Information and Communication Technology as a Tool for Support in Home Care

Experiences of Middle-Aged People with Serious Chronic Illness and District Nurses

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Luleå 2012

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To Roger & Martin

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ABSTRACT

The overall aim of this doctoral thesis was to elucidate experiences of needs of middle-aged people with serious chronic illness living at home and the use of information and communication technology (ICT) as a tool for support from district nurses (DNs) in home care.

   The doctoral thesis includes five papers; a systematic literature review, which comprises both qualitative and quantitative studies, and four papers that take qualitative approaches. The literature review (I) provides an overview of 107 studies that describe the use of ICT in home care. The quality of these studies was appraised and data extracted and placed within a matrix of different areas. Paper II elucidates meanings of needs of middle-aged people with serious chronic illness living at home. Twelve people with serious chronic illnesses who were also living at home were interviewed. The interviews were analysed using phenomenological hermeneutic interpretation. Paper IV describes DNs' attitudes regarding the implementation of ICT in home care. Data were collected via focus group discussions (FGDs) with 19 DNs and analysed with qualitative content analysis. Papers IV and V utilised case study designs and included an intervention that made use of ICT. Semi-structured interviews were performed with two people who had serious chronic illnesses and were living at home and with their respective DNs. These interviews focused on the experiences of the ill people and their DNs using an ICT application to communicate. Data were analysed with thematic content analysis.

   The findings of the literature review (Paper I) show that in the last ten years, the number of published studies on the use of ICT in care at home has rapidly increased. About half of the studies included in the review were published between 2007 and 2009. Most of the studies identified were performed in North America, while about one third were performed in Europe. Many different terms for the technology were used. Studies of means of supporting people with chronic illnesses were common, and heart and lung diseases were the most common diagnoses. Video equipment was commonly used, with a focus on communication between nurses and patients.

   The findings of Paper II show that meanings of needs of people with serious chronic illnesses living at home can be understood as maintaining control in everyday life, which makes life meaningful. Maintaining control means striving for independence in one's surroundings by manipulating care and support. It also seemed important for participants to choose how their lives would be and to be together with others who listened to and understood them as they were.

   The findings of Paper III show that DNs wanted to influence the design of ICT applications and be a part of their introduction and implementation in home care. The DNs viewed the use of ICT in home care as improving accessibility both for themselves and for the ill people at home. They thought that ICT could help them gain better access to information about their patients and could save time - but also take time. They discussed that the use of ICT can encroached on the autonomy of their patients and their patients' relatives living at home. Furthermore, they observed that the use of ICT in home care is not suitable for everyone and that people cannot be replaced by ICT.

   The findings of the case study (Papers IV, V) demonstrate that using an ICT application improved accessibility for people with serious chronic illnesses living at home. The use of the ICT application also saved time and eased DNs' work. In the case study, their use also resulted in more direct communication between the ill people and their DNs, which facilitated communication and led to less limitations on everyday life for the ill people, which seemed to mediate the development of more trusting relationships.

   In conclusion, the findings of this thesis could be used to help develop a more person-centred form of home care for people with serious chronic illnesses. The findings also show the importance of ill persons' talking about their life situations with nursing staff, especially early in their illnesses. The use of ICT can complement communication in home care.

Keywords: Information and communication technology, chronic illness, home care, experiences, qualitative research

ORIGINAL PAPERS

This doctoral thesis is based on the following papers, which will be referred to by their Roman numerals.

I   Lindberg, B., Nilsson, C., Zotterman, D., Söderberg, S., & Skär, L. Information and communication technology as a tool for accessibility to home care - A systematic literature review. Manuscript submitted.

II   Nilsson, C., Lindberg, B., Skär, L., & Söderberg, S. Meanings of needs of middle-aged people with serious chronic illness living at home. Manuscript submitted.

III   Nilsson, C., Skär, L., & Söderberg, S. (2008). Swedish district nurses' attitudes to implement information and communication technology in home nursing. *The Open Nursing Journal, 2,* 68-72.

IV   Nilsson, C., Öhman, M., & Söderberg, S. (2006). Information and communication technology in supporting people with serious chronic illness living at home – an intervention study. *Journal of Telemedicine and Telecare, 12,* 198-202.

V   Nilsson, C., Skär, L., & Söderberg, S. (2010). Swedish district nurses' experiences on the use of information and communication technology for supporting people with serious chronic illness living at home – a case study. *Scandinavian Journal of Caring Sciences, 24,* 259-265.

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DEFINITIONS AND ABBREVIATIONS

MIDDLE-AGED PEOPLE

In this thesis middle-aged people are defined as between the ages of 40 and 67 years.

SERIOUS CHRONIC ILLNESS

Chronic illness is defined as 'a disease or injury that has lasted more than 6 months and had caused an individual to significantly alter of his or her day-to-day activities' (Ironside et al., 2003, p. 172). 'Serious' means that the chronic illness is not curative and that the person has an extensive need for help and support.

HOME CARE

Care provided to a person in his/her own home. Home care covers a wide range of activities from preventive visits to care at the end of life (Thome, Dykes & Rahm Hallberg, 2003). Other terms exist to describe home care, e.g., home nursing, home health care. In this thesis the term 'home care' is used most frequently and includes help and support both from professionals and from others, such as family members and relatives.

DISTRICT NURSES (DNs) IN HOME CARE

In Sweden, a DN has a graduation diploma and has the education needed to work in various areas within primary health care, such as children or adolescent health, telephone advice in health care or in home care.

PERSONAL ASSISTANCE

Under Swedish law (SFS 1993:387; SFS 2010:480) people younger than 65 who are living with disabilities have the right to personal assistance in their daily lives.

INFORMATION AND COMMUNICATION TECHNOLOGY (ICT)

ICT enables people to communicate, gather information and interact with distance service more easily, without the limitations of time and space (Campbell, Dries & Gilligan, 1999).

eHEALTH

eHealth refers to health-related ICT tools and services whether the used behind the scenes by healthcare professionals or directly by patients and their relatives (European Commission, 2012).

INTRODUCTION

During the last few years, people with serious illnesses have been discharged from hospitals more rapidly than was previously the case. Therefore, people with chronic illnesses, who have complex needs for help and support, have come mostly live and be cared for at home (The National Board of Health and Welfare, 2008). This development has meant an expanded need by people with serious chronic illnesses who are living at home for support and care by professionals (Öhman, Söderberg & Lundman, 2003). Therefore, it is important that high quality care be attained in home care (Walshe & Luke, 2010). About 250,000 people in Sweden received home care in 2008 (The National Board of Health and Welfare, 2008), and nearly eight per-cent of women and three per-cent of men had chronic illnesses that required day-to-day care in 2011 (Statistical yearbook of Sweden, 2011). Hence, it is a challenge to develop appropriate means of supporting people with serious chronic illnesses living at home. One way to achieve this may be to use suitable applications of information and communication technology (ICT). This doctoral thesis aims to give an insider view of the experiences of people with serious chronic illnesses living at home and to test the utility of an ICT application as a means of supporting people with serious chronic illness living at home to communicate with their district nurses (DNs).

A naturalistic perspective

This thesis is within the naturalistic perspective, as its intention is to describe experiences of people with serious chronic illnesses and DNs' experiences and attitudes toward ICT use in home care. Research within the naturalistic perspective takes place in real-world settings (Patton, 2002, p. 39) which are also called 'natural settings' (Lincoln & Guba, 1985, pp. 189-192). Research that adopts a naturalistic perspective focuses on participants' own experiences (Patton, 2002, p. 341). The research presented in this thesis was conducted in the context of home care and with attention to the perspectives of people with serious chronic illnesses and district nurses working in home care, i.e., with attention to insider perspectives. The insider perspective approach focuses directly and explicitly on the experience of existing with illness. This perspective is in contrast to the outsider perspective, which implies the minimisation or ignoring of the subjective reality of the ill person (Conrad, 1987). No phenomenon can be understood without relation to the time and context to which it belongs. In this thesis, 'natural settings' were the homes where people with serious chronic illnesses lived in extensive need of help and support in their everyday lives.

Living at home with a chronic illness

Living with chronic illnesses changes daily life in several ways, both for people with chronic illnesses (Haahr, Kirkevold, Hall & Østergaard, 2011; Morse, 1997; Rapley & Fruin, 1999; Öhman et al., 2003) and for their partners (Söderberg, Strand, Haapala & Lundman, 2003) and family members (Jumisko, Lexell & Söderberg, 2007; Öhman & Söderberg, 2004b). Substantial research has described the daily lives of people with chronic illnesses (e.g., Corbin & Strauss, 1987; Ek, Sahlberg-Blom, Andershed & Ternestedt, 2011; Olsson, Lexell & Söderberg, 2008; Paterson, 2001; Rapley & Fruin, 1999; Söderberg, Lundman & Norberg, 1999; Thorne & Paterson, 2000; Toombs, 1993). The loss of their previous bodies, to which they were habituated, affects their daily lives in different ways, causing a sense of lack of control (Ahlström, 2007; Brännström, Ekman, Norberg, Boman & Strandberg, 2006; Melin-Johansson, Ödling, Axelsson & Danielson, 2008; Olsson et al., 2008; Öhman et al., 2003) and a lack of independence and freedom (Ellefsen, 2002; Strandmark, 2004; Söderberg et al., 1999). According to Ironside et al. (2003), loss of one's previous body means restriction of one's freedom. All losses of freedom implies, among other things, being dependent on care. Being dependent on care requires the adoptions of a new way of looking at oneself and relating life before diagnosis to life after it (Ironside et al., 2003).

People living with chronic illness may habitually feel loneliness and isolation (Brännström et al., 2006; Charmaz, 1983; Ek et al., 2011; Melin-Johansson et al., 2008). According to Öhman et al. (2003) loneliness among people with serious chronic illness may lead to a sense of being left out, even if they have close relatives near. Unintentional isolation can occur, which means being cut off from the outside world (Melin-Johansson et al., 2008). Experiences with lack of understanding by others (Ellefsen, 2002; Söderberg et al., 1999), loss of respect by and changes in relations with others, loss of privacy in everyday life and difficulty agreeing with caregivers about the planning and implementation of one's own care (Ellefsen, 2002) are common among people with chronic illness and disability. For people suffering from chronic illness, basic life prerequisites are uncertain and identities associated with social roles are challenged (Delmar et al., 2005). Whittemore and Dixon (2008) emphasise that integrating chronic illness into daily life and getting back control is a difficult and complex process that means staying afloat, weathering the storm, and adjusting to illness.

Being at home means more than being in a physical environment. At home,

people develop different relationships that also become part of their self-concepts (Moore, 2000). Usually, home is conceived of a place in which privacy and identity is protected; it is familiar and linked to comfort (Rousch & Cox, 2000). But the home can also be perceived as something limiting, and associated with force, demands and obligations (Moore, 2000). Therefore, the concept of being at home can be described as ambiguous.

It is seen as important for people with chronic illness to be able to live at home, (Appelin & Berterö, 2004; Benzein, Norberg & Saveman, 2001; Melin-Johansson et al., 2008; Öhman et al., 2003), because home, for them means security (Appelin, Brobäck & Berterö, 2005; Melin-Johansson et al., 2008; Öresland, Määtä, Norberg & Lűtzén, 2009) and can provide a sense of independence (Melin-Johansson et al., 2008). Home, for those with illness, is thought of as a safe and privileged place, engendering feelings of familiarity that may lead to wellbeing (Appelin et al., 2005; Melin-Johansson et al., 2008). Being at home despite a serious illness, may entail the performance of daily routines and the maintenance of one's social interaction and dignity. But the home also turns into a public arena where the door always remains open, partly for health professionals. This in turn, implies that the ill person's integrity and that of the ill person's family is affected (Appelin et al., 2005; Öhman et al., 2003). Wilkes, Cioffi, Warne, Harrison and Vonu-Boriceanu (2008) emphasise that people with complex and chronic illnesses see it as important to avoid care at hospitals and, instead, be cared for at home.

Needs among people with chronic illnesses living at home

The concept of 'needs' has been explained in different ways. Maslow (1970) has described needs as a hierarchy, extending from physical needs to self-realization. Eriksson (1987, pp. 60-63) differ between needs and desires, and means that needs comprise only person's basic needs such as eating and sleeping. Desires means longings, hopes and wishes and are more important than needs. According to Eriksson (1990, p. 83) needs can be satisfied, but desires increase when they are activated. To desire is to take a risk that requires courage (Eriksson, 1990, p. 83). However, needs in this thesis, means needs experienced by people with serious chronic illness living at home.

For people living with chronic illnesses it is important to live as normally as possible (Ek & Ternestedt, 2008; Jeon et al., 2010; Taylor, Gibson & Frank, 2008), to be met with respect and engagement (Jeon et al., 2010) and to get help

and support on their own terms of need (Olsson, Skär & Söderberg, 2011). Several studies (Melanson & Downe-Wamboldt, 2003; Toombs, 1993; Öhman et al. 2003; Öresland et al., 2009) also show that people with chronic illnesses experience a need for control and independence in their everyday lives, without which feelings of anxiety and fear arise (Toombs, 1993; Öhman et al., 2003). People with illness living at home refer that nurses are more concerned with doing tasks than communicating with them personally, being supportive, and fostering feelings of wellbeing (Öresland et al., 2009). People cared for in their homes emphasise the importance of nurses' listening to them without judging or violating their opinions (Olsson et al., 2011; Öresland et al., 2009). They also state that it is their routines that should be followed and not health professionals' routines (Öresland et al., 2009). Therefore, a basic priority of people who are cared for at home is having support and resources available to facilitate their daily lives (Appelin et al., 2005).

Living with chronic illness means relying on assistive devices to facilitate daily life (Ek et al., 2011; Strandmark, 2004; Öhman et al., 2003), but this can also be seen as demeaning (Ek et al., 2011; Toombs, 1993). People with chronic illness must evaluate new experiences and develop new insights into the resources they still have for adapting to the situations (Rapley & Fruin, 1999) and to illness (Strandmark, 2004). Delmar et al. (2005) illustrate that reaching harmony with oneself when living with chronic illness demands a move towards acceptance of chronic suffering and illness, which can be difficult to achieve.

Research (Jumisko et al., 2009; Olsson, Skär & Söderberg, 2010) has shown that people living with chronic illnesses use different strategies to feel well. Being able to do what one want to do is important to feeling well (Corbin, 2003; Toombs, 1993), as is being involved in decisions about one's own care (Benzein et al., 2001; Öresland et al., 2009).

Previous research describing the needs experienced by people living with chronic illness has mostly consisted of studies with older people (e.g. Carling Elofsson & Öhlen, 2004; Olofsson, Andersson & Carlberg, 2005) or studies with mixed-aged adults (Jooste, Chabeli & Springer, 2010; Melin-Johansson et al., 2008; Wilkes et al., 2008). A literature review (Algera, Francke, Kerkstra & van der Zee, 2004) shows lack of studies describing the needs experienced by and care delivered to people with long-term illnesses living at home.

District nurses in home care

Nurses, or DNs, in home care consider their roles to be central and think of themselves as coordinators when care at home is provided (Dunne, Sullivan & Kernohan, 2005; Karlsson, Morberg & Lagerström, 2006; Scott & Lundgren, 2009; Wright, 2002). At the same time, they see themselves as guests when visiting other people's home (Andrée-Sundelöf, Hansebo & Ekman, 2004; McGarry, 2003; Öhman & Söderberg, 2004a; Öresland, Määttä, Norberg, Winther Jörgensen & Lűtzén, 2008). Despite this, they point out the importance of taking their profession seriously (Öhman & Söderberg, 2004a; Öresland et al., 2008). In some cases, this can be difficult, because close relationships are established with the ill person and his or her families (Öhman and Söderberg, 2004a). However, the need to be professional can be seen as the need to maintain a balance between being professional and being private. Skilled nurses and other necessary resources must be available to coordinate and customize care for people with complex care needs living at home (Andrée-Sundelöf et al., 2004).

Studies (Berterö, 2002; Walshe & Luker, 2010; Wright, 2002) have shown that DNs consider their relationships with people care for at home to be significant and meaningful on a fundamental level. Walshe and Luker (2010) show that good relationships between DNs and ill people are linked to quality of care. Berterö (2002) and Karlsson et al. (2006) describe how DNs try to maintain continuous communication with the ill person care for at home, so as to be available, and have control of their work. According to Dunne et al. (2005), DNs assert that communication is best if the same person is responsible for the overall care of the ill person. The time and geographical distance are factors that influence their building up relationship in home care (Öresland et al., 2008). However, DNs say trust and reliance in relationships with ill people at home grow over time, despite the existence of suspicion at the beginning on the part of the ill (Öhman & Söderberg, 2004a).

Several studies (Dunne et al., 2005; Evans, 2002; McHugh, Pateman & Luker, 2003; Rout, 2000; Walshe & Luker, 2010) show that DNs find their work stressful. One reason is lack of control and time and the inability to handle situations (Wilkes et al., 1998). Feelings of disappointment and anxiety may appear, when DNs do not feel able to provide the care they would like to give (Berterö, 2002). A review (Walshe & Luker, 2010) shows that DNs experience their work in palliative care at home was undervalued and emotional difficult.

The workload for DNs in home care continues to increase which demands changes in the way they work (McHugh et al., 2003).

Information and communication technology in healthcare

Over the last decade, the use of ICT has helped develop new ways of providing efficient and secure healthcare. This has resulted in a rapid increase in the use of ICT applications in health care, collectively, commonly referred to as eHealth (European Commission, 2012; World Health Organization (WHO), 2006). The concept of 'ICT' can be seen as an umbrella term for a variety of areas in our society, not limited to health care. In this respect, ICT contrasts with eHealth, which can be seen as an umbrella concept merely for the use of ICT in health care. Different incarnations of ICT are used in health care, e.g., telecare, telemedicine, telehealth, telenursing and eHealth. A systematic review (Oh, Rizo, Enkin & Jadad, 2005) has identified 51 definitions of eHealth in published materials. This indicates the importance of agreeing on common strategies for using definitions of eHealth.

Information and communication technology as a tool in home care

Several ICT applications have been tested and used in healthcare to support ill people in different areas, e.g., among caregivers for ill people at hospices (Demiris, Parker Oliver, Courtney & Porock, 2005), among frail older people living at home (Engström, Ljunggren, Lindqvist & Carlson, 2005; Ezumi et al., 2003; Magnusson, Hanson & Borg, 2004), among children with multiple or critical illnesses and their families (Lindstrand, 2002; Morgan, Grant, Craig, Sands & Casey, 2005), among mothers during their infants' first years (Nyström & Öhrling, 2006), among young people with diabetes (Rasmussen, Dunning & O'Connel, 2007), among those with leg wounds treated at home (Jönsson & Willman, 2007), among parents of preterm infants (Lindberg, Axelsson & Öhrling, 2009) and among people with mental illnesses at home (Godleski, Cevone, Vogel & Rooney, 2012).

Several studies have been performed on the use of ICT applications by and with older people, both internationally and nationally. It might be prejudicially assumed that age is a barrier to the use of ICT, but studies show the opposite (Demiris, Speedie & Finkelstein, 2001; Levy, Jack, Bradley, Morison & Swanston, 2003; Magnusson et al., 2004). Demiris et al. (2001) describe how older people felt initial fear about using ICT, but this fear seemed to diminish after a while. Studies (Allen, Roman, Cox & Cardwell, 1996; Arnaert & Delesie,

2001; Finkelstein et al., 2004) have shown that older people with chronic illnesses living at home are satisfied with the use of various ICT applications as part of their home care. Engström, Lindqvist, Ljunggren and Carlsson (2006) have shown that ICT helps older, cognitively impaired people living in nursing homes communicate with their families. The use of ICT applications may lead to family members becoming more involved in the care of relatives with dementia (Sävenstedt, Brulin & Sandman, 2003). Family caregivers can also be helped and supported by ICT, which reduces isolation, creates presence and provides easier access to care professionals (Magnusson et al., 2002). A review (Magnusson et al., 2004) shows the importance of employing user-friendly ICT applications in the care of older people with chronic illnesses living at home.

Johnston, Wheeler, Deuser and Sousa (2000) have shown that the use of remote video technology in home healthcare settings with people living with chronic illnesses is effective, well received and enables quality of care to be maintained. According to Agrell, Dahlberg and Jerant (2000), ill people living at home and using ICT feel increased access to nurses and have positive views of ICT's effects on their state of health. Simultaneously, they feel uncomfortable disclosing intimate information and perceive their social togetherness with nurses as being reduced. A review (Botsis & Hartvigsen, 2008) shows that patients who use telecare at home prefer a combination of ICT and traditional health care delivery. Some of the advantages of telecare considered by health professionals are its ability to save time and avoid the need for travel. Avoidance of travel is also a benefit for ill people who need care (Hailey, Roine & Ohinmaa, 2002; Larcher et al., 2002).

A systematic review (Eland-de Kok, Os-Medendorp, Vergouwe-Meijer, Bruijnzeel-Kommon & Ros, 2011) of the effects of eHealth's use with patients with chronic illnesses shows that cost-effectiveness, quality of life and patient satisfaction are rarely investigated. It is important to research the role of home telehealth in improving accessibility and communication for both staff and patients. Such research will help determine the impacts, benefits and limitations of developing feasible solutions for home telehealth (Koch, 2006).

RATIONALE

Recent changes in health care have led more people with serious chronic illnesses to live in their own homes. This has led to increased care/nursing care at home. The literature review reveals that making it possible for people with serious chronic illnesses to live at home requires that these people feel they receive support and security from their nursing staffs and also feel that this support is based on their needs. A challenge for DNs, therefore, is to find new ways of providing this support. Therefore, in this thesis, the ability of an ICT application to enhance communication between people with serious chronic illnesses living at home and their DNs is tested. The goal of this application is to increase accessibility, security and safety for people with serious chronic illnesses living in their own homes. Increased knowledge about this issue can highlight opportunities to improve and change home care for people with serious chronic illnesses in ways that respond to these people's needs.

THE AIM OF THE DOCTORAL THESIS

The overall aim of this doctoral thesis was to elucidate experiences of needs of middle-aged people with serious chronic illness living at home and the use of ICT as a tool for support from DNs in home care.

Specific aims of the papers

Paper I   to provide an overview of characteristics of studies describing the use of ICT in home care.

Paper II   to elucidate meanings of needs of middle-aged people with serious chronic illness living at home.

Paper III   to describe DNs' attitudes regarding the implementation of ICT in home nursing.

Paper IV   to describe the experience of people with serious chronic illness who use ICT in communicating with their DN.

Paper V   to describe the DNs' experiences of using ICT to communicate with people with serious chronic illness living at home.

MATERIALS AND METHODS

Design

An inductive approach, with a qualitative method, was used in this thesis (II-V). This choice meant that the researcher established no predetermined course for the phenomenon, but instead allowed it to evolve naturally, i.e., adopted a naturalistic perspective (Patton, 2002, p. 39). The systematic literature review presented in Paper I is a summary of research on a specific questions that follow methodology according to DiCenso, Guyatt and Ciliska (2005, pp. 138, 139). The interviews in Paper II were analysed with phenomenological hermeneutic interpretation, inspired by Ricoeur (1976) in order to develop deeper understanding of meanings of needs of people with serious chronic illness living at home. Paper III has a qualitative descriptive design in order to describe DNs' attitudes of using ICT in home care. Papers IV and V have a qualitative single case study design that includes two embedded units of analysis inspired by Yin (2009, pp. 46-53). This choice was made in order to describe separately the ill people's and DNs' experiences using the ICT application. Another reason was to enable following the process during a limited period, to gain deeper understanding of experiences using ICT to communicate. The case consisted of two middle-aged people with serious chronic illnesses living at home and the DNs responsible for their nursing care, who used an ICT application to enabled for the ill person to communicate with their DN and vice versa when the need arose. An overview of design, data material/participants, methods of data collection, number of interviews and methods of analysis is presented in Table 1.

Table 1. Overview of design, data material/participants, methods of data collection, number of interviews and methods of analysis

Paper	Design	Data material/ participants	Data collection	Number of interviews	Analysis
I	Systematic literature review	107 studies	Systematic database searches		Quality appraisal, data abstraction and analysis
II	Qualitative	12	Interviews	12	Phenomenological hermeneutic interpretation
III	Qualitative	19	Focus group discussions	5	Content analysis
IV	Qualitative case study	2	Interviews	8	Thematic content analysis
V	Qualitative case study	2	Interviews	6	Thematic content analysis

Context

This doctoral thesis was conducted within the primary health care system in the County Council of Norrbotten in northern Sweden. Nine primary health care centres were included. Two were found in sparsely populated areas and the others in densely populated areas. The population in Norrbotten today is about 249,000. The vicinity includes 14 municipalities and 38 primary health care centres, 6 of them private. This thesis focused on middle-aged people with serious chronic illnesses who lived in their own homes and had extensive need of help from others, such as their families, close relatives, friends and nursing staff, e.g., DNs and personal assistants.

Data material/participants and procedure
The systematic literature review (I)
In the systematic literature review presented in Paper I, the inclusion criteria for the selected studies were: ICT interventions, studies published in scientific journals from 2000 to 2010 and studies written in the English language. The criteria for exclusion were ICT interventions that included technological systems not involving people (no active patient acceptance), such as monitoring by cameras, alarm systems, and use of ordinary telephones, but telephones could be

used as complements to other ICT applications. The systematic literature review was performed according to following steps: Formulate a research question, conduct literature search, apply inclusion and exclusion criteria, abstract data and conduct analysis (DiCenso et al., 2005, pp. 138, 140).

Middle-aged people with serious chronic illnesses (II, IV)

In the study presented in Paper II, a purposive sample (Morse, 1991) of 12 middle-aged people, seven women and 5 men with serious chronic illnesses, participated. The inclusion criteria were middle-aged people between 40 and 67 years of age living at home and in extensive need of help and support in daily life. The participants included in the study were between 40 and 66 years old (md=57), and their illnesses had been in progress from 4 to 39 years (md=26), with the exception of one participant, who had been ill from birth. Eight lived alone, four were married and nine had children. All had help from nursing staff, including DNs, occupational therapists, physiotherapists and physicians. They had personal assistance, except for two, who had help and support merely from their families and close relatives. The duration of help and support from personal assistants (n=10) varied from 4 to 24 hours every day (md=12). Four of the participants had help and support both day and night. All except one participant used a wheelchair. Disease diagnoses in the sample included multiple sclerosis, stroke, serious diabetes and leg amputation, spina bifida with hydrocephalus and neck and back injuries with paralysis.

Participants were recruited from four primary health care centres in northern Sweden. Two of these were located in sparsely populated areas and the other two in more densely populated areas. Participants were selected by DNs from the four primary health care centres, in keeping with the inclusion criteria for the study (II). First, DNs gave potential participants oral information about the study and a written information letter with a reply form, where informed consent to participate was requested. Three participants were recruited by an interest association at whose meeting I gave information on my study and left information letters with reply forms. After people with serious chronic illnesses had agreed to participate, I phoned each person to supply additional information about the study and obtained agreement on a time and place for an interview.

In the study presented in Paper IV, two middle-aged people with serious chronic illnesses living at home participated. Both had difficulty talking, as a result of their conditions. The criteria for participation were living at home, needing extensive

help and support and establishing contact with the DN responsible for nursing care. Both participants needed extensive help with all their basic needs, such as eating and personal care. One was interested in using a computer and Internet and had used, before the study started, a home computer activated by the participant's own voice. This participant lived in a flat with a close relative who helped a lot with everyday tasks. The participant also had help and support from a personal assistant both day and night. The other participant had little experience using computers and needed help from personal assistants when using ICT. This participant was single and lived in a private house with help and support from personal assistants at all hours of the day. A great deal of help and support was also given from a close relative who lived nearby.

In this study (IV), the heads of two primary health care centres in northern Sweden were contacted and consented to participate. Information about the study was given, and informed consent was obtained. The DNs from the two primary health care centres who participated in the study (the same DNs who participated in the study presented in Paper V) each selected one person with a serious chronic illness who was living at home and fulfilled the criteria for participation. Both oral and written information about the study was provided. I informed the potential participants of the study's purpose and distributed information letters with reply forms on which to indicate informed consent to participate. After receiving permission, I obtained agreement on times and places for interviews before, during and after intervention.

District nurses (III, V)
In the study presented in Paper III, a purposive sample of 19 female DNs participated. The criteria for participation were being a registered nurse with a DN graduation diploma and working as a DN. The ages of participants ranged from 30 to 64 years (md= 47). The DNs had been registered nurses for 2 to 37 years (md=19) and had worked as DNs for between 1 and 23 years (md=5). Eleven DNs worked during the day, and eight worked in the evenings and at night.

I phoned the heads of the four participating primary health care centres and provided information about the study (III). All gave their permission for the study to be carried out. The heads provided information to DNs and distributed information letters with reply forms on which to indicate informed consent to participate in the study. Oral information about the study was conveyed to the

DNs at a planning meeting for the study by me and my co-supervisor. After receiving their consent to participate, I contacted them and obtained agreement on times and places for focus group discussions (FGDs).

In the study presented in Paper V, two DNs participated. The criteria for participation were being a registered nurse with a DN graduation diploma, possessing an established contact with a person with a serious chronic illness and being responsible for that person's nursing care. Both DNs who participated had long work experience, having been registered nurses for between 23 and 39 years and DNs for between 13 and 16 years. Both had experience using computers in their work, because the case record system was computerised.

The same heads in the study presented in Paper IV gave their permission for the DNs to participate in this study (V). Information about the study was given to the DNs, and informed consent was obtained. After receiving the DNs' permission to participate, I contacted them, supplied additional information about the study and obtained agreement on times and places for interviews before, during and after intervention.

The intervention (IV, V)

A computer program called Rexnet® was used in the intervention presented in Papers IV and V, to enable communication by text between people with serious chronic illnesses living at home and their DNs. The program consists of different virtual rooms in which people communicate through text messages, using any computer with an Internet connection. Rexnet® is reputed to be user-friendly in the context of the intervention performed (IV, V), and the program was secure against intrusion. A program that used text messages was considered a suitable form of communication, as the people with serious chronic illnesses in this study had difficulty talking, due to their conditions.

The intervention took place from the beginning of November 2003 to the end of February 2004 (Figure 1). Prior to the start of the study, participants received information about how to use the ICT application, and during the intervention, they had access to user support. The DNs also carried out traditional home visits during the intervention. Mobile phones with Internet connections made it possible for them to receive and reply to messages via Rexnet® wherever they were. The people with serious chronic illnesses living at home used the ICT application both day and night, unlike the DNs, who used it merely during their

daytime working hours. An overview of the intervention is presented in Figure 1.

Before the intervention	During the intervention				After the intervention
⋆ ⋆ ⋆ ⋆ P1 P2, P1 P2 ⋆ ⋆ DN1 DN2	⋆ ⋆ P1 P2 ⋆ ⋆ DN1 DN2				⋆ ⋆ P1 P2 ⋆ ⋆ DN1 DN2
Oct 2003	Nov	Dec	Jan 2004	Feb	Mar

Figure 1. A schematic overview of the intervention study

⋆ Semi-structured interviews with the participants (P and DN) before, during, and after the intervention.
P = People with serious chronic illness living at home

Data collection

Search strategy and selection process – systematic literature review (I)

The electronic bibliographic databases PubMed, Scopus and CINAHL were used in the literature search. This search was limited, to include only English language studies and studies published from 2000 to June 2010. The main keywords used were: telemedicine, information and communication, ICT, technology, e-Health, home care services, home and nursing. The search strategy was customized for each database. All studies retrieved were imported into a reference manager (EndNote®). The literature search resulted in a total of 1,276 studies. After duplicates were discarded, 923 articles remained. A search alert was also created to get the latest published articles, which amounted to eleven.

The first selection, based on article titles and abstracts, identified articles that were within the scope of the research question. A number of 320 studies remained for closer review. This review started with a reading of all abstracts, to identify how and between whom communication occurred in each study. During this phase, discussions between the authors occurred, with the aim of reaching consensus.

This reduced the number of relevant studies to 139. Of these, nine were unavailable both electronically and in paper form. Therefore, 130 studies remained.

Focus group discussions – district nurses (III)

In the study presented in Paper III, FGDs were carried out with a total of five groups; four groups included four participants each, and one group included three participants. The FGDs were carried out from May 2005 to March 2006 and gleaned DNs' attitudes regarding the implementation of ICT in home care. I was the moderator of all FGDs, each of which was attended by my main supervisor, who provided summaries that concluded the discussions. The intent of the moderator is to generate discussion, ask questions and encourage everyone in the group to participate in the discussion (Kitzinger, 1995; Kitzinger & Barbour, 1999, p. 4). Kitzinger (1995) emphasises that FGDs are appropriate for studies of attitudes, experiences and ideas. According to Morgan (1997), FGDs produce data through group interaction, and the topics to be discussed should be decided in advance by the researcher.

Before each FGD, I introduced the topic to be discussed. Two examples of ICT use were presented. The first was a field case that included different types of ICT equipment. Pictures of the field case content were shown to the participants in each focus group, to stimulate discussion (cf. Kitzinger & Barbour, 1999, pp. 11, 12). The second example was the use of an ICT application that had been used in the case study presented in Papers IV and V to enhance communication between people with serious chronic illnesses living at home (IV) and their DNs (V).

The FGDs took place in a quiet, comfortable room free from interruption, either in participants' primary health care centres (n=2) or in the university department (n=3). Each FGD started with a request that the participants introduce themselves. An interview guide was used with various questions concerning DNs' views about using ICT in their work, including, for instance, such subjects as how the use of ICT could influence care at home, expectations and the opportunities and risks involved in using ICT in home care work. These topics were also discussed from an ethical perspective. Clarifying questions were asked, e.g., 'Please, give an example', 'What do you think?' The FGDs lasted for about 90 minutes, were tape recorded, and were later transcribed verbatim.

Interviews – middle-aged people with serious chronic illnesses (II, IV) and district nurses (V)

In the study presented in Paper II, personal interviews were conducted in 2010. Kvale and Brinkman (2009, p. 44) have determined that interviews are suitable for describing and understanding the meaning of essential themes in interviewees' life worlds. In the study presented here, interviews started with a broad question: 'Please tell me about your need for help at home related to your illness'. Examples of topics that were mentioned include security, safety, help from others, relationships, loneliness, spare time occupations and the possibility of influencing own's care. During the interviews, probing questions were asked and comments made to clarify participants' comments. Examples included: 'Give an example', 'Explain that further', 'Tell me what happened then' and 'What do you mean?' Two participants brought assistants for support during their interviews; one had his son, and the other had a personal assistant. The interviews ranged from 31 to 66 minutes. They were digitally recorded and then transcribed verbatim. All participants preferred to be interviewed in their homes.

In the case study with a performed intervention (IV, V), semi-structured interviews were used to collect participants' descriptions of their experiences using ICT to communicate. These interviews covered a specific set of topics (cf. Kvale & Brinkman, 2009, pp. 150-156; Polit & Beck, 2012, p. 537) and were performed before, during and after the intervention, from October 2003 to March 2004. The interviews before the intervention started with an opening question, which, for the people living with serious chronic illnesses, was, 'Tell me about your experiences living with your illness in everyday life' and, for the DNs, was, 'Tell me about your experiences caring for people with serious chronic illnesses at home'. Opening questions can yield spontaneous and rich descriptions of participants' experiences of the present (Kvale & Brinkman, 2009, p. 150). They were followed by various questions that narrowed the topic, with the support of an interview guide that consisted of themes with questions about treatment, accessibility, continuity, safety/security, trust, loneliness and communication. Follow-up questions such as 'What happened then?' and 'How did you feel then?' were asked. These interviews lasted about 40 to 60 minutes. Before the intervention, DNs were interviewed once, whereas the ill people were interviewed twice, because they had difficulties talking, owing to their illnesses. The second interview with the ill people gave them a chance to further clarify their experiences.

In addition, follow-up interviews were performed during and after the intervention, which lasted about 30 minutes for each participant. For these interviews, an interview guide was used to select questions based on answers to the questions asked in the interviews before the intervention. Questions were formulated as opening questions, to give participants the opportunity to talk freely and in their own words. Sometimes, follow-up questions were asked, as Kvale and Brinkman (2009, pp. 150, 151) note that these can help develop a wider context by demonstrating the curiosity, persistence and critical mind of the interviewer. All of the people with serious chronic illnesses were interviewed in their homes, while the DNs were interviewed in their places of work, according to their wishes. The interviews were tape-recorded and transcribed verbatim.

Data analysis

Quality appraisal and data abstraction (I)

A quality appraisal was performed of the remaining 130 studies in the systematic literature review. These studies were rated as 'high', 'good', 'fair' or 'low quality'. Different protocols, adapted for studies with quantitative and qualitative approaches, were used (cf. Willman, Stoltz & Bahtsevani, 2011). The questions in the protocols could be answered with 'yes', 'no' or 'unclear'. The number of questions answered 'yes' was divided by the total number of questions and converted to a percentage. The percentage was then transformed to a rating of 'high', 'good', 'fair' or 'low quality'. Studies of low quality were excluded (n=23). After the quality appraisal, 107 articles remained for further analysis.

Data were extracted from the included studies and placed into a matrix in the following areas: country of origin, year of publication, study approach, journal, communication strategies, type of technology, type of communication, disease diagnosis, quality appraisal. Each study was indexed. Then, data from each study was categorized by such criteria as country of origin, year of publication, study approach, journal, communication strategy, type of technology, type of communication, disease diagnosis and quality appraisal. Finally, data from each study was extracted and entered into a matrix.

The phenomenological hermeneutic interpretation (II)

A phenomenological hermeneutic interpretation, inspired by Ricoeur (1976) and developed by Lindseth and Norberg (2004), was used to analyse the interview texts. By interpreting a text, meanings can be clarifies and mediates, with the intention of understanding lived experiences. Lived experiences are always personal, but their meanings can be mediated and presented to others through narratives (Lindseth & Norberg, 2004; Ricoeur, 1976). During the analysis, movement between nearness and distance occurred as did movement between understanding and explanation (cf. Ricoeur, 1976). This led the researchers toward a deeper understanding of the phenomena under study. This required a dialectic movement between understanding the texts as wholes and explaining their different pieces (Ricoeur, 1976, pp. 71-74). To understand a text means to follow the text's movement from sense to reference (to gain an understanding of the meaning of the text); that is, to move from what the text says to what it talks about (Ricoeur, 1976, pp. 87-88). Geanellos (2000) has interpreted Ricoeur's words 'What the text says' to mean explanations of parts of a text. 'What the text talks about' refers to the meaning of what a text reveals. In the case of this study, interpretation of the texts at hand was performed in the three phases that make up the phenomenological hermeneutic interpretation: naïve understanding, structural analysis and comprehensive understanding with reflection (Lindseth & Norberg, 2004).

The interpretation started with several readings of the texts. An open mind was maintained, in order to grasp the broader meaning of the texts. According to Ricoeur (1976, p. 74), this phase (naïve understanding) could be viewed as a first interpretation. Structural analysis is the second phase and aims to explain a text (Lindseth & Norberg, 2004). In this phase, the texts were read again and divided into meaning units based on similarities and differences. These units were condensed and compared, guided by naïve understanding. They were sorted into groups in several stages. Structural analysis is not a linear process, but is, rather, a process of moving back and forth between the whole and parts of the text. Subthemes and themes were abstracted, to elucidate meanings of the needs of middle-aged people with serious chronic illnesses living at home. To validate or invalidate the findings, the themes and subthemes were compared with the naïve understanding. In the last phase, comprehensive understanding, the texts were read again, and comprehensive understanding with reflection was formulated on the naïve understanding, the subthemes, themes, our pre-understanding and relevant literature.

Qualitative content analysis (III)

Qualitative content analysis, with a manifest approach, was performed in the study presented in Paper III, in order to enhance our understanding of the phenomena under study. Manifest content refers to the visible, obvious parts of a text (Downe-Wamboldt, 1992). Our analysis started with several readings of the interview texts, to achieve a sense of their content (cf. Sandelowski, 1995). Qualitative content analysis implies several steps of analysis, resulting in categories that are reduced in number with each step (Downe-Wamboldt, 1992).

The interview texts were divided into textual units, guided by the aim of the study, and condensed while preserving the cores of the textual units. Then, the textual units were sorted into groups, according to the answers to the questions: What is this? What does this stand for? Each group was labelled with a code. The contents in each group were sorted into categories. These categories were brought together in several steps, to form broader categories.

Thematic content analysis (IV, V)

Based on Baxter (1991), thematic content analysis was performed in the case study presented in Papers IV and V, in order to describe both manifest and latent content. Analysis started in the same manner as in Paper III, described above, i.e., manifest analysis was performed first, and then it was complemented with a latent analysis. Latent analysis refers to interpretation of the underlying meaning of a text (Catanzaro, 1988). Themes emerged from the previously identified categories, which Baxter (1991) has described as threads of meaning that appear in category after caregory.

The interviews in the study presented in Paper IV were analysed separately before, during and after the intervention. However, during our analysis, we discovered that the content of the interviews was rather similar. Therefore, the results gleaned during and after are presented together as 'post-intervention'. In the study presented in Paper V, the interviews during and after the intervention were analysed together and presented as 'after the implementation'.

Ethical considerations

In the studies presented in Papers II-V, all participants received both oral and written information about the studies' aims, as well as the procedures and methods used in data collection. They were also informed that participation was voluntary and that they could withdraw at any time without any further

explanation. Informed consent was obtained and confidentiality guaranteed concerning all data. The anonymous presentation of the findings was confirmed. Participants in the focus groups (III) agreed not to talk to anyone outside their groups about the contents of the FGDs. During all FGDs, I tried to be attentive, so that all participants had a chance to express their views. The study presented in Paper II (Dnr 210-175-31M) and Paper III (Dnr 05-059) have been approved by the Regional Ethical Review Board in Umeå, Sweden, while the studies in Papers IV and V have been approved by the local Ethical Group at the University.

It was thought that interviews could be strenuous for people with serious chronic illnesses because of their difficulty talking (IV) or because of their general conditions (II, IV). I tried to ask clear and short questions and show kindness, sensitivity and openness (cf. Kvale & Brinkman, 2009, pp. 182, 183). All personal interviews with the middle-aged people with serious chronic illnesses were performed in their own homes (II, IV). Therefore, it was essential to show respect for all participants and their surroundings during my visits, when the interviews were performed. After each interview, I had a dialogue with the participant and asked if anything was unclear or if the participant had any questions or thoughts.

In the research testing of technical equipment where people are involved and where the equipment will not be used after testing, there is a risk that users will feel that they have lost something that might have functioned well. Therefore, follow-up meetings with people with serious chronic illnesses were performed (IV) about eight months after the intervention had been completed, in order to give participants the opportunity to express how they felt when the ICT equipment was removed. In the case study (IV, V) both the people with serious chronic illnesses and the DNs said that they missed the ICT application. In the studies presented in Papers II and IV, people living with serious chronic illnesses participated. Living with serious chronic illness means being in a vulnerable situation due to dependence on care. However, the research process can be positive for participants who realize that they are the focus of a researcher who is interested in their opinions. It can also clarify participants' own ideas and thoughts about issues (Oliver, 2003, pp. 35, 148). The use of ICT applications in people's homes may encroach on their integrity and entail the involvement of family members. In the case study (IV, V), we were aware of this and took it into consideration for the length of the intervention study's duration.

Table 2. Overview of findings in Papers I–V

Paper	Aim	Theme	Area/Subtheme/Category
I	Provide an overview of characteristics of studies describing the use of ICT in home care		Study approach Quality appraisal Publication data Terminology used for defining the technology Disease diagnosis Type of technology Communication between participants
II	Elucidate meanings of needs of middle-aged people with serious chronic illness living at home	Striving for independence	Having care that works Getting support to facilitate daily life
		Choosing one's own way	Being able to live at home Being able to see the possibilities in life
		Being together with others	Having a network that works Being seen and understood
III	Describe DNs' attitudes regarding the implementation of ICT in home nursing		Possibilities to influence the design and be a part of the instruction Improvements and risks People cannot be replaced by technology

Table 2. (continue) Overview of findings in Papers I-V

Paper	Aim	Theme	Area/Subtheme/Category
IV	Describe the experience of people with serious chronic illness who use ICT in communicating with their DN	Struggling to achieve a functioning every day	*Before the intervention* Feeling well Feeling secure and being shown respect Expectations of improved accessibility
		Everyday life has improved	*After the intervention* Belief and trust in the ICT Being less limited Fulfilled expectations
V	Describe the DNs' experiences of using ICT to communicate with people with serious chronic illness living at home	Striving for a trusting relationship	*Before the implementation* Mediating of security through interaction Working for accessibility
		Achieving a more trusting relationship	*After the implementation* A facilitator for nursing care Increased accessibility

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FINDINGS

The findings in each paper are presented separately. An overview of the findings (I-V) is presented in Table 2.

Paper I – *Information and communication technology as a tool for accessibility to home care*

The systematic literature review provides an overview of the characteristics of studies that describe the use of ICT in home care. Of the 107 studies included, just under half were rated high quality (n=48). Most had a quantitative approach (n=74), and one-fifth were part of larger projects (n=21). About half of the studies were published from 2007 to 2009. The two most common journals where studies had been published were the Journal of Telemedicine and Telecare (n=15) and the Telemedicine Journal and e-Health (n=12), which together accounted for almost one-quarter of the total number of publications. Most of the studies were performed in North America (n=67), while 34 were performed in Europe, where the United Kingdom and Italy were the most common countries.

Many different terms were used in the studies included to define the use of ICT applications in home care. The most frequent terms were 'telehealth' (n=32), 'telemedicine' (n=27), and 'technology' (n=11). Mostly, the use of ICT was about supporting people with chronic illnesses living at home (n=86), and the most common diagnoses were heart and lung diseases (n=38). In 12 studies, ICT was used to support people with chronic illnesses that were undefined with any diagnosis.

Most of the studies comprised the use of videophones or video conferencing equipment (n=49), text messages (n=26) and patient health monitoring (n=17). In several studies (n=31), more than one technical appliance was used to communicate or send information. About half of all the studies focused on the self-monitoring of patients who sent health data to healthcare professionals for analysis. Different types of communication via ICT were described, with the most frequent communication taking place between patients and nurses (n=49).

Paper II - *Meanings of needs of middle-aged people with serious chronic illnesses living at home*

This study elucidates meanings of needs of middle-aged people with serious chronic illnesses living at home. The findings suggest that the meanings of the needs of middle-aged people with serious chronic illnesses living at home can be understood as maintaining control in everyday life, which provides meaningfulness.

Striving for independence was related to participants' experiences of care that works with competent nursing staff and support to facilitate daily life. Being dependent on others was difficult to accept. Participants protected their autonomy by not asking for help every time they needed it. This seemed to be a way to protect their dignity. It is human nature to cope with one's most basic needs and desires as long as possible. Simultaneously, participants expressed a need to get help and support in daily life. They asked for flexible and continuous help and support from nursing staff that cared for them in their homes. Participants also expressed a need to feel confident in their nursing staffs. This meant feeling that their expressed needs were being listened to, which gave a sense of involvement in daily life and enabled participants to make their own decisions. Being confirmed helped participants maintain their dignity and reconcile themselves to their present life situations. Participants lacked information on their rights to help, support and assistive devices, especially in the early stages of their illnesses or when their need for help and support increased. Support from friends and neighbours and meetings with people in similar situations facilitated their everyday lives, fostering awareness that life must go on. This seemed to suggest that human support could compensate for such negative feelings as worthlessness, fear, uncertainty and distrust. Also, assistive devices and rebuilding at home were important needs, the fulfilment of which seemed to mean feelings of freedom.

Choosing one's own way was related to being able to live at home and see possibilities in life, despite illness or disability. Living at home entailed security and freedom and enabled participants to influence their daily lives, i.e., do what they wanted to do. Participants' desire to live at home, with greater freedom, could be seen as an expression of the need to take control over life. To get control means to obtain the ability to make one's own decisions. Simultaneously, participants described living at home as necessitating help and support from nursing staff, close relatives and friends. It was necessary for participants to

become accustomed to their illnesses by revaluing and familiarizing themselves with their situations, which required trust in themselves. Participants had found new interests that made them feel well. It seemed important for them to be aware of the possibilities in their lives. Such awareness, however, seemed to depend on the attitudes they had chosen.

Being together with others was related to having networks that worked and to being seen and understood. Close relatives and friends and meaningful activities, undertaken with others and on participants' own terms, were important in participants' everyday lives. Togetherness can be seen as something that gives people the strength to keep living and promotes a positive self-image. Simultaneously, participants expressed a need to be alone sometimes, which seemed to imply a need to become aware of oneself. They expressed a need to be understood by others and to be seen as the people they were. Being listened to and believed and getting explanations if something was unclear meant that they were respected. Feelings of being respected could be interpreted as feelings of being confirmed and worthwhile. Participants wanted relationships with nursing staff and friends who were engaged and kept open minds about their needs; these qualities seemed to increase participants' general sense of security and wellbeing. Sometimes, they needed to talk of more existential things, which they meant could be a task for the DN.

Paper III - *Swedish district nurses' attitudes to implement information and communication technology in home nursing*

This study describes DNs' attitudes toward the implementation of ICT in home care. DNs emphasised the importance of being able to influence the designs of ICT applications and of being a part of the introduction of new ICT applications in their work. They stressed that ICT must be easy to use and adapted to their work and that clear routines must be established prior to ICT's introduction. They emphasised the importance of educating themselves and patients in the use of ICT. They pointed out that learning and using technology was an individual task and that, therefore, the amount of time each person needed to learn to use technology would vary.

The DNs had experiences using new technology and remarked on both the benefits and risks of ICT's use. They saw the possible improvements that could results from using computerised case records on laptops, which would enable the sharing of information regardless of location and result in safer care. The DNs

also remarked on the fact that ICT could reduce stress, save time by reducing travel time and increase accessibility, which would lead to improved security for ill people living at home.

The risks of using ICT were also discussed. DNs perceived that the use of ICT might lead them to lose holistic views of patients' situations. They mentioned the stress and uncertainty associated with handling ICT equipment and suggested that ICT use could make demands on DNs' time when problems in installation or management in patients' homes arose. Some DNs discussed the possibility that DNs would not be needed in the future, as a lot of information would be available on the Internet.

DNs noted that people cannot be replaced by ICT and pointed out the importance of physical and human presence. They believed that the use of ICT could complement traditional nursing care but stressed that home visits revealed so much more. Some DNs emphasised the need to be aware of the fact that the use of ICT was not suitable for everybody. They also observed that ICT equipment might be regarded as an encroachment on the home or a threat to patients' autonomy. DNs agreed that the use of ICT could not be avoided in the future but acknowledged that their work routines needed to change.

Paper IV - *Information and communication technology in supporting people with serious chronic illness living at home – an intervention study*
This study describes how people with serious chronic illnesses living at home experienced the use of ICT to communicate with their DNs. The findings are presented in two parts: pre–intervention and post–intervention.

Pre-intervention, the findings showed that participants seemed to struggle to achieve functioning everyday lives. One participant suggested that feeling well meant doing what you wanted to do. The other felt well when working at the computer because it was a personal interest. Living at home with competent personal assistants who could provide help and support implied security. Participants described the importance of being respected and treated as human beings. Participants described what a properly functioning DN caring for them meant; a DN should be a good listener, as this is a prerequisite for a good relationship. Due to their difficulty speaking, participants described the frustration they felt when people in their surroundings did not understand what they said but gave the impression of understanding. Participants stated that their DNs were

difficult to reach. One limitation in their daily lives was the long wait they endured for answers from their DNs once they had contacted them. It was also difficult to remember everything they wanted to say when their DNs finally contacted them. Both described difficulties being able to act spontaneously, which demanded a great deal of planning. Participants expected improved accessibility with the use of ICT.

Post-intervention, participants seemed to feel that using ICT had improved their everyday lives. Its use in communication with their DNs made them feel safe and secure. They felt uncertain about whether their messages had reached their DNs, and whether there was anybody at all on the other end. They received no indications that their messages had arrived or that the receivers had read them. However, use of the ICT application reduced participants' feelings of limitation. They were able to avoid long waits by using ICT to correspond with their DNs. Another advantage of ICT was the ability it afforded participants to write messages at any time, so that they did not have to remember everything they wanted to say when their DNs contacted them. These advantages improved accessibility. The ability to write directly to their DNs gave participants a feeling of greater accessibility, and they said that they had time to think about what to write. Both said their expectations about using the technology had been fulfilled and that reaching their DNs with ICT had worked well.

Paper V - *Swedish district nurses' experiences on the use of information and communication technology for supporting people with serious chronic illness living at home – a case study*
This study describes how DNs experienced the use of ICT to communicate with people with serious chronic illnesses living at home. The result is presented in two parts: before and after implementation.

Before implementation, the DNs seemed to strive to achieve trusting relationships with ill people living at home. One of their main intentions was to mediate security and safety, which they tried to do by making extra phone calls and home visits. Knowing their patients gave the DNs a feeling of security and increased their chances of knowing what could happen. Sometimes, they felt limited, and, therefore, cooperation with other colleagues was considered necessary to make the ill people feel secure. The DNs also acknowledged that, on some occasions, they felt insufficient and dissatisfied with the care they provided. They felt that they were not always accessible enough to patients. None of the DNs had direct

telephone contact with the ill people but were, instead, in contact with their close relatives or personal assistants. Participants saw ICT applications as making DNs more accessible.

After implementation, DNs seemed to feel that the use of ICT had created more trusting relationships. Their expectations had been realized, and they were positive about the continued use of the ICT application in their work. They had worked out routines for using the ICT application, such as visiting the messaging program at fixed times, which they thought organised their work better. By reading messages regularly, they experienced increased awareness of their patients' needs. They stressed that traditional home visits could not be replaced but added that the use of ICT could be seen as a complement to it. They also noted that they would risk missing something important by ceasing physical visits.

The DNs described increased accessibility, reduced stress, time saved and more secure working situations as the results of using the ICT application. They thought that the use of ICT provided more direct communication with their patients and led to more realistic views of patients' situations. They appreciated the opportunity to write messages from wherever they were, which they said saved them time and enabled them to provide help and support to other ill people at home. DNs said they could reduce their number of home visits by using the ICT application. They further said that they felt some uncertainty when using the ICT application, because they were inexperienced and would not know what to do if technical problems occurred.

DISCUSSION

The overall aim of this doctoral thesis was to elucidate experiences of needs of middle-aged people with serious chronic illness living at home and the use of ICT as a tool for support from DNs in home care. This thesis shows that research describing the use of ICT in home care have increased during the last ten years. Further, it shows that people with serious chronic illnesses living at home need to be independent in their daily lives and to have care that works. Being aware of opportunities and close relatives and significant others is important to ill people. The findings show that when people with serious chronic illnesses used an ICT application to communicate with their DNs, they experienced improved accessibility and lessened feelings of being limited in their daily lives. The DNs also perceived improved accessibility but emphasized that ICT cannot replace home visits and physical presence (I-V). An overview of the findings is presented in Figure 2.
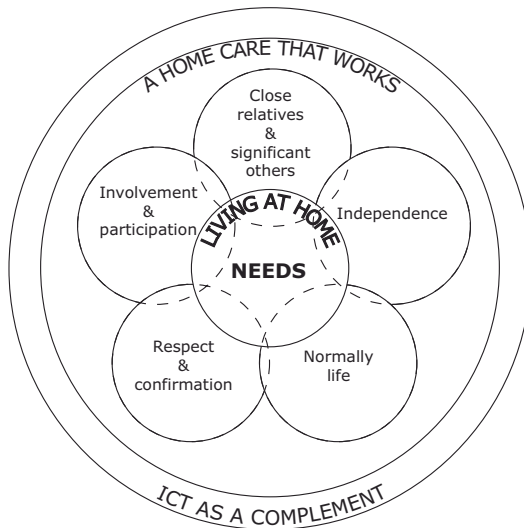

Figure 2. Overview of the main findings

Increased use of information and communication technology in home care

The systematic literature review (I) shows a rapid increase in publications of studies describing the use of ICT in home care, especially from 2007 to 2009, with lung and heart diseases being the most common diagnoses. This indicates that ICT is a rather common tool in home care. Most of the studies in the systematic literature review included the use of video-conferencing equipment (I). The use of such equipment can be seen as an expression of the need for other ways to communicate with people in need of home care. One reason, from a nursing perspective, to use video equipment is the importance of seeing patients. In nursing care, communication is one of the most important factors in a well-functioning relationship (Lawton & Carroll, 2005; McCabe, 2004).

Being able to live at home

People with serious chronic illnesses felt secure when they were able to live at home. Simultaneously, they pointed out that living at home necessitated extensive need of help and support from nursing staff (II, IV) and from close relatives and others in their surroundings (II). Melin-Johansson et al. (2008) have noted that for people with extensive care needs, being able to live at home confers a sense of possibility and well-being and allows for the preservation of independence. According to Benzein et al. (2001), people's homes are often thought of as secure and familiar places, where personal decisions can be taken and where the possibility of hope in life can be felt. Experiences of hope can help ill people cope with the stress of illness and suffering. People with serious chronic illnesses described the importance of being able to see the opportunities open to them, despite their illness and disability (II). According to Duggleby et al. (2012), hope is an important resource for people living with chronic illness, enabling them to see possibilities. This suggests the importance of tailoring nursing interventions to promote hope among people with serious chronic illnesses who are of various ages and needs and who live at home.

Living as normally as possible was important to the people in this study who were living with serious chronic illnesses at home. They expressed a need to do what they wanted (II, IV). It was necessary for them to reevaluate and become familiar with their current situations (II). Keeping up with interests and activities and setting short-term goals led to feelings of being able to live as normally as possible. Being involved in their own care and seeing themselves as experts on their illnesses also helped them live as normally as possible (Skuladottir &

Haldorsdottir, 2011). People with serious chronic illnesses pointed out the importance of nursing staff listening to their needs (II, IV), which led to their feeling involved in their daily lives (II). Patients' wanting to be involved in their own care can be seen as one way of trying to get control. According to Thorne, Paterson and Russel (2003), being in control means reconciling the effects of illness and thereby enabling oneself to live as normally as possible. Therefore, understanding the daily lives of people with serious chronic illnesses living at home requires listening to them and using their stories to shape satisfying forms of communication and relationships (cf. Tropea, 2011).

The findings show that for people with serious chronic illnesses, values that no longer could be reach could be replaced by new values and interests (II). Maintaining one's dignity when living in need of extensive help means finding strategies to maintain one's autonomy, integrity, and participation in daily life (Wadensten & Ahlström, 2009). King et al. (2003) note that one way ill people protect their lives is by compensating for losses with other things.

People with serious chronic illnesses living at home seemed to manage their daily lives by being aware of the choices they had in life, despite their illness (II). To feel free is to have unfettered and unrestricted choice from a given range of options or alternatives. It is crucial to be able to see alternatives and know that one's choice of alternatives is not constrained in any way (Agich, 1995, p. 136). Sense of freedom is highly individual, which is important to take into account in the planning of nursing care for people with serious chronic illnesses living at home.

To people with serious chronic illnesses living at home, the need to reevaluate their situations and to recognize that life was as it was salient (II). This could be seen as a manner of managing their life situations. According to Kralik, Koch, Price and Howard (2004), people with chronic illnesses identify self-management as creating a sense of order in their daily lives, which means recognizing boundaries, mobilizing resources, managing their self-identities and feeling that they achieve a balance of their own resources through planning and prioritizing in daily life. This requires new ways of looking at the meaning of their illnesses, their relationships with others, and their views of their diseased bodies i.e., learning the best ways to take charge of their own lives (Thorne, Con, McGuiness, McPherson & Harris, 2004).

The need to be independent in daily life

People with serious chronic illnesses living at home wanted to feel independent in their daily lives, at the same time as they invoked the importance of functioning care (II, IV). According to Jooste et al. (2010), feeling independent is of the utmost importance for people with physical disabilities who need care at home. Being dependent on others is difficult and frustrating and implies the loss of much of one's freedom of choice in daily life (Strandberg, Norberg & Jansson, 2003). People in need of home care have described their autonomy as becoming limited, because they must adapt to schedules of care, i.e., the possibility of flexibility in their daily lives is restricted (Ellefsen, 2002). Therefore, it seems that it is common for people with chronic illnesses to retain their feelings of independence and learn ways of achieving it, which facilitates their sense of control in daily life (Kralik et al., 2004). This can be seen as an expression of independence in daily life and shows the importance of individualized nursing care for people with serious chronic illnesses living at home. Obtaining assistive devices was also important to the ill people, because it gave them a sense of freedom in their daily lives (II). This shows that people with serious chronic illnesses living at home appropriate help and support and adapt assistive devices in ways that foster feelings of independence. The participants in this study also pointed out the need for competent and flexible nursing staff (II). Wilkes et al. (2008) have stated that people with chronic complex conditions who receive care at home point out the importance of competent and experienced nurses and note that nurses should coordinate and adapt care based on caretakers' needs.

While people with serious chronic illnesses living at home expressed their need to be independent, they simultaneously emphasised how essential their personal assistants were (II, IV). According to Wadensten and Ahlström (2009), the help and support of personal assistants plays an important role, for people living with severe disabilities, in the achievement of autonomy, integrity and participation in everyday life. Edlund (2002) has observed that reduced freedom of movement and long waits for help can be experienced as insults to the dignity of people with illnesses. This indicates the need for people who are in extensive need of help and who live at home to reach nursing staff easily. Therefore, it is essential to develop means of facilitating the accessibility of nursing staff in home care – and of patients. One way of doing this is to utilize the ICT solutions available today.

It was important for people with serious chronic illnesses living at home to have continuity with the nursing staff who visited them in their homes (II). Sundin, Bruce and Barremo (2010) have shown that lack of continuity in relationships with nursing staff creates uncertainty. Lack of continuity related to no specific nurse being responsible for nursing care may lead to feelings of not being seen and heard. There was a need to feel confident and confirmed, which seemed to help patients maintain their dignity (II). This showed the importance of trusting relationships. A significant aspect of the relationships between ill persons and nurses is trust (Johns, 1996; Mahoney, 2001). Respectful communication is important in establishing trusting relationships (Agich, 1995, pp. 139, 140). It is also important that ill persons' needs be understood and that holistic care be provided (Mok & Chiu, 2004). According to Bell and Duffy (2009), trust between the ill person and the nurse is defined as hopeful acceptance of a vulnerable situation, following careful assessment, where the ill person believes that his or her nurse will do the best for him or her.

Improved access to care with information and communication technology

Before using the ICT application tested in this thesis, people with serious chronic illnesses living at home described difficulties reaching their DNs. Waiting for responses from DNs was bothersome and could be seen as an expression of being dependent on care. After using ICT, the ill persons noted that it had become easier to reach their DNs, which made them feel less limited. They were not governed by time; instead, they could send messages to their DNs as needed (IV). According to Öhman et al. (2003), people with serious chronic illnesses who make their own decisions and have control feel independent and free, which gives them a sense of satisfaction. Törnkvist, Gardulf and Strender (2000) have observed that patients' satisfaction with care at home by DNs is largely related to the perceived accessibility of help and support from nursing staff.

District nurses thought to use ICT solutions could enhance the accessibility in home care, both for tehm and for the ill people living at home (III). After testing the ICT application both people with serious chronic illnesses and their DNs appreciated the enhanced ability to communicate with each other that resulted from ICT use. They experienced more direct contact than before (IV, V), as the use of ICT helped avoid long waits for answers from the DNs (IV). In nursing care, well-functioning, communicative relationships are essential (Attree, 2001; Fosbinder, 1994; Thorsteinsson, 2002) and can be seen as indicators of quality

(Hallström & Elander, 2001). An important need of people with serious chronic illnesses living at home seemed to be having people in their close surroundings, which helped them feel secure (II). The use of ICT can enable nurses in home care to give immediate assessments when patients call them (Dimmick, Mustaleski, Burgiss & Welch, 2000). Thus, for ill people living at home, ICT can enhance the accessibility of nursing staff when needs arise.

However, people with serious chronic illnesses and their DNs not only discussed the advantages of using ICT to communicating with one another. They also expressed feelings of uncertainty (IV, V). People with serious chronic illness, for instance, expressed doubt that their messages reached their DNs, i.e., that there was anyone on the receiving sides of their messages (IV). Normally, people trust one another naturally, but special circumstances can disturb this trust and lead to feelings of mistrust (Løgstrup, 1992, p. 41). In this case, the use of ICT can be seen as a special circumstance. Feelings of uncertainty are a burden that can challenge self-esteem (Ellefsen, 2002). Therefore, it is important, in the future, to develop methods of confirming that messages sent with ICT applications have reached their receivers. This will foster trust in the use of such applications.

The use of ICT to communicate can also be experienced as a threat to physical presence (III, V), and a risk to lose holistic views of the ill person's situation (III). DNs pointed out that physical presence and visits cannot be replaced by the use of ICT in home care. Instead, ICT should be seen as a complement to these other things (III, IV). This notion is in agreement with the assertions of Demiris, Parker Oliver and Courtney (2006), who state that the use of ICT in healthcare is as a supplement, rather than as a replacement. It is important to take into consideration the significance of physical presence and touch in home care. The use of ICT can be seen as a way of offering care that facilitates and complements nursing care.

METHODOLOGICAL CONSIDERATIONS

The use of a qualitative approach requires reflection upon and awareness of the researcher's pre-understanding. Otherwise, risk exists of obtaining findings that are first and foremost reflections of past experiences or unrecognized beliefs. This can result in merely confirming current understandings and preventing new understandings from occurring (Dahlberg, Drew & Nyström, 2001, p. 118). In qualitative research, the researcher must show openness during data collection and acknowledge the fact that pre-understandings may guide research. In other words, it is important that researchers consider how their own pre-understandings affect the research process. In research, pre-understanding must always be acknowledged and problematized (Ricoeur, 1993).

The participants in this thesis were selected through purposive sampling. According to Morse (1991), a purposive sample consists of participants who are strategically selected for their ability to provide information and knowledge that is needed. Participants were selected according to predetermined criteria that ensured that they had knowledge of the topic under study. A total of 25 people participated in this thesis, and 31 interviews were performed. The number of participants can be seen as few. However, trustworthiness in qualitative research is gained more by the richness of data than by sample size (Sandelsowski, 1995).

Using a case study design in this thesis enabled the researcher to carefully study the participants for a predetermined period. In this case, the participants were followed for several months, and interviews were performed continuously, which resulted in a wealth of data (cf. Polit & Beck, 2012, p. 503). One limitation of the case study's design could have been the hindrance to completion that might have occurred if one or more of participants had withdrawn, due to the fact that there were few participants. None of the participants withdrew.

All interviews were recorded (cf. Morse, 1991, p. 217), which increased dependability. In the interviews and FGDs, participants were allowed to talk as freely as possible. Interview guides were used to ensure that predetermined areas were discussed. The interviews and FGDs yielded substantial data.

Following a systematic literature review that identified common practices, the quality appraisal was initially performed together by two of the authors, to obtain as equal an assessment as possible. Quality appraisals are more credible if conducted by two independent reviewers (Willman et al., 2011). One limitation

of our approach could have been its use of relatively few databases in the literature search; relevant studies might have been missed. This was avoided by making use of a search alert.

While conducting analysis for the other studies in this thesis, textual units, categories and themes were occasionally returned to and compared with those presently under study, to ensure the credibility of analysis. The analysis and findings were discussed with all co-authors and with other colleagues, to confirm their trustworthiness. Sandelowski (1998) has pointed out that an 'outsider' expert is a resource who contributes by asking important questions about the data and helping the researcher look at data in new ways, or by suggesting new frameworks to be drawn from the interpretation and representation of the data.

One of the studies in this thesis utilized the phenomenological hermeneutic interpretation method. This method holds that texts can be interpreted in more than one way but that all interpretations are not equally probable (Ricoeur, 1976, pp. 78, 79). The probability of each interpretation's accuracy is considered in relation to its interpretation (cf. Lindseth & Norberg, 2004). The findings presented in this thesis represent the interpretations that we considered to be the most credible understandings of the texts.

The findings in this thesis cannot be generalised. One reason for this is that studies are predominantly context- bound. However, this is not the intention in qualitative research. Instead, findings in one context can be transferred to similar situations, and the knowledge acquired in one context can be useful in another. Procedures, contexts and findings have been described as accurately as possible, to ensure the credibility and transferability of the study (cf. Lincoln & Guba, 1985).

CONCLUSIONS AND IMPLICATIONS

This thesis provides additional understanding of the needs of middle-aged people with serious chronic illnesses living at home and their use of ICT to support communication with their DNs. Participants in this thesis asked to receive information from and discuss their life situations with nursing staff, especially early in their illnesses. This required that nursing staff listen to their stories and provide encouragement and support for the resources that the ill people still had. The provision of help and support that is based on the individual needs and desires of people with serious chronic illnesses is of paramount importance, and that support should start in the early stages of illness. More research is needed to develop appropriate interventions for this purpose.

People with serious chronic illnesses living at home expressed a salient need for normal lives. This required that the ill persons' individualised needs be met and that all nursing staff collaborate with one another. Walshe and Luker (2010) have highlighted the fact that DNs are sometimes reluctant to work with other professionals to provide care. Therefore, more research on home care is needed, with a focus on the collaboration of different types of professionals, to enhance safety and security for people with serious chronic illnesses living at home.

As shown by the findings of this thesis, ill people and their DNs used ICT to communicate valuably. The experiences and views of people with serious chronic illnesses and their DNs can be seen as useful resources for the introduction of ICT applications in home care. The intention of this thesis was to test whether the use of ICT improved communication between people with serious chronic illnesses at home and their DNs. It is important to take into consideration that the starting point is ill people's needs and not ICT equipment, i.e., the technology must be adapted to the ill people's needs. More research is needed on how ICT applications can be adapted to the needs of people living with serious chronic illnesses, with the goal of improving home care.

To achieve more satisfactory in home care, an obviously person-centred approach to care is needed. This requires well-planned and -executed care for the unique person. Person-centred care results in ill persons being respected and listened to, getting honest information, being involved in decisions and being valued (Kvåle &Bondevik, 2008). Person-centred care is influenced by the care environment, i.e., the work and culture of an organization (McCabe, 2004). Thus, high-quality person-centred care requires functioning organizations, i.e.,

systems that empower ill people to participate in their daily lives and to form effective relationships with their staff and the organizations supporting them.

SUMMARY IN SWEDISH - svensk sammanfattning

Informations- och kommunikationsteknologi som stöd inom hemsjukvård – *Upplevelser hos medelålders personer med svår sjukdom och distriktssköterskor*

Personer med svåra kroniska sjukdomar vårdas i större utsträckning än tidigare i sitt eget hem. Denna utveckling har fört med sig ett ökat behov av stöd och vård hos personer med svår kronisk sjukdom för att kunna bo hemma. Därför är det viktigt att vården i hemmet har en hög kvalitet. Det kan ses som en utmaning att utveckla medel för att stödja personer med svår kronisk sjukdom som bor hemma. Ett sätt för detta kan vara att använda lämpliga informations- och kommunikationsteknologi (IKT) tillämpningar. Denna doktorsavhandling har ett naturalistiskt perspektiv, eftersom dess avsikt är att beskriva upplevelser hos personer med svår kronisk sjukdom och upplevelser och attityder hos distriktssköterskor av att använda IKT inom hemsjukvård. Forskning inom ett naturalistiskt perspektiv fokuserar på deltagarnas egna upplevelser.

Litteraturgenomgången visar att leva med kroniska sjukdomar ändrar det dagliga livet på många sätt. Det är viktigt att kunna bo hemma, eftersom hemmet ger en trygghetskänsla. Samtidigt blir hemmet en offentlig arena, där dörrarna alltid står öppna för vårdpersonal, som innebär att integriteten hos personen och dennes familj påverkas. För personer med kronisk sjukdom är det viktigt att kunna leva så normalt som möjligt. Distriktssköterskor som arbetar inom hemsjukvård ser sig som samordnare i vården i hemmen. De anser att en bra relation med dem som vårdas hemma är betydelsefull. En sak som påverkar deras arbete är att de upplever stress i sitt arbete, bland annat på grund av att de inte anser sig ha kontroll och tid att hantera olika situationer.

Det sista tio åren har användningen av IKT varit en hjälp till utvecklingen av en effektiv och säker vård, som har resulterat till en snabb ökning av att använda olika IKT tillämpningar. Flera studier har utförts gällande användning av IKT för äldre personer. Forskning visar att effekter av kostnadseffektivitet, livskvalitet och patienters tillfredsställelse sällan är undersökta angående användningen av IKT bland personer med kroniska sjukdomar.

Rational

Ändringar i hälso-och sjukvården har lett till att fler personer med svåra kroniska sjukdomar bor kvar i sina hem i större utsträckning än tidigare, som har lett till ökad vård/omvårdnad i hemmet. Litteraturgranskningen visar att möjliggöra för personer med svåra kroniska sjukdomar att kunna bo hemma kräver att personen känner stöd och trygghet från hälso- och sjukvården och att hjälp och stöd är baserat på deras behov. En utmaning för distriktssköterskor inom hemsjukvård är därför att hitta nya sätt att tillhandahålla detta stöd. I denna avhandling, testas därför en IKT tillämpning för att kommunicera, för personer med svår kronisk sjukdom i hemmet och deras distriktssköterskor. Målet med IKT tillämpningen är att öka tillgänglighet, säkerhet och trygghet för människor med svåra kroniska sjukdomar som bor i sina egna hem. Ökad kunskap inom detta område kan belysa möjligheter att förbättra vården i hemmet på ett sätt som svarar mot de behov som personer med svår kronisk sjukdom har som bor hemma.

Syfte

Det övergripande syftet var att belysa upplevelser av behov hos medelålders personer med svår kronisk sjukdom som bor hemma och användningen av IKT som stöd från distriktssköterskor inom hemsjukvård.

Syften i de delarbeten som ingår i doktorsavhandlingen

Delstudie I   Att erhålla en översikt av studier som beskriver användning av IKT inom vård i hemmet.

Delstudie II   Att belysa innebörder av behov hos medelålders personer med svår kronisk sjukdom som bor hemma.

Delstudie III   Att beskriva distriktssköterskors attityder av att använda IKT i hemsjukvården.

Delstudie IV   Att beskriva upplevelser hos personer med svår kronisk sjukdom som använder IKT för att kommunicera med sin distriktssköterska.

Delstudie V   Att beskriva distriktssköterskors upplevelser av att använda IKT för att kommunicera med personer som har en svårt kronisk sjukdom och som bor hemma.

Metod

En induktiv ansats och en kvalitativ metod har huvudsakligen använts i denna avhandling (II-V). *Delstudie I* är en systematisk litteraturöversikt där summering av forskning från tidigare studier som beskriver användning av IKT inom vård i hemmet har utförts. Litteraturöversikten är utförd från en specifik forskningsfråga med ett systematiskt arbetssätt, där ett urval av 107 studier gjordes. I *Delstudie II* intervjuades 12 medelålders personer. Intervjutexterna analyserades med en fenomenologisk hermeneutisk tolkning för att utveckla en djupare förståelse av innebörder av behov hos personer med svår kronisk sjukdom som bor hemma. *Delstudie III* utgår från en kvalitativ deskriptiv design. Fokusgruppdiskussioner utfördes där distriktssköterskor diskuterade attityder till att använda IKT inom hemsjukvård. Sammanlagt 19 distriktssköterskor deltog indelade i fem grupper med fyra deltagare i fyra grupper och tre deltagare i en grupp. Data analyserades med en kvalitativ innehållsanalys.

Delstudie IV och V har en fallstudie design där en intervention är utförd. Två medelålders personer med svår kronisk sjukdom deltog (IV) och deras respektive distriktssköterska (V). En IKT tillämpning användes där personerna med svår kronisk sjukdom och deras omvårdnadsansvariga distriktssköterska kunde kommunicera med varandra när behov uppstod. Den teknik som användes möjliggjorde att kommunicera genom textmeddelanden som ansågs lämpligt på grund av att de personer med svår kronisk sjukdom som deltog hade talsvårigheter. IKT tillämpningen användes hela dygnet av personerna med svår kronisk sjukdom, till skillnad från distriktssköterskorna som använde den enbart under dagtid. Även traditionella hembesök av distriktssköterskan utfördes under interventionen. Distriktssköterskorna hade även tillgång till mobiltelefoner med Internetuppkoppling, som gjorde det möjligt att ta emot och sända meddelanden oberoende av var de befann sig under tiden då interventionen pågick. Intervjuer utfördes före, under och efter interventionen med deltagarna (personerna med svår kronisk sjukdom och deras respektive omvårdnadsansvariga distriktssköterska). Intervjutexterna analyserades med en tematisk innehållsanalys.

Resultat

Delstudie I

Den systematiska litteraturöversikten ger en översikt över egenskaper i internationella studier som beskriver användning av IKT inom vård i hemmet. Av de inkluderade 107 studierna var knappt hälften bedömda som hög kvalitet (n =48). De flesta hade en kvantitativ metod (n=74), och en femtedel av studierna

tillhörde ett större projekt (n=21). Ungefär hälften av studierna publicerades från 2007 till 2009, där de två vanligaste tidskrifterna var Journal of Telemedicin and Telecare (n=15) och Telemedicin Journal and eHealth (n=12), som tillsammans stod för nästan en fjärdedel av det totala antalet publikationer. De flesta var utförda i Nordamerika (n=67), medan 34 var utförda i Europa, där Storbritannien och Italien var de vanligaste länderna.

Många olika termer användes för att definiera användningen av IKT-tillämpningar inom vård i hemmet. De vanligaste termerna var 'telehealth'(n=32), 'telemedicin'(n=27) och 'technology' (n=11). Störst var användningen av IKT hos personer med kroniska sjukdomar som bor hemma (n=86), och de vanligaste diagnoserna var hjärt-och lungsjukdomar (n=38). I 12 studier framgick inte någon diagnos hos dem som deltog.

De flesta av de studierna omfattade användning av ljud och bild (n=49), därefter textmeddelanden (n=26) och hälsoövervakning (n=17). I flera studier (n=31) användes en tekniklösning för att kommunicera eller skicka information. Ungefär hälften av alla studier fokuserade på egenkontroll där patienter skickade data angående deras hälsa till vårdpersonal för analys. Olika typer av kommunikation via IKT beskrevs och den mest frekventa kommunikationen skedde mellan patienter och sjuksköterskor (n=49).

Delstudie II

Denna delstudie belyser innebörder av behov hos medelålders personer med svår kronisk sjukdom som bor hemma. Resultaten tyder på att innebörden av behov hos dessa personer kan förstås som att ha kontroll i det dagliga livet, som ger meningsfullhet.

Strävan efter oberoende var relaterat till deltagares upplevelser av vård och stöd som gavs av kompetent vårdpersonal för att underlätta det dagliga livet. Att vara beroende av andra var svårt att acceptera. Deltagare skyddade sin autonomi genom att inte be om hjälp varje gång de behövde det, som även verkade vara ett sätt att skydda sin värdighet. Det är i människans natur att klara sina mest grundläggande behov och begär så länge som möjligt. Samtidigt uttrycktes ett behov av att få hjälp och stöd i dagligt liv. De ville ha flexibel och kontinuerlig hjälp och stöd från vårdpersonalen i sina hem. Deltagare uttryckte också ett behov att känna sig trygga i sin omvårdnad, som innebar en känsla av att bli lyssnad till som i sin tur gav en känsla av delaktighet och en möjlighet att ta egna

beslut. Att bli bekräftad hjälpte deltagare att behålla sin värdighet och förlika sig med sin nuvarande livssituation. De saknade information om sina rättigheter för att få hjälp, stöd och hjälpmedel, särskilt i ett tidigare stadie av sjukdomen eller när deras behov av hjälp och stöd ökade. Stöd från vänner och grannar, möten med människor i liknande situationer underlättade deras vardag och att livet måste gå vidare. Detta antyder att mänskligt stöd kan motverka negativa känslor som värdelöshet, rädsla, osäkerhet och misstro. Dessutom var hjälpmedel och ombyggnader i hemmet viktiga behov, vars uppfyllande tycktes betyda känslor av frihet.

Att välja sin egen väg var relaterat till att kunna bo hemma och se möjligheter i livet, trots sjukdom eller funktionshinder. Att bo hemma innebar trygghet och frihet och en möjlighet att påverka sin vardag; göra vad de själva ville. Deltagares önskan att bo hemma, kan ses som ett uttryck för behovet av att ta kontroll över sitt liv och att känna frihet. Att ha kontroll innebär att få möjligheten att ta egna beslut. Samtidigt beskrev deltagare att för att kunna bo hemma behövdes hjälp och stöd från vårdpersonal, närstående och vänner. Det var nödvändigt för dem att värdera och bekanta sig med sin situation, som krävde tillit till sig själv. Deltagare hade funnit nya intressen som medförde att de mådde bättre. Det verkade viktigt för dem att vara medveten om möjligheterna i sitt liv, som verkade bero på den attityd de hade valt till livet.

Vara tillsammans med andra var relaterat till att ha nätverk som fungerade och att bli sedd och förstådd. Nära släktingar och vänner och meningsfulla aktiviteter, som genomfördes med andra eller på deltagarens egna villkor, var viktigt för dem i deras vardag. Samhörighet kan ses som något som ger människor kraft till att bo kvar hemma och främjar en positiv självbild. Samtidigt uttryckte de ett behov av att vara ensam ibland, som verkade vara något som ökade den egna självmedvetenheten. De uttryckte ett behov bli förstådd, lyssnad till och ses som den person de var som verkade ge en känsla att vara respekterad av andra. Deltagare ville ha vårdpersonal och vänner som var engagerade och hade ett öppet sinne för deras behov. Ibland hade de ett behov att få prata om bland annat mer existentiella saker, som de menade skulle kunna vara en uppgift för distriktssköterskan.

Delstudie III

Delstudie III visar vikten att ha möjlighet att påverka och vara delaktig i utformningen och införandet av IKT tillämpningar som ska användas i omvårdnadsarbetet inom vård i hemmet. Distriktssköterskor såg en möjlighet att IKT kunde förbättra tillgängligheten av distriktssköterskan för den sjuke personen i hemmet. De såg också möjligheten för dem själva att kunna få bättre information om hur personerna i hemmet mådde. De ansåg att använda IKT kunde spara tid men också ta tid. Resultatet avslöjade även att distriktssköterskor såg en risk att IKT tillämpningen kunde uppfattas som ett intrång och att hot av autonomin för den sjuke och dennes familj i deras hem. Vidare ansåg de att användningen av IKT i omvårdnaden i hemmet inte passar alla och att människor inte kan ersättas genom användningen av IKT.

Delstudie IV och V

Fallstudien (IV, V) indikerar att det var svårt att nå distriktssköterskan för personer med svår kronisk sjukdom som bor hemma. Genom användningen av IKT uppnåddes en förbättrad tillgänglighet, en mer direkt kontakt mellan den sjuke och distriktssköterskan, vilket underlättade kommunikationen som ledde till en känsla av att vara mindre begränsad i det dagliga livet för personerna med svår kronisk sjukdom som bodde hemma.

Deltagare beskrev också en osäkerhet i användningen av tekniken. Personerna med svår kronisk sjukdom uttryckte en känsla av osäkerhet om meddelandet verkligen nådde fram till distriktssköterskan. Distriktssköterskorna beskrev att de kände en osäkerhet i början av användningen på grund av att det var ovant att använda IKT tillämpningen, samt på grund av att en del tekniska problem med användningen av mobiltelefonerna inträffade. Tekniken ansågs av distriktssköterskorna som ett komplement i omvårdnaden i hemmet som underlättade deras arbete men ansågs inte kunna ersätta traditionella hembesök. Användningen av IKT verkade även främja en mer tillitsfull relation mellan distriktssköterskan och personen med svår kronisk sjukdom som bodde i sitt hem.

Slutsatser och implikationer

Denna avhandling ger ytterligare förståelse för behov som medelålders personer med allvarlig kronisk sjukdom har som bor hemma och deras användning av IKT som stöd i kommunikationen med sin distriktssköterska. Deltagare uttryckte ett behov att få möjlighet att prata om sin livssituation med vårdpersonal, särskilt i ett tidigare skede i sin sjukdom. Detta kräver att vårdpersonalen lyssnar på personens

egna berättelser, uppmuntrar och ge stöd utifrån de resurser som den sjuke fortfarande har. Hjälp och stöd som grundar sig på de behov som personen med svår kronisk sjukdom har är en avgörande faktor, och att stödet börjar i ett tidigare skede i sjukdomen. Mer forskning behövs för att utveckla lämpliga interventioner för detta ändamål.

Ett framträdande behov som personer med svår kronisk sjukdom som bor hemma uttryckte var att leva så normalt som möjligt. Detta kräver att den sjukes individuella behov uppnås och att all vårdpersonal samarbetar. Forskning visar att distriktssköterskor har en ovilja att arbeta med andra yrkesverksamma i vården. Därför behövs mer forskning inom vård i hemmet som fokuserar på samarbete mellan olika yrkesgrupper för att öka trygghet och säkerhet för personer med svår kronisk sjukdom som bor hemma.

Som framgår av resultaten i denna avhandling upplevde personer med svår kronisk sjukdom och deras distriktssköterskor att användningen av IKT för att kommunicera med varandra var värdefullt. Upplevelser och attityder som personer med svår kronisk sjukdom och deras distriktssköterskor har kan ses som användbara resurser för introduktioner av IKT-tillämpningar inom vård i hemmet. Avsikten med denna avhandling var att testa om användning av IKT förbättrade tillgängligheten och kommunikationen mellan personer med svår kronisk sjukdom i hemmet och deras distriktssköterskor. Det är viktigt att ta i beaktande att utgångspunkten är sjuka människors behov och inte IKT tillämpningen, därmed måste IKT tillämpningarna anpassas till sjuka personers behov. Därför behövs mer forskning om hur IKT kan anpassas för personer som lever med svår kronisk sjukdom, med målet till en förbättrad vård i hemmet.

För att uppnå en mer tillfredsställande vård i hemmet behövs en tydlig personcentrerad vård som kräver en väl utförd vård utifrån de individuella behov som den sjuke personen har. En personcentrerad vård innebär att den sjuke personen respekteras, blir lyssnad till, får uppriktig information, är involverad i beslut och blir sedd med ett värde (Kvåle & Bondevik, 2008). En personcentrerad vård påverkas även av rådande vårdmiljö; arbetet och kulturen i nuvarande organisation (McCabe, 2004). Detta kräver en väl fungerande och stödjande organisation och goda relationer med och mellan vårdpersonal som gör det möjligt att känna delaktighet för personer med svår kronisk sjukdom som bor hemma att känna delaktighet.

ACKNOWLEDGEMENTS

All my lovely friends, for reminding me about life outside my work and for our fellowship, with lots of fun and laughter. Thank you, Kjell Vikström for your help with the photo on the cover page. It is so beautiful! A special thanks to Maggie for your unconditional support; our talks have always given me energy. You are the 'sister' I have never had.

My close relatives, who have showed interest in my thesis work and supported and encouraged me.

Finally, but most of all, Roger and Martin for your love, patience and encouragement during the time this work has been carried out. You have always been present for me. You are the most important people in my life.

REFERENCES

Agich, G. J. (1995). Chronic illness and freedom. In S. Kay Toombs, D. Barnard & R. A. Carson (Eds.), *Chronic illness. From experiences to policy* (pp. 129-153). Bloomington and Indianapolis: Indiana University Press.

Agrell, H., Dahlberg, S., & Jerant, A. F. (2000). Patients' perceptions regarding home telecare. *Telemedicine Journal and e-Health, 6,* 409-415.

Ahlström, G. (2007). Experiences of loss and chronic sorrow in persons with severe chronic illness. *Journal of Nursing and Healthcare of Chronic illness* in association with *Journal of Clinical Nursing, 16,* 3a, 76-83.

Algera, M., Francke, A. L., Kerkstra, A., & van der Zee, J. (2004). Home care needs of patients with long-term conditions: literature review. *Journal of Advanced Nursing, 46,* 417-429.

Allen, A., Roman, L., Cox, R., & Cardwell, B. (1996). Home health visits using a cable television network: user satisfaction. *Journal of Telemedicine and Telecare, 2,* 92-94.

Andrée-Sundelöf, E-M., Hansebo, G., & Ekman, S-L. (2004). Friendship and caring communion: The meaning of caring relationship in district nursing. *International Journal of Human Caring, 8,* 13-20.

Appelin, G., & Berterö, C. (2004). Patients' experiences of palliative care at home. *Cancer Nursing, 27,* 65-69.

Appelin, G., Brobäck, G., & Berterö, C. (2005). A comprehensive picture of palliative care at home from the people involved. *European Journal of Oncology Nursing, 9,* 315-324.

Arnaert, A., & Delesie, L. (2001). Telenursing for the elderly. The case for care via video-telephony. *Journal of Telemedicine and Telecare, 7,* 311-316.

Attree, M. (2001). Patients' and relatives' experiences and perspective of 'good' and 'not so good' qualitative care. *Journal of Advanced Nursing, 33.* 456-466.

Baxter, L. A. (1991). Content analysis. In B. M. Montgomery & S. Duck (Eds.), *Studying interpersonal interaction* (pp. 239-254). New York, London: The Guilford Press.

Bell, L., & Duffy, A. (2009). A concept analysis of nurse-patient trust. *British Journal of Nursing, 18,* 46-51.

Benzein, E., Norberg, A., & Saveman, B-I. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine, 15,* 117-126.

Berterö, C. (2002). District nurses' perceptions of palliative care in the home. *American Journal of Hospice & Palliative Care, 19,* 387-391.

Botsis, T., & Hartvigsen, G. (2008). Current status of future perspectives in telecare for elderly people suffering from chronic diseases. *Journal of Telemedicine and Telecare, 14,* 195-203.

Brännström, M., Ekman, I., Norberg, A., Boman, K., & Strandberg, G. (2006). Living with severe chronic heart failure in palliative advanced home care. *European Journal of Cardiovascular Nursing, 5,* 295-302.

Campbell, P., Dries, J., & Gilligan, R. (1999). *The older generation and the European information society: Access to the information society.* European Institute for the Media. Dusseldorf and the Netherlands Platform Older People and Europé: Utrecht.

Carling Elofsson, L., & Öhlen, J. (2004). Meanings of being old and living with chronic obstructive pulmonary disease. *Palliative Medicine, 18,* 611-618.

Carter, H., MacLeod, R., Brander, P., & McPherson, K. (2004). Living with terminal illness: patients' priorities. *Journal of Advanced Nursing, 45,* 611-620.

Catanzaro, M. (1988). Using qualitative analytical techniques. In N. F. Woods & M. Catanzaro (Eds.), *Nursing Research. Theory and Practice.* (pp. 437-456). St. Louis: Mosby.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically illness. S*ociology of Health and Illness, 5,* 168-195.

Conrad, P. (1987). The experiences of illness: Recent and new directions. *Research in the Sociology of Health Care, 6,* 1-31.

Corbin, J. M. (2003). The body in health and illness. *Qualitative Health Research, 13,* 256-267.

Corbin J. M., & Strauss, A. L. (1987). Accompaniments of chronic illness. Changes in body, self, biography, and biographical time. *Research in the Sociology of Health Care, 6,* 249-281.

Dahlberg, K., Drew, N., & Nyström, M. (2001). *Reflective lifeworld research.* Lund: Studentlitteratur.

Delmar, C., Bøje, T., Dylmer, D., Forup, L., Jakobsen, C., Møller, M., Sønder, H., & Pedersen, B. D. (2005). Achieving harmony with oneself: life with chronic illness. *Scandinavian Journal of Caring Sciences, 19,* 204-212.

Demiris, G., Parker Oliver, D. R., & Courtney, K. L. (2006). Ethical considerations for the utilization of telehealth in home and hospice care by the nursing profession. *Nursing Administration Quarterly, 30,* 56-66.

Demiris, G., Parker Oliver, D. R., Courtney, K. L., & Porock, D. (2005). Use of technology as a support mechanism for caregivers of hospice patients. *Journal of Palliative Care, 21*, 303-309.

Demiris, G., Speedie, S. M., & Finkelstein, S. (2001). Change of patients' perceptions of telehomecare. *Telemedicine Journal and e-Health, 7,* 241-247.

DiCenso A., Guyatt, G., & Ciliska, D. (2005). *Evidence-based nursing. A guide to clinical practie.* St Louis, MO: Elsevier Mosby.

Dimmick, S.L., Mustaleski, C., Burgiss, S. G., & Welsh, T. (2000). A case study of benefits & potential savings in rural home telemedicine. *Home Healthcare Nurse, 18,* 125-135.

Downe-Wamboldt, B. (1992). Content analysis: Method, applications, and issues. *Health Care for Women International, 13,* 313-321.

Duggleby, W., Hicks, D., Nekolaichuk, C., Holtslander, L., Williams, A., Chambers, T., & Eby, J. (2012). Hope, older adults, and chronic illness: a metasynthesis of qualitative research. *Journal of Advanced Nursing, 68,* 1211-1223.

Dunne, K., Sullivan, K., & Kernohan, G. (2005). Palliative care for patients with cancer: district nurses' experiences. *Journal of Advanced Nursing, 50,* 372-380.

Edlund, M. (2002). *Människans värdighet – ett grundbegrepp inom vårdvetenskapen* [Human dignity – a basic caring science concept]. (Doctoral Dissertation) Åbo: Åbo Akademis förlag, Samhälls- och vårdvetenskapliga fakulteten.

Ek, K., Sahlberg-Blom, E., Andershed, B., & Ternestedt, B-M. (2011). Struggling to retain living space: patients' stories about living with advanced chronic obstructive pulmonary disease. *Journal of Advanced Nursing, 67,* 1480-1490.

Ek, K., & Ternestedt, B-M. (2008). Living with chronic obstructive pulmonary disease at the end of life: a phenomenological study. *Journal of Advanced Nursing, 62,* 470-478.

Eland-de Kok, P., van Os-Medendorp, H., Vergouwe-Meijer, A., Bruijnzeell-Koomen, C., & Ros, W. (2011). A systematic review of the effects of e-health on chronically ill patients. *Journal of Clinical Nursing, 20,* 2997-3010.

Eldh, A-C., Ekman, I., & Ehnfors, M. (2008). Considering patient non-participation in health care. *Health Expectations, 11,* 263-271.

Ellefsen, B. (2002). Dependency as disadvantage – Patients' experiences. *Scandinavian Journal of Caring Sciences, 16,* 157-164.

Engström, M., Lindqvist, R., Ljunggren, B., & Carlsson, M. (2006). Relatives' opinions of IT support, perceptions of irritations and life satisfaction in dementia care. *Journal of Telemedicine and Telecare, 12,* 246-250.

Engström, M., Ljunggren, B., Lindqvist, R., & Carlsson, M. (2005). Staff perceptions of job satisfaction and life situation before and 6 and 12 months after increased information technology support in dementia care. *Journal of Telemedicine and Telecare, 11,* 304–309.

Eriksson, K. (1987). *Pausen* [The Pause]. Stockholm: Nordstedts Förlag.

Eriksson, K. (1990). *Pro-caritate – en lägesbeskrivning av caritativ vård* [Caritative Caring – A positional analysis]. Åbo: Åbo Akademi.

Eriksson, I., & Nilsson, K. (2008). Preconditions needed for establishing a trusting relationship during health counseling - an interview study. *Journal of Clinical Nursing, 17,* 2352-2359.

European Commission. (2012). *What is eHealth? ICT for health, Europe's Information Society*. Retrieved May 12, 2012 from http://ec.europa.eu/information_society/activities/health/whatis_ehealth/index_en.htm

Evans, L. (2002). An exploration of district nurses' perception of occupational stress. *British Journal of Nursing, 11,* 576-585.

Ezumi, H., Ochiai, N., Oda, M., Saito, S., Ago, M., Fukuma, N., & Takenami, S. (2003). Peer support via video-telephony among frail elderly people living at home. *Journal of Telemedicine and Telecare, 9,* 30-34.

Finkelstein, S., Speedie, S. M., Demiris, G., Veen, M., Lundgren, J. M., & Patthoff, S. (2004). Telehomecare: Quality, perception, satisfaction. *Telemedicine Journal and e-Health, 10,* 122-128.

Fosbinder, D. (1994). Patient perceptions of nursing care: an emerging theory of interpersonal competence. *Journal of Advanced Nursing, 20,* 1085-1093.

Geanellos, R. (2000). Exploring Ricoeur's hermeneutic theory of interpretation as a method of analysing research texts. *Nursing Inquiry, 7,* 112-119.

Godleski, L., Cervone, D., Vogel, D., & Rooney, M. (2012). Home telemental health implementation and outcomes using electronic messaging. *Journal of Telemedicine and Telecare, 18,* 17–19.

Haahr, A., Kirkevold, M., Hall, E. O. C., & Østergaard, K. (2011). Living with advanced Parkinson's disease: a constant struggle with unpredictability. *Journal of Advanced Nursing, 67,* 408-411.

Hailey, D., Roine, R., & Ohinmaa, A. (2002). Systematic review of evidnce for the benefits of telemedicine. *Journal of Telemedicine and Telecare, 8* (Suppl. 1), S1:1-7.

Hallström, I., & Elander, G. (2001). A comparison of patient needs as ranked by patients and nurses. *Scandinavian Journal of Caring Sciences, 15,* 228-234.

Ironside, P. M., Scheckel, M., Wessels, C., Bailey, M. E., Powers, S., & Seeley, D. K. (2003). Experiencing chronic illness: Co creating new understanding. *Qualitative Health Research, 13,* 171-183.

Jeon, Y-H., Jowsey, T., Yen, L., Glasgow, N. J., Essue, B., Kljakovic, M., Pearce-Brown, C., Mirzaei, M., Usherwood, T., Jan, S., Kraus, S. G., & Aspin, C. (2010). Achieving a balanced life in the face of chronic illness. *Australian Journal of Primary Health, 16,* 66-74.

Johns, J. L. (1996). A concept analysis of trust. *Journal of Advanced Nursing, 24,* 76-83.

Johnston, B., Wheeler, L., Deuser, J., & Sousa, K. H. (2000). Outcomes of the Kaiser permanente tele-home health research project. *Archives of Family Medicine, 9,* 40-45.

Jooste, K., Chabeli, M., & Springer, M. (2010). The health care needs of the physically disabled patient in a home-based care environment: Implications for the training of ancillary health care workers. *Health SA Gesonheid, 15,* 1-8.

Jumisko, E., Lexell, J., & Söderberg, S. (2007). Living with moderate or severe traumatic brain injury: The meaning of family members experiences. *Journal of Family Nursing, 13,* 253-268.

Jönsson, A-M., & Willman, A. (2007). Implementation of telenursing within home healthcare. *Telemedicine and e-Health, 14,* 1057-1061.

Karlsson, B., Morberg, S., & Lagerström, M. (2006). Strong as individuals but weak as a group. A qualitative study about district nurses' perceptions of their work situation and occupation. *Vård i Norden, 26,* 36-41.

King, G., Cathers, T., Brown, E., Specht, J. A., Willoughby, C., Miller Polgar, J., MacKinnon, E., Smith, L., & Havens, L. (2003). Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research, 13,* 184-206.

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *British Medical Journal, 311,* 299-302.

Kitzinger J., & Barbour, R. (1999). Introduction. The challenge and promise of focus groups. In R. S. Barbour & J. Kitzinger (Eds.), *Developing focus group research. Politics, theory and practice* (pp. 1-20). London, Thousand Oaks, New Dehli: Sage.

Koch, S. (2006). Home telehealth – Current state and future trends. *International Journal of Medical Informatics, 75,* 565-576.

Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing, 13,* 259-267.

Kvale, S. & Brinkman, S. (2009). *Den kvalitativa forskningsintervjun* [InterViews]. Lund: Studentlitteratur.

Kvåle, K., & Bondvik, M. (2008). What is important for patient centred care? A quality study about the perceptions of patients with cancer. *Scandinavian Journal of Caring Sciences, 22,* 582-589.

Larcher, B., Berloffa, F., Demichelis, F., Eccher, C., Favaretti, C., Galvagni, M., Martini, G., Sboner, A., Graiff, A., & Forti, S. (2002). An evaluation of the use of and user satisfaction with a teleconsultation system in oncology practice. *Journal of Telemedicine and Telecare, 8 (Suppl. 2),* 28-30.

Lawton, S., & Carroll, D. (2005). Communication skills and district nurses: examples in palliative care. *British Journal Community Nursing, 10,* 134-136.

Levy, S., Jack, N., Bradley, D., Morison, M., & Swanston, M. (2003). Perspectives on telecare: the client view. *Journal of Telemedicine and Telecare, 9,* 156-160.

Lincoln, Y. S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Lindberg, B., Axelsson K., & Öhrling, K. (2009). Taking care of their baby at home but with nursing staff as support: The use of videoconferencing in providing neonatal support to parents of preterm infants. *Journal of Neonatal Nursing, 15,* 47-55.

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences, 18,* 145-153.

Lindstrand, P. (2002). ICT (Information and communication technology): A natural part of life for children with disabilities? *Technology and Disability, 14,* 75-83.

Løgstrup, K. E. (1992). *Det etiska kravet* [The ethical demand]. Göteborg: Daidalos. (Original work published 1956)

Magnusson, L., Hanson, E., & Borg, M. (2004). A literature study of information and communication technology as support for frail older people living at home and their family carers. *Technology and Disability, 16,* 223-235.

Magnusson, L., Hanson, E., Brito, L., Berthold, H., Chambers, M., & Daly, T. (2002). Supporting family carers through the use of information and communication technology – the EU project ACTION. *International Journal of Nursing Studies, 39,* 369-381.

Mahoney, J. S. (2001). An ethnographic approach to understanding the illness experiences of patients with congestive heart failure and their family members. *Heart & Lung, 30,* 429-436.

Maslow, A. H. (1970). *Motivation and personality.* New York: Harper & Row, Publishers, Inc.

McCabe, C. (2004). Nurse-patient communication: an exploration of patients' experiences. *Journal of Clinical Nursing, 13,* 41-49.

McGarry, J. (2003). The essence of 'community' within community nursing: a district nursing perspective. *Health & Social Care in the Community, 11,* 423-430.

McHugh, G., Pateman, B., & Luker, K. (2003). District nurses' experiences and perceptions of cancer patient referrals. *British Journal of Community Nursing, 8,* 72-79.

Melanson, P. M., & Downe-Wamboldt, B. (2003). Confronting life with rheumatoid arthritis. *Journal of Advanced Nursing, 45,* 125-133.

Melin-Johansson, C., Ödling, G., Axelsson, B., & Danielsson, E. (2008). The meaning of quality of life: Narrations by patients with incurable cancer in palliative home care. *Palliative and Supportive Care, 6,* 231-238.

Mok, E., & Chiu, P. C. (2004). Nurse-patient relationships in palliative care. *Journal of Advanced Nursing, 48,* 475-483.

Moore, J. (2000). Placing home in context. *Journal of Environmental Psychology, 20,* 207-217.

Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd ed.) London: Sage.

Morgan, G. J., Grant, B., Craig, B., Sands, A., & Casey, F. (2005). Supporting families of critically ill children at home using videoconferencing. *Journal of Telemedicine and Telecare, 11 (Suppl. 1),* 91-92.

Morse, J. M. (1991). *Qualitative nursing research. A contemporary dialogue.* Newbury Park: Sage.

Morse, J. M. (1997). Responding to threats to integrity of self. *Advances in Nursing Science, 19, 21-36.*

Nyström, K., & Öhrling, K. (2006). Parental support: mothers' experience of electronic encounters. *Journal of Telemedicine and Telecare, 12,* 194-197.

Oh, H., Rizo, C., Enkin, M., & Jadad, A. (2005). What is eHealth: A systematic review of published definitions. *Journal of Medical Internet Research, 7, e1,* doi: 10.2196/jmir.7.1.e1

Oliver, P. (2003). *The student's guide to research ethics.* Philadelphia: Open University Press.

Olofsson, A., Andersson, S–O., & Carlberg, B. (2005). 'If only I manage to get home I'll get better' – Interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical Rehabilitation, 19,* 433-440.

Olsson, M., Lexell, J., & Söderberg, S. (2008). The meaning of women's experiences of living with multiple sclerosis. *Health Care for Women International, 29,* 416-430.

Olsson, M., Skär, L., & Söderberg, S. (2010). Meanings of feeling well for women with multiple sclerosis. *Qualitative Health Research, 20,* 1254-1261.

Olsson, M., Skär, L., & Söderberg, S. (2011). Meanings of being received and met by others as experienced by women with MS. *International Journal of Qualitative Studies on Health and Well-Being, 6:* 5769 – doi: 10.3402/qhw.v6il.5769

Paterson, B. L. (2001). The shifting perspective model of chronic illness. *Journal of Nursing Scholarship, 33,* 21-26.

Patton, M. Q. (2002). *Qualitative evaluation and research methods* (3rd ed.). Thousand Oaks: Sage.

Polit, D. F., & Beck, C. T. (2012). *Nursing research; Generating and assessing evidence for nursing practice* (9th ed.). Philadelphia: Wolters Kluwer Health/ Lippincott Williams & Wilkins.

Rapley, P., & Fruin, D. J. (1999). Self-efficacy in chronic illness: The juxtaposition of general and regimen-specific efficacy. *International Journal of Nursing Practice, 5,* 209-215.

Rasmussen, B., Dunning, P., & O'Connell, B. (2007). Young women with diabetes: using Internet communication to create stability during life transitions. *Journal of Nursing and Healthcare of Chronic illness* in association with *Journal of Clinical Nursing, 16,* 3a, 17–24.

Ricoeur, P. (1976). *Interpretation theory: discourse and the surplus of meaning.* Texas: Christian University Press.

Ricoeur, P. (1993). *Från text till handling. En antologi om hermeneutik.* (Eds. P. Kemp & B. Kristensson Uggla). Stockholm: Symposium.

Rousch, C. V., & Cox, J. E. (2000). The meaning of home. How it shapes the practice of home and hospice care. *Home Healthcare Nurse, 18,* 388-394.

Rout, U. R. (2000). Stress amongst district nurses: a preliminary investigation. *Journal of Clinical Nursing, 9,* 303–309.

Sandelowski, M. (1995). Focus on qualitative methods. Qualitative analysis: What it is and how to begin. *Research in Nursing and Health, 8,* 371-375.

Sandelowski, M. (1995). Focus on qualitative methods. Sample size in qualitative research. *Research in Nursing and Health, 8,* 479-482.

Sandelowski, M. (1998). The call to experts in qualitative research. *Research in Nursing & Health, 21,* 467-471.

Scott, C., & Lundgren, S: M. (2009). Complexity and contradiction; home care in a multicultural area. *Nursing Inquiry, 16,* 223-231.

Skuladottir, H., & Halldorsdottir, S. (2011). The quest for wellbeing: self-identified needs of women in chronic pain. *Scandinavian Journal of Caring Sciences, 25,* 81-91.

Statistical yearbook of Sweden. (2011). *Health and medical care.* Retrieved April 15, 2012 from http://www.scb.se/statistik/_publikationer/OV0904_2011A01_BR_21_A01BR1101.pdf

Strandberg, G., Norberg, A., & Jansson, L. (2003). Meaning of dependency on care as narrated by 10 patients. *Research and Theory for Nursing practice, 17,* 65-84.

Strandmark, K. M. (2004). Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering. *Scandinavian Journal of Caring Sciences, 18,* 135-144.

Sundin, K., Bruce, E., & Barremo, A-S. (2010). Elderly women's experiences of support when living with congestive heart failure. *International Journal of Qualitative Studies on Health and Well-being, 5.* doi:10.3402/qhw.v5i2.5064

Sävenstedt, S., Brulin, C., & Sandman, P. O. (2003). Family members' narrated experiences of communicating via video-phone with patients with dementia staying at a nursing home. *Journal of Telemedicine and Telecare, 9,* 216-220.

Söderberg, S., Lundman, B., & Norberg, A. (1999). Struggling for dignity. The meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research, 9,* 575-587.

Söderberg, S., Strand, M., Haapala, M., & Lundman, B. (2003). Living with a woman with fibromyalgia from the perspective of the husband. *Journal of Advanced Nursing, 42,* 143-150.

Tailor, R. M., Gibson, F., & Frank, L. S. (2008). The experience of living with a chronic illness during adolescence: a critical review of literature. *Journal of Clinical Nursing, 17,* 3083-3091.

The National Board of Health and Welfare (2008). *Hemsjukvård i förändring. En kartläggning av hemsjukvården i Sverige och förslag till indikatorer* [Home nursing care in change. A survey of home nursing care in Sweden and suggestions to indicators] Retrieved April 23, 2012 from http://www.socialstyrelsen.se/publikationer2008/2008-126-59

Thorsteinsson, L. S. (2002). The quality of nursing care as perceived by individuals with chronic illnesses: the magical touch of nursing. *Journal of Clinical Nursing, 11,* 32-40.

Thorne, S., & Paterson, B. (2000). Two decades of insider research: what we know and don't know about chronic illness experience. *Annual Review of Nursing Research, 12,* 3-25.

Thorne, S., Paterson, B., & Russel, C. (2003). The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research, 13,* 1337-1352.

Thorne, S., Con, A., McGuiness, L., McPherson, G., & Harris, S. R. (2004). Health care communication issues in multiple sclerosis: An interpretive description. *Qualitative Health Research, 14,* 5-22.

Toombs, S. K. (1993). *The meaning of illness. A phenomenological account of the different perspectives of physician and patient.* Dordrecht: Kluwer Academic Publishers.

Tropea, S. (2011). 'Therapeutic emplotment': a new paradigm to explore the interaction between nurses and patients with a long chronic illness. *Journal of Advanced Nursing, 68,* 939-947.

Törnkvist, L., Gardulf, A., & Strender, L-E. (2000). Patients' satisfaction with the care given by district nurses at home and at primary health care centres. *Scandinavian Journal of Caring Sciences, 14,* 67-74.

Wadensten, B., & Ahlström, G. (2009). The struggle for dignity by people with severe functional disabilities. *Nursing Ethics, 16,* 453-457.

Walshe, C., & Luke, K.A. (2010). District nurses' role in palliative care provision: A realist review. *International Journal of Nursing Studies, 47,* 1167-1183.

Whittemore, R., & Dixon, J. (2008). Chronic illness: the process of integration. *Journal of Nursing and Healthcare of Chronic illness* in association with *Journal of Clinical Nursing, 17,* 7b, 177-187.

Wilkes, L., Beale, B., Hall, E., Rees, E., Watts, B., & Denne, C. (1998). Community nurses' descriptions of stress when caring in the home. *International Journal of Palliative Nursing, 4,* 14-20.

Wilkes, L., Cioffi, j., Warne, B., Harrison, K., & Vonu-Boriceanu, O. (2008). Clients with chronic and complex conditions: their experiences of community nursing services. *Journal of Nursing and Healthcare of Chronic Illness* in association with *Journal of Clinical Nursing, 17,* 7b, 160-168.

Willman, A., Stoltz, P., & Bahtsevani, C. (2011). *Evidensbaserad omvårdnad. En bro mellan forskning & klinisk verksamhet.* [Evidence-based nursing. A bridge between research and clinical practice] Lund: Studentlitteratur.

World Health Organization [WHO]. (2006). *Building foundations eHealth.* Retrieved April 15, 2012 from http://www.who.int/goe/publications/bf_FINAL.pdf

Wright, K. (2002). Caring for the terminally ill: the district nurse's perspective. *British Journal of Nursing, 11,* 1180-1185.

Yin, R. K. (2009). *Case study research. Design and methods* (4th ed.). Thousand Oaks, CA: Sage.

Öhman, M., & Söderberg, S. (2004a). District nursing – sharing and understanding by being present. Experiences of encounters with people with serious chronic illness and their close relatives in their homes. *Journal of Clinical Nursing, 13,* 858-866.

Öhman, M., & Söderberg, S. (2004b). The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research, 14,* 396-410.

Öhman, M., Söderberg, S., & Lundman, B. (2003). Hovering between suffering and enduring. The meaning of living with serious chronic illness. *Qualitative Health Research, 13,* 528-542.

Öresland, S., Määttä, S., Norberg, A., & Lűtzén, K. (2009). Patients as 'safeguard' and nurses as 'substitute' in home health care. *Nursing Ethics, 16,* 219-230.

Öresland, S. Määttä, S., Norberg, A., Winther Jörgensen, M., & Lűtzén, K. (2008). Nurses as guests or professionals in home health care. *Nursing Ethics, 15,* 372-383.

Information and communication technology as a tool for accessibility to home care: A systematic literature review

Running Head: ICT a tool for accessibility to home care

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Author contributions

S. Söderberg was responsible for the design in collaboration with the other authors. All of the authors have contributed significantly in the development of this work. All authors read and approved the final manuscript.

Abstract

Background: eHealth tools are today becoming more and more a natural part of healthcare systems for delivering high quality healthcare to people with chronic illness living at home.

Aim: The aim of this systematic review was to provide an overview of characteristics of studies describing the use of ICT in home care.

Methods: A literature review was conducted that identified 1,276 studies published between 2000 and 2010. The literature search strategy was performed using the electronic bibliographic databases PubMed, Scopus, and CINAHL.

Results: The selection process resulted in a total of 107 studies being classified as relevant to the research question. The review show that this field of research contains mostly quantitative studies and that the field has grown in recent years. A variety of terms are used to define information and communication technology (ICT); the most frequently used are "telehealth" and "telemedicine." The technology is more often used for communication between healthcare professionals and patients or family members.

Conclusion: A variety of ICT tools are used for information exchange and communication between healthcare professionals and patients or family members, which indicates that ICT could increase accessibility to home care based on the patient's needs.

Background

Due to an ageing population and a shortage of hospital beds, it has become a challenge to find new ways to support and care for people with chronic illness living at home. Living with chronic illness changes the lives of those affected, who are often in need of support and nursing care in their homes (Appelin et al. 2005; Roback & Herzog 2003; Öhman et al. 2003). eHealth has the potential to become a means of providing good care at home (Demiris 2006), which is especially challenging with regard to this emerging field (Koch & Hägglund 2009). "eHealth" refers to information and communication technology (ICT) tools and services for health, whether the tools are used behind the scenes by healthcare professionals or directly by patients and their relatives (European Commission 2012). ICT tools can be used to access a wide variety of technological solutions for communication, including text messaging, gathering and monitoring data, diagnosis and treatment at distances, and retrieving electronic health records (Koch 2006; Koch & Hägglund 2009). According to the World Health Organization [WHO] (2005), eHealth is used in the health sector for the transmission of digital data, including data stored and retrieved electronically to support health care, both at the local site and at a distance.

eHealth also includes the interaction between patients and health-service providers, or peer-to-peer communication between patients and/or health professionals. Interest has primarily focused on the use of ICT tools in the care of older (cf. Finkelstein et al. 2004) and severely chronically ill people (cf. Nilsson et al. 2006). Although ICT has been increasingly used in the healthcare sector in recent years, efforts across countries have been fragmented and could benefit from improved cross-boarder coordination. eHealth tools and services have been widely introduced and implemented, and the potential benefits

ICT can bring people with chronic illness will increase significantly (European Commission 2012).

The review

Aim

The aim of this systematic review was to provide an overview of characteristics of studies describing the use of ICT in home care.

Design

The design for conducting a systematic review was guided by DiCenso et al. (2005), with the following steps taken: formulating a research question, conducting a literature search, applying inclusion and exclusion criteria, abstracting data, and undertaking an analysis.

Selection criteria

The inclusion criteria for this literature review were set as follows: ICT interventions, studies published in scientific journals between 2000 and 2010, and in the English language. Criteria for exclusion were ICT interventions that included technological systems not involving people (no active patient acceptance) such as monitoring by camera, alarm systems, and use of ordinary telephones, noting that telephones can be used complementarily to other techniques. Letters, editorials, and news items were also excluded.

Search strategy

In the literature search the following electronic bibliographic databases were used: PubMed, Scopus, and CINAHL. Limits were set to English language studies published from 2000 to June 2010. The search strategy was customized for each database and included controlled vocabulary such as the National Library of Medicine – Medical Subject Headings (MeSH) and keywords. The main keyword used were: telemedicine, information and communication, ICT, technology, e-health, home care, home, and nursing. However, to maximize the search results, multiple keyword sets were used. All studies retrieved from the search in databases were imported into a reference manager (EndNote®). The literature searches resulted in 1,276 studies; after duplicates were discarded by EndNote®, 923 studies remained. A search alert was created to get the latest published, which resulted in 11 additional studies. The final total to be reviewed was 934. The literature search was performed with support from librarians.

Selection process

A first selection was based on the titles and abstracts of the 934 studies to identify whether or not they were within the scope of the research question. Next, a selection based on relevance was conducted according to a focus on studies of ICT used in home settings with adult participants. After this selection, a total of 320 studies remained for closer review. All the abstracts were then read and initially categorized based on type of communication applied in the studies. To increase reliability, the authors jointly analyzed numerous audits and discussed ambiguities, so agreement was reached. This reduced the number to 139 studies relevant to the research question. However, nine relevant studies were unviable both electronically and in paper form, which thereby excluded them from

this review, leaving 130 studies. Selection process for the studies reviewed is presented in Figure 1.

---------------------------- Insert Figure 1 about here ----------------------------

Quality appraisal

All eligible studies (n=130) were evaluated for quality (cf. Willman et al. 2006). In appraising the quality, different protocol were used for studies with a quantitative approach and for studies with a qualitative approach. The protocols contained questions to be answered with yes/no/unclear. The number of questions answered yes was divided by the total number of questions, and thereafter converted to percentage. The percentage was transformed to high (80-100%), good (70-79%), and fair (60-69%) quality. The studies that scored less than fair were excluded (n=23). The quality appraisal was performed by two of the authors, initially together to obtain an equal assessment. Thereafter, when uncertainties arose, the authors discussed them until consensus emerged. After the quality appraisal was undertaken, 107 studies remained.

Data abstraction

Finally, a total of 107 studies were classified as relevant to the research question and meeting the criteria for being included in the data abstraction. Each of the 107 studies was given an indexation, and then categorized according to a number of different areas based on the following characteristics: country of origin, year of publication, study approach, journal, communication strategies, type of technology, type of communication, disease diagnosis, and quality appraisal. Thereafter, data from each of the included studies were extracted and entered into a matrix.

Results

The main findings are summarized in areas including study approach, quality appraisal, publications data, terminology used for defining the technology, disease diagnosis, type of technology, and type of communication.

Studies' approach

Most of the included studies had a quantitative approach (n=74). Only about one-fifth had a qualitative approach (n=21). Further, some of the studies used mixed methods, with both qualitative and quantitative approaches (n=12). Twenty-one studies were part of larger projects.

Quality appraisal

In the critical quality appraisal of all 107 studies, just under half were rated high-quality (n=48). Compare that to studies rated as good quality (n=23) and fair to good quality (n=36).

When comparing the quality appraisal between qualitative and quantitative approaches, differences could be noted. A greater proportion of the qualitative approach studies (n=21) were rated as high quality (n=15). In comparison, less than half of the quantitative studies (n=74) were rated as high quality (n=29).The opposite was the case with qualitative (n=2) and quantitative (n=28) studies rated as fair quality. Good quality ratings were found in both qualitative (n=4) and quantitative (n=17) studies. The studies with mixed methods (n=12) were appraised as follows: high (n=4), good (n=2), and fair (n=6) quality.

Publication data

All of the 107 included studies were published between January 2000 and June 2010, so only part of 2010 was included. During this period the number of publications increased by time, with about half of the included studies (n=53) published between 2007 and 2009. Note that 2009 alone represents 23 studies of the total publications (Figure 2).

-------------------------------- Insert Figure 2 about here ----------------------------------

The studies included were published in 69 different scientific journals. The two most common journals were Journal of Telemedicine and Telecare (n=15) and Telemedicine Journal and e-Health (n = 12), together representing almost one-quarter of the total number of publications. The rest of the studies (n= 80) were spread over a variety of other journals (n=67). The impact factor in the journals ranged between 0.348 and 14,293.

The majority of the studies were performed in North America (n = 67). About one-third of the studies were done in Europe (n=34), with the United Kingdom (n=13), Sweden (n=7), and Italy (n=5) being most prominent. Only a few studies (n=6) were conducted outside North America and Europe; those were done in Asia (n=5) and Australia (n=1). Only one study (n=1) was a combined study involving the continents of North America and Europe.

Terminology used for defining the technology

The results shows that 13 different terms were used to define the technology utilized to increase accessibility to home care services and home nursing. The most frequently used terms were "telehealth" (n=32), "telemedicine" (n=27), "technology" (n=11), and "telecare" (n=10). "Telehealth" and "telemedicine" together (n=59) account for more than half of the terms used in the included studies. Other terms used three times or more were "e-Health" (n=3), "ICT"/"IT" (n=7), "telehealthcare" (n=3), "telemonitoring" (n=6), and "telenursing" (n=4). Further, in some studies (n=4) other terms were used as follows: "e-rehabilitation" (n=1), "teleassistance" (n=1), and "telerehabilitation" (n=2).

Disease diagnosis

The ICT were used for a wide range of different conditions through the life span of the studies. In the majority of the studies (n=86), the technology was developed specifically for supporting people with chronic illness living at home. The most frequent diseases studied were heart and lung diseases (n=38), chronic wounds (n=9), diabetes (n=7), cancer (n=6), and stroke (n=5). Chronic illness was used in 12 studies (n=12) without any definition of the specific disease. Other conditions were, for example, infectious diseases (n=2), spinal cord injuries (n=2), and end of life care (n=2). A number of studies included did not specify the diagnoses (n=13).

Types of technology

The different types of ICT used for accessibility to home care comprised videophones or video conferencing equipment (n=49), text messages (n=26), and monitoring patient health (n=17). A small number of studies (n=4) included all these types of ICT. In some

of the studies, a mix of text messages and pictures or audio was used (n=6) and in a few studies only pictures were used (n=3). A few studies did not specify the used ICT (n=2). An important result was that a mix of more than one technical appliance to communicate or send information was used in several studies (n=31).

Video technology

The most frequently used type of technology was video technology (n=53); the number includes studies using more than one technical appliance. In several of those studies (n=32), the main focus of the intervention was the use of videophones or videoconferencing equipment. Another use of video technology was to complement patient health monitoring (n=12). It is notable that Web-based video conferencing was used only in a small number of studies (n=3). In all studies involving parents of children with chronicle illness, video equipment was used to communicate.

Text messages

As shown in many studies (n=30), a common way of communicating was via text messages. For sending text messages, websites or web-based programs were used in some studies (n=7). In other studies (n=8), mobile phones or hand held equipment was used to send the text messages. A handheld platform, such as a mobile phone or a laptop computer, was used by patients to both send and receive information as well as to communicate (n=11).

Health monitoring

About half of the total studies (n=52) focused on self-monitoring patients who sent health data to be analyzed by healthcare professionals. In some of those studies (n=35), a special device was used to collect the health data. In most of the studies that looked at monitoring patient health, text messaging or video technology was used to communicate the data (n=35). Other forms of communication were also used, including the telephone (n=17). The types of patient health data collected were, for example, weight, blood pressure, and pulse. Health Buddy®, a system that connects patients in their homes with care providers, was the most commonly used device for monitoring patient health (n=8).

Communication between participants

Different types of communication via ICT were described as being used between participants, who were typically as nurses, health professionals, patients, or family members. The most frequent line of communication in the studies was between patients and nurses (n=49) or other health professionals (n=34). ICT was used most for communication between nurses and patients. In 24 studies (n=24), the patient was not the focus for communication. Instead, it was common for the technology to be used for communication with family members (n=14). In some of the studies with a focus on family members, the ICT was developed for healthcare personnel giving support to parents (n=5). In some studies (n=10), the communication was merely between healthcare professionals and neither patients nor family members were part of the communication.

Discussion

The results of this review show that ICT in home care is an expanding field of interest, with a variety of ICT tools beginning to be evaluated significantly. Still, there is a lack of knowledge about how to use ICT solutions to meet the needs of people with chronic illness. In specific, there are a lack of qualitative studies that relate to these people's needs according to their life situation. A challenge is, therefore, to use existing ICT tools to meet needs of people with chronic illness based on their experiences (Bardram et al. 2005).

The review shows a trend that most studies were accomplished in North America and Europe, where the United Kingdom, Sweden, and Italy were represented. This is noticeable since Italy is one of the European countries in which less than 30 percent of the population uses the Internet on a daily basis. The maturity of Internet use in daily life is an indicator of how far the digitalization of the healthcare sector should have come (Kairos future 2012). For instance, despite Sweden being a small country, seven of the studies included in this review were performed there, which might be explained by the fact that 75 percent of the population uses the Internet on daily basis.

The review showed further that a wide variety of terms were used in the reviewed studies to define ICT. Most common were "telehealth" and "telemedicine," which is in accordance with Koch's (2006) findings in her review of the current state and future trends in home telehealth. The term "telehealth" has been broadly defined as the use of telecommunication and information technologies for provision of healthcare to individuals

at geographical distance (Liss at al. 2002). Telehealth involves a wide variety of specific modalities including telephone-based interactions, Internet-based information, still and live imaging, personal digital assistants, and interactive audio–video communication or television (Sato et al. 2009). However, eHealth is described as the overall umbrella field that includes both ICT and telehealth, a combined use of electronic communication and information technology used in healthcare (Mitchell 1999), which could explain the many terms used in this area.

A variety of appropriate tools for home care environments are presented in the reviews, which describe challenges and the need for unambiguous valuation of the setting in which the tools will be used. According to Bardram et al. (2005), design of home care monitoring and technology for treatment must take into consideration the role that home care technology plays in a closely coupled collaborative setup between patient and healthcare professionals. Neglecting this aspect may lead to technology that does not provide the needed support for communication, coordination, knowledge sharing, and mutual awareness. According to Koch et al. (2009), research and practice of health-enabling and ambient-assistive technologies may significantly contribute to this aim if technical solutions are explored in a social context and in relation to individual needs. Telehealth systems in the form of online and mobile tools are already opening up the possibilities for home care. Similarly, tools can also enable health professionals who travel to see patients to provide more specific treatments. eHealth services promise to raise the quality of care in more remote and rural areas, thanks to modern communication infrastructure (European Commission 2012). Widespread implementation of eHealth will therefore enable the development of more patient-friendly healthcare services. This will

offer healthcare professionals a change to become more flexible and better able to address the differing needs of individual patients (DePalma 2009). An interesting result was that the most frequent line of communication was between patients and nurses or other health professionals. This might show a change of user focus shifting from tools for professionals to tools for patients and family members. The trend toward tools and services not only for professionals but also for patients and citizens observed by Koch (2006) is validated.

Across the literature, outcomes for telehealth-based services are generally comparable to outcomes for services delivered face to face (Sato et al. 2009). However, according to Charlton et al. (2008), many of the studies pointed out that the style of communication the healthcare professional uses influences patient outcomes. A literature review (Botsis & Hartvigsen 2008) shows that patients who used telecare at home preferred a combination of telecare and traditional health care delivery. Therefore, telemedicine must be used as an adjunct and not as replacements for standard care; otherwise, the positive results might not be replicated (Williams et al. 2001). Many patients prefer being involved in deciding on the type of care they will receive. Despite this, most researchers develop programs without caregiver participation (Ducharme et al. 2001).

The strength of this study is the broad literature search that finally resulted in 107 studies being reviewed. The literature search was systematically conducted using selected computer databases based on keywords relevant for the field. To get the latest published studies, a search alert was created with assistance from librarians. During the selection process, a quality appraisal was conducted; thereby, the methodological quality of the included studies could be ensured. A limitation of this review is that it is likely that

relevant studies may have been missed because of the selection to English language sources. Further, the use of a wide variety of terms in the field of eHealth is not always sensitive enough, according to the many definitions used in the field, and may have meant that not all relevant studies were found.

Conclusion

The findings from this systematic review have given insight into types of characteristics of studies describing the use of ICT in home care. The total number of studies included in this review show that this field of research has prompted mostly quantitative studies and that the research field has grown in recent years. Most research is published in specific journals focusing on telemedicine and telecare. Furthermore, the review showed that a variety of terms are used to define the technology, which might be due to the many definitions of eHealth. The studies in this review showed that ICT is mostly used as a tool for communication between healthcare professionals and patients or family members, and could thereby be a tool to increase accessibility to home care.

References

Appelin, G., Brobäck, G. & Berterö, C. (2005) A compressive picture of palliative care at home from the people involved. European Journal of Oncology Nursing, 9, 315–324.

Bardram, J.E., Bossen, C. & Thomsen, A. (2005) Designing for transformations in collaboration :A study of the deployment of homecare technology. International Conference on Supporting Group Work, 6 (9), 294–303.

Botsis, T. & Hartvigsen, G. (2008) Current status and future perspectives in telecare for elderly people suffering from chronic diseases. Journal of Telemedicine and Telecare, 14 (4), 195-203.

Charlton, C.R., Dearing, K.S., Berry, J.A. & Johnson, M.J. (2008) Nurse practitioners' communication styles and their impact on patient outcomes: An integrated literature review. Journal of the American Academy of Nurse Practitioners 20, 382–388.

Demiris, G. (2006) The diffusion of virtual communities in health care: concepts and challenges. Patient Education and Counselling, 62 (2), 178-188.

DePalma, J.A. (2009).Telehealth in the community: A research update. Home Health Care Management Practic, 21, 205-207.

DiCenso, A., Guyatt, G. & Ciliska, D. (2005) Evidence-based nursing: A guide to clinical practice. Elsevier Mosby, St. Louis.

Ducharme, F., et al. (2001) Development of an intervention program for Alzheimer's family caregivers following diagnostic disclosure. Clinical Nursing Research, 8, 44-67.

European Commision. (2012) What is eHealth? ICT for health, Europe's Information Society.
http://ec.europa.eu/information_society/activities/health/whatis_ehealth/index_en.htm (accessed 25 March 2012).

Finkelstein, S., et al. (2004) Telehomecare: Quality, perception, satisfaction. Telemedicine Journal and e-Health, 10, 122-128.

Kairos future. (2012). The data explosion and the future of health. What every decision-maker in the health and healthcare industries need to know about the coming revolution. Stockholm, Sweden.

Koch, S. (2006) Home telehealth: Current state and future trends. International Journal of Medical Informatics, 75 (8), 565–576.

Koch, S. & Hägglund, M. (2009) Health informatics and the delivery of care to older people. Maturitas, 63 (3), 195-199.

Koch, S., et al. (2009) On health-enabling and ambient-assistive technologies: What has been achieved and where do we have to go? Methods of Information in Medicine, 1, 29-37.

Liss, H.J., Glueckauf, R.J. & Ecklund-Johnson, E.P. (2002) Research on telehealth and chronic medical conditions: Critical review, key issues, and future directions. Rehabilitation Psychology, 47, 8–30.

Mitchell, J. (1999) From telehealth to ehealth: The unstoppable rise of ehealth. John Mitchell & Associates for the Federal Australian Department of Communications, Information Technology and the Arts (DOCITA).

Nilsson, C., Öhman, M. & Söderberg, S. (2006) Information and communication technology in supporting people with serious chronic illness living at home – an intervention study. Journal of Telemedicine and Telecare, 12, 198-202.

Roback, K. & Herzog, A. (2003) Home informatics in healthcare: Assessment guidelines to keep up quality of care and avoid adverse effects. Technology and Health Care, 195-206.

Sato, A.F., Clifford, L.M., Silverman, A.H. & Davies, W.H. (2009) Cognitive-behavioral interventions via telehealth: Applications to pediatric functional abdominal pain. Children's Health Care, 38, 1–22.

WHO. (2005) eHealth for Health–care Delivery [Electronic version].
http://www.who.int/eht/eHealthHCD/en/index.html (accessed 17 March 2012).

Williams, T.L., May, C.R. & Esmail, A. (2001) Limitations of patient satisfaction studies
in telehealthcare: A systematic review of the literature. Telemedicine Journal and e-
Health, 7 (4), 293–316.

Öhman, M., Söderberg, S., & Lundman, B. (2003) Hovering between suffering and
enduring: The meaning of living with chronic illness. Qualitative Health Research, 13 (4),
528–524.

The literature search in databases yield potentially relevant studies
n=1276

Studies excluded as duplicates
n=353

Studies screened after excluding duplicates and including from search alert
n=934

Studies excluded after examining titles and abstract
n=614

Studies remaining for closer review
n=320

Studies excluded as not meeting criteria for inclusion
n=181

Studies remaining relevant to the aim of the studie
n=139

Studies excluded due to un-aviable electronically or by paper
n=9

Studies undergoing quality appraisal
n=130

Studies not measuring up to the quality
n=23
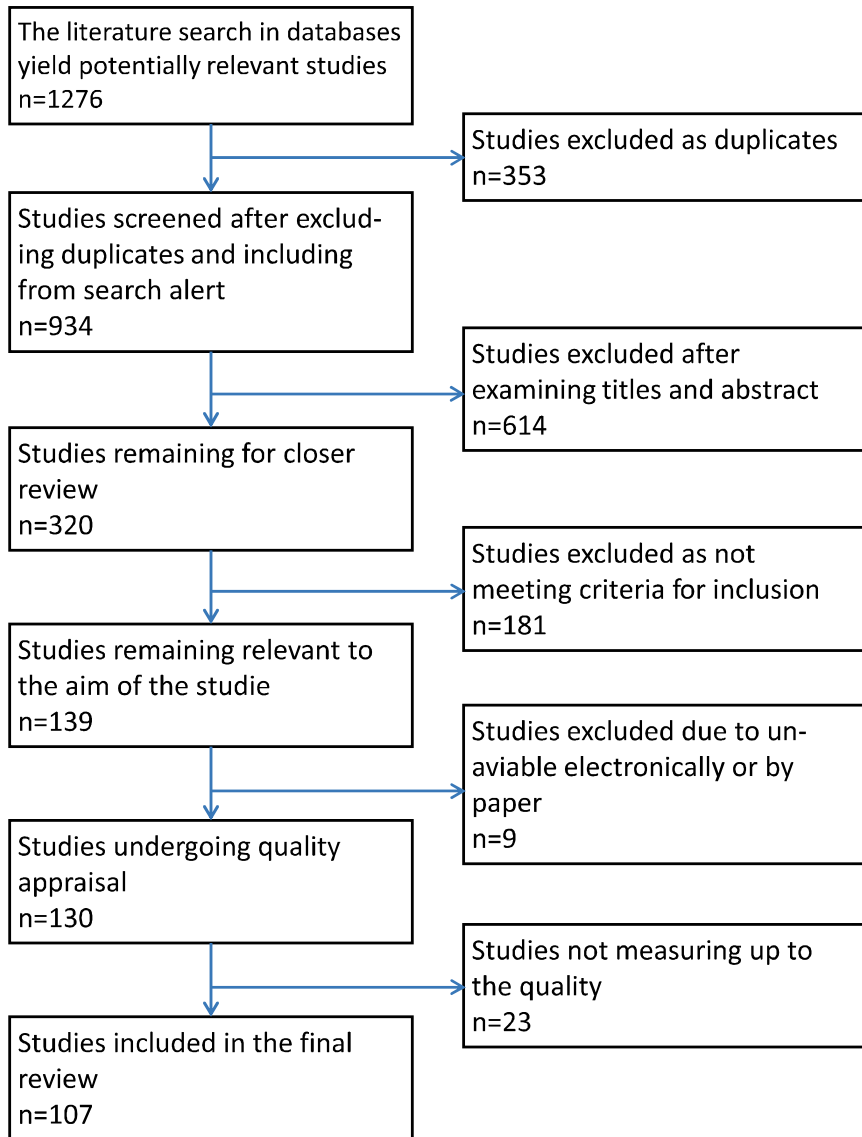
Studies included in the final review
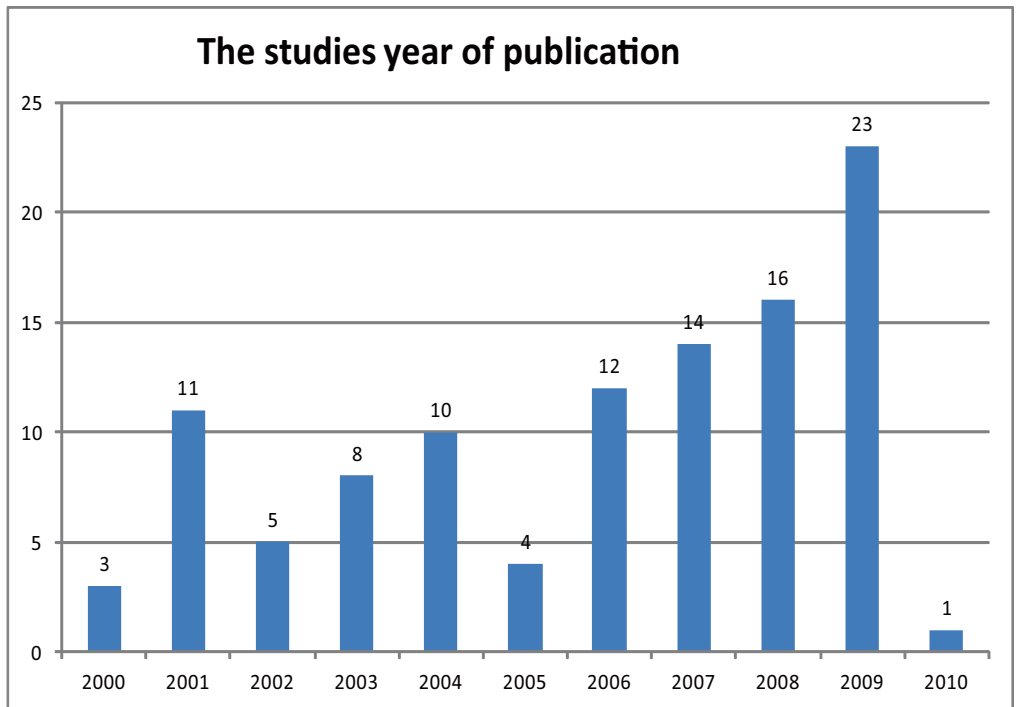n=107

Fig. 1. Flow chart of search result.

Fig. 2. Number of studies published per year between 2000 and June 2010.

Meanings of Needs of Middle-aged People with Serious Chronic Illness Living at Home

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Abstract

Background

Many people live with chronic illnesses that impact their daily life to a great extent. Middle-aged people with serious chronic illness living at home are in need of help and support to manage their daily lives. Therefore, the aim of this study was to elucidate meanings of needs of middle-aged people with serious chronic illness living at home.

Methods

A purposive sample of twelve middle-aged people with serious chronic illness living at home were interviewed about their needs relating to be ill. A phenomenological hermeneutic interpretation was used to analyse the interview text.

Results

Meanings of needs of people with serious chronic illness living at home can be understood as maintaining control in everyday life, which gives meaningfulness to life. This means striving for independence through care and support in their surroundings. It was also important for participants to choose how their lives would be and to be together with others who listened and understood them for who they are.

Conclusions

This study shows that listening to people in need of help and support means acquiring knowledge that will bring with it a greater understanding of the experiences of life with chronic illness. Increasing the possibility of supporting people with chronic illness gives people power by which they can support themselves so they can live a meaningful life, i.e. a life in dignity. By listening, the nursing staff has an opportunity to interpret and understand the needs that middle-aged people with serious chronic illness experience while living at home.

Keywords: Needs, people with serious chronic illness, living at home, qualitative

Background

Living with chronic illness influences and changes daily life in several ways, both for people with chronic illness [1-4] their partners [5] and other family members [6,7]. Studies [2,8] have described that people with chronic illness experienced losses such as the loss of freedom and understanding from others [2] as well as the loss of autonomy and respect in dealings with their caregivers [8]. Feelings of insecurity, anxiety and fear in daily life, especially in situations when help is needed, have been described by people living with serious chronic illness at home [4]. The loss of their previous habitual body causes lack of control in daily life [9]. All these losses lead to dependence on care, and, therefore, help and support in daily life. Being dependent on care requires a new way to look at themselves and relate to their lives and the vast changes that occur after the diagnosis [10]. According to [11] integrating one's chronic illness into one's daily life and regaining control is a difficult and complex process.

People living with chronic illnesses use different strategies to feel well [12,13]. Feeling well was achieved for people with chronic illness when it was possible to do what they chose [14-16]. Central to feeling well was living a life as normal as possible [17-19] and being treated with respect and engagement by health care professionals [17]. It was also important to be involved in decisions about their own care [18,20]. According to [4,21,22] it was important for people with chronic illness to live at home, because home represented security for them [20-22].

Previous research in this area [e.g. 23,24] embraces mostly studies with older people or studies with mixed ages of adults [22,25,26]. Studies describing meanings of needs of middle-aged people with serious chronic illness living at home are rare. A literature

review [27] shows a lack of studies describing experienced needs and the care delivered among people with long-term illness living at home. Understanding meanings of needs of middle-aged people with serious chronic illness living at home could improve help and support and enable the development of interventions in order to increase wellbeing in their lives. Thus, the aim of this study was to elucidate meanings of needs of middle-aged people with serious chronic illness living at home.

Methods

Participants and procedure

In this study a purposive sample of 12 middle-aged persons, seven women and five men, participated. The participants were aged between 40-66 years (md=57). The inclusion criteria for participating consisted of being a middle-aged person between 40 to 67 years living at home with an extensive need of help and support in daily life. Their illnesses had been in progress from 4 to 39 years (md=26), except for one participant who had had the illness from birth. Eight of the participants lived alone, four were married, and nine of them had children. All of them had help from nursing staff, including district nurses (DNs), occupational therapists, physiotherapists and physicians. All had personal assistance, except two who had merely help and support in daily life from the family and close relatives. The participants' (n=10) help from personal assistants varied between 4 to 24 hours every day (md=12). Four of them had help and support both day and night. All except one participant used a wheelchair. The participants had disease diagnoses such as multiple sclerosis, stroke, serious diabetes and leg amputation, spina bifida with hydrocephalus, and neck and back injuries with paralysis.

The participants were recruited from four primary health care centres in northern Sweden. Two of the primary health care centres were located in sparsely populated areas and the other two were in more densely populated areas. They were selected by DNs from primary health care centres, which agreed to the inclusion criteria of the study. First, DNs gave oral information about the study and a written information letter with a reply form, where informed consent to participate was requested. Three of the participants were recruited by an interest association, where the first author (CN) gave information during a meeting, and left information letters with reply forms. After the people with serious chronic illness had agreed to participate, the first author (CN) phoned each person to supply additional information about the study and obtained agreement of time and place for an interview.

Interviews

Personal interviews were conducted with the participants in 2010. Kvale and Brinkman [28] determined that interviews are suitable for use in describing and understanding the meaning of essential themes in the interviewees' life world. The interview started with a broad question: 'Please tell me about your need for help at home related to your illness'. Examples of topics that were mentioned were security, safety, help from others, relationships, loneliness, spare time occupations, and possibilities of influencing their care. During the interviews probing questions were asked and comments were made in order to clarify the participants' comments. Examples include: 'Give an example', 'Explain that further', 'Tell me what happened then' and 'What do you mean?' Two of the participants brought assistants for support during the interview; one had her son, and the other had a personal assistant. The interviews were performed by the first author (CN) and ranged from 31 to 66 minutes

(md = 55). They were digitally recorded and then transcribed verbatim. All participants preferred to be interviewed in their homes.

Ethical considerations

The interviews were performed with informed consent about the nature of the study, both verbally and written. The participants were informed that they could withdraw at any time, without affecting their care. They were guaranteed confidentiality and an anonymous presentation of the results. The Regional Ethical Review Board approved the study (Dnr 210-175-31M).

The phenomenological hermeneutic interpretation

A phenomenological hermeneutic interpretation, inspired by the philosophy of Ricoeur and developed by Lindseth and Norberg [29], was used to analyse the interviews. The phenomenological hermeneutic interpretation involves three phases: naïve understanding, structural analysis and a comprehensive understanding with reflections [29]. The analysis and interpretation of the text consisted of alternating between understanding and explanation in order to create a deeper understanding of the phenomena under study. This required a dialectic movement between understanding the text as a whole and explaining the different pieces of the text [30]. To understand a text means to follow the text movement from sense to reference, from what the text says to what it talks about [30].

The analysis and interpretation started with the naïve understanding. The text was read several times with an open mind in order to grasp the meaning as a whole. This phase could be viewed as a surmised result.

In the next phase, the structural analysis, the intention was to explain the text, and this section began with reading the text again. Guided by the aim of the study, the text was divided into meaning units, which were condensed and compared, based on similarities and differences. The meaning units were grouped together in several stages. During the structural analysis, the text was viewed as objectively as possible. Six subthemes and three themes were abstracted and formulated to give the essential meanings of needs for middle-aged people with serious chronic illness living at home. In order to validate or invalidate the results, the themes and sub-themes were compared with the naïve understanding.

The phase of comprehensive understanding started with reading the text again with the naïve understanding and the validated subthemes and themes in mind. Simultaneously, we used our imagination, pre-understanding and relevant literature to widen and deepen the understanding of the text. The focus was on the possibilities of lived experiences that the interview text had addressed [29].

Results

Naïve understanding
Needs for middle-aged people with serious chronic illness living at home mean working against the illness in order to protect independence and autonomy in everyday life. Simultaneously, it means having professional care as well as support from people in one's immediate surroundings. A strong will seems to be needed to enable reconciliation with life with illness. Fellowship with other people including mutual respect and confirmation for protecting 'the person you are' was an important need. To manage daily life a need of being aware of the possibilities available despite

illness or disability seemed to be essential. A balance between the possibilities and abilities meant balance in daily life.

Structural analysis

The structural analysis resulted in three themes and six subthemes, presented below and illustrated with quotes from the interview text

Striving for independence

Having care that works. Participants said that it was of most importance that the help they received functioned. The help must be flexible as their needs change from day to day. They expressed that the staff, independent of their profession, must have competence and skill in their work tasks.

It provides security when you know there is someone who tries to do the best for me. She [DN] is amazing really. It gives me a little hope.

Participants described that it tried their patience and it was difficult to accept the dependence on others to manage everyday life. They struggled to protect their autonomy by not asking for help every time that it was needed. They also emphasised, however, that their personal assistants were essential for them to manage in everyday life. One participant said: *They are my arms and legs.*

First, in the beginning, I tried to struggle on the course and divided half of the dishes when I picked them out of the dishwasher. I lost a lot of dishes...I wanted to feel that I managed it myself and to do much more than I could do.

Participants said that they needed continuous visits from their personal assistants. It was important to have a familiar feeling and continuity with all staff.

I also think it's very important that this person [staff] can be close to me in my life, they shouldn't come and go. They will get to know me, and I'll get to know them.

Participants emphasised a need to make their own decisions, even if they had difficulty in expressing their needs. When they experienced that they were listened to and had the opportunity to express their needs, they felt involved. One need they described was the possibility of influencing the healthcare organisations on a higher level, this was something they missed. One participant said: *For influencing my care I must be a medical expert to be able to require the help I need*. Another participant said: Y*ou must be healthy to have the strength to be ill.*

Participants expressed that it was of the utmost importance to get information about their rights concerning help, support and technical aids in everyday life. That was an area in which they felt was in need of improvement. They described how they must fight and struggle because they did not get this information, especially in the beginning of their illness.

I don't know what I miss when I don't really know what is available.

Participants lacked information about possibilities for rehabilitation. In order to determine what was available, they had to contact a private physiotherapist to get rehabilitation at home. They explained that this lack of rehabilitation affected their illness, as it became gradually worse. Another area of concern was the financial situation in healthcare organisations. They expressed anxiety over the possibilities to get help and support in the future, because of limited financial resources.

Unfortunately, no one supports me and takes me out...they just come up with ideas, but then it becomes nothing more, and I must do the rest myself. It's sad.

Participants described that they dreaded seeking help and support because they felt that the nursing staff were more stressed than in the past. They described a lack of support for the thoughts they had for their future.

Getting support to facilitate daily life. Participants described that help and support from friends and neighbours facilitated their everyday life. Meetings with people in similar situations were also experienced as supportive. Participants said that these meetings brought about positive feelings and an awareness that life must go on despite all.

I have telephone contact with one who also has MS, but she is in better condition than I am. With her I could talk...it gives me strength...she usually gives energy...she also has tough days.

Participants described that suitable technical aids and rebuilding at home made it possible for them to be involved in household chores, manage personal hygiene and be outdoors. These activities reduced their feelings of limitation in daily life. To have access to an electric moped or an electric wheelchair gave participants the feeling of freedom.

It's my lifeline [the electric moped]. I'm outdoors very much. The only way for me to get out is with the moped. I drive to the store, yes everywhere...in the forest where we can go and pick mushrooms. I suggest that there are mushrooms and then we pick mushrooms.

Choosing one's own way

Being able to live at home. Participants expressed a need to live at home as long as possible. Living at home provided them with feelings of recognition, security, wellbeing and freedom, and enabled them to live as normally as possible. It gave them opportunities to determine their own lives and do as they wished. Being able to live at

home necessitated a need for help and support from close relatives, nursing staff, and neighbours, as well as getting adapted technical aids to increase the security at home. Participants had domestic animals such as dogs, which they said secured their everyday life at home.

I can't imagine living elsewhere [than at home] because living at home is everything. I don't know if I would like to be somewhere else, just because I think I would start to feel imprisoned. The home is still a place where you can do what you really want to do.

Being able to see the possibilities in life. Participants described a need to have the possibilities to do the same things that they did when they were healthy. They felt loss when they wanted to do more than they could manage. For them it was necessary to become accustomed to their illness and disability, through revaluing and familiarising their situation. They tried to see the possibilities that remained and to recognise that the life was as it was.

[On needing help] Well, now I see it as a natural part. But in the beginning it was not so easy. It was difficult to accept that I needed help all the time by somebody, but then I began to think, of course, that's just for my own best they help me.

Participants pointed out the importance of living in the present to feel well. They described a need to build an 'inner strength', a trust in oneself, which helped them to manage their lives. Participants said that being tenacious and aware of the possibilities they had enabled them to take charge of their lives and make the best of their situation. They did not want to be a victim in their changing life and worried about

losing their memory and sense of feeling well. If this happened, they felt that it would influence their possibility to maintain control in their daily lives.

I know I'm good at this and I've done it myself, there is no other. They've [people in the surroundings] been supportive, of course, but the job to get where I am today, I've done myself and it's really well done.

I've started painting; I feel, to give out something. It feels better when you've painted. I participate in a watercolor painting course once a week. It's great fun…I have got other interests and other friends.

Being together with others

Having a network that works. Participants described the need to have their family and close relatives near them. They also expressed a need to have friends visit and talk with them and to have meaningful activities together with others on their own terms. Participants participated in a 'sitting dancing' group and travelled with people in similar situations or with their personal assistants.

Sitting dance means a lot to me during the winter months. We spend time together in this group where some of them use wheelchairs. We stick together in this group.

Participants described that their relationships with others had changed due to their illness, or their friends from the past had disappeared when the illness or the injury occurred or worsened. Instead, they had come to know new friends who they felt understood them better. Participants were saddened when social contacts disappeared and they could no longer continue working. Social media did provide a sense of

fellowship. Participants living alone regretted not having anyone close and dear, with whom they could cuddle and hug and share thoughts.

But some days it feels like I want someone near and dear, one I would like to share with. It's something I miss a lot.

Participants described the need to be alone at times, which gave them time to reflect over their own thoughts and their changed lives. They felt that unintentional loneliness depended on self-management, and one way of dealing with it was to visit or call somebody.

Well it feels good to be alone sometimes with my thoughts, to sit and think about my life and how you have it and how you would like to change it. It feels nice.

Being seen and understood. Participants described a need for them to be seen as the person they are and to be understood by others. Being understood meant asking for explanations if something was unclear; this entailed a feeling of being respected. Not being respected and confirmed occurred when other people talked over their heads or did not listen to them. Being able to say what they thought and not only agree with, gave a feeling of being confirmed. Participants said that a beneficial relationship was achieved when nursing staff were skilful in communicating, and showed engagement with an open mind for their needs. They described their relationships with nursing staff mostly as obliging, kind and emphatic. By comparison they felt that the personal assistant was more like a friend and someone with whom they could have fun.

The people that help me must respect me. It's absolutely the most important…and see the human in me, not my disability or that I'm sitting in a wheelchair, but they see the

human and they respect me for who I am. I feel it when I am respected and taken

seriously.

Participants described a need to be met with respect, be listened to and be believed by the nursing staff and the head of the care system. Sometimes they felt that the head did not care about them as human beings with individual needs, and instead saw them as some kind of 'instrument'. The same feeling occurred with visiting physicians. *But health professionals, yeah [laughs] I can tell you that I don't have the best relations. Unfortunately, we do not really get along. She doesn't listen; instead, she has her own opinions. Everything is so tedious for her.*

An important need that participants expressed was to have friends that cared about them, listened and supported them, which they thought increased security and wellbeing in everyday life. The need to talk of more existential things sometimes occurred, which they thought could be a task for DNs, because the DN was easy to talk with and had knowledge about them. In some cases, they preferred support of existential needs by talking with their relatives or friends, because they know and trust them well.

Well, anyway that you feel that they [DNs] have the time, but now, there's no time. It's gone. Yeah, all the time. There has been a withdrawal of staff.

Comprehensive understanding and reflections

This study suggests that meanings of needs of middle-aged people with serious chronic illness living at home can be understood as maintaining control in everyday life provides meaningfulness to life. Participants needed to feel independent in their

everyday lives. This meant to have a care that worked, including support from family and friends. They wanted to be able to influence and decide in matters regarding their daily lives and to discover the possibilities they had, despite the illness and disability. Also salient was the need to choose their own way in life, including being confirmed by others and being seen as the person they are.

Participants wanted to feel independent despite extensive need for assistance and support. This can be seen as a need of participation in their care and other everyday tasks. To effectively participate in care the participant must be given recognition of his/her individual needs and concerns [31]. Participants thought it was difficult to accept when they first needed help and support or when these needs increased. They struggled to protect their autonomy by not asking for help every time it was needed. According to Edlund [32] receiving help and support is seen as a threat to one's dignity. It is human nature to cope with the most basic needs and desires as long as possible. For they who are forced to ask for help, i.e., participants in this study, and then find that no one sees or understands their needs, brings about suffering and a loss of dignity. A suffering person needs confirmation of his/her dignity as a human being [33]. A way to maintain dignity may be to accept the need for help and the dependence on others. This may entail reconciliation with the new situation [32]. Human support can compensate for negative feelings of worthlessness, fear, uncertainty, and distrust and can help a vulnerable person feel more valued [34]. An important need for the person is to revaluate his/her potentials in life and appreciate the abilities which still remain. This can create a new perspective on life [35].

Participants in our study clearly expressed that they needed care that works. Simultaneously, they wanted to make decisions and influence their own daily lives, which seemed to bring a sense of independence. This can be seen as an expression that they wanted to take control over their life situation. Mairis [36] suggests that a way to strengthen human dignity is through exerting control in daily life and give the opportunity to a person to make his/her own decisions. According to Ek and Ternestedt [37] planning daily life, setting priorities and choosing activities contributes to that daily life so that the person can prolong meaningfulness in life.

An important need for participants was to make their own choices in daily life. Being able to choose one alternative over another is an important need and a major source of a person's sense of freedom and autonomy, even though the choices are not always viable [38]. In contrast, powerlessness can arise when the illness limits the possibilities to choose [34]. People can always make their own choices, which can mean to choose one's attitude in a given set of circumstances [39]. The possibility to make one's own choices can engender a sense of control and hope [38]. For the ill person it is important to have hope in life to feel well. Being able to hope means not giving up; rather, it can be seen as a faith in the future. Hope gives people the possibility of reaching their goals in the future [40]. Therefore, to keep hope is central for middle-aged people with serious chronic illness living at home in order to achieve a meaningful life.

Participants expressed a need to realise that life was as it was in order to see possibilities they once had despite illness or disability. According to Frankl [39] focusing on future goals can generate a reconstruction of daily life for the person. For

a person to see possibilities in life depends on the ability to maintain one's courage, dignity and unselfishness. The choice a person makes shows if he/she has realised or misspent the available possibilities. Participants in this study seemed aware of possibilities they had despite their illness and disability.

According to Frankl [41] possibility depends on the attitude a person chooses in life, either a view that life is meaningfulness or a view of meaninglessness. Further, Frankl [41] stated that meaning of life can never be taken for granted; it must be found by oneself. Frankl [39] referred to Nietzsche's statement, 'Those who have a why to live, can bear with almost any how'. Frankl pointed out that not only must people wait on what the life has, but also what life expects of them, i.e., to achieve the meaning in life. People should not ask what the meaning of life is; instead they should realise that it is the person himself who answers this question. People have always been responsible for their own lives. This responsibility is the real essence of human life [39]. People can also contribute to a sense of freedom by taking responsible for their daily lives.

It is important to remember that the meaning of life is constantly changing [39,41]. The participants in our study described how they replaced previous values in their lives with new meaningful values. This can be interpreted as a way to reconcile themselves with their current situation. Eriksson [33] explains that reconciliation is to create conditions for human beings to meet themselves, other people, and their God. If they do not reconcile with their situation, it could result in a lower sense of dignity.

Participants clearly expressed the need for fellowship with others. According to Eriksson [40], love is the bridge between the self and others. Similarly, Ek and Ternestedt [37] describe that one of the most important needs is sharing connections with others, something that gives strength and encouragement to keep living. Fellowship can promote the person's self-image, and enable one to be seen as the person they are, a desire also expressed by the participants in this study. Eriksson [42] emphasises the importance for humans to feel confirmed by others, and the need for courage and energy to move forward life and feel well.

Participants expressed a need to sometimes be alone with their thoughts, which can be seen as a self-selected loneliness. Eriksson [40] indicates that loneliness can mean becoming aware of one's self. Some people live totally alone; despite that, they do not feel alone or abandoned, because they have a fellowship with their own existence [33]. According to Wadenstedt and Ahlström [43], people living with severe functional disabilities found the solitude natural, which means that sources of enjoyment in their life had changed, and ordinary everyday events were more important than grand ones. Being alone can also be viewed as undesired loneliness, which participants in our study managed using different strategies. According to Eriksson [33], being excluded from all fellowship can be a type of suffering.

Participants described limited support about the future, a fact that concerned them and affected their wellbeing. Frankl [39] argues that faith in the future is an important need for survival. Faith expresses a will [40] and creates trust in difficult situations [41]. Life can only be promoted if there is faith, i.e. a trust in the life itself [33]. Faith means being certain about something in the future. It means to struggle and make

choices to continue life instead of running away, with the confidence that the struggle leads to satisfaction and growth, which can be seen as an expression of desire. To help each other by talking about faith and showing openness can provide relief [40]. Therefore, middle-aged people living with serious chronic illness at home need support to enhance their faith in life.

The need to be seen and understood was expressed by participants in this study. They described meetings with the nursing staff where they not had been listened to. To be heard is central for feelings of confirmation. Eriksson [42] states that to be listened to means to be confirmed. Being seen, believed and listened to confirms that you are worthwhile [32].

Methodological considerations

A phenomenological hermeneutic interpretation was used to interpret data as the aim of the study was to elucidate meanings of needs of middle-aged people with serious chronic illness living at home. The intention was to reveal possible meanings of the lived experiences [29]. Descriptions of the procedures, context and results have been described as accurately as possible to achieve validity, reliability and transferability of the study. The participants were asked to carefully describe their lived experience of needs. Probing questions were asked in order to avoid misunderstanding. The interviews were rich, had depth and varying content.

Nine participants were first recruited, and to ensure rich and varying data of lived experiences three additional participants were added. All participants had long lived experiences because their illness or disability had been in progress between 4-39

years. During the analyses we tried to remain as open as possible to the text. Our preunderstanding had been visualised, but also bridled in order to not misunderstand the text [cf. 44]. The authors continuously and critically reflected upon the interpretation of the text. Using a phenomenological hermeneutic interpretation means that not all interpretations are equally probable. The probability in relation to the interpretation has, therefore, been considered [29]. A text can be interpreted in several ways [30]. The results of this study represent one way of understanding meanings of needs of middle-aged people with serious chronic illness living at home.

Conclusions

This study suggests that meanings of needs of middle-aged people with serious chronic illness living at home are primarily to maintain control in everyday life, thus giving meaningfulness to life. For participants it was important to get help and support early in their illness; help and support that were based on their individualised needs and desires. Supportive dialogues about thoughts of the future seemed to be needed with someone outside the family. Another important consideration is to strengthen the people's own power for enabling them to take control of their lives. Therefore, listening to the people in need of help and support means acquiring knowledge that will bring with it a greater understanding of the experiences of life with a chronic illness. This increases the power and possibility of self support, which ultimately improves the quality, meaningfulness, and dignity of life. By seeing and listening, the nursing staff has an opportunity to interpret and understand the needs of middle-aged people with serious chronic illness living at home.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

CN and SS designed the study. CN performed the interviews. CN, BL, LS and SS contributed to the analysis and interpretation of the interviews and drafting of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

The authors would like to thank those who participated in this study for their valuable contributions.

References

1. Morse J: **Responding to threats to integrity of self.** *Adv Nurs Sci* 1997, **19:**21-36.

2. Söderberg S, Lundman B, Norberg A: **Struggling for dignity: The meaning of women's experiences of living with fibromyalgia.** *Qual Health Res* 1999, **9:**575-587.

3. Rapley P, Fruin DJ: **Self-efficacy in chronic illness: The juxtaposition of general and regimen-specific efficacy.** *Int J Nurs Pract* 1999, **5:**209-215.

4. Öhman M, Söderberg S, Lundman B: **Hovering between suffering and enduring. The meaning of living with serious chronic illness.** *Qual Health Res* 2003, **13:**528-542.

5. Söderberg S, Strand M, Haapala M, Lundman B: **Living with a woman with fibromyalgia from the perspective of the husband.** *J Adv Nurs* 2003, **42:**143-150.

6. Jumisko E, Lexell J, Söderberg S: **Living with moderate or severe traumatic brain injury: The meaning of family members' experiences.** *J Fam Nurs* 2007, **13:**353-369.

7. Öhman M, Söderberg S: **The experiences of close relatives living with a person with serious chronic illness.** *Qual Health Res* 2004, **14:**396-410.

8. Ellefsen B: **Dependency as a disadvantage - Patients' experiences.** *Scand J Caring Sci* 2002, **16:**157-164.

9. Ahlstöm G: **Experiences of loss and chronic sorrow in persons with severe chronic illness.** *J Clin Nurs* 2007, **16,3a:**76-83.

10. Ironside PM, Scheckel M, Wessels C, Bailey ME, Powers S, Seeley DK, **Experiencing chronic illness: Co creating new understanding.** *Qual Health Res* 2003, **13:**171-183.

11. Whittemore R, Dixon J: **Chronic illness: The process of integration.** *J Clin Nurs* 2008, **17,7b:**177-187.

12. Jumisko E, Lexell J, Söderberg S: **The meaning of feeling well in people with moderate or severe traumatic brain injury.** *J Clin Nurs* 2009, **18:**2273-2281.

13. Olsson M, Skär L, Söderberg S: **Meanings of Feeling well for women with multiple sclerosis.** *Qual Health Res* 2010, **20:**1254-1261.

14. Corbin JM: **The body in health and illness.** *Qual Health Res* 2003, **13:**256-267.

15. Nilsson C, Öhman M, Söderberg S: **Information and communication technology in supporting people with serious chronic illness living at home—An intervention study.** *J Telemed Telecare* 2006, **12:**198:202.

16. Toombs SK: *The meaning of illness. A phenomenological account of the different perspectives of physician and patient.* Dordrecht: Kluwer Academic Publishers; 1993.

17. Jeon Y-H, Jowsey T, Yen L, Glasgiw NJ, Essue B, Kljakovic M, Pearce-Brown C, Mirzaei M, Usherwood T, Jan S, Kraus SG, Aspin C: **Achieving a balanced life in the face of chronic illness***. Aust J Prim Health* 2010, **16:**66-74.

18. Skuladottir H, Halldorsdottir S: **The quest for well-being: Self-identified needs of women in chronic pain.** *Scand J Caring Sci* 2011, **25:**81-91.

19. Taylor RM, Gibson F, Frank, LS: **The experience of living with chronic illness during adolescence: A critical review of the literature.** *J Clin Nurs 2008,* **17:**3083-3091.

20. Öresland S, Määttä S, Norberg A, Lűtzén K: **Patients as 'safeguard' and nurses as 'substitute' in home health care.** *Nurs Ethics* 2009, **16:**219-230.

21. Appelin G, Brobäck G, Berterö C: **A comprehensive picture of palliative care at home from the people involved.** *Eur J Oncol Nurs* 2005, **9:**315-324.

22. Melin-Johansson C, Ödling G, Axelsson B, Danielson E: **The meaning of quality of life: Narrations by patients with incurable cancer in palliative home care.** *Palliat Support Care* 2008, **6:**231-238.

23. Elofsson CL, & Öhlen J: **Meanings of being old and living with chronic obstructive pulmonary disease.** *Palliat Med* 2004, **18:**611-618.

24. Olofsson A, Andersson S-O, Carlberg B: **'If only I manage to get home I'll get better' - Interviews with stroke patients after emergency stay in hospital on their experiences and needs.** *Clin Rehabil* 2005, **19:**433-440.

25. Jooste K, Chabeli M, Springer M: **The health care needs of the physically disabled patient in a home-based care environment: Implications for the training of ancillary health care workers.** *Health SA Gesondheid* 2010, **15:**3-8.

26. Wilkes L, Cioffi J, Warne B, Harrison K, Vonu-Boriceanu O: **Clients with chronic complex conditions: their experiences of community nursing services**. *J Nurs Healthc Chronic Illn* 2008, **17:**160-168.

27. Algera M, Francke A, van der Zee J: **Home care needs of patients with longterm conditions: Literature review.** *J Adv Nurs* 2004, **46:**417-429.

28. Kvale S, Brinkman S: *The Qualitative Research Interview.* Lund: Studentlitteratur; 2009. (In Swedish).

29. Lindseth A, Norberg, A: **A phenomenological hermeneutical method for researching lived experience.** *Scand J Caring Sci* 2004, **18:**145-153.

30. Ricoeur P: *Interpretation Theory: Discourse and the Surplus of Meaning.* Fort Worth TX: Texas Christian University Press; 1976.

31. Eldh AC, Ekman I, Ehnfors M. **Considering patient non-participation in health care.** *Health Expect* 2008, **11:**263-271.

32. Edlund M: **The Human dignity.** *PhD thesis.* Åbo Academy University; 2002. (In Swedish).

33. Eriksson K: *The Suffering Human Being.* Stockholm: Liber; 1994. (In Swedish).

34. Strandmark M: **Ill health is powerlessness: A phenomenological study about worthlessness, limitations and suffering.** *Scand J Caring Sci* 2004, **18:**135-144.

35. Strandberg G, Norberg A, Jansson L: **Meaning of dependency on care as narrated by 10 patients.** *Res Theory Nurs Pract* 2003, **17:**65-84.

36. Mairis ED: **Concept clarification in professional practice: Dignity.** *J Adv Nurs* 1994, **19:**947-953.

37. Ek K, Ternestedt B-M: **Living with chronic obstructive disease at the end of life: A phenomenological study.** *J Adv Nurs* 2008, **62:**470-478.

38. Travelbee J: *Interpersonal Aspects of Nursing.* Philadelphia: Davis Company; 1971.

39. Frankl V: *Man's Search for Meaning.* Stockholm: Natur och Kultur; 2006. (In Swedish).

40. Eriksson K: *Caring Idea.* Stockholm: Nordstedts Förlag; 1987a. (In Swedish).

41. Frankl V: *The will to Meaning.* Stockholm: Natur och Kultur; 1995. (In Swedish).

42. Eriksson K: *The Pause.* Stockholm: Nordstedts Förlag; 1987b. (In Swedish).

43. Wadensten B, Ahlström G: **The struggle for dignity by people with severe functional disabilities.** *Nurs Ethics* 2009, **16:**453-465.

44. Dahlberg K, Drew N, Nyström M. *Reflective Lifeworld Research.* Lund: Studentlitteratur; 2001.

III

Swedish District Nurses' Attitudes to Implement Information and Communication Technology in Home Nursing

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Abstract: The use of information and communication technology has increased in the society, and can be useful in nursing care. The aim of this study was to describe district nurses' attitudes regarding the implementation of information and communication technology in home nursing. The first and third authors performed five focus group discussions with 19 district nurses' from five primary healthcare centres in northern Sweden. During the focus group discussions, the following topics were discussed: the current and future use of information and communication technology in home nursing; expectations, advantages, disadvantages and hindrances in the use of information and communication technology in home nursing; and the use of information and communication technology from an ethical perspective. The transcribed focus group discussions were analysed using qualitative content analysis. The results showed that district nurses' attitudes were positive regarding the use of information and communication technology in their work. They also asked for possibilities to influence the design and its introduction. However, the use of information and communication technology in home nursing can be described as a complement to communication that could not replace human physical encounters. Improvements and risks, as well as the importance of physical presence in home nursing were considered vital. The results revealed that the use of information and communication technology requires changes in the district nurses' work situation.

INTRODUCTION

This study is a part of a research project in Swedish primary healthcare, regarding implementation of information and communication technology (ICT) to increase the accessibility of care for chronically ill people living at home. The knowledge gained through this study can be used for planning further research where ICT will be used as a tool for supporting people with serious chronic illness living at home.

In the last few years, time spent in hospital care has decreased resulting in that people with illness have been discharged from hospitals earlier and sicker, than previously been reported [1]. For this reason, it has become a challenge to find new ways to support people with serious chronic illness living at home. One way to achieve this may be through suitable applications of ICT, which offers possibilities for people to communicate, gather information, and interact with distance services faster, easier, and without limitations of time and space [2]. According to the National Strategy for e-Health [3], ICT could enable caregivers and healthcare decision-makers to improve care for patients. Koch [4] stated that research concerning home telehealth for improved accessibility and communication for health professionals and their patients are rather few. Therefore, research is important to determine impacts, benefits, and limitations in developing feasible solutions for home telehealth. According to a review study [5] describing the use of teleconsulting

applications, the most frequent teleconsultings were between doctors in real time, and the most infrequent one was between the nurse and patient. The rapid growth of technical and scientific knowledge in society has also generated many changes in health and nursing care. However, nurses have always used tools and technology for achieving valued outcomes in their work [6, 7]. Nurses are exposed both to complex and sophisticated technologies in their work, such as heart-lung machines, as well as to simpler technologies like the thermometer [8].

District nurses (DNs) have the responsibility of supporting people with chronic illness living at home [9, 10]. The work as a DN in Sweden includes caring for people of different ages, and one priority is to support seriously ill people and their relatives [10]. To create a close relationship in nursing care, communication and mutual relationship is essential [11-13], and part of the DN's role is to develop a trusting relationship with the patient [14].

Communication skills in nursing care could be inhibited by environmental social barriers, as well as structural or cultural aspects of healthcare [15]. According to Häggman-Laitila and Åstedt-Kurki [16] and McCabe [17], an important factor is to use a patient-centred communication to achieve quality and a positive relationship in nursing care. To enable DNs to improve their support for people with chronic illness living at home, suitable tools are needed, and methods and knowledge should be developed. The use of ICT can, therefore, be viewed as a part of the DNs' work. Previous research [18] has shown that the key themes in the use of ICT are "user-friendliness" and clinical appropriateness. Therefore, the aim of this study was to describe DNs'

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attitudes regarding the implementation of ICT in home nursing.

METHODS

A qualitative approach was used to obtain an increased understanding of DNs' attitudes to use ICT in their work. Furthermore, the qualitative approaches provided insights from the participants' perspective [19]. Data were collected through focus group discussions and analysed by content analysis.

Participants and Procedure

This study comprised a purposive sample of 19 female DNs. The inclusion criteria were that the participants must be registered nurses with a DN graduate diploma, and must be working as a DN. The participants' age ranged from 30 to 64 years (md = 47), and their work experience as DNs ranged from 1 to 23 years (md = 5). They worked at five primary healthcare centres in two municipalities in northern Sweden. Eleven participants worked in daytime shifts, while eight worked in the evenings.

The DNs were selected with the assistance from the heads of five primary healthcare centres. Information was given about the nature of the study, and participation was voluntary with the possibility of withdrawing at any time. Information letters were distributed to the heads, who informed the DNs, and the heads distributed the letters to the DNs. The DNs were assured of confidentiality and anonymous presentation of the results. The Regional Ethical Review Board in Umeå, Sweden (05-059M) approved the study.

Data Collection and Analysis

Data were collected from May 2005 to March 2006 through focus group discussions to describe DNs' attitudes regarding the implementation of ICT in home nursing for people with serious chronic illness living at home. According to Morgan [20] focus group discussions is a method that can explore new research areas and is well suited for obtaining research information from the participants' perspective. Through the interaction of the group, data will arise according to the specific topic being discussed [21]. In this study, four focus groups with four DNs and one group with three DNs were included.

During data collection, the first and third authors were represented as moderators. The first author's role was to lead the discussion and create a non-threatening supportive environment that encourages all the participants to share their views, i.e., facilitating interactions among the participants and interjecting probing comments and transitional questions [20]. Before commencing the focus group discussions, the participants were instructed not to talk about the contents of the discussion to others outside the group. The first author started the focus group discussion with an introduction to the aim of the study and the different topics that should be discussed: the current and future use of ICT in home nursing; expectations, advantages, disadvantages and hindrances in the use of ICT in home nursing; and the use of ICT from an ethical perspective.

To stimulate the discussions among the participants, two examples of ICT applications were presented and explained.

The first example described a field case used in home visits that included different equipment, such as laptop with access to the computerised case-record system, digital camera, web camera, mobile phone, bladder scan, and electrocardiograph with the possibility to send test results to physicians. The second example defined an ICT application with text messages used for communications between people with serious chronic illness living at home and their DNs [22]. The discussions started with the question, "Tell me about your views on using different types of technology in your work as DN". Two of the focus group discussions were carried out in the participants' workplace, and three in a university department. Each focus group discussion lasted for about 90 min, and was audio taped and later transcribed verbatim.

The transcribed focus group discussions were analysed using a qualitative content analysis. The goal of this analysis method was to provide knowledge and understanding of the phenomenon under study [23]. The interview texts were read several times to gain a sense of the content [24]. Bearing in mind the aim of the study, textual units were identified, condensed, and coded. The textual units with similar content were sorted into areas, and consequently, the areas were sorted into categories in several steps. During the whole process, the researchers occasionally went back to the original textual units and compared the results.

RESULTS

The analysis resulted in three categories: (1) possibilities to influence the design and be a part of the introduction; (2) improvements and risks; and (3) people cannot be replaced by technology. The categories are presented below and illustrated by quotations from the DNs.

Possibilities to Influence the Design and be a Part of the Introduction

The DNs pointed out the significance of being a part of the development of new technology to influence the design. This was a prerequisite for using ICT in their work and they pointed out the importance of ICT being simple, user-friendly, and suitable. In their experience, some technical equipment were too advanced, unnecessary, or unsuitable for their use in nursing care. The DNs indicated that some technical equipment were designed by people who were unfamiliar with the DNs' work, as was discussed in the following citation:

…it should be easy to use and less moment. (DN 17) Yes (DN 19) …I think that the one who work with it, should design it, now it has been the IT-personnel…it must be the personnel who work with it, who develop the technique... (DN 18).

The DNs described the importance of being a part of the introduction of ICT in nursing care. They asserted that instructions on how to use the technology and who would have access to the technology must be clear from the beginning, because they had earlier experienced how difficult it was not to have been a part of the introduction. They also pointed out that information and education were necessary, since from their experience they found that technologies often lacked instructions. They remembered when the case records were computerised a few years ago, and this experience gave them a negative perception of the new technology from the begin-

ning. However, as they observed the benefits of the computerised case-record system, the DNs now had a better understanding of what these technologies demanded from them as users. One DN described:

…this must be solved first otherwise it's no idea that we go there with an equipment …it's no idea to take a test if I am not able to do something about it… (DN 9).

Based on the DNs' experiences, learning, and using the technology was an individual task. They also pointed out that the use of technology in nursing care for the ill person must be voluntary. The DNs said that those who are ill should be a part of the introduction and that they, together with the DNs, should have time to practise using the technology. The following citation illustrates the dialogue between the DNs:

...important is that you really get the time you need [for practice], otherwise it could be wrong and you don't have the strength to do the job you have to do. (DN 18) Yes, so be part of it. (DN 19).

Improvements and Risks

From the DNs' experience, new technology such as the computerised case records improved the nursing care. They mentioned that the computerised case records in the laptop enabled them to give and receive information independently, irrespective of where they are. They believed that it was a safer system. The DNs thought that ICT could improve their work. They referred to the ill person's case record from a laptop in the person's own home that made it possible to give information, prescriptions, or getting information when the ill person visited the primary healthcare centre.

By using ICT in communicating with the ill person at home, the DNs stated that the use of ICT could decrease stress because of decreased travelling time and home visits. The DNs also observed that the technology was time saving. They affirmed that ICT could improve accessibility and security for ill people staying at home, especially for those living in thinly populated areas or for those who refuse to visit hospitals or primary healthcare centres. Two DNs stated the following:

With that [the technology] you can give answers at once if they, for example, will know how the test I took a week ago. I can answer at once and don't have to return to the primary health care centre and call back. (DN 9) ...this reduce the stress factor of going back and look into the case records and read the record and search for results...instead I can read the case record here in the patient's home… (DN 10).

The DNs in another focus group also discussed the same topic:

I think it can be received safely if a patient, in an easy way, can be in contact with the DN at any time. (DN 4) …to use ICT is an alternative to drive far away to a patient and you will avoid risky drives in the dark and slipperiness… (DN 1).

On the other hand, the DNs pointed out that the use of ICT at home could bring difficulties and uncertainties. Some of these difficulties could be in retaining a holistic perspective on nursing care, and in obtaining important information from the ill person. The DNs also expressed an uncertainty about handling the equipment, which could be stressful. They also described the possibility that the use of ICT could be frightening, especially for older people. They mentioned that promoting the use of ICT in nursing care could take time, because of problems in the installation and management of the technology in the ill persons' own home.

People Cannot be Replaced by Technology

The DNs expressed anxiety about not being needed in the future, because information would be available online. They viewed the use of ICT rather as a complement to facilitate nursing care. Before using ICT for communicating, the DNs stressed that it is important to get to know the ill person first. They pointed out how important physical encounters are in building up a trusting relationship with the ill people staying at home. If the appropriate information given and the relationship with the ill person were satisfactory, the DNs considered that there would be no disadvantage in using ICT in their work. They indicated that the use of ICT would not be suitable for everybody, and home visits are valuable in terms of revealing so much more information about the ill person.

The DNs further expressed that the technical equipment could encroach in the ill person's own home as well as on other family members. They discussed on how the autonomy of the ill person and the family would be threatened if anyone in the family did not want the equipment. The DNs pointed out the importance of being observant about how the technology was used, and in making sure that it did not hurt anybody. They discussed that in the future, the use of ICT in nursing care would increase, which would require changes in their work situation:

ICT can never replace the personal contact...someone can experience that nobody notice them. (DN 15). You cannot replace the human contact with the person, because it's also another language that you have when you meet a person in real because sometimes you feel in the atmosphere that even if not the words say anything you can understand that here it's not right. You must take it [ICT] as a complement I think that it cannot replace the human being. (DN 18)

DISCUSSION

The results show how important it is for the DNs to have the opportunity to influence the design and implementation of ICT in home nursing. The DNs regarded that the implementation of ICT in their work would comprise both improvements and risks. They stressed that technology cannot replace people, instead technology can be seen as a complement in supporting people living at home with serious chronic illness.

This study demonstrates that DNs want to be a part of the development of new technology to influence the design. Implementation of new technology should be based on satisfaction of the individual. Satisfaction should come from human needs and the person's rights, such as the right to integrity and the right to equality [25]. Participation in the introduction of ICT in nursing care includes getting necessary information and training. Starren *et al.* [26] demonstrated that participation in the introduction of ICT is of importance at the beginning of the process. In this study, the DNs pointed out the importance of taking part in the introduction and routines of using ICT in their work. This indi-

cates that the organisation wherein the ICT equipment will be used must be prepared before its introduction. Collste [25] argued that an analysis of the consequences of implementing new technologies should be based on and compared with alternatives, and thereby provide solutions for those who are involved. Furthermore, a strategy for educating personnel on the use of ICT should be addressed [27].

The DNs believed that ICT could improve security for ill people living at home, and at the same time, improve their own work situation. They realised the possibility that ICT applications could save time owing to decreased travelling time and fewer home visits. This is in line with several studies that demonstrated that the use of technology in healthcare could save time [28-30]. The results further reveal that the use of ICT could demand time, such as during the process of connecting ICT equipment in homes. The use of technology in surgical nursing affects nurses negatively when the technology makes their daily practice of nursing care more demanding, more time-consuming, and distracting [31].

In this study, the DNs stressed that the use of ICT could not be suitable for all people and noted that home visits revealed much more. The DNs asserted that ICT cannot replace people, and physical and human presence is still important. This is in line with the observation by Söderlund [32] who examined the use of ICT as a support tool for older people with severe disabilities in need of help when living at home. To satisfy their needs, practical help and physical encounters were essential. Sävenstedt, Sandman, and Zingmark [33] stated that ICT could promote human care, but ICT could also lead to dehumanised care.

The DNs pointed out the importance of physical encounters in home nursing to build a trustful relationship. Mok and Chiu [34] stressed the importance of a trustful relationship and that nurses meet the demands both of themselves, and of those who are ill and their families. If ICT replaced physical encounters, the quality of care could be questioned [35]. The DNs stated the importance of getting to know the ill person before starting to communicate through ICT. Knowing the patient is an important part of nursing care; it signifies understanding the patients' needs and creating interventions for the person [36, 37]. Hence, getting to know each other seemed to be important for both the ill person and the health professional to build a trustful relationship [38].

The results showed that ICT could be a complement in nursing care. The DNs pointed out that if ICT should be a part of their work, then it would result in certain changes. According to Aas [39], aspects of these changes can include less travelling, more time for other work, new contacts, and increased sense of professional security and satisfaction of seeing partners in communication. Heinzelmann, Lugn, and Kvedar [40] concluded that the integration of ICT within the healthcare will offer ill people and their providers many possibilities in the future.

Methodological Considerations

The strength of this study was the use of focus group discussions to optimise the understanding of the complexities of the research questions. The discussions encouraged the DNs to express their points of view related to their experiences on the use of ICT. The moderator tried to avoid steering the discussion, and instead, allowed the DNs to discuss

as freely as possible. To retain the focus of the discussion, an interview guide was used. The results showed that the focus group discussions ended up with agreement in almost all the questions discussed. To reach trustworthiness in the study, the findings were discussed with other researchers and colleagues.

The limitation of the study was mainly with the sampling issue. The number of available participants was limited and the number of focus groups was therefore few. The groups consisted only of DNs working in the same county council, which means that the sample is not representative of all DNs. However, the findings of this study cannot be generalised, as this is not the goal of qualitative research. Instead, the findings can be transferred to similar situations by modifying them to comply with the context [19].

CONCLUSION

The results in this study indicate that DNs attitudes were positive to the use of ICT in their work. They questioned on the possibilities of influencing the design and introduction of ICT. Using ICT in nursing care was described as a complement for communication and was not seen as a replacement for physical encounters. To promote the quality of nursing care ICT could be one of the tools, however, this area is sparsely studied. This study indicates that the use of ICT could be a facilitator in the DNs' daily work.

ACKNOWLEDGEMENTS

REFERENCES

[1]　Karlsson B, Morberg S, Lagerström M. Strong as individuals but weak as a group. A qualitative study about district nurses' perceptions of their work situation and occupation. Vard Nord (Care in the Nordic Countries) 2006; 26: 31-41.

[2]　Campbell PJ, Dries J, Gilligan R. The older generation and the European information society: access to the information society. European Institute for the Media, Dusseldorf and the Netherlands Platform Older People and Europe, Utrecht, 1999.

[3]　Government Offices. National Strategy for E-health. Stockholm: Ministry of health and social affairs, 2006.

[4]　Koch S. Home telehealth - Current state and future trends. Int J Med Inform 2006; 75: 565-76.

[5]　Jaatinen PT, Forsström J, Loula P. Teleconsultations: who uses them and how? J Telemed Telecare 2002; 8: 319-24.

[6]　Barnard A. Technology and nursing: an anatomy of definition. Int J Nurs Stud 1996; 33: 433-41.

[7]　Barnard A, Cushing A. In: Locsin RC, Ed. Advancing, technology, caring, and nursing. Westport Connecticut, Auburn House 2001, 12-21.

[8]　Sandelowski M. Devices & desires. Gender, technology, and American nursing. Chapel Hill N.C: University of North Carolina Press, 2000.

[9]　Wright K. Caring for the terminally ill: the district nurse's perspective. Br J Nurs 2002; 11: 1180-85.

[10]　Öhman M, Söderberg S. District nursing - sharing and understanding by being present. Experiences of encounters with people with serious chronic illness and their close relatives in their homes. J Clin Nurs 2004; 13: 858-66.

[11]　Fosbinder D. Patient perceptions of nursing care: an emerging theory of interpersonal competence. J Adv Nurs 1994; 20: 1085-93.

[12]　Attree M. Patients and relatives experiences and perspectives of "good" and "not so good" quality care. J Adv Nurs 2001; 33: 456-66.

[13] Thorsteinsson L. The quality of nursing care as perceived by individuals with chronic illnesses: the magical touch of nursing. J Clin Nurs 2002; 11: 32-40.

[14] Cody A, Squire A. Nurses' perceptions of good nursing care. Prof Nurse 1998; 13: 578-82.

[15] Chant S, Jenkinson T, Randle J, Rusell G. Communcation skills: some problems in nursing education and practice. J Clin Nurs 2002; 11: 12-21.

[16] Häggman-Laitila A, Åstedt-Kurki P. What is expected of the nurse-client interaction and how these expectations are realized in Finnish health care. Int J Nurs Stud 1994; 31: 253-61.

[17] McCabe C. Nurse-patient communication: an exploration of patients' experiences. J Clin Nurs 2004; 13: 41-9.

[18] Magnusson L, Hanson E, Borg M. A literature review study of information and communication technology as a support for frail older people living at home and their family carers. Technol Disabil 2004; 16: 223-35.

[19] Polit DF, Beck CT, Eds. Nursing research. Principles and methods, 7th ed. Philadelphia: Lippincott Williams & Wilkins, 2004.

[20] Morgan DL. Focus groups as qualitative research. 2nd ed. Thousand Oaks: Sage Publications, 1997.

[21] Kitzinger J, Barbour R. In: Barbour RS, Kitzinger J, Ed. Introduction. The challenge and promise of focus groups. Developing Focus Group Reasearch. Politics, Theory and Practice, London: Sage Publications 1999, pp. 1-20.

[22] Nilsson C, Öhman M, Söderberg S. Information and communication technology in supporting people with serious chronic illness living at home - an intervention study. J Telemed Telecare 2006; 12: 198-202.

[23] Downe-Wamboldt B. Content analysis: Method, applications, and issues. Health Care Women Int 1992; 3: 313-21.

[24] Sandelowski M. Qualitative analysis: what it is and how to begin. Res Nurs Health 1995; 18: 371-5.

[25] Collste G. Etik i datasamhället (Ethic in the computerized society). Stockholm, Carlssons, 1993.

[26] Starren J, Tsau C, Bakken S, *et al.* The role of nurses in installing telehealth technology in the home. Comput Inform Nurs 2005; 23: 181-9.

[27] Whitten P, Adams I. Success and failure: a case study of two rural telemedicine projects. J Telemed Telecare 2003; 9: 125-9.

[28] Demiris G, Speedie SM, Finkelstein S. Change of patients' perceptions of telehomecare. Telemed J E Health 2001; 7: 241-7.

[29] Hailey D, Roine R, Ohinmaa A. Systematic review of evidence for benefits of telemedicine. J Telemed Telecare 2002; 1: 1-7.

[30] Hjelm NM. Benefits and drawbacks of telemedicine. J Telemed Telecare 2005; 11: 60-70.

[31] Barnard A, Gerber R. Understanding technology in contemporary surgical nursing: a phenomenographic examination. Nurs Inq 1999; 6: 157-66.

[32] Söderlund R. The role of information and communication technology in home services: Telecare does not satisfy the needs of the elderly. Health Informatics J 2004; 10: 127-37.

[33] Sävenstedt S, Sandman PO, Zingmark K. The duality in using information and communication technology in elder care. J Adv Nurs 2006; 56: 17-25.

[34] Mok E, Chiu PC. Nurse-patient relationships in palliative care. J Adv Nurs 2004; 48: 475-83.

[35] Demiris G, Oliver DP, Courtney KL. Ethical considerations for the utilization of telehealth technologies in home and hospice care by nursing profession. J Adv Nurs 2006; 30: 56-66.

[36] Radwin LE. 'Knowing the patient': a review of research on an emerging concept. J Adv Nurs 1996; 23: 1142-6.

[37] Luker KA, Austin L, Caress A, Hallett CE. The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. J Adv Nurs 2000; 31: 775-82.

[38] Andreassen HK, Trondsen M, Kummervold PE, Gammon D, Hjortdahl P. Patients who use E-mediated communication with their doctor: new constructions of trust in the patient-doctor relationship. Qual Health Res 2006; 16: 238-48.

[39] Aas IHM. Changes in the job situation due to telemedicine. J Telemed Telecare 2002; 8: 41-7.

[40] Heinzelmann PJ, Lugn NE, Kvedar JC. Telemedicine in the future. J Telemed Telecare 2005; 11: 384-90.

IV

► Information and communication technology in supporting people with serious chronic illness living at home – an intervention study

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Summary

We studied the experiences of two people with serious chronic illness who used information and communication technology (ICT) to communicate with their district nurse. The study was a qualitative case study. The intervention was performed using an electronic messaging program. The program was accessible to any computer with an Internet connection. The programme consisted of different virtual rooms, where people could communicate using text messages. The participants used the program 2–4 times each week from the beginning of November 2003 to February 2004. Semistructured interviews were performed before, during and after the intervention and were analysed using thematic content analysis. The results showed that the participants' communication with the district nurse was improved because of easy accessibility and that they felt increased security. They also felt there were fewer limitations and that their everyday life was improved, which can also be seen as an improvement in care.

Introduction

Living with chronic illness brings changes in the lives of the people affected.[1–4] People with chronic illness who live in their own homes often need support and help from district nurses (DNs) in order to manage their daily lives.[5] Good communication is an essential part of nursing and without a mutual relationship or adequate communication, no satisfactory nursing can be provided.[6] According to Hallström and Elander,[7] well-functioning communication is important, both for the people who receive care and for nurses.

Several studies have shown that using information and communication technology (ICT) at home as a means of communication with nursing staff is experienced as satisfactory by people with illness.[8–11] Campbell et al.[12] described ICT as a broad concept, which enables people to communicate, gather information and interact with distance services, more quickly, more easily and without limits of time and space.

Johnston et al.[11] demonstrated that using video-conferencing between nurses and people with chronic illness in home health care was appreciated by the users. According to Demiris et al.,[13] elderly homebound patients are able to cope with videoconferencing and Internet equipment. The participants believe that the nurses gain a good understanding of their problems, and they feel that the technology saves time for the nurses. Erkert[9] suggested that to use ICT with video communication via a broadband connection as a support will improve the quality of life for elderly or ill people living at home. According to Öhman et al.,[4] everyday life is experienced as insecure and unsafe for people with serious chronic illness. Using ICT in the communication between DNs and people who are living at home with chronic illness may provide a better chance of support, which in turn may improve the feelings of security and safety, and reduce uneasiness.

The aim of the present study was to describe the experience of people with serious chronic illness who used ICT in communicating with their DN.

Methods

A qualitative case study with single-case design was adopted. The qualitative case study is a holistic description and analysis of a unit or a phenomenon where the focus is on process, understanding and interpretation.[14] The case in this study comprised two people living with serious chronic illness and their responsible DNs. Two middle-aged people (persons A and B) with serious chronic illness participated in the study. Both of the participants had difficulties in talking related to their chronic illness. The criteria for inclusion in the study were that the participants were living in their own homes, had a serious chronic illness that demanded extensive nursing care, and had an already established contact with the DN who was responsible for their care.

Person A. The person's chronic illness began at approximately 40 years of age. The participant lived alone in a private house, and had help from a personal assistant day and night, and a sister who gave help and support. The children had grown up and moved away from home. This person had little experience in using a computer and had difficulties in coping with it independently. Therefore during the intervention the person received help from the personal assistant with writing messages using the ICT equipment

Person B. The person's chronic illness began in adolescence. Previously the participant lived alone in a flat, but now lived with a close relative. The person needed help and support from personal assistants throughout the day. During the night personal assistants were accessible and came at specified intervals while the close relative was accessible all the time. The person was very interested in using the computer and the Internet and owned a computer before the study started, activated by the participant's own voice.

Participation was voluntary. The ethics committee at the university approved the study. The study started in October 2003 and ended in March 2004.

The intervention

The intervention was performed using a computer program called Rexnet for communication between the participants and their DNs. The program was accessible to any computer with an Internet connection. The programme consisted of different virtual rooms, where people could communicate using text messages. Communicating in this way with text was considered to be more suitable for the participants who had difficulties in talking due to their illness. The DNs had mobile phones with Internet access, allowing them to receive and reply to messages from the participants. The participants could use the technology at any time, and they were informed that the DNs would read the messages during normal working hours.

Data collection and analysis

The participants were interviewed four times over a period of five months. Before the intervention, they were interviewed on two occasions because it was difficult for them to talk. An interview guide was used with themes, e.g. treatment, accessibility, continuity, safety, loneliness and communication. The interview started with the question, 'Please, tell me about your experiences of living with your illness' and follow-up questions like 'What happened then?' or 'How did you feel then?' were asked. The interviews lasted for 40–60 min. Follow-up interviews were conducted two months after the intervention started and immediately after it finished. During the follow-up interviews a guide was used with themes derived from the answers given in the pre-intervention interviews. The interviews lasted for 20–30 min, were conducted in the participants' homes and were tape-recorded and transcribed *verbatim*.

The interviews before, during and after the intervention were analysed separately. The interview texts were analysed using a thematic content analysis in order to describe the manifest and latent content of the text.[15] The interviews were read several times in order to obtain a sense of the content (cf. Sandelowski[16]). Textual units were identified, coded and categorized. Categories with similar content were brought together in several steps to form broader categories. The final categories were compared and themes were formulated, i.e. threads of meaning that appeared in several categories (cf. Baxter[17]).

Results

According to the DN, the participants used the program 2–4 times each week from the beginning of November 2003 until February 2004.

Pre-intervention

The theme 'Struggling to achieve a functioning everyday life' was constructed from three categories:

1. *Feeling well*: Feeling well for one of the participants meant that everyday life functioned well and the person could manage to do whatever they wanted. The other participant was very interested in working with the computer, and that made the

person feel well. Both said that they were healthy and one of them believed that their health would improve despite the chronic illness.

2. *Feeling secure and being shown respect*: The participants described security as being able to live at home and have a daily life with a personal assistant who functioned well. Insecurity was felt when there were several personal assistants who were not efficient. The participants described how important it was to be respected and treated as a human being, both by the personal assistant and the DN. They said that it was desirable that the DN met them as somebody, cared for them and was a good listener if a good relationship were to be established.

The participants found it extremely difficult to speak and it was very frustrating when people in their surroundings did not understand what they were talking about, but gave the impression of understanding.

3. *Expectations of improved accessibility*: The communication with the DN was described as good, but she was difficult to contact, the telephone hours were limited and she was often out on duty. The participants described that when they needed contact with the DN, the personal assistant or a close relative left a message at the health-care centre. They experienced a long wait for the DN's answer.

Contact with the DN was felt to be a limitation. There could also be a problem remembering everything when the DN finally contacted the participants. It demanded a certain amount of planning and carrying out, which made it difficult to do anything spontaneously. They emphasized that the DN always visited if needed, and that made them feel good.

The participants hoped that by using the ICT, accessibility would be better and simpler.

Post-intervention

The theme 'Everyday life has improved' was constructed from three categories:

1. *Belief and trust in the ICT*: The participants described that it was important that they could trust the technology, that it worked and that the messages they sent reached the DN. They felt uncertain about whether the message had reached the DN, and if there was anybody at all at the other end. Participants thought it would be better if there was an indicator to show that a message had arrived and that the receiver had read the message. Their

experiences were that it felt safe and secure to use the technology when communicating with the DN.

2. *Being less limited*: The participants described that using the ICT reduced their feeling of limitation, and it was an advantage to be able to correspond with the DN using the technology. If she could not come at once, she sent a message, which gave a sense of certainty and the experience of waiting was avoided. One of the participants thought that the possibility of writing directly to the DN gave them a feeling that she was more available than before, and this improved their daily life. Using the technology meant that they did not have to remember everything they wanted help with when they heard from the DN or when the DN visited them.

The possibility of writing to the DN had several advantages. For example, it gave them time to think about what to write. It was also an advantage that the answer from the DN arrived more quickly.

3. *Fulfilled expectations*: Both participants described that their expectations concerning the technology had been fulfilled. Both participants experienced that reaching the DN by using ICT worked well. One of them thought it was better than using the telephone. The DN was always contacted, which made them feel calmer. One of the participants thought that sometimes the DNs had a hostile attitude towards using a computer, but that at the same time it was useful in practice to receive messages through the technology.

This participant also had ideas about future use of the technology and about how it would work if the DN was responsible for many users simultaneously.

Discussion

The results of the present study indicate that a messaging program can facilitate communication between the DN and people with serious chronic illness living at home who have difficulties in talking. The use of ICT improved feelings of safety in their daily life. The participants described that to be able to feel wellness and security and to achieve a functioning daily life, it was important to be able to obtain a quick response from the DN. Attree[18] suggested that accessibility is one attribute when people appreciate the quality of care, such as the nurse having time to talk, listen and be with them when they are needed.

The ICT had a positive influence on the participants' daily life and security. Everyday life was facilitated and they were happy to use the ICT application when communicating with the DN. Studies show that the use

of ICT as a support can be experienced both as satisfactory and as a privilege in daily life for people living at home, and also for their relatives[19,20] and in communication with their nurse.[21] The participants felt that it was easier to communicate with the DN by using ICT, and the accessibility of care increased. This meant safety and security for them. According to Whitten *et al.*,[22] the nurse is more accessible when ICT is used, and gives the patient a feeling of increased security and comfort because they have interaction with the nurse.

The participants experienced that they felt less limitation regarding the time available when using ICT. Communication with the DN was faster, and they were not restricted to a certain time when the DN could be reached. According to Corbin,[23] time for people with illness is often restricted by various rules, which gives the person a feeling of limitation in everyday life. Strandmark[24] suggested that limitations for people with illness lead to restrictions on their own choice and ability. The participants in this study felt that ICT gave them the chance to improve communication with the DN. Lindsey[25] stated that it was important for people living with chronic illness to have relationships with others and a mutual caring relationship for achieving health. Magnusson and Hanson[26] pointed out that using ICT reduces feelings of loneliness and isolation. According to Kralik *et al.*,[27] people living with chronic illness find other ways to achieve daily activities that give them a sense of independence. Self-management is a means of creating a sense of order in their lives.

The results showed that it was of a great importance for the participants to trust in the technology and the person they communicated with. When the DN showed that she could manage the technology, it gave them a feeling of security. According to Kawaguchi *et al.*,[28] it takes time to get accustomed to using the equipment, which leads gradually to increased trust in the technology. This indicates that it is important not to forget the human factor when technology is used. Fosbinder[29] stated that trust for patients is when the nurses accept responsibility, anticipate needs and show that they enjoy their work.

The present study indicates that ICT offers the possibility of supporting people with serious chronic illness, but further research is needed involving studies with larger numbers of participants. In the present study, the ICT gave the participants a feeling that they were not governed by time; instead they could write their message regardless of the time and then receive an answer. The ICT became a support mechanism in their communication with the DN, which can be seen as an improvement in care. This shows the possibility of improving access to care for people with serious chronic illness living in their home.

References

1 Corbin J, Strauss AL. Accompaniments of chronic illness: changes in body, self, biography, and biographical time. In: Roth JA, Conrad P, eds. *Research in the Sociology of Health Care: A Research Annual*. Vol. 6. The Experience and Management of Chronic Illness Greenwich, CN: JAI Press Inc., 1987;249–81

2 Morse JM. Responding to threats to integrity of self. *Adv Nurs Sci* 1997;**19**:21–36

3 Soderberg S, Lundman B, Norberg A. Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qual Health Res* 1999;**9**:575–87

4 Ohman M, Soderberg S, Lundman B. Hovering between suffering and enduring: the meaning of living with serious chronic illness. *Qual Health Res* 2003;**13**:528–42

5 Ohman M, Soderberg S. District nursing – sharing an understanding by being present. Experiences of encounters with people with serious chronic illness and their close relatives in their homes. *J Clin Nurs* 2004;**13**:858–66

6 Cody A, Squire A. Nurses' perceptions of good nursing care. *Prof Nurse* 1998;**13**:578–82

7 Hallström I, Elander G. A comparison of patient needs as ranked by patients and nurses. *Scand J Caring Sci* 2001;**15**:228–34

8 Allen A, Roman L, Cox R, Cardwell B. Home health visits using a cable television network: user satisfaction. *J Telemed Telecare* 1996;**2**:92–4

9 Erkert T. High-quality television links for home-based support for the elderly. *J Telemed Telecare* 1997;**3**:26–8

10 Huston JL, Burton DC. Patient satisfaction with multispecialty interactive teleconsultations. *J Telemed Telecare* 1997;**3**:205–8

11 Johnston B, Wheeler L, Deuser J, Sousa KH. Outcomes of the Kaiser Permanente Tele-Home Health Research Project. *Arch Fam Med* 2000;**9**:40–5

12 Campbell P, Dries J, Gilligan R. *The Older Generation and the European Information Society: Access to the Information Society.* Dusseldorf: European Institute for the Media; Utrecht: The Netherlands Platform Older People and Europe, 1999

13 Demiris G, Speedie SM, Finkelstein S. Change of patients' perceptions of TeleHomeCare. *Telemed J E-Health* 2001;**7**:241–8

14 Merriam SB. *Case Study Research in Education.* San Francisco: Jossey-Bass, 1988

15 Catanzaro M. Using qualitative analytical techniques. In: Woods NF, Catanzaro M, eds. *Nursing Research. Theory and Practice.* St. Louis: Mosby, 1988;437–56

16 Sandelowski M. Qualitative analysis: what it is and how to begin. *Res Nurs Health* 1995;**18**:371–5

17 Baxter LA. Content analysis. In: Montgomery BM, Duck S, eds. *Studying Interpersonal Interaction.* New York: The Guilford Press, 1991;239–54

18 Attree M. Patients' and relatives' experiences and perspectives of 'Good' and 'Not so Good' quality care. *J Adv Nurs* 2001;**33**:456–66

19 Magnusson L. Carers tap into the information highway. *Nurs Times* 1999;**95**:48–50

20 Magnusson L, Hanson E, Brito L, Berthold H, Chambers M, Daly T. Supporting family carers through the use of information and communication technology – the EU project ACTION. *Int J Nurs Stud* 2002;**39**:369–81

21 Finkelstein SM, Speedie SM, Demiris G, Veen M, Lundgren JM, Potthoff S. Telehomecare: quality, perception, satisfaction. *Telemed J E-Health* 2004;**10**:122–8

22 Whitten P, Collins B, Mair F. Nurse and patient reactions to a developmental home telecare system. *J Telemed Telecare* 1998;**4**:152–60

23 Corbin JM. The body in health and illness. *Qual Health Res* 2003;**13**:256–67

24 Strandmark MK. Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering. *Scand J Caring Sci* 2004;**18**:135–44

25 Lindsey E. Health within illness. Experiences of chronically ill/disabled people. *J Adv Nurs* 1996;**24**:465–72

26 Magnusson L, Hanson EJ. Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home. *Health Soc Care Commun* 2003;**11**:431–9

27 Kralik D, Koch T, Price K, Howard N. Chronic illness self-management: taking action to create order. *J Clin Nurs* 2004;**13**:259–67

28 Kawaguchi T, Azuma M, Ohta K. Development of a telenursing system for patients with chronic conditions. *J Telemed Telecare* 2004;**10**:239–44

29 Fosbinder D. Patient perceptions of nursing care: an emerging theory of interpersonal competence. *J Adv Nurs* 1994;**20**: 1085–93

EMPIRICAL STUDIES

Swedish District Nurses' experiences on the use of information and communication technology for supporting people with serious chronic illness living at home – a case study

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Swedish District Nurses' experiences on the use of information and communication technology for supporting people with serious chronic illness living at home – a case study

The aim of this case study was to describe two District Nurses' (DN) experiences of using information and communication technology (ICT) to communicate with chronically ill people in their homes. An electronic messaging program via computers and mobile phones with an Internet connection was used, enabling DNs and the ill people to exchange messages to and from anywhere. The program comprised different virtual rooms, and communication was via text messages. The DNs in this study used the program two to four times each week from November 2003 to March 2004. Semi-structured interviews were performed before, during and after the implementation of the new technology and were analysed using thematic content analysis. The results showed that the DNs felt that the technology increased accessibility to nursing care through a more direct communication with the ill person meaning that a more trusting relationship could be created. The DNs also experienced that the use of ICT saved working time. This study indicates that the use of ICT for communication allowed the DN to better support a chronically ill person at home leading to improved home nursing care. This method of communication cannot replace physical presence, but can be seen as a complement to nursing care at home.

Keywords: District Nurse, home care, information and communication technology, support, case study, thematic content analysis.

Submitted 8 February 2008, Accepted 20 March 2009

Introduction

This study was a part of a larger project within the context of primary health care. The overall aim was to test information and communication technology (ICT) as a tool for the District Nurse (DN) to increased accessibility to care for people with serious chronic illness living at home. Chronic illnesses, such as cancer, diabetes, multiple sclerosis and cardiovascular disease are common in the western world. Chronic illness entails ongoing disruptions and changes in life (1, 2) and may change the very foundation of life as the illness brings with it new and different conditions (1). People with serious chronic illness spend most of their time in their home and often need help and support from the DN. In Sweden, DNs are usually responsible for providing nursing care at home, and can be compared with community nurses or home care nurses in other countries. During the last few years, the number of people cared for, in their homes has increased as a result of a shift in care provision from hospitals to primary and community care. According to The National Board of Health and Welfare (3) approximately 250 000 persons in Sweden have some form of home nursing care today. Eighty-seven per cent is over 65 years old and the majority is women. This has influenced the work of DNs and has led to the situation where an important part of their work is to support people with chronic illnesses who live at home (4, 5).

Literature review

Easy and appropriate ways for DNs and people who live at home with chronic illnesses to communicate are required for the achievement of satisfactory accessibility to nursing care. Equally important for DNs is a good relationship with both the ill person living at home and their relatives (4, 6). The meaning of a caring relationship for DN has been

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described keeping a balance between simultaneously professional and private with the ill person and their family. It is necessary for DNs in caring relationships with ill people to be on hand when needed, to be able to give time and inspire confidence in the ill person and their families. At the same time, DNs describe the importance of setting limits to maintain their own integrity (7). DNs see themselves as guests when they visit the homes of ill people (7, 8).

Communication skills are essential for successful nursing. Brennan (9) believes that the interaction between patient and nurse is central in caring, and mutual interaction is probably no less important when communication occurs via computers; it is just different. One feasible method by means of which DNs could support chronically ill people living at home could be the use of ICT. ICT enables people to communicate, gather information and interact with distance services quickly and more easily without the limitation of time and place (10).

Using ICT can also support family caregivers by reducing isolation and maintaining a sense of presence through providing easier access to healthcare professionals (11). An earlier study (12), indicated that everyday life for seriously chronically ill people living at home seemed to be improved by the use of ICT. The results showed that the participants' communication with the DN improved because of easy accessibility and that they felt increased security. They also felt that there were fewer limitations and that their everyday life was improved, which can also be interpreted as an improvement in nursing care.

According to Jaatinen et al. (13) the most common ICT application used in health care is video conferencing, mainly in real time. It has also been shown that the use of ICT can improve the quality of care for older people living in a residential home (14, 15), and that its use led to the personnel being more satisfied with their work situation (16). Furthermore, nurses who used virtual visits in the course of telecare projects felt that the quality of care was equal to that provided in physically meetings (15). This is in line with Kawaguchi, Azuma and Ohta (17) who stated that nurses could improve ongoing nursing care and predict impairment in the patient's condition when using a telenursing system. Another study (18) has described the nurse–physician–patient interaction in teleconsultation via videoconferencing. The interaction was complex and the nurse had the role of facilitator of the interaction. The finding showed the importance of interpersonal dynamics in this type of teleconsulting.

To sum up, recent changes in health care have had the effect that there are more people with serious chronic illness living at home than before. This has led to increased care and nursing care and requires DNs to find new ways of working to facilitate communication and be more accessible to such people. Using ICT could support DNs in providing efficient nursing care through, for example, enabling increased accessibility and participation for people with serious chronic illness living at home. We, therefore, suggest that using ICT is one possible way of developing nursing care at home. We found it important to test how DNs experienced the use of ICT as a support tool in nursing care in their work with seriously chronically ill people living at home. Thus, the aim of this study was to describe the DNs' experiences of using ICT to communicate with people with serious chronic illness living at home.

Methods

Study design

A qualitative case study design was chosen to optimize the understanding of the complexities of the research question (19). Case studies allow the researcher to gain a unique and holistic knowledge about various phenomena in real-life events. Case studies are in-depth investigations of a single entity or a small series of entities. Typically, the entity is an individual, a group or institution. The researcher conducting a case study attempts to analyse and understand the phenomena that are important for the development, or care of an individual or an individual's problem (20). In this case study, the entity was the DNs and the ill people who lived at home and their experiences of using text messages via a computer program as a means of communication. The focus of case studies is typically on determining the dynamics of *why* the individual experiences, behaves or develops in a particular way. Understanding this requires a detailed study over a considerable period of time; in this study the case was followed during an implementation period of 5 months. Data were collected by means of repeated semi-structured interviews (21) and analysed using thematic content analysis (22) with an inductive approach (23). An approach based on inductive data moves from the specific to the general, so that particular instance are observed and then combined into a larger whole.

The case

The case consisted of two DNs using an ICT application for communicating with two of their patients with serious chronic illness living at home. The focus was on the DNs' experiences of using this new channel of communication available to the nurses. The DNs had worked within health care for a long time (23 and 39 years respectively). They worked in different healthcare centres and both had computer knowledge since the case-record system was computerized. The people with chronic illness required extensive 24 h care from personal assistants. The case was selected by the head of two healthcare centres. The DNs

were chosen based on the following criteria: (i) possessing a graduate diploma within primary healthcare specialist nursing; (ii) responsible for an ill person's nursing care at home; (iii) having an established contact with the ill person and (iv) having computer skills. When the DNs were selected and had agreed to participate, they in turn were asked to select one patient each; whom they thought would be able to communicate with them via the ICT application.

Ethical considerations

District nurses received both oral and written information about the study and were informed that participation was voluntary and that they could withdraw at any time. Informed consent was obtained and all data were confidential. The ill people were informed about the aim of the study and how to communicate with the DN through the ICT application. They were also informed that the focus was on improving accessibility to health care. This study was approved by the ethics committee of the university.

The implementation of new technology and data collection

For communication between the DNs and the people with chronic illness living at home, new technology in the form of an electronic messaging program via a computer program called Rexnet® and mobile phones with an Internet connection was used. The program comprised different virtual rooms, and enabled the DNs to communicate with the ill person through receiving text messages from and sending text messages to the ill person from anywhere. It was also considered the most suitable form of communication because the ill people had difficulty talking. The DNs used the program two to four times each week, November 2003–March 2004. The program was reputed to be user-friendly and secure. Information about using the equipment was given to the DNs and the people with chronic illness before the use of the new technology started. Traditional home visits were also carried out by the DNs and technical support was available during the whole implementation period.

The DNs were interviewed three times using semi-structured interviews (21). They were interviewed before the implementation started, 2 months after the implementation had started and finally after the implementation period had finished. The first interview was based on an interview guide with questions on topics such as experiences of communication, and the needs of people with chronic illness accessibility to care. The interview guide was developed from earlier literature and research describing the use of ICT in health care. The interview opened with the question, 'Please tell me about your experiences of caring for and communicating with people

with chronic illness living at home and their needs regarding care and communication with DNs'. Follow-up questions such as 'Can you give an example?', 'What happened then?' or 'How did you feel then?' were asked. The interviews lasted for about 40 minutes each. The remaining interviews were conducted 2 months after the implementation started and after it finished. An interview guide was also used this time and contained topics such as communication, the needs of people with chronic illness for accessibility to care, security and difficulties. Questions deriving directly from the answers given in the preimplementation interviews and questions about experiences of using ICT were also asked. The interviews lasted for about 30 minutes each time. All the interviews were conducted in the DNs' work place, were tape-recorded and later transcribed verbatim.

Data analysis

A thematic content analysis was used to analyse the interview texts to describe the manifest and latent content (22). The interview texts from before the implementation of the new technology was analysed separately, and the interview texts during and after the implementation were analysed together, as their content was rather similar. However, the analysis process was similar for all data. To obtain an overall sense of the data and the content of the interviews the texts were read several times (24). The most important decision in the analysis – the selection of textual units for analysis – was guided by the aim of the study. In this study, the selected textual units were every communicative act in which the DNs narrated experiences of using ICT to communicate with people with chronic illness. Each textual unit was then condensed, i.e. the textual unit was shortened while still preserving the core (22). Next, the condensed textual units were coded and a pattern of preliminary categories started to emerge from the data. The next step in the analysis was to read the transcribed data and the preliminary categories again to obtain an understanding of the DNs' experiences of using ICT to communicate with people with chronic illness. After that, the preliminary categories were subsumed into final categories based on similarities and differences in content. The final categories were then compared to identify themes, i.e. threads of meaning that appeared in several categories (25) and two themes, one for preimplementation and another for postimplementation were formulated (Table 1).

Results

The analysis resulted in two themes each with two categories. Themes and categories are presented before and after the implementation of the new technology supplemented with quotations from the interview texts.

Table 1 Overview of themes and categories that emerged from analysis of the interviews with the District Nurses

Theme	Category
Before the implementation	
Striving for a trusting relationship	Mediating of security through interaction
	Working for accessibility
After the implementation	
Achieving a more trusting relationship	A facilitator for nursing care
	Increased accessibility

Before the implementation

The theme 'Striving for a trusting relationship' was constructed from the two categories, 'mediating of security through interaction' and 'working for accessibility'.

Mediating of security through interaction

The DNs described both the importance of making the ill person felt secure and at the same time how difficult this was. If the need for more security was warranted, the DNs made home visits and extra phone calls more often or personnel in the home care service or relatives were contacted to visit more often. The DNs emphasized that knowing the ill person engendered feelings of security and made it easier to predict what would happen, but it could also mediate feelings of being limited and indispensable. Both DNs said that cooperation with their DN colleagues and other professionals, such as like general practitioners, was essential for mediating security for the ill person as well as for themselves.

> …it's a very good thing having colleagues that you can talk to. Yes, helping each other and often it's someone who has something sensible to say I think…

The DNs stressed further the great responsibility of visiting and caring for people in their homes. Sometimes they felt insufficient and dissatisfied with the nursing care they gave, because it was difficult to understand and fulfil the needs of the ill person and mediate security. One DN mentioned that ill people were sometimes anxious and contacted the DN immediately after the DN had left them. The other described a sense of powerlessness when there was a lack of continuous communication with ill people or when many needed help at the same time. Both DNs described how they gave priority to ill people who were judged to be in the greatest need of security, but that this was not always easy.

> …yes, you want to split yourself in two…but it's not possible, instead you must try to decide who has the greatest need.

Working for accessibility

The DNs felt that they were not always accessible enough to the ill people. One DN used a mobile phone at work. The guidelines for its use were that the ill person phoned the receptionist who delivered a message to the responsible DN who then contacted the ill person. One DN pointed out that many things could happen when the DN was inaccessible. To increase accessibility, this DN gave her private mobile number to ill people who were cared for at home and required more attention. Both DNs stated that people close to the ill people made the phone calls, not the ill people themselves. The proximity to the ill person's home was an important factor for the DNs in deciding how quickly home visits could be made. Both DNs said that they saw ICT as a possible solution to increasing accessibility to care for ill people.

After the implementation

The theme 'Achieving a more trusting relationship' was constructed from the two categories, 'a facilitator for nursing care' and 'increased accessibility'.

A facilitator for nursing care

The DNs talked about their situation after they became accustomed to the use of ICT, and said it facilitated their work. They were pleased with the support they received from the messaging program. Both described how they had worked out routines, such as visiting the messaging program at fixed times, which organized the working situation. One DN stated that reading the messages regularly gave her an opportunity to know what the ill person needed. The contacts included questions about medicines, physical problems and practical things such as ordering aids and agreements about the time for home visits. Both DNs thought communicating by using the technology with the ill person was a positive experience. They stressed that traditional home visits could not be replaced by the use of ICT, but ICT could be an aid in their work. One of them pointed out, however, that not everything to do with ill persons living at home had to be done in face-to-face physical meetings. One of them believed that the use of ICT could reduce the number of home visits, and the other claimed that if a lot of many ill people used the technology at the same time, there could be difficulties in managing it. They said that their expectations had been realized, and they were positive about continuing to use the ICT application in their work.

> Well, it's just as I said, I simply send a message to her and then I get reply. I check these things regularly so I know exactly what she wants and I can tell her how and when I'll arrive.

Increased accessibility

The DNs described how the use of ICT made them more accessible to their patients by using ICT. One DN said that being accessible reduced her stress and made her working situation more secure. The DNs experienced more direct communication with the ill person by using ICT. One of them mentioned that the use of ICT eliminated second-hand information given by others, and presented them with a more realistic view of the situation; it was easier to determine whether the condition of the patient was critical. The other DN said that the possibility of writing messages wherever you were made the work easier. Both DNs expressed a sense of saving time by using ICT. They were able to reduce the frequency of visits to the healthcare centre between home visits, had possibilities of giving a quick answer, were able to reduce the number of phone calls, and had the possibility to go back to the message and check what had been written. One DN pointed out that a more extensive use of ICT could gave them more time to help other ill people.

> …I know they can reach me, it's no problem. This makes me feel secure, and therefore I don't need to make any extra home visits which I otherwise usually do. It saved my time.

Despite increased accessibility the DNs mentioned that they were unaccustomed to using the ICT application at the beginning of the implementation period and that the technical problems gave them a sense of uncertainty. The DNs described problems with receiving and sending messages via the mobile phone with an Internet connection, and they were not satisfied with the instructions and support they received. They said that they had sometimes made home visits for safety's sake to maintain the accessibility, although using the technology would probably have been sufficient.

Discussion

The aim of the study was to describe the DNs' experiences of using ICT to communicate with people with serious chronic illness living at home. The results show that the use of the messaging program and mobile phones with an Internet connection in the DN's work seemed to give DNs a more trusting relationship with the person with serious chronic illness living at home. Furthermore, the results indicate that using ICT increased the possibilities of reaching the DN, saved time, assisted direct communication with the ill people and provided increased knowledge of and control over the ill person's situation. People living with chronic illnesses believed that a trusting relationship with the nurse is an important quality factor in nursing care (26). According to Lögstrup (27) trust is developed in a good relationship. To show or ask for trust implies being more open to oneself and to another person, and helping

to improve another person's quality of life. In order to mediate security, the DNs strove to establish a good relationship with the ill person. Establishing mutual trust and confidence is essential in relationships between DNs and their patients. Communicating by using ICT affected the aspect of trust in relationships. A trusting relationship in the interaction between patients and healthcare providers has the same importance when ICT is used as it has in physical meetings (28). In telehome care, nurses are physically separated from direct patient contact and building a trusting relationship in such setting requires different strategies. Telehome care allow the ill people to contact the nurse whenever they need, which may leads to increased trust in their relationship (29).

Before the implementation of the new technology started, the DNs explained the importance of knowing the ill person and providing security; this was important to create the conditions for individual care. Radwin (30) maintains that knowing the ill person ensures individual care, which includes continuous contact and a sense of closeness in the nurse–patient interaction. Knowing the other person through the use of ICT in patient–caregiver relationships may facilitate the achievement of trust (28).

The DNs felt they were not accessible enough and sometimes felt insufficient in relation to the ill people. This can be seen as an expression of not being able to control their work. Once the technical problems were solved, the DNs thought the use of ICT facilitated their work and gave them more knowledge about the ill person. Using ICT allowed working conditions to be more organized and also increased accessibility, which for one DN meant reduced stress. This could be seen as a way of gaining control over what happens in their work. According to Berterö (6), DNs in home palliative care tried to find their own solutions to the organization of the caring situation so that they could control it. Studies (31, 32) have shown that not having control leads to DNs feeling stress.

The DNs experienced that it was possible to communicate with the ill person by using the technology despite not seeing each other. They stated at the same time that home visits were necessary. Whitten et al. (33) have described how nurses perceived a difference between using traditional home nursing and home telenursing as a result of the lack of physical contact with the patient. However, Whitten et al. claimed that using telenursing did not always lead to deterioration; instead, it could enhance the frequency of contacts in the nurse–patient interaction. One DN believed that using ICT might reduce the number of home visits. This could be seen as an advantage by reducing the stress for the DN, but also as a disadvantage because of the lack of physical contact with the ill person. Physical touch is an important form of nonverbal communication in nursing care (34, 35). This is an important issue in nursing care, but it has not been the focus in this study.

Because of technical problems, the DNs were not entirely in favour of using the mobile phones with an Internet connection. According to Wakefield et al. (36), it is important that the technology is clinically appropriate and that the users are given proper training and support. Nevertheless, the DNs maintained that using ICT had increased accessibility because they were able to write messages wherever they were. Being accessible gives DNs control of the caring situation (6). The DNs said that they saved time by using the technology and that meant they were available to others who needed help. This can be seen as improving nursing care quality. According to Attree (37), accessibility of care practitioners is a quality factor for ill people. In summary, this study shows that ICT is a possible way to improve the nursing care for people with serious chronic illness living at home.

Methodological considerations

The strength of this study is the DNs perspective of the implementation of ICT, i.e. the DNs themselves described their experiences of using ICT in nursing care. The design of the study, a single case study, offers insights into the case before and after the implementation of new technology from the perspective from the DNs' experiences. The data collection in the form of repeated interviews served to enhance the understanding of the case and produced a broader interpretation. However, this strength is also a potential weakness because the familiarity of the researcher with the person may make objectivity more difficult. Perhaps, the most serious disadvantage of the case study method is its lack of generalizability. That is, if the researcher reveals the existence of important relationships, it is generally difficult to know whether the same relationships would manifest themselves in other subjects (38). Generalization in this case study is therefore more of an analytic generalization and is not applicable to all kinds of care. There are also technical limitations in transferring communication between DNs and ill persons and it seems to create special demands on the participants that can be met to some extent by verbal communication within the triad of participants. The results were discussed with other researchers and colleagues to confirm the trustworthiness of the study (38).

Conclusion

Because of a shift of care from hospitals to home care, the use of ICT in communication implies need for new strategies in nursing care. The physical environment and the distance become less important. This study indicates that using ICT improved nursing care at home by permitting increased accessibility, providing a more direct communication and control over the ill person's situation and by the resulting savings in time. This can be interpreted as the DNs reaching a more trusting relationship with the ill person living at home. However, the use of ICT cannot replace physical presence in nursing care, but it can serve as a complement to home nursing care. The participating DNs stated that using ICT meant that they sometimes missed the opportunity to see the ill person. Therefore, ICT with pictures and sound, to enable communication between seriously chronically ill people living at home and their DNs need to be developed. This study gives support for further research in this area but studies with a large sample are needed to strengthen the credibility of the results.

Author contributions

This study was designed by C. Nilsson and S. Söderberg. C. Nilsson also conducted and transcribed the interviews. C. Nilsson and S. Söderberg analysed the data. All the authors contributed with critical revision of the manuscript and collaborated in the drafting and completion of the manuscript.

References

1 Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982; 4: 167–82.
2 Curtin M, Lubkin I. What is chronicity? In *Chronic Illness. Impact and Intervention* (Lubkin I, Larsen PM eds), 1998, Jones and Barlett Publisher, Sudbury, MA, USA, 3–25.
3 The National Board of Health and Welfare. *Hemsjukvård i förändring. En kartläggning av hemsjukvården i Sverige och förslag till indikatorer [Home Nursing Care in Change. A Survey of Home Nursing Care in Sweden and Suggestions to Indicators]*. http://www.socialstyrelsen.se/NR/rdonlyres/3B3ACC8B-E3F6-4847-B19E-926403FCBFD8/12439/2008/2659.pdf (last accessed 15 April 2009).
4 Wright K. Caring for the terminally ill: the district nurse's perspective. *Br J Nurs* 2002; 11: 1180–5.
5 Öhman M, Söderberg S. District nursing – sharing an understanding by being present. Experiences of encounters with people with serious chronic illness and their close relatives in their homes. *J Clin Nurs* 2004; 13: 858–66.
6 Berterö C. District nurses' perceptions of palliative care in the home. *Am J Hosp Palliat Care* 2002; 19: 387–91.

7 McGarry J. The essence of 'community' within community nursing: a district nursing perspective. *Health Soc Care Community* 2003; 11: 423–30.

8 Andree-Sundelöf E-M, Hansebo G, Ekman S-L. Friendship and caring communion: the meaning of caring relationship in district nursing. *Int J Hu Caring* 2004; 8: 13–20.

9 Brennan PF. The future of clinical communication in an electronic environment. *Holist Nurs Pract* 1996; 11: 97–104.

10 Campbell P, Dries J, Gilligan R. *The Older Generation and the European Information Society: Access to the Information Society*. 1999, European Institute for the Media, Dusseldorf and the Netherlands Platform Older People and Europe, Utrecht, The Netherlands.

11 Magnusson L, Hanson E, Brito L, Berthold H, Chambers M, Daly T. Supporting family carers through the use of information and communication technology. The EU project ACTION. *Int J Nurs Stud* 2002; 39: 369–81.

12 Nilsson C, Öhman M, Söderberg S. Information and communication technology in supporting people with serious chronic illness living at home – an intervention study. *J Telemed Telecare* 2006; 12: 198–202.

13 Jaatinen PT, Forsström J, Loula P. Teleconsultations: who uses them and how? *J Telemed Telecare* 2002; 8: 319–24.

14 Allen A, Roman L, Cox R, Cardwell B. Home health visits using a cable television network: user satisfaction. *J Telemed Telecare* 1996; 2: 92–94.

15 Demiris G, Speedie S, Finkelstein S, Harris I. Communication patterns and technical quality of virtual visits in home care. *J Telemed Telecare* 2003; 9: 210–5.

16 Engström M, Ljunggren B, Lindqvist R, Carlsson M. Staff perceptions of job satisfaction and life situation before and 6 and 12 month after increased information technology support in dementia care. *J Telemed Telecare* 2005; 11: 304–9.

17 Kawuguchi T, Azuma M, Ohta K. Development of a telenursing system for patients with chronic illness. *J Telemed Telecare* 2004; 10: 239–44.

18 Troppa A, Timonen O, Keinänen-Kiukaanniemi S, Larivaara P, Leiman M. Patient–nurse–doctor interaction in general practice teleconsultation – a qualitative analysis. *J Telemed Telecare* 2006; 12: 306–10.

19 Kazdin AE. *Single-Case Research Designs. Methods for Clinical and Applied Settings*. 1982, Oxford University Press, New York, USA.

20 Yin RK. *Case Study Research. Design and Methods*, 3rd edn. 2003, Sage Publications, Thousand Oaks, CA, USA.

21 Kvale S. *Interviews. An Introduction to Qualitative Research Interviewing*. 1996, Sage Publications, Thousand Oaks, CA, USA.

22 Catanzaro M. Using qualitative analytical techniques. In *Nursing Research. Theory and Practice* (Woods NF, Catanzaro M eds), 1988, Mosby, St Louis, CA, USA, 437–56.

23 Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008; 62: 107–15.

24 Sandelowski M. Qualitative analysis: what it is and how to begin. *Res Nurs Health* 1995; 18: 371–5.

25 Baxter LA. Content analysis. In *Studying Interpersonal Interaction* (Montgomery BM, Duck S eds), 1991, The Guilford Press, New York, USA, 239–54.

26 Thorsteinsson LS. The quality of nursing care as perceived by individuals with chronic illnesses: the magical touch of nursing. *J Clin Nurs* 2002; 11: 32–40.

27 Lögstrup KE. *Det etiska kravet [The Ethical Demand]*. 1992, Daidalos, Göteborg, Sweden.

28 Andreassen HK, Trondsen M, Kummervold PE, Gammon D, Hjortdahl P. Patients who use E-mediated communication with their doctor: new constructions of trust in the patient–doctor relationship. *Qual Health Res* 2006; 16: 238–48.

29 Shea K, Effken JA. Enhancing patients' trust in the virtual home health care nurse. *Comput Inform Nurs* 2008; 26: 135–41.

30 Radwin LE. 'Knowing the patient': a review of research on an emerging concept. *J Adv Nurs* 1996; 23: 142–6.

31 Rout UR. Stress amongst district nurses: a preliminary investigation. *J Clin Nurs* 2000; 9: 303–9.

32 Wilkes L, Beale B, Hall E, Rees E, Watts B, Denne C. Community nurses' descriptions of stress when caring in the home. *Int J Palliat Nurs* 1998; 4: 14–20.

33 Whitten P, Collins B, Mair F. Nurse and patients reactions to a developmental home telecare system. *J Telemed Telecare* 1998; 4: 152–60.

34 Chang SO. The conceptual structure of physical touch in caring. *J Adv Nurs* 2001; 33: 820–7.

35 Routasalo P, Isola A. Touching by skilled nurses in elderly care. *Scand J Caring Sci* 1998; 12: 170–8.

36 Wakefield BJ, Holman JE, Ray A, Morse J, Kienzle MG. Nurse and patient communication via low- and high-bandwidth home telecare systems. *J Telemed Telecare* 2004; 10: 156–9.

37 Attree M. Patients' and relatives' experiences and perspectives of 'good' and 'not so good' quality care. *J Adv Nurs* 2001; 33: 456–66.

38 Stake R. Case studies. In *Handbook of Qualitative Research* (Denzin N, Lincoln Y eds), 2nd edn, 2000, Sage Publications, London, UK, 435–54.

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