or practical aspects of being disturbed by telephone calls about and from the cared for person during work (n=47, 53.4%).

Higher levels of work-care conflict were associated with higher levels of value for nearly all forms of support. Strongest associations were of moderate positive correlation ($r_{pb} = .300$ to .500, Field, 2013). Among ICT-based support, these were connected to ICTs for relief and respite, and independence for the care recipient (i.e. being introduced to ICTs such as alarms, sensors and equipment for communication, to receive information or be able to locate the care recipient outdoors, and using ICTs such as alarms and sensors during work hours). However, using sensors and cameras in the home of the care recipient for emergency alerts (e.g. in case of falls and use of windows and doors) was not significantly associated.
Discussion

The overall purpose of this thesis has been to gain an understanding about support for working carers of older people via the use of ICT. In this section, specific findings will be discussed relative to other carer literature, followed by methodological considerations. Specific findings that are connected to aspects of empowerment and disempowerment of working carers, balancing of work and care, temporality in ICT-mediated support, timing and balance, and ICT-mediated tools for professionals working with family care support will be discussed.

Aspects of working carers’ empowerment

In all thesis studies, results relating to carer empowerment were present. Advantages and benefits of ICT-mediated support via the web indicate that carers were provided with the means to manage their caring situation. Notably, support interventions were sometimes multicomponent (e.g. psycho-educational), and findings cannot be generalised to all web-based support. A summary of the findings reveals that information (e.g. about disease and support) (I, III), education and problem solving (I) (e.g. about caregiving matters) increased carers’ capacity to care (c.f. Stoltz et al., 2007). In this way, working carers felt empowered in their caring situation by feeling more confident, competent and prepared in their caring role, by strengthening their positive self-appraisal of their situation and self-efficacy in handling caregiving demands (I, II, III) (c.f. Schumacher et al., 1998).

The importance of such empowerment for working carers is described by Wang et al. (2013), showing that when greater preparedness was achieved among carers with a limited work-care conflict, role strain decreased and mental health was maintained even when faced with high caregiving demands. Given that empowerment at this level (psycho-social) may affect and expand people’s resources longitudinally (Rapaport, 1987), a timely proactive source of support is important. However, a troublesome finding in Study IV revealed that support which helped contribute to working carers’ empowerment, e.g.
information and education about aspects in caregiving, and emotional and social support, was actually received by very few of the study participants.

Working carers were also provided channels to share their frustrations and burdens via web-based online forums for emotional and social support between working carers, care professionals and other peer carers (I, II, III). This led to working carers feeling less burdened by their caregiving role and it helped to promote their well-being (I, III). A process of empowerment was arguably likely related to: the psychological impact of writing (III); being able to express and connect to emotions, such as guilt (III); the opportunity to obtain and to share information and knowledge, and the promotion of interpersonal relationships and social processes (I, II, III) (c.f. Barak et al., 2008).

Positive outcomes from web-based online support specifically expressed in Studies II and III, but likely also present in several reviewed studies (I), were similar to ‘disinhibition effects’ described by Barak et al. (2008). Such effects, allowed for flexible asynchronous communication (that is carers having the option to respond at different times from one another) for delayed reactions, anonymity of identity and invisibility for more personal and emotional communication (i.e. averted communication). One-quarter of the working carers that valued being able to remain anonymous and the near majority that valued online support for meeting other caregivers and sharing experiences (IV) indicate that such support may be appropriate for a large group of working carers.

**Aspects of support for balancing paid work and care**

Findings (I–IV) support what others have described, namely that working carers experience psychological, practical and logistical challenges when combining work and care (Sand, 2010; Eldh & Carlsson, 2011; NBHWS, 2012; Ulmanen, 2015; Sand, 2016). ICT-mediated support facilitated working carers to balance work obligations and care responsibilities (I, II, III).

Positive evaluation of tele-care for balancing work and care was due to working carers being assisted in caregiving, being helped to achieve peace of mind and respite, having reduced burdens and stress as well as reduced work interference and increased work productivity and participation (I).

Importantly, findings in Study I are based upon demographic compositions of working carers’ caregiving and working situations in six countries with mostly low levels of government support for formal home care (Berridge, Furseth, Cuthbertson & Demello, 2014). Such differences in welfare systems may result in care recipients having to rely more on their families. An important question that needs further research is therefore whether Swedish working carers experience the same level of benefit. Nevertheless, findings in Study IV indicate that between one-third and two-fifths of the Swedish working carers viewed tele-care as valuable for relief and respite, or allowing
the care recipient to have a sense of independence e.g. via communicating with the cared for person from a distance, locating the care recipient outdoors and monitoring daily activities. Interestingly, views of what is of value were also indicated to be associated with increased work-care conflict generated from psychological, practical and logistical challenges in the work-care situation (IV). Therefore, it is interesting that about two-fifths of Swedish working carers in Study IV indicated that they valued having the possibility to use technologies during work hours (e.g. alarms, cameras, video, GPS).

Positive evaluations of web-based support for balancing paid work and care were partly due to the flexible access and use of information and peer support from places and at times best suited to one’s personal schedule (I, III). Similar findings have been described by Carretero et al. (2015). Given the substantial number of working carers that experience difficulties in accessing and using onsite support (IV), flexibility in access and use may therefore be a necessity rather than complementary.

However, it must be pointed out that an obstacle for ICT-mediated support in some cases was ‘lack of prioritisation’, which was reflected in carers refraining from accepting support and needing to prioritise caring for their family member (III). In Study IV, about two-fifths reported having refrained from caregiver support (unspecified) for oneself because the subsequent time needed to both perform care and take up the offered support for her/himself was deemed to be lacking. Chiu and Eysenbach (2011) suggested that when carers are under significant stress, the perceived effort to use ICTs can be so great that they become reluctant to access it. Nevertheless, drawing on the evidence base presented in Study I, several ICTs may be used to individualise support to best match the needs and preferences of the working carer.

ICT-based support may also be used in caring interventions as caring tools to bridge the gap between paid work and care by offering carers to utilise support at the workplace (I). Such support may include web-based support for education, future planning, decision making, problem solving (c.f. Beauchamp et al., 2005; Kuhn et al., 2008), information, consultation with professionals, emotional and social support, and tele-care support (Mahoney et al., 2008). The fact that a substantial number of carers valued having the possibility to use technologies during work hours (IV) is therefore interesting, indeed. Future studies in Swedish settings are thus needed to further explore such support.

Aspects of temporality in ICT-mediated support

Due to short study periods often findings in the thesis are mostly based on snapshots in time and there are limited views of how ICT-mediated support may influence individual carers over time (I, III, IV). Considering that caring for an older family member often lasts for multiple years (which often was the case in the studies), this limits the evidence of how carers may be empowered
over time. Nevertheless, by compiling snapshots from carers at different stages of caregiving, findings describe how ICT-mediated support benefitted working carers during different stages of their caring situation.

Using Nolan et al.’s (1996; 2002; 2003) temporal model of family care to interpret findings, the web-based family support service, AGP, (III) was found to be effective in helping carers cope with being a working carer (novice and more experienced) such as via seeking information and knowledge, and the possibility to network and share experiences with other peer carers. These findings are consistent with other literature acknowledging novice carers as especially in need of information (Magnusson et al., 2005). No results were revealed of ICT-mediated support being a support for potential working carers in deciding whether or not to ‘take on the role’ (Nolan et al., 1996; 2002; 2003) and becoming a working carer. A reason for this may be due to the fact that participant carers had already taken on the role for a period of time prior to them participating in the studies.

It is evident that ICT-mediated support benefitted working carers in the stage of ‘working through it’ (Nolan et al., 1996; 2002; 2003). This was revealed by the positive experiences and usefulness of support for coping with caregiving (I, III). Findings also revealed that as caregiving needs (e.g., to have new information and to learn new things) change over time having access to a web-based family care support over time allowed for intermittent use (III). Support for ‘working through it’ is likely also the case in Study IV among the majority of working carers that valued support for health and social care management, social, peer-to-peer and emotional support, relief and respite and promoting independence of the care recipient. These findings are also given credence by the practical, emotional and physical outcomes for working carers revealed in the integrative review study (I).

An often under acknowledged stage in caregiver support is ‘passing the caregiving role over’-helping a family member to make an informed choice (whenever feasible) as to whether or not to take on the role of carer and for the carer to be able to freely decline to take on such a role (Nolan et al., 2003). It has previously been clearly acknowledged that a key role of carer support is to assist a carer to decide whether or not to take on (or continue) a caregiving role (Askham, 1998). Nonetheless, few results in the thesis revealed that support specifically focused on or helped with ‘passing the caregiver role over’. This may be due to the fact that reviewed studies mostly focused on interventions to support working carers to cope and be able to continue to combine work and care (I). However, during the ‘tough’ editing of paper III, obliging to the word limit of the journal, a quote was regretfully edited out revealing that if the web-based family care support service AGP had been received at an earlier stage, the care recipient would likely have moved into a nursing home sooner. This expression is likely to mean that the working carers had been in the process of seeking support previously to help ‘pass the role over’. Also, in Study III, there were expressions of peer support in the stage of
bereavement, which affected participants emotionally. However, the level of analysis in the description did not explore those experiences further. Further research would therefore be beneficial to study ICT-mediated support in the post-caring or bereavement phase for carers (Eurocarers, 2015).

**Aspects of symmetry (balance) and synchronicity (timing) in ICT-mediated support provision and receipt**

Findings revealed that the ICT-mediated support was sometimes out of sync with carers’ situation, and that the timing and balance of ICT-mediated support was experienced as important for support to be useful (II, III). Although timing and balance of support are universal to all family care support, these findings appear essential in order for ICT-mediated support to be a means of empowerment over the span of a long caring situation or experience. Nolan and colleagues (2003) proposed in their temporal model of family caring that in order for support to be facilitative, the content of support needs to be in balance (symmetry) with the goals and needs of the carer, and in timing (synchronicity) with the stage of caregiving. When not in sync, support is likely to be non-facilitative. This is exemplified in the findings by the fact that the web-based support (the AGP) was experienced as less ‘relevant in changing life circumstances’ when provided late in the caring trajectory (as described above) (III). Findings also revealed that support content was not always in balance so that it matched carers’ goal and needs. This was exemplified by carers over-relying on tele-care beyond its support capacity (I), when tele-care and assistive devices reduced respite by adding caring responsibility in already stressful lives (I), and when information or a peer network group on a web-based family support service did not match the individual carer situation (III). Using Nolan’s analogy, such out of sync factors can be viewed as the support provision being ‘asynchronous’ with carers needs and with the current stage and situation (Nolan et al., 2003). These findings reveal, therefore, the importance of support being offered early on in the caregiving process and in a way that will provide most assistance relative to carers’ needs and preferences over the duration of the caring experience.

It is evident from Study IV that Swedish working carers’ receipt of support was beyond asynchronous. Up-take of support was low (for both ICT and non ICT forms) and few that valued support had received it, which may suggest a high degree of unmet needs for support. Such needs may also be inflated by work-care conflict (IV). Although it is difficult to generalise the findings in Study IV to the larger population without further validation, the findings highlight what has been suggested by Sand (2010; 2016), namely that the Swedish municipal family support system may be underdeveloped and often fails to directly acknowledge the situation of working carers and/or fails to provide information on the availability of support.
Tele-care and assistive devices helped working carers to provide care and thus benefit from respite (I). However, a discrepancy was revealed indicating that such ICTs may also reduce respite from the added burden connected to responding to sensor alerts and technological malfunctions (I). Such a discrepancy is arguably related to the timing of place (c.f. Nolan et al., 2003) and combination of spaces (c.f. Roberts & Mort, 2009), such as the workplace and the care recipient’s home. Such combination of places creates and thus expands to new spaces in which caring takes place. Roberts and Mort (2009) argued that such spaces are not empty spaces free from differences and interrelations that will make caring un-problematic. One such space was connected to the workplace and employment itself, which has been suggested to be a form of respite from caregiving (Phillips, 2005). Nevertheless, it is evident from the findings that some carers experienced work-conflict from worry, loss of energy and being disturbed by phone calls from and about the care recipient (I, IV). In this way, Study I posed further issues that warrant closer scrutiny, namely, to what degree does ICT-mediated support explicitly help to combine roles of work and care by contributing to respite and if ICT-mediated support such as tele-care contributes to working carer’s burden from feeling that one must respond.

**ICT-mediated caring tools for family care support professionals**

It is evident from the findings that ICT-mediated support can be a means for care professionals to support carers. However, it is also evident that ICTs may create obstacles and carry risks which may have an adverse impact on the caring process. Sandelowski (1997) explained that opposing views about the benefits or risks of technology can be more realistically viewed as a continuum, in which there are varying degrees to which use of technology by care professionals leads towards differing degrees of reconcilability and irreconcilability within caring practice, which in turn creates an inherent interactive ‘push-pull’ relationship. At one end of this continuum, technology is viewed as creating a greater degree of pull away from what some care professionals consider to be the essence of caring which is more ‘hands on’ support, and which is viewed as detracting them from carrying out their caring role. In contrast, at the other end of the spectrum, technology is viewed as a means or assistive device/tool to help care professionals in varying degrees to move closer to their main goals of caring more effectively (Ibid).

When tele-care and distance communication technologies were used in the care of older people, such ICTs made it possible for working carers to actively monitor care related aspects, or more passively rely on being informed, in case of safety and emergency alerts, from a proximal distance (I). Positive findings concerning tele-care (I) revealed a potential for care professionals (formal care) to share information about alerts and adverts (e.g. from alarms and sensors) with working carers. Such sharing of information benefitted working
Carers’ respite, peace of mind, and ability to balance care with work (I). Although such interventions are primarily intended to promote independence, well-being, and safety of care recipients, findings revealed a multipurpose support that is in line with a gerontechnology perspective (Dara-Abrams, 2008; Shultz et al., 2015). It can thus be argued that such sharing of information via telecare may help care professional in their work to push closer towards a caring goal of supporting working carers, more effectively. Nevertheless, it is evident in Study I that such information may also burden working carers by creating additional caring responsibilities for their older relative when formal support was low. It can then be argued that such situations may cause care professionals to ‘pull away’ from the caring goal/s outlined above. Drawing on these findings, it is necessary to ensure tailored or individualised use so that ICTs do not become perceived as an additional burden by working carers.

Web-based support made it feasible for care professionals to ‘push towards’ the goal of providing support to a group of carers that due to caring responsibilities and working obligations may not have access to support during daytime hours. A lack of access was indeed experienced by carers in Studies I and III, and was reported by a substantial number of carers in Study IV. Web-based ICTs also provided care professionals with instruments to help facilitate working carers with caring activities and with empowering actions (II). In particular, they provided a means for working carers to feel more informed and more prepared in their caregiving role, thus empowering them, which can be seen as a step towards partnership working with working carers. In other words, such support was a means for shifting from professionals holding the authoritative expertise to carers themselves becoming experts regarding their own caring situation (Brown et al., 2001; Nolan, 2003). It can be argued that contributing to such a shift was support that helped care professionals to ‘foster a sense of empowerment’ among working carers that wished to rely on self and peers rather than care professionals (c.f. Barak et al., 2008). An example of this was found in Study II where care professionals reported that some working carers expressed simply wanting access to the AGP but did not want professional support. Contributing to such a shift was also ICT-mediated support that benefitted carers by networking and helping other carers (III), sharing experiences and identifying with other carers (III) (c.f. Barak et al., 2008). Such ICT-mediated support was present in Studies I, II and III.

However, a hindrance, and thus a ‘pull away’ from ICT-mediated empowerment, was related to caring professional’s own technical challenges. Although positive to the use of ICT, the process of becoming comfortable with its use and one’s own need for technical support (II) was an expressed issue. Notably, it might be that these technical challenges were due to a steep learning curve for care professionals, in combination with premature evaluation of the intervention.
Aspects of disempowerment of working carers

In addition to the challenges regarding care professionals’ lack of digital literacy skills, there were also technical obstacles hindering empowerment of working carers. Such barriers included lower digital and communication skills, which in turn led to working carers de-prioritising the communication aspects of web-mediated support or the support all together (II, III). Such obstacles in combination with ‘techno-fear’ may help to explain why web-based forms of networking with other peers were slightly less valued (five per cent less) compared to onsite forms (IV). The impact of such obstacles may not be that great if other onsite alternative forms of support are available. However, further development of ICT-mediated support without actions to build working carers’ digital and communicative skills, may risk the exclusion of carers from such support. Mariën and Prodnik (2014) argued that the emergence of ICTs and the ongoing digitisation of life domains have led to both structural mechanisms of empowerment and of disempowerment. The level of digital skills and the ability to use ICTs to one’s own social, economic, cultural or political benefit, defines one’s capacity to become empowered. According to the EU digital agenda scoreboard for 2014–2016, there has been an increase in basic digital skills among the Swedish workforce. Nevertheless, twenty-one per cent of the population are still considered to have insufficient digital skills (low or no skills) (European commission, 2016). For the proportion of working carers (35–39%) in Study IV that had been hindered from accessing and participating in support, especially during the daytime due to work and care commitments, such digital exclusion may be problematic. Thus, actions to build on family carers’ technical and computer skills early on in the caregiving process for those carers who are interested in doing so, are therefore important to help facilitate the overall social inclusion of working carers within today’s information society and to help stimulate optimal use of available web-based ICTs. Supportive actions for education, training and showrooms to demonstrate and try new technologies were described as facilitating strategies (II).

Methodical considerations

The combination of descriptive qualitative and quantitative research methods has helped to gain an understanding regarding support for working carers of older people via the use of ICTs. The integrative review (I) made it possible to compile existing research into an integrative review which provided breadth as to what types of ICT-based support may actually provide support, and also detail on how these were experienced by working carers. Qualitative interviews and content analysed data (II–III) has provided in-depth access to Swedish working carers and professional staff’s views on and experiences of
using web-based support. The survey and descriptive analysis (IV) has provided breadth and a cross-sectional perspective on what Swedish working carers view as valuable support (including several of the ICT-based support forms in Studies I, II and III) and the extent to which such support has been received. Study IV also provides insights on caregiving characteristics and work-care conflicts that may influence the caregiving situation and the value of support. These findings are also validated by findings in Study I describing support that might mediate such adverse influence.

To strengthen the trustworthiness of findings, several considerations have been made during sampling, data collection and analysis. In qualitative studies, trustworthiness comprises credibility, dependability and transferability, which are equivalent to what in quantitative terms is referred to as validity, reliability and generalisability (Patton, 2002). In the following section, I will discuss considerations and steps taken to achieve trustworthiness of findings and conclusions drawn in this thesis. I will use terminology as appropriate in relation to sampling procedures, data collection and analysis.

Methodical considerations regarding sampling procedures

Several sampling procedures have been used in the thesis. In Studies I–III, purposive sampling has been conducted to some degree i.e. to select information-rich cases from which to gain insights about the studies’ phenomenon (Patton, 2002) and to achieve representativeness of the population (i.e. sampling validity) (cf. Krippendorff, 2013).

In Study I, the degree to which working carers are represented in the reviewed studies varies, which may be a critique. However, to achieve representativeness of findings, the screening procedure to include or exclude studies followed a robust criteria based inclusion and evaluation procedure to achieve rigor and to describe the representativeness. In quantitative and mixed method studies, this procedure evaluated sample characteristics (checking for employment), statistical analysis (checking for co-relational and causal comparative measures such as employment and work-related constructs) and findings. In qualitative studies with smaller percentage of working carers, the procedure became very much text driven, searching for text that more clearly indicated to represent experiences or views of working carers. Arguably, the chosen method for identifying studies was appropriate in that regard.

It might be argued that the mix of ICTs will reduce the depth at which any single ICT (such as web-based) can be explored. However, this purposive sampling was performed in order not to exclude any ICTs and support that might add insight into the phenomenon. In fact, this openness to alternative technologies focusing on “support” rather than ICTs can be argued to have provided broader and deeper insights about ICT-mediated support for working carers.
As mentioned in the discussion of the results, differences in gender, culture, family values and level of government support for home care may influence transferability of findings, in particular with regards to those findings related to differences in working carers’ needs, preferences, perceptions and views. However, by specifically focusing on the Swedish context in Studies II–IV, these issues were somewhat addressed in the thesis.

Bias such as small samples and convenient samples may affect transferability of outcomes in Study I, upon which the findings of this thesis is founded. However, given that the findings in Study I validated findings in Studies III and IV, transferability of the findings are improved.

In Study II, which was based on two evaluation projects, the population (sample) was readily determined in the beginning. The sample represented two groups of professional staff from two Swedish municipalities that had introduced web-based support in their work to support working carers. Arguably, this sample may be described as a convenience sample as not much selection took place i.e. all staff were invited. Nevertheless, the sample in the two sets of data represented a range of professionals, which added heterogeneity. Further, the decision to merge the two sets of data was purposive to add a maximum variation (heterogeneity) in the sample and of web-based ICTs (c.f. Patton, 2002), which arguably adds strength to the study.

In Study III, participants were sampled for heterogeneity with regard to employment, life situation, intensity and length of the caregiving process. A critique might be that participants were sometimes caring for an older person living in a long term care setting (as is also seen in Study IV), and that one participant was seeking work rather than working and had recently lost her mother after a difficult period. Some might argue that these participants are not working carers at all and therefore not representative. However, these participants were purposively recruited (or not excluded) to add further perspectives. The ‘cases’ added both breadth and depth to the findings, in terms of the influence of web-based support seen in a temporal caregiving process.

During the recruitment process in Study III, an effort was made as far as possible to avoid positioning the family care advisor in a potential power relationship with regards to participants. As the family care advisor was assisting with the recruitment, the risk of ‘gate keeper’ is plausible, thus, risking bias simply by not asking all potential participants. Nevertheless, considering the difficulties to gain access to the field, this was a calculated risk.

In Study IV, sampling in ‘carer friendly’ settings via the Swedish Dementia Association and National Swedish Carers Association, combined with the use of a web based survey cannot rule out self-selection bias, attracting those most eager (but not necessarily the most representative) to participate. Such bias might have skewed the value of support in one way or another, thus, affecting generalisability. However, several findings are
validated by the results in Studies I–III and in other carer literature, which can be seen to add (validity) to the transferability of the findings.

It has been acknowledged that very nearly equal numbers of Swedish men and women provide care (Ulmanen, 2015). A limitation of the findings may therefore be that they are primarily represented by female working carers, limiting their transferability to male populations. Despite ambition, efforts to recruit an equal mix of both men and women in Studies I–IV were not successful. This underrepresentation is unfortunate since male carers are a hidden group of carers in carer support research due to lack of participation. A possible reason for this is that male carers may have other preferences of support and that many support services are specifically geared towards female carers (Greenwood & Smith, 2015). More research is needed about male working carers and more specifically about the potential of ICT-mediated support.

The sample sizes are restricted in Studies II–IV, which limits the generalisability and transferability of findings. However, considering the explorative nature of this project, I argue that the sample size is sufficient.

Methodical considerations regarding data collection

In Studies II and III, semi-structured group and individual interviews were conducted to allow participants the freedom to express their own experiences of and conceptions about using web-based support, which has provided depth, detail and individual meaning to the use of web-based support (cf. Patton, 2002). I view the semi-structured interviews as a form of negotiated accomplishment by me as interviewer and the participants. It is a negotiated accomplishment that is shaped or constructed by the context and situation in which they take place (Oltmann, 2016). While the group interviews in Study II provided a convenient method to collect data, this method also most importantly helped to create a synergy of insights and experiences within the groups themselves that may not have been expressed individually (cf. Patton, 2002). A major reason for conducting telephone interviews in Study III was to adapt to working carers’ situation as they are a known group to have time constraints due to their work and caring situation. Telephone interviewing was chosen as way to most successfully set up a situation to enable working carers’ participation. A commonly argued opinion is that that telephone interviewing provides less of a rapport, and thus affects quality, as nonverbal language is inaccessible. However, it was still possible to discern auditory cues such as pauses, tone of voice, verbal tension manifested by curt responses, sadness, irritation or happiness (cf. Oltmann, 2016). Audio recording in combination with field notes provided rich in-depth data, thus, increasing credibility and dependability of findings.

In Studies II and III, semi-structured interview guides (with emphasis on guides) were used to generate data, more independent of the researcher (Irwin,
2013). What is common for both Studies II and III is that the interview technique is crucial to be able to remain open to what is being expressed and not be led by one’s preconceptions (Patton, 2002). For the most part, this was achieved. However, an example of the latter that I experienced in Study II was paying too little attention to other ICTs used than purely web-based ICTs. This regretfully led to missing out on the chance to explore the use of tele-care to support family carers, which in retrospect would have added further knowledge to this thesis. However, this is counter-balanced by the fact that in Study I, the review included the role of tele-care support.

The survey in Study IV comprised the instrument work-care-conflict scale, which has a clear origin, and known validity (Pearlin et al., 1990; Aneshensel et al., 1995). Test for internal consistency of the components through Cronbach’s alpha reliability reveals a good alpha of 0.75 in the original study. In Study IV, Cronbach’s alpha 0.85 revealed good reliability in the sample. It is noteworthy that the work-care-conflict scale has its origin in the US. The translation-back translation procedure was performed in a triangulated fashion with both native Swedish and English speaking translators. The scale has not, to the best of my knowledge, been tested for reliability in a Swedish population, which may affect validity. A concern may be that working carers in the US experience work-care conflict differently to Swedish working carers due to corporate and cultural differences. However, content of the items of the scale are validated by experiences of Swedish working carers, presented by Eldh and Carlsson (2011).

The 11.6–18.6% missing values in the support items in Study IV might have introduced bias into the remaining sample. For instance, missing value analysis revealed patterns of not completing the whole survey i.e. giving up half-way through ($n=26$), which may have to do with having technical issues when doing the web survey or finding the survey too extensive due to ‘caregiver fatigue’ or technical problems (both were implied in free text responses). Consequently, the findings may be representing a less burdened sample, thus, affecting validity of the results (see considerations made below for the analysis on Study IV in this regard).

Support variables in Study IV included a ‘don’t know’ response indicating that participants were unsure whether they valued a support or not. Indeed, there are disadvantages with such an approach as it may provoke convenience responses (Shoemaker, Eichholz & Skewes, 2002) that equates with a missing response and thereby reduces data and increases the risk for type 2 error. However, given that participants were asked to value support that may be viewed progressively in nature (e.g. tele-care), which many had not received (see results), the chance of imputing non-valuable responses would have been an alternative risk, which would have been worse.

To ensure reliability and validity in Study I, the literature search comprised a predefined and well-described search strategy (i.e. including search terms, electronic databases and decision tree), data evaluation and description of
analysis procedures, which improve reliability (Hopia et al., 2016). In the quality assessment stage, content validation and reliability testing using the Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011) was used. To achieve rigor in the data collection, the search was performed while consulting a librarian. The search terms were formulated to scope the ICT area widely in order to focus on working carers rather than particular ICTs. Based on the scope of studies, this strategy was successful. It has been recommended by Pluye et al. (2011) and Whittemore and Knafl (2005) that multiple researchers should be included in the data evaluation process to obtain reviewer consensus as a strategy to limit bias in the selection process of studies. This was not feasible during this study, which may limit validity. The review included a non-peer reviewed study (i.e. grey literature not published in scientific journal). No evidence of inferior quality was found. Importantly, the study disclosed in-depth positive and negative aspects with ICT-mediated support, which was not presented by other studies. Including such a study (i.e. grey literature) in the review arguably improved validity as it reduced the risk of exaggerating ‘meaning and effectiveness’ of ICTs due to publication bias (Hopia et al., 2016).

Methodical considerations regarding analysis

In Studies I–IV, overview and descriptions of the analysis has been demonstrated for transparency when reporting the results. Presentation of descriptive data and a detailed description of the context have contributed to transferability in all studies. These two steps also strengthen dependability of the analysis i.e. repeatability, which may however be difficult to achieve in qualitative studies due to the researchers role.

Studies I (integrative review), II and III (content analysis) are to be considered as qualitative methods where I have used text driven analysis. Final judgement as to whether a result is believable or sound is best made by the reader. Nevertheless, different steps have been taken during the research process to assure credibility. First, during analysis (I, II, III), multiple coding (Oliver, 2011) was conducted, in which the categories and themes developed by the first author were questioned and discussed in comparison with the primary contexts during sessions with the second and third co-authors. Such ongoing critical reflection under supervision have helped to spot bias such as inappropriate interpretations that have no bearing in the data. Second, in Study I, a synthesis was made of the findings in 14 studies, and in Study II a secondary analysis was performed of two primary data sets. For credibility in Studies I and II, attention has been paid to remain close to the primary contexts in order to avoid falsely construct findings. In both studies, efforts were also made to remain as contextually close as possible to data that act as identifiers of the primary settings and the reviewed studies (e.g. support organisation and ICTs (II) and ICTs and authors (I) (c.f. Major & Savin-
Conclusions

The blend of descriptive qualitative and quantitative studies help to provide both a breadth and depth of perspectives that when taken together can lead to an understanding about support for working carers of older people via the use of ICT. Due to the exploratory descriptive design of the studies, and restricted evidence base of the integrative review, there are limitations concerning the generalization of findings. Nevertheless, based on the findings, the following conclusions can be drawn:

- A number of working carers were empowered in their caring situation as the provision of web-based information, e-learning and education enabled them to feel more competent and prepared in their caring role and it helped strengthen their self-efficacy and positive self-appraisal of their situation.
- A number of working carers expressed feeling less burdened by their caregiving role and felt a greater sense of well-being from sharing their frustrations and burdens via online forums for emotional and social support.
- Carer support via web-based ICTs helped a number of working carers to access support that was otherwise inaccessible due to working obligations.
- Reconciliation of work obligations and caregiving activities was made easier in some instances for working carers. For example, some carers benefitted from tele-care and assistive devices by having practical assistance, such as monitoring aspects of wellbeing of their older relative from a distance, receiving safety alerts, and from the care recipient becoming more independent. Carers also benefitted from experiencing emotional and/or physical respite from caregiving.

Thirdly, in Studies II–III, verbatim descriptions (quotes) of participants during interviews have been provided to support the analysis (Graneheim & Lundman, 2004; Lundman & Graneheim, 2008; Patton, 2002).

In Study IV, a potential problem with performing statistical analysis on data with missing values is that the estimates will be biased and thus affect validity. To make sure that the pairwise deletion of cases performed in each bivariate test would not create such bias, Little's MCAR test was performed (Field, 2013). The non-significant test indicated that data were missing completely at random i.e. missing data is assumed not to matter for the statistical analysis per se, thus, did not affect the validity of the test result.
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- A number of working carers were empowered in their caring situation as the provision of web-based information, e-learning and education enabled them to feel more competent and prepared in their caring role and it helped strengthen their self-efficacy and positive self-appraisal of their situation.

- A number of working carers expressed feeling less burdened by their caregiving role and felt a greater sense of well-being from sharing their frustrations and burdens via online forums for emotional and social support.

- Carer support via web-based ICTs helped a number of working carers to access support that was otherwise inaccessible due to working obligations.

- Reconciliation of work obligations and caregiving activities was made easier in some instances for working carers. For example, some carers benefitted from tele-care and assistive devices by having practical assistance, such as monitoring aspects of wellbeing of their older relative from a distance, receiving safety alerts, and from the care recipient becoming more independent. Carers also benefitted from experiencing emotional and/or physical respite from caregiving.
• However, in contrast some carers experienced an additional workload and burden when the energy needed to manage the ICT and respond to information generated via tele-care was perceived by them to be excessive.

• Further, some working carers expressed dis-empowering aspects related to using ICT-mediated support which arose as a result of perceived lack of time to prioritise their own needs for support. Further, technical barriers were evident which stemmed from a lack of sufficient digital skills among some working carers to be able to make optimal use of the ICT-mediated support offered.

• Working carers viewed ICT-mediated support as complementary to existing forms of family carer support.

• Level of adverse psychological, practical and logistical influences on carers’ work situation connected to care obligations, such as from worry and less energy for work was associated with the majority of support, (that is both traditional forms of support and ICT mediated support) being viewed as more valuable.

• ICT-mediated support has the potential to support carers through different phases of caregiving. To ensure optimal benefit for working carers, it is necessary that ICT-mediated support is sufficiently flexible to be able to respond to carers’ unique needs and preferences which change over the course of time. Further, wherever feasible, the support needs to be introduced as early as possible within the caregiver process.

• Care professionals predominantly perceived web-based ICTs as caring tools that helped them in their support work with carers. Nevertheless, to be able to ensure a higher uptake of ICT mediated support for carers, family care support professionals themselves need to feel more comfortable with using ICT in their routine work with carers.

Policy & Practice implications
The findings in the thesis may be useful for decision makers at local, regional, national and European levels to highlight the strengths and drawbacks associated with ICT-based support targeted at working carers of older people in Sweden. Findings may act as an interesting example of current practice that highlights innovative forms of support for a group of carers that have previously been largely neglected, and how support can be used to help
empower working carers who wish to care for their older relative by facilitating the reconciliation of work and care.

- To address low take-up of support services, access to and information about ICT forms of support needs to be optimized. For instance, information about support services for working carers should be made more easily and routinely accessible in health and social service settings, at work places and at occupational health clinics.

- When implementing ICT-mediated support, it would be useful to consider combinations of ICTs such as web-based, telecare and assistive technologies together with a range of existing carer support services. More comprehensive strategies are needed in order to be able to offer working carers a broader repertoire of support options that best fit their particular situation, as opposed to a ‘one size fits all’ approach. This in turn may help to ensure a higher uptake of carer support services by working carers who currently represent the largest group of carers in Sweden.

- Whenever gerontechnology based support is used to support older people it would be beneficial for practitioners to also invite working carers that wish to and would benefit from such a support into such a partnership. In addition to continuous assessment of older people’s needs, assessment of working carers’ needs and preferences is also necessary to promote carer well-being and prevent burden. In particular, it would help with professionals’ systematic work with carers if there could be included a direct question about new technologies within all routine care assessments. For instance, ‘Would ICT forms of support help this person or be useful to her/him?’ Such a question may help to raise discussions about the potential of new technologies among professionals, older care recipients and carers themselves.

- It would help in workplace carer support if there could be included a direct question in routine human resource employee surveys that both asks employees if they routinely help support and/or care for a relative on a regular basis and if so to directly ask for their views about using ICT-mediated support at the workplace. For instance, ‘Would ICT-based forms of support that are utilized during workhours help this person or be useful to her/him to more easily balance work and care?’

- To avoid working carers’ disempowerment resulting from a lack of sufficient digital skills and subsequent risk of social exclusion from
the current information society, policies are needed at local, regional and national levels to help ensure accessible digital skills training as part of the support process. For example, training and showrooms to demonstrate and try new technologies were highlighted as possible facilitating strategies by carer support professionals.

- To avoid a low carer uptake of ICT mediated support resulting from carer support professionals’ lack of ease with using ICT in their routine work with carers, local initiatives to provide digital skills training are needed. For example, training in practical use and in ICT-based carer support work methods may be facilitating strategies.

**Further research**

To gain further knowledge and to validate results from these studies, the following suggestions for research are put forward:

- To extend knowledge of how (if at all) ICT-mediated support can facilitate working carers' health, wellbeing and/or situation over the course of a prolonged period of caring (that may extend over several or a number of years), further studies would benefit from adopting more longitudinal perspectives.

- To validate findings concerning ICT mediated support that facilitates the balance of work and care, more research is needed about ICTs’ contributory role concerning working carers’ respite. For example, the degree of freedom (or otherwise) from the potential burden that they feel obliged to respond to telecare or to assist the older person with daily maintenance and use of assistive devices.

- Further knowledge is needed about the role of ICT-mediated support at the workplace to support those working carers that experience disempowerment as a result of them finding it challenging to prioritise support for themselves.

- More research is needed about gender differences within working carer support in general, and more specifically, with regards to ICT-mediated support.

- To be able to offer ICT-mediated support during different stages of the caregiving process, further research would benefit from studying the role of ICT-mediated support in the pre-caring stage, and post-caring or bereavement phases.
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Trots en växande medvetenhet om vikten av att stödja förvärvsarbetande anhöriga som ger vård, hjälp och stöd till äldre närstående råder det brist på kunskap om stöd specifikt utformade för denna grupp. Stöd baserat på Informations och Kommunikation Teknologi (IKT) kan vara ett sätt. IKT-stöd anses idag allmänt vara ett betydelsefullt redskap för en effektivare vård och omsorg. Emellertid har såväl forskning som praktik fram för allt varit inriktat på IKT-stöd för gruppen äldre anhöriga. Det råder brist på kunskap kring hur IKT specifikt kan vara redskap i stödet av förvärvsarbetande anhöriga som ger vård, hjälp och stöd till äldre närstående. Allmänt gäller hur IKT kan (om alls) utgöra redskap att främja vårdande processer över tid och bidra till partnerskap mellan anhöriga, vårdtagare, personal under olika faser av anhörigas vårdande. Särskilt gäller det hur IKT-baserade stöd kan underlätta för anhöriga (om alls) att hantera svårigheter i vårdandet i sig och de svårigheter som kan uppstå i att balansera arbetsliv med att ge vård, hjälp och stöd.

Det övergripande syftet med avhandling en var att nå en ökad förståelse om stöd via IKT för förvärvsarbete anhöriga som ger vård, hjälp och stöd till äldre närstående genom att utforska förvärvsarbetandes anhörigas perspektiv, men även professionella anhörigstödjares inom kommunalt anhörigstöd.

Avhandlingen bygger på en litteraturstudie och tre empiriska studier.

I delstudie (I) utforskades internationell litteratur i syfte att kartlägga nuvarande evidensen kring IKT-baserade stöd för förvärvsarbetande anhöriga. En integrativ granskningsmetod har använts för att söka svar på vilket sätt IKT baserade stöd inverkar på anhörigas situation.

I delstudie II intervjuades professionella anhörigstödjare (N=17) inom två kommunala anhörigstöd. Syftet var att beskriva uppfattningar/upplevelser (såsom fördelar, möjligheter och nackdelar) av att använda web-baserade anhörigstöd (´En bra plats´ och ´Anhörigstödsportalen´) i arbetet att ge stöd till förvärvsarbetande anhöriga. Data analyserades med kvalitativ innehållsanalys.

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Sammanfattning på svenska

Trots en växande medvetenhet om vikten av att stödja förvärvsarbetande anhöriga som ger vård, hjälp och stöd till äldre närstående råder det brist på kunskap om stöd specifikt utformade för denna grupp. Stöd baserat på Informations och Kommunikation Teknologi (IKT) kan vara ett sätt. IKT-stöd anses idag allmänt vara ett betydelsefullt redskap för en effektivare vård och omsorg. Emellertid har såväl forskning som praktik fram för allt varit inriktat på IKT-stöd för gruppen äldre anhöriga. Det råder brist på kunskap kring hur IKT specifikt kan vara redskap i stödet av förvärvsarbetande anhöriga som ger vård, hjälp och stöd till äldre närstående. Allmänt gäller hur IKT kan (om alls) utgöra redskap att främja vårdande processer över tid och bidra till partnerskap mellan anhöriga, vårdtagare, personal under olika faser av anhörigas vårdande. Särskilt gäller det hur IKT-baserade stöd kan underlätta för anhöriga (om alls) att hantera svårigheter i vårdandet i sig och de svårigheter som kan uppstå i att balansera arbetsliv med att ge vård, hjälp och stöd.

Det övergripande syftet med avhandlingen var att nå en ökad förståelse om stöd via IKT för förvärvsarbetande anhöriga som ger vård, hjälp och stöd till äldre närstående genom att utforska förvärvsarbetandes anhörigas perspektiv, men även professionella anhörigstödjares inom kommunalt anhörigstöd.

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I delstudie II intervjuades professionella anhörigstödjare (N=17) inom två kommunala anhörigstöd. Syftet var att beskriva uppfattningar/upplevelser (såsom fördelar, möjliketer och nackdelar) av att använda web-baserade anhörigstöd (’En bra plats’ och ’Anhörigstödsportalen’) i arbetet att ge stöd till förvärvsarbetande anhöriga. Data analyserades med kvalitativ innehållsanalys.
I delstudie III intervjuades förvärvsarbetande anhöriga (N=9) om sina upplevelser av att ha tillgång till och använda det web-baserade anhörigstödet ’En bra plats’ som erbjudits av det kommunala anhörigstödet. Studien syftade till att beskriva vad anhöriga upplevde som fördelar, möjligheter och (eller) nackdelar och hur (om alls) de upplevde stöd i sin situation att ge vård, hjälp och stöd till äldre närstående. Data analyserades med kvalitativ innehållsanalys. I delstudie IV genomfördes en enkätundersökning med syftet att undersöka vad för stöd förvärvsarbetande anhöriga (N=129) uppfattar som värdefull (om alls) och vilka stöd de fått, med fokus på stöd via IKT. Data analyserades med deskriptiv statistik och bivariata korrelationsanalyser.

Kombinationen av kvalitativa och kvantitativa studier bidrar till att ge ett brett och djupt perspektiv som tillsammans ger en ökad förståelse av stöd till yrkesverksamma anhöriga. Den explorativa beskrivande designen av studierna och den integrativa litteraturgenomgången medför begränsningar i generaliserbarheten av resultaten. Utifrån avhandlingens resultat kan emellertid följande slutsatser dras:

- Flera förvärvsarbetande anhöriga blev stärkta i sin situation av information, e-lärande och utbildning. Detta bidrog till en känsla hos dem att vara mer kompetent och förberedd (preparedness) i anhörigrollen, samt till ökad tilltro till sin egen förmåga i vårdgivandet (self-efficacy) och förbättrad självbedömning av sina egna styrkor och svagheter (self-appraisal).

- Flera förvärvsarbetande anhöriga upplevde minskad belastning och påfrestning i rollen som anhöriga samt ökat välbefinnande genom möjligheterna att få dela sina frustrationer och påfrestningar med andra via web forum för känslomässigt och socialt stöd.

- Web-baserade anhörigstöd hjälpte flera förvärvsarbetande anhöriga att få tillgång till stöd som annars var otillgängligt för dem på grund av att de arbetade.

En del förvärvsarbetande anhöriga upplevde sig dock ibland extra belastade och påfrestade av att hantera välfärdsteknologin och svara an på den information som genererades.

Några förvärvsarbetande anhöriga uttryckte aspekter av mindre egenmakt kopplat till användningen av IKT-baserade stöd. En aspekt var avsaknad av tid att prioritera sitt eget stöd på grund av vård- och arbetssituationen. En annan aspekt var tekniska svårigheter att använda web-baserade IKT-stöd på grund av otillräckliga kunskaper, vilket minskade möjligheten att använda stöden på ett optimalt sätt.

De förvärvsarbetande anhöriga uppfattade IKT-baserade stöd som komplement till andra existerande former av anhörigstöd.

Graden av negativ psykisk, praktisk och logistisk påverkan i arbetssituationen kopplat till att ge vård, hjälp och stöd, såsom från oro och mindre energi för arbetet, samvarierade med en högre grad av värdefullhet för majoriteten av stöd.

IKT-baserade stöd har potentialen att stödja förvärvsarbetande anhöriga genom de olika faserna i anhörigvårdandet. För att säkra optimalt stöd, är det nödvändigt att de IKT-baserade stöden är tillräckligt flexibla för att kunna motsvara anhörigas unika och föränderliga behov över tid. Stöden bör också bli introducerat så tidigt som möjligt i anhörigvårdsprocessen.

Anhörigstödjande personal uppfattade/upplevde web-baserade stöd till största delen som vårdande redskap i det anhörigstödjande arbetet. För att säkerställa en så effektiv användning som möjligt är det viktigt att personalen själva är bekväma med att använda IKT och att de ser det som ett redskap i stödet till anhöriga.
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