Towards Effortless Use of Information Technology in Home Healthcare with a Networked Digital Pen

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Cover drawings "Pain diary" by Gustav Lind, 5 years, and "Digital pen and mobile phone" by Gustav Lind, 9 years.

Everything should be made as simple as possible, but not simpler.

(Albert Einstein)

To Inga Linnéa, Johan and Gustav

List of Papers included in this thesis

I. Lind L, Sundvall E, Karlsson D, Shahsavar N, Ahlfeldt H. Requirements and prototyping of a home health care application based on emerging JAVA technology. *Int J Med Inform*. 2002 Dec 18;68(1-3):129-39.

II. Lind L, Karlsson D. A system for symptom assessment in advanced palliative home healthcare using digital pens. *Med Inform Internet Med*. 2004 Sep-Dec;29(3-4):199-210.

III. Lind L, Karlsson D, Fridlund B. Patients' use of digital pens for pain assessment in advanced palliative home healthcare. (Submitted for publication).

IV. Lind L, Karlsson D, Fridlund B. Digital pens and pain diaries in palliative home healthcare: Professional caregivers' experiences. (Submitted for publication).

Related publications by the author

Lind L, Sundvall E, Ahlfeldt H. Experiences from development of home health care applications based on emerging Java technology. *Medinfo*. 2001;10:830-4.

Herzog A, Lind L. Network solutions for home health care applications. *Technol Health Care*. 2003;11(2):77-87.

Lind L, Karlsson D. Symptom assessment in home healthcare using digital pens. *AMIA Annu Symp Proc*. 2003;914.

Lind L, Karlsson D. Digital pen technology in palliative home healthcare. *Medinfo*. 2004;2004(CD):1723.

Lind L, Karlsson D. Home healthcare patients using digital pens for pain assessment. *Telemed J E Health*. Apr 2005, Vol. 11, No. 2: 242-266.

Abstract

When care is moved from the hospital to the home the demands for high quality care still remain. For problems arising from the geographical separation of patients and professional caregivers, information and communication technology may offer important solutions. The overall aim of this thesis was to describe relevant requirements, to design and implement an IT-based system, and finally to evaluate the system's influence on symptom control and support for both patients/next-of-kin and professional caregivers in advanced home healthcare. Of importance were needs in basic as well as advanced home healthcare, as were usability perspectives of both patients and professional caregivers. Requirement areas such as security, mobility, and responsibility, which should be considered when monitoring patients in the home, were identified. A prototype system for everyday assistance for diabetes patients was designed, and a system for frequent pain assessment for palliative home healthcare patients using a pain diary, digital pen and mobile Internet technology, was developed and evaluated through a qualitative content analysis approach. Twelve palliative cancer patients and six professional caregivers participated. The data collected included an ease-of-use questionnaire, and interviews with patients, spouses and professional caregivers. Patients expressed increased and improved contact with the caregivers, increased participation in their own care, a sense of increased security, and easiness in using the equipment in spite of severe illness and difficulties in comprehending the technology and system intervention. The professional caregivers showed a shifting outlook towards the pain assessment method; an initial cautious outlook due to low expectations of the patients' abilities to use the pain assessment method and the caregivers' own reluctance to use the system and change their way-of-working. Despite this, the professional caregivers experienced positive outcomes in terms of an increased awareness of pain, and positive patient influences including increased participation in their care, increased security and improved changes in pain treatment as a response to reported pain assessments. In conclusion, the networked digital pen system provided an effortless method for pain assessment and had positive influences on the care. The results imply that digital pen technology is suitable for the assessment of symptoms by palliative patients since these patients often have a limited capacity to handle technology due to their state of health.

Keywords: Home care services, Hospital-based; Requirements; Pain Assessment; Visual Analogue Scale; Palliative care; Digital pens; Mobile phones; Internet.

Contents

Acknowledgement

References

Original Papers I – IV

1. Introduction

In recent decades the proportion of elderly people, and particularly those over 80, has increased significantly (Davies, 2004a). Today, nearly every fifth person in high-income countries, among them Sweden, is over 65 years of age (Parker, 2005). However, although we live longer, we still do not escape the risk of contracting diseases and/or functional impairments when the later stages of life approach (Davies & Higginson, 2004b). As populations age, people die in greater numbers after long illnesses from heart disease, cerebrovascular disease including stroke, chronic respiratory disease and respiratory infections and cancer. These five illnesses are predicted to be the leading global causes of death in the next twenty years (Murray & Lopez, 1997).

Older people are frequently admitted to acute hospital care. For example, in the United States persons over 65 years of age account for almost 50 % of hospital expenditure (Parker, 2005). However, care in the later stages of life is moving out from the hospital to the own home as well as to housing provided by the municipalities. In Sweden, this development was expected and was one of the aims of the so-called Ädel Reform, which was implemented in Sweden in 1992 (SoS, 1996). There is a tendency towards a decreased number of hospital beds in most OECD countries (median 3.8 hospital beds per 1000, year 2005). In Sweden, with 2.4 hospital beds per 1000 inhabitants, the lengths of stay in the hospital also have decreased (SoS, 1996; SoS, 2005a; Wimo, 2000). Several factors contribute to the expansion of home healthcare, for example, demographic changes in the population, the demand for healthcare cost reduction, increased availability of complex medical equipment in the home and an increased focus on self-care, to name a few (Pepe et al., 2004). The trend towards the decrease in hospital care and the development and expansion of home healthcare leads to the possibility of staying at home even during grave illness. Investigations have shown that home healthcare is preferred even when severe illness is involved (Higginson & Sen-Gupta, 2000; Fried et al., 1999; Townsend et al., 1990; Thorpe, 1993; LF, 1998). As much as 50 % to 80 % of people receiving care for a serious illness say they would prefer home care at the end of life (Higginson & Sen-Gupta, 2000; LF, 1998).

In the last decades in Sweden there has been a shifting of place-of-death from the hospital to the housing provided by the municipalities and the own home. A comparison of place-of-death during the years 1987–2003 in Sweden showed that the number of deaths in hospitals or comparable institutions was around 75 % before the Ädel Reform (in year 1992) and 35 – 40 % after. Of the over-80 age group, twice as many died outside of the hospital compared to those who died in the hospital during the years 1997–2003 (SoS, 2005b).

Depending on the context, home healthcare can mean everything from a few visits by healthcare professionals in the home to care which intends to fully replace hospital care (Thomé et al., 2003). With this increase in home healthcare—both in terms of quantity i.e., the number of patients and days of care, and in terms of illness i.e., very ill patients will be receiving home care—patients will need support in taking greater control over their condition (NHS, 2005) and caregivers will need improved support in the remote control of the patient's state of health (Lamothe et al., 2006; Hebert & Korabek, 2004; de Wit & van Dam, 2001). Improved support is also needed due to the physical distance between home healthcare patients and their caregivers (Gagnon et al., 2006; Demiris et al., 2005; de Wit et al., 1999; Mooney et al., 2002; Parkes, 1985; Wilkes, 1984; Morris et al., 1986). Within advanced home healthcare a great number of patients are in a palliative state and for these patients symptom control is one of the most central parts of the care process (Heedman & Strang, 2001; Strömgren et al., 2001).

There are additional patient groups other than the most severely ill who will have a need to report current symptom and status parameters to the caregivers (Koch, 2006; Davies & Higginson, 2004c; Lamothe et al., 2006). By discussing symptom and status parameters with the caregivers the patients themselves will learn to understand and treat their illness in a more appropriate way (Lamothe et al., 2006). Examples of such patient groups can be patients suffering from diabetes, congestive heart failure, asthma and chronic obstructive pulmonary disease (Davies & Higginson, 2004c; Louis et al., 2003; Foster et al., 1999; Heidenreich et al., 1999; Finkelstein et al., 2000; Tu et al., 1997). Information and communication technology (IT/ICT) systems, developed to facilitate symptom and status assessment in home healthcare, give the possibility of improving symptom and status control and thereby the patient's health status (Lamothe et al., 2006; Kobb & Dimmick, 2006). The breakthrough of wireless and Internet technology has introduced new possibilities for designing, developing and implementing IT systems supporting home healthcare (Herzog & Lind, 2003). In

connection with these developments the term *telemedicine* is often used. Telemedicine has been described as:

> "Telemedicine is the use of medical information exchanged from one site to another via electronic communications to improve patients' health status. Closely associated with telemedicine is the term 'telehealth', which is often used to encompass a broader definition of remote healthcare that does not always involve clinical services. Videoconferencing, transmission of still images, e-health including patient portals, remote monitoring of vital signs, continuing medical education and nursing call centres are all considered part of telemedicine and telehealth."[1]

A shorter definition of telemedicine has been "medicine at a distance". *Home monitoring* is in this thesis defined as ranging from: patients and professional caregivers having remote contact via for example ordinary or video telephony, to patients carrying body sensors measuring vital sign parameters, which are sent continuously or intermittently to a clinic. In this thesis home monitoring covers different methods for the reporting of symptom and status parameters by using ICT. In the literature other terms with similar meaning are for example, use of *telehomecare*, *eHealth*, *telecare,* and *home telehealth* (Koch, 2006).

The development of safe and easy-to-use methods and techniques supporting home healthcare is reported to be a major challenge for the medical informatics community since, for example, patients' and caregivers' needs differ and organisational, societal and legal changes are required (Lamothe et al., 2006; Hebert & Korabek, 2004; Beuscart & Bricon-Souf, 2004; Koch, 2006). In a study on the current state of home telehealth, Koch (2006) concludes that though there is a trend towards the use of home telehealth tools and services for patients and citizens, as well as for professionals, their impact on the patient—caregiver relationship needs to be more fully investigated. Koch furthermore concludes that to overcome various hinders, such as incompatible information systems and the lack of guidelines for implementation of home telehealth applications, further research including privacy and confidentiality issues, better design solutions considering usability aspects and evaluation studies, to name a few, are needed.

Rationale for this thesis

When planning for this thesis in 1999, the shift towards increasing home healthcare was a fact. Although the use of home telecare was old—as old as the installation of the first home telephone (Wilson et al., 2000)—studies regarding the use of IT-based systems in advanced home healthcare aimed at considering

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[1] The American Telemedicine Association (http://www.atmeda.org/)

patients' and professional caregivers' needs and at supporting both patients and caregivers in a balanced way, were limited. Thus we planned our research, of which this thesis is a part, to cover some of the missing knowledge concerning professional caregivers' dilemmas and needs for improved support in terms of the remote control of patients' health status within advanced home healthcare, as well as to investigate both patients' and caregivers' experiences of using such IT-based systems. The fact that only the primary healthcare organisations used electronic healthcare records whereas the other home healthcare organisations used paper-based medical records in Linköping Sweden by that time was taken into consideration. The overall research question was: *Can IT-based systems solve some of the problems associated with symptom and status control of the patient at home and function as support for both professional caregivers and patients/next-of-kin thereby improving the symptom and status control in advanced home healthcare?*

Since we could expect a complex interplay between care processes, technology development and human reactions, a research approach involving the development of prototype systems was selected. These prototypes were meant to serve as the basis for exploring requirement areas and for evaluation of user acceptance, with a special interest in problems and opportunities in connection with emerging technical solutions. Our investigations included the design and development of a system for everyday management of diabetes, and the design and implementation of a system for the follow-up of pain treatment for palliative patients in advanced home healthcare. In both cases front-line technologies, for example a networked digital pen with a high potential for ease-of-use, were sought for.

The research described in this thesis has been accomplished through the "Advanced Home Healthcare Environment" (AHHE) project, consisting of several sub-projects, in collaboration with the diabetes clinic during 2000 and the hospital-based home care (HBHC) clinic during 2000-2003, both at the University Hospital in Linköping, Sweden.

2. Background

Home healthcare

The definition of the term *home healthcare* has changed over time in Sweden (LF, 1998; Andersson, 2002; SoS, 2002; SKL, 2005) as well as in other countries and, in addition, home healthcare is used with different meanings in different situations (Thomé et al., 2003). According to The Swedish National Board of Health and Welfare and The Swedish Association of Local Authorities and Regions the term *home healthcare* now (2006) means "Health and medical treatment when given in the patient's home or similar housing and where the responsibility for the medical measures are coherent over time"[2] (SKL, 2005)

In Sweden, home healthcare is divided into two parts:

♦ *Basic home healthcare*—care given in the patient's own housing or in housing provided by the municipality, which otherwise should not require hospital care, i.e. it constitutes a complement to hospital care. The care is often given by e.g., a district nurse or a nurse employed by the municipality, who works alone or together with assistant nurses. It furthermore means that the care is often given during daytime only and little or no medical technology is used. Another term often with the same meaning is *general home care* (LF, 1998; Andersson, 2002). Hereafter, in this thesis, the term basic home healthcare will be used.

♦ *Advanced home healthcare*—care given in the patient's own housing or in housing provided by the municipality, which otherwise should require hospital care, i.e. advanced home healthcare constitutes an alternative, rather than a complement, to hospital care for those patients who so wish. Advanced home healthcare has the following characteristics: it is team-based and led by a physician; the team can be reached day and night; the use of advanced medical technology is common. Other terms, often with the same meaning, are *specialised home healthcare* and *medically extensive home care* (LF, 1998; Andersson, 2002). Advanced home healthcare is synonymous with the two other terms mentioned here, but since the term

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[2] Translated by the author.

advanced home healthcare seems to be used more often in other countries it will be used in this thesis hereafter.

The organisation of advanced and basic home healthcare is different in different parts of Sweden. Either a hospital clinic or a primary care unit provides the advanced home healthcare. Basic home healthcare is often provided by primary care units and concerns patients living in their own housing. For patients living in housing provided by the municipality the care is provided by the municipalities with the aid of primary healthcare physicians (LF, 1998).

In order to meet the patients' wishes to stay at home even during the last stages of a fatal illness, the Motala hospital-based, home care service was initiated in 1977. The aim was to provide the patients with all the resources of the hospital and, in contrast to existing home care programmes, help was offered on a 24-hour basis. This programme came to be known as the Motala Model and was the first advanced home healthcare programme in Sweden to offer an alternative to the hospital (Beck-Friis & Strang, 1993). Advanced home healthcare programmes in Sweden have been, and still are, dominated by palliative care (44 % in 1998) and chronic diseases (34 % in 1998) (SBU, 1999; Andersson, 2002). The World Health Organization, WHO, describes palliative cancer care in the following way:

> "Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement."[3]

Generally *symptoms* are mentioned together with *signs*. The U.S. National Library of Medicine gives the following definition of the MeSH (Medical Subject Headings) term *Signs and Symptoms* (introduced 1998):

> "Clinical manifestations that can be either objective when observed by a physician or subjective when perceived by the patient."[4]

The Medline Plus Health Information, which is a service of the U.S. National Library of Medicine and the National Institutes of Health, defines *symptoms* as:

> "Subjective evidence of disease or physical disturbance observed by the patient."[5]

Symptom control means that symptoms are assessed and reported by the patient (or with the aid of next-of-kin) and acted upon and documented by the caregiver.

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[3] The World Health Organization, WHO (http://www.who.int/en)

[4] The U.S. National Library of Medicine, Medical Subject Headings (http://www.nlm.nih.gov/mesh/)

[5] U.S. National Library of Medicine and the National Institutes of Health
(http://www.nlm.nih.gov/medlineplus/mplusdictionary.html)

Examples of symptoms are nausea, drowsiness, and pain. *Status control*, in this thesis, refers to control of measurable physiological "parameters" of a more objective nature. Examples of status parameters are weight, blood pressure and heart rate.

Pain control in palliative care

Adequate symptom control is one of the most important components of delivering effective palliative care (Dudgeon et al., 1999; Strömgren et al., 2001), whether care is given in a hospital or at home. As people come closer to death their symptoms change rapidly and their need to communicate with their families, friends and health professionals also changes (Davies & Higginson, 2004c). For cancer patients in a palliative state a systematic assessment of pain is crucial (Strömgren et al., 2001; Grossman, 1994; Heedman & Strang, 2003; Davis & Walsh, 2004). It is estimated that, worldwide, nearly 10 million cancer patients experience pain every day (Mindbranch, 2004). Cancer pain affects 20 % to 50 % of patients at the time of initial diagnosis and treatment and 55 % to 95 % of patients with advanced cancer (Allard et al., 2001). Assessing pain is an attempt to gain an objective understanding of a subjective experience. Pain is a private and personal experience and belief in a person experiencing pain is crucial. Patients may feel better by telling a caregiver about the pain and knowing they are believed (Carr, 1997).

The American Cancer Society, ACS, (2006) states that it has become increasingly important to provide adequate pain and symptom control in palliative care. The ACS has established policies that support palliative care, with particular focus on pain and symptom management, and to repeal policies that prevent cancer patients from being able to adequately control their pain and other cancer-related symptoms. In the year 2005 revision of The American Pain Society's *Quality Improvement Guidelines*, the recommendations for high-quality pain management include appropriate assessment and frequent reassessments of patient responses to treatment (Gordon et al., 2005). In Sweden, the Swedish National Board of Health and Welfare has stated that it is essential to introduce new routines in the care of gravely ill patients suffering from pain. Letting the patients assess their pain by using a 100 mm visual-analogue scale (VAS) where the scale is anchored by the words "No pain—Severe pain", the Swedish National Board of Health and Welfare states VAS 30 mm as the highest acceptable rating for pain. The purpose of such routines is to safeguard the care of terminal patients suffering from pain, in the same way as for patients suffering from postoperative pain (SoS, 2001).

During the early and mid 1990s, Rawal et al. (1993) and Arner et al. (1995) reported about the lack of performing pain analysis and pain assessments among doctors caring for Swedish cancer patients suffering from pain. Strang (2002) pointed out the importance of actively asking about and assessing the pain for elderly patients with cancer pain, since the prolonged cancer pain is not "visible" in the same way as is a more acute pain (rapid pulse, stickiness etc.). Australian studies performed by Lewis et al. (1995) suggest that very frequent measurements of pain should be made if a full understanding of chronic pain is to be reached. According to Stone et al. (2003a) intensive assessment schedules (several times per day) of patients' momentary pain can capture pain variations during the day and allow the caregivers to describe the pain pattern over time. In a study including palliative patients at a hospital, Dudgeon et al. (1999) showed the importance of assessing the patients' symptoms twice daily, during the first three days, for those who initially score VAS >= 50 mm (VAS 0 – 100 mm) for the symptoms pain, nausea, depression, anxiety, loss of appetite and shortness of breath.

Pain can be assessed in various ways of which assessing the intensity is one. A tool that assesses the pain intensity, a unidimensional tool, is not always considered enough (Bird, 2005; Ferrell et al., 2000), at least not initially for older patients with pain. Instead, a multidimensional assessment should be performed in the early phase. A multidimensional assessment tool assesses the pain intensity and also describes the pain experience holistically (e.g. pain location, affect and duration) (Bird, 2005). In a study by Heedman and Strang (2003) including 191 palliative cancer patients, with and without pain, the Edmonton Symptom Assessment System (ESAS) (Bruera et al., 1991) was used for symptom assessment at admission and after one week of hospital-based home care. Results from the study included that pain should be described with reference to location, onset and quality, and that a proper pain analysis is essential in pain evaluation. Thus, there is a need for a more frequent collection of pain assessments in palliative care. However, pain assessment of older people is often complicated by sensory and cognitive impairment, motor loss and communication difficulties (Bird, 2005).

As compared to hospitalized patients, it is more difficult to assess home care patients' pain and the degree to which they have responded to the pain therapy (de Wit et al., 1999; Mooney et al., 2002). According to Mooney (2002), it is a challenge to monitor the symptoms of home care patients with post-chemotherapy symptoms since many patients do not know when to call to report their symptoms and they are reluctant to bother the caregivers. To support

caregivers and patients in this matter, home care patients are often asked to use diaries for assessing and reporting their pain (de Wit et al., 1999; Maunsell et al., 2000).

Monitoring symptoms and physiological parameters in home healthcare

When caring for more patients, and sicker patients, in the home, caregivers will need improved support in terms of the remote control of the patient's state of health (Louis et al., 2003; Gagnon et al., 2006). The breakthrough of wireless and Internet technology has introduced new possibilities for home healthcare (Hensel et al., 2006; Gritzalis & Lambrinoudakis, 2000; Bellazzi et al., 2001; Ogawa et al., 1998; Doughty et al., 1996; Herzog & Lind, 2003). IT systems, developed to facilitate symptom and status control in home healthcare, give the possibility of improving control of the patient's health status, increasing patient compliance and reducing healthcare costs (Louis et al., 2003; Noel et al., 2004; Kobb et al., 2003). Observational studies on telemonitoring involving patients with heart failure have shown a reduction of hospital bed-days occupancy, early detection of deterioration, reduced readmission rates and a high patient acceptance and compliance with the system (Louis et al., 2003).

Various networks are involved in systems monitoring the patient in the home (Herzog & Lind, 2003):

♦ Home network—a network within the patient's home consisting of e.g., sensors, input devices and a processing unit for evaluation and display of measured data.

♦ Home-to-server network—a network between the patient's home and the healthcare organisation.

♦ The healthcare organisation's Intranet with databases, work stations and further network connectivity to other healthcare networks.

The network at home and equipment (sensors and processing unit) have to be simple to install and uninstall, as it must be easy to move equipment from one patient's home to another. This is probably more difficult to fulfil with a wired solution, as a good deal of work is involved in connecting the cables correctly and securing the installation so that patients and family members are not endangered or disturbed by the cables. However, the choice between wired and wireless technology within the different networks is not obvious and sometimes

a mix can be the most convenient solution (Herzog & Lind, 2003). Bluetooth[6], a wireless technology for short distances, has been proposed to have advantages over other wireless standards, such as IrDA[7], IEEE 802.11b[8] (Herzog & Lind, 2003), and ZigBee[9], for use in wearable monitoring applications (Yao et al., 2005). IrDA requires line-of-sight between sender and receiver, IEEE 802.11b has complex protocols, a high price and high power consumption, and ZigBee has a limited data rate. Bluetooth operates at 2.4 GHz, uses frequency-hopping to prevent eavesdropping, has low power consumption and a reasonable price (Yao et al., 2005). Wireless technologies for longer distances, suitable for use between the home and the healthcare server are GSM/GPRS/EDGE/UMTS[10] (Herzog & Lind, 2003).

Implementing telemedicine applications in home healthcare makes the role of the patient become more central (Bellazzi et al., 2001). The patient is often more actively involved in the care process and responsible for collecting measurements. Doughty et al. (1996) have described the evolution of telecare systems as divided into three generations by the degree of complexity of the applications. The first generation includes technically very simple systems, for example, personal emergency telephones. The second generation constitutes continuous monitoring of medical as well as environmental parameters, while the third generation adds the possibility of on-line services such as tele-consultation. While the potential of IT- supported telecare systems increases with the generations of the systems, so do the risks and problems associated with the systems. Thus, the study of requirements becomes more important.

Ogawa et al. (1998) have discussed requirements from a biomedical engineering perspective, stating criteria for home health monitoring: data acquisition should be non-invasive and unobtrusive; systems should be fully automated; capable of simultaneous measurement and long-term storage of multiple parameters. According to Bellazzi et al. (2001) several issues, such as security, privacy, confidentiality and usability, should be considered in the definition of web-based telemedicine systems in home healthcare. According to Gritzalis and Lambrinoudakis (2000) the healthcare provider should design, develop and offer patient home monitoring services in a way that conforms to certain evaluation

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[6] Bluetooth (https://www.bluetooth.org/)

[7] Infrared Data Association (http://www.irda.org/)

[8] IEEE 802.11™ Wireless Local Area Networks - The Working Group for WLAN Standards
(http://grouper.ieee.org/groups/802/11/)

[9] ZigBee Alliance (http://www.zigbee.org/)

[10] GSM World (http://www.gsmworld.com)

criteria, such as interoperability of IT components and data protection. Other factors, necessary for success when introducing home monitoring systems, are for nurses to address issues such as technology compatibility with patient capability and motivation (Frantz, 2003). Studies have shown that home telehealth applications mostly concern patients with chronic diseases, such as cardiac and/or pulmonary diseases (Koch, 2006; Meystre, 2005). However, the use of home monitoring also has the potential to facilitate access to healthcare services for vulnerable populations such as palliative patients. Since patients with chronic conditions and severe illnesses can experience difficulties in travelling, home monitoring seems particularly appropriate for these patients (Gagnon et al., 2006).

According to Jovanov et al. (2005) there are certain drawbacks with existing systems for continuous vital sign monitoring; for example, wires between sensors and a processing unit are cumbersome, wireless communication channels shared by multiple devices interfere with each other and there is no support for massive data collection and knowledge discovery. A new technology for health monitoring is the Wireless Body Area Network (WBAN), which integrates a number of very small, lightweight, ultra-low power monitoring devices for physiological sensing with wireless communications. Taking advantage of advanced ultra low-power RF (radio frequency) technology, body area networks wirelessly connect implanted medical devices and on-body sensors with monitoring tools to provide patient health data in real-time. With a two-way RF link, professional caregivers can remotely monitor the health of patients and wirelessly adjust the performance of the implanted device. Research in textile fibres, biomedical sensors and mobile telecommunications integrated with telemedicine, aims at developing intelligent biomedical clothing for personalized management of health and disease (Lymberis & Olsson, 2003; Axisa et al., 2005).

Several vital signs monitoring and communication devices are in use today in the USA; the HomMed[11] is one example, which collects a variety of vital signs such as heart rate, blood pressure, oxygen saturation, body weight and temperature on a daily basis and is used by the patients in their own homes. The data are transmitted via digital wireless technology over a virtual private network for review by clinicians at a local healthcare agency or hospital. The HomMed speaks to users to guide them through the daily vital-signs monitoring process. Disease specific questions are asked and the patient responds to each question by

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[11] Honeywell HomMed (http://www.hommed.com/)

pressing the "yes" or "no" button on the monitor. Other examples are the CareStation[12], and the Health Buddy[13] for symptom reporting. Other technologies for the assessment and reporting of symptoms from the patient's home include the use of mobile and handheld devices (Gaertner et al., 2004; Jamison et al., 2001; Kearney et al., 2006; Koop & Mosges, 2002; Stone et al., 2003b), PCs (Wilkie et al., 2003), telephones (Mooney et al., 2002; Heidenreich et al., 1999), or networked digital pens (Papers II-IV). Different technologies have different strengths and drawbacks and require different kinds of infrastructure, such as wired or wireless networks, in the patient's home. Electronic, handheld pain diaries have been found useful and to provide a high degree of patient satisfaction in studies with patients suffering from chronic pain (Gaertner et al., 2004; Stone et al., 2003b; Jamison et al., 2001). In a study by Kearney et al (2006) the use of a handheld symptom management tool was accepted and rated feasible by patients' receiving treatment for cancer, and by their professional caregivers. Patients reported that by enhancing their knowledge and control, the system helped them to monitor their symptoms, promote self-care and improve symptom management. Cancer patients using a PC with a touch-screen to assess and report their pain, and answer questions, showed a high acceptability and were able to complete all questions in a short amount of time (Wilkie et al., 2003).

Schumacher (1992) has focused on the strengths and weaknesses of phone-based interfaces (PBI) and found that some of the strengths of PBIs are: 1) familiarity, 2) availability, 3) speed—sometimes services are available faster through interactive voice response and 4) privacy—it can feel more private to deal with an interactive voice response instead of a person. According to Schumacher, some weaknesses of PBIs are: 1) the telephone has only auditory output, which places demands on hearing, 2) information is presented serially, which places heavy demands on short-term memory, 3) the telephone keypad has only 12 keys and 4) some cellular telephones can interfere with dual-tone multifrequency input, and also some telephones have the touch pad on the handset itself, causing problems if insufficient pause times are not built into the dialogue. Some of the strengths of PBIs are also the strengths of digital pen technology: familiarity (with using a pen), speed, and privacy. On the other hand, the technologies do not share the same weaknesses: patients who have hearing or short-term memory problems will not be prevented from using the digital pen technology and they will not be dependent on sufficient pause times being built into the system. Depending on the type of digital pen technology, other weaknesses such

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[12] SCOTTY (http://www.scottygroup.com)
[13] Health Hero Network (http://www.healthhero.com/)

as distance limitations for Bluetooth radio links, the current operator's coverage for GSM/GPRS and limitations in user feedback, can be addressed (Paper II).

Digital pen technology

Digital pen technologies have been on the market and in use in different areas, such as healthcare, for a few years (Bång et al., 2004; Cole et al., 2005; Despont-Gros et al., 2005; van Terheyden, 2004; Briggs, 2004; Papers II-IV). There are several different digital pen technologies on the market today, for example, the Compupen™ from Pen2Net[14], the VPen™ from OTM Technologies[15] and the Anoto™[16] digital pen. Several manufacturers use the Anoto technology in their digital pens, for example, Sony Ericsson, Nokia and Logitech, with the digital pens Sony Ericsson Chatpen™[17], Nokia Digital Pen SU-1B[18], and Logitech® io2™[19] respectively.
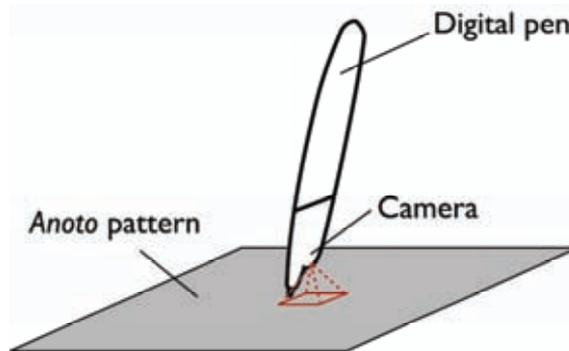

Figure 1. The Anoto digital pen (reprinted with permission from Anoto AB)

The Anoto Technology consists of the Anoto pattern, paper and printing, the digital pen, architecture and interfaces. It is based on a digital pen and a paper printed with a pattern that is almost invisible to the eye. The Anoto digital pen looks and feels like an ordinary ballpoint pen and is used in the same way. The

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[14] Pen2Net (http://www.compupen.com/)
[15] OTM Technologies (http://www.otmtech.com/)
[16] Anoto (http://www.anoto.com)
[17] Sony Ericsson (http://www.sonyericsson.com)
[18] Nokia (http://www.nokiausa.com/)
[19] Logitech (http://www.logitech.com/)

difference is the internal part of the pen, which consists of a camera, an image processing unit and a communication unit. The paper consists of ordinary paper printed with a dot pattern, which is visible as an off-white coloured background on the paper. The dots—100µm in diameter—are slightly displaced from a square grid with a nominal spacing of 0.3 mm. By using this displacement it is possible for the pen to know its exact position in the whole pattern space. The small camera in the tip of the digital pen registers the pen's movement across the grid surface on the paper (see **Figure 1**) and stores it as a series of map co-ordinates.

The Anoto Functionality enables the digital pen to communicate with a device, for example a mobile phone or a PC. In the case of a mobile phone, for transmitting the written information the user simply puts a tick in a special area of the page—the send box ("Magic box"). Ticking the send box makes the pen
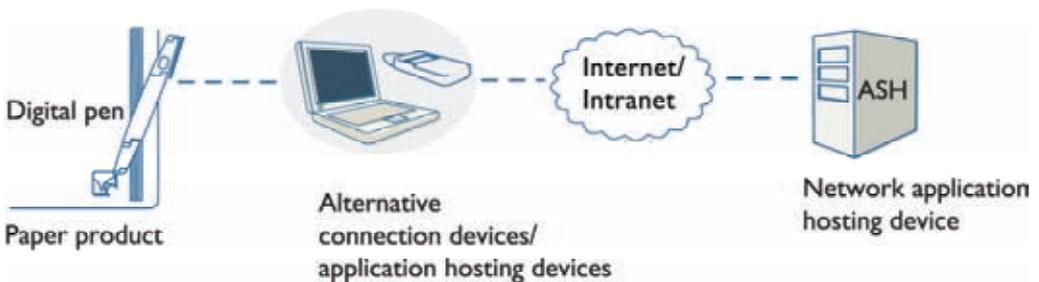

Figure 2. *Service enabled by Anoto functionality (reprinted with permission from Anoto AB)*

vibrate, which constitutes feedback about data transmission from the pen to the user. The data are sent from the pen using a Bluetooth radio link to the mobile telephone, which passes the data further to the Application Service Handler (ASH) over, for example, the GSM/GPRS mobile network (see **Figure 2**).

3. Aims of the thesis

The overall aim of this thesis was to describe relevant requirements, to design and implement an IT-based system, and finally to evaluate the system's influence on symptom control and support for both patients/next-of-kin and professional caregivers in advanced home healthcare.

The specific aims of the thesis were:

Paper I: to establish and describe requirement areas to be considered when monitoring a patient in the home.

Paper II: to design, develop and implement a pain assessment system by use of a pain diary, digital pen and mobile Internet technology, aimed at functioning as support for both professional caregivers and patients/next-of-kin.

Paper III: to explore and describe palliative home healthcare patients' experiences of assessing their pain by using the pain assessment system.

Paper IV: to explore and describe professional caregivers' experiences of palliative home healthcare patients' use of the pain assessment system.

4. Materials and methods

The research carried out through the AHHE projects covers problem areas and needs in both basic and advanced home healthcare and combines the usability perspectives of patients as well as professional caregivers. Important requirement areas to be considered when monitoring patients in home healthcare, such as security, mobility, and responsibility, had to be analyzed together with possible technical infrastructures in terms of network solutions. A prototype system was designed and developed for everyday assistance for diabetes patients and also a system for the follow-up of pain treatment for palliative home healthcare patients was designed and implemented in routine care at a hospital-based home care clinic. The latter system explored the potential of supporting advanced home healthcare with digital pen and mobile Internet technology. The choice of digital pen technology was taken in regard to the fact that the hospital-based home care clinic used paper-based medical records. For an overview of the design, objectives, approaches, data collection and participants in Papers I-IV, see **Tables 1 – 3**.

Requirement areas (Paper I)

The design and data collection used in Paper I comprised a literature study, structured discussions and also discussions with professional caregivers and personnel responsible for security issues and the formation of a requirements-and-design group. For an overview, see **Table 1**.

The literature study aimed at: (a) identifying dilemmas and needs within home healthcare in general; (b) finding conformities and differences in different home healthcare settings; (c) finding research work related to the monitoring of patients in the home; and, (d) identifying requirement areas to be considered at the prospect of monitoring a patient in the home. Examples of MeSH terms used in the Medline search for articles about home healthcare were: *Home Care Services, Hospital-Based; Palliative Care; Terminal Care; Aged, 80 and over; Health Services for the Aged; Geriatric Nursing, methods; Nursing Homes; Family Practice; Geriatric Assessment; Quality Assurance, Health Care; Quality of Life; Delivery of Health Care; House Calls.* Some of the MeSH terms used in articles about the use of information and telecommunication technologies within home healthcare were: *Telemedicine; Telephone; Computer Communication Networks; Monitoring, Physiologic;*

Monitoring, Ambulatory; Remote Consultation; Technology; Automatic Data Processing; Computers, Handheld; and *Computer Security*. Various combinations of the above-mentioned MeSH terms were used and other terms (not MeSH), such as, *home monitoring, telemonitoring, telecare, telehomecare* and *home telehealth* were added. Structured discussions with professional caregivers within home healthcare organisations in Linköping, i.e., HBHC which provides advanced home healthcare, and primary healthcare, which provides basic home healthcare, and discussions with personnel responsible for security issues were accomplished on several occasions with the aim of identifying dilemmas and needs within local home healthcare. Furthermore, the aim was to identify requirement areas for remote monitoring. For the design and development of a prototype IT-support system the formation of a requirements-and-design group was carried out with the purpose of collecting data. An iterative approach including low-fidelity and high-fidelity prototypes (Walker et al., 2002), was used during the five occasions the group met (Sundvall, 2003).

Table 1. *Overview of the design, objectives, data collection, content, researchers and participants in Paper I*

Paper	Design/ Objective	Data collection/Content	Researchers/ Participants
I	Literature study/ Identify dilemmas and needs within home healthcare; identify requirement areas for remote monitoring; search for conformities and differences in different home healthcare settings	Search through Medline, University library, The Swedish Federation of County Councils', and, The Swedish National Board of Health and Welfare's web-sites	Main researcher, 1 under-graduate student
	Identify dilemmas and needs within home healthcare; identify requirement areas for remote monitoring	Structured discussions. 4 occasions	2-4 physicians, 1 nurse, and 2-3 researchers
	Identify requirement areas for remote monitoring	Discussions. 2 occasions	1-2 personnel responsible for IT-security, and 2 researchers
	Design and develop a prototype IT-support system	Requirements-and-design group discussions. Use of a low-fidelity prototype. 5 occasions	2 nurses, 1 researcher, 1 graduate and 8 under-graduate students

Pain assessment in palliative home healthcare (Papers II-IV)

System design and development

See **Table 2** for an overview of the design, objectives, data collection and participants in the design, development and implementation of an IT-support system for frequent pain assessment by use of a pain diary and digital pen technology (Paper II).

A requirements-and-design group was formed with the aim of identifying requirements for the system and related routines, concerning the design of a pain diary form and the design and functionality of the web-based clinical application (Ålund, 2003; Berggren, 2003) and daily routines for management of the pain assessment system. Two nurses, one physician, two researchers and three undergraduate students formed the group, which met on 16 occasions during 6 months. Occasionally two other physicians participated in the meetings. For the design of the web-based system an iterative approach including low-fidelity and high-fidelity prototypes (Walker et al., 2002), was used.

Evaluation

The research methods used for evaluation in the study on patients' use of pain diaries and digital pen technology for frequent pain assessment were:

- ♦ a qualitative descriptive and explorative case study design with a cross-case content analysis approach, which included interviews with patients and spouses, an ease-of-use questionnaire, medical records and the system log (Paper III).

- ♦ a qualitative descriptive and explorative design with a content analysis approach, which included interviews with professional caregivers, the system log and the participating patients' medical records (Paper IV).

The qualitative approach was chosen in studies III-IV with the purpose of describing the patients', spouses' and professional caregivers' experiences of patients' use of pain diaries and digital pen technology for frequent pain assessment and to structure and organise the analysis material to enable reduction, interpretation and the drawing of conclusions (Graneheim & Lundman, 2004). See **Table 3** for an overview.

Table 2. Overview of the design, objectives, data collection, content, researchers and participants in Paper II

Paper	Design/ Objective	Data collection/Content	Researchers/ Participants
II	Literature study/ Explore digital pen technology	Searches through Internet (e.g. Anoto's, Pen2Net's web-sites) and Medline	2 researchers
	Explore the possibility of using Anoto digital pen technology for symptom assessment within HBHC	Performance of a usability try-out/ Usability try-out including the filling out of symptom assessment forms by use of a Chatpen. Questionnaire for the patients	5 patients, 2 nurses, 1 under-graduate student and main researcher
	Design an IT-support system for frequent pain assessment by use of a pain diary and digital pen technology	Requirements-and-design group discussions. Use of low-fidelity and high-fidelity prototypes. 16 occasions	2 nurses, 1-3 physicians, 2 researchers, 3 under-graduate students
	Develop and implement the IT-support system (receiver and clinical application)	Pen requests, interpretations and storage of data by Java Servlet. Showing of assessment data by a three-tier web application	1 researcher, 2 under-graduate students
	Establish security guidelines for the system	Discussions. 4 occasions	1-2 personnel responsible for IT security and medical devices, 2 researchers
	Educate professional caregivers on how to use the system and handle the digital pen and pain diary	Training in groups of 5 persons during 1 hour. Distribution of information material such as user's guide and instructions for patients	2 researchers, 1 under-graduate student

Table 3. Overview of the design, selection, data collection and data analysis in Papers III and IV

Paper	Design/Approach	Selection/ Participants	Data collection	Data analysis
III	Descriptive and explorative/ palliative home care patients' experiences of assessing their pain by using a pain diary together with digital pen and mobile Internet technology	Purposive sampling performed by the professional caregivers after fulfilling inclusion criteria/ 12 patients and 4 spouses	Interviews, ease-of-use questionnaire, the pain assessment system (data from log files and patient data from the system database) and medical records forming 12 patient cases	Qualitative cross-case content analysis
IV	Descriptive and explorative/ professional caregivers' experiences of palliative home healthcare regarding patients' use of pain diaries and digital pen technology for frequent pain assessment	Purposive sampling by the researchers/ 2 physicians, 3 nurses and 1 secretary	Interviews, patients' medical records and the system log	Qualitative content analysis

Setting and context

The study on patients' use of pain diaries and digital pen technology for frequent pain assessment was conducted between December 2002 and September 2003 at the hospital-based home care clinic (HBHC) at Linköping University Hospital. The HBHC clinic served around 500 patients per year. Travelling by car it should take no more than 30 minutes for the professional care team to reach a patient's home; therefore all patients lived in, or near to, Linköping.

Traditionally, patients receiving care from the HBHC clinic had frequent contact with their professional caregivers, either via a telephone or home visits, during which they conveyed their pain and other symptoms. The reporting of pain could be accomplished in a non-structured way through an informal talk about the pain with the visiting nurse or on the phone. Occasionally pain assessment could be performed using a VAS instrument carried by the nurse. Quality assurance work with the focus on pain control was initiated during 2002 within the HBHC clinic, at the same time as the clinic moved to a new location in the hospital and underwent organisational changes. The intervention involved the introduction of pain management clinical guidelines, which consisted of

guidelines for pain treatment for patients assessing at least moderate pain (visual analogue scale, VAS >= 35 mm rounded to 4 cm). A system for frequent pain assessments and the follow-up of pain treatment for the clinic's palliative patients at home was designed and implemented. This included the use of a pain diary and digital pen technology. The pain diary form consisted of a VAS (0 – 100 mm) for pain intensity and boxes for the number of consumed extra doses of analgesics. Security guidelines were drawn up, which concerned the simultaneous use of medical devices and devices emitting radio frequencies, in this case mobile phones (GSM/GPRS) and digital pens (Bluetooth). The patients assessed their immediate pain three times per day at regular times. During daytime the secretaries checked the system and printed the assessments. In the evenings and at weekends, the assessments were examined, printed and signed by the nurse responsible. Before the onset of the study, the professional caregivers were instructed about how to use the system and how to inform and instruct patients.

Ethical considerations

Prior to the study approval was given by The Regional Ethical Review Board at Linköping University, Sweden.

Patients (Paper III)

The researchers were not involved in the information and instruction of the participating patients, instead the professional caregivers informed the patients about the voluntariness to participate and they received written information about the study. After four days of use the caregivers asked the patients to fill out a questionnaire and immediately after the pain assessment period the patients were asked to participate in a face-to-face interview with one of the researchers. When a patient consented to be interviewed, the main researcher made contact by telephone and arranged a time and place for the interview. If the patient lived with a spouse, a question about interviewing the spouse as well, on a separate occasion, was posed. The interviews were performed by the main researcher in the patients' homes.

Professional caregivers (Paper IV)

Interviews with the professional caregivers were performed at the HBHC clinic on separate occasions. The main researcher and a co-researcher performed an equal number of interviews.

Patients, spouses and professional caregivers (Papers III – IV)

A thorough explanation of the study was given by the interviewer prior to the interview and the informants were reassured that they could interrupt the interview at any time. Informants—patients, spouses and professional caregivers—were assured of confidentiality. The names of all informants were erased following the transcription and codes were used to identify the informants. The audiotapes were stored in a locked cabinet in a locked room and the transcripts were stored on a server. Only the participating researchers had access to the data.

Participants

Patients (Paper III)

Inclusion criteria required the patients to be mentally clear and Swedish-speaking to the level of understanding the pain diary form and how to use the equipment. Further, necessary infrastructure in the patient's home included one wall socket and sufficient coverage for GSM/GPRS. Twelve patients fulfilled the criteria and participated (**Table 4**). Of those 4 were women and 8 men, aged 58 to 79 years in range (median 65.5 years, mean 67 years), nine lived with a partner, eleven had regular opioid analgesics for pain control plus opioids prescribed for the relief of intermittent pain; so-called extra doses of analgesics. Nine patients answered an ease-of-use questionnaire and six were interviewed. Additionally, four spouses (all women, 56 to 73 years) were interviewed.

Table 4. *Socio-demographic and clinical data from the patients at the hospital-based home care clinic*

P*n*	Gender (F/M)	Age[a] (years rounded to the nearest five)	Period length with the pain assessment method[b] (days)	Number of assessments[b]	Per cent of pain assessments VAS >=4 cm[b] (%)	Total number of extra doses of analgesics per period[b] (reported by patient)	Number of days in life after the period[a] (days)
P1	F	60	14	33	12	26	10
P2	M	80	12	35	63	2	49
P3	M	80	7	21	81	3	121
P4	M	60	17	52	58	20	27
P5	M	65	6	15	7	9	7
P6	M	65	8	19	84	42	56
P7	M	65	4	7	57	7	0
P8	F	65	10	26	4	0	21
P9	F	60	13	40	25	4	223
P10	M	60	10	28	0	0	144
P11	F	75	8	20	20	14	3
P12	M	75	13	37	30	81	153

a. Data collected from the medical records.
b. Data collected from the pain assessment system.

Professional caregivers (Paper IV)

Purposive sampling was used where the maximum number of variations of informants was sought; i.e., different background and education, years of experience with palliative home care, age and gender. An inclusion criterion for the professional caregivers was to have been responsible for at least one of the participating patients during his/her pain assessment period. Accordingly, six staff members—five women and one man, 37 to 62 years in range (mean 48.5 years, median 47 years)—at the HBHC clinic were interviewed. Of these, three were nurses, two were physicians and one was a secretary. Their experiences of palliative home care varied from 1½ to 15 years. In order to avoid identification of the participating professional caregivers a table with caregiver data is excluded.

Data collection

During the in-depth, face-to-face interviews, interview guides—supporting the interviewer's memory and triggering the discussion (Patton, 2002; Kvale, 1996)—

were used and each informant was asked to talk about experiences during the pain assessment period.

Patients (Paper III)

The questions in the interview guide, posed to the participating patients and spouses, concerned experiences from using the digital pen and pain diary including possible changes in the contact with the professional caregivers, the patients' health status during the assessment period and reflections on the technology. The interviews were tape-recorded and lasted between 30 – 60 minutes. In addition, data were collected from the ease-of-use questionnaire, the pain assessment system and medical records. The questionnaire contained open-ended and structured questions concerning ease-of-use of the digital pen, ease-of-use of the pain assessment instrument, information and instructions from professional caregivers, change in caregiver contact patterns and, change in quality of care.

Twelve patient cases (Patient 1-12) were formed including interview texts from four spouses, which were coupled to four of the patients' cases respectively. Of the twelve patient cases six were more complete, each including patient interview texts and four of them including spouse interview texts.

Professional caregivers (Paper IV)

In the interviews with the professional caregivers, the guiding questions concerned expectations, motives to use the system, caregivers' experiences of the system and caregivers' perception of the patients' experiences. The interviews lasted 20 – 60 minutes, were audiotaped and transcribed verbatim. In addition to the interview texts, data from the system, i.e. data from log files, the requirements-and-design document and the participating patients' medical records were collected. The major analysis material consisted of interview texts from the interviews.

Data analysis

Description of case studies and qualitative content analysis

A case study means organising the data by specific cases for in-depth study and comparison (Patton, 2002). Cases can for example be groups, individuals, organisations, cultures, or a stage in the life of a person or a programme. What constitutes a case is usually determined during the study design and becomes the basis for purposeful sampling in qualitative studies.

> Case data consist of all the information one has about each case: interview data, observations, the documentary data (e.g. program records or files, newspaper clippings), impressions and statements of others about the case, and contextual information — in effect, all the information one has accumulated about each particular case goes into that case study (Patton, 2002, p. 449).

According to Stake, the use of a case study is a choice of what is to be studied, i.e. it is not a methodological choice. A case can be studied in different ways; analytically or holistically for example, or by mixed methods and it should capture the complexity of a single case (Stake, 1995; Stake, 2000).

> We study a case when it itself is of very special interest. We look for the detail of interaction with its context. Case study is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances (Stake, 1995, p. xi)

Also Hamel et al (1993) discuss whether a case study is a method or an approach.

> But is the case study a method? Or is it an approach? … Case studies employ various methods. These can include interviews, participant observation, and field studies. Their goals are to reconstruct and analyze a case from a sociological perspective. It would thus be more appropriate to define the case study as an approach, although the term *case method* suggests that it is indeed a method (Hamel et al. 1993, p. 1).

Hamel et al. (1993) state that the case study has proven to be in complete harmony with the three key words that characterize any qualitative method: describing, understanding, and explaining. According to Patton (2002) a case study represents an analysis process by its specific way of collecting, organising and analysing data. By gathering in-depth and systematic information about each case of interest the analysis process results in a product: the case study. The question of whether case studies can be generalized is discussed by Stake (1995) who claims that case study seems a poor basis for generalization. Instead of generalization in case study, the real business is particularization, according to Stake. Particularization is taking a particular case and coming to know it well, not in the first place as to how it is different from others but what it is and what it does. The emphasis is on uniqueness, which implies knowledge of others that the case is different from, but the primary emphasis is on understanding the case itself. Cases are units of analysis (Patton, 2002). What constitutes a unit of analysis is often determined during the design stage of the study and becomes the basis for purposeful sampling. The fieldwork often involves several smaller case studies of various units of analysis—individuals, groups, activities, etcetera—which together make up the overall case study. If more than one object of study is included in the fieldwork the case study may be layered and nested. A part of the data for the overall case study can then be the results from a cross-

case pattern analysis of the smaller, individual cases. An example is when the primary focus of the study is variations in the experiences of individuals. Here it is suitable to begin the analysis by writing a case description of each individual and continue with a cross-case content analysis.

Content analysis is used to identify core consistencies and meanings in a volume of qualitative material, and these core meanings are often called patterns or themes. In the case of interview material for analysis the researcher can choose to begin with a case analysis (as exemplified above) or a cross-case/cross-interview analysis which, for example, means grouping together answers from different people to common questions. If an interview guide approach has been used during the interviews the latter analysis approach can be implemented by using the guide as a descriptive analytical framework for analysis, grouping answers from different individuals by different topics in the guide. Qualitative studies often include both individual cases and cross-case analyses — it is more a question of which to begin with (Patton, 2002).

Qualitative content analysis as a method has several characteristics, among them it focuses on the subject and context and it also points out differences and similarities between and within categories (Graneheim & Lundman, 2004). Graneheim and Lundman discuss the confusion with concepts used in qualitative content analysis, among them the use of concepts describing trustworthiness which, according to the authors, is predominated by concepts within quantitative research. The authors give definitions of and suggestions for suitable concepts in qualitative content analysis together with definitions and explanations on three aspects of trustworthiness – credibility, dependability and transferability.

Data analysis (Paper III – IV)

The qualitative content analysis was accomplished in six steps (Graneheim & Lundman, 2004). In Paper III, the units of analysis were the twelve patient cases. In Paper IV the units of analysis were the interview texts together with additional analysis material.

1. *Impression*. The main researcher started the analysis by reading the transcripts, and comparing them with the audiotaped interviews, with the purpose of checking accuracy. The medical records and patient data from the system database were studied. In study III the ease-of-use questionnaire answers were read through. Thereby, a first impression of the material was achieved.

2. *Rereading*. The material was read through several times to obtain a sense of the entirety and was thereafter shown to two researchers otherwise not involved in the study.

3. *Coding.* While analysing, the researchers searched for patterns in the material. Meaning units in the transcribed interviews, which corresponded with the aim, were coded. Two researchers coded the texts; thereafter the codes were discussed and compared with one another and the text until agreement was reached. Subsequently the texts and codes were discussed with the two researchers, otherwise not involved in the study, to gain new insights and ideas and to reach agreement on the codes. When agreement was reached, adjustments to the coding were made.

4. *Inductive process.* In this step the texts were condensed in order to filter out irrelevant information. This was done by the main researcher who scrutinized the texts with the intention of identifying patterns that appeared meaningful.

5. *Reduction.* The condensed texts were read through and compared with the original texts after which they were reduced and re-coded in broad groups. They were thereafter discussed with a researcher with long experience of qualitative analysis.

6. *Validation process.* The codes and the original interview and, in study III, questionnaire texts were considered and descriptive categories were formed based on the aim of the study. All noteworthy quotations were documented under the respective category/subcategory. To verify that the quotations were in agreement with the categories and subcategories the texts were read through once more and discussed by the main researcher and a co-researcher until agreement was reached.

During the analysis all complementary material was taken into consideration. Subsequently, the writing process began. The main researcher abstracted the meaningful information in the most conspicuous parts of the text in each category.

5. Summary of Papers I-IV

Requirement areas (Paper I)

Paper I (and III) pointed out the local home healthcare problem areas *organisation and communication*, *quality of care*, *security*, *responsibility*, *confidence and trust* and *symptom and status control*. Focus for further investigations was the area preserving and improving symptom and status control. Systems for monitoring the patient with regard to certain medical parameters, as well as assessed symptoms, could be tried out as a way of improving the patient's state of health. There are, however, certain differences between monitoring an in-hospital patient and a patient in the home. Paper I established requirement areas to be considered before monitoring medical parameters in the home and sending data to remote information systems. The requirement areas were *security*, *responsibility*, *integrity*, *mobility* and *ease-of-use*. The need for *event monitoring* including data reduction and data-driven alarms was also discussed.

The design of a prototype system with the purpose of helping the patients to understand their own diabetes was described. The system was designed for the patients to be in control of exactly which data they chose to send to the healthcare professionals and which way data were sent over the network. In this way, the patients were free to choose the most convenient and familiar device for data input combined with the most trusted and convenient ways to send the data. The scenario in **Figure 3** shows the following: (1) The patient calls a telephony gateway and enters information through a touch tone or mobile phone, for example sends an SMS message about food and exercise. (2) The information is converted to an e-mail that is sent to the mail server that the patient has chosen. (3) When the patient is at home, he/she can download all mails to his/her own PC and diabetes application while, at the same time (4) he/she can extract stored glucose measurements from the glucose meter. The patient can now visualise the measurements and events in a diagram, which shows food and insulin intake, blood glucose levels etc., and before sending the data to the healthcare centre, (5) the patient can select the data he/she wants to keep private. That is, the patient owns and controls his/her medical data. (6) The patient sends the medical data to his/her healthcare provider, for example a diabetes clinic. The prototype system has not been tried out by any patients.
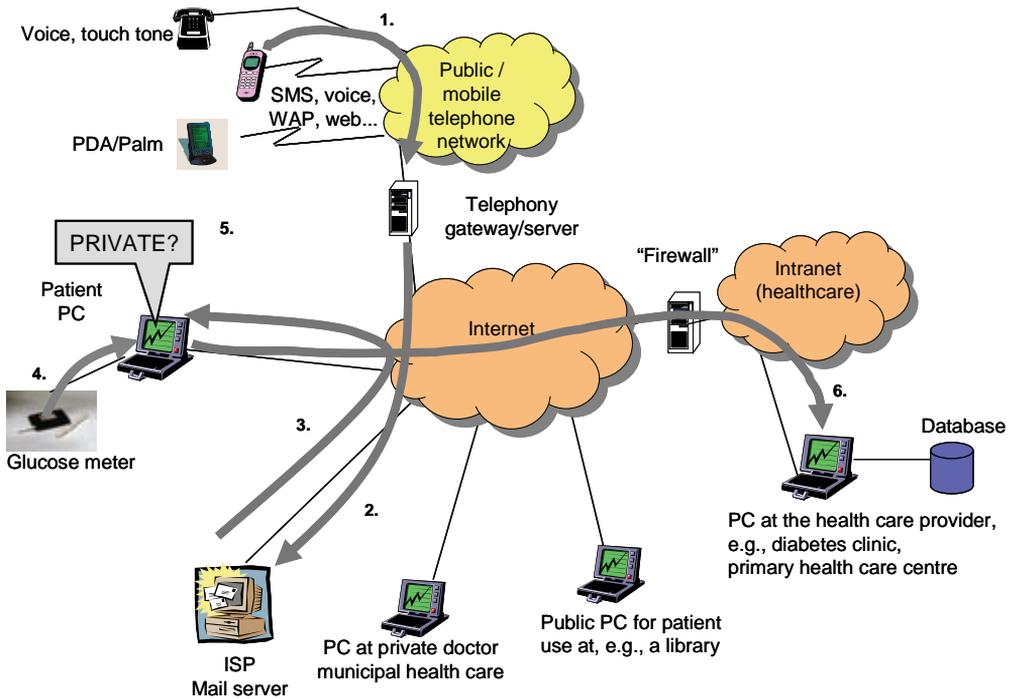
Voice, touch tone

1.

Public / mobile telephone network

SMS, voice, WAP, web...

PDA/Palm

Telephony gateway/server

"Firewall"

Intranet (healthcare)

5.

PRIVATE?

Patient PC

Internet

4.

Glucose meter

3.

6.

Database

2.

ISP Mail server

PC at private doctor municipal health care

Public PC for patient use at, e.g., a library

PC at the health care provider, e.g., diabetes clinic, primary health care centre

Figure 3. Design of a diabetes prototype system.

Use of digital pens for pain assessment: System description, and patients' and professional caregivers' experiences (Papers II-IV)

System development

Paper II compared different technologies for the reporting of symptoms in home healthcare; e.g., a PC/PDA, a touch-tone telephone and a digital pen, which all require different kinds of infrastructure in the patient's home (see **Table 5**), and which differ in strengths and weaknesses.

Table 5. Comparison of alternative technologies for symptom assessment (adapted from Hallgren, 2002)

	Without use of any technology	With digital pen technology (Anoto)	With phone-based interface	With fax	With PC
Ease-of-use	Good. Most patients are able to talk	Good. Most patients are able to handle pen and paper	Varies. Hearing and short-term memory problems may be an issue	Poor. Most patients are not used to handling a fax machine	Poor. Many older patients have never used a computer
Learning time	None	Very short. Short introduction enough for most patients	Very short	Varies. Depends on previous experiences and type of fax machine	Long. Requires computer education
Automation	No	Yes	Yes	Requires recognition software	Yes

The requirements-and-design group identified requirements for the system and related routines, such as the caregivers judging whether a patient would be able to use the digital pen and the pain diary; that it should be possible to display the pain assessments both as a diagram and as an image of the pain diary originally submitted by the patient; security guidelines should be drawn up; the clinic's secretaries should help with checking the system for incoming assessments and printing the assessments during the daytime.
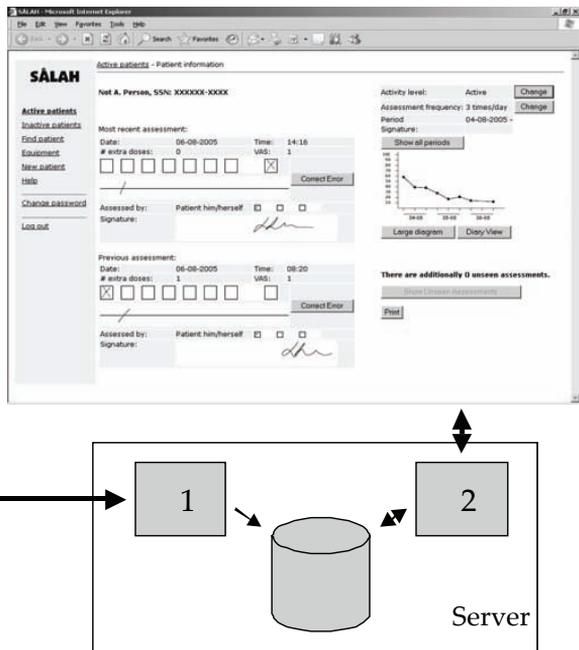
Figure 4. Infrastructure and system components (translated into English)

A system for frequent pain assessments and the follow-up of pain treatment for palliative patients at home was designed and implemented at the HBHC clinic during a period of nine months. The system was based on WWW technology. In the home, pen strokes were captured using digital pen technology and were transferred digitally over the GSM/GPRS mobile phone network from the patient's home to the HBHC clinic. The system was developed using Java Servlet and Java Server Pages technologies. On the server side, the system consisted of two components: (1) the receiver application and (2) the clinical application (Ålund, 2003; Berggren, 2003) (see **Figure 4**). The receiver application was responsible for receiving information from the digital pen and for storing received data in a database. The clinical application implemented the client functionality. A pain diary form was designed and consisted of a VAS (0 – 100 mm) for pain intensity and boxes for the number of consumed extra doses of analgesics (see **Figure 5**).

Pain diary

Prescribed daily analgesics: ……………………………………………………

…………………………………………………………………………………………

Extra doses, analgesics: …………………………………………………………

Date:…………………..   Time:………………………   No
                                                                       extra dose
Number of extra doses since last
assessment: (mark each with a tick)   ☐ ☐ ☐ ☐ ☐ ☐ ☐   ☐

No   Severe
pain ——————————————————————————   pain

Assessed by: Patient ☐ Help from next-of-kin ☐   Help from caregiver ☐

Signature:………………………………….   Send to HBHC

Figure 5. Part of the pain diary (translated into English)

Patients used the pain diary and digital pen technology to assess their momentary pain three times per day at regular times. The professional caregivers used the clinical application (**Figure 6**) to monitor the patients' pain status. The application allowed caregivers to view patients currently using a digital pen and, on a single screen, view the patient's two latest assessments and a curve describing the pain assessments of the last three days. Furthermore, it was possible to view historical data, both in a form mimicking the original pain diary form and as a graph displaying both VAS data and number of intakes of extra doses of analgesics. For each assessment, one could view the time and date, the number, and exact time of intakes of extra doses of analgesics and the assessment and the signature of whoever filled in the form. Administration of patients and pens in the system could be carried out. The system required no installation in the homes of the patients and the patients did not need to configure or use the mobile phone during the study (Paper II).
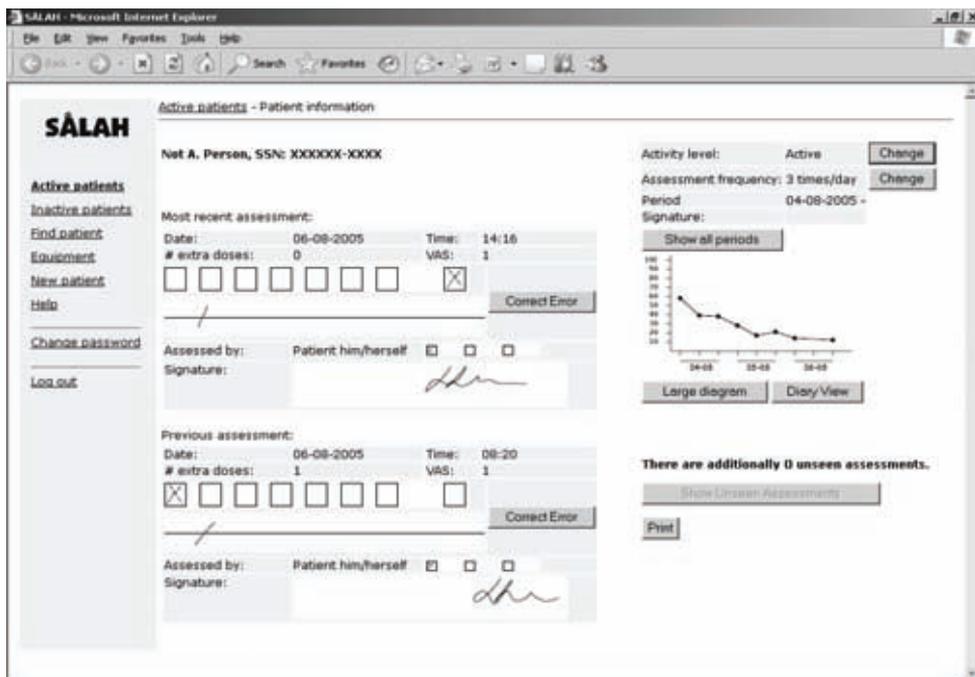
Figure 6. The client, demo version (translated into English)

Evaluation of the pain assessment system

Evaluation of the pain assessment system aimed at exploring and describing patients' and professional caregivers' experiences of the system. For an overview of socio-demographic and clinical data from the study patients at the hospital-based home care clinic, see **Table 4**.

Six sub-categories showing patients' experiences of using a pain diary and digital pen technology for frequent pain assessment were identified and described in two categories: (1) *Effortless method for pain assessment* and (2) *Positive influences on the care* (**Table 6**)*.* One selected original quotation, translated into English, from each category is presented to illuminate the experiences of the patients.

Table 6. Categories and sub-categories concerning the patients' experiences

Categories and Sub-categories
Effortless method for pain assessment
Difficult to understand the technology and system but easy to use the equipment
Managed to assess the pain in spite of one's health condition
Overcome technical problems
Positive influences on the care
Increased and improved contact with the caregivers
Increased participation in one's own care
A sense of increased security

The professional caregivers' experiences of the patients' use of pain diaries and digital pen technology for frequent pain assessment resulted in two categories: (1) *Shifting outlook towards the pain assessment method* and (2) *Positive patient influences*, emerging from seven sub-categories (**Table 7**). One selected original quotation, translated into English, from each category is presented to illuminate the experiences of the professional caregivers.

Table 7. Categories and sub-categories concerning the professional caregivers' experiences

Categories and Sub-categories
Shifting outlook towards the pain assessment method
Low expectations
Reluctance to use the system
Positive caregiver outcomes
Suggestions for future use
Positive patient influences
Improved changes in pain treatment
Increased participation in the care
Increased security

Effortless method for pain assessment

The pain assessment method was regarded as being effortless in spite of the patients' state of health. The patients made it clear that they could handle the digital pen, which was looked upon and used as an ordinary pen, and they could easily interpret all parts of the pain diary. They did not need help from their

next-of-kin in writing with the digital pen. The spouses did not help with writing but could help with other things, such as reminding the patient to perform the assessment. It was furthermore revealed that understanding of the technology and pain assessment system was limited but the motivation to use the method was not decreased by technology problems.

"No, I was never too bad to use the pen."(*Patient 4*)

Positive influences on the care

The patients perceived an increased and improved contact with their professional caregivers. Using the digital pen and pain diary was described as superior to using the phone for reporting the pain, since the former was seen as a less intrusive way. The method also made it possible to report improvements in pain in an easy way. The patients took a greater part in their own care. By keeping the original pain diaries the patients could go back and see for themselves how the pain had varied over time and this led to a wish to continue with the pain assessment after the period using the digital pen. What the patients appreciated above all with the pain assessment method was that it resulted in a sense of increased security.

"Well I must say it's absolutely clear that it is positive … and only has advantages, for it is considerably faster. I can reach them [the caregivers] easier and that means a feeling of greater peace for me, which is the main thing." *(Patient 12)*

Shifting outlook towards the pain assessment method

The professional caregivers' outlook was initially cautious due to low expectations concerning the patients' abilities and due to uncertainty about how to use the system. Contemporary organisational changes put the caregivers under stress and the pain assessment system was described as increasing their workload. Although they were reluctant to use the system and change their way-of-working, the caregivers experienced positive outcomes. They found it valuable to receive information on the patients' pain situations and they had learnt to be more aware of and focus on the patients' pain. The improvement suggestions for future use comprised assessment of all pain locations and assessment of more symptoms.

"Somehow we use the VAS in a little more objective way than we did before … I don't say in words that the patient is in more or less pain, instead I say that 'The patient assesses pain VAS six'. Later on in the afternoon he perhaps assesses VAS three … then it is not my subjective judgment of what he tells me, but his objective." *(Nurse 1)*

Positive patient influences

This category comprised the professional caregivers' perception of the participating patients' experiences. The patients had benefited from the pain assessment method by means of increased participation in their care, increased security and by improved responses to pain fluctuations in terms of changes in treatment. According to the caregivers, patients sometimes seemed to be somewhat amused by using the pain assessment method, which led to continued pain assessment after the period.

> "I believe that some patients have received much quicker help than if we had handled this in routine care." *(Physician 2)*

6. Discussion

Methodological considerations

The overall aim of this thesis was to describe relevant requirements, to design and implement an IT-based system and, finally, to evaluate the system's influence on symptom control and support for both patients/next-of-kin and professional caregivers in advanced home healthcare. To accomplish this, three types of triangulation have been used: *data triangulation*—the use of a variety of data sources, such as scientific databases, results from discussions in requirements-and-design groups and from study evaluation; *investigator triangulation*—the use of several different researchers and evaluators such as professional caregivers, patients and researchers; and, *methodological triangulation*—the use of different methods such as literature study, qualitative content analysis and qualitative cross-case content analysis. According to Patton (2002), the use of triangulation strengthens a study. Triangulation has also been proposed to be particularly appropriate for home telehealth evaluations (Gagnon et al., 2006).

Limitations in the study of literature

Scientific papers about home healthcare and the use of information and telecommunication technologies within home healthcare in Medline and other scientific databases have increased during the last 5-10 years (Koch, 2006). Nevertheless, due to lack of uniform indexing in Medline, search results may not be fully complete and reliable (Funk & Reid, 1983; Koch, 2006).

Prototype application for diabetes patients

In designing and developing the prototype application for diabetes patients no patients were directly involved and this can be seen as a limitation. The decision for this was, however, taken as a result of the limited scope of designing and developing a prototype application only. The two nurses, who had daily contact with diabetes patients, represented both the caregivers and the patients in the requirements' engineering work.

Pain assessment in palliative home healthcare

The choice of using VAS as an instrument to assess the pain was made due to the fact that HBHC's nurses and physicians traditionally used this instrument, although not very often, and they wished to continue with using the VAS. The VAS is considered valid to assess pain intensity in clinical trials and in other types of studies (Caraceni et al., 2002). However, alteration of the length of the 100 mm VAS line can make interpretations and comparisons less precise (Lundeberg et al., 2001). This was considered during the system implementation and tests of printouts from all HBHC's printers were carried out to make sure that the VAS line was exactly 100 mm long.

There were certain limitations to the study, which will be discussed. One limitation concerned the requirements-and-design group, which did not include any patients. However, in the try-out before the study start five patients participated and tried out the digital pen together with an ESAS (Edmonton Symptom Assessment System) (Bruera et al., 1991) form and a body image pain chart, both printed on paper with Anoto pattern. All patients were able to use the digital pen and fill out the forms (Hallgren, 2002). Another limitation was the fact that, of the interviewed patients only one was a woman while of the interviewed spouses all four were women. However, palliative patients at their end-of-life constitute a very frail group, which means that it is not always possible to collect data from them to create similar and complete cases (Caraceni et al., 2002). A few of HBHC's patients who were in pain and suitable for trying the pain diary and digital pen for pain assessment, were excluded due to their use of an electronic infusion pump. The reason for the exclusion was to minimize the risk of influence from the mobile phone on the infusion pump for the participating patients.

The qualitative descriptive and explorative design for evaluation comprising a content analysis was used in Papers III-IV in order to capture patients' and professional caregivers' experiences of patients' use of pain diaries and digital pen technology for frequent pain assessment in advanced palliative home healthcare. Qualitative content analysis was deemed suitable due to the fact that it focuses on the subject and context, and it points out differences and similarities between and within categories. Furthermore, it preserves the core of the original analysis material. For the purpose of ensuring the quality of results and methods used in Papers III and IV, trustworthiness in terms of credibility, transferability and dependability will be discussed (Graneheim & Lundman, 2004).

Credibility was achieved by using a reliable method and by using all possible data from all participating patients/spouses and professional caregivers, thus including participants with as varied experiences as possible. Since palliative patients at their end-of-life are very frail it is not always possible to collect data from them to create similar and complete cases. The data collection was carried out in agreement with the interviewed patients/spouses and caregivers and there was an atmosphere of trust between the researchers and informants, which furthermore ensured the credibility.

Dependability was accomplished through a rigorously described research process including all steps in the analysis. The researchers were not involved in the patients' care, so thereby bias was avoided.

Transferability was facilitated through a clear and distinct description of participants, data collection and process of analysis. Triangulation of data collection methods (interviews, system log files, medical records) and researchers with long experience of the qualitative method approach, were used in order to strengthen the credibility and transferability. However, it is for the reader to decide if the result can be applied to other contexts.

General discussion of the results

This thesis provides a description of problem areas and needs within basic and advanced home healthcare together with requirement areas when monitoring a patient in the home with respect to symptom and status parameters. Furthermore, a description of two systems with the purpose of giving support to patients and professional caregivers is given. The prototype system for diabetes patients was designed to support patients in basic home healthcare while the system for the follow-up of pain treatment for palliative home healthcare patients, which was designed and implemented in routine care at a hospital-based home care clinic, explored the potential of supporting advanced home healthcare with digital pen and mobile Internet technology. Evaluation by means of qualitative content analysis of the pain assessment system combined patient and professional caregiver perspectives.

Requirement areas for remote monitoring

Experienced problem areas such as communication, organisation, security, responsibility, trust and symptom and status control, in home healthcare, have been observed and described earlier (Strang, 1999; Arras & Dubler, 1994; Oliver, 1996; Grande et al., 1997; Johansson & Lundell, 1990; de Wit et al., 1999) and are

in accordance with the problem areas pointed out during our structured discussions with local home healthcare organisations. Since the focus of our research concerned the problem area *symptom and status control in home healthcare*, the identified requirement areas to be considered when monitoring patients in home healthcare—*responsibility*, *integrity*, *mobility*, *ease-of-use*, and *security*—will be discussed below.

Bringing new technologies into healthcare may change the responsibility areas for certain groups of professionals. Therefore, it is important to decide the roles and responsibilities within all organisational levels before a new technology is introduced (Arras & Dubler, 1994). There may also be a shift in the roles between caregivers and patients, for instance due to increased responsibility and participation in decision-making for the patients (Johansson & Lundell, 1990; Hebert & Korabek, 2004; Gagnon et al., 2006). Giving care in the home is different from giving care at a hospital. A "home" can mean different things to different persons depending on, for example, the culture to which a person belongs. According to Tamm (1999) it is a human right to be able to have privacy in a home setting and privacy allows the individual to feel like a complete person, independent of others. The loss of privacy can, however, occur when other individuals intrude into the home. Giving care in the home means that the patient may influence both where and when the care shall be given (Tamm, 1999). Patients, who assume more control over their own care, feel empowered and their quality of life and outcomes improve (Short & Saindon, 1998; Hebert& Korabek, 2004; Kearney et al., 2006; Kobb & Dimmick, 2006). However the possibility for a patient to partly control and influence his/her own care in some cases can jeopardise the professional caregiver's demands on the work environment (Johansson & Lundell, 1990; Tamm, 1999). Therefore, in home healthcare one should strive for a balance between the patient's and the professional caregiver's responsibility and integrity areas (Johansson & Lundell, 1990).

There are certain differences between monitoring an in-hospital patient and a patient in the home. One such difference concerns the infrastructure, i.e., measuring instruments, computer networks, servers, etc. In a hospital, secure Intranets and firmly tested and reliable instruments are used. The hospital has also taken some measures against different devices interfering with one another. In the home, on the contrary, insecure computer networks (mostly the Internet) have to be used (Herzog & Lind, 2003; Herzog et al., 2001). Equipment, firmly tested at the hospital, has to be re-tested and adapted in the home. Security requirements needed when using IT support for healthcare are described by the

Swedish SITHS (Secure IT in Health Services) project (SITHS, 2002). The model is based on PKI (Public Key Infrastructure) and smart cards to secure communication of medical data and enable secure e-mail, electronic signatures and access to several different systems via the single-sign-on technique.

Decisive for the choice of technology should be the patient's degree of mobility and the kind of monitoring to be performed. Patients may be more or less mobile—from totally immobile/bedridden to fully mobile—and therefore the choice of monitoring equipment has to be flexible enough to fit different situations and patients. To avoid a technology-driven approach when designing systems for elderly patients at home, and to be able to choose the appropriate technologies, it is important to consider the patients' needs (Demiris et al., 2004; Ryan et al., 2003), and also the clinicians' needs of measured or assessed parameters depending on the patients' illnesses (Frantz, 2003). Patients and healthcare professionals are not primarily technicians, which is a good reason to strive for ease-of-use regarding technical equipment in home healthcare. Another reason is that the patient and next-of-kin often are involved in the care. The introduction of new technologies in the home of a very ill patient can be scaring for the patient and family, especially if they are not offered adequate support and education on the care and management of the equipment (Strang, 1999; Arras & Dubler, 1994). Earlier studies of systems for monitoring patients in the home have concluded that patients generally are capable of using technical equipment after an introduction and with support from care providers (Brennan, 1997; Dansky & Bowles, 2002). The possibility to handle technical equipment correctly, which implies ease-of-use of the equipment, is the condition that must be fulfilled to receive validity in the measurements (Finkelstein et al., 2000).

Literature about home telehealth technology often recommends that home healthcare systems should be designed to minimize the obtrusiveness to the end users (for example Ogawa et al., 1998; Doughty et al, 1996; Meystre, 2005)—most often without defining the term obtrusiveness, which has been used inconsistently (Hensel et al,. 2006). However, Hensel et al. give a definition of this term and group 22 categories into eight dimensions of what may be perceived as obtrusive in home telehealth technology. The eight dimensions are physical aspects, usability, privacy, functionality, human interaction, self-concept, routine and sustainability. Aspects from the requirement areas security, integrity, responsibility, mobility and ease-of-use, as discussed in Paper I, can also be found in these dimensions.

System development

The two systems described in this thesis—the prototype application for diabetes patients and the system for pain assessment in palliative home healthcare—were designed and developed with consideration to the requirement areas security, responsibility, integrity, mobility and ease-of-use described in Paper I.

Prototype application for diabetes patients

Since the individual variations among diabetes patients can be very large it is not possible to just follow a standard procedure, for example with insulin dosage, for everybody. An individual plan needs to be drawn up by the patient and healthcare professional together (Foster et al., 1999; Bergenstal & Gavin, 2005). New patients and those who change their individual plan need to measure their blood glucose levels several times a day during a few weeks. The prototype application made possible a balance between the patient's and professional caregiver's responsibility and integrity areas, i.e., due to the fact that the patient could select the data he/she wanted to keep private. The system was designed for the patients to choose the most convenient and familiar device for data input combined with the most trusted and convenient ways to send the data. By using common standard equipment (of 2001), such as ordinary personal glucose meters with a standard serial interface, measured and time-stamped glucose values could easily be transferred to a computer and be viewed in diagrams and tables. Together with other useful data including meals, insulin intake, extensive physical work, infections, temperature etc., a more complete picture of the patient's diabetes was given. Such events should be easy for the patient to enter when they occur and later be added to the program used to present the glucose values.

Pain assessment system

Digital pen technology was found suitable in regard to the fact that the HBHC clinic used paper-based medical records. Printouts from the system and original pain diaries, collected from the patients' homes after the periods, were kept together with the medical records. Since the nurses already used a computer-based system for administrative purposes, the web-based system for follow-up on the patients' pain and treatment could be used without installing new computers. To safeguard the privacy of patient data the most secure level in the Anoto Functionality was used, which comprised both encryption and authentication of devices. In addition, a signature for authentication of the patient was written on the pain diary. Furthermore, no identification data (social

security number or name) were sent over the Bluetooth or GSM/GPRS links by the digital pen. The system mapped the pen requests to the current patient by using the information in the database and the unique serial number of the pen. Another security aspect concerned the risk of influence from the mobile phone on electronic medical devices, which led to the exclusion of patients using electronic infusion pumps. A balance between responsibility and integrity was reached with respect to patients and professional caregivers by, for example, letting the patient decide when to perform an assessment. The equipment was wireless and mobile, allowing the patients to stay mobile. Ease-of-use was attained by the fact that the patients only had to *write* with the digital pen. Configuration of the digital pen or the mobile phone was never necessary for the patients. Ease-to-use was also attained through professional caregiver participation in the design work and requirements on an intuitive system from the caregivers (Gagnon et al., 2006). Moreover, the digital pen technology did not require any additional infrastructure and/or software in the patients' homes so therefore it was easy for caregivers to "install" and "uninstall" the equipment.

Mobile and handheld devices have been used for electronic symptom/pain diaries in several studies (Gaertner et al., 2004; Jamison et al., 2001; Kearney et al., 2006; Koop et al., 2002; Stone et al., 2003b). The advantages of electronic diaries over traditional paper diaries have been reported earlier (Stone et al., 2003b; Jamison et al., 2001; Koop et al., 2002; Aaron et al., 2004) and include mainly an increased compliance, a reduction of data fabrication and the ability to capture time-stamped data for uploading to a computer. In a study using both electronic pain diaries (PDAs) and paper diaries Gaertner et al. (2004) found that patient satisfaction with the electronic version was excellent but that not all patients were able to handle a PDA and the authors do not recommend a complete conversion from paper to electronic pain diaries. As compared to the patients in our study, these patients were both younger and non-palliative.

The strengths of both paper-based diaries and diaries in small, handheld devices, such as PDAs and telephones for example, are the possibility for patients to stay mobile. However, ageing can affect the functioning of sense organs (e.g. vision) (STAKES, 2006; Hanson, 2001), and older people can have difficulties with small font sizes and font colours due to vision impairments (Hanson, 2001). It has been recommended to use at least 14-point sized fonts for presenting online text to older readers (Demiris et al., 2001; Bernard et al., 2001).

Evaluation of the pain assessment system

During the study the participating patients assessed their momentary pain three times per day at regular times. The advantages of letting patients assess their momentary pain several times per day, instead of asking the patients to recall and summarize their pain over a period of time (e.g. one day), have been shown by, for example, Stone et al. (2005) and Lefebvre and Keefe (2002).

The success of home telehealth depends on both patients' and professional caregivers' acceptances. Home telehealth interventions change the caregivers' practice patterns and have an impact on their way-of-working. Also, the level of patient acceptability is influenced by the way in which patients understand the technology and intervention (Demiris et al., 2005). In a Canadian home telehhealth project, involving palliative patients using video visits, the caregivers were concerned by the impact of the new technology on their usual work patterns; time and effort needed for the technology were seen as a large investment, whereas the benefits were less obvious (Gagnon et al., 2006). The professional caregivers in our study reported reactions which showed initial similarity with the Canadian study; the caregivers at HBHC showed an initial cautious outlook due to their own reluctance to use the system and change their way-of-working. Contemporary organisational changes put the caregivers under stress and the pain assessment system was described as contributing to an increase in the workload for the caregivers, since they had to use the computer-based system and handle both the equipment and all pain assessments on paper. Due to low expectations of the patients' abilities to use the pain assessment method certain patients, especially older women, were never asked to participate. This can be coupled to the professional caregivers' own feelings of uncertainty towards the technology which was transferred to the patients. To compensate for possible caregiver reluctance towards the technology, individual positive experiences of technology usage were important. Such positive experiences were described and contributed to a shifting outlook towards the pain assessment method. Another positive experience expressed was the fact that they had become more aware of the patients' pain and that also the patients had become more aware, which could make pain assessment and reporting easier since they "spoke the same language" by using VAS as an instrument.

Although stated in the pain management clinical guidelines, the clinic's pain analysis form was seldom used. Instead initial pain analyses were documented in a less structured manner in the medical records, but the professional caregivers still believed that they had learnt to document the patients' pain

situations in a better way compared with before the intervention. The striving for a good and proper documentation of the patients' pain could be experienced as a dilemma for the caregivers since it sometimes was more important to just be with and "follow through on the patient" even when the patient was in a state of denial due to the illness. The attitude towards the use of technology in palliative care in general varies among caregivers and traditionally, care of the dying patient has been underpinned by a low-technology philosophy including an emphasis on the need of "being with" the dying patient (Tinnelly et al., 2000). However, technological advances have influenced the care of terminally ill patients in home care, leading to the possibility of remotely monitoring patients in the home (Doolittle et al., 1998; Maiolo et al., 2003). Although a sentiment among caregivers in palliative care can be one of suspicion towards highly technical interventions there is also, in Western society, a tendency to glorify technology, e.g. to think that new technological innovations will mean an improvement in healthcare and quality of life (Tinnelly et al., 2000). For some patients a life with high-technology medical devices may be viewed as a challenge or adventure, but for others the introduction of new technologies in the home of a very ill patient can be scaring. If the patient experiences himself/herself as being "tethered" to a machine for a significant portion of each day this may lead to difficulties such as a distorted body image that erodes self-esteem (Arras & Dubler, 1994; Hensel et al., 2006). Digital pen technology, although belonging to the high-technology area, has more of a low-technology approach since the use of a pen and paper is familiar to everyone and since digital pens have a large similarity to ordinary pens.

The professional caregivers' improvement suggestions for future use comprised an inclusion of patients in a somewhat more healthy state, assessment of all pain locations and assessment of more symptoms. It has earlier been proposed that pain should be described with reference to location, onset and quality (Heedman & Strang, 2003), and that the assessment of other symptoms—such as suffering— should be performed as well (Payne, 2000). To be able to reach a full understanding of chronic pain and to capture pain fluctuations during the day and night, frequent assessments of the pain should be made (Stone et al., 2003a; Lewis et al., 1995). In our study, none of the patients ticked the extra dose boxes at the same time as they took their extra doses and the interviews showed that the patients did not know about this possibility. This could have given additional valuable information to the professional caregivers, for example by indicating pain breakthroughs around the clock (Caraceni et al., 2005).

The patients in the Canadian study showed quite similar reactions to the patients in our study; the Canadian patients had positive reactions towards the technology though they were not familiar with it, also, they seemed "readier" than their caregivers to use the monitoring equipment (Gagnon et al., 2006). The patients in our study found the pain assessment method as being effortless in spite of severe illness and limited understanding of the technology and system intervention, and they did not need help from their next-of-kin in performing the assessments. In an earlier study, seriously ill cancer patients have been able to fill in a traditional paper-based pain diary twice daily for 2 months in their homes (de Wit et al., 1999). The patients in our study expressed that they took a greater part in their own care during the pain assessment period. Their motivation was that it felt good to co-operate with the professional caregivers and to see one's own pain variations and have control over consumed extra doses of analgesics. Eldh et al. (2006) have described the meaning of participation for patients with chronic heart failure, and their nurses. The patients' experience of participation comprised feelings of being in tune with, and respected by, the caregivers. Furthermore the patients experienced participation as both being responsible and accepting responsibility. In our study, both patients and spouses experienced an increased and improved contact with the professional caregivers which lead to a sense of increased security and calmness. Chronically ill patients, subject to a phone support service, reported increased feelings of security and positive emotional effects leading to better control of their condition due to this service (Gagnon et al., 2006).

The professional caregivers experienced several positive patient influences from the pain assessment method, which were in accordance with the results from patients/spouses interviews and patients ease-of-use questionnaire and which contributed to the shifting outlook, namely that the patients took a greater part in their own care and that they experienced an improved contact with their caregivers, which in turn led to a sense of increased security. There was also a quick response to variations in the patients' health status by means of changes in medical treatment, as shown in the medical records. By using digital pen and wireless Internet technologies together with pain diary forms for pain assessment, our system combines many of the good parts from systems using electronic diaries and systems using traditional pens and paper-based diaries.

7. Conclusions

♦ Before the onset of remotely monitoring patients in home healthcare the requirement areas security, responsibility, integrity, mobility, and ease-of-use should be considered (Paper I).

♦ The palliative patients expressed an easiness to use the equipment in spite of severe illness and difficulties to comprehend the technology and system intervention (Papers II and III).

♦ The palliative patients perceived an increased and improved contact with their professional caregivers, they took a greater part in their own care and they had a sense of increased security (Paper III).

♦ The professional caregivers showed an initially cautious outlook towards the pain assessment method, but after having experienced positive outcomes for themselves and the patients their outlook shifted (Paper IV).

♦ The medical records showed a quick response to variations in the patients' health status by means of changes in medical treatment (Papers III and IV).

♦ The home healthcare solution provided an effortless method for pain assessment with a high degree of user acceptance for palliative patients which, together with the IT support for professional caregivers, had positive influences on the care (Papers II-IV).

♦ Palliative patients in their end-of-life stage can learn to use new technologies and adapt to new methods.

8. Implications

Clinical implications

♦ For palliative patients in advanced home healthcare there is a need for ease-of-use interfaces in handling technology, therefore digital pen technology is suitable for the assessment of symptoms since these patients often have a limited capacity to handle technology due to their state of health.

♦ IT-based systems can solve some of the problems associated with symptom control of the patient at home and function as support for both professional caregivers and patients/next-of-kin thereby improving the symptom control in advanced home healthcare.

♦ Since palliative patients in their end-of-life stage were able to handle the digital pen technology and assess their pain, such technology and systems could preferably be used by healthier patients in other home care settings, for example patients with chronic conditions such as congestive heart failure, chronic respiratory disease and diabetes cared for by basic home care organisations.

♦ When introducing new technologies in home healthcare professional caregivers need continuous education and support.

♦ Sufficient and continuous education and support are also needed for home healthcare patients/next-of-kin to be able to handle new technologies and take a greater part in their care.

Implications for future research

♦ Our ongoing work to introduce status control in home healthcare is based on the insights from the results reported in this thesis and will strive for user-friendly, effortless, home healthcare solutions.

♦ Further research is needed about requirement areas to be considered at the introduction of home monitoring systems in order to develop proper

guidelines for design, development and implementation of home monitoring systems.

♦ Because of the limited number of patients and professional caregivers in the pain assessment study, large scale randomized clinical trials with long-term follow-up on the use of IT-support systems including digital pen technology are needed.

♦ Further qualitative studies are needed to gain a deeper knowledge of home care patients' experiences from using IT-support systems including digital pen technology.

♦ Additional qualitative research is also needed to gain insights into various professional caregivers' experiences of using such IT-support systems including digital pen technology in home healthcare. Additional caregiver groups of various ages can, for example, be collected from primary home healthcare.

9. Summary in Swedish

När vården flyttas från sjukhuset till patientens hem kvarstår kraven på en hög vårdkvalitet. Med hjälp av informations- och kommunikationsteknologi kan problem lösas som uppstår på grund av geografiska avstånd mellan patienter och professionella vårdgivare. Det övergripande syftet med denna avhandling var att beskriva väsentliga krav i sammanhanget, samt att designa och implementera ett IT-baserat system, och slutligen utvärdera systemets möjligheter att förbättra symtomkontroll och stöd till såväl patienter/anhöriga som professionella vårdgivare i avancerad hemsjukvård. Av vikt var behov och användarperspektiv hos patienter och vårdgivare i både basal och avancerad hemsjukvård. Kravområden, såsom säkerhet, mobilitet och ansvar, som är viktiga att beakta vid monitorering av patienter i hemmet, identifierades. Ett prototypsystem för daglig hjälp till diabetespatienter designades som ett led i kravanalysen. Vidare har ett system som möjliggör täta smärtskattningar, med hjälp av en smärtdagbok samt digitalpennteknik och mobilt Internet, för patienter i palliativ hemsjukvård utvecklats och utvärderats. Design och datainsamling för att identifiera behov och kravområden i avancerad hemsjukvård har omfattat litteraturstudier och strukturerade diskussioner med professionella vårdgivare. För att utvärdera såväl patienters som professionella vårdgivares erfarenheter rörande patienternas användning av en nätverksbaserad digital penna vid smärtskattning har en metod med kvalitativ innehållsanalys tillämpats. Sex professionella vårdgivare och tolv palliativa cancerpatienter deltog i en fältstudie med det utvecklade systemet. Datainsamlingen bestod av en "användbarhetsenkät" till patienterna samt intervjuer med patienter, anhöriga och professionella vårdgivare. Patienterna gav uttryck för en ökad och förbättrad kontakt med vårdgivarna, ett ökat deltagande i den egna vården, en känsla av ökad säkerhet samt lätthet att använda utrustningen trots svår sjukdom och svårigheter att förstå tekniken och systeminterventionen. De professionella vårdgivarna uppvisade en förändrad inställning till smärtskattningsmetoden under försöket. Initialt hade man en försiktig inställning på grund av låga förväntningar på patienternas möjligheter att använda smärtskattningsmetoden och en inneboende försiktighet mot att använda det nya systemet och ändra sitt arbetssätt. Trots detta erfor de professionella vårdgivarna positiva erfarenheter efterhand, dels i form av en ökad medvetenhet om patienternas smärtupplevelse, dels i form av en positiv

patientpåverkan inkluderande en ökad delaktighet i den egna vården, ökad säkerhet och en förbättrad smärtbehandling som svar på rapporterade smärtskattningar. Sammanfattningsvis utgjorde systemet med den nätverksbaserade digitalpenntekniken en enkel och obesvärad metod för smärtskattning med en positiv påverkan på vården. Resultaten visar att digitalpennteknik lämpar sig väl vid symtomskattning för palliativa patienter eftersom dessa patienter ofta har en begränsad förmåga att hantera teknik på grund av sitt hälsotillstånd. Vidare visar resultaten på att den studerade tekniken utgör en lovande lösning inom både basal och avancerad hemsjukvård vid sökandet efter en lättanvänd metod som inte kräver någon större ansträngning av användaren för tillgång till IT-baserade vårdtjänster.

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