Medical technology and its impact on palliative home care as a secure base experienced by patients, next-of-kin and district nurses

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Abstract

The overall aim of this thesis was to explore and describe how medical technology is experienced by patients, their next-of-kin and district nurses in palliative home care. The chosen approaches were critical incident technique (study I) and phenomenography (studies II, III and IV).

Study I describes situations influencing next-of-kin caregivers’ ability to manage palliative care in the home. The next-of-kin maintained control by taking sole responsibility for the patients care. They lost control when they lacked professional support or experienced inadequacy and powerlessness.

Study II describes district nurses conceptions of medical technology in palliative homecare. District nurses perceived vulnerability due to increased demands, exposure and uncertainty in their handling of medical technology. It demanded collaboration between all involved actors and self-reliance to convey security to the patients. Awareness about patient-safety and sensitivity to what technology the families both could and wanted to handle was required.

Study III describes next-of-kin conceptions of medical technology in palliative home care. Next-of-kin were responsible for the technology and acted as the district nurses’ assistant and the patients’ representative. The healthcare personnel’s management of the medical devices and their function created uncertainty among the next-of-kin. Medical technology affected their social life and private sphere but they adapted to their new conditions. However, medical technology also gave them comfort, security and freedom.

Study IV describes patients’ ways of understanding medical technology in palliative home care. The masterful patient controlled the technology and was mostly independent of healthcare personnel. The adjustable patient accepted and adapted life to the technology, while the restricted patient was daily reminded of the devices and was dependent on personnel’s support and assistance. The patients transferred between the different ways of understanding medical technology depending on health condition, personnel’s support and how the technology affected their daily life.

This thesis highlights the importance of security when medical technology occurs in the homes and its impact on palliative home care as a secure base.
The findings show how district nurses mediate security to the next-of-kin and to the patients, who become independent and masterful patients. This movement of mediating security can also occur in the opposite direction such that an insecure district nurse can become a masterful district nurse. Continuity among the healthcare personnel is a prerequisite to reach this security and thereby a patient-safe care.
Original papers

The thesis is based on the following papers, which are referred to by their Roman numerals in the text:

Paper I

Paper II

Paper III

Paper IV
Munck B., Sandgren A., Fridlund B., Mårtensson J. Patients’ understanding of medical technology in palliative home care; a qualitative analysis. Accepted for publication in Journal of Hospice and Palliative Nursing 2011

The articles have been reprinted with the kind permission of the respective journals.
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Introduction

People 65 years and older are an increasing group, representing 15% of the European population in 2009 and expected to encompass more than 25% of the population 2050. An ageing population means an increased number of people who suffer from diseases like cardiovascular disease, obstructive lung disease, diabetes, cancer and dementia, all associated with multiple health problems. To meet the needs from these increasing patient groups, palliative care services urgently need to be developed. It has been suggested that patients in palliative care should be allowed to choose where they wish to be cared for the final period of their lives. Between 50% and 70% of patients with a serious illness would prefer to die in their own homes, but in most countries the majority of these people die in hospitals or in nursing homes. An overall vulnerability in terms of physical, psychological, social and spiritual weakness of the patients and their family has a significant influence on the possibility for the patients to return home at the end of life. The significance of the next-of-kin in palliative home care has increased and become an important part in the care of patients. However, as caregivers they are in an exposed position, jeopardizing their own health while their need for support increases in proportion to the patients’ deterioration.

The shift from institutional care to home care is a common trend today, resulting in a growing number of medical devices accompanying the patients home. The increasingly advanced medical devices found in home care allow patients with serious illnesses to receive intensive care at home that previously would require hospital care. In hospitals the medical technology is handled by professional and experienced personnel, while in home care the users are primarily a nonprofessional group composed of patients and their next-of-kin, with a diverse background of age, physical and mental fitness and experience in dealing with the technology. This heterogeneous group is a great challenge for designers and manufactures of medical technology in their attempts to create safe and user-friendly devices for home care.

Feelings of security are one of the basic needs for the patients and their next-of-kin in palliative home care. To feel secure requires sufficient support,
adequate symptom control and a well-functioning communication and information flow.\textsuperscript{3,9,12} Medical technology’s impact on the daily lives of patients and their next-of-kin is described in several studies\textsuperscript{13-18} but only a few studies describe its impact on patients’ in palliative home care and their next-of-kin’s daily lives.\textsuperscript{19-22} Therefore the focus of this thesis is to illuminate this knowledge gap.

**Background**

**Palliative care**

The word palliative originates from the Latin word pallium which means cloak and symbolizes its embracing and alleviating ability regarding to protect the patient.\textsuperscript{23} The term hospice derives from medieval times and was used to describe special buildings for pilgrims and travellers. Dame Cicely Saunders, a nurse who later became both a counselor and a physician pioneered the modern hospice movement. In 1967, she opened St. Joseph’s Hospice in London using a donation from one of her patients. This was the first modern teaching and research hospice unit whose care was directed toward dying patients and their families.\textsuperscript{3} With the hospice as base, home care was developed in collaboration with hospitals and general practitioners (GPs) and hospice was then redefined as a movement instead of a special house. The care of dying patients was at this time termed terminal care, which later 1987 was changed to palliative care.\textsuperscript{24}

Palliative care does not refer to a special place or building. It is a philosophy of care that is applicable in all care settings, and an approach to improve the quality of life for patients with a life-threatening illness and for their next-of-kin. Palliative care aims to prevent and relieve suffering through early identification, assessment and control of symptoms, psychological, spiritual and emotional support, support for the family and bereavement support.\textsuperscript{3,25,26}

Palliative care is not intended for any specific disease but is applicable to patients based on their needs and likely prognosis. Identified target groups are patients with a serious, severe or complex illness. A fundamental principle of this care is symptom relief, access to care when needed, use of an interdisciplinary team and an open and sensitive communication.\textsuperscript{3,12}
Access to professional palliative care at any time when needed implies a feeling of security for patients and their next-of-kin. Patients benefit when palliative care is implemented early in their course of illness, as they can get access to adequate symptom control and the support they need. Palliative care is an active form of care, which can be compared to intensive care. Different medical treatments are common and being proactive for preventing symptoms is of great importance in this care.

Palliative care and the organization
Palliative care should be integrated into all healthcare settings with attention to the culture of the organization. Palliative care can be provided in hospitals, nursing homes and at the patient’s own home, preferably performed by a multiprofessional team with special experience and ability to meet the patients’ and families’ physical, psychological, social, and spiritual needs. The goals of the care are the same regardless of where the patients receive it. According to Wright et al. hospice palliative care services exist in varying degrees in 115 of a total of 234 countries, and these countries encompass 88% of the global population. There is a strong association between the level of palliative care and the human development in the countries. However, data from 35 European countries show differences in the organization of care, personnel training, cultural and ethical conditions and the availability of morphine drugs. Palliative care can be organized in different clinical models. Hospice care is intended for patients with a prognosis of six months or less. Palliative care in-patient units provide palliative care by an interdisciplinary team with special skills. Hospital-based palliative care teams occur in ambulatory care settings and community palliative care teams occur in communities as consultative teams. Palliative day care units where the patients can meet others in the same situation and have the opportunity to talk to personnel is yet another model. Palliative care can also be divided into non-specialist and specialist palliative care. The large majority of palliative care is provided by non-specialists which includes informal caregivers, volunteers, district nurses, GPs and non-palliative care specialists. Specialist palliative care services have palliative care as their core activity and the personnel possess a higher level of professional skills. They also have an important role in supporting other healthcare personnel in their role as caregivers.
Specialist palliative care services have increased rapidly in recent years in the U.S. and are the most common and effective models when integrated into specific care settings as hospitals, nursing homes, and home care. Consultations from these teams reduce the palliative patients’ symptoms, hospital costs and length of hospital stay, facilitate new treatment orders, improve the quality of end-of-life care for in-patients, and reduce the need for primary care and urgent care visits for out-patients. In Sweden the counties provide non-specialist, so-called general palliative home care and specialist palliative home care. The general palliative home care is performed by nurses with support from physicians and addresses patients with mild symptoms and can be offered in about 85% of the counties. The specialist palliative home care is physician-led and usually hospital connected, including patients with more severe symptoms and can be provided in about 60% of the counties.

Patients, next-of-kin and district nurses in palliative home care

Patients prefer to die at home, but in reality most die in institutions. The strongest predictions for dying at home are not living alone and the presence of more than one caregiver. Contacts with health care services and GPs who make home visits are also a contributing factor to fulfil this preference. Hospital nurses have an important role to increase the patients’ chance to die at home, by assessing the patients’ and their next-of-kin’s desire and opportunities for end of life care at home and then to support early transfer to palliative home care. Patients are satisfied to be cared for in their own homes in the end-of-life, since they can continue their everyday life together with their next-of-kin and thus maintain a kind of independence. Access to palliative home care teams, with availability 24-hours a day, implies security for the families. The teams improve the patients’ recumbent hours during the day and symptoms are significantly improved, affecting the patients’ global quality of life. Patients in palliative care desire to live in the present with their loved ones, but they also feel anxiety to be an encumbrance for them. The patients express feelings of powerlessness and helplessness, which are linked to their life threatening diagnosis, different symptoms,
limitations in their daily life, dependence of others, ignorance, social and existential isolation, uncertainty due to absence of normal time references and difficulties with short and long term planning.\textsuperscript{41} Using different coping strategies; such as togetherness, involvement, hope and continuance, the patients preserve their links to life and keep death at a safe distance.\textsuperscript{42} Maintaining close personal relationships and participating in social activities gives the patients a reason to live.\textsuperscript{43} According to patients in palliative care, good end-of-life care is a need to be secure, which can be achieved by continuity and the competence of the healthcare personnel, to be as comfortable as possible, to be recognized and known by the personnel, welcomed to participate in own care, to have trust in the judgement and treatments provided by the healthcare personnel. They need to be relieved of responsibility, to be informed and to have the possibility to continue with as much of their former everyday life as possible.\textsuperscript{44,45} Security protects against feelings of helplessness and powerlessness and is facilitated by a trusting relationship, practical and emotional support from family and friends and access to palliative care teams.\textsuperscript{46}

\textbf{Next-of-kin}

In this thesis next-of-kin is defined as ’a person who the patient claims to have a close relationship with’ and the family is defined as ‘the patient and their next-of-kin’. Most palliative care is performed by the next-of-kin in the patients’ homes with different kinds of support.\textsuperscript{3,47} The families’ need for support is emphasized in several studies,\textsuperscript{8,9} and their need for support increases in proportion to the patient’s deteriorating condition.\textsuperscript{3,4,48} To prevent social declines due to consequences of their caregiving, a specific support is also stated.\textsuperscript{3} When palliative care is provided at home by the next-of-kin, the care must be based on voluntary initiative and an agreement between the family members.\textsuperscript{34,49,50} However, due to reductions in hospital beds and new hospital reforms, next-of-kin feel they have lost their freedom of choice and are pushed into the role as caregiver in the home,\textsuperscript{49,51-53} The sustainability of keeping the patients at home in end of life depends on how close the next-of-kin are to the patients and how they manage to cope with the care.\textsuperscript{50} The primary goal of palliative home care according to next-of-kin is for the patient to achieve a peaceful death with dignity and to be respected in a supportive environment. The next-of-kin also have a desire to be present
at the time of the patient’s death. A general research overview of next-of-kin’s experiences with end-of-life caregiving shows emotional and psychological difficulties such as fear, dread, anger, anxiety, guilt, regret, grief, helplessness and hopelessness. They are affected by physical illness, occupational disruption, financial strain, restrictions in activity and social life, problems in communication and challenges with patient care and household tasks. Being a next-of-kin caregiver in palliative home care is emotionally intensive and an exhausting experience, with constant worry and demands for alertness. Their normality is broken down and they lose control of their daily life. Most next-of-kin are not accustomed to caring for a palliative patient in the home, which thus creates feelings of uncertainty and feelings of guilt, blaming themselves for not having done enough for the patient. Tiredness and tensions implies feelings and reactions they do not recognise in themselves. Next-of-kin describe their isolation at home and restricted social life as they dare not leave the patient alone. To get their own time and yet remain near the patient is regarded as important. They struggle to keep their daily life as normal as possible. With the use of different coping strategies, such as own activities and taking one day at a time, they learn to manage their situation. However, a good patient care can decrease the next-of-kin’s workload and stress. The next-of-kin can be involved in the care with openness, respect and confirmation, i.e. involved in the 'light' or, when they not are acknowledged by the health care personnel, be involved in the 'dark'. Lack of support and communication are often reported in studies. Lack of knowledge often results in feelings of isolation, frustration and distress for the next-of-kin. Information about the patient’s condition, symptoms and treatments and what to expect during the course of the care-giving are expressed to be valuable knowledge.

**District nurses**

District nurses’ role as caregivers in palliative home care is to enable and assist the patients and their next-of-kin to achieve their identified goal, which requires sensitivity in responding to their shifting needs. When the patients receive their diagnosis, it is important to create a contact with the family as soon as possible for establishing a care relationship. A trusting care relationship makes it easier for the district nurses to support and assess
patients’ and the next-of-kin’s need for information, communication and education. District nurses perceive palliative care as satisfying, with an opportunity to do something for a critically ill patient, while gaining valuable knowledge and experience which increase their awareness, insight in life and professional development. They strive to do right and do good for the patients, which is their motivation for caring. They consider themselves to be the one who knows the patients’ situations best and feel responsibility towards the family. They experience palliative home care as both challenging and rewarding, but also emotionally draining and stress filled. Caring for patients in a palliative phase while also caring for other patients in a curative phase, is associated with difficulties. District nurses encounter next-of-kin in palliative care who are worried, tired and stressed and they notice next-of-kin’s needs for support. District nurses state that next-of-kin can be both a resource and a burden. They can be a resource when they are present and allow open communication, but a burden when they are demanding and show their suffering. District nurses’ role is not only to support the family but also to support and inform home care assistants who can be uncertain and sometimes fear what they encounter in the palliative care. The nurses experience poor support and commitment from managers and lack of appreciation when doing this kind of care. They often travel alone to home visits and work predominantly without collegial support in the homes. They feel that they are working in a ward without walls, as they cannot limit the number of beds in their catchment area, implying no control over the workload. Their increasing workload leads to deterioration of patient care and is a threat to patient safety, giving them feelings of guilt, stress and dissatisfaction. District nurses consider GPs are insecure in the palliative care, requiring the nurses to provide suggestions for them about appropriate arrangements for the patients. GPs often base their decisions concerning the patients in home care on the district nurses assessments. District nurses feel forced to take too much responsibility in palliative home care, while they have too little formal power. However, they want to be more involved and more influential on end-of-life decisions and feel uncomfortable when the GPs make decisions without regarding their opinions.
Medical technology in home care

A medical device is a product used for people to detect, prevent, treat, monitor or relieve diseases.\(^{73,74}\) Due to global demographic changes and developments in the health care system, an increasing amount of medical technology is moving out from the hospitals to the community. The medical devices are used in home care by a heterogeneous group, consisting of personnel and families, representing a variety of experiences, ages and levels of professionalism.\(^{11,75}\) How people relate to medical technology depends on their underlying expectations, assumptions and knowledge about the technology. Their previous experience and which technological frame of reference they assume affects how they accept and make sense of the technology.\(^76\) Use of medical technology in the home differs from the conditions that exist in the hospital and the products must be adapted to the current situation. Each user’s home is unique and the environments are uncontrolled, unpredictable and changeable. Factors to be considered are the users' changing knowledge, existing alternative options if the medical devices fail, long appearance time for personnel to be in place at alarm and home environment that is not adapted to the technology. In addition, to avoid accidents there must be an organization, personnel and practices that can be implemented if technical and management errors occur.\(^{11,73}\) High risk medical devices, which are linked to their complexity, are ventilators and home haemodialysis. These medical devices require more skilled users to avoid errors. Before the medical devices are introduced in home care, the healthcare personnel must ensure that the family understands how the devices should be handled and have a picture of the security in the home environment.\(^77\)

Medical technology in nursing can be described as three layers of meaning where the most obvious layer is the physical objects such as the medical devices. Next layer is the knowledge about the technology and how it is used. The third and more holistic layer is technology in relation to human activities. The technology is not a neutral object, but can affect the nurses more than they realize in the care relationship.\(^78,79\) This care relationship may be harmed when the focus is on the devices instead of on the patient.\(^80,81\) The technology facilitates treatments and makes the nurses more secure but it also complicates their work and challenges their knowledge about the devices. When several different types of devices are in use, the nurses
express feelings of insecurity. Being able to master the technology gives nurses a sense of security and is a sign of theoretical competence, while insecurity about the devices is connected to incompetence. Novice nurses perceive medical technology as something transferred to them from the physicians, while experienced nurses use the technology as something whereby they can improve the patients’ outcomes.

**Medical technology and the users in home care**

Previous research about medical technology in home care notes its impact on the families’ daily life. The presence of the devices encroaches on the families’ space and the medical devices transform the home to a miniature intensive care unit. Families experience a loss of privacy due to the personnel who are accompanying the technology, and their social lives are restricted by the regularity of treatments. Anxiety, stress, exhaustion and economic impacts are their constant companion. The transition of technology-dependent children from hospital care to home care is very demanding for the family, when a parallel shift of responsibility for the medical technology occurs from the healthcare personnel to the parents. The parents are expected to take responsibility for technical devices and procedures for which they do not have proper training, which previously was the healthcare personnel's responsibility. Having to perform clinical procedures causing pain to their own children is the most distressing part of the caregiving. However, the families develop routines and make independent decisions without the personnel’s advice or sanctions, to reduce the intrusion of the technology. Children, youth, as well as adults living with medical technology in the home have an ambivalent relationship to the technology which both enables and disables them, both improving and constraining their lives. The technology sustains and improves their health and relationships and enables social participation, but it is a source of discomfort as they always are aware of its presence. The use of medical technology in home care by non-palliative care patients is a process of learning, accepting and managing the technology in daily life. Practical and emotional support from healthcare personnel and next-of-kin are a prerequisite in connection with its use. Living with medical technology implies mental preparation for a life with the medical devices. Patients dependent on a home-ventilator perceive their medical device as a saviour
and an opportunity for them to be at home. The medical devices give them support, rest and strength so they can continue to live a fairly good and active life.\textsuperscript{89} Patients with long-term oxygen treatment suffer from their deficiency in freedom of movement. They understand the need for the treatment which also makes it easier for them to accept it. They need to live in their own life rhythm, which means to learn in another way and to adapt to a new situation. Feelings of being tied up are linked to the treatments and their strict time schedule. However, patients also express feelings of freedom and less restriction to time as they can avoid travelling to hospitals for the treatments.\textsuperscript{90} To maintain a social life, the family adjusts the time of day and duration of the treatments to fit the planned activities for the days.\textsuperscript{87} Being connected to a ventilator changes the appearance of the patients’ face, although well-designed devices mean freedom and joy for the patients and improve their quality of life.\textsuperscript{89} Patients desire to improve the technology and invent practical and convenient solutions in connection with its use.\textsuperscript{87,88}

Patients with severe chronic heart failure in palliative home care describe their situation with medical technology as an adaption and acceptance of dependency.\textsuperscript{21} Treatments with medical technology in palliative home care, such as home parenteral nutrition implies a sense of security for the next-of-kin, because the patients can meet their nutritional needs, which increases the patients’ strength, energy and independence. The regular home visits by personnel in connection with the treatments are also appreciated.\textsuperscript{19,20}

**Ethical issues related to medical technology**

Palliative care aims neither to hasten nor postpone death, and medical technology must not be used to prolong life in an unnatural way. If treatments are futile and unnecessarily burdensome the physicians have no obligation to continue them.\textsuperscript{3} Medical technology makes it possible to prolong life, but at the same time ethical questions occur such as the patient's right to refuse treatment, withdrawal of life-sustaining treatments and euthanasia.\textsuperscript{91} Nurses experience anxiety and sorrow to participate in unnecessarily aggressive treatments or the prolonged use of life-saving technology.\textsuperscript{92} Medical technology can create ethical dilemmas in the decision of whether to withdraw medical treatments or not. Nurses consider neither they nor the next-of-kin are sufficiently involved in this decision making process,\textsuperscript{67,82} which implies that nurses sometimes make their own
treatment decisions based on what they think is best for the patients. However, another study shows that physicians and nurses in intensive care units are united in the decision about the level of life support treatment. The use of nutritional treatments in end of life care differs depending on culture and attitudes among the healthcare personnel. The majority of the patients with home parenteral/enteral nutrition have a survival longer than four months after the treatments are introduced, which is an indication that these treatments are not introduced in late palliative phases. However questions may arise about what a dignified death is. Is it a death with a low or high technology presence? For nurses, the problem with the technology is not the technology itself, instead it is about what they and the patients consider is a humane, natural and dignified care and death.

The concept secure base

Patients and next-of-kin in palliative home care express a desire to feel secure, because they are facing a constant threat in their daily lives with a severe disease associated with death and dying. The importance of feeling secure in palliative home care has been shown in several studies. A feeling of security protects against perceptions of powerlessness and helplessness. Receiving support and trusting in healthcare personnel gives a sense of security, which may be even more important than empowerment, participation and decision-making in palliative care. Security is defined as ‘freedom from danger, fear and anxiety’ and the meaning of safety is ‘being safe from undergoing or causing hurt, injury or loss’. The concept security has been used in relation to the attachment theory as a theoretical framework for describing how patients with cancer and their caregivers cope with stress, severe illness and bereavement. The attachment theory arises from a biological function to protect a person from danger and implies that the attachment system is turned on and attachment behaviors are activated and strive to normalize the threatened situation. When the threat is averted the attachment system is switched off and feelings of security are achieved. The attachment behaviors are highest in the early childhood and in old age when death is approaching. The attachment theory was initially developed for children, but is also suitable when a person is exposed to threats such as serious illness. A central concept in this theory is ‘a secure base’ which is described as: ‘If I encounter an obstacle and/or become distressed, I can
approach a significant other for help; he or she is likely to be available and supportive; I will experience relief and comfort as a result of proximity to this person; I can return to other activities\textsuperscript{106} (p.21). Healthcare personnel have been suggested to serve as a secure base for cancer patients as well as psychiatric patients.\textsuperscript{107,108} Palliative home care has been characterized as a secure base by Milberg et al.,\textsuperscript{45} to promote a sense of security for the patients and their next-of-kin in the home. Four underlying meanings of palliative home care as a secure base are identified; sense of control, inner peace, being oneself and hope. To have a sense of control in the daily life implies trust in one's ability to get access to reliable competence when needed. To have inner peace is identified as meaningful and implies that the families are in comfort and welcomed to contact the palliative home care team when needed. Still being oneself and maintaining and continuing with everyday life together with the family is another meaning to feel secure. The meaning of hope implies relying on the healthcare personnel and their competence to meet the families’ future needs.\textsuperscript{45}

**Rationale for the thesis**

Studies indicate that most patients with terminal cancer prefer to die in their own homes, but in reality most of them die in institutions.\textsuperscript{33} There are several studies showing the pressure on the next-of-kin caregivers during palliative home care,\textsuperscript{22,55-58} but only a few studies about the actual reasons the home care is interrupted.\textsuperscript{34,35,109} Describing the situations influencing the next-of-kin caregivers’ ability to manage palliative home care gives an opportunity to study the discrepancy between the patients’ expressed desires to be cared for at home during the end-of-life and the disruption of home care. Being aware of the reasons for disrupting home care is of great importance when planning for palliative home care. Medical technology has in recent years increased in palliative home care\textsuperscript{11,16,75} resulting that district nurses faces new tasks. Studies show how medical technology affects surgical and intensive care nurses,\textsuperscript{79-82} but there is a lack of knowledge about how district nurses perceive medical technology in home care as well as in palliative home care. District nurses work predominantly alone and make autonomous decisions and GPs often base their decisions concerning the patients in home care on their
assessments.\textsuperscript{66,67,70,72} It is therefore of relevance to show if medical technology has an additional affect on their work situation and, in an extension, an impact on patient safety.

There are several studies showing how medical technology influences the families’ lives and their home environment from parents’ points of view,\textsuperscript{13,14,17,18,84-86} but a lack of studies about how next-of-kin to patients in palliative home care perceive the medical technology. Next-of-kin often play a significant role in the home care by monitoring and taking care of the technology,\textsuperscript{13,14,17,18} and it is therefore important to describe their perceptions of the medical technology and what impact it made on their lives.

How patients experience medical technology in home care is described in several studies,\textsuperscript{87-90} but there are only a few studies on medical technology in palliative home care from a patient perspective.\textsuperscript{19-21} To capture the patients’ perceptions regarding the technology’s impact on their lives and the devices’ function and appearances is important to enable improvements in both the technology and palliative home care.
Aims of the thesis

The overall aim of the present thesis was to explore and describe how medical technology is experienced by patients, their next-of-kin and district nurses in palliative home care.

The specific aims of the different studies were:

- to describe situations influencing next-of-kin caregivers’ ability to manage palliative care in the home (I).
- to describe district nurses’ conceptions of medical technology in palliative home care (II).
- to describe next-of-kin’s conceptions of medical technology in palliative home care (III).
- to describe patients’ ways of understanding medical technology in palliative home care (IV)

Material and Method

Design and settings

In the thesis an explorative and descriptive design with a qualitative approach was applied to describe next-of-kin caregivers’ ability to manage palliative care in home and patients’, their next-of-kin’ and district nurses’ perceptions of medical technology in palliative home care (Table 1).
Table 1. Overview of the studies’ design, approach, data collection and data analysis

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<td>Design</td>
<td>Explorative, descriptive, qualitative approach</td>
<td>Explorative, descriptive, qualitative approach</td>
<td>Explorative, descriptive, qualitative approach</td>
<td>Explorative, descriptive, qualitative approach</td>
</tr>
<tr>
<td>Approach</td>
<td>Critical Incident Technique</td>
<td>Phenomenography</td>
<td>Phenomenography</td>
<td>Phenomenography</td>
</tr>
<tr>
<td>Data collection</td>
<td>Semi-structured interviews</td>
<td>Semi-structured interviews</td>
<td>Semi-structured interviews</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Critical Incident Technique, Flanagan 10</td>
<td>Phenomenography, Dahlgren &amp; Fallsberg 111</td>
<td>Phenomenography, Dahlgren &amp; Fallsberg 111</td>
<td>Phenomenography, Larsson &amp; Holmström 112</td>
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</tbody>
</table>

The studies were conducted in a county council in the southern part of Sweden, with a population of 350,000 individuals living both rural and urban. The county provided both a general palliative home care around the clock and a specialist palliative home care daytime, five days a week. The general palliative home care was based on primary care and was performed by a multiprofessional team consisting of district nurses, GPs, home care assistants, occupational therapists, physiotherapists, counsellors, social workers and when necessary other professions. The specialist palliative care teams were hospital-affiliated and had specialized skills in symptom relief and thus fulfilled an important role to support district nurses and GPs with this task. They also provided the opportunity for more advanced treatments to be performed in the homes, such as abdominal paracentesis and blood transfusions.

Participants
The participants were recruited between 2005 and 2011 (Table 2). The patients referred to in this thesis were enrolled in palliative home care, which implied access to professional support around the clock with the possibility to be transferred to another site for further care if the home healthcare failed. Some next-of-kin caregivers had sole responsibility for the care of the patients, while others had help from home care assistants. Some next-of-kin...
caregivers were able to get support and relief by personnel, who watched over the patients parts of the day or nights.

Table 2. Characteristics of patients in palliative home care, their next-of-kin and district nurses. N= number of participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Study I N=9</th>
<th>Study II N=16</th>
<th>Study III N=15</th>
<th>Study IV N=15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>5</td>
<td>3</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Women</td>
<td>4</td>
<td>13</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td><strong>Range (age)</strong></td>
<td>49-79</td>
<td>38-64</td>
<td>39-83</td>
<td>38-88</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&lt; 50</td>
<td>1</td>
<td>6</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>50-60</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>&gt;60-70</td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>&gt;70</td>
<td>2</td>
<td>6</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Nine-year compulsory school</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td></td>
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<tr>
<td>Upper secondary school</td>
<td>2</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>University</td>
<td>16</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Relationship to patient</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Husband</td>
<td>5</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>3</td>
<td>6</td>
<td></td>
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<tr>
<td>Child</td>
<td>1</td>
<td>3</td>
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<tr>
<td>Sibling</td>
<td>1</td>
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<tr>
<td>Niece</td>
<td>1</td>
<td></td>
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<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Together with the patient</td>
<td>8</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Together with own family</td>
<td>1</td>
<td>5</td>
<td></td>
<td></td>
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<tr>
<td>Patient had access to specialist palliative care team</td>
<td>6</td>
<td>9</td>
<td></td>
<td></td>
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<tr>
<td>Had access</td>
<td></td>
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<tr>
<td>Had no access</td>
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<tr>
<td>How long experience of medical technology in home care</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>-5 months</td>
<td>8</td>
<td>8</td>
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<tr>
<td>&gt;6-12 months</td>
<td>3</td>
<td>4</td>
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<tr>
<td>&gt;12 months</td>
<td>4</td>
<td>3</td>
<td></td>
<td></td>
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<tr>
<td>Years of working as district nurse</td>
<td></td>
<td></td>
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<tr>
<td>&lt;5</td>
<td>2</td>
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<tr>
<td>5-9</td>
<td>5</td>
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<tr>
<td>≥10</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Frequency of working with medical technology</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&lt;5 patients/year</td>
<td>4</td>
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<td></td>
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<tr>
<td>5-19 patients/year</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>≥20 patients/year</td>
<td>4</td>
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Study I

*Critical Incident Technique*

In study I, a descriptive design with Critical Incident Technique (CIT) according to Flanagan\textsuperscript{110} was chosen. CIT is an inductive, qualitative research method for collecting information on behaviour through critical incidents\textsuperscript{110} and therefore considered appropriate for study I. The aim of this method is to collect important facts of behaviours or activities in a defined situation. This method was developed by Flanagan during World War II, when there was an urgent need to train pilots, and analyses what kind of specific behaviours led to failure or success related to their mission.\textsuperscript{110} CIT has then been used for a variety of purposes, for instance in industry and business, to develop guidelines for acting in critical situations and improving job performance criteria.\textsuperscript{113,114} The method is also popular to examine aspects of nursing practice, to evaluate nursing performance and to teach professionalism.\textsuperscript{115-117}

According to Flanagan\textsuperscript{110} an incident is defined as any observable human activity that is sufficiently complete in itself to permit inferences and predictions about the person performing the action\textsuperscript{110} (p. 327). The incident is critical ‘if it makes a significant contribution, either positively or negatively, to the general aim of the activity’. To be a critical incident, it must occur in a situation where the aim of the activity and its consequences cannot be misinterpreted by the observer\textsuperscript{110} (p.338).

Some procedural steps are characteristic in CIT. The first step is to establish the general aim of the activity, which is important before developing the interview guide.\textsuperscript{118} The second step is to set plans and specifications, which means to decide which situations should be observed and which activities should be noted. The observed situations must include information about the context, the observers, the activity and the conditions. The observed behaviours must also be relevant to the general aim.\textsuperscript{110} The accuracy of this technique depends on the researcher’s competence to recall the participants’ memories and participants’ ability to remember and recount clear and concise descriptions of the activities.\textsuperscript{114} Flanagan\textsuperscript{110} considers that data collection should be done when the observers have the facts and the situations still fresh in memory. The period from the patient’s death to the
The interview of the next-of-kin was limited to a maximum of 18 months, to ensure that they could remember the period of care as well as possible. The third step is collecting the information. The most common method for data collection is interviews in which the observers can describe in detail situations from the past. The descriptions can consist of situations that occurred repeatedly and not solely in separate situations. According to Flanagan a critical incident should be clearly defined and consist of a clear beginning and end, but Norman et al suggest that an incident can be a summary of incidents of similar type rather than a clearly-recalled single event. In study I the situations are identified both according to Flanagan’s and Norman’s definitions.

The advantages of CIT is that data can be collected quickly, usually in 15 to 20 minutes, and the size of the sample is not determined by the number of observers but the number of collected incidents. In study I 138 situations were identified, which according to Flanagan can be considered sufficient. The number of incidents needed depends on the complexity of the aim and it can be sufficient to collect 50 to 100 incidents if the studied activity is relatively simple. The limitations of this methodology are its dependence of the participants’ ability to recall detailed accounts of situations that has occurred. It might also be difficult for the researcher to define and separate the situations from the story, if there is a summary of situations within the same events.

**Participants and data collection**

The participants in this study consisted of nine next-of-kin caregivers to patients in palliative home care. The patients had expressed a desire to be cared for at home during their final days of life. However, for various reasons the home care was disrupted and the patients were moved from the homes to another care site where they later died. The next-of-kin caregivers were selected to obtain variation in sociodemographic data and experiences as caregivers (Table 2). District nurses in general palliative home care contacted eligible next-of-kin about participating in the study. Data collection consisted of tape recorded and semi-structured interviews conducted by the main author during 2005. The interviews took place predominantly in the participants’ homes. The interview questions were about how palliative care in the home had functioned and if there were any
specific situations when they did not receive the support they needed. They were also asked if there was a specific situation that caused the discontinuation of home care and how they felt about that. Both positive and negative situations about the care were requested. The interviews were then verbatim transcribed by the main author.

**Data analysis of study I**

The fourth step is data analysis, which is an inductive process to classify and categorize the collected information. This was done in collaboration with the co-authors. Insight, experiences and judgement is requested when grouping the incident and formulating the categories. Norman et al.\(^{118}\) suggest that the basic units are the observed activities revealed by the incident. They mean that the term ‘revelatory incident’ is more appropriate than critical incident, because the activities are only critical if they are identified as meaningful by the observers. The first step of the analyses started with identifying positive and negative situations related to the aim of the study and which were identified as meaningful by the next-of-kin caregivers. This resulted in 138 situations. These situations were studied and compared with each other according to their nature and content, and then classified into groups. The next step was to reformulate the groups of situations into different kind of behaviours which were arranged into 17 subcategories and classified according to their content. Similar subcategories were further grouped together in five categories which were entitled according to their content. These categories were finally brought together under two main themes. The last step was to discuss and disseminate the findings. The result of the study was presented as recommended to an independent judge to strengthen the credibility of the data and to make the categorization less subjective.\(^{118}\) The inter-rater reliability test’s concordance with the result of the study was for the subcategories 74%, for the categories 94% and the themes 100%. The subcategories and categories which were inconsistent were again discussed with the supervisor and then partially reformulated to a final result. According to Andersson and Nilsson\(^{113}\) the agreement about subcategories of independent judges is not especially high when it is below 70%, but an agreement of categories more than 80% suggest that the category system is plausible.
Studies II, III and IV

Phenomenography

In studies II, III and IV a descriptive design with a phenomenographic approach according to Marton\(^{120}\) was chosen. Phenomenography is an approach about learning and understanding in the educational environment and was developed in the 1970s by researchers from the Department of Education at the University of Gothenburg in Sweden. The word phenomenography means descriptions of things as they appear to us. The experience of a phenomenon includes an internal relationship between a subject and the world. The experience is non-dualistic, and consists of different ways people perceive a given phenomenon and how a given phenomenon is perceived by different people. How people handle and act in relation to a situation depends on how they perceive the situation. It is the variation of different ways of perceiving a phenomenon which is requested in phenomenography.\(^{121}\) In order to characterize the variation it is important to understand what it means to experience a phenomenon in a particular way. The reality can be perceived from two perspectives where the first-order perspective contains a ‘what’ aspect, and corresponds to the object itself and valued in relation to other statements. The second-order perspective contains a ‘how’ aspect and describes how something is perceived to be, which relates to the act and how to perceive a phenomenon. In the first order perspective the researcher focuses on the object and brackets his/her own perceptions, while in the second-order perspective the researcher focuses on how others perceive the object. In phenomenography the interest is in the second-order perspective.\(^{120}\) Phenomenography aims to describe the total number of variations in the way people perceive a phenomenon. A phenomenon can be perceived in an endless number of ways, but when the reality is conceptualized, there seems to exist a relatively limited number of qualitatively different ways of understanding it.\(^{112,120,121}\) In order to experience a particular aspect of a phenomenon, factors such as discernment, variation, contemporaneousness and simultaneity are important. To perceive a ‘what’ is to discern part of a whole in a focused awareness and relate it to the context. The various aspects of the phenomenon as discerns simultaneously in a focused awareness is the ‘how’ and the result.\(^{121,122}\) The different ways of perceiving a phenomenon are logically and hierarchally related to each other and together they constitute the outcome space.
consisting of different description categories. In study IV the differences between the what-aspect and how-aspect were in focus in general and with special focus on the differences between the how-aspect concerning the outcome resulting in three ways of understanding medical technology.

**Participants and data collection of study II**

In study II, 16 district nurses were strategically chosen by the main author (Table 2). In phenomenography the researcher must be aware of his/her own presuppositions in the selection process and set own assumptions aside, so called 'bracketing'. In selection of the district nurses it was important to not consciously select those who were supposed to have certain perceptions of the requested phenomenon. The selection procedure started with an attempt to recruit as many male participants as possible because there is a predominance of female district nurses. The next step was to obtain variation in: age, years of working as district nurse, experience of working with medical technology, experience of working in general or specialist palliative home care and if they had experience of working predominantly in primary care or in hospital care. Data collection consisted of tape-recorded, semi-structured interviews, which were conducted by the main author. The interviews took place at the district nurses’ working place during 2007. They were asked to describe the impact medical technology had regarding their work situation and their care relation to the patients and their next-of-kin. They were also asked questions about environment and safety in the homes when working with medical technology. In the interview situation, it was important for the main author to bracket her presuppositions to avoid being influenced by her own personal prior knowledge as a district nurse, which increased the opportunity to hear and understand what the participants said. The interviews were transcribed by the main author.

**Participants and data collection of studies III and IV**

Fifteen next-of-kin to patients with medical technology in palliative home care were strategically chosen for study III and eighteen patients with medical technology for study IV. The selections were made by district nurses who knew the patients with medical technology and their next-of-kin, to obtain variation regarding sex, age, education, living arrangements and experiences of medical technology (studies III, IV), relationships to
patients, and access to specialist palliative care teams (study III) (Table 2). Data collection was conducted by the main author and consisted of semi-structured tape-recorded interviews during 2009-2011. Eighteen patients were willing to participate but, as their physical condition quickly deteriorated from one day to another, three patients had to decline participation despite several rescheduling of the interview sessions. Finally interviews were conducted with fifteen patients who were eligible during the period. The interview questions were designed on the basis of what emerged from previous interviews with district nurses and what has been shown to be important in other studies in terms of: participation, support, impact on daily life and security in relation to the medical technology. The main author used the same questions in studies III and IV, in order to have an opportunity to compare the next-of-kin’s and patients’ conceptions of medical technology in palliative home care. The interviews took place predominantly in the participants’ homes. Some of the participants were next-of-kin to patients who were participants in study IV. However, to avoid reflected answers and provide opportunity for the participants to be open in the interview situation, the interviews took place at different times. Two of the patients had difficulties in speaking and used computer and paper and pen in their communication. These interviews were also tape-recorded, not to miss important audio information during the interview situation. Finally the interviews were transcribed by the main author.

Data analysis of studies II and III

The interviews in studies II and III were analysed by the main author in cooperation with the co-authors, nurse researchers with extensive knowledge in both subject and methodology. After analysis of the 13th interview in study II and analysis of the 12th interview in study III, no new categories were revealed. Three additional interviews were then conducted and analysed to confirm this in a seven step process according to Dahlgren and Fallsberg.

- Familiarization: The transcribed interviews were read through several times to get an idea of and to become familiar with the contents.
• **Condensation:** The most distinctive statements related to the purpose were selected and the quotes were condensed to obtain the key for each view.

• **Comparison:** The selected statements were peer compared to find similarities and differences in informants’ conceptions of medical technologies in the palliative care at home.

• **Grouping:** Similar statements were grouped together in conceptions.

• **Articulating:** A preliminary attempt was made to describe each conceptions and its essence, to find limits and to ensure that the conceptions were distinct and qualitatively separated.

• **Labelling:** Each conception was labelled with something that characterized its content.

• **Contrasting:** On a more abstract level, the conceptions were compared with regard to similarities and differences and finally summarized into five description categories.

**Data analysis of study IV**

The analysis of study IV was performed by the main author in cooperation with the co-authors in a seven-step process according to Larsson and Holmström\(^\text{112}\). They consider the outcomes of many phenomenographic studies to be only different description of categories, representing the participants’ different ways of understanding a requested phenomenon. However, this outcome of description categories is usually related to each other in a hierarchical and structural way. A further step and development in the phenomenographic analysis can be to find this structural relation between the different ways of understanding the phenomenon.

• In the first step, each transcribed interview was read through.

• In the second step, the text was reread again and statements where the interviewed answered the aim of the study were identified and marked.

• In the third step was identified what was in the focus of the patients’ attention and how they described their understanding of medical technology. A preliminary description of each patient’s dominant way of how to relate to medical technology in home care was then made.
In the fourth step, the descriptions were grouped into categories based on similarities and differences, and for each category a common description was formulated.

In the fifth step, the non-dominant ways of understanding the phenomenon medical technology were looked for, i.e. other ways of understanding the phenomenon to ensure that no aspect was overlooked.

The sixth step was to identify the internal relations between the different categories investigated and to create a structure in the outcome space.

In the seventh and last step each category of descriptions were assigned a metaphor.

**Ethical considerations**

In accordance with the Swedish law, regarding the ethical review of human beings, an approval from Research Ethics Committees was not needed at the time when study I and II were made. Consent for studies III and IV was obtained from the Regional Committee for Human Research at Linköping University, Linköping (diary nr. 1209). All studies were also approved by the operation managers of the respective primary care districts where the research took place and informed consent, both orally and written, was obtained from the participants prior the interviews. During the interviews the participants were again informed about voluntary participation and their right to at any time and without explanations terminate the interview. The basic principle in research on a vulnerable patient group is to generate knowledge relevant to the patient group's health needs. Research should not be conducted on a vulnerable group if it can be performed on another similar group instead. Conducting research with patients in palliative care and their next-of-kin is difficult for practical reasons and ethically challenging. There is a risk that they may experience discomfort and a feel of violation of their integrity. However, by excluding this population, valuable knowledge about them is not generated, and several authors emphasize the importance of research on patients in palliative care. The main author’s experience as district nurse and previous experience to care for and interview patients in palliative care was a benefit to determine whether or when the interview
should be interrupted because of the patient’s health condition. The judgement was that they were grateful for the opportunity to converse with some person not involved in their care and who wanted to listen to them.

The four ethical principles: the principle of autonomy, the principle of justice, the principle of non-maleficence and beneficence\textsuperscript{131} have been taken into consideration in the studies. The principle of autonomy means to respect the informants’ ability and right to self-determination, their participation in decision-making, their integrity and their ability to independently evaluate the information of alternative actions.\textsuperscript{125} In the studies this was taken into consideration by the participants possibility to decide whether they wanted to participate or not, and by the information of voluntary participation, both orally and in writing. The principle of justice means that all persons should be treated equally and includes the informants’ right to privacy and fair treatment. In the selection of participants, the district nurses might have done a selection which disadvantaged some participants, thus denying them their right to participate in a study and the opportunity to express their opinions. A fair treatment was considered if the participants experienced the interviews as exhausting, why it was important to be sensitive to their strength and not prolong time of the interview. The principle of non-maleficence, the so-called protection requirement, implies that people must not be subjected to unnecessary discomfort, e.g. inquisitive questions that may violate their privacy.\textsuperscript{125} This principle was considered by the researcher’s sensitivity in the interview situation. The principle of beneficence implies that everyone should strive to do good and prevent or avoid injury and is motivated by the knowledge requirement,\textsuperscript{132} which is justified by the results of the studies which generated new knowledge with opportunities to improve palliative care for patients with medical technology and for their next-of-kin.

**Methodological considerations**

When qualitative researchers want to establish trustworthiness in their studies they often refer to Lincoln and Guba,\textsuperscript{133} who use the terms *credibility, dependability, confirmability* and *transferability*. *Credibility* refers to how data are obtained and interpreted. To establish credibility prolonged engagement in the field is recommended, which provides increased opportunities to learn about the culture and the participants.
Another way to get credibility is triangulation which is the combination of multiple and different methods, sources or researchers. Dependability is referred to the stability of measurements over time, which in qualitative research can be compared to intercoder agreement and means the multiple coders’ consistency in data analysis. Confirmability is the value of the data and can be compared to objectivity or neutrality of data. A reflective mind during the research process strengthens the confirmability. Transferability refers to generalizability of data and the extent to which the result can be transferred to other groups and settings. To get transferability thick description is suggested, which means a detailed description of the sampling and the context.\textsuperscript{134}

Credibility

The main author’s profession as district nurse and extensive experiences of working in palliative home care facilitated to obtain rich information from the participants. Data triangulation is another way to strengthen the credibility. Person triangulation consists of collecting data from more than one level of persons, i.e. set of participants, where the researcher uses data from one level of person to validate data from the second or third level of person.\textsuperscript{135} To choose similar interview questions in the four studies and same questions in study III and IV was an advantage to compare the participants’ different or similar perspectives of medical technology in palliative home care. A disadvantage may be that the results in one study could have had an impact on the analyses of another study. To limit this, the analyses were done in close cooperation with the co-authors who discussed the different steps of the analysis and then agreed on the results. The participants in studies I, III, and IV were selected by district nurses who know the palliative patients and their next-of-kin. The help of district nurses in the selection of participants can be seen as a disadvantage due to their ability to filter out those which they considered inappropriate for an interview. On the other hand, the district nurses know the families where medical devices exist in the home and presumably this is the best way to get contact with the families. The main author had no caregiver contact with the patients and next-of-kin, giving them greater opportunity to be open and honest in the interview situation. It was especially important to emphasize their voluntary
participation, so they did not feel forced to participate to make their previous caregiver satisfied.
The selection of district nurses in study II was performed by the main author. It was therefore important not to select district nurses who were close colleagues or in a position of dependence on her. Some doubts can prevail regarding the gender distribution in this study, as the participants consisted of only three male district nurses. Perhaps more male district nurses could have influenced or added other aspects of the phenomenon.
The sample in study I consisted of a strategic selection of 9 next-of-kin caregivers (Table 2). Although the sample consisted of only 9 participants it can still be considered as rather varied regarding to gender, age and relationship. The process of analysis was carried out in close cooperation with the co-authors who followed the process and discussed and reflected on the statements that emerged.

**Dependability**
To strengthen the *dependability*, the results in study I were presented to an independent judge in an ‘inter-rater reliability test’. The statements which were inconsistent were again discussed with the co-authors and then partially reformulated. To avoid misunderstandings, the participants in studies II-IV were given a definition before the interviews of what kind of medical technology was included in the studies. The use of a semi-structured interview guide in the studies meant that all participants received the same overall questions, to get stability of data and to simplify a comparison between the interviews.

**Confirmability**
According to *confirmability* the most important thing is to be aware of personal prior presuppositions and to have an awareness of these pre-understandings during the whole research process. The first author’s own experience as a district nurse can possibly have had an impact on the outcome in the studies but, on the other hand, to be familiar to the culture and context strengthens the credibility of the study. The co-authors objective scrutiny in the analysis process also helped to maintain awareness of possible influences on the results. In connection with the informed consent obtained from the participants in studies II-IV, they also were given
information about the aim of the study and what kind of phenomenon was of interest and being studied. In phenomenography it is the peoples’ unreflective ways of perceiving a phenomenon that are described and this procedure may instead have influenced their perceptions to be reflective. However, it was considered important for the participants to know before the interviews what would be studied.

**Transferability**

Because of limited previous research in this area, an explorative descriptive design was considered as the most appropriate method to describe the requested phenomenon. The use of a quantitative method would have given a different type of information on the phenomenon. It can be seen as a disadvantage to only have qualitative methods in this thesis and that three of the studies have the same approach, but the advantage is the opportunity to compare the participants’ perceptions of the phenomenon.

It is reasonable to assume that the findings in studies I, III and IV can be used by healthcare personnel with other patients and their next-of-kin caregivers who have the same characteristics as the participants in this study. The results in studies III and IV can be considered as transferable to similar contexts with non-palliative patients using medical technology in home care and to their next-of-kin.
Summary of findings

This thesis is based on four studies which describe situations influencing next-of-kin caregivers in palliative home care and perceptions of medical technology as experienced by patients, their next-of-kin and district nurses.

Study 1
Situations influencing next-of-kin caregivers in palliative home care - from control to loss of control

The next-of-kin desired to maintain control in their otherwise chaotic and insecure daily life. They demonstrated this by physically and mentally being available day and night and having the patients 24 hours on their mind. They took comprehensive responsibility for managing the home and for the patient’s entire care. This provided the next-of-kin with the satisfaction of being involved in the care and the patient with a sense of security. The next-of-kin also emerged as the strong individual who encouraged and supported the patient to sustain hope for the future. As the patient’s health declined, the next-of-kin’s workload increased and they gradually began to lose control over their situation. The next-of-kin lost control when they missed professional support, due to inadequate information or insufficient resources. They were inadequate and became exhausted when the patient’s care became increasingly overwhelming and they no longer had the physical and mental strength to care for the patient at home. This in combination with a constant lack of time caused feelings of guilt. They were powerless when the patient developed symptoms which were difficult to treat and relieve. They were also powerless when the patients refused help from outsiders or lost their strength and wanted to be cared in another site. The most common reasons for discontinuing care in the home were acute or difficult to treat symptoms in combination with complete exhaustion of the next-of-kin (Table 3).
Table 3. Decisive situations of importance for how the next-of-kin caregivers (NC) managed palliative care in the home.

<table>
<thead>
<tr>
<th>Subcategories (number of situations)</th>
<th>Categories</th>
<th>Main areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>NC took responsibility for daily care (13)</td>
<td>Being available day and night</td>
<td>Maintaining control</td>
</tr>
<tr>
<td>NC took night watch (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC took responsibility of home care (7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC had the patient always on their mind (7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC had nursing responsibilities (6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC gave encouragement and support (6)</td>
<td>Sustaining hope</td>
<td></td>
</tr>
<tr>
<td>Inadequate information from medical service (10)</td>
<td>Missing professional support</td>
<td>Losing control</td>
</tr>
<tr>
<td>Inadequate support from medical service (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate communication with medical service (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited contribution from medical service (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC became exhausted (8)</td>
<td>Being inadequate</td>
<td></td>
</tr>
<tr>
<td>NC experienced lack of time (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NC had guilt feelings (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The patient developed symptoms that were acute or difficult to treat (30)</td>
<td>Being powerless</td>
<td></td>
</tr>
<tr>
<td>The patient’s personality changed physically and mentally (9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The patient refused home assistance (5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The patient lost his/her strength (2)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Study II
District nurses’ conceptions of medical technology in palliative home care

The study resulted in the five description categories. District nurses consider medical technology led to vulnerability in their work situation due to increasing demands and changing tasks. Time and resources were not always sufficient and they had to prioritize. They felt exposed in the patients’ homes with different conditions from those in hospitals and felt the distance to GPs and other colleagues. Medical devices that they rarely came into contact with created uncertainty, while regular use and continuity created a patient safe care. Medical technology demanded collaboration for the palliative care to work in an optimal way. District nurses encouraged the next-of-kin to participate in the care and were dependent on their assistance with the medical devices in the home. District nurses were also dependent on peer support from other colleagues and specialist palliative care teams, when they were uncertain how the medical devices should be handled. It demanded self-reliance to manage medical technology in palliative home care. This was acquired by the district nurses through long work experience and a basic security. Depending on district nurses’ personality and experiences, the use of medical technology in home care was considered to be a challenging and stimulating task, which they did not want to be without. Medical technology required awareness of patient safety when it was used in home care. Long distance to the patients and an unpredictable work environment in the homes increased the risks and the uncertainty factor. Medical technology also created ethical dilemmas, when it was used as life-sustaining treatments. District nurses meant that GPs did not always take their responsibility to end these treatments. However, medical technology provided freedom for patients with increased opportunities to get special treatments at home and possibilities to choose care site in end-of-life. Participation in their own treatments made the patients more independent and thus the number of home visits could be reduced (Table 4).
Table 4. Description categories and conceptions of the phenomenon medical technology among district nurses in palliative home care

<table>
<thead>
<tr>
<th>Description categories</th>
<th>Conceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical technology leads to vulnerability</td>
<td>Implies increased demands</td>
</tr>
<tr>
<td></td>
<td>Creates uncertainty</td>
</tr>
<tr>
<td></td>
<td>Implies increased exposure</td>
</tr>
<tr>
<td>Medical technology demands collaboration</td>
<td>Requires mutual dependence</td>
</tr>
<tr>
<td></td>
<td>Requires collegial support</td>
</tr>
<tr>
<td></td>
<td>Creates participation</td>
</tr>
<tr>
<td>Medical technology demands self-reliance</td>
<td>Demands security</td>
</tr>
<tr>
<td></td>
<td>Demands experience</td>
</tr>
<tr>
<td>Medical technology requires awareness</td>
<td>Requires a patient-safety thinking</td>
</tr>
<tr>
<td></td>
<td>Requires own responsibility</td>
</tr>
<tr>
<td></td>
<td>Requires sensitivity</td>
</tr>
<tr>
<td></td>
<td>Creates ethical dilemmas</td>
</tr>
<tr>
<td>Medical technology provides freedom for patients</td>
<td>Makes the patients independent</td>
</tr>
<tr>
<td></td>
<td>Provides increased opportunities for the patients</td>
</tr>
</tbody>
</table>
Study III
Next-of-kin’s conceptions of medical technology in palliative home care

This study resulted in five description categories. Next-of-kin perceived that medical technology in palliative home care required responsibility and their presence day and night. They acted as the district nurses’ assistants by providing practical help or by monitoring the medical devices, which was an opportunity to participate in the care and to reduce the number of home visits by the personnel. They were the patient’s representative and questioned the patient’s medical technology or made sure they had access to appropriate devices. Medical technology implied uncertainty for the next-of-kin due to its function, capacity and user-friendliness. They were concerned that the medical devices could be damaged by the patients and felt a need to monitor the devices day and night. Personnel’s uncertainty when handling the medical devices resulted in lack of confidence and insecurity among the next-of-kin. Medical technology trespassed on daily life and led to restrictions in the next-of-kin’s social life, since they had to stay home during the patient’s treatments. Medical technology also affected the next-of-kin’s private sphere because of more home visits from personnel and bulky materials requiring storage space. However, medical technology enabled comfort and security for the next-of-kin when they saw its benefits for the patient and understood it as a precondition for the patient to be cared for at home. Treatments with medical technology implied more and regular home visits from personnel, which the next-of-kin perceived as a security. Newer medical devices, designed and adapted for outdoor use, implied more freedom both for the patients and the next-of-kin. Living with a patient with medical technology required adjustment to new conditions. To make life more comprehensible and manageable the next-of-kin searched for information and tried to find solutions to minimize the medical technology’s impact on their daily life (Table 5).
Table 5. Description categories and conceptions of the phenomenon medical technology among next-of-kin in palliative homecare

<table>
<thead>
<tr>
<th>Description categories</th>
<th>Conceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical technology required responsibility</td>
<td>Medical technology required an assistant</td>
</tr>
<tr>
<td></td>
<td>Medical required a representative</td>
</tr>
<tr>
<td>Medical technology implied uncertainty</td>
<td>Medical technology caused worry</td>
</tr>
<tr>
<td></td>
<td>Medical technology created a lack of confidence</td>
</tr>
<tr>
<td>Medical technology trespassed on daily life</td>
<td>Medical technology led to restrictions</td>
</tr>
<tr>
<td></td>
<td>Medical technology affected the private sphere</td>
</tr>
<tr>
<td>Medical technology enabled comfort</td>
<td>Medical technology implied security</td>
</tr>
<tr>
<td></td>
<td>Medical technology implied freedom</td>
</tr>
<tr>
<td>Medical technology required adjustment</td>
<td>Medical technology required comprehensibility and manageability</td>
</tr>
<tr>
<td></td>
<td>Medical technology implied adaption</td>
</tr>
</tbody>
</table>
Study IV
Patients’ understanding of medical technology in palliative home care; a qualitative analysis

Three categories regarding patients’ understanding of medical technology in palliative home care were revealed. The masterful patient wanted independence which they indicated by taking control over the medical technology and participating in the care, which also reduced the personnel’s home visits. The masterful patient moderated the medical treatments to his/her intended plans for the days. An effective treatment with medical technology implied more strength and possibilities to participate in daily activities. The masterful patient also desired to have impact on the design of the medical devices and hoped his/her suggestions for improvements would be helpful for other patients.

The most common way to understand medical technology was as an adjustable patient, who accepted the medical technology and adapted his/her daily life to it and tried to find solutions to minimize its impact on their life. The adjustable patient was satisfied with the medical technology and the support he/she got from the palliative care teams, which implied security and an opportunity for him/her to be cared at home.

The restricted patient was daily reminded of the medical technology as it obstructed him/her, disturbed the night’s sleep and caused side effects. The restricted patient experienced a limited freedom of movement and restriction in relations to friends. Medical technology created dependence on personnel, with their regular home visits and treatments that were necessary for him/her to survive. Lack of information also created a restricted patient. Patients exhibited various ways of understanding. Although one was more dominant, a transfer between the different ways of understanding occurred depending on the patient’s health condition, the support he/she got and the medical technology’s impact on his/her daily life. A movement simultaneously occurred between independence and dependence (Figure 1).
Figure 1. The outcome space illustrated the relationship between the three ways of understanding medical technology in palliative home care.

Discussion

Based on the results of the studies in this thesis, palliative home care and medical technology in palliative home care can be illustrated by using the concepts; participation, support, safety and impact on daily life. The result of study I about next-of-kin caregivers’ loss of control due to their participation in care, lack of support and their requirement to monitor medical devices during the nights was a source of inspiration for study II. The district nurses’ perceptions about medical technology in study II were, in addition to participation and support, moreover about safety in home care and medical technology’s impact on their working conditions and were therefore a foundation for the following studies III and IV. The advantage of this structure of the studies was the opportunity to describe patients’,
kin’s and district nurses’ different perspectives about palliative home care and medical technology in palliative home care.

Palliative home care’s impact on daily life
The next-of-kin caregivers (study I) were physically and emotionally overburdened with their 24-hour responsibility, including patient care, medical and household tasks, and constant concern over the patients’ disease progression. When they no longer had the strength to carry on the home care, they expressed feelings of insufficiency and guilt. When they saw the patients’ mental and physical changes it meant a psychological strain for them. Feelings of guilt and unfamiliar reactions are confirmed by other studies.\textsuperscript{60,61}

Medical technology in palliative home care had, in different ways, more or less physical and/or emotional an impact on the daily lives of the patients and the next-of-kin (studies I-IV). Next-of-kin living with their own families (study III) were often emotionally affected by the patients’ medical devices. They expressed feelings of sadness and found it especially difficult to accept situations where the patients were tied to their medical devices and their nutrition artificially administered by a tube. However, both the patients and the next-of-kin were grateful for the nutrition treatment and had no thoughts about terminating any life-sustaining measures (studies III, IV). Next-of-kin to patients with difficulties to swallow express similar feelings of gratefulness which turns to security when the patients get their nutrition administered by tubes.\textsuperscript{19}

Nutritional support in palliative care aims to provide the patients wellbeing and symptom relief rather than prolong their lives.\textsuperscript{94} The patients in palliative care accepted their regular treatments and realized they were necessary for them to survive. The treatment also gave them more energy and strength which increased their forces (study IV). They instilled hope for the patients and the next-of-kin, instead of the hopelessness that can follow when a person gets a diagnosis of a severe illness. To preserve hope for the patients and their next-of-kin is an important task for the healthcare personnel working with this kind of care. This can mean to do something special for the families and to try fulfil their desires. Patients in palliative care do not establish long-term goals, they try to live in the present with their loved ones and strive for normality.\textsuperscript{40,136}
District nurses expressed ambivalence toward patients nutritional feed, which they considered must be meaningful and not unnaturally prolong the patient’s life. They stated that the GPs did not take their responsibility to remove the medical treatments before patient’s end of life, forcing them to continue a treatment which sometimes was more tormenting than useful for the patient (study II). Nurses experience anxiety and sorrow to participate in unnecessarily aggressive treatments or the prolonged use of life-saving technology. They want more influence in end-of-life decisions, and experience their knowledge of the patients is undervalued by the physicians. Nurses and next-of-kin also consider they are not sufficiently involved in the process of withdrawing medical treatments. Nutrition is an important task in palliative care and shortage of dietitians means that the district nurses have a greater responsibility to be updated about nutritional recommendations to this patient group. District nurses need more knowledge about calculating patients’ caloric intake and nutritional requirements to assure an optimal treatment.

The medical devices in palliative home care were perceived as disturbing as they were too heavy and bulky, had long hoses which risked being entangled and connections to tubes that came loose and created worry (studies III, IV). When the patients required parenteral nutrition at night, this implied a disturbed night sleep for the next-of-kin, because of monitoring the nutrition drip (study I). The medical devices also required large spaces for storage, preparation and waste management, which encroached on the families’ space (study III, IV). The medical devices can change a private home to a mini-hospital where personnel pass in and out. However, it is the patient as home owner who decides the rules and how the nurses, as guests, should behave. It is convenient for the healthcare personnel to have all equipment stored in the patients’ homes, but they must try to limit their storage space to avoid requiring next-of-kin to make sacrifices in their own homes.

Treatments with medical technology implied a lot of home visits from personnel which both restricted the patients and their next-of-kin’s private sphere and time and was an intrusion on their privacy. Too many personnel were involved in the care and the lack of continuity implied insecurity. There were patients and next-of-kin who appreciated these home visits since they gave them a sense of security, while others wanted to avoid them and tried to do as much as they could themselves (studies I, III and IV). The patients and
next-of-kin were especially satisfied with the skilled healthcare personnel in palliative home care teams who represented continuity and security (study III, IV). District nurses in the United Kingdom emphasize the importance of continuity among healthcare personnel in palliative home care and consider that ‘hospice at home’ teams may be helpful to implement this. Palliative care teams and a trusting relationship with the healthcare personnel is, according to next-of-kin, a prerequisite in palliative home care. The palliative care teams inspire security and relieve the next-of-kin’s caregiver burden. Medical technology also implied freedom for the patients and the next-of-kin. A new and more user-friendly nutrition pump adapted for outdoor use made the patients and their next-of-kin more independent of district nurses’ home visits and gave more freedom of movement which they appreciated (study III, IV). Feelings of freedom and independence are confirmed by patients undergoing dialysis and oxygen treatments at home, thereby avoiding frequent hospital visits.

Medical technology has changed the district nurses working situation as it requires more planning and organization before the home visits to patients with medical technology. They need to take personal responsibility for regularly updating themselves and preparing before their home visits (study II). Continuity in palliative home care is a prerequisite for the patients’ and next-of-kin to feel secure. District nurses working both in clinics and general palliative home care have a fragmented work situation, resulting in lack of continuity, implying insecurity for the families, jeopardizing patient safety and thus risking to harm the care relationship. Organizational changes may be necessary but also the district nurses need to select orientation and specialize, either to work with palliative home care or to do clinic work.

**Participation in palliative home care**

The next-of-kin caregivers (study I) took sole responsibility for the patient’s palliative home care. This participation gave them satisfaction and allowed them to maintain control of their otherwise chaotic lives and provided a sense of security for the patients when home visits from healthcare personnel could be minimized. However, this participation implied next-of-kin’s availability day and night, leading to restrictions and a loss of personal freedom. The next-of-kin had constant feelings of guilt when they could not live up to the demands that were placed on them (study I). To be a next-of-
Kin caregiver is a very stressful and exhausting experience with physical and emotional burdens, implying they lose control and normality in their daily life is broken down.\textsuperscript{22,55-58} Sole responsibility for the patient’s care increases the risk that home care must be discontinued, which is confirmed in other studies.\textsuperscript{34,139} A close relation between the next-of-kin and the patients favours the opportunities to terminate palliative care at home.\textsuperscript{50} It is important as healthcare personnel to be aware that having only one caregiver reduces the chances of completing palliative home care. Consequently, they must as soon as possible convince the next-of-kin of the importance of introducing home assistance in the care. An open communication between healthcare personnel and the families enable this. Communication is also important to avoid ethical conflicts if the patients and the next-of-kin have different preferences about where the palliative care should be conducted.\textsuperscript{8}

The district nurses (study II) were dependent on and often expected some assistance with the medical technology from the patients and their next-of-kin. They encouraged them to participate in the care and were of the opinion that next-of-kin frequently offered their help to relieve the healthcare personnel. This was also an opportunity for the next-of-kin to be useful and for the patients to be more independent. To participate in care and discussions about treatments is important and is confirmed by other studies.\textsuperscript{44,45}

The next-of-kin (study III) considered they needed to help the district nurses with the patients’ medical technology and perceived themselves as the district nurse’s extended arms. They acted as supervisors of the medical technology during nights and kept track of materials and equipment. Monitoring the medical devices was an opportunity for some next-of-kin to participate in care, while others did not want to deal with that, as they felt they lacked sufficient knowledge about how they should handle it.

The question of responsibility is highlighted in a study about parents to technology-dependent children. To have their child discharged from hospital dominates the parents’ thoughts to such an extent that no agreements were reached on who should take responsibility for the technical procedures at home.\textsuperscript{85}

The masterful patients (study IV) took every opportunity to participate in their own care. They showed this by taking responsibility for their own medical devices and desired knowledge of both their function and the
treatments they received, in order to assist the district nurses if any problems arose. They also gave suggestions for improving the medical devices’ design and user friendliness. A desire to influence and improve the medical devices’ appearance is confirmed by other studies.\textsuperscript{10,87}

Participation in their own care gave the patients more freedom and independence, as the number of home visits by personnel were reduced (study IV). Patients’ need of being involved in their own care has early been highly valued, which make their lives more comprehensible and manageable.\textsuperscript{53,87,140-142} The patients’ and next-of-kin’s participation in the care and monitoring of the medical devices reduced the personnel’s home visits, which was an advantage for these patients and next-of-kin who wanted maintain their integrity (studies I, III and IV). District nurses considered this assistance facilitated their working situation if the patients lived far away from their working place (study II). Due to the distance, the patients and next-of-kin fully understood that it was difficult for the district nurses to support them for trivial things if the medical devices failed to function, and tried to solve the problems themselves (studies I, III and IV).

However, there is a risk that district nurses implicitly expect some assistance from these patients and next-of-kin, who live in remote areas, resulting in their accepting a greater responsibility than they actually would like. It is important for district nurses not to use these situations to facilitate their own working conditions. They need to carefully consider what the patient and the next-of-kin are capable to taking care of with the prevailing technology. It requires sensitivity of the district nurses to decide what they dare to delegate to the families without unnecessarily overburden them.

The need of support in palliative home care

Next-of-kin caregivers (study I) were mostly satisfied with the support they received. However, they felt a lack of professional support when they did not get information and not were involved in the decision making process, which was a prerequisite for managing the care. They also lacked concrete support in specific situations, resulting in that they lost control in their life (study I). Lack of professional support in terms of lack of information and communication implies feelings of isolation, frustration and distress for the next-of-kin.\textsuperscript{8,22} Sufficient information enables the next-of-kin to understand and confirm the situation and to be mentally and practically prepared for the
future. The next-of-kin consider it is their natural right to receive this information.143 Patients’ and next-of-kin’s needs of being informed and involved in care are confirmed in several studies.87,140,142 Support group programs for meeting the family’s needs of information, practical care, emotional support and assurance of good palliative care can be useful interventions.144

The medical technology in palliative home care was often a precondition for the patients to be cared for in the homes, but it also meant regular home visits by district nurses and specialist palliative home care teams. The patients and the next-of-kin were contented with the healthcare personnel’s availability, attentiveness, skills and their support, which implied security for them. When the specialist palliative care team provided special treatments for the patients in the home, this was especially appreciated as the patients avoided tiresome hospital visits (studies III, IV). It has been shown that next-of-kin are more satisfied with symptom relief, participation and information from comprehensive palliative program than from conventional care program.145 Need of support in connection with medical technology is important and confirmed in others studies.10,87,90

District nurses encouraged and supported the patients and their next-of-kin who wanted to take own responsibility for the medical devices. The district nurses were instead in the background and stepped in when needed. District nurses also meant it was important to get peer support from other colleagues and specialist palliative care teams, when they felt uncertain about how the medical devices should be handled (study II). GPs and district nurses experience improvement of treatments and care in their collaboration with specialist palliative home care teams.64,97 The district nurses’ desire to provide a good palliative care competed with their prevailing work conditions, risking physical and emotional overloading and alienation in patient care (study II). Hospital nurses express similar feelings when they strive for emotional survival to manage their work situation in connection with the care of palliative patients.146 Managers have an important role to acknowledge, appreciate and support the healthcare personnel working with palliative care. Their role is also to organize the care so it can be provided by a multi-professional team characterized by accessibility, continuity, safety and competence. District nurses, with their specific knowledge, are an
important complement to these teams, with an opportunity to implement the philosophy of palliative care in the team’s approach and in the home care.

Safety and security in palliative home care

The next-of-kin caregivers’ comprehensive responsibility for every aspect of the patients’ care implied satisfaction of being involved in care and a sense of control in their daily life. For the patients, this implied security as it was their desire to be cared for by their next-of-kin. However, the next-of-kin lost their control when lacking professional support, and when they felt inadequacy and powerlessness, thus resulting in insecurity (study I).

Patients’ and next-of-kin’s need of security in palliative home care means trust in health care personnel and their competence and access to care and services when needed. It is also about being respected and treated as individuals, being as comfortable as possible and being relieved of responsibility by the healthcare personnel. Most the patients relied on their medical devices and were not worried about safety. Instead the medical devices meant security for the patients and implied they could be cared for in the home. They were especially satisfied with their pain pumps, which were associated with security when they could press on additional doses if necessary (study IV). However, the patients and next-of-kin became worried when the medical devices were not functional, such as dislodging tubes and catheters or a suction’s incapacity to provide symptom relief (studies III and IV). Sufficient cognitive capacity is needed in the management of the technical procedures in order to remember to perform them correctly and in the right order. Healthcare personnel must ensure that the users of the medical devices in home care have sufficient knowledge of their technology to feel safe and secure. Patients’ desire to influence the design of medical devices and their suggestions to improve patient safety and user-friendliness must be utilized and not neglected by manufacturers of the medical technology.

Patients’ became familiar with their medical devices and were sometimes more knowledgeable about them than the healthcare personnel. The patients did not regard this as something strange, instead they were helpful to the personnel who were uncertain in their management of the current devices (study IV). How people relate to the technology is dependant on their previous experience and which technological frames of reference they
However, next-of-kin felt insecurity when the personnel were uncertain about the management of the medical devices. They believed this was due to discontinuity among the personnel who performed the tasks too rarely (study III). Continuity among healthcare personnel is important in developing trust and mutual understanding of respective knowledge and expertise. District nurses considered it demanded a fundamental security in their role as district nurse when working with medical technology in home care. They meant it required awareness as the medical devices could not be monitored by the healthcare personnel and the homes were unpredictable environments with poor lighting, uncomfortable positions and difficulty in maintaining sterility. They felt exposed in families’ home when preparing treatments and handling unfamiliar medical devices in front of next-of-kin’s scrutinizing eyes (study II). Preparation of treatments with medical devices is often done in the presence of the next-of-kin who can notice any uncertainty among the personnel, which in turn can create insecurity among the next-of-kin. To avoid this uncertainty it is important for the district nurses to be updated on current medical technology and use them regularly, which also ensures patient safety. Healthcare personnel must have sufficient education, knowledge and guidance in their management of medical devices. District nurses considered that their working situation has changed with increasing workload and new tasks and demands, which could jeopardize patient safety (study II). Their isolated and exposed work situation has been confirmed in other studies. District nurses’ uncertainty can be reduced by more education in medical technology, continuity in care and supportive and engaged managers who allow sufficient time and resources for the development of palliative home care.

Comprehensive understanding

This thesis describes the importance of security when medical technology occurs in palliative home care (Figure 2) and how medical technology is experienced by patients, next-of-kin and district nurses in palliative home care as a secure base (Figure 3). Palliative home care as a secure base is characterized by the four underlying meanings; sense of control, inner peace,
still being oneself and hope. These underlying meanings are partly overlapping each other and are facilitated by trust in staff, being in comfort, being recognized as an individual, being relieved of the burden of responsibility, feeling welcomed, being informed and continuing everyday life at home. 

The mediating of security in palliative home care in relation to medical technology

The district nurses claimed they needed a fundamental security to be able to handle medical technology in palliative home care and master the various situations that could occur. Regular use of the medical devices and a personal confidence are the very foundation for creating a patient safe care. Having personal confidence was a prerequisite for the district nurses to convey security to the next-of-kin and to patients who thereby dared to take responsibility for the medical devices and thus obtain independence. When the district nurses were secure in the care situation they could invest in the care relationship (study II). Next-of-kin who were secure dared to take responsibility for the care and monitor and handle the medical devices, which gave them a sense of control in their daily life (studies I, III). This in turn gave a sense of security for the patients, who personally desired to take responsibility for the technology, to be able to maintain their integrity and reduce their dependence on the healthcare personnel. It promoted the emergence of the masterful patient (study IV). Security was thereby mediated from a secure district nurse, to the next-of-kin and to the patient (Figure 2 a).

The masterful patients had a fundamental security and wanted a sense of control in their daily life, which they demonstrated by taking care of their medical devices and treatment. By personally or together with their next-of-kin taking responsibility for the medical technology, they avoided a lot of home visits by healthcare personnel. Knowledge about their medical devices implied a readiness to act if any problems arose and thus a security for the family (study IV). Patients find an inner security when they have confidence that their own resources can improve their situation. 

The masterful patient’s security in the handling of the technology gave conditions for a secure next-of-kin (study IV). When a patient is in comfort and feels secure,
the next-of-kin develop similar feelings. When patients and next-of-kin participated in the care and took responsibility for the medical technology, they gained independence. Having confidence in the availability and competence of the health care personnel resulted in a secure family. A secure family can mediate security and knowledge to an unsecure district nurse if he/she possesses the self-confidence to take advantage of the family’s knowledge about their medical technology (study II). When an uncertain district nurse feels security in the care relationship, his/her uncertainty can be transformed into security. Thus an unsecure district nurse can transfer to a masterful district nurse, characterized as having personal self-confidence to convey security to the family (Figure 2 b.)

![Diagram](image)

**Figure 2 a, b.** Mediating of security in palliative home care in relation to medical technology in palliative home care a) from a secure district nurse, to the next-of-kin and the patient and b) from a secure patient, to the next-of-kin and the district nurse

**Medical technology and its impact on palliative home care as a secure base**

The first underlying meaning of palliative home care as a secure base is to have a ‘sense of control’ in the daily life and have confidence that arising problems can be solved. For patients and their next-of-kin, this means to have trust in the healthcare personnel and their availability, competence, continuity, support, attentiveness and reliability. It also means being relieved
from the burden of responsibility by palliative home care teams and having the ability to get in touch with them when needed. Access and support by skilled and attentive healthcare personnel at any time when needed implied security for the patients and their next-of-kin which enabled them to preserve their integrity and independence (studies III, IV).

District nurses’ fundamental security in their work with medical technology in palliative home care, implied they did not worry if they encountered an unexpected situation (study II). To maintain this security they needed to regularly use of the medical devices that existed in the homes. This in turn favored a safe management, a patient safe care and a ‘sense of control’ in their work situation. When district nurses felt confident in their handling of the medical devices they could focus on the patients and the next-of-kin instead of the technology when preparing the treatments and handling the devices, which promoted a good care relationship (study II). Being informed gives a sense of security and helps the patients and the next-of-kin with both mental and practical readiness. Medical technology required adjustment to new conditions. To make their life more comprehensible and manageable, the patient and next-of-kin searched information about the medical devices and took control of and moderated their medical devices to fit their intended plans for the day. Lack of information caused unnecessary worry among the next-of-kin and restricted patients (studies I, III and IV).

‘Inner peace’, is identified as the second underlying meaning of palliative home care as a secure base and means that the patients and the next-of-kin can relax and avoid concerns about the medical technology. To have inner peace and be in comfort implies effective symptom relief and support from the palliative home care team when needed. The medical technology fostered the opportunity to be in comfort and the patients especially highlighted the pain pumps’ qualities to get effective pain relief. The patients with nutrition drip got increased strength and forces and newer medical devices adapted for outdoor use implied more freedom of movements for the families. Regular home visits by palliative care teams were usually appreciated and implied security for the families (studies III, IV), while lack of professional support created insecurity (study I).

District nurses felt an inner peace when they were familiar with the medical devices. With regular use and long experience they got self-reliance and security, which meant that medical technology became both a stimulating
and challenging task. However, district nurses became insecure when they did not use the medical devices regularly. They also felt insecure and exposed in the families homes far from colleagues and involved GPs (study II).

The third underlying meaning is ‘still being oneself’ and implies to be secure in the home environment and ‘feel welcomed’ to participate in care. Receiving care in home is the very basis to meet these conditions. The masterful patients wanted to personally or with the next-of-kin participate in the care and take responsibility for the medical technology, thereby maintaining their autonomy. Monitoring the medical devices was an opportunity for the next-of-kin to participate and have control over the situation (studies I, III and IV). District nurses encouraged and welcomed the patients and their next-of-kin in this participation. But they stated that it required sensitivity to determine what patients and the next-of-kin wanted or could manage regarding the current medical technology (study II).

Continuing everyday life represents the patients’ and the next-of-kin’s healthy part of life. To be at home and continue to do familiar things means feelings of security, which reduces the perceptions of threats and a progressing illness. Medical technology was often a prerequisite for the patients to receive care at home. Comfortable and user friendly medical devices provided opportunities for the patients and their next-of-kin to experience more freedom and practice outdoors activities (studies III, IV).

Being recognized as an individual illuminates the importance of the personnel’s knowledge about the patient’s medical history and family situation, which promotes feelings of retaining one’s personal worth and autonomy. Continuity among the personal provides these conditions. Lack of continuity among the personnel complicated the management of the medical devices, causing insecurity among the next-of-kin (studies II, III).

The fourth underlying meaning of palliative home care as a secure base is ‘hope’, which means a trust in the personnel’s opportunities to meet the families’ needs. Medical technology implied security for the patients and their next-of-kin as they received regular visits and support from the healthcare personnel. They appreciated the personnel’s attentiveness and were particularly satisfied with the specialist palliative care teams and their specialized competence (studies III, IV). District nurses’ ability to convey trust that medical technology created conditions for end-of-life care in the
home meant hope for the families (study II). However, the families felt insecurity when they lacked professional support, were given insufficient information or communication, and if the personnel lacked competence in the management of the medical devices, which was linked to discontinuity among the personnel (studies I, III and IV).

Figure 3. Mediating of security in palliative home care in relation to medical technology. Medical technology and its impact on palliative home care as a secure base with its underlying meanings: sense of control, inner peace, being oneself and hope.
Conclusions

- The chances of completing palliative home care are reduced when there is only one next-of-kin caregiver (study I).
- The most common triggers for discontinuing home care are acute or difficult-to-treat symptoms (study I).
- District nurses consider that the next-of-kin are an important resource to monitor the medical devices and assist with different nursing tasks, which also creates participation (study II).
- Participation in care and management of medical technology must be voluntary and on the families’ own conditions (studies II, III and IV).
- Lack of continuity in the management of the medical devices creates uncertainty among district nurses, possibly jeopardizing patient safety, while long experience and continuous usage of the medical technology creates safety and security (study II).
- Healthcare personnel’s uncertainty in the management of medical devices causes insecurity among the next-of-kin (study III).
- Continuity among personnel, who are familiar with the patient and their next-of-kin, is a prerequisite for the family to get security and a patient-safe care (study III).
- Patients transfer between different ways of understanding medical technology depending on their health condition, the medical technology’s impact on daily life and the support they receive (study IV).
- Continuous information and support concerning the medical technology transforms a dependent patient to an independent patient, while lack of information and support has the opposite effect (study IV).
- Security is an important concept in relation to medical technology in palliative home care. District nurses can mediate security to the next-of-kin and to the patient, who thus becomes an independent and masterful patient. This movement of security can also occur in the opposite direction, implying that an insecure district nurse can become a masterful district nurse.
Palliative home care as a secure base can be used to describe how medical technology affects patients, their next-of-kin and district nurses in palliative home care.

**Clinical and research implications**

- To provide a secure and safe care, it is of great importance to organize and maintain continuity among the healthcare personnel who perform the home visits.
- Managers must organize palliative home care so it will be provided by a multiprofessional team, in which district nurses can be an important and useful part.
- When planning for palliative home care with only one caregiver, it is important to early convince the family to accept home assistance.
- It is important not to implicitly expect some assistance with medical technology from the families who live in remote areas. Their involvement in the care must be voluntary and requested with great sensitivity.
- Patients want to have an influence on the design and appearance of medical devices and manufactures should take notice of their points of view.
- Next-of-kin caregivers have a great need of their ‘own time’, and need to be encouraged to take breaks during the healthcare personnel’s home visits.
- To decrease their dependence of healthcare personnel, the families need useful information about the function of the medical devices and what to do if something fails.
- It is important to limit the storage place in the families’ homes so they do not have to make unnecessary sacrifices in their own homes.
- In order for district nurses to manage medical devices in home care in a patient-safe way without feeling uncertainty and exposure, they need to be more specialized in palliative home care.
- District nurses need more training in the various medical devices and more regular reviews of the devices that occur in the homes.
• It is important that the management of the medical devices must be performed exclusively by skilled and knowledgeable healthcare personnel.
• In order to meet next-of-kin caregivers’ needs in palliative home care it is important to develop interventions, e.g. by support group programs.
• Further research is needed about ethical dilemmas in relation to nutrition treatments in palliative homecare.
• Further research is also needed about the healthcare personnel’s perceptions of exposure in palliative homecare.
• Within the concept palliative home care as a secure base, more research is needed about what improvements are important for the families and healthcare personnel when medical technology is used in palliative home care.
Swedish summary

Bakgrund
En alltmer åldrande befolkning innebär ett ökat antal personer med omfattande hälsoproblem och därmed ett ökat behov av palliativ vård. Flertalet patienter med allvarlig sjukdom önskar få vård i hemmet i livets slut vilket innebär att sjukhusvården överflyttas till hemsjukvården. Detta medför också att medicintekniken följer med patienten till hemmet. Trygghet är ett grundläggande behov för patienten och deras närstående inom palliativ vård i hemmet och för att känna trygghet krävs kontinuitet bland personal, tillräckligt med stöd och symtomkontroll, samt en välfungerande information och kommunikation. Ökningen av medicinteknik inom hemsjukvården får till följd att även de som hanterar medicintekniken ökar. Användarna av medicintekniken är familjemedlemmar och sjukvårdspersonal, som har en skiftande kunskap samtidigt som hemmet är en oförutsägbar miljö. Detta kan leda till osäkerhet och otrygghet vilket i sin tur kan äventyra patientsäkerheten.
Det finns ett antal studier om hur medicinteknik påverkar familjens dagliga liv och då speciellt familjer med teknikberoende barn. Däremot saknas studier om hur medicinteknik inom palliativ vård i hemmet påverkar familjen, varför denna avhandlings fokus syftar till att belysa detta område.

Syfte
Det övergripande syftet med denna avhandling var att undersöka och beskriva hur medicinteknik uppfattas av patienter, deras närstående och distriktssköterskor inom palliativ vård i hemmet.

Metod
ventilator, volym och nutritionspump, smärtpump, syrgas, sug, blodtransfusion, subcutan venport, nefrostomikateter och digital smärtpenna. Ansatsen för studierna var kvalitativ fördelat på critical incident teknik (studie I) och fenomenografi (studier II, III och IV).

Resultat

Närståendevårdare inom palliativ vård i hemmet från kontroll till förlust av kontroll (studie I)

Syftet med denna studie var att beskriva situationer som påverkade närståendevårdarnas möjligheter att hantera palliativ vård i hemmet. Deltagarna i studien bestod av nio närståendevårdare till patienter inom palliativ vård i hemmet. Datainsamlingen skedde med semistrukturade intervjuer och frågorna belyste; hur den palliativa vården i hemmet fungerat, om det var någon speciell situation där familjen inte fått det stöd de behövt och om det var någon speciell situation som orsakade själva avbrytandet av vården i hemmet. Intervjuerna skrevs därefter ut och analyserades i olika steg enligt critical incident teknik.

Resultatet visade att de närstående önskade behålla kontrollen i sin för övrigt kaotiska och otrygga tillvaro. Detta visade de genom att vara tillgängliga dygnet runt både fysiskt och psykiskt. De tog det övergripande ansvaret för hemmets skötsel och patientvården, vilket de utförde med en tillfredsställelse över att få vara delaktiga i vården samtidigt som det ingav trygghet för patienterna. De närstående var också patientens stödpersoner som uppmuntrade och hjälpte patienten att upprätthålla modet och hoppet inför framtid.

Allt eftersom patientens tillstånd försämrades blev arbetsbördan för de närstående tyngre och de började succesiellt förlora kontrollen över tillvaron, vilket inträffade när de saknade professionellt stöd pga. bristfällig information och brist på resurser. De kände sig otillräckliga då de blev alltför utmattade av patientvården, vilket tillsammans med en ständig tidsbrist förorsakade skuldkänslor. En maktslöshet infann sig när patienten inte heller ville ta emot hjälp från utomstående. De kände även en maktslöshet när patienten fick svårbehandlade symtom som de inte kunde hantera eller att patienten förändrades fysiskt och mentalt.

Den vanligaste orsaken till att vården avbröts var akuta eller svårbehandlade symtom i kombination med att de närstående var helt utmattade. De närstående upplevde däremot inga skuldkänslor över att vården i hemmet
avbrutits fastän patienten haft en önskan om att få vårdas i hemmet till livets slut.

**Distriktssköterskors uppfattningar av medicinteknik inom palliativ vård i hemmet (studie II)**

Syftet med studie II var att beskriva distriktssköterskors uppfattningar av medicinteknik inom palliativ vård i hemmet. Deltagare i studien bestod av 16 distriktssköterskor som arbetade både inom specialiserad hemsjukvård och allmän hemsjukvård. Datainsamling skedde med hjälp av semistrukturerade intervjuer och frågor om; hur medicintekniken påverkade distriktssköterskornas arbetsrelation och vårdrelation, om miljön i hemmet och patientsäkerheten i samband med hantering av medicinteknik. Intervjuerna analyserades därefter enligt en sjustegsprocess.

Distriktssköterskorna ansåg att medicintekniken *ledde till en sårbarhet* i deras arbetsrelation med förändrade arbetsuppgifter och ökade krav. Det innebar en utsatthet att arbeta i patientens hem med andra förhållande än på sjukhusen och långt från kollegor och engagerade distriktsläkare. De uppfattade en osäkerhet när de kom i kontakt med ny medicinteknik som de var ovana vid eller sällan hanterade, och ansåg därför att kontinuitet vid hantering av medicinteknik var en nödvändighet för en patientsäker vård. Medicinteknik *fordrade samarbete* och distriktssköterskorna uppmuntrade de närstående till delaktighet i vården, vilket ledde till ett ömsemåttigt beroende av varandra. Distriktsköterskorna var även beroende av kollegialt stöd från andra distriktsköterskor och från specialiserade palliativa team eller sjukhusavdelningar, när de kände osäkerhet i samband med hanteringen av medicintekniken. Det *fordrade en självtillit* att hantera medicinteknik i hemmet vilket distriktssköterskorna erhöll genom sin grundläggande trygghet och lång arbetslivserfarenhet, vilket medförde att medicintekniken blev både en utmanande och stimulerande uppgift som de inte ville vara utan. Medicinteknik *krävde en medvetenhet* om patientsäkerhet. Långa avstånd till patienterna och en hemmiljö som var obekväm, oförutsägbar och svårigheter med hygienrutiner var faktorer som skapade osäkerhet. Distriktsköterskorna var medvetna om att det fordrades eget ansvar att hålla sig uppdaterad för att klara av att hantera medicintekniken. Distriktsköterskorna var ofta beroende av familjens hjälp med medicintekniken, men det krävdes en lyhördhet för
vad de vågade delegera till familjen och för vad patienten och de närstående orkade ta hand om. Medicinteknik skapade också etiska dilemma i samband med livsuppehållande åtgärder. Distriktsköterskorna menade att distriktslåkarna inte tog tillräckligt ansvar vid dessa situationer. Medicintekniken ansågs kunna ge patienterna frihet och därmed ökade möjligheter att få vård i hemmet. När patienterna själva deltog i sina behandlingar bidrog detta till familjens oberoende.

**Närståendes uppfattningar av medicinteknik inom palliativ vård i hemmet (studie III)**

förhållanden, och de sökte därför information om tekniken för att få förståelse och gjorde ommöbleringar i hemmet för att göra livet mer hanterbart. Samtidigt innebär det en sorg och mental anpassning att se patienten bunden till tekniken.

**Patienters förståelse av medicinteknik inom palliativ vård i hemmet (studie IV)**

Syftet med studie IV var att beskriva patienters förståelse av medicinteknik inom palliativ vård i hemmet. Deltagare i studien var 15 patienter med medicinteknik inom palliativ vård i hemmet. Patienterna fick svara på liknande frågor som de närstående i studie III; om delaktighet, stöd, påverkan på dagligt liv och säkerhet i relation till medicinteknik i hemmet. Interjuerna analyserades därefter utifrån en sjustegsmodell där tre olika sätt att förstå medicinteknik framkom.

*Den mästerliga patienten* önskade vara oberoende av personalen genom att själv kontrollera medicintekniken och ansvara för sina behandlingar vilket därmed minskade personalens hembesök. Den mästerliga patienten anpassade tider och varaktighet för sina behandlingar så de passade hans/hennes planer för dagen. Bra och effektiva behandlingar gav dem mer styrka och kraft att delta i dagliga aktiviteter. Den mästerliga patienten ville även påverka medicinteknikens utseende och utförande och önskade att deras synpunkter och förslag på förbättringar skulle vara till nytta för andra patienter.

Det vanligaste sättet att förstå medicinteknik var *den anpassningsbara patienten*, som accepterade sin medicinteknik och anpassade sitt dagliga liv efter tekniken och försökte istället finna lösningar för att minska dess inverkan på deras dagliga liv. Den anpassningsbara patienten var nöjd med medicintekniken och det stöd de fick från palliativa team. De kände sig trygga med tekniken som gav dem möjlighet att vårdas i hemmet.

*Den begränsade patienten* påmindes dagligen om sin medicinteknik då den hindrade dem i deras dagliga aktiviteter, störde deras nattsömn och orsakade biverkningar. Den begränsade patienten hade en inskränkt rörelsefrihet och kände sig begränsad i sina sociala relationer. Bristande information skapade också begränsningar. Medicintekniken innebar att patienten blev beroende av personalen som utförde regelbundna behandlingar. Patienterna uppvisade
 olika sätt att förstå sin medicinteknik, medan ett sätt var mer dominerande än de andra. Patienten förflyttades mellan olika sätt att förstå medicintekniken, beroende på hälsotillstånd, personalens stöd och hur medicintekniken påverkade hans/hennes liv. Samtidigt skedde en rörelse från att vara en oberoende patient till en beroende patient och i motsatt riktning.

Övergripande förståelse

Avhandlingen visar på trygghetens betydelse när medicinteknik förekommer inom palliativ vård i hemmet. Den visar även medicinteknik och dess påverkan på palliativ vård i hemmet som en ”trygghets bas” med dess underliggande meningar; känsla av kontroll, inre frid, att få vara sig själv och hopp.

Distriktsköterskorna ansåg att det behövdes en grundläggande trygghet självtillit och kontinuitet för att hantera medicinteknik på ett tryggt och patientsäkert sätt. Denna trygghet kunde förmedlas vidare till närstående och patient som vågade ta ansvar för sin medicinteknik och därmed bli en oberoende och mästerlig patient. En trygg patient kunde i sin tur förmedla trygghet till närstående och vidare till en osäker distriktsköterska som kunde dra nytta av deras kunskap och därmed bli trygg i sin roll och transformeras till en mästerlig distriktsköterska, kännetecknad av personlig självtillit och förmåga att förmedla trygghet vidare till närstående och patient.

Medicintekniken och dess påverkan på palliativ vård som en trygghetsbas är att ha ”en känsla av kontroll” vilket innebär stöd och förtroende för personalen och deras kompetens. Tillgång till information och stöd av kunnig personal vid behov innebar en trygghet för familjen, medan bristande information skapade otrygghet. Regelbunden användning av medicinteknik ledde till en trygg och säker distriktsköterska som kunde fokusera på vårdrelationen istället för medicintekniken.

Effektiv symtomlindring och stöd från palliativa team innebär ”en inre frid”. Patienterna uppskattade speciellt smätpumparna som gav dem effektiv smärtlindring och nutritionsdropp som ökade patienternas krafter och ork så de blev mer aktiva. Regelbundna hembesök av palliativa team innebar en trygghet medan brist på professionellt stöd orsakade otrygghet.

**Slutsats**

- Med bara en närståendevårdare minskar möjligheten att vården avslutas i hemmet (studie I).
- Vanligaste orsaken till att vården i hemmet avbryts är akuta och svårbehandlade symptom (studie I).
- Bristande kontinuitet vid hantering av medicinteknik skapar osäkerhet bland distriktssköterskor, vilket kan äventyra patientsäkerheten, medan regelbunden användning av medicintekniken skapar säkerhet och trygghet (studie II).
- Delaktighet i vården och ansvar för medicinteknik måste vara frivilligt och på familjens egna villkor (studier II, III och IV).
- Kontinuitet bland personalen som känner familjen är en förutsättning för en trygg och patientsäker vård (studie III).
- Regelbunden information och stöd gällande medicintekniken kan göra en beroende patient till en oberoende patient, medan bristande information och stöd har en motsatt effekt (studie IV).
Trygghet är en viktig faktor i samband med medicintecknik inom palliativ vård i hemmet. Distriktssköterskan kan överföra trygghet till närstående och till en patient som därmed blir en oberoende mästerlig patient. Denna rörelse av trygghet kan även ske i motsatt riktning.

Palliativ vård som en trygghetsbas kan användas för att beskriva hur medicintecknik påverkar patient, närstående och distriktssköterskor inom palliativ vård i hemmet.

Kliniska och forsknings Implikationer

- För att utföra en säker palliativ vård i hemmet är det viktigt med kontinuitet bland personalen vilket också skapar en trygghet hos familjen.
- Vid planering av palliativ vård i hemmet med endast en närstående vårdare är det viktigt att övertyga familjen att acceptera hjälp från hemtjänst annars är risken att vården i hemmet avbryts.
- Då familjer bor långt borta får de inte känna sig tvingade att hjälpa till med medicinteckniken, utan delaktigheten i vården måste vara på deras egna villkor.
- Om distriktssköterskor ska klara av att hantera medicintecknik i hemmet utan att känna osäkerhet, behövs regelbunden träning på befintlig teknik samt att de specialiserar sig mer inom palliativ vård.
- Det är viktigt att utveckla stödgrupper för närståendevårdare med speciellt utformade program som behandlar deras behov.
- Mer forskning behövs om distriktssköterskornas utsatthet inom palliativ vård i hemmet.
- Med begreppet palliativ hemsjukvård som en trygghetsbas behövs mer forskning om vilka förbättringar som är viktiga när medicintecknik förekommer i palliativ hemsjukvård.
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Next-of-kin caregivers in palliative home care – from control to loss of control

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Abstract

Title. Next-of-kin caregivers in palliative home care – from control to loss of control.

Aim. This paper is a report of a study to describe situations influencing next-of-kin caregivers’ ability to manage palliative care in the home.

Background. Palliative home care often involves major resources from next-of-kin, municipal and county personnel. Next-of-kin caregivers’ situation is depicted as so demanding and exhausting that it can affect their mental health and limit their ability to continue as a caregiver.

Methods. A qualitative study using the Critical Incident Technique was conducted. Nine next-of-kin caregivers from palliative home care were strategically chosen and data were collected using audiotaped interviews in 2005.

Findings. The analysis resulted in two main areas: ‘Maintaining control’ and ‘Losing control’. Next-of-kin caregivers wanted to maintain control over their lives by being continuously available 24 hours a day and by supporting and taking complete responsibility for all of the patient’s needs. They lost this control when professional assistance was lacking and they described feelings of inadequacy when their physical energy or time was insufficient. They felt incapable as the patient’s physical or mental persona metamorphosed or as serious symptoms developed that they could not control.

Conclusion. Next-of-kin caregivers and the patients must feel free to choose where palliative home care will be provided and that their choice at any time can be re-evaluated, due to insecurity or workload changes. When planning for palliative care, they should be informed that having only one caregiver reduces the chances of completing palliative care in the home.

Keywords: caregivers, Critical Incident Technique, home care, next of kin, nursing, palliative care, primary care, support

Introduction

Palliative home care is often very demanding and requires major resources from all local government levels. A strong engagement by next-of-kin caregivers is also required for successful home care. Some, however, do not have the capacity to care for the patient at home until death and would prefer another form of care, such as a hospice or special housing (Thorén-Todoulos 1999). To avoid undesirable relocations of patients near the end of life, it is important
to identify the reasons why such relocations become necessary and what support next-of-kin caregivers require in such situations.

Background

WHO has developed general recommendations for palliative care according to countries’ resource levels (Sepulveda et al. 2002). Home-based care is considered to be the best way of achieving good quality care and coverage in low-resource settings, while in countries with medium to high levels of resources, palliative care should be adopted at all levels of care, including home-based care. Studies have shown that palliative home care must be based on voluntary initiative and an agreement between the patient and their next-of-kin caregiver (Thorén-Todoulos 1999, Cantwell et al. 2000). If the next-of-kin and patient are not in agreement about palliative home care, the next-of-kin can feel unprepared and ill-informed, and experience irritation at not being involved in the decision (Stajduhar & Davies 2005). Some next-of-kin feel that they have lost their freedom of choice and feel pushed into the role of home caregiver (Wennman-Larsen & Tischelman 2002, Stajduhar 2003, Milberg & Strang 2004, Stajduhar & Davies 2005) The most important requirement for a successful completion of home care is a well-informed patient with a desire to die at home (Gyllenhammar et al. 2003). Good information reduces the patient’s fears and anxiety as they can build their expectations on clear facts (Brännström et al. 2005). According to Singer et al. (2005), dying at home is four times more likely if next-of-kin caregivers have had access to professional help than if such assistance is not available. Having access to advanced palliative home care gives a feeling of security and is greatly appreciated by both patients and next-of-kin caregivers (Orrevall et al. 2005, Brännström et al. 2006). Being a next-of-kin caregiver in palliative care is described as an intensive, stressful and very exhausting experience (Payne et al. 1999, Strang et al. 2002), with lack of sleep (Steele & Fitch 1996, Carter 2002), lack of personal time (Steele & Fitch 1996, Milberg & Strang 2000, Brobäck & Bertero 2003, Proot et al. 2003, Hudson 2004), reduced freedom of movement (Proot et al. 2003), and limited lifestyle. These strains can be due to a fear that something serious will happen or that the patient will die while the next of kin is not by their side (Brobäck & Bertero 2003).

Next-of-kin have described how their mental health deteriorated to such an extent that they could not continue as a caregiver (Steele & Fitch 1996, Carter 2002, Hudson 2004). However, studies show that next-of-kin and patients are more satisfied with palliative care in the home than with hospital care (SBU 1999, Singer et al. 2005). Next-of-kin appreciate being able to be together in the home during the final stages, experiencing self-esteem due to the valuable task they accomplish (Koop & Strang 2003, Hudson 2004).

Many researchers describe the pressure placed on next-of-kin caregivers during palliative home care, but only a few have explored the actual reasons for the discontinuance of home care (Van den Eynden et al. 2000, Gyllenhammar et al. 2003) and no study was found that illustrates this phenomenon using a qualitative approach. According to Gyllenhammar et al. (2003), next-of-kin and home care personnel indicate that the primary reasons for discontinuation of home care are factors in connection with lack of symptom control, and medical treatments and complications that cannot be managed in the home.

The study

Aim

The aim of this study was to describe situations influencing next-of-kin caregivers’ ability to manage palliative care in the home.

Design and method description

An explorative and descriptive design was chosen, using the Critical Incident Technique (CIT) according to Flanagan (1954). CIT is a systematic inductive method for collecting information on behaviour through critical incidents. A critical incident is defined as an important experience with a clear beginning and end and which has a decisive significance, either positive or negative, for a situation’s outcome. CIT has been developed in recent decades to fit nursing research. Accordingly, Norman et al. (1992) suggested that an incident does not need to be demarcated by a clear beginning and end. Informants’ descriptions of incidents can be a summary of incidents of similar type rather than a clearly-recalled single event. The number of informants is based on the number of situations collected. If the situations are clearly-defined, it can be sufficient to collect 50 to 100 situations (Flanagan 1954).

Participants

Nine participants who were next-of-kin to patients enrolled in palliative home care and who took part in the caregiving were strategically chosen for an interview to ensure variation in sociodemographic data and experiences as a next-of-kin caregiver (Table 1). The patients had expressed a desire to be
cared for at home during the final stages of their lives. For various reasons, such as acute deterioration or nutritional problems, home care was disrupted and the patients were moved from their homes to another care site, where they later died. To ensure that the next-of-kin caregivers’ memories of the home care period were fresh, the death had to have taken place in the past 18 months. A request for informants was sent to palliative home care teams in a county in southern Sweden. District nurses responsible for palliative teams were contacted and informed about the purpose of the study and the need for informants. These district nurses then contacted appropriate people to ask if they were willing to participate in the study. All participants had had some form of support or assistance from home care personnel.

Data collection

Data collection took the form of audiotaped single interviews during 2005. A semi-structured interview schedule (Table 2) was used to ensure that responses elucidated the purpose of the study, thus simplifying processing and data analysis (Polit and Beck (2004). A majority of the interviews took place in informants’ homes, as the home environment is familiar and instills a calm atmosphere. One interview took place at the informant’s place of work. The next-of-kin caregivers were encouraged to relate both positive and negative experiences regarding how the palliative home care had functioned. They were then encouraged to describe situations where they were given or not given the support they needed and the situations that finally resulted in discontinuation of home care.

Ethical considerations

The study was approved by the heads of the respective primary care districts where the palliative patient was registered. The principal researcher sent a letter to prospective informants describing the purpose of the study, stating that participation was voluntary and that the data would be treated as strictly confidential. A week later potential interviewees were telephoned and, if they agreed to participate, a time and place for the interview was planned. Informants gave consent to participate in the study in accordance with Swedish law (SFS 2003).

Data analysis

To obtain a clear summary of what participants meant, the interviews transcripts were reread several times. The parts describing positive or negative situations that were considered by the informant as meaningful, and that were related to the purpose of the study, were then identified. The situations were compared with each other according to their nature and content, and then classified into groups. The groups were reformulated into different kind of behaviours that were arranged in different subcategories and classified according to their content. Subsequently, similar subcategories were further grouped together and each group titled according to content. These categories were then brought together under main areas (Flanagan 1954). Changes and regroupings took place regularly during the analysis in order to obtain categories that did not overlap. The analysis resulted in 138 situations that were classified into 17 subcategories; these

<table>
<thead>
<tr>
<th>Table 1 Participant demographics (n = 9)</th>
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<tr>
<td>Men</td>
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<td>Age (years)</td>
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<td>Nine-year compulsory school</td>
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<td>Upper secondary school</td>
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<td>Living arrangement</td>
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<td>Together with the patient</td>
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<td>Together with own family</td>
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<td>Time between death and interview (months)</td>
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<td>3–6</td>
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Table 2 Questions asked of next-of-kin caregivers about managing palliative care in the home

1. Why did you choose palliative care in the home?
2. How did the palliative care in the home work?
   Is there anything you find particularly valuable?
   Is there anything you find less valuable and that you would like to change?
3. Can you describe a specific incident/situation when you did not receive the support you needed as next-of-kin?
   What could have been done better?
   What do you feel was missing?
4. Was there a specific incident/situation that caused the discontinuation of home care?
   How did you feel about that?
5. Is there anything else you would like to add?
were then grouped together into five different categories, which finally formed two main areas (Table 3).

Rigour

The terms applicability, security, concordance and accuracy may be used in relation to rigour in qualitative studies. (Fridlund & Hildingh 2000). Applicability means that the researcher’s choice of method, selection and data collection is appropriate for identifying and studying the phenomenon of study. The sample in this study was limited to nine informants as palliative care in the home is normally completed with the support and nursing teams available. In CIT it is not the number of informants but the number of situations that is most important. We identified 138 situations which, according to Flanagan (1954), can be sufficient the phenomenon being studied is clearly defined. The use of interviews as a data collection method was advantageous as it allowed for greater nuances in the responses and new angles of approach in the questioning. Security has to do with how the data are obtained and processed. In this study, the study process and participants were described precisely and the analysis was done in collaboration between the researchers. The data were also subjected to a ‘inter-rater reliability test’, strengthening their credibility. To avoid informants feeling obligated to satisfy their former caregivers, it was particularly important for the researcher to emphasize that participation was voluntary. Also, the principal researcher had no previous caregiving contact with the informants, which made it easier for them to be honest in the interview situation. Concordance has to do with how exactly the information matches reality. The character and the content of the interview questions were therefore carefully adapted and a pilot interview was done to test the relevance of the questions. Data in the form of, for example, a quote should be able to be linked to the source, which was done in this study. The data were collected within 18 months of the death to ensure that participants could remember the care period as well as possible since there was a great risk that negative memories would diminish with time, thus giving an exaggerated positive view of the palliative period.

Findings

The study resulted in two themes: ‘Maintaining control’ and ‘Losing control’. Next-of-kin caregivers expressed a desire to maintain some sort of control in their otherwise chaotic and insecure daily lives. They demonstrated this by taking comprehensive responsibility for managing the home and all of the patient’s care, and by constantly being physically and mentally present 24 hours a day. This gave caregivers the satisfaction of being involved and the patient a sense of security. They also emerged as the strong individual who encouraged and supported the patient to preserve hope for the future. As the patient’s health declined, the next-of-kin caregivers’ workload increased and they gradually began to lose control over their situation. They expressed worries about losing control when the professional support they needed was not available, due to inadequate information or insufficient resources. They described feelings of inadequacy as the patient’s care became increasingly overwhelming and
they no longer had the physical and mental strength to give the care at home. They felt incapable when the patient refused help from outsiders and when the patient developed symptoms that were difficult to treat and that they could not influence and soothe. The most common reasons for discontinuing care in the home were acute or difficult-to-treat symptoms, in combination with complete exhaustion of the next-of-kin.

Maintaining control

Being available day and night
Participants described situations of being restricted and losing personal freedom as their physical and mental presence was required day and night in the home. Oftentimes they had sole responsibility for every aspect of the patient’s care and for household tasks: *Then I began to help her, take care of her hygiene and do her laundry and housecleaning, and my brother, he shopped for her.* Even when became overburdened, next-of-kin accepted the burden as completely natural or as a desire to meet the patient’s wishes. It also gave them a feeling of being in control by participating in caregiving: *At the same time, when I was home I wanted to do what I could, and at the same time that’s also what she wanted.* Interviewees often also assisted with medical tasks such as managing medicines, injections, bandaging and supervising drops: *So someone came and taught me how to give those injections that he needed to have for clots. These he needed to have every evening. At times they had little chance to rest during the night and were often woken by the patient needing help with, for example taking medicine or going to the bathroom: I was perhaps also a little tired – it was night and day. When he needed something at night, you had to get up and get it for him. So I didn’t sleep well then. I slept very lightly and woke up with his slightest movement. When patients required parenteral nutrition during the night, the caregiver slept restlessly as they considered themselves responsible for monitoring the equipment: I lay awake all night and watched that thing, because as soon as she turned herself, it stopped.* The patients were on caregivers’ minds around the clock, restricting their lifestyle and opportunities for rest and relaxation. They felt constant responsibility and concern that something could happen while they were absent: *It was a constant anxiety as long as he was at home. I was afraid something would happen. There were short periods when I went out, but otherwise, I was at home the entire time.*

Sustaining hope

Next-of-kin caregivers took on the role of being a pillar of strength, whose task was to encourage and support the patient to sustain courage and hope for both themselves and the patient. That meant also reassuring the patient and lifting their spirits when difficult and unpleasant treatments were needed. One caregiver described an occasion when the patient said that she no longer had the strength for more treatments: *When we were going in May, she said, ‘I’m not going there any more, I don’t have the energy any longer’. I said, ‘We must go there. We must do what we can.’*

Losing control

Missing professional support
Most next-of-kin caregivers were pleased with the support they received from healthcare personnel and thought they had received the help they needed in different situations. However, they lost control of their situation when professional support was lacking. They functioned as deputy home care personnel, but thought that they did not get the information and support to which they were entitled. One interviewee reported how she and the patient had wanted more involvement in the decision-making process and how they lacked adequate medical information. While in hospital, the patient had been registered for palliative care and been given a folder to take home to simplify information transfers about the palliative care. The patient, however, never understood the significance of being registered for palliative care or the meaning of the folder, and the next-of-kin was very frustrated that no one had explained it for her: *He himself was so surprised. ‘Yes,’ he said, ‘It is a folder with information about my medicines and diagnosis.’ But no one has ever explained the meaning of it… I learned later what it meant, and then I really lost it.* Another participant described deficiencies both in information transfer and communication between them and healthcare personnel: *You must excuse me that neither mom nor I are nurses, but we are not stupid. We see how sick he is. Then she said, ‘Hasn’t the doctor talked with you?’ These deficiencies implied that the next-of-kin was not mentally prepared for the patient’s deteriorating condition and the meaning of being a caregiver. Sometimes next-of-kin caregivers lacked concrete support in specific situations, increasing their strain. One described how she was required to drive her husband to the hospital with a spontaneous fracture: *I got him into the car and drove him with a broken thigh bone. Then she informed us that we had the right to have a doctor come home to us. We had no idea about that. Some participants also said that the healthcare system limited their care if there was a long distance to the patient’s home. Due to the distance, they did not ask home care personnel to come for small things because they fully understood the problem with distances: It was constantly messing up and...*
sometimes it stopped and they had to get it going again (patient’s infusion). So it wasn’t easy for us here at home to have it and so far for the nurse to come to us.

Feeling inadequate

When the palliative care became too much of a strain and the next-of-kin no longer had the strength to carry on, a feeling of insufficiency appeared and they lost control over the situation they had tried to maintain: Of course, it was difficult and I was tired of it sometimes, and I was angry with her sometimes, and sometimes thought and felt ‘God can she not be taken some place’. These thoughts increased the caregivers’ bad conscience and guilt feelings because they had not lived up to the demands that were placed on them. One had guilt feelings about not being available enough when his wife missed out on pain relief at night because she did not want to wake him and ask for help: The only feeling I have, but there’s nothing I can do anything about, is the feeling that she was hardly willing to wake me sometimes when she had pain … and that hurts. Caregivers described frustration at not having enough time for everything due to the heavy workload. Those who had a regular job as well as doing the palliative care found it especially difficult to find time for the little extras that were needed. One had her own family and children to think about and had constant guilt about her neglect: Because I felt that she really wanted to get out and be pushed in her wheelchair, but there was so little time for that. There was never time left over.

Being powerless

The most common triggers for discontinuing home care were acute or difficult-to-treat symptoms. In those situations, the next-of-kin caregivers felt powerless seeing their loved one suffer. They lost their footing and control over their life situation. Examples of such acute symptoms were breathing or gastro-intestinal problems. Symptoms that appeared to be difficult to treat were usually nutritional and elimination problems, such as as nausea, vomiting and constipation: I think she was so into herself and her suffering, she couldn’t think of anything else. Many times she went directly from the table to the toilet and threw up. I felt completely helpless. Caregivers experienced a tremendous psychological strain as the patient’s health deteriorated and their physical and mental changes worsened. One described how his wife’s physical being changed so dramatically that he could not bear to be around her in the final days: That a person can change in that way is completely incomprehensible, I say. Anyone who had not known her before, but who saw her that way for the first time, would have thought she was 80 years old and she was 63. I think that is the worst part. I have difficulty bringing up a picture of her when she was healthy. I see only that. I could not stand to be there toward the end. Even the patient’s psychological changes, from being mentally alert to being increasingly more distant, could be difficult for next-of-kin to understand. One caregiver described how he did everything in the home but towards the end never received a thank you in appreciation from the patient. Still another explained how the patient’s humour changed, something that increased the next-of-kin’s feeling of hopelessness: That illness made her so angry. Not with people who came here, but against us she became angry. Most of the patients did not want help from social and home care personnel for their care and domestic tasks; instead they preferred their next-of-kin to take care of those tasks. This worked well in the beginning, but not as the patient’s health deteriorated and the workload for the next-of-kin increased: We then started to talk about outside help, but she was absolutely against that. So I continued to take care of her. It was horribly tiring. Finally, there would be a stage when the patient also lost energy and wished to discontinue home care. This might be due to insecurity or simply a desire to stop pretending that they were healthier than they really were to protect the next-of-kin from unnecessary worry: She said to the nurse, ‘I don’t want to be at home any longer. I can’t manage being home any more. I don’t have the strength to be at home any more. I’m finished now.’

Discussion

Study limitations

Since CIT is regarded as particularly appropriate for collecting data about care actions, it was judged to be the most suitable approach to answering the research questions (Kemppainen 2000). The study had only nine informants, which is a limitation; however, in CIT it is the number of situations that is important and 138 critical incidents were sufficient for the purposes of this study (Flanagan 1954). The extent to which the findings can be applied in palliative home care is uncertain, because of the qualitative approach used. However, it is reasonable to assume that the findings can be used by healthcare personnel with other patients and their next-of-kin caregivers who have the same characteristics as the participants.

Maintaining control

Common for the next-of-kin caregivers was that they had sole responsibility for the patient’s care, meaning that they were available day and night for the patient’s every need.
Having more than one next-of-kin caregiver increases the chances for successful palliative care in the home (Cantwell et al. 2000, Maida 2002). Refusing outside assistance was often a conscious choice at the beginning. However, as the workload increased, this choice needed to be re-evaluated. In Milberg and Strang’s (2004) study, next-of-kin carers described feeling isolated when they had sole responsibility for nursing and the patient refused outside help. If home-assistance is not put into place as soon as possible, there is a clear risk that the next-of-kin carer functions only as a nurse, with no time or energy to take care of their own needs or to do the little extras for the patient. Twenty-four hour responsibility meant insufficient sleep for the next-of-kin caregivers over long periods, gradually adding to their exhaustion. Much of the wakefulness was due to constant worry about the patient and the need to help with various healthcare tasks at night. Sleep deprivation affects next-of-kin caregivers to such a degree that they become angry and irritated with the patient, which creates guilt feelings leading to symptoms of depression (Carter 2002). Participants repeatedly described how the patient was on their mind 24 hours a day, even when they were not physically present. That meant a constant worry that something could happen while they were away from the patient’s side. It is very important to facilitate personal time for next-of-kin to maintain their own mental health (Steele & Fitch 1996, Proot et al. 2003, Hudson 2004).

Next-of-kin carers also assisted with nursing tasks, such as giving injections and monitoring intravenous infusions. These should be voluntary tasks, taken on to increase feelings of participation and self-esteem. They must never be forced on the next-of-kin due to limited healthcare resources or because the patient lives too far away. One interviewee described how he stayed awake every night to monitor the infusion. This could have been avoided if he had had more support at night from home nursing personnel. Next-of-kin carers can feel insecure and frightened at caring for a seriously ill patient and believe that they have taken on too much responsibility (Brobäck & Berterö 2003, Milberg & Strang 2004).

New Control

In this study, the most common reasons for discontinuing home care were acute or difficult-to-treat symptoms. Similar reasons, in combination with psycho-social factors, were found in the study by Gyllenhammar et al. (2003). Patients cared for in our study had nutritional and bowel movement problems – everything from difficulty in drinking and eating, to nausea and vomiting. If their next-of-kin caregivers had had more professional support from, it is possible that some of these symptoms could have been relieved earlier. Our interviewees expressed feelings of inadequacy when their strength diminished as a result of the enormous workload. This shows how exhaustion can turn into anger and irritation over a patient’s demands and helplessness. According to Brobäck and Berterö (2003), care can be experienced as two-sided: on one side is the desire to return the love received in the past, while on the other side is the feelings of complete exhaustion, expressing itself in the form of irritation and squabbles with the patient.

The patient can also lose their strength and wish to discontinue home care – something that must be respected and provided for. Sometimes it is difficult for the patient to be cared for in the home as they try to hide their pain in an attempt to prevent the next-of-kin from worrying. Feelings of insecurity can occur as the patient begins to understand the increased pressure and responsibility being placed on their next-of-kin (Appelin & Berterö 2004). The actual death process and watching the patient suffer is a tremendous psychological strain for next-of-kin (SBU 1999), and many have difficulty admitting to and daring to express their

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**What is already known about this topic**

- Some next-of-kin caregivers in palliative home care experience lack of freedom of choice and feel forced into the role of caregiver by healthcare reforms focusing on care in the community.
- Being a next-of-kin caregiver in palliative home care is an intensive, stressful and very exhausting experience.
- Next-of-kin caregivers and patients are usually more satisfied with palliative home care than with hospital care.

**What this paper adds**

- Next-of-kin caregivers were satisfied with what they had accomplished and had no feelings of guilt that the home care had been discontinued prematurely, even though it had been their desire from the start that the patient should die at home.
- Next-of-kin caregivers can experience so much discomfort in watching the physical and psychological changes that occur during the patient’s final days that they cannot continue to stay with the patient.
- When next-of-kin caregivers assist with nursing tasks, they should do so from their own free choice and not because of limitations in the healthcare system.

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thoughts and feelings about how the patient suddenly looks so old and changes mentally.

Next-of-kin caregivers also lost control and the ability to take care of their situation when resources in the form of professional support were not sufficiently available. They felt that deficiencies in information distribution and communication had reduced their chances for some form of structure and order in their chaotic daily lives. Many of these deficiencies were due to professional caregivers’ inability to give adequate medical information, which matches findings in other studies (Eriksson & Lauri 2000, Milberg & Strang 2000, Brobäck & Berterö 2003).

Our interviewees often felt relief when home care was discontinued as they felt they were unable to provide the same security and quality of nursing tasks at night. Rather, they felt satisfied with what they had managed and were satisfied with the feeling that the patient received better nursing elsewhere. It is useful for home care personnel to know that it is not always necessary to continue palliative care at home until death. The patient and next-of-kin may experience a greater sense of security if the palliative care is completed elsewhere.

**Conclusion**

When palliative care takes place in the home, both patients and caregivers must be given all the support they need and the healthcare system must not limit nursing assistance due to distance or resource limitations. Night-time assistance may be all that is needed for caregivers to maintain their strength by not being responsible for nursing tasks at night. When planning for palliative care, both patients and next-of-kin should be informed that having only one caregiver reduces the chances of completing the palliative care in the home. An attempt should be made to convince them to accept home assistance and other professional help at an early stage. Regular information in the form of private conversations between the next-of-kin caregiver and the primary physician about medical information, symptom reduction, and commonly-occurring physical and psychological changes in the palliative patient can reduce their fear and anxiety and give them the opportunity to participate in the nursing care.

Since nursing needs in palliative home care can change abruptly from one moment to the next, next-of-kin caregivers and patients must feel free to choose where care will be provided. Placing responsibility for nursing care on next-of-kin is usually a practical arrangement for the healthcare system. However, there is a risk that these daily nursing tasks drain next-of-kin caregivers’ strength and energy and prevent them from simply being present with their loved ones or from processing their own grief.

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**Author contributions**

BM & JM were responsible for the study conception and design. BM performed the data collection. BM, BF & JM performed the data analysis. BM, BF & JM were responsible for the drafting of the manuscript. BM, BF & JM made critical revisions to the paper for important intellectual content. BM obtained funding. BM provided administrative, technical or material support. BF & JM supervised the study.

**References**


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District nurses’ conceptions of medical technology in palliative homecare

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Introduction

Palliative care is multi-professional, requiring interdisciplinary teams with skills to respond to the physical, psychosocial and spiritual needs of the patients and their next-of-kin. Palliative care planning should focus on achieving and maintaining optimum quality of life for the patients and their next-of-kin (Council of Europe 2003). Most palliative care is performed by the family in the patients’ homes with different kinds of support (Council of Europe 2003, Melissa et al. 2007). In Sweden the patient is either offered a palliative homecare, performed by district nurses (DNs) with support from physician or a physician-led palliative homecare, which usually is hospital connected (Beck-Fris & Strang 1993, The National Board of Health and Welfare 2006). Homecare is like a ward without walls, constantly expanding because of an unlimited number

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District nurses’ conceptions of medical technology in palliative homecare

Aim The aim of this study was to describe district nurses’ conceptions of medical technology in palliative homecare.

Background Medical technology has, in recent years, been widely used in palliative homecare. Personnel with varying degrees of training and knowledge must be able to handle the new technology.

Methods A descriptive design with a phenomenographic approach was chosen to describe qualitatively different conceptions of the phenomenon medical technology. Interviews with 16 district nurses working with palliative homecare were analysed and five descriptive categories emerged.

Results Medical technology in palliative homecare led to vulnerability because of increasing demands and changing tasks. When medical technology was used in the home it demanded collaboration between all involved actors. It also demanded self-reliance and an awareness of managing medical technology in a patient-safe way. Medical technology provided freedom for the palliative patients.

Conclusions To maintain patient safety, more education and collaboration with palliative care teams is needed. Next-of-kin are considered as an important resource but their participation must be based on their own conditions.

Implications for nursing management District nurses need regular training on medical devices, must be more specialized in this kind of care and must not fragment their working time within other specialties.

Keywords: district nurses, medical technology, palliative homecare, phenomenography

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of patients. Such conditions make DNs feel dissatisfaction because of increased workload and lack of time, affecting patient safety and quality of care (Haycock Stuart et al. 2008). Furthermore, DNs travel mostly alone and work predominantly without collegial support or supervision in the homes (Lang et al. 2008). General practitioners (GPs) often base their decisions and orders concerning patients in homecare on the DNs’ assessments and reports (Wallerstedt & Andershed 2007, Hov et al. 2009, Modin et al. 2009). Institutional patient safety does not fit well within homecare because of factors such as unregulated and uncontrolled settings, patients’ and next-of-kin’s autonomy and isolation (Lang et al. 2008). To increase patient safety in the home requires a major rethink of underlying institutionally oriented assumptions and guidelines.

In recent years, the use of medical technology in homecare has increased in most industrialized countries, resulting in people with varying degrees of training and knowledge to come into contact with these medical devices (Lehoux 2004). A medical device is a product used to diagnose, prevent, monitor, treat or alleviate diseases, or compensate for an injury or disability (Council of Europe 1993), and it requires specialist knowledge and skills for appropriate and safe use (Neal & Guillet 2004). It is the nurse manager’s liability to organize the work to facilitate a safe use of medical devices and ensure that the personnel are adequately educated (The National Board of Health and Welfare 2008).

Commonly used medical devices and treatments present in the homes include ventilators, various pumps, peritoneal dialysis, oxygen therapy and parenteral nutrition (Lindahl et al. 2003, Lehoux 2004, Orrevall et al. 2004). According to Barnard (1997) technology is not a neutral object and affects the nurses more than they realize. Their underlying expectations, assumptions and knowledge about the technology influences their interpretations and actions toward it and affects how they accept, relate and make sense of the technology (Orlikowski & Gash 1994). The technology facilitates treatments and decreases the nurses’ workload but may also complicate their work if the devices are difficult to handle and not completely trustworthy (Wikström et al. 2007). It can be time-saving but it is also viewed as more time-consuming and distracting, limiting the opportunities for individualized care (Barnard 2000). The technology harms the care relationship (Cooper 1994, Barnard & Gerber 1999) when the focus is placed on the devices instead of the patients (Almerud et al. 2008).

According to Haycock Stuart et al. (2008), the workload of DNs is overwhelming and knowledge is lacking about how the increasing amount of medical technology in palliative homecare influences and affects their ambition to provide a good and patient-safe care. Accordingly, the aim of this study was to describe DNs’ conceptions of medical technology in palliative homecare.

Methods

Design and method description

To study the phenomenon ‘medical technology in palliative homecare’, a descriptive design with a phenomenographic approach was chosen (Marton 1981). Phenomenography is substance oriented and aims to describe peoples’ qualitatively different and unreflective ways of perceiving, experiencing and understanding the same phenomena in the world around them. In order to grasp the variation in how district nurses experience medical technology in palliative homecare, we need to know the differences in their experiences. A conception is different ways to interpret, understand, conceptualize or constitute knowledge of something that also depends on the individual’s personal history. Reality can be perceived from two perspectives, where the first-order perspective describes what something is and the second-order perspective describes how something is perceived to be. In phenomenography the interest is in the second-order perspective and focus is on the individual’s way to perceive any aspect of the world (Marton 1981).

Participants

The main author (BM) selected DNs from a strategic sample with respect to age, sex, health-care experience and years of working as a DN. Nineteen DNs working with palliative homecare in a county council in southern Sweden were asked to participate; three of them declined (Table 1). The DNs worked at primary health care centres, homecare or both with a catchment area that comprised both rural and urban populations.

Data collection

A letter was sent to the DNs with information about the study and its purpose. Medical technology was defined and confined to the more advanced devices that may be present in the home, such as ventilators, suction devices, oxygen and various ports and pumps. After a positive response from the DNs to participate, the data collection was conducted by the main author and consisted of tape-recorded interviews using a semi-structured interview guide designed to cover topics regarding medical
technology in palliative homecare. The interviews lasted between 25 and 60 minutes. Data collection in phenomenography is usually collected through semi-structured interviews with some entry questions (Sjöström & Dahlgren 2002). The overall questions were:

- Can you describe the impact medical technology has had with regard to your: work in palliative care at home; relationship to next-of-kin and patient; relationship to the physical working environment and safety in the home?

In order to expand and clarify, follow-up questions were asked:

- What do you think of that? How did you handle it?

The interviews took place during 2007 in the DNs’ workplace. Two interviews were done to test the relevance of the questions. Although minor language improvements were needed, the interviews were deemed satisfactory and were included.

Data analysis

Data analysis was conducted in a seven step process according to Dahlgren and Fallsberg (1991) by the main author, a DN with long experience, in cooperation with the supervisors (BF) and (JM) – nurse researchers with knowledge in the subject as well as methodological experience. During the process there was a constant interplay between the various steps of the analysis (Box 1). After analysis of the 13th interview, no new information was revealed. This was confirmed by the analysis of the 16th interview, which was with a DN with considerable experience of using medical technology.

Ethical considerations

Permission to carry out the study was requested from the operations manager of the DNs. Informed consent based on written information regarding the study, voluntary participation and guaranteed confidentiality was obtained from the participants before the interviews. The DNs were not close colleagues and not in a state of dependency on the authors. In accordance with the Swedish law regarding the ethical review of human beings, approval from Research Ethics Committees was not needed at the time the interviews were made (SFS 2003, 460).

Results

Five description categories emerged: medical technology led to vulnerability in DNs’ work situation, it demanded collaboration, self-reliance and awareness of managing in a patient-safe way, but it also provided freedom for the patients. The 14 conceptions, which are illustrated using different quotations, illuminate the relation between the description category and the actual condition (Table 2).

Medical technology leads to vulnerability

District nurses perceived vulnerability in their work situation caused by increasing demands and changing tasks. Lack of continuity and support in the management of medical devices gave rise to uncertainty and exposure in the home.

Implies increased demands

The work situation of DNs has changed substantially over the years. The increase in palliative patients requiring medical technology in the home has meant

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<td>Characteristics of district nurses (n = 16)</td>
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<td>5–19 patients/year</td>
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Box 1

The analysis process of district nurses’ conceptions

Familiarization: the transcribed interviews were read through several times to get an idea of and to become familiar with the content

Condensation: the most distinctive statements related to the purpose were selected and the quotes were condensed to obtain the key for each view. A total of 488 statements were identified

Comparison: the selected statements were peer compared to find similarities and differences in informants’ conceptions of medical technologies in the palliative care at home

Grouping: similar statements were peer grouped together in 14 conceptions

Articulating: a preliminary attempt was made to describe each group and its essence, to find limits and to ensure that the groups were distinct and qualitatively separated

Labelling: each conception was labelled with something that characterized its content

Contrasting: on a more abstract level, the conceptions were compared with regard to similarities and differences and finally summarized into five description categories
increased demands, new tasks and a harsher environment.

‘...more seriously ill patients, who remained in the hospital before, are now being cared for in their homes; and then the technique comes with... Vein port and central venous catheter... they are everyday things now...’ (Informant [I] 16)

The hospitals were very demanding when technology-dependent patients were discharged to the homes, and sometimes the DNs lacked knowledge about their devices.

‘It feels like we must be much more updated on absolutely everything. A great amount of knowledge is expected of us and the patients want to come home with their medical devices’ (I 11)

The use of medical devices in the home requires more preparation and advance planning so that all equipment should be in place and every member of the personnel properly educated on its use. Planning and the requirement to keep themselves updated in medical technology along with other duties were stress factors for DNs and their time and resources were not sufficient for this, which meant that they had to set new priorities.

‘We do not have much time to work preventively.... we do not have time for it’ (I 10)

**Creates uncertainty**

Uncertainty was created when the DNs came in contact with new medical technology or with tasks that were rarely performed.

‘... we know it can sometimes go a little long between times, so it’s a little rusty’ (I 13)

A prerequisite for safe management is to use medical devices regularly, which was not possible for DNs in small towns because they only met a few palliative patients with such medical devices per year. Problems also arose during weekends when the DNs were responsible for a larger district with other patients and other medical devices than those they were accustomed to.

‘Before a weekend service, it can feel uneasy since no-one in my area needs special devices, but I know that someone in their area has some, and that I must have that knowledge on Saturday....’ (I 5)

Handling unfamiliar medical devices in front of relatives’ scrutinizing eyes also created insecurity:

‘... they know it almost better than oneself sometimes, so their confidence can make us feel unsure’ (I 13)

**Implies increased exposure**

The DNs felt exposed in patients’ homes, where conditions were different from those in hospitals.

‘Next-of-kin can probably not quite understand that you need to have this little moment if you’re going to program the pumps... You need to be really focused... it is a little different in a hospital, we can go away in a preparation room. In the home you sit in the middle of the family and do this, maybe someone stands looking over your shoulder’ (I 1)

Work as a DN was not recommended for new graduate nurses because DNs often were required to make autonomous decisions.

‘Everything is much further away... at the hospital you have access to course colleagues and physicians when things get complicated. You are rather alone and it is difficult to find a doctor if you want to ask something’ (I 7)

In the absence of the GP involved, they took considerable individual responsibility for the palliative patient.

‘... sometimes you wish that they [GP] would be the authority... they refer to us all the time... you can decide, and so on’ (I 10)

**Medical technology demands collaboration**

Medical technology demanded collaboration between personnel, patients and next-of-kin involving participation and mutual dependence among each other. This,
combined with collegial support, provided the prerequisites for an effective palliative homecare.

Requiring mutual dependence
The DNs were dependent on and often expected that next-of-kin would help with the medical devices in the home. This meant that the number of home visits were reduced, which was advantageous if there was a long distance to the patients' homes. Next-of-kin frequently offered their help to relieve the personnel and, with a satisfactory guidance, they functioned as a resource for the DN.

'... and some say too 'well, I can do that so you don't need to drive here... it makes it easier for the staff' (I 16)

The DN was instead in the background as a support and help when needed.

'It relieves us of course very well, but at the same time we also want to have some control so that you never release it altogether for families' (I 2)

The DN and the responsible GP deliberated in each case as to what was appropriate to delegate based on how much the patient and next-of-kin wanted to do and could take responsibility for. The next-of-kin helped with simple tasks such as monitoring of devices or assisting the personnel, but also with more advanced tasks.

'... And we have also relatives who have assisted when we had long distances who have connected the drip and removed the drip and given injections and pain pumps, and we have taught them ... it has worked great' (I 2)

Requiring collegial support
A good peer support was a necessity when there was uncertainty about how medical devices should be handled. The DNs often visited the hospital department before the patient was discharged to obtain information and guidance on the patient's medical device. The most common support, however, came from other colleagues performing joint home visits the first time a new task needed to be executed.

'... you go up to the hospital and look at it or go home to the patient, together with someone who can, and so and you learn it that way' (I 4)

Other valuable assistance consisted of palliative care teams or telephone contact with pain clinics.

'If it is complicated to reprogram something or so... I would like to have someone with me... or if

I choose, to call the pain unit and have them guide me by phone' (I 10)

Participation of the GPs in palliative homecare was also considered to be a necessary support.

Creating participation
Next-of-kin desired to assist with the medical device in order to participate in and develop an affinity with the health care. Participation in the care was sometimes demanded from the patient, but usually it was an opportunity for the next-of-kin to be useful.

'As a relative, you want to do everything I think... this how it is with participation... if I must lose a husband, a wife or a child... then maybe it feels pretty good to know that I have helped' (I 6)

The DNs encouraged next-of-kin to assist with the medical devices because it was important that they had tasks to do.

'I think it is good if relatives can help as much as possible if they want to, for it can feel good for them if they can also do something useful' (I 2)

Medical technology demands self-reliance
In order to manage medical technology, self-reliance and security were a necessity, which the DNs developed after long experience and continuous usage. This confidence resulted in medical technology becoming both a stimulating and a challenging task.

Demanding security
A fundamental security in their role as a DN was a necessity to be able to handle various situations during work.

'It's not that you always need to be a major specialist if you just have the confidence that you have learned it once and that you can learn it again and repeat it again...' (I 2)

Personal confidence was a precondition for conveying security to the patients, who thus dared to take their own responsibility for the medical device and also became more independent.

'But it requires that you are really secure as caregiver and district nurse to pass on...' (I 5)

If the DNs were secure with the technology, they invested in the care relationship instead of concentrating on the actual performance.

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‘... if I am comfortable with the technology, I can focus on the conversation’ (I 5)

When patients and next-of-kin were informed and knowledgeable about their own medical device, confidence was required of the DNs to take advantage of their knowledge.

‘This young girl was good at it, and it was actually reassuring sometimes... this is nothing which bothers me’ (I 13)

A sense of security also meant that the medical technology was seen as both a stimulating and challenging task.

‘It is stimulating for us to work with this. It is great fun and educational’ (I 10)

**Demands experience**

Considerable work experience and regular use of medical technology provided a safe working situation.

‘... you should be familiar with a job before you do it. You can achieve that only through experience and that experience comes only through many contacts with patients using medical equipment’ (I 5)

Previous experience with emergency care was an advantage.

‘I think it is good if the staff has experience in intensive care or emergency care in their luggage so that they do not need to focus on this technology’ (I 5)

**Medical technology requires awareness**

Awareness of the safe use of medical devices in the home and the personal responsibility to keep informed in order to use them in a patient-safe manner were required. Sensitivity was also required to the various ethical dilemmas that could arise and to what responsibilities patients and next-of-kin were able to undertake regarding existing medical equipment.

**Requires a patient-safety thinking**

Medical technology in the home involved risks to the palliative patients because it could not be monitored by personnel around the clock. Long travel times before the personnel were in place in case something happened were an uncertainty factor.

‘But I still argue that it is always a certain risk to choose care at home because we cannot monitor technology 24 hours a day at home’ (I 16)

Work environments in homecare with poor lighting, uncomfortable positions, inadequate prescriptions and difficulty in maintaining sterility were also problems for the safe use of medical devices. Sometimes patients and families lacked respect and handled the medical devices in an incautious way

‘... when the patient does not understand that they should not smoke and then you leave the concentrator and perhaps oxygen tubes...’ (I 12)

The DNs considered that homecare personnel should have more respect for the medical devices and that the same preventive security work found at the hospital clinics, with regular reviews of the various products, should also be routine in homecare.

**Requires own responsibility**

It was assumed that the DNs took personal responsibility to ensure that they could manage the current medical devices before a home visit.

‘...if I know that I’m going there and that I cannot do it, I find it out before’ (I 3)

This meant a regular update of how medical devices should be used in a patient-safe manner. Supervision of other colleagues was common and was considered to work well. Other ways to be informed were to read current check lists, seek information on the internet and participate in various training courses. Education in medical technology was an important element but occurred too rarely.

‘... When we were in those training days, it was so nice to get this update, but we have not had it for a while now’ (I 13)

**Requires sensitivity**

Sensitivity to what patients and families wanted and could manage was required in order to decide what kind of medical device the DNs dared to delegate. Some next-of-kin considered that it was sufficient just to be involved in the care or simply be present with the patient, some felt intimidated by the medical technology and therefore dared not take any responsibility for it, and others were willing to help.

‘There are those who avoid this... and those who want to learn. I think you must be very sensitive to this’ (I 5)
Sensitivity and attention to the patients concerns was required as well as the ability to convey trust in medical technology and its functions. ‘They understand that with this advanced technology... they can be home to the end-of-life’ (I 1)

**Creates ethical dilemmas**

Medical technology created ethical dilemmas in palliative homecare. Its use should be meaningful to the patients and preferably preceded by an ethical assessment.

‘I think it can go a bit too fast sometimes to start, as it is called “an intravenous drip for the relatives”, perhaps more tormenting than useful’ (I 1)

Medical devices were not always of benefit to the palliative patients. Regular assessment is required to decide how long a treatment should continue before the end-of-life.

‘The medical facilities, no one taking responsibility for removing them...’ (I 5)

Medical technology could also harm the care relationship if, owing to insecurity, the DN had to focus more on the devices than on the patient.

**Medical technology provides freedom for patients**

By personally taking responsibility for the medical devices, the palliative patients maintained their independence and autonomy. Medical technology increased their opportunities and freedom to select which location they wanted to be cared for in end-of-life.

**Makes the patients independent**

Medical technology gave the palliative patients the opportunity to maintain their independence. Participation in their own care and access to the support they needed provided the patients with a more independent and autonomous life.

‘I think it is about wanting to take care of oneself, as long as possible, not to fall into dependence’ (I 12)

Taking responsibility for their pain treatment and being able to take additional doses if necessary meant security, independence and more freedom of movement as they could avoid appointments by a DN.

‘... It is rather a freedom for the patient that they can stay home, move around, go out shopping and can ride away to other relatives’ (I 2)

The number of visits in the home could be reduced, which was an advantage.

‘... that they want high integrity and want to be more for themselves and not have their home open like a hostel, but want to manage it all in the family (I 1)

**Provides increased opportunities for the patients**

Medical technology in palliative homecare was beneficial for patients, giving them greater freedom to choose where they wanted their end-of-life care and was often a prerequisite for allowing the palliative patient to be cared for at home.

‘... it is necessary for the patient’s care... otherwise he is not able to be at home’ (I 3)

The increased opportunities were positive for the patient, as many treatments could be performed in the home and the patient therefore avoided tiring trips to the hospital.

‘Just the security that they need not leave home for some examinations, even abdominal paracentesis and similar treatments can be performed at home’ (I 1)

When medical technology became a part of palliative homecare, the DN was able to get to know the patients and their family at an earlier stage, which was positive for the care relationship.

**Rigour**

In qualitative studies the concepts applicability, security, concordance and accuracy are used (Fridlund & Hildingh 2000). Applicability means that the choice of method, selection and data collection is appropriate to identify and study the phenomenon referred to. Before the interviews, the participants were given a definition of what kind of medical devices would be covered in the study in order to avoid misunderstandings. The sample was considered to be sufficiently varied with regard to age, experience and years of working. However, some doubts may exist regarding the gender distribution as the participants consisted only of three male district nurses. Perhaps more male district nurses could have influenced or added some conceptions. However, as the number of male district nurses in relation to female is lower, the sample is still considered to represent reality and the study was not conducted to describe gender differences. Furthermore, with regard to applicability and transferability the result in this study can be
considered as transferable to similar context non-palliative patients with medical technology in homecare. Using interviews for data collection is useful and is recommended in phenomenography as it provides greater opportunities for more nuances in the answers and, with the use of follow-up questions, it is possible to expand the interview. Security refers to how well the data captures the informant’s reality, which means that data in form of citations should be able to be linked to the source and be visible. The semi-structured interview guide was tested and showed good feasibility and comprehensibility (i.e. capturing the aim of the study). Concordance refers to how the data was generated and then processed. In this study the data and the sample are clearly described. The analyses were carried out in close cooperation with the supervisors who followed the process and discussed and reflected on the statements that emerged. Conceptions and description categories were then constituted. After analysis of the 13th interview, no new statements were revealed. Three additional interviews were then conducted and analysed to confirm this. Accuracy is the authors’ awareness and reflections during the research process. The first author’s own experience as a DN may possibly have an impact on the outcome. This, however, was reduced by an awareness of the pre-understanding. The supervisors’ objective scrutiny in the analysis process also helped to maintain awareness of possible influences on the results.

Discussion

The DNs perceived vulnerability in their work situation because of increasing demands with a growing number of palliative patients requiring medical devices at home. Management of medical devices required regularity, something the DNs in small towns often lacked because there were few such patients. Most of the DNs worked both in clinics and homecare, leading to a stressed and fragmented work situation, as both activities demanded much time and commitment. Better organization of the work is especially important in small cities with only a few DNs, whereas in larger cities the DNs could avoid this fragmented work situation by choosing to work either with palliative care or clinic work with more focus on prevention of illness. The DNs stated they have not much time to work preventively, which was also confirmed by Lindberg and Wilhelmsson (2005). Lack of time and continuity, in combination with an increased workload and responsibility for decision-making about medical treatments, created uncertainty, possibly jeopardizing patient safety. The isolated and exposed work situation of DNs has been confirmed in other studies (Lang et al. 2008, Modin et al. 2009). More collaboration with palliative care teams is one solution, but the availability of these teams varies depending on time of day and where you live (The National Board of Health and Welfare 2006). According to Ringdal et al. (2002) next-of-kin are more satisfied with symptom relief, participation and information coming from palliative care teams than from conventional palliative homecare. In the UK, DNs are predominantly satisfied with the collaboration with these teams (Sullivan et al. 2005). The DNs requested more training in various medical devices, which they believed occurred too rarely. They also called for more respect in the homes for the devices and for more regular reviews of the products, similar to those taking place at hospitals. To perform safe care with medical devices, the personnel must receive the training and support they need. It is important to organize care so the DNs have sufficient education, knowledge and guidance in their management of medical devices (The National Board of Health and Welfare 2008).

Working with medical devices in a professional manner in a home is difficult and sensitivity to the family’s desires and wishes is required. A balance between maintaining the private life of the family and making necessary changes for patient safety in the working environment must be established, although this sometimes can meet with resistance from the next-of-kin. According to Öresland et al. (2008, 2009) the nurses see themselves both as guests and professionals in the patients’ homes, while the patients, as home owners, decide the rules and how the nurses should behave as guests in their homes.

Next-of-kin were considered to be an important resource for monitoring and assisting with the medical equipment. The DNs were of the opinion that next-of-kin were willing to assist in order to become involved in health care and relieve the personnel but also to minimize the number of visits in their home. The DNs’ expectations of assistance from the family could be linked to distance travelled. A reduced number of home visits to remote areas saved time and resources in the DNs’ stressful work situation. This, however, must be carefully considered in each case, to avoid jeopardizing patient safety. To pursue palliative care at home usually means a lot of personnel who come and go in the patient’s home, which may be perceived as intrusive and encroaching on the family’s privacy. The patients’ control over their private sphere is a way for them to maintain their self and identity (Widäng et al. 2007). The families’ involvement in care must be on their own terms and with great sensitivity to what they want to
take responsibility for and not be related to remoteness of the patient’s home (Munck et al. 2008). Medical technology provided freedom for the patients by allowing them to maintain their independence and giving them more opportunities to choose the location of care in end-of-life, which the DNs considered was the palliative patient’s right and the DNs’ mission to satisfy. The feeling of freedom is confirmed by patients undergoing dialysis and oxygen treatment at home; they therefore avoid frequent travelling times to hospitals for scheduled care, allowing them to be at home and to be less dependent on others (Fex et al. 2009).

The DNs experience satisfaction with direct patient care. Constant lack of time, however, coupled with an ambition to provide good quality care for palliative patients, leads to dissatisfaction (Wallerstedt & Andershed 2010). In this study, the DNs’ desire to provide a good quality of care competed with the prevailing work conditions, which can lead to alienation in patient care and ultimately burnout symptoms. To continue working as a nurse, conditions in the work environment, as well as the relationship and support from managers are important factors (Tourangeau et al. 2009). District nurses want managers who demonstrate understanding and respect by offering their own assistance when there is a lack of personnel (Dols et al. 2010).

Conclusions

The DNs perceived vulnerability in their work situation caused by increasing demands when more patients with medical devices were discharged to the home. Lack of time and continuity, in combination with increased workload, created uncertainty, possibly jeopardizing patient safety. This uncertainty can be reduced by more education, supportive managers and collaboration with palliative care teams. Next-of-kin are considered to be an important resource for monitoring and assisting with the medical devices, which must be based on sensitivity to what they want to do and not be related to the remoteness of the patient’s home. Medical technology is beneficial for the patients and gives them increased opportunities and independence.

Implications for nursing management and relevance to clinical practice

If DNs are to be able to manage medical technology in palliative homecare in a patient-safe way without perceiving exposure, they must become more specialized and work exclusively with this kind of care and should not fragment their working time within other specialties. This may require organizational changes and more collaboration with palliative care teams. The DNs also need regular training in the use of current medical devices and regular reviews of the various medical devices similar to those occurring in the hospital clinics should also be routine in homecare. The nurse manager must become more aware of the current working conditions of the DNs. To gain a deeper understanding of medical technology in palliative homecare it is important to include next-of-kin’s and patients’ perspective in future studies.

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Next-of-kin’s conceptions of medical technology in palliative homecare

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Abstract

Aims and objectives
The aim of this study was to describe next-of-kin’s conceptions of medical technology in palliative homecare.

Background
Next-of-kin to palliative patients are in an exposed position with increasing responsibility. The more involved they are in the care, the greater caregiver burden they describe. Medical technology has become increasingly common in the palliative homecare and previous research notes that the devices transform the homes to a hospital ward, thus shifting responsibility from the personnel to the next-of-kin.

Design
An explorative descriptive design with a phenomenographic approach was chosen to describe qualitatively different conceptions of the phenomenon medical technology.

Method
Interviews with 15 next-of-kin to patients in palliative homecare were analysed in a seven step process where 10 conceptions emerged in five description categories.

Results
Medical technology in palliative homecare required next-of-kin’s responsibility in monitoring or providing practical help. It also implied uncertainty among the next-of-kin because of worries about its safety or due to an improper handling. It trespassed on daily life since it restricted and affected the private sphere. Medical technology enabled comfort as it implied security and was a prerequisite for the patient to be cared for at home. It also required an adjustment to comprehend and manage the medical technology.

Conclusions
Medical technology resulted in an increased caregiver burden and uncertainty among the next-of-kin. Although it meant restrictions and affected their social life, they had great confidence in its possibilities.

Relevance to clinical practice
It is important to limit the amount of personnel and materials in the home to avoid trespassing on the family’s daily life. The personnel also have to be sensitive to what next-of-kin have the strength to do and not utilize them as informal caregivers.

Keywords: Medical technology, next-of-kin, palliative homecare, phenomenography
Introduction

Palliative care is an approach aiming to prevent and relieve suffering for patients with a serious illness and to improve the quality of life for them and their next-of-kin (WHO Europe 2004). The concept of palliative care has been developed during the last decades to a comprehensive active and individualized patient care, support to the family, multiprofessional teamwork and effective communication (Meghani 2004). The significance of the next-of-kin has grown and become an important part of palliative homecare. It has been shown that their need for support increases in proportion to the patient’s deteriorating condition (Council of Europe 2003, WHO Europe 2004, Meghani 2004). A systematic review about next-of-kin to palliative patients indicates that they are in an exposed position with increased vulnerability and responsibility (Andershed 2006). Their lives are being put on hold and they lose control of their normality (Sandgren et al 2010). Their situation gives rise to anxiety, tiredness, difficulties with sleep, lack of time and financial burdens. To handle the situation they use different coping strategies such as own activities, having control and taking one day at a time (Andershed & Harstäde 2007). The more next-of-kin participate in patients’ activities of daily living and the higher the number of patients’ symptoms, the higher report of caregiver burden and depressive symptoms (Brazil et al 2003, Given et al 2004). The next-of-kin’s need for support, participation in care, as well as a trusting relationship with the personnel is well confirmed (Andershed & Ternestedt 1998, Andershed 2006). Palliative care teams have increased rapidly in recent years in the United States as well as Europe and these teams facilitate the palliative care for patients and provide support to the next-of-kin (WHO 2004, Cliemins et al 2007, Hansson et al 2008, National Consensus Project for Quality Palliative Care 2009). Access to these teams implies a feeling of security for the next-of-kin and of being relieved from the responsibility for the care (Brännström et al 2007).

Medical technology in homecare has increased in most industrialised countries as a result of health reforms and a shift from inpatient to outpatient care (World Health Organization 2011). Treatments such as home mechanical ventilation, peritoneal dialysis, and oxygen therapy have become increasingly common in the home (Fex et al 2009) which means that patients and their next-of-kin are faced with new challenges (Lehoux 2004). Moreover, patients describe medical technology as a process of learning, mental preparing, accepting and planning for situations. It is also about restriction and how the technology affects their social life both in time and space (Ring & Danielson 1997, Lindahl et al 2003, Lehoux 2004, Fex et al 2009). In particular, if the patients live in remote areas, next-of-kin are considered as an important resource to monitor and assist in the medical devices in the home (Munck et al 2011).
Nevertheless, use of the devices in a patient safe way requires specialist knowledge and skills (Neal & Guillet 2004, The National Board of Health and Welfare 2008). Previous research about medical technology notes its impact on daily life, such as devices that transform the homes of technology-dependent children to a hospital-like environment with lack of privacy. The responsibility for the devices shifts from the personnel to the next-of-kin (Mentro & Steward 2002, Wang & Barnard 2004, Kirk et al 2005, Floriani 2010). There are several studies on how parents experience medical technology in homecare (Mentro & Steward 2002, Wang & Barnard 2004, Kirk et al 2005, Floriani 2010), but no studies on how next-of-kin to patients in palliative homecare perceive the medical technology. The aim of this study was therefore to describe next-of-kin’s conceptions of medical technology in palliative homecare.

Methods

Design and method description
An explorative descriptive design with a phenomenographic approach was chosen to study the phenomenon medical technology in palliative homecare. In the phenomenographic approach, reality can be perceived from two perspectives, as conceptual and as unreflective thinking. In the first-order perspective, the participant talks about a phenomenon which is consciously made, and describes what something is. The second-order perspective describes how something is perceived to be, which means that the participant himself must discern the phenomenon from the whole by reflecting upon it (Martin & Booth 1997). In phenomenography the interest is in the second-order perspective and how the phenomenon is perceived in reality and is concerned with individuals’ conceptions of that reality (Marton 1981). Phenomenography is substance-oriented and focuses on peoples’ qualitatively different and unreflective ways of perceiving, experiencing and understanding the same phenomenon in the world around them. The search for the underlying structure of variance is the essence of phenomenography (Marton 1981, Marton & Booth 1997). Accordingly, the study outcome was a description of qualitatively different essential variations of next-of-kin’s conceptions of medical technology.

Participants
Sixteen next-of-kin to palliative patients with medical technology in homecare were selected from a county in southern Sweden and all but one agreed to participate. District nurses who
knew the palliative patients and their next-of-kin took the first contact to see if the next-of-kin were interested in participating, and if so, an appointment for an interview was made by the main author (BM). Further, the participants were strategically chosen to ensure variation in sociodemographic data with respect to sex, age, education and clinical data (Table 1). Their experience with different kinds of medical devices consisted of pain, nutrition and volume pumps, oxygen concentrators, suctions and inhalation devices, percutaneous endoscopic gastronomy (PEG) and subcutaneous vein ports. There were also next-of-kin who, as a result of their professional background, had experiences with other medical devices.

**Table 1**

Characteristics of next-of-kin to patients in palliative homecare (N= 15)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>6</td>
</tr>
<tr>
<td>Women</td>
<td>9</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>39-83</td>
</tr>
<tr>
<td>≤ 50</td>
<td>4</td>
</tr>
<tr>
<td>51-70</td>
<td>5</td>
</tr>
<tr>
<td>≥ 70</td>
<td>6</td>
</tr>
<tr>
<td>Relationship to the patient</td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>4</td>
</tr>
<tr>
<td>Wife</td>
<td>6</td>
</tr>
<tr>
<td>Children</td>
<td>3</td>
</tr>
<tr>
<td>Sibling</td>
<td>1</td>
</tr>
<tr>
<td>Niece</td>
<td>1</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Nine-year compulsory school</td>
<td>8</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>2</td>
</tr>
<tr>
<td>High school</td>
<td>3</td>
</tr>
<tr>
<td>University</td>
<td>2</td>
</tr>
<tr>
<td>Patient had access to palliative team</td>
<td></td>
</tr>
<tr>
<td>Had access</td>
<td>6</td>
</tr>
<tr>
<td>Had no access</td>
<td>9</td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
</tr>
<tr>
<td>Together with the patient</td>
<td>10</td>
</tr>
<tr>
<td>Together with own family</td>
<td>5</td>
</tr>
<tr>
<td>How long experience of medical technology in the home as next-of-kin</td>
<td></td>
</tr>
<tr>
<td>1 ≤ 6 months</td>
<td>8</td>
</tr>
<tr>
<td>&gt;6 -12 months</td>
<td>3</td>
</tr>
<tr>
<td>&gt; 12 months</td>
<td>4</td>
</tr>
</tbody>
</table>
Data collection
In phenomenographic research, the preferred method of data collection is the semi-structured interview (Marton & Both 1997). Data collection conducted by the main author, a district nurse with extensive experience of palliative homecare, lasted from autumn 2009 to spring 2010. Data consisted of tape recorded interviews using a semi-structured interview guide, starting with an overall question about what perceptions the next-of-kin had about the current medical technology in palliative homecare. Then questions were asked about how the next-of-kin perceived the medical technology with regard to impact on their daily life, their participation as a caregiver, security in the homecare and the support they received. The interview was expanded by follow-up questions such as: What do you mean by that? What do you think of it? Two test interviews were conducted and, as the interview guide was considered appropriate, these were included. The interviews were conducted in the participants’ home, except for two. One took place at the workplace of the participant and the other at the workplace of the main author.

Ethical considerations
Permission to perform the study was granted by the Regional Ethics Committee for Human Research at Linköping University, Sweden. Permission was also obtained from the operation managers involved. Informed consent was obtained and information on voluntary participation and guaranteed confidentiality were given to the participants prior the interviews.

Data analysis
Data analysis was conducted by the main author in a seven step process according to Dahlgren & Fallsberg (1991) in cooperation with the co-authors, all nurse researchers with extensive area subject and/or methodological experience. In the first step ‘familiarization’, the transcribed interviews were read through several times to get an idea of and to become familiar with the content. In the second step ‘condensation’, the most distinctive statements related to the aim were selected. A total of 235 statements were identified. The third and fourth steps were ‘comparison’ and ‘grouping’, and the selected statements were peer compared to find similarities and differences about the phenomenon. Those with similar content were grouped together, in all into 10 conceptions. In the fifth step, a preliminary attempt was made to describe each group and their essence, ‘articulating’, to establish borders
between the groups and to ensure that these were distinct and qualitatively separated. In the sixth step, each group or category was ‘labelled’ and their contents were characterized and then summarized into five description categories. Finally in the seventh step, the categories were compared with regard to similarities and differences on a more abstract level called ‘contrasting’ to ensure the relevance of the outcome.

**Results**

Next-of-kin in palliative homecare perceived that medical technology required responsibility, implied uncertainty, trespassed on daily life, enabled comfort and required adjustment (Table 2).

Medical technology required responsibility

Next-of-kin perceived they were an assistant to the district nurses by providing practical help or by monitoring the medical devices which demanded their presence. However, the number of home visits was reduced when they themselves were responsible for the medical devices. Next-of-kin were also the patients’ representative and responsible to precede the patients’ interest and needs.

Medical technology required an assistant

Next-of-kin perceived they were the district nurse’s extended arm and often helped with practical tasks. ‘The nurse comes about nine o’clock and she connects the first bag (nutrient solution) and fills up these shots she has and then when the first bag is empty, dad comes and puts on the next’ [says a daughter]. The next-of-kin perceived they need to help the district nurses to ensure that all equipment and nutrient solutions were available before their visit. They also perceived their task were to be supervisors of medical technology during nights to assure that the equipment was not damaged or removed by the patient during sleep. Alarmed pumps demanded the presence of next-of-kin and meant that they never completely could relax from the responsibility of medical technology. There were next-of-kin who considered monitoring of medical devices as an opportunity for participation and control over the situation, while others absolutely did not want to deal with it, as it required some technical knowledge if any problems arose. When the next-of-kin themselves were responsible for monitoring the medical devices, the home visits of personnel were reduced, which was considered an
advantage. 'It is about how many people I want to have here at home. If I take care of some by myself it reduces the number of personnel who will come'.

Medical technology required a representative
Next-of-kin considered they were responsible for representing the interests of patients. 'Many times if one is ill and wants to have the better stuff, then it is important that you know it yourself, and can speak for them'. Next-of-kin questioned if the patient had medical technology which they regarded inappropriate, or made sure that the patient had access to the medical technology they thought the patient needed. 'It was my merit to say that he on the whole got oxygen, for otherwise he would not get it if I had not required it'. They also had comments and ideas about how the medical devices could be improved to be more user-friendly.

Medical technology implied uncertainty
Next-of-kin perceived worry about the medical devices when they were not functional or perhaps damaged. They also had concerns about the patients’ life-sustaining treatments. Lack of confidence in the personal’s handling of medical devices caused uncertainty.

Medical technology caused worry
Next-of-kin perceived that medical devices created worry and uncertainty when they were not functional and user-friendly, such as when long hoses to pain pumps stuck to everything and threatened to pull out the needle and when connections to tubes came loose. 'She gets her medicine by that way (the PEG) which is pretty important. So what happened last time...the stopper went out...then they did not know if she had received the medicine or not'. Difficulties in reading the right setting on oxygen concentrators caused worry that the patient might receive a wrong dosage. Being dependent on medical technology at night implied a disturbed night sleep for the next-of-kin due to concerns that the patient could damage the medical device in their sleep. 'Then this anxiety to have the tube in the stomach which is movable... it is just a small air bubble. It is easy to pull it out'. The suction’s incapacity to provide adequate relief for patients with swallowing disorders was a concern, as was the next-of-kin’s involvement in the decision to cancel or terminate life-sustaining treatment. 'If she earlier when she was healthy had expressed that she would not be lying, it is still a difficult and almost an impossible decision to make for the next-of-kin...you feel powerless'.
Medical technology created a lack of confidence

Next-of-kin lacked confidence in the personnel and their management of medical devices. ‘But it is often they cannot handle it (the nutrition pump)....they are unable to start it, they forget they say...well, they forget to open the tube’. A contributing factor was that too many personnel were involved and they performed the task too rarely. The personnel’s improper handling of the devices made the daily life more complicated for the next-of-kin. ‘It was not easy...because it loops up sometimes and it beeps and says stop... But of course the device itself is good if handled properly’. Next-of-kin perceived that the patients sometimes knew more about managing their own medical devices than personnel who had not worked with it for several years.

Medical technology trespassed on daily life

Next-of-kin perceived that medical technology restricted their social life, because they were not free to do whatever they wanted. The medical devices also affected their private sphere because of the many home visits by personnel and the large space required for the handling and storage.

Medical technology led to restrictions

Next-of-kin perceived that medical technology led to restrictions in their social life. Patients with a nutrition drip were restricted to the home during the infusion. ‘It takes three hours for pumping it and that means six hours a day. Then it is not easy to go anywhere’. Although there was access to a portable pump, the patient and the next-of-kin were not comfortable using it. A patient with a pain pump could no longer drive. ‘We sold the car because I did not dare to ride with him or let him run’, which limited their social life. Next-of-kin to patients with oxygen concentrators had to avoid candles, which was considered especially boring at Christmas time. One patient with oxygen treatment had problems with his nasal cannula and therefore wanted to remove it, which meant that the next-of-kin did not dare to leave him alone.

Medical technology affected the private sphere

Next-of-kin perceived that medical technology affected their private sphere because it usually led to more home visits by personnel. ‘Well, it is that I always have people running in and out of my home’. Patients with a nutrition drip required large spaces for storage, preparation and waste management which was disturbing for the next-of-kin. Next-of-kin also had to make room in the kitchen for the district nurse when infusions were prepared. ‘Sometimes it is hard to
always expect that they will enter and now they have a place here and have put up all their boxes of equipment’.

Medical technology enabled comfort

Next-of-kin perceived that medical technology implied security for them because it was useful for the patient, which improved the family situation. An additional security was the personnel’s regular home visits for management of the medical devices. The family also found a freedom of movement with newer medical devices adapted for outdoor use.

Medical technology implied security

Next-of-kin relied on medical technology, which they considered be safe and functioned well. A pain pump that replaced the syringes every four hours meant a good night’s sleep for both the patient and the next-of-kin. It implied security when they had alternative solutions if medical devices stopped working such as prescribed injections if the pain pump breaks down and battery-powered options or their own generator during a power failure. Having medical technology in the home meant regular visits by district nurses which the next-of-kin appreciated and which also implied a security for them. They also appreciated the skilled and attentive personnel and were particularly satisfied with the palliative care teams and their ability to provide special treatments with the medical devices. ‘That he gets blood (transfusions) at home is great, not to have to go away…it feels great’. Medical technology was often a precondition for the patient being cared for at home and also a better option than before with concerns that the patient was not receiving adequate nutrition. ‘I thought it was great when they came here and put a drip, so I knew that he then got nourishment’. The next-of-kin realized that nutrition pumps were also the only option that remained when the patient had difficulties to swallow.

Medical technology implied freedom

Next-of-kin considered that newer medical devices, better designed and adapted for home use implied more freedom of movement for the patients and themselves. Medical devices adapted for outdoor use meant more opportunities for living a normal social life. ‘It’s a great freedom with this pump that you can go away…we went to Spa this weekend…before, mom was really nervous about this…but it went great…. Then she said that she wanted to go on more adventures’. Medical technology meant also more freedom for the next-of-kin as they could take ‘own time’ while the personnel took care of the patient and their medical devices. ‘But sometimes I will go my
way, because I know they will come and put the drip. So I go and do business in town’. A pain pump instead of regular pain injections meant that a next-of-kin was able to work part-time.

Medical technology required adjustment

Next-of-kin perceived that medical technology implied an adjustment to new conditions for the next-of-kin, being involved by searching for information about the medical devices, adapting the home in relation to what the technology required and accepting patient’s medical device as part of the current situation.

Medical technology required comprehensibility and manageability

The next-of-kin desired some sort of understanding of the medical technology and their new situation, which meant searching for information about the current medical equipment. ‘I called the University... who are leaders in research of ALS...I needed to talk to somebody who knows what will happen with this kind of PEG’. To make their lives more manageable, the next-of-kin refurnished and moved the patient’s bedroom to the ground floor to avoid taking intravenous pole up the stairs. They learned to control the drip rate so the patient got more free time. ‘You are very tied up, but now we give the infusion faster, so there are longer periods that she does not need a pump. I can be away from her one hour without problems’.

Medical technology implied adaption

Next-of-kin perceived sadness seeing the patient tied to their medical device or getting their daily nourishment solely by a PEG, but they had to accept the circumstances and the life-sustaining treatment. ‘In the beginning I thought it was very sad...but you get used to everything’. To see the patient be sucked was perceived as a state of humiliation. ‘She is in a bad condition when you suck her and she coughs, so I think it’s a bit humiliating you could say, but you need to do it’. Next-of-kin to patients with oxygen concentrators had become accustomed to constant buzzing and long oxygen tubes on the floor.
**Table 2**

Description categories and conceptions of the phenomenon medical technology among next-of-kin in palliative homecare

<table>
<thead>
<tr>
<th>Description categories</th>
<th>Conceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical technology required responsibility</td>
<td>Medical technology required an assistant</td>
</tr>
<tr>
<td></td>
<td>Medical technology required a representative</td>
</tr>
<tr>
<td>Medical technology implied uncertainty</td>
<td>Medical technology caused worry</td>
</tr>
<tr>
<td></td>
<td>Medical technology created a lack of confidence</td>
</tr>
<tr>
<td>Medical technology trespassed on daily life</td>
<td>Medical technology led to restrictions</td>
</tr>
<tr>
<td></td>
<td>Medical technology affected the private Sphere</td>
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<tr>
<td>Medical technology enabled comfort</td>
<td>Medical technology implied security</td>
</tr>
<tr>
<td></td>
<td>Medical technology implied freedom</td>
</tr>
<tr>
<td>Medical technology required adjustment</td>
<td>Medical technology required comprehensibility and manageability</td>
</tr>
<tr>
<td></td>
<td>Medical technology implied adaption</td>
</tr>
</tbody>
</table>

**Rigour**

Four concepts are significant for scrutinising qualitative studies; *applicability, security, concordance,* and *accuracy* (Fridlund & Hildingh 2000). *Applicability* means that the choice of method, selection and data collection is appropriate to identify and study the phenomenon referred to. Phenomenography was considered as an appropriate approach to describe next-of-kin’s qualitatively different conceptions of the phenomenon medical technology in palliative homecare. Since there was a lack of research in this area, interviews were preferred for data collection to obtain new knowledge and gain a deeper understanding of the phenomenon. To avoid misunderstandings, the participants were given a definition of what kind of medical devices would be covered in the study. In phenomenography it is the people’s unreflective ways of perceiving a phenomenon that are important, and this procedure may therefore have influenced the next-of-kin’s perceptions to be reflective. The help of district nurses in the selection of next-of-kin can be seen as a disadvantage due to their ability to filter out those who might have negative descriptions of the care. On the other hand the district nurses know
the families where medical devices exist in the home and presumably this is the best way to get in contact with the families. Security means trustworthiness and how data are obtained and received and how well it captures the participants’ conceptions. The main author had no relationship with the next-of-kin, which gave them greater ability to be honest in the interview situation and before the interviews they were informed about voluntariness and confidentiality. Data in the form of quotations should be visible and be able to be linked to the source. To help guarantee the security of the study, several quotations were included in the result. Concordance means reasonableness; how data are interpreted and described. The analyses were carried out in close cooperation with the co-authors who during the analysis process discussed and reflected on the constituted conceptions and description categories and then agreed on the outcome. Accuracy relates to the researcher’s awareness and reflecting during the research process (Fridlund & Hildingh 2000). In the interview situation, the researcher must bracket the presuppositions to avoid being influenced by one’s own personal prior knowledge (Ashwort & Lucas 2000). The main author’s own experience as a district nurse could possibly have affected the outcome of the study but was reduced through awareness, bracketing and reflecting with the co-authors throughout the process of analysis.

Discussion
Next-of-kin’s perceptions showed that medical technology in palliative homecare required an assistant, which was a role the next-of-kin living with the patients took more or less voluntarily. They assisted the district nurses while they monitored the medical devices and provided practical help or made sure that the store of materials was available before the home visits. This was something the next-of-kin did because they considered it was their responsibility, or an opportunity to participate in the care, or because the medical devices required it. For others it was a conscious way to reduce the personnel’s home visits. There were next-of-kin who did not consider it was a problem to monitor the technology, while others absolutely did not want to take that responsibility. According to Orlikowski and Gash (1994), how they relate to medical technology depends on people’s self-reliance, previous experience and which technological frame of reference they assume. The next-of-kin’s need for participating in the care does not necessarily mean an involvement in managing the devices. It is important for personnel to be sensitive to what next-of-kin want to do and whether they have the strength to take responsibility for medical devices; otherwise it will be an additional caregiver burden, which is confirmed by district nurses (Munck et al 2011). To
be a caregiver in palliative homecare can affect the next-of-kin’s physical and mental health to such an extent that they cannot continue as caregivers (Carter 2002, Hudson 2004, Sjövall et al 2009). The personnel must therefore encourage the next-of-kin to accept home assistance and other professional help at an early stage, especially if there is only one next-of-kin caregiver, otherwise their increasing caregiver burden can lead to an interruption of the palliative care (Munck et al 2008). It is also important as personnel to encourage the next-of-kin to take breaks during the home visits instead of feeling responsible to service and provide assistance to the personnel. Next-of-kin need their ‘own time’ which is confirmed in several studies (Milberg & Strang 2000, Proot et al 2003, Brobäck & Berterö 2003, Hudson 2004).

Treatment with nutrition pumps implied a lot of home visits by personnel who connected and disconnected the drips several times a day, which the next-of-kin perceived as tiresome and trespassing on their private sphere. To reduce the home visits, they instead tried to handle the nutritional treatments by themselves, which according to Widäng et al (2007) is a way to maintain the self and the identity. The great amount of material in the home was also perceived as trespassing on the family’s private sphere. To have the equipment stored in the home is convenient for the personnel, but the opposite for the next-of-kin. The personnel must try to limit their storage space to avoid requiring next-of-kin to make sacrifices in their own homes. According to Kirk et al (2005) the medical devices can change a home from a private sphere to a mini-hospital where the personnel pass in and out. In the planning of palliative homecare it is important to minimize the number of personnel around the patient to maintain continuity, leading to a feeling of family security and a patient safe care. The next-of-kin were especially satisfied with the skilled personnel in the palliative care teams which meant continuity and safety which also is confirmed by Cliemins et al (2007).

Next-of-kin lacked confidence in the personnel who were uncertain in their management of medical devices leading to alarmed devices and leaking connections, mostly due to the personnel’s lack of continuity. District nurses confirm this uncertainty especially when they had to handle medical devices they were unfamiliar with (Munck et al 2011). District nurses often delegate the management of nutrition pumps to home assistants, which implied involvement of more personnel and a greater uncertainty. The district nurse must, before a delegation, ensure that the personnel who receive the delegated task can perform it in a satisfactory manner (The National Board of Health and Welfare 1997). The next-of-kin had great confidence in the medical devices and considered that the devices with their own presence were often a prerequisite for the patient to be cared for at home and sometimes the only option that remained. Their satisfaction depended on which medical device the patient
had, mostly with the pain pumps, while they had an ambivalent perception about the nutrition pumps. Next-of-kin also claimed that newer medical devices, better designed and adapted for home use implied more freedom of movement, while patients in the Lehoux et al study (2004) showed ambivalence, as the opportunity to participate in social life increased, but also restricted their daily life. In our study the next-of-kin were grateful for the nutrition pumps, supporting daily nutritional needs, which were confirmed by other next-of-kin (Orrevall et al 2004) who experience the nutrition drip as a positive alternative, instead of the desperation and helplessness they feel when the patient cannot eat due to nausea and swallowing disorders. Nevertheless the nutrition pumps gave rise to anxiety and powerlessness when the next-of-kin saw the patient tied to and dependent on the medical device and considered it an impossible decision for them to make; withdrawing this life-sustaining treatment in a terminal stage. Medical technology must not be used to prolong life in an unnatural way and if treatments are futile and unnecessarily burdensome, the physicians have no obligation to continue them (Council of Europe 2003). As a district nurse it is important to question such treatments and notify the physicians if such conditions prevail. According to Hov et al (2008) nurses want to have more influence on the end of life decisions, and they feel undervalued when their knowledge of the patients is neglected by the physicians. This is in line with other studies (Svantesson et al 2003, Wikström et al 2007) which show that patients, next-of-kin and nurses are not sufficiently involved in this decision process.

Conclusions

Next-of-kin perceived medical technology in palliative homecare required an assistant, a role next-of-kin took more or less voluntarily resulting in an increased caregiver burden. The personnel’s uncertainty in the handling of the devices created uncertainty among the next-of-kin, a problem which can be reduced if the management exclusively is performed by skilled personnel or by palliative care teams who handle these kinds of devices daily. The medical technology limited the next-of-kin’s social life as they were not free to do whatever they wanted. It also affected their private sphere because of a lot of home visits by personnel which was tiring. However the next-of-kin had great confidence in the medical technology and its possibilities.
Relevance to clinical practice

The personnel must be sensitive to what next-of-kin want to take responsibility for concerning existing medical devices, otherwise there is a risk they will be used as informal caregivers. It is important to limit the number of personnel and amount of materials in the home to avoid trespassing on the next-of-kin’s daily life. It is also important to encourage and support the next-of-kin to take ‘own time’ and support them to do pleasant activities together with the patient.

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Patients’ understanding of medical technology in palliative home care; a qualitative analysis

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Abstract

Healthcare reforms and reductions in the number of hospital beds are leading to an increasing amount of medical technology moving from hospitals into home care, affecting the daily lives of patients. The aim of this study was therefore to describe patients' ways of understanding medical technology in palliative home care. With use of a phenomenographic approach, 15 patients with medical technology were interviewed and data were analyzed in a seven step process. Three ways of understanding the phenomenon emerged; a masterful patient, an adjustable patient and a restricted patient. Masterful patients took control over the medical technology and were mostly independent of assistance from personnel. Adjustable patients accepted and adapted their lives to the medical technology and were satisfied with assistance from the personnel. Restricted patients were daily reminded of the medical technology and dependent on assistance from personnel. Depending on the patients' health conditions, the support from the personnel and the impact of medical technology, a transfer between the different ways of understanding occurred with a simultaneous movement between independence and dependence. The patient exhibited various ways of understanding, although one way of understanding was more dominant.

Keywords

Medical technology, patient, palliative home care, phenomenography
Introduction

Global demographic changes and developments in healthcare systems, such as reductions in the number of hospital beds and shorter hospital stays, have resulted in an increasing amount of medical technology being transferred from hospitals into the community to be used by patients at home. A medical device is a product used for human beings to diagnose, prevent, monitor, treat or alleviate diseases or compensate for an injury or disability. The users of medical devices in home care are a heterogeneous group of personnel, patients and their next-of-kin, representing a variety of experiences, ages, and levels of professionalism. In addition, homes are unpredictable and uncontrolled settings, where each home must be seen as unique. The security of the medical devices can be compromised by electrical interactions with other devices in the home, a dusty and non-sterile environment, inappropriate illumination and confined spaces. The perspective of home care safety differs between patients and personnel. Patients consider their home to be a safe place even though they can describe examples of risky situations. The personnel’s concerns about safety focus on patients’ physical security, such as evaluating risks and minimizing drug errors.

Conventional institutional patient safety does not fit well in this context. One aspect that differs is patients’ autonomy and their decisions not to follow recommendations for home care. According to district nurses and next-of-kin, a desire to assist with medical devices is an opportunity for participation in home care, but the desire for participation differs between patients. Older patients often do not feel comfortable with the technical devices, and chronic patients in general seem more keen to take responsibility for them. However, the shift of responsibility for medical devices from personnel to patients can cause anxiety when patients perform a task they believe is reserved for nurses. Regular support from personnel and next-of-kin is therefore a prerequisite for patients using medical devices at home, but peer support from other patients is also valued. Medical technology affects patients’ daily lives, with regular treatments, alarming pumps, anxiety for dislodging catheters and fear of smokers or open flames.

Patients sometimes express ambivalence towards their medical technology. On the one hand, medical technology represents a lifesaver and a symptom reliever which increases their opportunity to participate in a social context and thus increases their sense of freedom. On the other hand, medical technology implies feelings of restriction, of being tied up and of being required to adapt to new situations. It also means that their daily lives needed to be
carefully planned and organized for everything to function\textsuperscript{12,13}. Although there are several studies on medical technology in home care, there are few studies that focus on medical technology in palliative home care from a patient perspective\textsuperscript{14,15,17}. The aim of this study was therefore to describe the patients' ways of understanding medical technology in palliative home care.

**Method**

**Design and method description**

The study applied an explorative descriptive design with a phenomenographic approach\textsuperscript{18} in order to describe palliative patients’ essential variations in their understanding of the phenomenon of medical technology in palliative home care and their different ways of experiencing it. The essence of phenomenography is the search for the underlying structure of variance. In order to characterize this variation of understanding a phenomenon, it is important to understand what it means to experience a phenomenon in a particular way. This contains a ‘what’ aspect, i.e. what medical technology is, which corresponds to the object itself, and a ‘how’ aspect, i.e. what medical technology is conceived to be, which relates to the act and what it means for the person concerned\textsuperscript{19,20}. The conceptions are grounded in the lived experience of the participants, and the researcher must be sensitive to the individuality of conceptions and set aside own assumptions\textsuperscript{21}.

**Participants**

Patients with medical technology in palliative home care were selected by district nurses from a county in southern Sweden. District nurses who knew the patients contacted them to see if they were interested in participating and, if so, an appointment for an interview was made by the main author (BM), a district nurse with extensive experience of palliative home care. Eighteen patients were asked to participate; three of them declined as their physical condition deteriorated. The sample was consequently composed of fifteen patients who were eligible during the study period (Table 1). The most common diagnoses among the patients were different types of cancer, amyotrophic lateral sclerosis (ALS), heart failure and chronic obstructive disease. Their experience of different kinds of medical devices consisted of pain pumps, nutrition and volume pumps, i.v. infusion, digital pain-pens, oxygen concentrators and
cylinders, nephrostomy catheters, percutaneous endoscopic gastronomy (PEG) and subcutaneous venous port implantation.

Table 1
Characteristics of patients in palliative home care (N= 15)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>7</td>
</tr>
<tr>
<td>Women</td>
<td>8</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>38-88</td>
</tr>
<tr>
<td>≤ 65</td>
<td>6</td>
</tr>
<tr>
<td>66-75</td>
<td>5</td>
</tr>
<tr>
<td>&gt; 75</td>
<td>4</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Nine-year compulsory school</td>
<td>7</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>5</td>
</tr>
<tr>
<td>High school</td>
<td>2</td>
</tr>
<tr>
<td>University</td>
<td>1</td>
</tr>
<tr>
<td><strong>How long experience of</strong></td>
<td></td>
</tr>
<tr>
<td>medical technology</td>
<td></td>
</tr>
<tr>
<td>≤5 months</td>
<td>8</td>
</tr>
<tr>
<td>6-11 months</td>
<td>4</td>
</tr>
<tr>
<td>≥12 months</td>
<td>3</td>
</tr>
<tr>
<td><strong>Number of medical devices</strong></td>
<td></td>
</tr>
<tr>
<td>1 medical device</td>
<td>4</td>
</tr>
<tr>
<td>2 medical devices</td>
<td>7</td>
</tr>
<tr>
<td>3 medical devices</td>
<td>4</td>
</tr>
</tbody>
</table>

**Data collection**

Data collection was conducted by the main author and lasted from autumn 2009 to spring 2011. Data consisted of tape recorded interviews with use of a semi-structured interview guide, as this is the preferred method of data collection in phenomenographic research. The interviews lasted between 15 to 60 minutes. The patients’ ways of understanding medical technology in palliative home care with regard to impact on daily life, participation, security and support were of interest and requested. The interview was expanded by follow-up questions such as: What do you mean by that? What does it mean to you? The interviews took
place in the patients’ homes. Two of the patients had difficulties in speaking and used computer, paper and pen in their communication.

Data analysis

The analysis was performed by the main author in cooperation with the co-authors, all nurse researchers with extensive knowledge in both subject and methodology. The interviews were transcribed and analysed in a seven-step process according to Larsson and Holmström,22 (Box 1).

**Box 1.** The analysis process of palliative patients’ different ways of understanding medical technology

- In the first step of the analysis, each transcribed interview was read through.
- In the second step, the text was reread again and statements where the interviewed answered the aim of the study were identified and marked.
- In the third step what was in the focus of the patients’ attention and how they described their understanding of medical technology was identified. This is illustrated by following quotation.

*(What)* ‘They suggested that I would switch to a digital pain pen...it works great...I have been able to regulate it myself when I need extra doses, so it’s not anyone else who decides it, but it’s me’.

*(How)* ‘It inspires just security, because as soon as I go somewhere I always have it with me: And that’s a huge security and knows...it takes no more than ten minutes; I have pain relief.

A preliminary description of each patient’s dominant way how to relate to medical technology in home care was then made.

- In the fourth step, the descriptions were grouped into categories based on similarities and differences, and for each category a common description was formulated.
- In the fifth step the non-dominant ways of understanding the phenomenon medical technology was looked for, i.e. other ways of understanding the phenomenon to ensure that no aspect was overlooked (Figure 1).
- The sixth step was the internal relations between the different categories investigated and a structure in the outcome space was created.
- In the seventh and last step, each category of descriptions were assigned a metaphor.
<table>
<thead>
<tr>
<th>Participants</th>
<th>Experience of medical devices</th>
<th>Number of medical devices</th>
<th>The restricted patient</th>
<th>The adjustable patient</th>
<th>The masterful patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>-5 months</td>
<td>3</td>
<td>+</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Male</td>
<td>-5 months</td>
<td>3</td>
<td>+</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>-5 months</td>
<td>1</td>
<td>+</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>-5 months</td>
<td>2</td>
<td></td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Male</td>
<td>6-11 months</td>
<td>2</td>
<td></td>
<td>++</td>
<td></td>
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<tr>
<td>Male</td>
<td>6-11 months</td>
<td>1</td>
<td>++</td>
<td>+</td>
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<tr>
<td>Male</td>
<td>≥12 months</td>
<td>3</td>
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<td>+</td>
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</tr>
<tr>
<td>Female</td>
<td>-5 months</td>
<td>2</td>
<td>+</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Female</td>
<td>-5 months</td>
<td>2</td>
<td>+</td>
<td>++</td>
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<tr>
<td>Female</td>
<td>-5 months</td>
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<td>Female</td>
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<td>1</td>
<td>+</td>
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<td>Female</td>
<td>≥12 months</td>
<td>1</td>
<td>+</td>
<td>+</td>
<td>++</td>
</tr>
</tbody>
</table>

Figure 1. Dominating (+++) and non-dominating (+) ways of understanding how 15 patients in palliative homecare experience their medical technology. Figures in brackets: Duration of experiences of medical technology (months), and number of medical devices.
Ethical considerations

The study was approved by the Regional Ethics Committee for Human Research at Linkoping University, Sweden. Permission was obtained from the operation managers to question the patients about participation in the study. Informed consent and voluntary participation were obtained from the participants during the phone call while planning the interview, and also with a written consent when the interview took place. There were patients who because of lack of strength had difficulties to conduct the interview, and thus it was important to be sensitive and not unnecessarily prolong the interview.

Results

Three description categories representing patients’ ways of understanding medical technology in palliative home care emerged in the analysis. A metaphor was then assigned to each of them. The three categories were: understanding medical technology as a masterful patient, as an adjustable patient, and as a restricted patient.

The masterful patient

The masterful patient desired to personally or together with his/her next-of-kin take responsibility for the medical technology and to participate in the care, by having knowledge of its management and function in order to assist if any problems arose. The patient and the next-of-kin ensured that drugs were at home, recorded drug doses of pain pumps, controlled settings and corrected medical devices that did not function or alarm. When they were familiar with their medical devices it became easier for the personnel, who did not have to make additional home visits in case of malfunctions. ‘I’m the one who uses it. Actually, it’s better that I can than anyone else...for if something happens, I can fix it myself, so we avoid calling them for a triviality that takes two minutes to fix’. If personnel were unsure how the medical devices were handled, the patient could instead help them, which he/she regarded as a natural task. The masterful patient moderated the medical technology so it would fit his/her intended plans for the day. The patient, who could be free from the oxygen treatment a few hours a day, disconnected it before he/she went out, and the patient with nutrition pump or drip was able to rest during the treatment and afterwards have the energy to participate in various activities. The patient with difficulty eating received regular drip which increased his/her strength. An effective pain relief implied more energy and strength to participate in daily activities, which he/she utilized by being out as much as possible. ‘It is a question of quality of life...when I got the
pump. I got a totally different quality of life...I could follow along and have energy to do things in a different way'. Oxygen cylinders placed on a walker or wheelchair worked great for outdoor use. Newer, convenient nutrition pumps and pain pumps were placed in a backpack for a trip. The patient who dosed his/her own pain relief experienced freedom and independence. ‘I have been able to adjust it by myself when I need additional doses, so there's no one who determines it, just me’.. Useful information from firemen and knowledge of the medical technology increased the patient’s freedom and possibilities. ‘If I go out somewhere in a café or so, there must of course be no lit candles in the vicinity... just where you sit, it does not need exist or a distance from, but then there is no danger if the other tables have it, then it doesn’t matter (oxygen cylinder). The masterful patient desired impact on the medical devices and had comments on their availability and design and hoped that his/her comments would be useful to other patients. He/she desired better connections to the medical devices that did not dislodge so easily and more user friendly pain pumps, which were considered to be heavy and bulky. The patient also thought it was a waste when large quantities of drugs in the cassettes of the pain pumps were discarded because of expiration dates, and they therefore requested smaller cassette sizes. In general the patient was more satisfied with the pain pump, which resulted in more consistent pain relief and less fatigue than tablets and hoped that more patients would be able to try it.

The adjustable patient

The adjustable patient adapted his/her life to the medical technology, organizing and planning the day according to it. The patient bought clothes or bags that hid the medical devices or tried to find own solutions to minimize their impact on his/her life. Gradually the patient got used to the medical devices and they became a necessary part of life and no longer an embarrassment. ‘Yes, it does not really affect me at all, it is very easy to accept, and I do not feel sick of it and it works perfectly’. The adjustable patient accepted the medical technology and realized its necessity for him/her to function and understood that no other options were available. The patient’s acceptance of the medical technology was linked to his/her attitude to life; living in the present and avoiding thoughts about the future. The adjustable patient was satisfied with the medical technology that gave him/her relief and security. The patient relied on the attentive personnel's skills and was content with the service and support he/she received. When needing help, or if medical technology failed, he/she could simply call for the personnel, which meant safety. ‘They come and I have their direct number, even if they are out they will reply and try to get here as fast as they can...that is the support, you know they are there’. The adjustable patient relied on the medical devices’ reliability and was not worried about their
security. Safety for the patient meant to feel safe with the medical technology, such as an opportunity to get additional doses if necessary at pain penetration, or having some form of backup if the medical technology defaulted. The medical technology was also an opportunity for him/her to be cared for at home. ‘Oxygen, it means that I can be at home... and it’s wonderful to come home and to be here’.

The restricted patient

The restricted patient was daily reminded of the medical technology which obstructed them during indoor and outdoor activities. The patient’s night sleep was disrupted, because of concern about dislodging tubes or catheters. The patient was restricted, not being able to drive or use public transport because of the medical technology. ‘It’s frankly shit, that I cannot move freely as I want. If I think, for example, about a bus ride; I cannot follow along, because I must not’. Medical technology restricted the patient when it created dependency due to its necessity for the patient with difficulties to swallow, but the restrictions were also related to lack of drugs when needles of pain pumps were dislodged and caused withdrawal symptoms. ‘At one point, this pump came loose, it resulted in that I did not get the morphine dose that I should have. I did not understand it, I was just bad, and I was very poor, with sweating, chills and nausea’.

Other side effects caused by the drugs or their administration were infections or bumps at the needles’ insertion points. Personnel therefore had to modify or change ways to administer the medicines. Medical technology limited the patient’s life as he/she was busy several times a day with home visits by personnel, who connected and disconnected drips. ‘Last Sunday, we went out skating, we were a group...just when we were grilling hot dogs, I had to go home, because I was supposed to have antibiotic’. When the patient intended to go somewhere, careful planning and organizing together with the personnel was required, and if the plans were changed, the patient felt awkward. The patient was also restricted in relations to friends, because he/she did not want to bring the medical devices when visiting them or was concerned about the bad odor caused by gastro tubes. ‘I cannot go to a party or such; and visit friends...I don't do that...I don't want to’. When the patient lacked information about why he/she required the medical technology or knowledge of its function, this caused worry and restrictions in the life.

Outcome space

The outcome space of the study consisted of the patients’ three ways of understanding medical technology in palliative home care and the internal relations between them. There
was a structural and overlapping relation between the understandings of the masterful patient, the adjustable patient and the restricted patient. Patients could express different ways of understanding at the same time, although one of them was more dominant, depending on how they could accept and handle the situation. The masterful patient took command of the technology and did not let the technology take control over his/her life. The adjustable patient accepted the technology and tried to find solutions to minimize its impact on his/her life. The restricted patient was mastered by the technology and subsumed his/her life after it. The patient transferred between the different ways of understanding partly because of his/her condition, but also depending on what kind of information and support he/she received, which either created security or undermined it. The patient was able to move from the restricted to the adjustable or masterful way of understanding if he/she felt safe and became accustomed to the medical devices, changed to another type of medical device or temporarily removed it. This movement also occurred in both directions, when the masterful patient was transferred to be the restricted patient, due to a failing health. The movement from a restricted patient through an adjustable patient to a masterful patient was related to a movement from dependence on to independence of support and assistance with the medical technology from the personnel (Figure 2).

Figure 1. The outcome space illustrated the relationship between the three ways of understanding medical technology in palliative home care.
Rigour

For scrutinizing a qualitative study, the four concepts *credibility, dependability, confirmability* and *transferability* are useful.\textsuperscript{23} *Credibility* refers to how data are obtained and interpreted and was strengthened by use of the semi-structured interview guide, which guaranteed that the same overall questions were posed to all participants. Palliative patients are a fragile and vulnerable group whose medical condition can change in a few hours,\textsuperscript{24} and it was therefore important to be sensitive to the patients' strength and capacity to participate in the interview. Doubts may arise whether it is ethical to do research on this vulnerable group. However, there are several studies that emphasize the importance of research on these patients.\textsuperscript{25-27} The main author’s familiarization with the subject and co-authors extensive knowledge both in methodology as well as in this subject strengthened the credibility. *Dependability* refers to trustworthiness and the stability of data over time and the authors’ consistency in data analysis. The analyses were carried out in cooperation with the co-authors who, during the analysis process, discussed and reflected on the constituted categories and then agreed on the final outcome. *Confirmability* is the value of the data and can be compared to objectivity. To get confirmability, quotations were included in the result thus insuring the trustworthiness. The main author’s own profession as a district nurse and work with patients in palliative care could possibly have affected the outcome of the study. *Transferability* refers to the generalizability and implies that choice of method, selection and data collection are appropriate to identify and study the phenomenon referred to. According to Marton and Booth,\textsuperscript{20} a strategic selection is preferred in phenomenographic research. The sample was composed of patients who were eligible during the period of data collection and therefore can be described as an eligible sample, but still considered to be sufficiently varied regarding sex, age and education. The help of district nurses in the selection of patients might be a disadvantage due to their ability to filter out those who might have divergent descriptions of the care. On the other hand the district nurses know the patients with medical devices in home care and this is presumably the best way to contact them. It is reasonable to assume that the findings of this study can be transferred to other non-palliative patients with medical technology in home care.
Discussion

The result of this study showed three ways of understanding medical technology in palliative home care; as a masterful patient, as an adjustable patient and as a restricted patient. The masterful patient was characterized by being sufficiently informed and knowledgeable about the medical devices and how to handle them. Knowledge about the medical devices created control of the situation, which implied security and independence. To be informed and involved in one's care is highly valued in several studies, and must be encouraged and supported by the personnel. Participation in their own care provides patients with comprehensibility and manageability in their daily lives, which also is confirmed by patients and next-of-kin in other studies, . However, participation in one’s care must be on the patients’ own terms and based on their free will to participate as well as on how much they can manage and have strength to do.

Despite difficulties, the masterful patient maintained freedom in his/her life and the possibility to participate in social activities, which was facilitated when the medical devices were suitable for indoor and outdoor use. Users of medical devices highly value products that are usable, comfortable and well-designed and wish that manufacturers would pay attention to their suggestions for improvements, which also are confirmed in this study. The pain pump was considered a reliever, although it was heavy and clumsy. Patients’ access to pain pumps when needed can differ depending on where the patients lives and health care providers' options to offer one, which is not care on equal terms. The masterful patient was secure with the medical technology and had no problem with teaching the personnel, who sometimes lacked knowledge about the handling of the devices. Trust in personnel’s competence differs between patients and their next-of-kin. According to Munck et al, next-of-kin are doubtful about the personnel’s skills regarding the patients' medical devices. District nurses consider that patients, who are informed and knowledgeable about their own medical devices, can lead to uncertainty among district nurses if they themselves are unsure how to handle them. It is therefore important to know what consequences personnel’s own uncertainty can cause patients and their next-of-kin, i.e. a masterful patient can be restricted due to lack of support to independency.

The most common way to understand medical technology was as an adjustable patient, who was satisfied with the care and the personnel’s support. The need for support in connection with medical technology is confirmed by other studies. The adjustable patient learned to
live with the medical devices, which gave symptom relief and viability, and the patient adjusted daily life to them. Studies describe patients’ adaption and dependence on their medical devices, but also their positive experiences of them. The adjustable patient felt secure with the medical technology and did not worry about it. Patients’ confidence in medical technology is important for them to feel safe at home, and personnel must therefore be mindful not to destroy this trust by showing ignorance in the handling of the medical technology. Patients’ self-esteem and identity in palliative care is affected and changed depending on different losses caused by their disease as well as by how they are treated by others during their illness. Being connected to a medical device can further alter a patient’s self-image and be an extra strain. It is therefore important that this additional concern gives patients an overall positive experience, which can be improved by personnel’s knowledge about the patients’ understanding of the medical technology.

The adjustable patient was pleased to be cared for at home and to get all help when needed, simply by calling for personnel’s assistance. According to Orrevall et al., home parenteral nutrition means security for the palliative patients as they get more home visits by palliative care teams. These teams enable an improvement in the quality of palliative care.

The restricted patient was mostly limited by the medical technology and predominantly had difficulties to accept the situation and the restrictions the medical devices entailed. The patients who had the strength and wanted to be outdoors were limited in their freedom of movement, due to regular treatments or prohibition to use public transportation with the oxygen cylinder, which is also confirmed by Ring and Danielson. The patient’s dependency on personnel’s assistance can be avoided if the patient is given more knowledge and information about how to handle the devices or sometimes even be allowed to perform own treatments. To increase the patient’s participation in the care, continuous and useful information about the function of the medical devices, as well as what to do if something fails, is needed. The patients also need information about how to use the medical technology in public places, thus reducing their concerns and allowing them more control over their situation. Patients obtain valuable knowledge from literature, Internet and other persons using the same type of medical devices. The restricted patient did not want to bring the medical devices when visiting friends, which is confirmed by patients with oxygen treatments and nasal tubes, who avoided visiting friends or going to restaurants. When patients cannot meet their nutritional needs in a normal way their social relations are affected.
Depending on the patient’s health condition, the support and the medical technology’s impact on his/her daily life, a transfer between the different ways of understanding occurred. This was also related to the patient’s dependence or independence on personnel’s assistance. The masterful patient was less dependent on the personnel and wished to take care of him/herself. Notable was that only female patients had this dominating way of understanding the phenomenon, which may imply that women are less willing to become dependent on others, trying to take care of themselves.

The adjustable patient did not endeavor for independence, but was satisfied with the support from the palliative care teams. The adjustable patient accepted the situation and tried to live in the present, avoiding thoughts about tomorrow. According to Benzein et al., patients in palliative care refuse to establish long-term goals. They desire to live in the present with their loved ones, and strive for normality by maintaining roles and continuing with their daily tasks. As nurses, it is important to support these patients and inspire hope in their daily lives. How long the patients had had their medical technology affected the way they understood it. The adjustable patient had more often short experience of the medical devices, while the restricted or the masterful patient more often had an experience of more than six months. However, the number of medical devices had no noticeable impact on what way the patient understood the technology. The restricted patient’s health condition and/or trouble with the medical devices created dependence on the personnel, which embarrassed them and interfered in with their lives. Self-confidence was needed by the district nurses to convey security to patients who dare to take responsibility for their own medical devices and thus become independent.

**Conclusions**

The results of this study showed three ways of understanding medical technology in palliative home care; as a masterful patient, as an adjustable patient and as a restricted patient. The masterful patient was mostly independent of personnel’s home visits and assistance with the medical devices and had control over the technology. The adjustable patient accepted the medical technology and adjusted his/her life to it. These patients felt safe with the technology and the personnel’s support. The restricted patient was instead mastered by the technology and dependent on assistance from the personnel, which limited his/her freedom of movement. Patients exhibited various ways of understanding and could transfer between them, although one way of understanding was more dominant. Treatments using medical technology
provided more energy and strength, which facilitated patients' participation in social activities. Continuous information about the technology and support from personnel when needed allowed a restricted and dependent patient to progress through an adjustable patient to a masterful independent patient, while lack of information and support gave the opposite effect.

Implications

The patients in palliative home care wanted medical devices to be more user friendly to facilitate their daily life. Improvements are needed regarding pain pumps that are too big and heavy for patients. For comparison, in Sweden there is a big difference in size between pain pumps and insulin pumps. Useful patient-tailored information about different types of medical devices is also needed and can be formulated in close cooperation with the patients. Support for patients in palliative home care is necessary, but they must also feel comfortable being at home with their medical devices. Knowing that support is available leads to security and increased independence.

Acknowledgements

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