LICENTIATE THESIS

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Using Information and Communication Technology to Support People with Serious Chronic Illness Living at Home

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CONTENTS

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ABSTRACT

The overall aim of this licentiate thesis was to describe the experiences of people with serious chronic illness and the points of view and experiences of district nurses concerning the use of information and communication technology in nursing care at home. The study has a qualitative approach. Data were collected by using focus group discussions with 19 district nurses describing their points of view about using information and communication technology in nursing care at home (I). An intervention study with a case study design were performed (II, III) using semi-structured interviews with two people with serious chronic illness living at home and their respective district nurses before, during and after the use of the ICT application. The data were analysed using a thematic content analysis.

The findings show the importance of district nurses having the opportunity to influence the design and to participate in the introduction to the use of information and communication technology. District nurses saw that the use of this technology in nursing care at home could improve the accessibility of the district nurse for the ill person at home. They saw a possibility for themselves to gain better access to information about ill people living at home, and that its use could both save time, but also take time. The findings revealed that the equipment could be regarded as an encroachment and that the autonomy of the people and their relatives at home could be threatened. Furthermore it appeared that the use of information and communication technology in nursing care at home was not suitable for everyone, and that people cannot be replaced by information and communication technology.

The findings in the intervention study indicate that it was difficult to reach the district nurse, and the use of information and communication technology improved accessibility. The messaging program provided a more direct communication between the ill people and their district nurses and facilitated communication with the district nurse, which led to fewer limitations in everyday life for people with serious chronic illness living at home. A feeling of uncertainty was salient in the use of the technology for the participants. The technology was seen as a complement to nursing care at home but not a replacement for traditional home visits.

The study indicates that the use of information and communication technology offers a possibility of improving nursing care at home for people with serious chronic illness with increased accessibility, safety and security. It also seemed to mediate a more trusting relationship between the ill person and their district nurse.

Key word: serious chronic illness, district nurse, nursing care at home, experiences, accessibility, security, trust, information and communication technology, qualitative thematic content analysis

ORIGINAL PAPERS

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

I   Nilsson, C., Skär, L., & Söderberg, S. (manuscript). District nurses' points of view on the use of information and communication technology in nursing care at home.

II   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.

III   Nilsson, C., & Söderberg, S. (submitted). District nurses' experiences on the use of information and communication technology for supporting people with serious chronic illness and living at home - an intervention study.

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INTRODUCTION

During the last few years hospital care has been reduced resulting in people with illness being discharged from hospital earlier and sicker than previously (Karlsson, Morberg & Lagerström, 2006). These changes have influenced the work of district nurses (DNs) and have led to a large and important part of their work being to support people with chronic illness so that they can live in their homes despite illness (Wright, 2002; Öhman & Söderberg, 2004a). For that reason it is a challenge for DNs to find new methods for supporting people with serious chronic illness living at home. One way to achieve this may be through the use of suitable applications of information and communication technology (ICT). Therefore, this licentiate thesis focuses on supporting people with serious chronic illness in their communication with their DN through the use of ICT.

Living with a chronic illness in everyday life

A lot of research has been performed describing daily living for people with chronic illness (e.g., Corbin & Strauss, 1987; Paterson, 2001; Thorne & Paterson, 2000; Toombs, 1993). There are several negative influences and losses in everyday life for people living with a chronic illness. Charmaz (1983) has described that people living with chronic illness experienced that their lives were restricted, a feeling of being discredited and a burden for others. According to Öhman, Söderberg and Lundman (2003) people living with a serious chronic illness experienced the body as a hindrance and loss of independence in the daily life. Söderberg, Lundman and Norberg (1999) described such feelings as loss of freedom and a struggle to be understood when living with a chronic illness. Loss of freedom implies, among other things, being dependent on care. Ellefsen (2002) stated that being dependent on care when living at home implied a limit on autonomy, loss of respect, changes in relations with others in their environment, loss of privacy in everyday life, and difficulties in agreeing with the caregiver about the planning and accomplishment of the care they received.

Their close relatives' lives are also influenced by the chronic illness, which is experienced as a burden for them (Faison, Faria & Frank, 1999; Robinson, 1998) and means many changes in their everyday life and adapting their own life to the ill relative's needs (Söderberg, Strand, Haapala & Lundman, 2003: Öhman & Söderberg, 2004b). Studies (Melanson & Downe-Wamboldt, 2003; Toombs, 1993; Öhman et al. 2003) have shown that people with chronic illness can experience a need for control and independence in their everyday life, something which can give rise to feelings of anxiety and fear (Toombs, 1993; Öhman et al., 2003). Ironside et al. (2003) described how people with a chronic illness experienced a major loss of control due to the loss of the previous habitual body, which required a new way of looking at themselves. Charmaz (1983) and Öhman et al. (2003) stated that people living with a chronic illness could feel loneliness in everyday life. According to Öhman et al. (2003) loneliness could lead to insecurity and helplessness for the ill person. Öhman et al. (2003) also showed that people with serious chronic illness living at home could feel left out, especially when there was an unexpected deterioration in their health or other things happened in their everyday life, despite their having close relatives/family members.

To live with a chronic illness means to adapt daily life to the illness and to avoid situations that cause difficulties. Daily life can be facilitated by using aids (Öhman et al. 2003) but this can also be seen as demeaning by the ill person (Toombs, 1993). Revaluations, new experiences and insights are demanded concerning the resources they still have for adapting their life to the situation (Rapley & Fruin, 1999). Delmar et al. (2005) illustrated that reaching harmony with oneself when living with a chronic illness meant moving towards acceptance of the chronic suffering and illness, which can be difficult to achieve. One compensation for the vulnerability of living with a chronic illness could be human support, close relations with others, and trying to adapt themselves to

their illness (Strandmark, 2004). Support from healthcare personnel could also be important (Lindsey, 1997).

In summary, research shows that people with a chronic illness live their lives strongly influenced by changes that challenge them to find ways to manage everyday life despite the illness.

District nurses and nursing care at home

District nurses view nursing care in the home as one of the main task in their work (Karlsson, Morberg, & Lagerström, 2006; Wright, 2002: Öhman & Söderberg, 2004a). They see themselves as guests when paying home visits to the ill person's own home (McGarry, 2003; Andrée-Sundelöf, Hansebo & Ekman, 2004; Öhman & Söderberg, 2004b). According to Öhman and Söderberg (2004a) it is important for DNs to be professional in their work, but in some ways this can be difficult because of the close relationship they established with the ill person living at home. Andrée-Sundelöf et al. (2004) have described this as 'balancing between being professional and being private'. According to Rydeman, Törnkvist and Gustafsson (2005) some preconditions were demanded of DNs in their support of the power of patients and relatives at home. One precondition was to allow the ill people and their relatives to be involved in the nursing care.

The nurse-patient relationship has a fundamental and significant importance concerning quality in nursing care (Fosbinder, 1994; Luker, Austin, Caress & Hallett, 2000). Wright (2002) has shown that DNs considered that the relationship had a significant and fundamental meaning in nursing care, for understanding and knowing the ill person and their family which demands time. DNs emphasised the importance of creating and maintaining a relationship with the ill person which they believe gave them something in return (Berterö, 2002).

In several studies (e.g., Dunne, Sullivan & Kernohan, 2005; Evans, 2002; McHugh, Pateman & Luker, 2003; Rout, 2000) DNs voiced the stress they can experience in their work. One reason why they experienced stress was due to deficiency of control, lack of time and the inability to handle some situations (Wilkes et al., 1998). Berterö (2002) has shown that DNs in palliative care at home sometimes felt disappointed and anxious because they did not feel able to provide the care they would like to give. However, the load for DNs in nursing care at home continues to increase which demands a change in the way they work (Mc Hugh et al., 2003).

Karlsson et al. (2006) and McGarry (2003) stated that DNs considered it important to assume a holistic view in nursing care at home. Berterö (2002) and Karlsson et al. (2006) described how DNs tried to have continuous communication and to be accessible to the ill person at home, which gave them control over their work. According to Dunne et al. (2005) DNs asserted that the communication improved if one person was responsible for the overall care of the ill person. Öhman and Söderberg (2004a) found that DNs felt that trust and reliance in the relationship with the ill person at home grew over time despite their being met from the beginning with suspicion.

In summary, research shows that DNs described some hindrance to their performing nursing care completely satisfactorily. In addition research reveals that DNs have a goal and an urgent need to establish a good relationship with the ill person as this is fundamental to nursing care at home.

Information and communication technology in healthcare
The use of ICT in our society is increasing constantly and rapidly, and occurs as a tool for communication in many different areas. According to Campbell, Dries and Gilligan (1999) ICT is a broad concept which enables people to

communicate, gather information and interact with distance service, more quickly, more easily and without the limitations of time and space. The concept ICT can be seen as an umbrella term for concepts in a variety of areas. Existing uses of ICT in healthcare are e.g., telecare, telemedicine, e-health, telehealth, and telenursing. The Swedish government has formulated a national strategy for using e-health, and pointed out that ICT support will improve participation and give greater accessibility to healthcare e.g., for people with chronic illness and older people (National strategy for e-Health, 2006). According to a review (Jaatinen, Forsström & Loula, 2002) the most frequent teleconsulting applications in healthcare are between physicians, and the most infrequent between patient and nurse. The most commonly used equipment is video conferencing, mainly in real time. Studies concerning home telehealth for improved accessibility and communication for both staff and patients are rather few, and research is therefore important in order to determine the impacts, benefits, and limitations in developing feasible solutions for home telehealth (Koch, 2006).

In summary, research shows that the use of ICT will probably play an increasing role in healthcare in the future. Research into accessibility and communication for both healthcare personnel and people dependent on care are sparse.

Information and communication technology in nursing care at home
Various ICT applications have been used in healthcare as support for ill people in several areas, e.g., at a hospice for the ill people's caregivers (Demiris, Parker Oliver, Courtney & Porock, 2005); as a support among frail older people living at home (Ezumi et al., 2003; Magnusson, Hanson & Borg, 2004); support for children with multiple or critical illness and their families (Lindstrand, 2002; Morgan, Grant, Craig, Sands and Casey, 2005); parental support for mothers during the infants' first year (Nyström & Öhrling, 2006) and in oncology

practice (Larcher et al., 2002). Engström, Ljunggren, Lindqvist and Carlson (2005) have found that the use of information technology can improve the quality of care for older people living in a residential home, and that the personnel were also more satisfied with their work situation.

Studies (Allen, Roman, Cox & Cardwell, 1996; Arnaert & Delesie, 2001; Finkelstein et al., 2004) have shown that older people with chronic illness living at home were satisfied with the use of various ICT applications for receiving nursing care at home. Studies (Engström, Lindqvist, Ljunggren & Carlsson, 2006; Sävenstedt, Zingmark & Sandman, 2003) showed that using ICT as a support for older, cognitively impaired people living in a nursing home to communicate with their family members had positive outcomes. The use of ICT led to family members being more involved in the caring process of their relatives with dementia living in a nursing home (Sävenstedt, Brulin & Sandman, 2003). Family carers were helped and supported by using ICT in their caring situation; it reduced their isolation, created a presence, and provided easier access to care professionals (Magnusson et al., 2002). A review study (Magnusson et al., 2004) of the use of ICT for family carers of older people living with chronic illness at home showed the importance of user-friendly ICT applications. One prejudice could be 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; Whitten, Mair & Collins, 1997). Demiris et al. (2001) described how some older people felt an initial fear about using ICT, but this seemed to diminish after a while. Sävenstedt, Zingmark, Hyden and Brulin (2005) have studied frail older people with dementia living in nursing home having conversations with their nurse by using videoconferencing technology. The findings indicated that limitations in transferring communication cues and in what the camera could reveal seemed to

be an advantage for older people with dementia because it helped to increase attention.

People living with chronic illness at home and their nurses were satisfied with ICT as a way of communicating (Whitten, Collins & Mair, 1998). Johnston, Wheeler, Deuser and Sousa (2000) tested a telehomecare system for people living with chronic illness. The results showed that remote video technology in a home healthcare setting was effective, well received by the ill people and enabled quality of care to be maintained. Agrell, Dahlberg and Jerant (2000) used ICT to allow ill people at home to communicate with the nurse. The findings showed that most of the ill people were positive about receiving telecare service at home in the future, and felt that they had increased access to the nurse. But they also pointed out that they felt uncomfortable disclosing intimate information and that the social togetherness with the nurse was reduced.

According to Whitten et al. (1998) nurses had strong opinions about who (nurses and ill people at home) were suited to the use of the technology, and also what sorts of illnesses could be included.

In summary, research shows that the use of ICT has been tested in various areas within healthcare. The use of ICT in nursing care at home has been tested especially for older people, their relatives and family carers. Studies show that its use has been experienced as positive for ill people living at home, their caregivers and nurses.

RATIONALE

The recent changes in healthcare have had the effect that people with serious chronic illness live in their own homes more extensively than before. This has led to increased care/nursing care at home. The literature review reveals that an important prerequisite for making it possible for people with serious chronic illness to live at home is that they feel they receive support and security from the healthcare providers. A challenge for DNs is therefore to find new ways of providing this support. This study suggests that one solution is to use ICT applications in the communication between people with serious chronic illness living at home and their DN. The goal with the ICT application in this study is, therefore, to increase accessibility, security and safety for people with serious chronic illness living in their own homes.

THE AIM

The overall aim of this licentiate thesis was to describe the experiences of people with serious chronic illness and the points of view and experiences of DNs of using ICT in nursing care at home. This licentiate thesis comprises three papers with the following specific aims:

Paper I - to describe DNs' points of view regarding the use of ICT in nursing care at home.

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

Paper III - to describe the DNs' experiences of using ICT for communicating with serious chronically ill people living at home.

METHODS

A qualitative approach has been chosen for this study, as the intention was to gain an increased understanding of people with serious chronic illness living at home and their experiences, and DNs' points of view and experiences of using ICT in nursing care at home. Selecting a qualitative approach meant that the participants' own perspectives could be described and they could share their world (cf. Patton, 2002, p. 341). Using a qualitative approach produces rich and in-depth information that describes a variety of dimensions of a phenomenon (Polit & Beck, 2004).

Design

Qualitative descriptive design (I)

The study presented in Paper I has a qualitative descriptive design in order to describe DNs' points of view about using ICT in nursing care at home. The goal of qualitative descriptive studies is to obtain a comprehensive summary of events in the everyday terms of those events (Sandelowski, 2000). Data were collected using focus group discussions in this study and then analysed using thematic content analysis. According to Sandelowski (2000) qualitative content analysis is a strategic choice of analysis method in qualitative descriptive studies.

Case study design (II, III)

Case studies is a comprehensive research strategy, appropriate for use in inquiries concerning a phenomenon in the real-life context, especially when the boundary between phenomenon and context is not obvious, and when the purpose is to find answers to questions of 'how' or 'why' (Yin, 2003, pp. 1, 13-14). The theoretical basis for case studies comes originally from a qualitative rather than from a quantitative research paradigm. A case study is a bounded system of a specific phenomenon, e.g., a program, an event, a person, a process

an institution or a social group and has been selected because it is important and interesting to examine it in order to obtain a closer knowledge and better understanding generally of the phenomenon (Merriam, 1994). A hallmark of case studies is the intensive focus on a phenomenon within the real context (Yin, 1999).

A qualitative single case design was chosen for the intervention study presented in Papers II and III. A case study design enabled the author to follow the process during a limited period in order to gain a comprehensive understanding of how the participants' experienced the use of ICT for communicating with each other. The case was strategically selected and consisted of two people with serious chronic illness living at home and their DNs, who had the chance to use ICT for communicating with each other in everyday life.

Inspired by Yin (2003, pp. 39-46), a single case design with embedded units of analysis has been used (II, III), including two units for analysis. One unit comprised two people living at home with serious chronic illness, and the other of their DNs. This choice was made in order to be able to describe separately the ill people's and the DNs' experiences of using the ICT application.

The intervention (II, III)
A computer program called Rexnet® was selected for use during the intervention, to enable communication between people with serious chronic illness at home and their DNs. Rexnet® is an intranet program that is used by schools in some Swedish municipalities, e.g., Uppsala and Stockholm. The program consists of different virtual rooms with the possibility for people to communicate through text messages, using any computer with an Internet connection. The program is reputed to be user-friendly in the context of this intervention study (II, III) because text messages were considered a more

suitable form of communicating as the people with serious chronic illness had difficulties in talking because of their illness. The program was also secure against violation.

The intervention (II, III) took place from the beginning of November 2003 to the end of February 2004 (Figure 1). Before the start the participants received information about how to use the ICT application, and during the intervention they had access to user support. Traditional home visits by the DNs were also carried out during the intervention. The DNs also used mobile phones with an Internet connection which made it possible for them to receive and reply to messages via Rexnet® wherever they were. The people with serious chronic illness living at home used the ICT application both day and night, but the DNs used the ICT only during their daytime working hours.

Before the intervention	During the intervention				After the intervention
* * * *			* *		* *
P1 P2, P1 P2			P1 P2		P1 P2
* *			* *		* *
D1 D2			D1 D2		D1 D2

Oct	Nov	Dec	Jan	Feb	Mar
2003			2004		

Figure 1 A schematic overview of the intervention study

* Semi-structured interviews with the participants (P and D) before, during and after the intervention.

P = people with serious chronic illness living at home
D = district nurses

Settings

This licentiate thesis was conducted within primary healthcare in the county of Norrbotten in northern Sweden. There were 33 primary healthcare centres in Norrbotten when the study was performed. The setting in the interview study (I) included five primary health care centres from two municipalities. The intervention study (II, III) included two primary healthcare centres from two municipalities.

Participants and procedure

District nurses (I)

In the study presented in Paper I, I phoned the heads of each healthcare centre which participated, and provided information about the study. All gave their permission for the study to be carried out. The heads provided information and distributed information letters with a reply form affirming the participants' informed consent to participating in the intervention. Oral information about the study was given to some of the DNs by me at a planning meeting for the study. After receiving their permission I contacted them and proposed a time and place for the focus group discussions.

A purposive sample (Morse, 1991) of 19 female DNs participated in the study presented in Paper I. The criteria for participation were to be a registered nurse with a DN graduation diploma and working as a DN. The age of the participants ranged from 30 to 64 years (md= 47). They 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 daytime and eight worked in evenings and at night.

District nurses (III)

In the study presented in Paper III the heads of two primary healthcare centres in northern Sweden were contacted and gave their permission for the DNs to

participate in the study. Both oral and written information about the study was provided. I informed and distributed information letters with a reply form affirming their informed consent to participate. After receiving their permission I contacted them before, during and after the intervention to agree a time and place for the interviews.

A purposive sample of two DNs participated. Criteria for participation were being a registered nurse with a DN graduation diploma, possessing an established contact with the person with a serious chronic illness, and being responsible for the nursing care. Both DNs who participated had long work experience and had worked as registered nurses for between 23 and 39 years and as DNs for between 13 and 16 years. Both had experience of using computers in their work because the case record system was computerised.

People living with serious chronic illness (II)
The same heads as in the study presented in Paper III gave their permission for participation in the intervention study. Information about the study was given, and informed consent to participation was affirmed simultaneously with the information reported in Paper III. The DNs from the two primary healthcare centres who participated in the study in Paper III each selected one person with a serious chronic illness living at home who fulfilled the criteria for participation. After receiving permission from the people with serious chronic illness I agreed a time and place for the interviews before, during and after the intervention.

Two middle-aged people with serious chronic illness living at home participated in the study presented in Paper II. Both participants had difficulties in talking, related to their illness. Criteria for participation were living at home, needing extensive nursing care, and having an established contact with the DN who was responsible for their care. Both participants needed extensive help with all their

basic needs in everyday life, such as eating and personal care. One of the participants was interested in using a computer and the Internet and had used a computer at home activated by their own voice before the study started. This participant lived in a flat with a close relative who helped them a lot with everyday life. The participant also had help and support from a personal assistant both during the day and at night. The other participant had little experience of using computers and needed help from personal assistants to write messages using ICT, also owing to the illness. This participant lived in a private house with round-the-clock help and support from a personal assistant, and a great deal of help from a close relative.

Data collection methods

Focus group discussions (I)

Paper I presents focus group discussions with five groups with four participants in each group, with the exception of one group which had three participants. The focus group discussions were carried out during May 2005 and March 2006, describing the DNs' points of view about using ICT in nursing care at home. I was the moderator in the focus groups and my supervisor attended the groups in order to provide summaries to conclude the discussions. The intention of the moderator was to generate discussion, ask questions, and encourage everyone in the group to participate in the discussion (cf. Kitzinger, 1995; Kitzinger & Barbour, 1999, p. 4). Kitzinger (1995) emphasised that focus groups are appropriate for the study of attitudes, experiences and ideas. According to Morgan (1997) data from focus group discussions are produced through group interaction, and the topic discussed is decided in advance by the researcher.

Before each focus group discussion I introduced the topic to be discussed. Two examples of using ICT were presented. The first example was a field case including different ICT equipments. Pictures of the field case's content were

shown to the participants in each focus group, in order to stimulate the discussion (cf. Kitzinger & Barbour, 1999, pp. 11-12). The second example was the use of an ICT application for communicating between people with serious chronic illness living at home and their DNs (II, III) when they needed to do so.

Each focus group discussion took place in a quiet, comfortable room free from interruption, either in the participants' primary healthcare centre (n=2) or in the university department (n=3). Each focus group started with the request that each participant introduce themselves. An interview guide was used with various questions concerning views about using ICT in their work as DNs, how its use could influence nursing care at home, expectations, possibilities and risks involved in using ICT in their work. The topic was also discussed from an ethical perspective. Clarifying questions were asked e.g., 'Please, give an example' 'What do you think?' The focus group discussions lasted for about 90 minutes, were tape recorded and later transcribed verbatim.

Interviews with people with serious chronic illness and district nurses (II, III)
The intervention study presented in Papers II and III used qualitative semi-structured interviews in order to describe the experiences of people living with serious chronic illness and their DNs of using ICT for communicating with each other. Requiring a specific set of topics to be covered led to the choice of semi-structured interviews for data collection in this intervention study (cf. Kvale, 1997, p. 32; Polit & Beck, 2004, p. 341). Semi-structured interviews were performed before, during and after the intervention between October 2003 and March 2004.

I started the interviews before the intervention according to Kvale (1997, pp. 32, 124), with an opening question, which for the people living with a serious chronic illness was 'Tell me about your experiences of living with your illness

in everyday life' and for the DNs was 'Tell me about your experiences of caring people with serious chronic illness at home'. The opening questions were followed with various questions that narrowed the topic, with the support of an interview guide consisting of themes with questions about; treatment, accessibility, continuity, safety/security, trust, loneliness and communication. Follow-up questions such as 'What happened then?' 'How did you feel then? were asked. These interviews lasted for 40-60 minutes.

Before the intervention DNs were interviewed once, whereas the two ill people were interviewed twice because they had difficulties talking owing to their illness. The second interview with the ill people gave them a chance to make clear their experiences. In addition, follow-up interviews were performed during and after the intervention which lasted about 30 minutes. For these interviews an interview guide was used, based on the answers in the interviews before the intervention. I encouraged the participants to talk freely and allowed them to use their own words. The questions were so formulated as to give the participants the opportunity to provide rich and detailed information about the phenomenon under study (cf. Polit & Beck, 2004, pp. 341-342). The people with serious chronic illness were interviewed in their homes and the DNs in their place of work according to their own wish. The interviews were tape-recorded and transcribed verbatim.

Data analysis
Thematic content analysis (I-III)
A thematic content analysis was performed based on Baxter (1991) of the focus group discussions (I) and the interviews (II, III) in order to describe both the manifest and latent content (cf. Catanzaro, 1988). The manifest content describes the visible and obvious parts of what the text says, and the latent content is an interpretation of the underlying meaning of the text. The intention

with content analysis is to describe the phenomenon according to a specific aim that generates knowledge and an increased understanding of the phenomenon studied. The method implies analysis in several steps, resulting in categories that are reduced with each step (Downe-Wamboldt, 1992).

The analysis for each study (I-III) started with reading the interview texts several times bearing in mind the aim of the study, in order to achieve a sense of the content (cf. Sandelowski, 1995). The interviews in Papers II and III, before the intervention started, were analysed separately. In the study presented in Paper II the interviews during and after the intervention were analysed separately. However, during the analysis we discovered that the content was rather similar, therefore the results during and after are presented together as 'post-intervention'. In Paper III the interviews during and after the intervention were analysed together.

The interview texts were divided to textual units, guided by the aim of the study, and condensed while preserving the core of the textual unit. We began to sort the textual units into groups according to the answer to the questions: 'What is this?', 'What does this stand for?' (cf. Polit & Beck (2004, p. 574). Each group was labelled with a code. The contents in each group were sorted into categories. The categories were brought together in several steps to form broader categories. The final categories were compared with each other and themes were formulated to find an underlying meaning. Themes emerged from the previously identified categories, which Baxter (1991) has described as threads of meaning that appear in category after category. Throughout the whole process we occasionally returned and compared the categories with those in the previous steps of the analysis, textual units and the original interview texts to ensure the credibility of the analysis. The authors also discussed the analysis process with other colleagues to confirm the results.

Ethics

In the studies on which this licentiate thesis is based (I-III), all participants received both oral and written information about the study aims, procedure and methods for data collections, and were informed that participation was voluntary and that they could withdraw at any time without any detrimental effect on their care or working situation. Informed consent was obtained and confidentiality was guaranteed concerning all data, and also an anonymous presentation of the results. The participants in the focus groups agreed not to talk to anyone outside the group about the content of the discussions. The study in Paper I has been approved by the Regional Ethical Review Board in Umeå, Sweden, and the studies in Papers II and III by the Ethical Committee at the University.

The interviews could be strenuous for the people with serious chronic illness because their difficulties in talking. Therefore, I gave them time to express their experiences without interrupting them. During the interviews I was aware of the importance to show respect, interest and attention (cf. Holloway & Wheeler, 2002, pp. 87-88) and I also tried to be clear, kind, sensitive and open for what they told (cf. Kvale, 1997, p. 138).

In the research testing of technical equipment with people, where the equipment will not be used after the test, there is a risk that the users might feel that they have lost something that might have functioned well. Therefore, follow-up meetings with interviews were performed with the participants (II, III) about eight months after the intervention had finished in order to give the participants the chance to express how they felt when the ICT equipment was removed. In our studies (II, III) both the people with serious chronic illness and the DNs said that they missed the ICT application. However, the research process can give positive experiences for the participant as they realize that they are in focus, and the researcher is interested in their opinions. It can also clarify their own ideas

about an issue (Oliver, 2003, pp. 35, 148). Introducing the use of ICT into people's own homes can risk encroaching on their integrity, and other family members can also be involved. In our study we were aware of this aspect and took it into consideration during the intervention study.

FINDINGS

The findings in each paper are presented separately. Themes and categories in Papers I-III are presented in Table 1.

Table 1 Overview of themes and categories from the studies presented in Papers I-III

Paper	Theme	Category
I	*Focus group discussions with DNs:*	
	Being a part of the introduction of ICT	Possibilities to influence the design The importance of participation in the introduction
	Being aware of possibilities and threats in the use of ICT	Seeing both improvements and risks People cannot be replaced
II	*Interviews with people living with serious chronic illness:*	
	Pre-intervention Struggling to achieve a functioning everyday life	Feeling well Feeling secure and being shown respect Expectations of improved accessibility
	Post-intervention Everyday life has improved	Belief and trust in the ICT Being less limited Fulfilled expectations
III	*Interviews with DNs:*	
	Pre-intervention Striving for a trusting relationship	Mediating security through interaction Feeling insufficient Working for accessibility
	Post-intervention Reaching a more trusting relationship	A complement to the performance of nursing care Feeling uncertainty Increased accessibility

Paper I

DNs' points of view on the use of information and communication technology in nursing care at home

This study describes DNs' points of view about the use of ICT in nursing care at home. DNs emphasised the importance of being able to influence the design of the ICT application that was to be used. They stressed that the ICT must be simple and easy to use and adapted to their work, and that clear routines must be decided on before the start. DNs described the importance of participation in the introduction of ICT applications in their work. They discussed experiences from the introduction of computerised case records in their work, and said that in the beginning the new system took more time but nowadays they agreed that computerised case records were indispensable. The chance to influence the design of the ICT and to participate when the ICT application is introduced could be seen as being a part of the introduction of the ICT.

DNs believed the use of ICT in nursing care could facilitate and improve nursing care at home, and also increase the security for the ill person at home. Using mobile, computerised case records DNs said could enable them to access information and check what had previously happened to the ill person more quickly. One improvement with using ICT they saw was that it could save time and therefore give them more time to support other ill people at home. They discussed the possibility of increasing security for ill people at home by being more accessible through using ICT. One risk with using ICT in nursing care, as the DNs described, was that connecting the equipment at home could take time. DNs thought there was a risk that older ill people at home could experience ICT as frightening and strange. DNs also thought that ill people at home could feel improved security with the use of ICT. Some DNs discussed the risk that DNs

may not be needed in the future as a lot of information would be available on the Internet.

DNs discussed the proposition that a person 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 discussed how the equipment might be regarded as an encroachment at home or a threat to autonomy. DNs agreed that the use of ICT could not be avoided in the future, but their work routines needed to be changed.

Paper II
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 illness living at home experienced the use of ICT in communicating with their DNs. The result is presented in two parts; pre-intervention and post-intervention.

Pre-intervention the results showed that the participants seemed to struggle to achieve a functioning everyday life. One participant described that feeling well meant being able to manage to do what you wanted to do. The other felt well when working at the computer because it was his/her interest. Being able to live at home with efficient personal assistants to help with everyday life implied security. They described the importance of being respected and treated as a human being. Participants described what a properly functioning DN caring for them meant - a DN who was a good listener, which entailed a good relationship. Due to their difficulties in speaking the participants described the frustration

they felt when people in their surroundings did not understand what they said, but gave the impression of understanding. Both participants stated that the DN was difficult to reach. One limitation in their daily life was the long wait for answers from the DN once they had contacted her. It was also difficult to remember everything they wanted to say when the DN finally contacted them. Both described difficulties in being able to do something spontaneously, which demanded a great deal of planning. Participants expected improved and easier accessibility with the use of ICT.

Post-intervention the participants seemed to feel that using ICT had improved their everyday life, and its use for communication with the DN made them feel safe and secure. They felt uncertain about whether their messages reached the DN, and whether there was anybody at all was at the other end. There was no indicator to show that a message had arrived and that the receiver had read it. However, the use of the ICT application reduced the participants' feelings of limitation. They were able to avoid the long waits by using ICT to correspond with their DN. Another advantage was the possibility of writing a message at any time so they did not have to remember everything they wanted when the DN contacted them. These advantages improved accessibility. To write directly to the DN gave them 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 reaching the DN by using ICT worked well.

Paper III

DNs' experiences on the use of information and communication technology for supporting people with serious chronic illness and living at home - an intervention study

This study describes how DNs experienced the use of ICT for communicating with people with serious chronic illness living at home. The result is presented in two parts; pre-intervention and post-intervention.

Pre-intervention the DNs seemed to strive to achieve a trusting relationship with the ill person living at home. One of their main intentions was to mediate security and safety for the ill person, which they tried to do by making extra phone calls and home visits. Knowing the ill person gave the DNs a feeling of security and increased their possibility of knowing what could happen. Sometime the DNs felt limited and therefore cooperation with other colleagues was considered necessary to make the ill person feel secure. The DNs also expressed that on some occasions they felt insufficient and dissatisfied with the nursing care they provided. They described a lack of continuous communication with some ill people at home and not always being accessible enough to the ill person at home. Neither DNs had direct telephone contact with the ill person, but were instead in contact with their close relatives and personal assistants. Both participants saw the possibilities of being more accessible by using the ICT applications.

Post-intervention the DNs seemed to feel that the use of ICT had created a more trusting relationship, and their expectations had been met. The use of ICT was seen as a complement to nursing care and as facilitating their work. However, they stated that traditional home visits could not be replaced. Routines had been designed for using the technology, which they thought meant they organised

their work better. Reading the messages regularly led to increased awareness of the ill person's needs.

Uncertainty about the use of the ICT application was described, especially at the beginning because the DNs felt they were inexperienced and also because of some technical problems with the mobile phones. Both were dissatisfied with the instructions and support in connection with the mobile phones, but pleased with the information and support concerning the messaging program. One DN said there was a risk of missing something important without physical visits and claimed that in nursing care much is revealed by the expression in the ill person's eyes, their breathing or skin colour.

The DNs described increased accessibility, reduced stress, and a more secure working situation as a result of using ICT. They also thought that the use of ICT provided more direct communication with the ill people, and second-hand information was avoided. The chance to write messages regardless of where they were, saved them time and enabled them to give help to other ill people.

DISCUSSION

The aim of this licentiate thesis was to describe the experiences of people with serious chronic illness and the points of view and experiences of DNs concerning the use of ICT in nursing care at home. The study indicates that ICT offers the possibility of improving nursing care at home and daily life for people with serious chronic illness through using it to communicate with their DN (I-III). The findings show that it is important for DNs to have the opportunity to influence the design and participate in the introduction of ICT (I). There are indications that using ICT entails increased accessibility, security and safety in nursing care at home, and that people with serious chronic illness who used it

felt fewer limitations in their everyday life. The findings also reveal that a feeling of uncertainty was salient in the use of ICT for the participants (II, III).

DNs emphasised the importance of influencing the design and taking part in the introduction of ICT in nursing care at home (I). Campbell, Fowles and Weber (2004) showed that when nurses had the opportunity to participate in the decision making this led to encouragement, which had a positive impact on job satisfaction. Starren et al. (2005) demonstrated that for optimal installation of telehealth technology at home combined technical and clinical knowledge is needed including knowledge of patient care. Giving a careful presentation helps to design well suited ICT applications adapted to the user's need and eliminates any possible fear on the part of the user (Andersson, Hanson & Magnusson, 2002). This means that close co-operation between the users and the team who install the ICT application is needed in order to create an ICT that can be acceptable and of benefit to the users. The DNs were dissatisfied with the information and support they had received concerning the mobile phones (III). The ICT application must be simple and easy to use and there must be time for training (I). Wakefield, Holman, Ray, Morse and Kienzle (2004) also stated that the equipment must be easy to use, and clinically appropriate, and the possibility for training and support must exist. This can contribute more willing acceptance of the use of ICT. Demiris et al. (2005) have emphasised that installing ICT applications in patients' home requires patients and caregivers to accept its use and that their understanding of the system influences how the extent of its use. Accepting the use of the application in home healthcare means that technical support has to be available and useful for the user (Roback & Herzog, 2003). According to the DNs, it was important that the ICT application was adapted to their work, and that clear instructions for using the technology exist (I). Whitten and Adams (2003) described the importance of examining the organization carefully before the introduction of telemedicine. Many factors in an

organization, such as fiscal, geographical and personal factors, will affect the introduction of telemedicine.

The findings of the focus group discussions show that DNs believed that ICT could facilitate and improve nursing care and increase the accessibility and security for ill people living at home. One improvement they discussed was that communicating through ICT could save time and consequently free up time for other patients (I, III). Some DNs also saw a risk that ICT could take more time because they thought it could take more time to connect the equipment in the ill person's home (I). According to Demiris et al. (2001) the use of telehomecare may enable timesaving both for the ill person and the nurse. Other studies have described a saving of time by using ICT in healthcare (Arneaert & Delesie, 2001; Demiris et al. 2000; Hjelm, 2005). Arnaert and Delesie (2001) have described time saving for nurses in home care through using ICT in the form of saved travel times, which instead could be used to increase the frequency of patient interventions in order to strengthen patients' self-care.

DNs described how using the ICT application in their communication with the ill people at home had contributed to improving their work situation by giving them the possibility to read the messages regularly. This had led to more knowledge and information about the ill persons living at home (III). Berterö (2002) stated that for DNs control and information are necessary for them to be able to support the ill person in an effective way. Hallström and Elander (2001) have found that a quality factor in nursing care was the possibility for nurses and patients to communicate. According to Dimmick, Mustaleski, Burgiss and Welch (2000), by using an ICT application nurses in homecare could give an immediate assessment when the patient called them. This shows that ICT could be useful for DNs in their work with an improved communication and accessibility for the ill person.

Before using the ICT application people with serious chronic illness described difficulties in reaching their DN. The waiting for a response from the DN was bothersome, impacted negatively on their everyday life and could be seen as an expression of being dependent on care (II). Being dependent on care implies losing much of one's freedom of choice in daily life and could be seen as a 'limit situation' (Strandberg, Norberg & Jansson, 2003). According to Edlund (2002) the limitation the ill person experiences because of reduced freedom of movement and the long waiting for help can be experienced by them as an insult to their own dignity. After the use of ICT they expressed an increased accessibility as it was easier to get in contact with their DN and they felt less limited in their everyday life. They were not governed by time, instead they could send messages to their DN based on their own needs (II). This means that in this study ICT supported a less restricted daily life for the participants. According to Öhman et al. (2003) people with serious chronic illness who could make their own decision and had control over their everyday life had a feeling of being independent and free which gave them feelings of satisfaction and self-esteem. According to Törnkvist, Gardulf and Strender (2000) patients' satisfaction with the nursing care given by DNs at home was largely related to the perceived accessibility of the nursing care. By using ICT in this study the quality of everyday life could be improved for the people with serious chronic illness living at home.

The people with serious chronic illness also felt that using ICT saved time as they did not need to wait for the DN, which allowed them to do other things during this time (II). Dimmick et al. (2000) showed that saving time for the ill person at home by using telemedicine made things easier for them because there were fewer journeys to the healthcare service, saving the ill person some suffering. A review (Mair & Whitten, 2000) showed that patients were satisfied with ICT which they thought gave them improved accessibility to healthcare

providers with fewer journeys and reduced waiting times. Clemensen, Larsen and Ejskjaer (2005) described how nurses who used telemedicine in their home visits for patients with leg ulcers to coordinate the treatment with experts at hospital, which saved hospital visits for the ill person.

The people with serious chronic illness and their DNs said that using ICT meant there was a more direct communication between them (II, III). Communication in nursing care is essential for developing a relationship (Fosbinder, 1994). By achieving a more direct communication the participants in this study experienced an improvement in security and safety (II, III). It is important for people living with serious chronic illness living at home to have people in their immediate surroundings to help and support them which may give them a feeling of security (Öhman et al. 2003).

In this study the participants expressed a feeling of uncertainty about using ICT in their communication between each other (II, III). DNs felt uncertain because of their inexperience in the use of the ICT application especially in the beginning and because of technical problems in the beginning of the use (III). According to Whitten et al. (1998) people who use ICT can feel uncertain in the beginning but this disappears after using it for a while. An anxiety the DNs expressed was that using ICT might make them redundant in the future (I). Sävenstedt et al. (2006) reported that DNs were afraid they would lose their work if the use of ICT proved to reduce healthcare costs. Magnusson and Hanson (2003) have reported that staff in a care setting feared that ICT would replace them and act as an alternative to traditional homecare services. Feelings of uncertainty and anxiety can be an obstacle to the use of ICT applications in home nursing care. It is, therefore, seen as important to reflect on how the use of ICT affects nursing care (cf. Sävenstedt, 2006).

The findings in this study revealed that the people with serious chronic illness living at home felt uncertain when using ICT in their communication with their DN. They expressed doubt that their messages reached the DNs and that there was anyone at the other end (II). Feelings of uncertainty are a burden which can challenge one's self-esteem (Ellefsen, 2002). Løgstrup (1992, p. 41) believed that in normal cases people meet each other with a natural trust, but special circumstances can disturb this trust and lead to feelings of mistrust. Therefore, it is important in the future use of ICT applications to develop methods which can confirm that the messages have reached the receiver thus reducing the feeling of insecurity. The challenge is to retain a human of quality in the use of ICT in this rapidly advancing development (Hughes, 2001).

Achieving a trusting relationship seemed to be important to the DNs and the use of ICT seemed to improve the trusting relationship with the ill person at home (III). Trust can be seen as a quality factor for people living with a chronic illness in their home (Thorsteinsson, 2002) and an important factor of the nurse-patient relationship (Johns, 1996). Factors important for a trusting relationship are affected by the use of ICT for communicating. A trusting relationship is fundamental in the use of ICT in the interaction between the patient and the healthcare provider, and therefore, personal trust seems to be a necessary factor when patients communicate with healthcare providers using ICT (Andreassen, Trondsen, Kummervold, Gammon & Hjortdahl, 2006).

DNs said that physical presence (I) and physical visits (III) cannot be replaced, but believed that the use of ICT in nursing care at home could be seen as a complement to traditional care (I, III). It is important to take in consideration the significance of human touch in the use of ICT application in care at home and for that reason its use in healthcare will be seen as a supplement rather than a replacement for traditional healthcare (Demiris, Parker Oliver & Courtney,

2006). Interpersonal dynamics in the ICT mediated encounters are important and require the learning of new skills (Torppa, Timonen, Keinänen-Kiukaanniemi, Larivaara & Leiman, 2006). The use of ICT in nursing care is not a professional speciality but could be seen as a way of offering a new care model to facilitate and complement traditional nursing care (Arneart & Delesie, 2001).

DNs discussed ethical issues which might affect nursing care if ICT is used, for example that the equipment could be regarded as an encroachment at home or a threat to the autonomy of ill people and their families, and that the ICT is not suitable for use with everybody (I). Magnusson and Hanson (2003) have reported that people and their families who used ICT applications at home were worried about privacy, but after an initial period most of the families became accustomed to using the technology and the feeling of worry wore off and instead they enjoyed using it. Further, Magnusson and Hanson also pointed out that it is important to consider the location of the equipment in the home, so as not to threaten people's privacy. According to Sävenstedt et al. (2006) a sense of ethical responsibility can be one reason for the resistance to the use of ICT applications, and therefore, ethical reasoning about such use is important.

METHODOLOGICAL CONSIDERATIONS

A description of pre-understanding is a part of the trustworthiness and credibility in qualitative studies. I have a long experience of working as a clinical DN, and have met several people with serious chronic illness in their homes. This can be seen as an advantage but might also be a risk because my pre-understanding as a DN could lead to that I belief that I knew what the participants were going to say in the interviews and therefore failed to question what appeared to be self-evident for me. The co-authors are experienced as professional registered nurses and nursing researchers in this area. During the

research process I remained aware of my pre-understanding, and that my role in the study (I-III) was as a researcher and not a DN.

The participants in this study (I-III) were selected through a purposive sample. According to Morse (1991) a purposive sample is one of participants appropriately selected to provide the information and knowledge that is needed. The samples were selected according to predetermined criteria which ensured that the participants had knowledge of the topic under study.

The intervention study (II, III) was a case study, which provides the possibility of studying a few people and following the process. Case studies provide rich data and can be a basis for subsequent studies (Polit & Beck, 2004, p. 259). The qualitative case study is an intensive and holistic description and analysis of a phenomenon focusing on process, understanding and interpretation (Merriam, 1994).

The ICT application presented in the intervention study (II, III) has not, as far as we know, been used between people with serious chronic illness living at home and their DNs, there could therefore be a risk that too many people were involved which could render it difficult to follow the course of the participants' experiences. On the other hand the accomplish ment of the study might be hindered if somebody withdraws because there are so few participants. However, in the intervention study (II, III) none of the participants withdrew from the study. The intention in the intervention study (II, III) was to follow the course and observe precisely the participants' experiences of using the ICT application. According to Polit and Beck (2004, p. 259) case study is an appropriate design for exploring phenomena have not previously been studied rigorously.

I was close to the participants and their setting, following them during the course of the intervention (II, III). I performed several interviews which led to a number of meetings. I also had contact with them during the intervention, regarding some technical problems with the ICT application. This familiar relationship can be seen as a weakness as bias may occur (cf. Polit & Beck, 2004, p. 259). The qualitative approach has been charged with being subjective because it implies a close personal contact with the participants and the setting that is being studied (cf. Patton, 2002). However, the strength of qualitative case studies and for qualitative research overall is that the researcher is close to the participants and the context under study. The participants in the intervention study (II, III) were positive and waiting to participate, which may also have influenced the findings, making them more positive that they would have been with participants who were somewhat hesitant about participating. However, it is difficult to collect relevant data if the participants are not interested in participating.

In this licentiate thesis knowledge is derived from focus group discussions (I) and interviews (II, III). Interviews alone have been used in the intervention study (II-III), which may be seen as a weakness of single method of data collection in a study with case study design. One possibility would have been to use other complementary methods of data collection. However, using interviews was found to be the most appropriate method because the intention was to acquire knowledge of the participants' experiences of using the ICT application. Despite that the people with serious chronic illness had difficult in talking, the interviews worked well. Consideration was taken to allow that the interviews took the time that was needed. Both strengths and weaknesses occur when using focus groups for data collection (I). One weakness might be that the moderator will influence the group's interaction. However, there is no hard evidence that the moderator's impact on the data is greater than in observation studies or

studies with individual interviews (Morgan, 1997, p. 14). We avoided steering the group and allowed the participants in each focus group to discuss as freely as possible. An interview guide was used to retain the focus on the topic and to assure that predetermined themes were discussed.

Qualitative studies have been criticised for their lack of generalizability. Lincoln and Guba (1985), however, have reported that results in one context can be transferred to similar situations and the knowledge acquired in one context can be appropriated in another. In this study the intention was not to reach any generalizability which is also not a goal in qualitative studies. Instead the intention was to obtain a rich and dense description from which to reach a deeper understanding of the use of ICT in nursing care at home. Qualitative studies are context bounded and the researcher is close to the participants under study. According to Lincoln and Guba (1985) knowledge in qualitative research is constructed by both the researcher and the participants under study. Therefore, the researcher must be sensitive to the context and immerse themselves in the setting or situation to achieve this goal (Holloway & Wheeler, 2002, pp. 10-11).

A weakness in this study could be that I have not returned to the participants and discussed the findings, in other words using member check. Member check demands a lot of time from both participants and researchers. There may also be some problems with the use of member check as the researcher's and participant's view may differ, that the close relationship with the researcher may prevent the participant from being critical, and perceptions may change over time (Holloway & Wheeler, 2002). Sandelowski (1993) considers member check problematic and complicated because of the different backgrounds that researchers and participants may have.

The analysis and findings were discussed with other researchers and colleagues to confirm the trustworthiness of the study. Sandelowski (1998) pointed out that an 'outsider ' expert is a resource who contributes by asking important questions of the data and leading the researcher to look at the data in new ways, or suggest new frameworks to be drawn from the interpretation and representation of the data. The procedure is described as carefully and accurately as possible to achieve credibility for the study (cf. Lincoln & Guba, 1985), and all interviews were tape-recorded (cf. Morse (1991, p. 217) which increases their dependability.

CONCLUDING REMARKS

This licentiate thesis indicates that ICT offers DNs a possibility to support people with serious chronic illness living at home. The trial use of ICT was very important for the people with serious chronic illness, but also for the DNs in this study. The use of ICT led to improved accessibility, security and safety in the ill person's daily life, and an increased security for the DN in her/his work. The experiences, views and ideas of people with serious chronic illness and their DNs are essential sources to be tapped in developing and attaining the satisfactory introduction of ICT applications in nursing care at home adapted to their needs. This study indicates that the use of ICT provided a more direct communication between the ill person and their DN. The use of ICT applications by people with serious chronic illness living at home can lead to an increased freedom due to a reduction in the limitations in their daily life.

The DNs in the intervention study (III) were near the ill person living at home and followed the process when the ICT application was tested, as apposed to the DNs who discussed their points of view with each other about the use of ICT in nursing care at home (I). Both perspectives are important to take in

consideration for implementing well suited ICT applications in nursing care at home.

The ill people and their DNs had the possibility to communicate with each other by ICT when the need arose, and the DNs could contact the ill person regardless of where they were. No similar studies have been found in the literature describing specific experiences of DNs and people living with serious chronic illness living at home of using ICT in communicating with each other. Many previous studies have focused either on the technology or in medical aspect. Several studies have described benefits with using ICT solutions in health care, and therefore it could be seen as a need of more research that could either reduce or eliminate feasible drawbacks (Hjelm, 2005). Therefore, several studies with the focus on using ICT in nursing care need to be performed in order to develop suitable ICT applications.

The use of ICT can be seen as a complement to improve DNs' work, providing increased security and accessibility and mediating a more trusting relationship with the ill person at home, thus improving the quality of nursing care at home. But the use of ICT in nursing care cannot replace a physical presence and home visits. This shows the urgency of achieving a balance between traditional nursing care and the use of ICT in nursing care at home.

SUMMARY IN SWEDISH - svensk sammanfattning

Att använda informations- och kommunikationsteknologi som stöd till personer med svår kronisk sjukdom som bor hemma

Under senare år har vården på sjukhus förändrats och minskat, vilket har medfört att personer lämnar sjukhuset tidigare. Dessa förändringar har ökat behovet av omvårdnad i hemmet och har påverkat distriktssköterskans arbete som lett till att en stor och viktig del av arbetet innefattas av att ge stöd till personer med svår kronisk sjukdom så att de kan bo kvar hemma trots sin sjukdom. En viktig förutsättning för att göra det möjligt är att personerna med svår kronisk sjukdom känner stöd och trygghet från vårdpersonalen. Därför är det en utmaning för distriktssköterskan att finna nya metoder för att kunna ge stöd och hjälp till personer med svår kronisk sjukdom som bor hemma. En lösning kan vara att använda information och kommunikationsteknologi (IKT) i kommunikationen mellan personer med svår kronisk sjukdom som bor hemma och deras distriktssköterska.

Det övergripande syftet med denna licentiatavhandling var att beskriva upplevelser som personer med svår kronisk sjukdom har av att använda informations- och kommunikationsteknologi (IKT) och att beskriva distriktssköterskors inställningar och upplevelser av att använda IKT inom omvårdnaden i hemmet. I denna licentiat avhandling ingår tre delstudier med följande syften:

Delstudie I	Att beskriva distriktssköterskors inställningar angående användningen av IKT i omvårdnad i hemmet.
Delstudie II	Att beskriva upplevelser hos personer med svår kronisk sjukdom som använder IKT för att kommunicera med sin distriktssköterska.
Delstudie III	Att beskriva distriktssköterskors upplevelser av att använda IKT för att kommunicera med svårt kroniskt sjuka människor som bor hemma.

I delstudie I användes fokusgrupp diskussioner som datainsamlings metod. Sammanlagt 19 distriktssköterskor deltog indelade i fem grupper med fyra deltagare i fyra grupper och tre deltagare i en grupp. Deltagarna diskuterade inställningar till att använda IKT i omvårdnadsarbetet i hemmet. En intervjuguide användes med olika frågeområden. Fokusgrupp diskussionerna spelades in på band och skrevs ut ordagrant. Texterna analyserades med en kvalitativ tematisk innehållsanalys.

Delstudie II och III är en interventionsstudie med en kvalitativ fallstudie design. Två medelålders personer med svår kronisk sjukdom deltog (II) samt deras respektive distriktssköterska (III). En IKT tillämpning användes där personerna med svår kronisk sjukdom och deras omvårdnadsansvariga distriktssköterska kunde kommunicera med varandra när behov uppstod. Båda personerna med svår kronisk sjukdom bodde i eget boende och hade en etablerad kontakt med sin omvårdnadsansvariga distriktssköterska. De hade ett stort behov av omvårdnad som innefattade hjälp med så gott som allt i det dagliga livet dygnet runt. Båda hade talsvårigheter på grund av sin sjukdom. Den ena personen var ensamboende och hade personlig assistent dygnet runt, samt en anhörig som var till stor hjälp. Denna person hade lite datorvana sedan tidigare och behövde hjälp av personlig assistent med att skriva meddelanden genom IKT

tillämpningen på grund av sin sjukdom. Den andra personen bodde tillsammans med en närstående och hade personlig assistent både dag och natt. Den närstående var en stor hjälp i det dagliga livet. Denna person var mycket intresserad av datorer och hade en röststyrd dator i hemmet som användes kontinuerligt av personen.

Den teknik som användes under interventionen var ett program som heter Rexnet® som ansågs vara ett säkert och användarvänligt program i detta sammanhang. Programmet möjliggjorde att kommunicera genom textmeddelanden som ansågs lämpligt på grund av att de personer med svår kronisk sjukdom som deltog hade talsvårigheter. Den utrustning som behövdes för att använda programmet var en persondator med Internetuppkoppling. Programmet användes hela dygnet av personerna med svår kronisk sjukdom, till skillnad från distriktssköterskorna som använde programmet enbart under dagtid i sitt arbete. Även traditionella hembesök av distriktssköterskan utfördes under interventionen. Distriktssköterskorna hade även tillgång till mobiltelefoner med möjlighet till 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) för att kunna beskriva deras upplevelser av att använda IKT tillämpningen. Före interventionen intervjuades distriktssköterskorna en gång och personerna med svår kronisk sjukdom intervjuades två gånger. Anledningen till att de intervjuades två gånger var på grund av deras talsvårigheter. En intervjuguide innefattande olika teman med frågor användes som stöd i intervjuerna. Uppföljningsintervjuerna under och efter interventionen utfördes med stöd av en intervjuguide baserad på svaren

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från intervjuerna före interventionen. Alla intervjuer spelades in på band och skrevs ut ordagrant.

Texterna analyserades med en tematisk innehållsanalys. Intervjuerna före interventionen analyserades separat. De uppföljnings intervjuer som utfördes i delstudie II under och efter interventionen analyserades separat. Emellertid upptäcktes att resultaten under och efter interventionen (II) var relativt lika och därför så presenterades dessa resultat tillsammans som 'post-intervention'. Intervjuerna under och efter interventionen i delstudie III analyserades tillsammans.

Resultatet (I) visar vikten att få möjlighet att påverka och vara delaktig i utformningen och införandet av IKT tillämpningar som ska användas i omvårdnadsarbetet. Distriktssköterskorna såg en möjlighet att IKT i omvårdnaden 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 också att distriktssköterskorna 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 distriktssköterskor att användningen av IKT i omvårdnad i hemmet inte passar alla och att människor inte kan ersättas genom användningen av IKT.

Resultaten i interventionsstudien (II, III) indikerar att det var svårt att nå distriktssköterskan och att med användningen av IKT uppnåddes en förbättrad tillgänglighet. Användningen av IKT tillämpningen bidrog till en mer direkt kontakt mellan den sjuke och distriktssköterskan, vilket underlättade kommunikationen med distriktssköterskan och som ledde till en mindre

begränsning i det dagliga livet för personerna med svår kronisk sjukdom som bodde hemma.

Deltagarna 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.

Sammanfattningsvis indikerar resultaten i denna licentiat avhandling att användningen av IKT är en möjlighet att förbättra omvårdnaden i hemmet för personer med svår kronisk sjukdom genom en ökad tillgänglighet, säkerhet och trygghet. Personerna med svår kronisk sjukdom kände sig även mindre begränsade i sin vardag genom att använda IKT tillämpningen. Användningen av IKT verkade även främja en mer tillitsfull relation mellan distriktssköterskan och personen med svår kronisk sjukdom som bodde i sitt hem.

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Paper I

DISTRICT NURSES' POINTS OF VIEW ON THE USE OF INFORMATION AND

COMMUNICATION TECHNOLOGY IN NURSING CARE AT HOME

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ABSTRACT

Aim. The aim of the study was to describe DNs' points of view regarding the use of information and communication technology in nursing care at home.

Background. An important task for district nurses is to achieve an effective means of communication with ill people at home resulting to quality and positive relationships. The use of ICT has increased in the community and it can be useful in nursing care at home.

Design and methods. A qualitative approach has been used. Five focus group discussions were performed with district nurses from five primary health care centres. Data were analysed using thematic content analysis.

Results. District nurses viewed that ICT applications in nursing care at home must have an easy and user-friendly design. Participation in the design and introduction of the technology was seen as an important factor for ICT applications. Both improvements and risks were noted with the use of ICT and the importance of physical presence in nursing care at home was pointed out.

Conclusions and relevance to clinical practice. Some factors are especially important in the introduction of ICT in nursing care at home. Firstly, the use must be suited to the application . Secondly, the users must be able to influence design and introduction of the application. Being aware of improvements and risks in the use of ICT can prevent pitfalls in the design and introduction. These factors can be of value towards the introduction of ICT in nursing care at home and can prevent some problems that may arise later.

Keywords: district nurses, focus groups, information and communication technology, nursing, point of views, thematic content analysis

INTRODUCTION

The use of information and communication technology (ICT) has become more common in recent years, including in the health care area. Using ICT gives possibilities for people to communicate, gather information and interact with distance services faster, easier and without limitations of time and space (Campbell *et al.* 1999). According to the National Strategy for E-health (2006), ICT could enable caregivers and health care decision-makers to improve care for patients. Wright *et al.* (2001) stated that empirical evidence of the practice and nurses' perceptions of using ICT is severely limited. Nurses who had used telenursing considered that in some cases, ICT could be a complement to traditional nursing practice (Arnaert & Delesie 2001). According to a review study (Jaatinen *et al.* 2002), a lot of applications with teleconsulting are used between doctors in real time, and only very little application between the patient and the nurse. 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 (Barnard 1996, Barnard & Cushing 2001). Nurses are exposed to complex and sophisticated technologies such as heart-lung machines; also to simpler technologies as the thermometer (Sandelowski 2000).

District nurses (DNs) have the responsibility of supporting people with chronic illness living at home (Wright 2002, Öhman & Söderberg 2004). Working as a DN in Sweden includes caring for people of different ages, and a priority part of the work is to support seriously ill people and their relatives. DNs can be seen as key persons for nursing care in the homes like a near relation with the ill person and their close relatives (Öhman & Söderberg 2004). To create a close relationship in nursing care, communication and a mutual relationship is

essential (Fosbinder 1994, Attree 2001, Thorsteinsson 2002), and the DN's role is to develop a trusting relationship with the patient (Cody & Squire 1998).

Communication skills in nursing care could be inhibited by environmental social barriers, as well as structural or cultural aspects of health care (Chant *et al.* 2002). According to Häggman-Laittila and Åstedt-Kurki (1994) and McCabe (2004), an important factor is to use a patient-centered communication for achieving quality and a positive relationship in nursing care. To enable DNs to improve their support to people with chronic illness in their homes, suitable tools are needed, and methods and knowledge should be developed. The use of ICT can therefore be seen as one part in the DNs' work of supporting people with chronic illness and living at home. The aim of this study was to describe DNs' points of view regarding the use of ICT in nursing care at home.

METHOD

Design

A qualitative approach was used to get an increased understanding of DNs' points of view regarding the use of ICT in their work. Qualitative approaches provided insights from the perspective of the participants (Polit & Beck 2004). Data were collected through focus group discussions with DNs, and analysed using a thematic content analysis (Baxter 1991).

Participants and procedures

A purposive sample of 19 female DNs participated in the study. The inclusion criteria were as follows: (1) the participants were registered nurses with a DN graduation diploma, and (2) working as a DN. The participants' ages ranged from 30 to 64 years (with 47 as median), and their work experience as registered nurse ranged from 2 to 37 years (with 19 as median). The

DNs who participated in the study worked at five primary health care centres in two municipalities in northern Sweden and had worked as a DN between 1 and 23 years (with 5 as median). Eleven participants worked at day-time and eight participants, at evenings and night-time.

The participating DNs were selected with assistance from the heads of the five primary health care centres. The first author contacted them by phone and gave information about the study and asked if they could send an information letter to DNs working in the primary health care centres. The information letters with inquiry to participate were distributed personally to the heads who then informed and distributed the letters to the DNs. The aim of the study was presented in the letter and the DNs contacted the first author when they made the decision to participate in the study.

Data collection

Data were collected in May 2005 and March 2006 through focus group discussions. Focus group discussions were chosen to describe DNs points of view regarding the use of ICT for nursing care in the ill people's own home. According to Morgan (1997), focus group discussions data are collected through group interactions with a specific topic decided by the researcher. One feature with focus groups is the use of group interactions for generating data (Kitzinger 1995, Kitzinger & Barbour 1999). Five focus groups with four DNs and one group with three DNs were included in the study.

The moderator (the first author) introduced the aim of the study and the topic to be discussed. The third author provided summaries to conclude the discussions (cf. Morgan, 1997). Initially, the participants were requested to introduce themselves. The discussions started then with the

question, 'Tell me about your views on using different types of technology in your work as DN'. An interview guide was used including different topics, namely: (1) use of ICT in nursing care at home today and in the future; (2) the ICT influence on nursing care at home - expectations, hindrance, advantages and disadvantages; and (3) use of ICT from an ethical perspective - is it right or wrong to use ICT in nursing care? To stimulate the discussions, two practical examples of using ICT were presented. The first example described a field case in home visits that included different ICT equipment, such as laptop with access to the computerised case record system, a digital camera, a web camera, a mobile phone, a bladderscan, and an electrocardiograph to send test results to physicians. The second example described an ICT application with text messages used for communications between people with serious chronic illness and living at home and their DNs (Nilsson *et al.* 2006). By facilitating the discussion, the moderator encouraged the DNs to describe their points of view of the discussed topics. Two of the focus group discussions were performed in a quiet room in the participants' working place, and three in a university department. Each focus group discussion lasted for about 90 minutes. Discussions were audiotaped and transcribed verbatim.

Data analysis

The focus group discussions were analysed with a thematic content analysis (Baxter 1991) to describe the manifest and latent content (Catanzaro 1988). To determine the sense of the content, the interview texts were read several times bearing the aim of the study in mind to gain a sense of the content (cf. Sandelowski 1995). The interview texts were then read again and textual units were identified, condensed and coded. The textual units with similar content were sorted into areas and a pattern started to emerge. The content in the areas were then sorted into categories in several steps. During the whole process, the researchers occasionally

went back to the original textual units and compared the results. Finally, six categories occurred and the categories that were related to each other were subsumed into two themes to formulate a descriptive underlying meaning, that is, i.e. threads of meaning that appear in several categories (Baxter, 1991). The researchers discussed the categories and themes that emerged to achieve credibility.

Ethics

Consent for the conduct of the study was obtained from the heads of five primary health care centres. Both oral and written information were given about the nature of the study, and it was advised that participation was voluntary with possibility to withdraw at any time. The participants were assured of confidentiality and anonymous presentation of the results. Before starting the focus group discussions, the participants agreed not to talk about the contents in the discussion to others outside the group. The study was approved by the Regional Ethical Review Board in Umeå, Sweden.

RESULTS

The themes and categories are presented in Table 1. The quotations from the focus group discussions were edited carefully to be more understandable.

Insert Table 1 about here

Being a part of the introduction of ICT

Possibilities to influence the design

The DNs described the importance of having influence on the design of ICT so they would be able to use it in their work. It is important that the design of the ICT should be easy, user-

friendly and suited for the nursing care of people with chronic illness in their homes. DNs also pointed out the importance of being part of the development of a new technology so that they can influence the design. In their experience, some technical equipment in health care could be too advanced, unnecessary or unsuitable for use in nursing care. Some DNs stated also that some technical equipment were designed by people who were unfamiliar with their work.

> …it should be easy to use and less moment. (DN 17)
>
> Yes (DN 19)
>
> … I think that the one who work with it will design it, now it has been the IT-personnel…it must be the personnel who work with it who develop the technique.
>
> …how it now will be designed and how we will be able to use… it will deal with our workday and then we have to be involved.. (DN 18)

The importance of participation in the introduction

The DNs described the importance of participation in introducing ICT in nursing care so they would be part of the process. They expressed that instructions of using the technology must be clear before the use of the technology is started. It should be clear also on which professions should have access to the technology. Clear instructions would be necessary since the use of some technologies lacked routines instructions based on the DNs' experience.

> …this must be solved first otherwise it's no idea we go there with an equipment … it's no idea to take a test if I not be able to do something about it. It's no idea to investigate if anybody see the results … (DN 9)

Some of the DNs had experience in the introduction of a new technology and shared how difficult it had been when they were not part of the introduction. They remembered when the case records were computerised in their work a few years ago, and some DNs expressed lack of participation in this introduction. In the beginning, work with the case records took longer time than writing on paper. This influenced their perception of the new technology in a negative way as a result of lack of information, education and practice. Today, they are accustomed on how the computerised system functions and they recognise that they could not manage without using the computerised case records. The DNs' experience based on this example was that it could have been easier to introduce the new technology if they had participated in the introduction and understand better the demands the technology had on them as users.

> .. you should talk about it, how it felt more deeply and not only overburden us with everything. Now we have to swallow and receive without thinking if it's relevant for us. However we get no chance, and this is the first time we talk about it. (DN 1)

Using ICT in nursing care of people with chronic illness also demands participation of the ill person in the introduction. Based on the DNs' experiences, this was very important because learning and using the technology is an individual task. The DNs pointed out that the introduction and use of technology in nursing care for the ill person must be voluntary. Taking time together with the ill persons to teach the use of the technology is also necessary so they know they are part of the process.

> **…**important is that you really got the time you need 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… you have to support the patients so they feel that they also get

something for participating in the project and start to use the ICT. (DN 19)

Being aware of possibilities and threats when using ICT

Seeing both improvements and risks

Using ICT in the nursing care involved both improvements and risks. The DNs experienced

that new technology such as the computerised case records improved nursing care when the

DNs had access to the case record system in a safer way than before. They saw improvement

in using the ill people's case record with a portable computer in the person's own home when

giving information or ordinations of drugs, giving results of laboratories and tests, and

checking what had happened previously when the ill person visited the primary health care

centre. DNs recognised that the use of portable computerised case records enabled them to

give and receive information independently wherever they were. DNs who worked in of what

they told to meevenings and night-time, saw the possible to read case records from their own

home in order to be prepared. Some DNs described that ICT applications could be a support

tool which could increase the level of security for seriously ill people in palliative care at

home.

With that you can give answers at once if they will know how the test I took for a week

ago was. 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 going back and look in the case records and read the

record and search for results.. ..instead I can read the record here in the patient's

home…(DN 10)

DNs points of view of communication with ill people at home using ICT with video and audio transference showed that ICT could save ill people's visit to hospital or primary health care centre. Further, ICT was seen as time saving for DNs because of decreased travelling time and home visits, thus increasing the time for supporting other ill people at home. To some DNs, the use of ICT could be an alternative for those who refuse to go to the hospital or primary health care centre. They saw that using ICT could improve the accessibility of the DN to ill people at home. This could increase the security for ill people at home, especially for those living in thinly populated areas. They also thought that ICT could be used as a support tool in nursing care for ill people at home.

> I think it can be received safely if a patient in an easily way can be in contact with the DN at any time (D 6)
> …to use ICT is an alternative to drive far away to a patient and you will avoid risky drivings in the dark and slipperiness.. (DN 1)

DNs pointed out that the use of ICT at home could be difficult and uncertain. One DN shared that one risk was the loss of holistic perspective in nursing care, as well as lack of important information from ill people. Some DNs expressed uncertainty on handling the equipment which could be stressful. They also described a risk that the use of ICT could be frightening especially for older people. DNs mentioned that using ICT in nursing care could take time because of concerns on the installation and management of the technology in each ill person's own home.

People cannot be replaced

Some DNs expressed that DNs may not be needed in the future because a lot of information is available on the Internet. They pointed out how important it was to have physical meetings with ill people in their own home to build up trust between each other. Before starting the use of ICT for communicating, some DNs stressed that it was important to know the ill person. They saw the use of ICT as a complement which could facilitate nursing care. If appropriate information was given and the relationship with the ill person was satisfactory, the DNs considered that there was no disadvantage in using ICT in nursing care at home. However, they stressed that the use of ICT could not be suitable for everybody and home visits are valuable in terms of revealing so much more information about the ill person.

> ICT can never replace the personal contact.. ..if you say so someone can experience that anybody take notice of them.. ..for chronically ill people which have a long history of illness and you not do home visits you can use ICT instead. I don't know, maybe they can experience that they will be ignored (D 15)
> You cannot replace the human contact with the person because it's also another language that you have when you meet a person and sometime you feel only in the athmosphere that even if not the words say anything you can understand that here it's not right and you know the person. ICT cannot replaced.. ..you must take it as a complement I can not think that it replaces the human being (D 18)

DNs also pointed out that the technical equipment could encroach in the ill person's own home as well as on other family members. Some DNs discussed that the autonomy of the ill person and their family could be threatened if anybody in the family does not want the equipment at home. Further, the DNs pointed out the importance of being observant on how the technology was used, and making sure it does not hurt anybody. DNs agreed that in the

future, the use of ICT in nursing care at home will occur more and more, and this requires changing routines in their work.

DISCUSSION

The aim of this study was to describe DNs' points of view regarding the use of ICT in nursing care at home. The results showed that it is important for DNs to be part of the introduction of ICT within nursing care at home. It is also important that the design of the ICT is user-friendly. To use ICT in nursing care would bring both improvements and risks based on the DNs points of view.

In this study, DNs pointed out that they wanted to influence the design of ICT so they would be able to use it in their work in an easier way. The design should be suitable and user-friendly for nursing care of people with chronic illness. This is also found in earlier research (Magnusson *et al.* 2004, Wakefield *et al.* 2004) which stated that the key theme in the use of ICT is 'user-friendly' and that ICT has a clinical appropriateness. The technology must be carefully designed to comply with different demands of design and use (Short & Saindon 1998). Therefore, careful presentation to the users could help adapt the ICT application to the users' needs (Andersson *et al.* 2002). The unnecessary technical details should not be overemphasised to avoid daunting the user (Hjelm 2005).

The importance of participation in the introduction of ICT in nursing care included getting information and training, if possible, both for the DNs and for the ill people at home. Starren *et al.* (2005) have described installing ICT in healthcare in homes, and stated that education and training is of importance in the installation process. According to Hughes (2001), when using ICT in nursing care in homes, the selection of appropriate technical equipment is

necessary, which means ease of installation and operation, and quality of picture and voice. DNs pointed out the importance of having clear routines in the use of ICT in nursing care at home. The use of ICT programmes in health care are positioned within a larger organisation. This meant that the organisation where the ICT equipment will be used must be examined carefully before the introduction started. For instance, a strategy for educating personnel on the use of ICT should be addressed (Whitten & Adams 2003).

Some DNs had positive experiences of the computerised case record system they used in their work which improved access and safety in handling case records. Darbyshire (2004) has described the opposite and showed that clinical nurses and midwives using a computerised information system in practice experienced disappointment rather than efficiencies. They declared that computerisation had neither enhanced the clinical practice nor enhanced the care of the patients. However, some DNs in this study expressed that from the beginning, the computerised system made their work more difficult because of lack information, education and practice. Training and support in the introduction of new technology are essential for making the users secure (Wakefield *et al.* 2004). The DNs in this study mentioned that the introduction of the computerised case record system could have been easier if they had been part of the introduction process.

DNs viewed that ICT could improve the security for ill people living at home and also improve their own work. They saw the possibility that the use of ICT applications could save time due to decreased travelling time and home visits. This could mean more time for supporting other needy ill people at home. On the other hand, they saw a risk that the use of ICT could demand time, as in making all the connections of ICT equipment in the homes. It is known that the use of technology in health care could save valuable time (Demiris et al. 2001,

Hailey et al. 2002, Hjelm 2005). Smith *et al.* (2002) described that nurses who communicated with patients by ICT compared to traditional home visits saved time because of less travel time. The findings also indicated the use of ICT was less expensive than traditional home visits. However, there are also studies that showed the opposite (Barnard & Gerber 1999). Use of technology in surgical nursing was found to affect nurses negatively when the technology made their daily practice of nursing care more demanding, more time consuming and distracted.

DNs in this study also discussed that using ICT in nursing care at home could cause distraction and uncertainty. The benefits of the use of ICT in healthcare are substantial, therefore, more research is needed for reducing negative factors (Hjelm 2005). Some DNs in this study believed that ICT could be frightening especially for older people. According to Demiris et al. (2001), using ICT in health care of older people could initially make them fearful and this fear seemed to diminish after a while. DNs stressed that the use of ICT could not be suitable for everybody and home visits revealed so much more. This is in line with Söderlund (2004) who examined the use of ICT as a support tool for people with severe disabilities in need of help when living at home. The results showed that the ICT benefit on telecare and telemonitoring is not enough to provide help to this group of ill people. To satisfy their needs, practical help is essential.

DNs in this study also viewed that people cannot be replaced by ICT in nursing care at home and that physical and human presence was important. Sävenstedt *et al.* (2006) have shown that carers could perceive the introduction of ICT applications as a threat to the care. They found that ICT could promote human care, but ICT could also lead to dehumanised care. DNs pointed out the importance of physical meetings in the ill peoples' own home to build a

trusting relationship between each other. A trusting relationship is seen as essential in nursing care at home (Thorsteinsson 2002). According to Mok and Chiu (2004), it is important in developing a trusting relationship that nurses understand the ill people's needs, display caring actions and attitudes, provide holistic care, and act as an advocate for the ill person. DNs described that the use of ICT could be a complement in nursing care, but could not replace people. Demiris *et al.* (2006) reported that if human touch is not seen as important, the use of a telehealth application may replace home visits. However, if touch is important, telehealth is a supplement rather than a substitute. DNs in this study were aware of that using ICT required changes in their work. According to Barnard and Gerber (1999) technology can be seen as a complex phenomenon which influences nursing history, nursing practice and its future. Heinzelmann *et al.* (2005) have concluded that the growth and integration of ICT into health care will give ill people and their providers possibilities in the future.

DNs further stated that it was important to know the ill person before starting to use ICT in communicating with the ill person living at home.This is in agreement with the concept 'knowing the patient' which is an important part in nursing care (Radwin 1996, Luker *et al.* 2000). Knowing the patient embraces two components for the nurse: to understand the patients' needs and to create individual interventions for the patient (Radwin 1996). To know the other person in the use of ICT in health care seemed important also for the patient to be able to trust the person 'at the other end' (Andreassen *et al.* 2006).

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 questions discussed.

Morgan (1997) stated that when a focus group consisted of homogeneous participants, data will be in agreement. The limitation of the study has to do 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 if the findings are modified to comply with the context (Polit & Beck, 2004). To reach trustworthiness the study, the findings were discussed with other researchers and colleagues.

CONCLUSION

This findings showed that ICT applications should be suited for nursing care at home with possibilities for DNs to influence the design and introduction. ICT should also be user-friendly since use of ICT in nursing care could bring both improvements and risks. Using ICT in nursing care cannot replace the meetings between the DN and the ill person, but ICT can be seen as a complement. Therefore, more knowledge is needed on which ICT applications can be used for ill people living at home to promote the quality of nursing care. However, it was also pointed out that ICT could be of advantage for ill people living at home so research is also needed from ill people's perspective.

AUTHOR CONTRIBUTIONS

Study design: CN, SS data collection and analysis: CN, SS, and manuscript preparation: CN, LS, SS

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Table 1 Overview of themes and categories based on the analysis of the focus group discussions

Theme	Category
Being a part of the introduction of ICT	Possibilities to influence the design
	The importance of participation in the introduction
Being aware of possibilities and threats in the use of ICT	Seeing both improvements and risks
	People cannot be replaced

Paper II

▶ ## 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 videoconferencing 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.

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Paper III

District Nurses' Experiences on the Use of Information and Communication Technology

for Supporting People with Serious Chronic Illness and Living at Home – an

Intervention Study

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District Nurses' Experiences on the use of Information and Communication Technology for Supporting People with Serious Chronic Illness and living at Home – an Intervention Study

Abstract

We studied the experiences of two district nurses who used information and communication technology to communicate with seriously and chronically ill people living at home. The study design was a qualitative case study where an intervention was performed. An electronic messaging program via computer and mobile phones with Internet connection was used, which enabled participants to receive messages from and send massages to the ill person from anywhere. The program consisted of different virtual rooms, with communication via text messages. The participants used the program 2-4 times each week from November 2003 to February 2004. Semi-structured interviews were performed before, during, and after the intervention and were analysed using thematic content analysis. The results showed that the participants considered the technology to render increased accessibility, a more direct communication with the ill person, and saved time for the participants, which meant a more trustful relationship with the ill person living at home.

Introduction

During the last years, people are cared for in their homes more often than before, because of a shift of nursing care from hospitals to primary and community care. This shift has influenced district nurses' (DNs) work and has led to the fact that an important part of their work is to support people with chronic illnesses and who living at home (Wright, 2002; Öhman & Söderberg, 2004). According to the Swedish government, helping and supporting chronically ill people who stay at home is priority work. Swedish DNs are usually responsible for nursing care at home, and can be compared with community nurses or home care nurses in other countries.

A feasible method by which DNs can support chronically ill people living at home is with the use of information and communication technology (ICT). ICT makes it possible for people to communicate, gather information, and interact with distance services quickly and more easily without the limitation of time and space (Campbell, Dries & Gilligan, 1999). Using ICT can also support family caregivers by reducing isolation and maintaining a sense of presence by providing easier access to health care professionals (Magnusson et al., 2002). Previous studies have shown that nurses are satisfied using ICT to communicate with chronically ill people living at home (Allen, Roman, Cox & Cardwell, 1996; Demiris, Speedie, Finkelstein & Harris, 2003; Kawuguchi, Azuma & Ohta, 2004; Whitten, Collins & Mair, 1998). Demiris et al. (2003) found that nurses who used virtual visits in a home telecare project did not feel better when the visits were carried out in person. This is in line with the study by Kawaguchi et al. (2004), which showed that using a telenursing system, nurses could improve ongoing nursing care and predict if the patient's condition became impaired. Evans (2002) and Rout (2000) have shown that the DNs' working situation is stressful with too much work, and therefore changes in their working routines are necessary (McHugh, Pateman & Luker, 2003).

Today, nursing care at home is increasing, which requires DNs to find new ways of working to facilitate communication and be more accessible to ill people living at home. Using ICT for communication in nursing care helps DNs provide efficient care with, for example, less travel time and possibilities for patients to participate in their own care (Arnaert & Delesie, 2001). Therefore, we find it important to test how the use of ICT in nursing care was experienced as support to serious chronically ill people living at home and for DNs in their work. A previous study indicated that the everyday life for serious chronically ill people living at home seemed to be improved by using ICT (Nilsson, Öhman & Söderberg, 2006). Thus, the aim of this study was to describe the DNs' experiences of using ICT for communicating with people with serious chronic illness living at home.

Methods

This study is part of an intervention study. A qualitative case study with single-case design was adopted. A qualitative case study is a holistic description and analysis of a unit or a phenomenon with focus on process, understanding, and interpretation (Merriam, 1994). Two persons with chronic illness and living at home, and their DNs, who used an ICT application for communication, were studied. The persons with serious chronic illness required extensive care from personal assistants during both day and night. The criteria for participating in the study were to be responsible for the ill person's nursing care at home and to have an established contact with the ill person. One DN had been a practicing nurse for 39 years, and had obtained graduation diploma as DN 16 years ago. The other DN had been a practicing nurse for 23 years, and had graduated as DN 13 years ago. They worked in different healthcare centres and both were computer literate because their journal system was computerised. Participation in the study was voluntary and the ethics committee at the university approved the study.

The Intervention

For communication between the DNs and the ill persons living at home, a computer program called Rexnet® was used. Traditional home visits were also performed by the DNs during the intervention. The program can be used on any computer with an Internet connection, and consists of different virtual rooms from where people can communicate through text messages. Communicating via text messages was considered the most suitable form of communication by ICT because the ill persons had difficulty talking. The program was reputed as user-friendly and secure. The DNs had mobile phones with Internet connection, with which they could receive and reply to messages wherever they were. Information about using the equipment was given before the intervention started. The participants used the equipment during their working hours in the daytime.

Data Collection and Analysis

The participants were interviewed three times with semi-structured interviews during the study. Before the intervention, the interviews were based on an interview guide with questions on communication, accessibility, security, difficulties etc. The interviews opened with the question, 'Please tell me about your experiences of caring for people with serious chronic illness and living at home'. Follow-up questions like 'Can you give an example?', 'What happened then?', or 'How did you feel then?' were asked. The interviews lasted for about 40 minutes. Two months after the intervention started and after the intervention had finished, follow-up interviews were conducted, where an interview guide was used with questions derived from the answers given in the pre-intervention interviews. The follow-up interviews lasted for about 30 minutes and were conducted in the participants' working place. All interviews were tape-recorded and transcribed verbatim.

The interviews before the intervention started were analysed separately, and the interviews during and after were analysed together because the content was rather similar. A thematic content analysis was used for analysing the interview text to describe the manifest and latent content (cf. Catanzaro, 1988). The interviews were read several times to get a sense of the content (cf. Sandelowski, 1995). Textual units were identified, coded, and categorised. 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 appear in several categories (cf. Baxter, 1991).

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Results

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According to the DNs, the program was used 2-4 times each week from the beginning of November 2003 until February 2004.

Pre-intervention

The theme 'Striving for a trusting relationship' was constructed from the three categories as follows:

Mediating security through interaction. Both participants described the importance of making the ill person feel secure. If more need for security was warranted, the participants undertook home visits and extra phone calls more often, or personnel in home care service or relatives were contacted for undertaking visits more often. The participants emphasised that knowing the ill person rendered feelings of security and made it easier to know what could happen, but it could also mediate feelings of being limited and indispensable. Both participants described that cooperation with their DN colleagues and other professionals like general practitioners was necessary to be able to mediate security to the ill person as well as for themselves.

Feeling insufficient. The participants described that they sometimes felt insufficient and dissatisfied with the nursing care they gave, and it was difficult to understand and fulfill the needs of the ill person. One participant mentioned that ill persons were sometimes anxious and contacted the DN immediately after the DN had left them. The other described a sense of powerlessness because of the lack of continuous communication with the ill persons or when many needed help at the same time. Both participants described that they prioritised the ill person who was judged to be in the greatest need, something that was not always easy.

Working for accessibility. The participants felt that they were not always accessible enough for the ill persons. One participant used a mobile phone at work and the routines for using it were that the ill person phoned the reception personnel who delivered a message to the responsible DN who then contacted the ill person. One participant indicated that many things could happen when the DN was inaccessible; and to increase accessibility, this participant gave the private mobile number to persons who required more attention. Both participants stated that people close to the ill persons made the phone call and not the ill persons themselves. The proximity of the DN was an important factor in deciding how fast home visits could be performed. Both participants said that they saw ICT as a possible solution to increase accessibility.

Post-intervention

The theme 'Reaching a more trusting relationship' was constructed from the three categories as follows:

A complement to the performance of nursing care. Both participants talked about their situation after becoming accustomed to the use of ICT, and said that it facilitated their work. They were pleased with the support they received from the messaging program. Both described that they had worked out routines such as visiting the messaging program on fixed

times, which gave organised working conditions. One participant stated that reading the messages regularly gave an opportunity to know what the ill person needed. The contacts included questions about medicines, physical problems, and practical things like ordering aids and agreements on the time for home visits. Both participants thought communicating by using the technology with the ill person was a positive experience. They emphasised 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 believed the use of ICT could decrease home visits, and the other claimed that if many ill persons used the technology at the same time, there could be difficulties in managing the use. They said that the expectations had been realised, and they were positive to continue using ICT equipment.

Feeling uncertainty. The participants mentioned that they were unaccustomed to ICT in the beginning and technical problems occurred, which gave them a sense of uncertainty. Both described problems with receiving and sending messages via the mobile phone, and they were unsatisfied with the instructions and support they received. They said that they had sometimes made home visits for safety's sake although using the technology had probably been sufficient. One participant voiced concern on missing details because of not seeing the ill person, because many things are revealed by the expression in the ill person's eyes, their breathing, or their skin colour.

Increased accessibility. The participants said that they were more accessible by using ICT. One participant said that being accessible decreased the stress and made the working situation more secure. The participants felt they obtained a more direct communication with the ill person by using the technology. One of them mentioned that the use of ICT eliminated second-hand information given by others, and gave a more realistic view of the situation; it

was easier to determine if the condition of the patient was critical or not. The other participant said that the possibility to write messages wherever you were made work easier. Both participants expressed a sense of time saving using ICT. They were able to decrease the frequency of visits to the health care centre between the home visits, had possibilities to give a quick answer, were able to decrease phone calls, and had the possibility to go back to the message and check what had been written. One participant pointed out that extensive use of ICT gave them more time for helping other ill persons.

Discussion

The use of the messaging program and mobile phones in the work seemed to give DNs a more trustful relationship with the person with serious chronic illness and living at home. Furthermore, the results indicate that using ICT increased the possibility of reaching the DN, saved time, assisted in direct communication with the ill persons, and gave more knowledge of and control over the ill person's situation. According to Lögstrup (1992), 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. For mediating security, the participants strived for a good relationship with the ill person. Establishing mutual trust and confidence is essential in relationships between DNs and their patients (Kennedy, 2002), and nurses who create a trustful relationship show a holistic approach to care (Mok & Chiu, 2004). Before the intervention started, the participants explained the importance of giving security and knowing the ill person, which facilitated the caring process. Radwin (1996) maintains that to know the ill person ensures individual care, which includes a continuous contact and a sense of closeness in the nurse–patient interaction. Lotzkar and Bottorff (2002) illustrated the importance of continuous nursing care for attaining a nurse–patient relationship in the best way.

The participants felt they were not accessible enough and sometimes felt insufficient in relation to the ill persons. This can be seen as a sign of not having the control they want over their work. Strandberg and Jansson (2003) illuminate the phenomenon 'dependency on care' from a nurse's perspective, which gave a burdensome responsibility and could render feelings of guilt and insufficiency for nurses because of loss of time for meeting patients' needs.

After the technical problems were solved, the participants thought the use of ICT facilitated their work and gave knowledge about the ill person. Using ICT gave a more organised working condition that also increased accessibility, which for one participant meant reduced stress. This could be seen as a mode of obtaining control over what happens in their work. According to Berterö (2002), DNs in home palliative care tried to find their own solutions of organising the caring situation so they could master it. Studies have shown that not having control is an occasion for DNs to feel stress (Rout, 2000; Wilkes et al., 1998).

The participants opined that it was possible to communicate with the ill person by using the technology despite that it implied not seeing each other. They stated at the same time that home visits were necessary. Whitten et al. (1998) have described that nurses perceived a difference between using traditional home nursing and home telenursing owing to the lack of physical contact with the patient. Furthermore, Whitten claimed that using telenursing did not always lead to deterioration; instead, it could enhance the frequency of contacts in the nurse–patient interaction. One participant believed that using ICT could decrease home visits. This could be seen as an advantage with decreased stress for the DN, but also as a disadvantage because of the exclusion of physical contact with the ill person. Physical touch is an important form of nonverbal communication in nursing care (Chang, 2001; Ruotsalo & Isola, 1998).

Because of technical problems, the participants did not agree with using the mobile phones. According to Wakefield, Holman, Ray, Morse, and Kienzle (2004), it is important that the technology is clinically appropriate and the users are given proper training and support. Nevertheless, the participants described that using ICT had increased accessibility through the possibility of writing messages wherever they were. To be accessible gives DNs control in their caring situation (Berterö, 2002). The participants said that time were saved by using the technology, and that meant they could be accessible to others who needed help. This can be seen as an improved nursing care quality. According to Attree (2001), accessibility of care practitioners is a quality factor for ill people.

Recommendations

This study indicates that using ICT improved nursing care at home with increased accessibility, provided a more direct communication and control over the ill person's situation, and resulted to time savings. This can be seen as that the DNs reached a more trusting relationship with the ill person living at home. However, the use of ICT cannot replace physical presence in nursing care, but can complement the traditional nursing care at home. The participant DNs stated that by using ICT, they sometimes missed the opportunity to see the ill person. Therefore, suitable interventions by using ICT to enable communication between serious chronically ill persons living at home and their DNs need to be custom-tailored for the situation.

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