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FROM NOVICE TOWARDS SELF-CARE EXPERT

**Studies of self-care among persons using
advanced medical technology at home**

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No man is an island

John Donne (1624)

From Devotions upon emergent occasions; Meditation XVII

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ABSTRACT

The use of advanced medical technology at home has increased in most industrialized countries. The overall aim of this thesis was to develop knowledge of self-care and transition and issues that influence daily life and health among persons using advanced medical technology at home.

Three qualitative studies were performed to describe the structure of self-care (I) and elucidate meanings of health-illness transition experiences among persons using long-term oxygen, or a ventilator, or performing blood or peritoneal dialysis (II), and to gain a deeper understanding of the meaning of living with an adult family member in this context (III). Ten interviews with adult patients (I-II) and ten with adult next of kin (III) in this context were performed and analysed with descriptive phenomenological (I), phenomenological hermeneutical (II) and hermeneutical (III) methods. A quantitative, descriptive, comparative, cross-sectional design was used to describe and find factors that influence self-care agency and perceived health in a larger group of persons (180 patients) using the enumerated types of advanced medical technology at home (IV).

In the results, (I) self-care among persons using long-term oxygen, a ventilator, or equipment for blood or peritoneal dialysis at home was described at a generic level, independent of the specific type of technology used. The general description of self-care in this context involved prerequisites for, activities for and consequences of self-care; (II) the health-illness transition among adult persons in this context was interpreted as contentment at being part of the active and conscious process towards transcending into a new state of living, in which the individual and the technology were in tune. The successful and healthy transition experience was characterized by human growth and becoming; (III) living with a family member who is using advanced medical technology at home was interpreted as meaning rhythmical patterns of being closely connected to but also separated from him or her, and of sorrow versus reconciliation. Dependence on others was reflected in a need for support from the healthcare professionals and significant others; (IV) health-related and technology-related variables in daily life were rated as satisfactory to quite a high extent, but participants using long-term oxygen perceived their health as significantly lower compared to the other technology groups. Further, a significant difference in sense of coherence was found between users of long-term oxygen and peritoneal dialysis. Factors that contributed to self-care agency and sense of coherence were found.

In conclusion, self-care in a high-tech home context means more than simply mastering the technology. With the goal of maintaining an active, social life, the health-illness transition involves a learning process of accepting and integrating the technology into daily life. With knowledge and support, patients and next of kin are able to assume substantial responsibility for self-care/dependent-care. Daily life seems to be manageable for patients using this kind of technology at home.

Key words: dependent-care, health, hermeneutics, home dialysis, home ventilator, long-term oxygen, next of kin, phenomenology, transition

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INTRODUCTION

The use of advanced medical technology at home has increased in most industrialized countries. An aging population with chronic, often lifestyle-related diseases like chronic obstructive pulmonary disease, obesity, diabetes or hypertension leading to kidney disease, increases the need for long-term oxygen (Gustafson *et al.* 2009), ventilators (Janssens *et al.* 2003; Midgren 2007) and dialysis (Sinclair 2008). Other examples of advanced medical technologies frequently used at home include intravenous cannulae for drug- or nutritional treatment (Lehoux 2004), and tubes for enteral feeding (Russel 2001). The present shift of patients and technology from hospitals to their homes is also caused by health reforms aimed at reducing the length of hospital stays (Arras 1995; McNeal 1996), together with improvements to medical technology, like ventilators, for use in the home (Janssens *et al.* 2003, Midgren 2007).

Some research expresses patients' contentment with the home technology situation. Studies on persons, e.g., performing blood dialysis (Ageborg *et al.* 2005; Polaschek 2005) or using a ventilator (Ballangrud *et al.* 2008) showed that self-care at home has the potential to enhance quality of life compared to hospital treatment. Ambivalence about the benefits and disadvantages of home technology from a patient's viewpoint is also reported, on the other hand. Restrictions in time and space have been found among persons performing blood dialysis (Polaschek 2003) and those using long-term oxygen at home (Ring & Danielson 1997), although the treatment was viewed as a benefit for the body. Persons using a home ventilator have described it as a life-giving force (Lindahl *et al.* 2005; Ingadóttir & Jonsdottir 2006), but also as being representative of lost dimensions in life (Lindahl *et al.* 2005), and even as a meaningless exertion (Ingadóttir & Jonsdottir 2006). In research focusing on the user-friendliness of long-term oxygen, peritoneal dialysis, parenteral nutrition and intravenous therapy (Lehoux 2004, Lehoux *et al.* 2004), patients have found the technology to be unfriendly to use and to have a negative influence on their home environment.

The decision to bring the technology home may also impact the family. Previous research on next of kin in this context gives a picture of vulnerability. The technology may, for example, be initiated at home without fully exploring the next of kin's opinions (Wellard & Street 1999; Luk 2002; Ingadóttir & Jonsdottir 2006). Some next of kin felt socially isolated and burdened by the caring responsibility (Wellard & Street 1998; Luk 2002; Takata *et al.* 2008). Besides caregiving tasks like meal preparation, transportation and managing supplies for technical equipment, next of kin have also given rich descriptions of caregiving activities requiring sophisticated powers of observation, decision making, knowledge and skills (Beanlands *et al.* 2005). Although the treatment entailed by technology at home can be stressful and affect the whole family, next of kin would still recommend it to others, because most of the time it is all right (Fleming Courts 2000). Positive experiences of the family being drawn closer together are also reported from a next of kin perspective (Luk 2002). The societal reliance on next of kin requires that further research also focus on their situation, in order to better understand and plan for their specific needs and caring tasks.

Persons using medical technology at home are performing what Orem (2001) describes as partly compensatory self-care. This means activities supported by others – next of kin and professional caregivers – in order to maintain, restore and improve health and well-being. Long-term changes in health and illness, however, create a process of transition, linked to shifts in self-care ability (Chick & Meleis 1986; Meleis 2010). A transition is characterized by an unstable passage between two more stable periods (Chick & Meleis 1986; Bridges 2004), for example from before the need for home technology until the situation with it is mastered. Thus, the safe, correct use of advanced medical technology and its integration into daily life activities involves transitions. Although facilitating transitions is highlighted as the focus in the discipline of nursing (Meleis *et al.* 2000; Meleis 2010), no previous study focusing on the meaning of adults' health-illness transition in this high-tech self-care context has been found.

Benner has described the differences in clinical performance among nurses. This involves a development process from being extremely limited, inflexible and dependent on context-free rules as a beginner, to perceiving situations in their entirety rather than in terms of aspects, and modifying the plan to fit the circumstances. Further, being a highly experienced nurse means having an intuitive grasp of the situation, and acting beyond the dependency on analytical principles and rules (Benner 1984). A corresponding self-care development might be expected among patients.

The home technology area has mainly been described with a focus on specific types of technology. But, as indicated, there are similarities to experiences of this context at a generic, overriding level, independent of the specific type of technology used. This thesis focuses on self-care, transitions and health among adult persons using advanced medical technology at home, and the meaning of living with a person in this situation. Such knowledge has the potential to provide a deeper understanding of their situation, and to contribute to generic clinical implications for caregivers in the support of patients and next of kin in this context.

AIMS

The overall aim of the thesis was to develop knowledge of self-care and transition and issues that influence daily life and health among adult persons using advanced medical technology at home. The specific aims were:

- to describe self-care among persons using advanced medical technology at home (I, IV),
- to describe factors that influence self-care and perceived health in a group of persons using advanced medical technology at home (IV),
- to elucidate meanings of health-illness transition experiences among persons using advanced medical technology at home (II), and
- to gain a deeper understanding of the meaning of living with an adult family member using advanced medical technology at home (III).

FRAMEWORK OF THE THESIS

In need of advanced medical technology at home

Technology is something more than just machinery. The concept of technology involves knowledge for dealing with the mechanical arts and sciences, technical know-how, machinery and equipment. Technology concerns the application of scientific knowledge for practical purposes, i.e., the technological process, method or technique (Oxford English Dictionary on line). In this sense, for example, the handling of an intravenous cannula or dialyser is technology, as is the cannula or dialyser itself. Heidegger (1993) supports the definition above, in claiming that technology is both a means to an end and a human activity, both belonging together. However, the essence of technology is nothing technological! It is ultimately a way of revealing the totality of beings, prior to and not as a consequence of the Scientific Revolution. Further, the essence of technology confronts the supreme danger of revealing, and means an attack on both nature and man. The essence involves *Ge-stell*, the furious framed, or duped, energy of nature (Heidegger 1993).

The WHO (2010a) states that medical technology is essential for the safe and effective diagnosis and treatment of illness and disease, in order to improve quality of life. The WHO has focused on the development and safe management of health technology, ranging from single-use devices to the most advanced medical equipment. Advanced medical technology requires special knowledge and skills to be managed safely (Arras 1995; Neal & Guillet 2004) and it has usually been handled by professional caregivers.

Self-care for breathing difficulties

Long-term oxygen treatment

Long-term oxygen therapy (LTOT) aims to correct arterial hypoxemia and prevent or reverse the pathophysiological changes and associated signs and symptoms of hypoxemia. Alleviation of dyspnea and reduction of negative impacts of hypoxemia on the internal organs (Gustafson *et al.* 2009), mastery and self-control over illness by relieving symptoms, thus enabling daily life activities to continue (Cornford 2000) are benefits of LTOT. For persons having severe hypoxia caused by chronic obstructive pulmonary disease (COPD), LTOT may double survival time (NOTT 1980 in Gustafson *et al.* 2009). In 2009, the prevalence of home LTOT users in Sweden was 26/100 000 inhabitants (Swedevox 2010), excluding patients in palliative care.

COPD - patients using oxygen are advised to use it for at least 16 hours a day but preferably 24 hours, even if they have no permanent dyspnea (Swedevox 2010). The selection of an oxygen system should be tailored to the individual's physiological needs and lifestyle. Three options for home oxygen therapy are available: 1) Compressed gas, provided in metal cylinders of various sizes, containing 100% oxygen under high pressure. A flowmeter allows the user to set the desired flow rate. When full, even portable cylinders may be heavy and awkward to handle, requiring a wheeled carrier for outdoor use. Inside the home, connecting tubing may offer some mobility; 2) A liquid oxygen system consisting of a steel container, similar to a thermos. It holds oxygen cooled to its liquid state, which allows more oxygen to occupy a smaller volume than when it is in its gaseous state. A smaller, portable oxygen unit

can be filled from the larger reservoir and carried as a shoulder bag, backpack or wheeled luggage cart. Users must be careful when filling the portable unit, due to the risk of thermal burns from the supercooled oxygen; 3) An electrical concentrator separating oxygen from carbon dioxide and nitrogen, as well as water vapour from room air, offering a cost-efficient delivery system for patients who need low-flow continuous oxygen. The oxygen is collected and delivered to the user through a flowmeter. Unlike cylinders and liquid oxygen, concentrators do not provide 100% pure oxygen. A backup system of, e.g., compressed gas systems is required in case of power failure, and so is a portable oxygen system for outdoor use. For all three oxygen options, a nasal cannula with extension tubing up to 15 meters will maintain an accurate flow rate (Findeisen 2001).

Oxygen therapy is a prescribed medication, and a too-high supply can be injurious (Francis 2006). Oxygen supports combustion, and fire will burn faster and be hotter in an oxygen-enriched environment, which is why it should not be used in the presence of combustible materials (such as oil, gasoline, lotion or aerosol sprays). Appliances capable of creating a spark, e.g. hair dryers or electric razors, are also to be avoided, and liquid or compressed oxygen must be stored away from heat sources and open flame (Findeisen 2001).

Ventilator treatment

The number of patients using a ventilator at home has increased, due to an aging population (Midgren 2007) and an increase in long-term ventilation therapy for, e.g., patients with COPD or obesity-hypoventilation syndrome, together with improvements to ventilators for use in the home in terms of user-friendliness and economic aspects (Janssens *et al.* 2003; Midgren 2007). The introduction of non-invasive ventilation via a mask and the recognition that more patient groups could benefit have stimulated and expanded home ventilator use during the past two decades (Lloyd-Owen *et al.* 2005). For persons suffering from obstructive sleep apnoea, neuromuscular diseases, obesitas or post-polio, the problem is most often alveolar hypoventilation due to an inability to heave the chest, mainly in a lying position like during sleep. Thus, an increased number of persons get intermittent breathing support, i.e., during periods of the day/night, from a home mechanical ventilator (HMV) (Phillips 2005; Swedevox 2008). The exact rate of HMV users is unknown, as many countries have not established a register. In 2005, the estimated prevalence in all European countries was calculated at 6.6/100 000 inhabitants, with the lowest figures in Poland (0.1/100 000) and the highest in France (17/100 000) (Lloyd-Owen *et al.* 2005). However, in Sweden 19/100 000 inhabitants were using a HMV in 2009 (Swedevox 2010), and the corresponding number in Norway was 20/100 000 inhabitants (Tollefsen 2009).

Non-invasive ventilation, i.e., without an endotracheal or tracheostomy tube, is the most common method for assisting patients' breathing at home. The patient usually wears an adjustable headset for attaching a tightly fitting nasal or facial mask, which is attached via wide tubing to a portable ventilator, which produces a rapid flow of air or oxygen that passes through the tubing. The effect of the quickly flowing gas passing through a small valve creates a back pressure that is transmitted to the patient's lungs, opening the airways and allowing gas to enter. Additional equipment may be a battery pack for travel or electricity failure, and a heated humidification unit (Phillips 2005).

The number of patients with a ventilator attached to a tracheostomy cannula is hard to determine. In Norway, however, this number accounts for eight percent of the HMV users (Tollefsen 2009). This type of ventilator connection requires a ventilator that sounds an alarm for cannula stoppage (Swedevox 2010) and a tracheostomy vacuum pump with catheters for suctioning phlegm. Treatment with invasive technology demands rigorous aseptic procedures in order to avoid infection (Morton *et al.* 2005; Francis 2006), which is why the tracheostomy has to be cleaned and bandaged daily, for example (Woodrow 2000).

Self-care for decreased kidney functioning

Kidney replacement therapy

When a patient is on the waiting list for a kidney transplant, or when such an operation is not suitable, haemodialysis (HD) or peritoneal dialysis (PD) provides a long-term alternative when kidney functioning has seriously decreased. Kidney replacement therapy involves a regular dialysis program and restrictions for dietary and fluid intake. Those who perform self-care involving PD or HD at home may have greater control over and more responsibility for their therapy. They trust in their own competence for self-care, and learn to make independent modifications to the therapeutic prescription within the limits they know are reasonable. This may help them maintain their normal lifestyle (Polaschek 2006). In New Zealand, the prevalence of home-based and self-care dialysis is highest in the world (MacGregor *et al.* 2006; Ashton & Marshall 2007), followed by Australia (MacGregor *et al.* 2006). In Sweden, 100 of 2700 patients on HD performed home HD, and 850 performed PD in 2008 (SNR/SSR 2009).

Haemodialysis

Haemodialysis is a process of cleaning the circulating blood through a dialyser, i.e., an external filtering device. HD is mainly performed at outpatient dialysis clinics, offering support from nurses and other healthcare providers. Home HD is an option for a small group of more stable and independent patients (Dor *et al.* 2007). Since the first home HD was performed in Japan in 1961, only a year after HD was introduced, home HD has been shown to increase patient survival compared to PD or clinic-based HD, to be cheaper than clinic-based HD, and to allow patients to become better rehabilitated (MacGregor *et al.* 2006). The dialysis treatment may last three to five hours (Baillod 1995). By performing HD at home, patients are able to dialyse for a shorter time but more frequently, which according to early evidence may improve survival (Blagg *et al.* 2005).

Some sort of vascular access connected to the dialysis machine is required; an arteriovenous fistula or graft requiring the patient to insert a needle to access blood flow in each dialysis, or a permanent plastic catheter extending outside the body (Morton *et al.* 2005). Inserting large-bore needles into the artificially dilated vein on the forearm is considered the patient's most stressful and difficult skill (Baillod 1995). As extending catheters are foreign bodies and are open to the environment they are prone to infection, and thus require rigorous aseptic handling. Treatment with HD risks, besides infections, imbalances in body fluids and electrolytes, which is why patients are required to perform daily observations of blood pressure and weight (Baillod 1995; Morton *et al.* 2005).

Peritoneal dialysis

In treatment with PD, the filtration is performed within the patient's body. The abdomen is filled with a fluid, allowing toxins to be filtered across the peritoneal membrane which lines the abdomen. The patient may either exchange the fluid via an abdominal catheter about every fourth to sixth hour, or connect the catheter and fluids to a machine, a cycler, that pumps the fluids in and out of the abdomen several times at night. Toxins are removed each time the fluid is changed (Heimbürger & Rippe 2008), and patients are able to remove more fluid by changing the dialysis fluid to higher osmotic strengths (Baillod 1995).

The practical skill involved in PD is, besides daily observations of blood pressure and weight, performing exchanges of peritoneal fluid. Without decontamination, which would lead to peritonitis, the patient has to connect the bag/s of dialysis fluid to the abdominal catheter via a plastic tube. Whilst the technical skills needed for this are less complex, the needs for indefinite, extremely high standards of sterility are far in excess of those entailed by HD (Baillod 1995).

Meanings of health

Although health is considered a vital concept in nursing and medicine, there are different opinions on its meaning. The World Health Organization (WHO 1986) defines health as a complete physical, psychological, social and spiritual sense of well-being. However, this maximal stance on health may be hard for most persons to reach, besides in passing moments. The accepted meaning of health has not remained static. In Greek, *health* is 'hygieia', which means to have a good life, and Hippocrates (460-370 B.C.) regarded health and disease as an entirety, whereby the body is in interaction with the environment. Galenos (129-99 B.C.) supported this humanistic paradigm, defining health as a condition in which we neither suffer nor are prevented from performing the functions of daily life (Medin & Alexandersson 2000).

A paradigm change occurs when the existing knowledge and ways of viewing the world do not seem to be relevant for explaining a phenomenon, causing them to be rejected and replaced with new ones (Kuhn 1996). In the 17th century, such a paradigm change may have occurred with regard to health. At that time technical innovations, e.g. the microscope, led to a natural scientific view of the body, whereby only what could be observed was considered to exist (Medin & Alexandersson 2000). This biological-statistical perspective, which defines health as the absence of disease, is today represented by the ideas of Christopher Boorse. Biological functioning and statistical normality are vital elements in this minimalistic standpoint on health, whereas disease is internal conditions that reduce the physiological, biological function beneath typical human levels (Boorse 1977). In this view, for example, a person dependent on dialysis is in ill health regardless of his/her own opinion of health.

Scandinavian health-philosophers Lennart Nordenfelt (2000) and Ingmar Pörn (1984; 1993; 1995) question and challenge the biological-statistical health perspective. They take a holistic stance on health, viewing man as an active agent in social situations. Disease impacts one's action ability, but does not constitute ill health. Health is partly characterized by one's feeling of well-being and partly by one's action ability or disability. Nordenfelt states that a person is

completely healthy if and only if he/she is in a bodily and mental state such that he/she has the ability, given accepted standard circumstances, to realize all his/her vital goals, i.e., goals whose realization is necessary for her long-term minimal happiness. An action also has as a prerequisite an intention to act. For instance, a dejected person's intention ability may inhibit her action ability. Further, one's daily condition may vary and can occasionally impact one's action ability (Nordenfelt 2000).

Pörn's (1984) theory of equilibrium is in line with Nordenfelt's (2000). However, Pörn emphasizes the concept repertoire, i.e. those abilities the person's physical and psychological conditions permit in form of knowledge and skills, and which are necessary to reach the goal or fulfil the plan. Further, it involves an inquiry system and a decision implementation stage (Pörn, 1984; 1993). The cognitive repertoire concerns one's ability to obtain and store information. The ability to imagine different alternatives for actions, survey the consequences, and judge the most desirable act constitutes the repertoire of decisions. Internal factors in the environment characterize functions of senses, energy and mobility, and external factors are of a physical, social or cultural nature (Pörn, 1995). The goals, repertoire and environment of human beings must be in equilibrium for health and adaptedness; i.e., the goal profile must be realistic, the repertoire adequate and the environment appropriate, all conditions in relation to each other during the period concerned (Pörn, 1993; 1995). In Nordenfelt's (2000) and Pörn's (1984; 1993; 1995) holistic stance on health, the dialysis-dependent person would be in good health despite decreased physical capacity, given the ability to realize his/her vital goals.

German philosopher Hans-Georg Gadamer (2003) reflected on health as a mysterious phenomenon, in line with Nordenfelt and Pörn's holistic equilibrium approach. Being healthy is not about certain kinds of feelings; it is one's being-in-the-world and togetherness with others, in fulfilling one's tasks in joy. Health is a state of equilibrium, not to be measured by standard values of average experience, transferred to a specific person. Health is concealed and quiet, although it shows up in some sort of well-being, which makes us active in enterprising and discovering the world, while forgetting about ourselves (Gadamer 2003).

Like Gadamer, Israeli medical sociologist Aaron Antonovsky also viewed health as a mystery. His research concerned why some persons overcome hard strain while retaining their health, whereas others in similar circumstances become sick. According to Antonovsky (1987; 1993), one's power of resistance depends on the extent to which one experiences the following factors in life: 1) comprehensibility, i.e., the extent to which one perceives the world as structured, predictable and explicable; 2) manageability, the extent to which one believes that resources to meet demands in daily life are available; and 3) meaningfulness, the extent to which one views those demands as challenges worthy of engagement. Together, the factors comprehensibility, manageability and meaningfulness constitute the concept of sense of coherence (SOC), which can be measured with the Sense Of Coherence scale (Antonovsky 1987). The SOC-scale is used worldwide to measure and predict prerequisites for health (Antonovsky 1993). Given that the dialysis-dependent person finds daily life with technology comprehensible, manageable and meaningful, according to Antonovsky (1987; 1993) he/she would have the prerequisites for being in good health. This is in line with Nordenfelt's (2000)

and Pörn's (1984; 1993; 1995) humanistic, holistic stance on health. Such a humanistic, holistic stance on health is applied in this thesis.

Self-care

A reborn phenomenon

Like perceptions of health, those concerning the locus of responsibility for healthcare have shifted through the ages. These perceptions are closely tied to the dominant philosophy of a society in a given period, and to the structure of the medical system of that society. Self-care and care by indigenous healers, e.g. women cultivating healing herbs and exchanging the secrets of their uses, thus acting as pharmacists, nurses and counsellors, have been the norm throughout Western history. Only the elite have received care from formally trained physicians (Lipson & Steiger 1996).

In the 19th century, Florence Nightingale provided tools to both professional and informal caregivers in the form of professional advice on how to care for their patients and family members (Nightingale 1859). In North America, family medical guides during the same period strongly urged readers to seek professional care. In the early 20th century, advancements in medical technology led to dramatic breakthroughs and reduced the mortality rates from, e.g. certain epidemic diseases. These advances contributed to convincing many people that only a formally trained physician, performing a battery of tests, was qualified to determine whether or not a person was in health. As medical interventions came to be held in high regard, self-care was increasingly devalued. People were neither thought nor encouraged to evaluate their own health- status, or to care for themselves and their families. Further, the representatives of traditional Western medicine left people short in terms of learning how to live with a disease and its symptoms. A review of medical and nursing literature performed in 1975 showed that self-care was regarded as providing oneself with the care that should ideally be given by healthcare professionals (Lipson & Steiger 1996).

Today, as the population increases and ages, chronic disease will continue to require significant medical intervention, placing added stress and costs on already compromised healthcare systems. It is thus vital to include patients in their own care, and encourage them to take some responsibility for self-care (Simmons 2009). Written self-care guides, available on CD-ROM for example, have been shown to decrease office visits (Lipson & Steiger 1996). As stated before, a growing population with chronic disease also increases the need for self-care involving the use of advanced medical technology at home (Midgren 2007; Gustafson *et al.* 2009; Sinclair 2008).

However, shortages regarding patient safety have been found on a general level, when judging whether a certain medical intervention could be considered for self-care. The decision regarding self-care has not always been based on the patient's situation and capability. For that reason regulations focusing on the patient, next of kin and the cooperation between the patient, healthcare and social care have recently been established in Sweden (SOSFS 2009:6).

Orem's theory of self-care

In this thesis, Dorothea Orem's (2001) self-care deficit nursing theory has been applied. Orem pioneered nursing self-care theory (Lipson & Steiger 1996). Her main work, "Nursing: concepts of practice", continuously refined since its first edition in 1971, has been used by nursing students, teachers and clinical nurses, and has influenced nursing curricula in many countries (Orem 2001). An update of the state of the art and science has allowed 150 research articles and 34 dissertations (global, in English) closely related to Orem's self-care deficit nursing theory to be published only in the recent period of 1999-2007 (Biggs 2008).

According to Orem (2001), self-care is "action of mature and maturing persons who have the powers and who have developed or developing capabilities to use appropriate, reliable and valid measures regulate their own functioning and development in stable or changing environments. Self-care is the valid means to control or regulate internal and external factors that affect the smooth activity of a person's own functional and developing processes or contribute to a person's personal well-being" (p. 43). Briefly, the self-care deficit nursing theory involves how a person's self-care capabilities balance universal, developmental and health-deviation self-care requisites. Due to the individual's self-care agency, i.e., the complex, acquired capability to know and meet continuing requirements for deliberate actions to regulate one's functioning and development, any deficit of self-care is compensated for by nursing actions. These actions are based on a supportive-educative, partly or wholly compensatory, nursing system. Accordingly, self-care is performed in interaction with healthcare professionals. Early on, Orem anticipated that persons with major health-deviation self-care requisites and a need for specialized technologies would be cared for in their homes to a great extent (Orem 2001).

Self-care and health are connected: Health is a basic conditioning factor that affects one's demands and capacity for self-care, but is also the goal of self-care activities. Orem viewed health in terms of structural and functional wholeness and soundness, including psychological, interpersonal and social aspects of living (Orem 2001).

The self-care deficit nursing theory includes dependent-care agency, i.e., the continuing health-related personal regulatory care provided by responsible next of kin or close friends, the dependent-care agents. Human beings' potential to develop knowledge and skills, and to uphold the motivation for self-care and care for dependent family members, is stressed. The roles of the dependent-care agent are dual, in 1) a continuing self-care system to meet one's own self-care demands and to exercise and develop one's self-care abilities, and 2) a continuing dependent-care system of knowing and meeting the dependent's therapeutic self-care demand, in whole or part, and to exercise and develop one's dependent-care abilities (Orem 2001).

Dependent-care systems may, like nursing- systems (Orem 2001), be partly compensatory when the patient is able to perform some self-care measures, or supportive-educative when he/she meets the self-care requirements and continues to learn and develop self-care abilities, in regular interaction with nurses and other caregivers (Taylor *et al.* 2001). To meet patients'

self-care demands is to gain knowledge, and to exercise and develop one's dependent-care abilities (Orem 2001; Taylor *et al.* 2001).

Models that support the theory of dependent-care were identified by Taylor *et al.* (2001) in discussions with Orem. They all claimed, like Biggs (2008) later did, that this area needs to be developed further.

Transitions

Already in 1986, nursing researchers Norma Chick and Afaf Meleis stated that technological advances in medicine were subjecting persons to transitions that no one could have imagined just a few decades earlier. The concept of transitions had previously been used in an anthropology context, describing the rites of passage of certain societies - that is, ceremonies for special events like becoming an adolescent or getting married, in order to help the individuals to let go of their past life chapter and replace it with a new one. The rites of passage involved phases of separation, transition and incorporation (Van Genneep 1965 in Olsson & Ek 2002). In 1980, Bridges (2004) broadened transitions to involve different kinds of changes in daily life, related to work life and relationships. However, changes are situational and transitions psychological. It is one's reorientation and self-redefinition, rather than the special event, that constitute a transition (Bridges 2004; Kralik *et al.* 2006). All transitions are composed of a time span with an endpoint, a neutral "being in between" or "passage" zone characterized by confusion, disconnectedness and reorientation, and an ending with a new beginning of stability (Chick & Meleis 1986; Bridges 2004). The time span between ending and new beginning may vary from a short period to several months, or even years (Chick & Meleis 1986; Olsson & Ek 2002).

Long-term changes in health and illness create a process of transition, linked to shifts in self-care ability (Chick & Meleis 1986; Meleis 2010). Thus, transitions and self-care are related. The transition framework also supports self-care in that nurses work with individuals and families to facilitate movements towards a healthier state (Lipson & Steiger 1996). Since patients in transition tend to be vulnerable to risks that may affect their health, facilitating transitions is in focus in the discipline of nursing (Schumacher & Meleis 1994) and, according to Meleis and Trangenstein (1994), even the mission of nursing! In order to offer support it is essential that the nurse understands the transition process (Schumacher & Meleis 1994), which demands knowledge of general patterns of healthy transitions (Chick & Meleis 1986; Meleis & Trangenstein 1994; Meleis *et al.* 2000). Only a person who has experienced transition can describe it from the inside (Chick & Meleis 1986; Olsson & Ek 2002). Accordingly, research focusing on the meaning of transitions among persons using advanced medical technology at home is also required, in order to offer this patient group professional support.

The emerging middle-range nursing theory of transitions has been built gradually, based on continuous studies and reviews. In relation to nursing, four types of transition are identified: developmental, involving phases like becoming an adolescent, getting pregnant or entering menopause; situational, like widowhood or family caregiving; organizational, representing

political, economic or social environmental changes; and health-illness transitions (Schumacher & Meleis 1994). This thesis focuses on the health-illness transition. However, there are different types of transitions along the health-illness continuum, e.g. the process from being healthy to critically or chronically ill, recovering from disease, or going from hospital to outpatient and home care (Schumacher & Meleis 1994). Further, patterns of transitions include whether the patient is experiencing a single transition or multiple transitions (Meleis *et al.* 2000).

Essential interrelated properties of transition experiences, i.e. the nature of transitions, are identified as awareness, engagement, change and difference, time span and critical points and events. Personal conditions and community and societal conditions can facilitate or inhibit the transition process. Outcome indicators for a healthy transition, besides mastery of the new situation and fluid integrative identities, involve indicators of feeling connected, interacting, being situated, and developing confidence and coping. Nursing therapeutics direct facilitators and inhibitors as well as patterns of response (Meleis *et al.* 2000; Meleis 2010).

METHODS

Study design

In this thesis, a qualitative approach was applied first. A descriptive phenomenological design was used to describe the structure of self-care among persons using advanced medical technology at home (I). A qualitative, phenomenological hermeneutical design was used to elucidate meanings of health-illness transition experiences in this context (II). A qualitative, hermeneutical design was used to gain a deeper understanding of the meaning of living with an adult family member using advanced medical technology at home (III). These qualitative studies were the basis of self-designed questions and chosen instruments in an ultimately quantitative, descriptive, comparative, cross-sectional design, applied to describe and find factors that influence self-care agency and perceived health in a larger group of persons using advanced medical technology at home (IV).

Qualitative methods

From descriptive phenomenology to hermeneutics

In the first interview study (I) a descriptive method, grounded in the phenomenological thought of Husserl and further developed by Giorgi (1985; 2009), was applied. The aim of a phenomenological research method is to seek the essence of human phenomena as lived and experienced, i.e., characteristics that constitute a phenomenon and that cannot be varied. In the application of this method, Husserl's dictum "back to the things themselves" was a lodestar. Simply, it means going to the everyday life-world where people live through various phenomena. In everyday life, certain segmented and practical ways of perceiving, understand-

ing and dealing with this are developed, but without the clarity or systematization that is demanded in a scientific perspective. Since descriptive phenomenology aims to do justice to the lived aspects of human phenomena, descriptions of these are necessary. This phenomenological method is descriptive but not interpretative (Giorgi 1985; 2009).

In order to reveal the meaning of lived experiences of health-illness transition in the present context, a phenomenological hermeneutical method inspired by the philosophy of Ricoeur (1976) and developed for healthcare research by Lindseth and Norberg (2004) was used in the second study (II). This phenomenological hermeneutical, i.e. interpretative method has the potential to offer an increased understanding by uncovering a deeper meaning of lived experiences through interviews transcribed as texts. Ricoeur (1976) states that there is a dialectic movement between the understanding of the whole and the parts of a text, and between what the text is saying semantically and what it is talking about, i.e. the possibilities opened up by the hermeneutic interpretation. Interpretation means to disclose the meanings in the text, which involves a movement from understanding to explanation, and further to comprehension.

The scientific approach of the third study (III) was hermeneutics. In this research tradition, drawing on interpretative phenomenology, lived experiences of individuals and how their experiences can be interpreted are in focus. Understanding will come into view through the fusion of the participants' and the researchers' horizons. According to Gadamer (2004), a horizon is the field of vision, i.e., everything that can be seen from one perspective. Interpreting a text is like looking for something new in it, seeking its hidden meanings and understanding it in a new way (Gadamer 2004). The third study (III) was guided by the steps in Fleming *et al.*'s (2003) research method, which is based on Gadamer's philosophy.

Preunderstanding

Preunderstanding is a central concept in a descriptive phenomenological (I) (Giorgi 1985; 2009), phenomenological hermeneutical (II) (Lindseth & Norberg 2004) and a hermeneutical (III) (Fleming *et al.* 2003; Gadamer 2004) study. Even if the awareness of researchers' preunderstanding is central in all, the view of how to handle this differs. First, in order to identify one's preunderstanding, reflection on it is recommended (Fleming *et al.* 2003; Dahlberg *et al.* 2008). Reported preunderstanding should, however, have a ready relationship with the research area and research question (Dahlberg *et al.* 2008). The researchers in this project are all registered nurses and have long experience from nursing education. Two are well experienced in research on self-care among old persons (Söderhamn *et al.* 1996a; 2000) and research on transitions (Olsson & Ek 2002). Being a former intensive care nurse, I have experience from different sorts of medical technology. The authors did not have any previous personal relationships with any person in this self-care context.

In Giorgi's descriptive phenomenological method (Giorgi 1985; 2009) (I), phenomenological reduction is a necessary attitude throughout the method. This involves bracketing, i.e., putting aside preunderstanding such as knowledge and ideas about the phenomenon. In order to allow new aspects of the phenomenon to appear, such preunderstanding must not influence either data collection or data analysis (Giorgi 1985; 1988; 2009). Lindseth and Norberg (2004) are

critical to pure phenomenology *ad modum* Husserl, in which essences are seen intuitively and uncontaminated by interpretation. In phenomenological hermeneutics (II), bracketing does not involve putting preunderstanding within brackets. Lindseth and Norberg (2004) argue that such bracketing would cause the meaning and essence to disappear as well. Rather, researchers' judgements about what the case is are to be bracketed, in order to allow the researcher to be open to the meaning of the phenomenon. Gadamer (2004) states that all understanding derives from previous experiences. Since researchers' preunderstanding may conceal meanings of a text, a significant step in Fleming *et al.*'s (2003) Gadamerian-based research method (III) is to identify and reflect upon this preunderstanding, which enables researchers to transcend the horizon. This means a movement beyond preunderstanding, in order to gain new comprehension of the phenomenon. The way to handle preunderstanding is described further in the *Analyses* and *Validity and reliability* sections below.

Sampling procedures and participants

In this thesis, adult persons using advanced medical technology at home, as well as next of kin of adults in this situation participated. Two different study groups were used in the three qualitative studies (I, II, III).

To find potential patients (I-II) and next of kin (III) to interview, five nurses were contacted. These nurses worked with caring for patients with respiratory or kidney disorders, at a hospital in western Sweden. Chronically ill patients in these groups are frequently required to make long-term use of different sorts of advanced medical technology. The nurses received verbal and written information about the study, and were asked to give a letter containing information and an invitation to participate to patients (I-II) and later next of kin (III) who accompanied a patient to a consultation, or to ask the patient to deliver the letter. Approval from the head of the clinic had been obtained, together with ethics committee approval. Inclusion criteria were to be an adult performing self-care at home involving the long-term use of oxygen/air from a cylinder/concentrator or ventilator, or performing blood or peritoneal dialysis, and having the physical capability to participate in an interview (I-II), or to be an adult next of kin of – i.e., living with or spending considerable time with – an adult in this situation (III).

Ten of 11 patients and 11 of 13 invited next of kin indicated their consent to be interviewed by sending their names, addresses and telephone numbers to me, in postage-paid reply envelopes that had been provided by the nurses (I-III) or patients (III) along with the initial information letter. These patients, and later the next of kin, were contacted by telephone and were interviewed soon after.

Study group 1 (I-II) comprised ten adult patients performing self-care at home, involving the long-term use of oxygen/air from a cylinder/concentrator (four participants) or ventilator (one participant), blood dialysis (three participants) or peritoneal dialysis (three participants). They had been diagnosed with the technology-related disease four to 25 years previously. All participants had been treated with the prescribed technology in hospital before their technical needs at home became apparent, and had been instructed and trained by hospital nurses in how to use the technology at home. The participants' experiences with technology at home

ranged from four months to ten years. All participants were living in the western part of Sweden; one of them had moved there from another northern European country. Their age ranged from 37 to 83 years, with five of them under 65 years. Five were men, and seven lived with a partner at home. Of ten participants (five former blue-collar workers, four white-collar workers and one housewife), one was currently in remunerated employment.

Study group 2 (III) comprised eleven next of kin of adult patients performing self-care at home, involving the long-term use of oxygen/air from a cylinder/concentrator (four patients) or ventilator (two patients), blood dialysis (one patient) or peritoneal dialysis (four patients). Next of kin's experiences with the patients' technology at home ranged from two months to 23 years. The age of the next of kin ranged from 57 to 72 years, with five of them under 65 years. Three under 65 years of age were in remunerated employment, and the other two were retired due to their technology-dependent family members' situation. All next of kin were living in the western part of Sweden. One patient using technology was 33 years old, and the others' ages ranged from 59 to 74 years. Two men and seven women were married to the patient, while two were parents of one patient. This couple narrated their story together in one interview, which is why the study resulted in ten interviews.

Interviews

All interviews were performed by me at the participants' homes during the summer of 2006 (I-II) and winter/spring of 2009 (III). One participant (III) preferred to be interviewed at the hospital. Besides the telephone call during which the participants were given continual information about the study and arrangements for the interviews were made, the interviewer and participants were unfamiliar to each other. To get to know each other a bit, some participants offered me a cup of coffee before the interview, while others served coffee during the interview or afterwards. When a patient was interviewed, his/her next of kin sometimes participated in this coffee-break, like a patient sometimes did when his/her next of kin was interviewed. When the next of kin (I-II) or patient (III) was at home during the interview, he/she was unable to hear the conversation. One exception to this was made (I-II), when a next of kin of an older participant being interviewed paced close by, anxious to help the participant remember certain facts. With the participant's approval, the next of kin was invited to join the interview.

The interviews were conducted like a conversation (Fleming *et al.* 2003). Mainly, just the participants name, address and type of medical technology in the home were known to the interviewer beforehand. After some questions concerning background factors, the main open-ended question focusing on the use of technology at home in daily life in connection with the prescribed treatment was asked to the patient (I-II), or focused on the meaning of living with a person using advanced medical technology at home (III). To attend to openness, which is striven for in phenomenological (I) (Giorgi 1985; 2009), phenomenological hermeneutical (II) (Lindseth & Norberg 2004) and hermeneutical (III) (Gadamer 2004) research, participants were provided with the opportunity to speak freely, openly and in-depth about their lived experiences in their present contexts. New aspects of the phenomenon must be allowed to appear fresh (Giorgi 1985; 1988; 2009). In order to deepen the understanding the main

question was followed up with additional elucidating questions, such as, “What did you do?”, “How did you feel?”, “What do you mean by that?”, “How?” etc. The patients (I-II) were also given the opportunity to talk about what self-care meant to them. The interviews were tape-recorded, and most lasted about 45 minutes (range 32 to 73 minutes). I transcribed all the interviews verbatim.

Analyses

Descriptive phenomenology

The interviews in Study I were analysed in a phenomenological way, using the descriptive phenomenological methods described by Giorgi (1985; 2009) and Karlsson (1995). First, the analyses followed the four steps set out by Giorgi (1985; 2009): 1) The entire text was read to get a sense of the whole. 2) The entire text was discriminated into meaning units by applying a nursing perspective and a focus on the phenomenon of self-care when using advanced medical technology at home. Meaning units were noted directly in the text whenever a change of meaning was identified. 3) The subjects’ everyday expressions were transformed into the language of the adopted perspective, i.e., the language of nursing science, with an emphasis on self-care. This was done through a process of reflection and imaginative variations. The subjects’ descriptions expressed multiple realities and the task was thus to elucidate the nursing science aspects appropriate for an understanding of self-care. 4) The transformed meaning units were synthesized into a consistent statement of the phenomenon of self-care. Every transformed meaning unit was taken into account. Through free imaginary variations (Giorgi 1985; 2009), 11 specific situated structures of the phenomenon were further composed to one single, general description. 5) In this step typological structures (Karlsson 1995) of the phenomenon emerged, i.e., constituents that showed the richness in variations of self-care in this context. The constituents were general for all participants, or typological for some. In line with recent recommendations from Giorgi (2009), the relationships between the constituents were finally presented in a diagrammatic form.

Phenomenological hermeneutics

Data from the previous interview study (I) were further analysed (II) following the three steps in Lindseth and Norberg’s (2004) phenomenological hermeneutical method for researching lived experience: 1) A naïve reading of the entire text was done in order to grasp the overall meaning of the phenomenon of transition. This involves reading the text several times with an open phenomenological attitude. A naïve understanding, i.e., a first conjecture of the meaning of transition in this context, was formulated. 2) In order to validate the naïve understanding, a first inductive, thematic structural analysis was performed. The whole text, interview by interview, was divided into meaning units focusing on the transition experience. Each meaning unit conveyed only one aspect of transition. Then, the essential meaning in each meaning unit was condensed and expressed in everyday words. Related condensed meaning units were abstracted into sub-themes, which were brought together into themes. Further, a second deductive structural analysis was performed, in order to disclose various meanings. This analysis was based on Pörn’s (1984; 1993; 1995) equilibrium theory of health and adaptedness, since a healthy transition means adaptedness in the new situation (Meleis *et al.* 2000). 3) The last step in the phenomenological hermeneutical analyses involved a comprehensive understanding, in

which all protocols from the naïve understanding and structural analyses were taken into account and interpreted as a whole.

Hermeneutics

The interviews in the third study (III) mainly followed the Gadamerian research steps set up by Fleming *et al.* (2003): 1) First, the appropriateness of the research question in relation to the foundation methodological assumptions was reflected on. The open question posed to the participants addressed what it means to live with someone who is using advanced medical technology at home. This seeking of a deep understanding of a phenomenon is central in the Gadamerian tradition. 2) Since researchers' preunderstanding may conceal meanings of a text, it was attempted to identify (described in *Preunderstanding*, above) and reflect upon it, in order to transcend the horizon beyond preunderstanding. An awareness of and a restraint from experiences from Studies I and II were striven for throughout the research process. 3) The third step was to gain understanding through dialogue with the participants. Understanding will come into view through the fusion of the participants' and researchers' horizons. The interviews are described in *Interviews*, above. 4) Step four involved gaining understanding through dialogue with the text. This text also included researcher's comments about the interview situation, which is why field notes describing the context and emotions not present on the tape were transferred to the interview text. Similar to Studies I and II, all interviews were read repeatedly, to get a good grasp of the whole. The whole text, interview by interview, was also divided into meaning units, and condensed meaning units from the participants' horizons were formulated. In the formulation of the condensed meaning units, the question asked regarding the text concerned meanings of living with a person using advanced medical technology at home. Furthermore, condensed meaning units, including a tentative interpretation, were formulated from the researcher's horizon. Through this dialogue with the text, fundamental meanings of living with a person in this home technology context were searched for. The two horizons were fused into a tentative interpretation. To gain a deeper understanding of every single meaning unit, this was related to the meaning of the whole text, by experiencing the hermeneutic circle. This involves a continuous movement from the whole to the parts and back to the whole, as the meaning of the whole will influence the understanding of every part. The sense of the whole text was thereby expanded, and the meanings of the parts widened (Fleming *et al.* 2003).

To arrive at a main understanding, according to Dahlberg *et al.* (2008), all interpretations that were considered valid were finally compared with each other and a concluding main interpretation was formulated. This main interpretation cut through all data and all the previous ten interview interpretations. The use of theory in lifeworld research has the single purpose of helping the researcher to see data and their meaning more clear (Dahlberg *et al.* 2008). Parse's (1998) theory of human becoming was used as a tool in this final stage.

Validity and reliability

Morse *et al.* (2002) have noted how the rejection of the concepts of validity and reliability in qualitative research since the 1980s has resulted in a shift concerning ensuring rigour of the researcher's actions during the whole research process, to the reader of the research. Thus,

they argue that validity and reliability remain appropriate concepts in qualitative research as well. This can be achieved via verification strategies that are both integral and self-correcting during the conducting of inquiry itself (Morse *et al.* 2002). Söderhamn (2001) also discusses aspects of validity and reliability in order to raise appropriate demands for knowledge and scientific acceptance, from his view considering phenomenological studies.

To attend to openness, i.e., to switch from the natural to the phenomenological open attitude towards the phenomenon, which is striven for in phenomenological and hermeneutical research (Giorgi 1985; 2009; Gadamer 2004; Lindseth & Norberg 2004), participants in this thesis were encouraged to speak freely about their lived experiences of daily life with technology (I, II, III). Open-ended additional elucidating questions were raised. Validity and reliability in phenomenological thought involve phenomenological reduction, which, according to Giorgi (1985; 1988; 2009), means bracketing prior ideas or knowledge about the phenomenon. Such ideas must not influence data collection or data analysis. In the first, descriptive phenomenological study (I), bracketing was maintained by keeping the language in the analysis as close as possible to the participants' own language, and through the avoidance of theoretical influence or expressions. Literature in relation to the phenomenon was read after the analysis. Phenomenological reduction also involves the avoidance of making existential claims about the phenomenon by claiming that the given factually is what it appears to be (Giorgi 1985; 1997; 2009). The search for essences, which in this context means the most invariant meanings assigned to self-care when using advanced medical technology at home (I), was achieved through the process Giorgi (1997; 2009) describes as free imaginative variation. In this process, the descriptive features of the phenomenon were varied to see what the truly essential or invariant features are.

Lindseth & Norberg (2004) view the influence of preunderstanding differently from Giorgi (1985; 1997; 2009). As people understand in relation to their preunderstanding, this is considered an advantage and a prerequisite for performing the analyses in Lindseth & Norberg's (2004) phenomenological hermeneutical method (II). The authors are all versed in transition theories, as well as in the health-adaptedness theory of Pörn (1984; 1993; 1995). The process of interpretation is not linear; To ensure rigour, the comprehensive understanding was compared with the naïve understanding and the steps in the structural analyses, commuting back and forth between the whole and the parts, and between understanding and explanation (Lindseth & Norberg 2004).

Also in Fleming *et al.*'s (2003) Gadamerian hermeneutical method, the question of establishing rigour permeates the whole research process. According to Fleming *et al.* (2003), each research step must be clearly described, which was striven for in this hermeneutic study (III) as well. With an open attitude involving avoiding quick decisions about what phenomenon in the next of kin context (III) means, and through reading literature related to phenomenon after the analysis, we tried to bridle our pre-understanding. No tentative interpretation that explained data more meaningfully was found, nor any incongruity in the data behind the interpretation. Tentative interpretations not considered valid were either developed further or

removed from the findings. Thus, according to Dahlberg *et al.* (2008), the validity of the interpretations was continually evaluated.

Mainly, I performed the qualitative analyses (I-III), i.e., performed the structural analyses, for example, and made up the tentative structures in the form of subthemes and themes. But these structures were continuously reflected on in dialogue with my supervisors, who had read some of the interviews. In these discussions, some tentative constituents (I), subthemes/themes (II) or interpretations (III) were merged, further abstracted, or removed.

Quantitative methods

Sampling procedures, participants and non-participants

In order to find participants for the questionnaire- study (IV), contact was made with eight nurses at four hospitals in western Sweden, who cared for adults performing self-care at home involving the use of advanced medical technology. Approval from the heads of all involved clinics had been obtained, together with approval from a regional ethical review board. The inclusion criteria were being an adult performing self-care at home involving the long-term use of oxygen/air from a cylinder, concentrator or ventilator, or performing blood or peritoneal dialysis. The exclusion criteria were being in terminal care or diagnosed with Amino Lateral Sclerosis (ALS), or using a ventilator due to sleep apnoea with no hypoventilation or simply during physiotherapy, according to the Swedevox (2008) definition of ventilator care. The nurses provided me with lists of names, addresses and year/month of birth for all patients who fulfilled the inclusion criteria, or mailed an encoded questionnaire by post to these patients directly. The questionnaire was mailed to a total number of 323 patients, who fulfilled the criteria. To be able to remind the non-responding patients who received the questionnaire directly from the nurses, a list of codes for these patients was sent to their nurses, together with a reminder letter and a questionnaire. The nurses delivered these by post. In order to describe the non-responding patients, information about their age and sex and the technology they used were received in the same way from the nurses, based on their codes. Data were collected from November 2009 to February 2010, with one reminder letter sent during this time.

Accordingly, study group 3 (IV) was a convenience sample of 180 (56%) of 323 invited adult patients performing self-care at home, involving the long-term use of oxygen/air from a cylinder/concentrator (62 patients) or ventilator (58 patients), blood dialysis (7 patients) or peritoneal dialysis (53 patients). One hundred and twenty-two patients (68%) had more than one year's experience of using the prescribed technology at home. Their ages ranged from 24 to 87 years, with a mean of 66.7 years (SD 11.5). One hundred and three patients (57%) were male. One hundred and forty-seven patients (82%) were on age- or disablement pension, eight (4%) were sick-listed, and 23 (13%) were in remunerated employment. One hundred and seven-teen (65%) were living with someone, and 164 (92%) were living in non-sheltered housing.

The group who refrained from participating (IV) included 143 (44%) of 323 invited patients. Besides hospital affiliation, the technology, age and sex of this group's members were known. The non-participants consisted of a greater proportion of ventilator users (48%; $p=0.005$) than among the participants (32%), and were younger, with a mean age of 62.7 years (SD 15.5; $p=0.009$). No statistically significant difference was found regarding sex between participants and non-participants.

The questionnaire

A questionnaire, sent to the patients described above (IV), consisted of nine opening questions on background factors regarding age, sex, cohabiting, housing, employment, occupation/former occupation, technology used, experience with technology, and disease.

Eight questions addressed health and daily life, such as "Do you perceive yourself as being in good health?" and "Do you have close contact with persons you consider significant to you?". Thirteen questions addressed daily life with medical technology, based on knowledge from Studies I-III, e.g. "Do you adjust the technical treatment in order to take part in important activities?" and "Does the equipment negatively impact your home environment?". Thirteen questions could be answered on ordinal scales ranging from "not at all" or "never" to "very much" or "very often", later transformed into scores from 1 to 4. When entering the answers into the computer software (SPSS), the most positive answer alternative was consistently given the highest score. Eight questions were answered with "yes" or "no". Swedish versions of the Appraisal of Self-care Agency (ASA-A) scale (Söderhamn 1996a) and the 13-item version of Antonovsky's SOC-scale (Antonovsky 1987, 1993) were part of the questionnaire.

Instruments

The Appraisal of Self-care Agency (ASA-A) scale, which is based on Orem's self-care deficit theory of nursing (Orem 2001), is an instrument for self-measuring activation of power and engagement in self-care activities (Evers 1989; Söderhamn 1996a). The group of American and Dutch researchers who developed the instrument initially abbreviated it 'ASA'. However, to complete the self-measuring made by the person in focus a second form, ASA-B, was developed to be used by his/her next of kin or caregiver. Thus, the initial ASA for self-appraisal is now referred to as ASA-A (Evers 1989; Söderhamn *et al.* 1996a). The ASA-A is a Likert-type scale including 24 items for self-appraisal, each with five response categories ranging from 1 ("totally disagree") to 5 ("totally agree"). Nine items are stated negatively and must be reversed in the summation of the scores. The maximal score is 120, with high scores reflecting a higher degree of self-care agency.

The Sense Of Coherence scale (SOC) was developed to predict and explain persons' movements toward the health end of the health ease/dis-ease continuum. Aaron Antonovsky, the Israeli originator of the SOC-scale, was interested in why some persons overcome hard strain while remaining in good health whereas others in similar circumstances become sick. Sense of coherence comprises the three components comprehensibility, manageability and meaningfulness. One's power of resistance to hard strain depends on the extent to which these components are experienced in life, and sufficient SOC is considered a key determinant of

good health (Antonovsky 1987; 1993). In a systematic review of nearly 500 scientific publications, Eriksson and Lindström (2005a) showed that SOC was strongly related to perceived health, and mental health in particular. Also, persons with high SOC seemed to be more resilient under stress, compared to those with low SOC.

The original version of the SOC-scale consists of 29 items, but the 13-item version (SOC-13), which was used in this study, has also been frequently used (Antonovsky 1993; Eriksson & Lindström 2005a). The SOC is a semantic differential scale with two anchoring phrases, ranging from 1 to 7 scores. In the SOC-13 five items reflect comprehensibility, four reflect manageability and four reflect meaningfulness. Five items are stated negatively and must be reversed in the summation of the scores. The maximum score is 91, with a high total score expressing high SOC, i.e., a predictive prerequisite for good health (Antonovsky 1987, 1993).

Statistical analyses

Power analysis was used for the analysis of variance (ANOVA) to estimate the sample size. Descriptive statistics were used to describe the study group. Numbers and/or percentages were used for nominal data, medians (Md) and inter-quartile ranges (iqr) for ordinal data, and mean values and standard deviations for interval data. Dependent on the data, differences between the study group and non-response group were analysed with independent samples t-test or chi-square test.

The one-way ANOVA test with the Bonferroni post hoc test was used to test differences in ASA-A and SOC-sums, respectively, among users of LTOT, ventilators, HD or PD. The Kruskal-Wallis test was used to test differences in perceived health between users of LTOT, ventilator, HD and PD. The Mann-Whitney U-test was used to test differences in scores between groups. The Cronbach's alpha coefficient (Cronbach 1951) was measured for ASA-A and SOC-sum in the total study group and in the different sub-groups.

Two multiple linear stepwise regression analyses were performed to investigate possible predictors of self-care agency and perceived health. The choice of independent variables was based on variables that in univariate analyses reached a p-value of maximum 0.2 (Altman 1999), compared to ASA-A sum and perceived health, respectively. Therefore, of a total of 33 variables, 17 were used as independent variables compared to ASA-A sum, and 18 compared to perceived health, which is also suitable in relation to the sample size (Altman 1999).

Randomly distributed missing ASA-A values (n=16) were given a neutral score of 3, i.e., "neither disagree nor agree", in agreement with Evers (1989) and Söderhamn *et al.* (2000). Answers from participants who had more than three missing values (n=9; 5%) were excluded from the ASA-A part of the questionnaire. Answers from participants who had more than two missing SOC-values (n=16; 9%) were excluded from the SOC-part, in agreement with Antonovsky (1993). Five randomly distributed missing SOC-values were given a neutral score of 4.

The computer software SPSS version 17.0 was used to analyse the data.

Validity and reliability

The ASA-A scale has been validated in Europe in different study groups by Evers (1989). It has been translated and validated in Swedish contexts, and has been shown to substantially measure what was intended. The Cronbach's alpha coefficient among older, lucid home-dwelling persons was shown to be 0.80 (Söderhamn *et al.* 1996b).

The SOC-scale has been tested for validity and reliability and is used worldwide (Antonovsky 1993). It has early been determined to be suitable in nursing (Sullivan 1989). The SOC has been tested among Swedish physically active older persons, and has been found to be a reliable and valid tool (Söderhamn & Holmgren 2004). The 13-item SOC-scale has been shown to be a cross-culturally applicable, feasible, valid and reliable instrument, showing Cronbach's alpha coefficient at 0.70-0.92 (Antonovsky 1993; Eriksson & Lindström 2005a). It has been confirmed that the 13-item scale can be substituted for the 29-item scale (Callahan & Pincus 1995).

Ethical considerations

Ethical principles of clinical research, i.e., autonomy, beneficence, nonmaleficence and justice (Beauchamp & Childress 2009) and the Declaration of Helsinki (WMA 2008) have guided these studies, and were followed throughout the thesis. Nurses who were asked to recruit the patients received initial verbal, and later verbal and written, information about the study. After the nurses' initial approval, the heads of involved clinics received verbal and written information, and agreed to the studies when approval from the Regional Ethical Review Board, Göteborg University (Registration No. 145-06 for Studies I-III, and No. 565-09 for Study IV), was received.

Patients and next of kin who participated in an interview (I-III) gave their informed consent in the form of a signed document, after receiving written information about the study and their rights in research. Each of these participants' understanding of the written information was followed up twice: during the phone call while planning the interview, and at the participant's home before the interview started. Ethical issues concerning the participant's rights in research (WMA 2008; Beauchamp & Childress 2009) were simultaneously raised. Patients who were invited to participate in the questionnaire study (IV) received written information about the study and their rights in research. Their answering and returning the questionnaire was regarded as informed consent.

Arrangements were made so as not to offend the users of technology when recruiting their next of kin (III). When the next of kin did not attend the nursing consultation with the patient, i.e., when the invitation to join the study was delivered by the nurse, the patient was asked to deliver it. Accordingly, the users of technology who were related to next of kin in Study III also received information.

Ethics in medical and caring research is mainly a question of preventing risks, in order to not offend participants who are in a vulnerable state and dependent on the professional care-

givers (WMA 2008; Beauchamp & Childress 2009). However, through taking an hour or so for an interview or responding to the questionnaire, the participants also had the chance to express their experiences of having the equipment at home and to, hopefully, help others - users of technology as well as next of kin and professional caregivers - in this context. This could be considered a benefit of participating. Efforts were continuously made to do justice to the rich data, in balance with the limitation in the form of a maximum number of words, dictated by the international scientific journals.

RESULTS

Description of self-care in relation to advanced medical technology (I, IV)

Qualitative description; Lived experiences (I)

The phenomenon of self-care consisted of several constituents and typological structures, showing the richness in variation of self-care in this context. Figure 1 (page 23) shows the relations between constituents (in italics) and typological structures.

Prerequisites for self-care

Support from professional caregivers and support from significant others were found to be prerequisites for self-care in this home technology context. The participants had been trained by nurses at hospital before the equipment was transferred to their homes, and were further instructed at home at the beginning of the self-care period. Although the participants had continuing consultations with professional caregivers, permanent access to nursing support whenever a practical problem arose was considered very important. The professional support could also be emotional in moments of aversion to the situation. Most participants living with a spouse received his/her practical support in managing activities in daily life. Due to difficulty breathing, participants using oxygen were all dependent on help with more demanding domestic duties. Emotional support from significant others involved acceptance of the situation with technology, such as acceptance of the need to adjust social activities and work according to the technology dependent's needs. Having someone to talk to whenever needed was highly appreciated. Prerequisites for sufficient cognitive capacity concerned the management of technical procedures, remembering to carry them out correctly and in the right order. Self-confidence in managing self-care and the realization that technology in fact facilitates life were aspects of having a positive attitude to life.

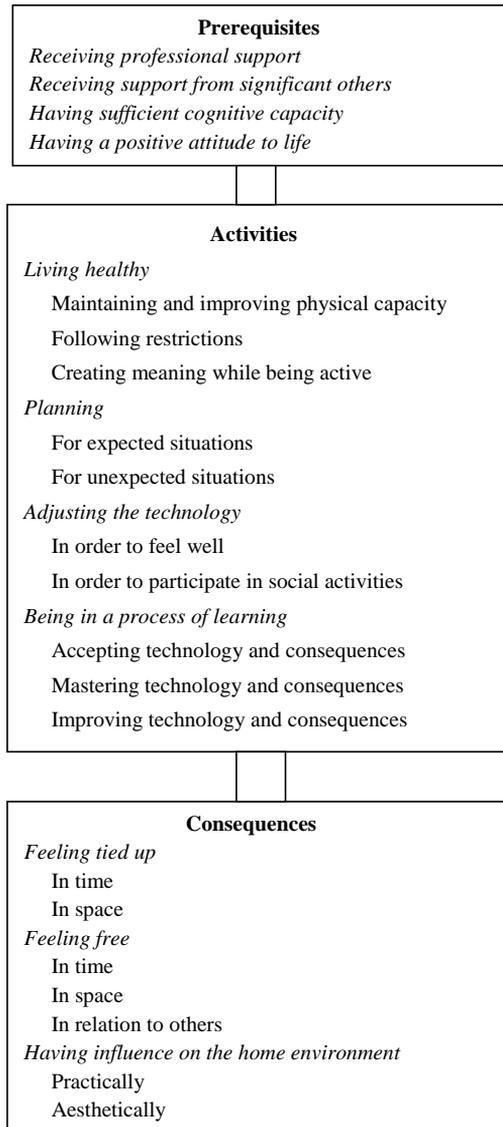


Figure 1 Interrelated constituents and typological structures of self-care

Activities for self-care

Activities for self-care concerned healthy living, planning and adjustments to the technology, while being in a process of learning. It was attempted to maintain and improve physical capacity through regular exercise and the deliberate intake of nutritious food. Hygiene restrictions were to be followed, as well as actions to prevent complications caused by food or liquid intake. Healthy living also meant creating some meaning in daily life, by being active in social events. Planning was done in relation to expected situations, like actions to ensure that the equipment would always be available and operational, but also for security in relation to an unexpected situation. This advanced planning included ordering or bringing along extra

equipment as a back-up measure, and educating next of kin in ways to manage the equipment. The participants were allowed to deviate from the regular routine by adjusting the technology to their actual health state, based on indicators such as heavy breathing, thirst or swollen feet, or in order to participate in special activities. Adjustments were made in time and space for treatment, and by balancing the supplement of oxygen or fluids for dialysis to optimize health. The first step in the learning process was to accept the technology and its consequences on daily life at home. This step was facilitated by seeing the gain in bringing the technology home. A participant with a rapidly deteriorating course of disease was initially reluctant to perform self-care. With nursing support, insight was gained into how the situation could be dealt with, and the participant felt that the decision to bring technology home was right. With nursing support and knowledge from literature, and through contact with others in the same situation, the participants learnt to master the technology and its consequences on daily life. Instructions were systematically followed in the beginning, but a gradual learning process was characterized by improvisation and an attempt to 'feel one's way' to improve daily life and health. Knowledge and experience led to improvements in making the technology more silent and easier to bring along, or to improvements to daily life with technology for oneself as well as for others, in facilitating journeys, for example.

Consequences of self-care

The daily routine with technology was associated with feelings both of being tied up and of feeling free; in time and space and in relation to others. The time-consuming treatment and the following of a strict time schedule directed social activities, and travelling could be an insurmountable challenge due to the need for excessive planning for bringing heavy, bulky equipment. Freedom was mainly experienced by participants performing dialysis, who did not have to spend time on frequent travel for hospital dialysis. But the ability to be able to adjust the time, place and duration of treatment was also appreciated by participants using long-term oxygen 16 hours a day, despite having no permanent difficulty breathing. Feeling free in relation to others concerned an increased capacity to be in control and manage things by oneself, being less dependent on others. The technology influenced the home environment practically and aesthetically. Arrangements were made for storing equipment and hazardous waste; demands for water, drainage and electricity for performing dialysis were met; and a suitable, comfortable place to be during treatment, within easy reach of technical equipment and materials needed for housework was arranged. Efforts were made to reduce the noise from the oxygen concentrator or PD cyclor. Most participants tried to hide the equipment, which was considered to negatively influence the home environment.

General description

Self-care among persons using long-term oxygen, a ventilator, or equipment for blood or peritoneal dialysis at home was described at a generic, overriding level (I), independent of the specific type of technology used. The general description of self-care in this context involved prerequisites for, activities for and consequences of self-care. Prerequisites for self-care when using advanced medical technology at home were found to be support from professional caregivers and significant others, cognitive capacity and a positive attitude to life. This type of self-care contains steps for living healthy, for planning, and for adjusting technology. Further,

it involves a process of learning as well as feelings both of being tied up, and of feeling free. Additionally, it has influences on the home environment.

Quantitative description (IV)

Health-related and technology-related variables in daily life were rated among 180 individuals. Ninety-five percent of the participants were content with the support from the healthcare professionals, initially for learning to manage the technology, as well as for having access to permanent support whenever needed (95.6%). Knowledge for managing technology safely, and experience of technology as easy to manage, were perceived by 97.2 and 96.7%, respectively. Negative impact of technology on the home environment was experienced to quite a low extent (Md=3, iqr=3-4), and 60% found the equipment easy to bring along when leaving the home. A positive attitude to technology from significant others was experienced to a very high extent (Md=4, iqr=3-4), and to quite a high extent from society in general (Md=3, iqr=3-4).

To quite a high extent, the participants perceived themselves as satisfied with life (Md=3, iqr=2-3). They had close contact with persons they considered important to a very high extent (Md=4, iqr=3-4). Regular help from next of kin was received by 77.2%, and regular help from society by 18.3%. To quite a high extent (Md=3, iqr=2-3) the participants considered themselves to have an active life. The daily routine with technology was seldom adjusted to attend social activities (Md=2, iqr=1-3) or to the daily health state (Md=2, iqr=1-3). Feelings of being tied up were experienced to quite a high extent (Md=3, iqr=2-3), but feelings of freedom (Md=4, iqr=3-4) dominated.

The mean ASA-A sum in the total study group was 87.8 (SD=11.3). ASA-A values for the different technology groups are displayed in Table 1.

Table 1 Self-care agency among 171 participants using different kinds of medical technology at home

	LTOT (n=57)	Ventilator (n=56)	HD (n=6)	PD (n=52)	p-value
ASA-A sum					
Scale range: 24-120, M (SD)	86.9 (10.2)	86.9 (10.8)	96.7 (10.3)	88.7 (12.8)	0.191
Cronbach's alpha	0.77	0.80	0.79	0.87	

LTOT=long-term oxygen therapy; HD=haemodialysis; PD=peritoneal dialysis; ASA-A=appraisal self-care agency scale. Higher scores for M indicate better perception of self-care agency.

Factors that influence self-care and perceived health (IV)

Factors that positively contributed to self-care agency were SOC-sum ($\beta=0.375$, $p<0.001$); having close contacts with other persons ($\beta=0.339$, $p<0.001$); not feeling helpless ($\beta=0.160$, $p=0.030$) and having sufficient knowledge for using the technology ($\beta=0.151$, $p=0.021$). These factors explained 45% of the variances of self-care agency (adjusted $R^2=0.45$).

The median of perceived health in the total study group was 3, i.e., to quite a high extent good health (iqr 2-3). Significant differences in perceived health were found between participants using LTOT and PD ($p<0.001$); LTOT and ventilator ($p<0.001$) and LTOT and HD ($p<0.001$) (Table 2).

The mean SOC-sum in the total study group was 65.2 (SD=13.5). A significant difference in SOC-sum was found between LTOT and PD users ($p=0.049$). SOC-values for the different technology groups are displayed in Table 2.

Table 2 Perceived health and SOC among participants (n=180; n=164) using different kinds of medical technology at home

	LTOT (n=62)	Ventilator (n=58)	HD (n=7)	PD (n=53)	p-value
Perceived health (Scale range: 1-4), Md (iqr)	2 (2-2)	3 (2-3)	3 (3-3)	3 (2-3)	<0.001
SOC- sum (Scale range: 13-91), M (SD)	61.6 (12.6)	64.8 (14.6)	71.6 (13.3)	68.5 (12.6)	0.035
Excluded patients, n	8	7		1	
Cronbach's alpha	0.81	0.90	0.92	0.87	

LTOT=long-term oxygen therapy; HD=haemodialysis; PD=peritoneal dialysis; SOC=sense of coherence. Higher scores for Md and M indicate better perception of perceived health and SOC.

Factors that positively contributed to perceived good health were being satisfied with life ($\beta=0.533$, $p<0.001$); having an active life ($\beta=0.225$, $p=0.001$); and not feeling helpless ($\beta=0.163$, $p=0.011$). Advanced age was a factor that negatively contributed to perceived good health ($\beta=-0.108$, $p=0.048$). These factors explained 66% of the variances of perceived good health (adjusted $R^2=0.66$).

Meanings of health-illness transition (II)

Several readings of the entire interview text ended up in a naïve understanding: The health-illness transition experience among adult persons using advanced medical technology at home means a learning process of accepting, managing, adjusting and improving daily life with technology. This process is facilitated by realizing the gain from technology at home. Further, the structural analyses emerged as four themes and 20 sub-themes (Table 3, page 27).

Table 3 Meanings of the health-illness transition experience among adults using different kinds of advanced medical technology at home

Accept technology in daily life

- Accept by experience
- Accept by feeling trust
- Accept by realizing the gain
- Accept being bound in time and space
- Accept technology without reservation

Manage daily life with technology

- Manage technology cognitively, manually and emotionally
- Manage to live healthy
- Manage through experience, training and professional support
- Develop bodily knowledge
- Integrate technology into daily life activities
- Manage advanced planning
- Manage by having a positive attitude
- Manage by receiving support from significant others
- Create new meaning despite technology

Adjust oneself and adjust technology

- Adjust home to technology
- Adjust technology to health, activity and experience
- Adjust activity to technology

Improve technology in daily life

- Find practical solutions in the home
 - Develop technology practically and aesthetically
 - Struggle for better circumstances
-

The themes are in italics.

The themes and sub-themes are further accounted for in an integrated text, theme by theme.

The transition process of accepting technology and its consequences on daily life was emotional and cognitive. Have experience of hospital care and thus being mentally prepared for future needs, for most participants accepting the technology for self-care at home was a natural step forward. Acceptance came about in consultations and with support from health-care professionals, family and other patients who had personal self-care experience. Some participants, however, regarded their acceptance as not involving a choice, but rather simply as a fact to accept without reservation or pondering. A growing trust in one's personal capacity to manage the technology, trust in the technology, and the realization of the gain from self-care at home facilitated the acceptance process. After some experience, the difficulties of daily life with technology were more obvious in costs for equipment and electricity, extra work due to the treatment, and feelings of being tied up in time and space. However, the participants were able to see the personal benefits, experienced as good health, a sense of freedom in time and space, an enhanced ability to control technology, and a decreased identity as a

patient. Continuously reconsidering their situation, especially in moments of aversion to it, participants could still feel relief in knowing they had made the right decision in accepting the technology.

The transition process of managing daily life with technology required abilities involving manual skills and a familiarity with the technology, but also required knowledge about the diagnosed disorder, doctors' orders, and healthy living. Sufficient cognitive ability was necessary in remembering to systematically carry out the technical procedures. The participants also had to learn how to overcome discouraging emotions. Professional support was frequently required in the beginning, to learn how to manage the equipment and solve and prevent practical problems. Later, permanent access whenever a problem arose was an important source of security. The bodily knowledge improved gradually, and with the ability to recognize signs of good or ill health participants became able to continuously evaluate their treatment. They learnt to plan ahead and to be prepared in case of unexpected situations. In the beginning, getting used to the situation and managing daily life at home were in focus. Later, when the participants felt ready to broaden their horizons, the planning involved with bringing heavy, bulky technology on journeys often proved to be too much of a challenge. The transition process was facilitated by a will to mobilize a positive attitude towards technology, which could be learnt with professional support, and by support from significant others in practical help, acceptance of the situation, and adjustments of social activities to the participant's capacity. Manage daily life with technology also involved creating a new meaning despite the technology, and maintaining a social life was of high priority.

The first step of the transition process of adjusting oneself and the technology involved adjusting the home to the technology, in the form of storerooms and requirements for electricity and plumbing. In time, the treatment was gradually adjusted in relation to the participant's actual physical health state, activities and experiences. Participants were satisfied at being able to modify the treatment in time and space, thus maintaining their social or working life. On the other hand, activities in daily life were also adjusted to the technology, in finding appropriate treatment routines, or learning how to deal with and appreciate less strenuous duties, or leaving the arduous work to one's partner when possible. With the goal of maintaining an active life, new interests and projects were found, in line with the demands of the technology. Life was experienced as good, with hopes for more time to enjoy good health.

With experience of using technology, participants became able to improve the technology and its consequences. Efforts and suggestions were made to make the equipment easier to carry, more silent, and less conspicuous, and to find convenient solutions in the house. Participants learnt who was in charge of obtaining increased support, to take courage in contacting these people in power and to fight for better circumstances, for oneself or fellow-patients. The participants enjoyed sharing their knowledge and experience with fellow-patients.

Finally, from a naïve understanding, the structural analyses and the authors' preunderstanding, the health-illness transition among adult persons using advanced medical technology at home was interpreted as contentment at being part of the active and conscious process

towards transcending into a new state of living, in which the individual and the technology were in tune. The successful and healthy transition experience was characterized by human growth and becoming.

Meanings of living with a family member using advanced medical technology at home (III)

Ten interpretations illuminating different meanings of living with an adult family member using advanced medical technology at home were found, followed by a main interpretation:

Everything in the universe is related to the flow of paradoxical patterns, which are rhythms within two dimensions. Whilst one is at the front and the other in the background, they are both simultaneously present (Parse 1998). Living with a family member who is using advanced medical technology at home means being closely connected to, but also separated from, him/her. By giving practical and psychological support, adjusting the home and means of transport, favouring and learning to deal with technology, and being constantly there focusing on the patient's needs, the next of kin becomes closely united with the patient. On the other hand, changing roles and performing certain activities alone that used to be performed together mean an involuntary separation from the patient. Seeking an explanation for the situation, worrying about the future and grieving life as having changed mean sorrow. But there is also a reconciliation involved in getting used to and making the best of the situation. Dependence on others is reflected in a need for support from the healthcare professionals and significant others.

In Table 4, the ten interpretations are related to the concepts in the main interpretation.

Table 4 Interpretations illuminating different meanings of living with an adult family member using advanced medical technology at home

Being closely connected

- Focusing on the patient
- Supporting practically and psychologically; constantly being there
- Favouring and learning to deal with technology
- Adjusting home and means of transport

Being separated

- Being autonomous and changing roles

Grieving

- Regretting life's having changed and worrying about the future
- Seeking explanation

Becoming reconciled

- Getting used to and making the best of the situation

Being dependent on others

- Needing support from healthcare professionals
 - Needing support from significant others
-

Being closely connected to the technology dependent family- member (further referred to as the patient) concerned the participant's constant focus on the patient's needs. Activities were chosen based on the patient's ability, and were adjusted to fit the treatment schedule. Thus, technology involved feelings of being tied up, and of isolation from others. Even though the

decision to bring the technology home seemed to have been made without the participants' input, and despite negative impacts of the technology on the home environment and noise that could also affect the participants' sleep, they had an overall positive stance toward it. Patients' benefits from technology were prioritized. The participants became the patients' arms and legs, due to the patients' connection to the technology or physical impairments. Their support could also be psychological, in supporting the patient in contacts with, e.g., municipal social workers, or in just being there; someone who listens and is an engaged source of security. The technology was viewed as a source of health, and as a means to make activities possible for the patient; to get their old beloved one back again. All participants were grateful for having access to technology. The home was adjusted to technical demands with solutions involving storerooms, water and drainage, as well as the family's car being adjusted to fit the technology. Some participants learnt how to manage the technology, while others were helpful in simply carrying heavy equipment and dealing with medical waste.

The involuntary separation from the patient involved changing roles and performing certain activities alone that used to be performed together, like taking a walk or a trip to another country. Also, the participants learnt to find interests on their own, and most of them took on more demanding domestic duties.

Grieving life as having changed, worrying about the future and seeking an explanation for the situation means sorrow. Patients' impairments and technology dependency made it such that life radically changed. Earlier hopes for mutual activities in their old age, e.g. journeys, could be out of reach. Sorrow was experienced when activities certainly were managed, but without the presence of the patient, like when the former closeness to the patient was broken due to negative psychological influences on the patient of the disease and treatment. The caregiving responsibility could already be burdensome, and the participants worried about what might happen the day their strength waned. Credible explanations related to, e.g., working environment were mainly presented as explanations for the disease and a further need for technology, but disease could also be viewed as punishment for a certain action.

Reconciliation involved getting used to and making the best of the situation. It was a learning process to get used to the patient's impaired strength, and daily life with technology. It was good to learn that when the patient had one or two bad days, this was not sign of permanently declined health; however, the participants had to get used to the difficulties in planning future activities for a certain day. Seizing the day and striving to have an eventful life despite technology were efforts to make the best of life now.

Dependence on others was reflected in a need for support from the healthcare professionals and significant others. The participants were familiar with the patient's nurses and physician, and considered it vital to have access to telephone support whenever a question arose, concerning technology or, e.g., the appropriateness of certain activities. Good relationships with the healthcare professionals and equipment suppliers were appreciated. However, the healthcare professionals focused on the patient's situation and seldom on that of the participant. The participants had difficulty in raising taboo questions about things like sex life and survival, and mentioned a need for be listened to in private. Dependence on good cooperation between

in-patient care, out-patient clinics and representatives of social service was also expressed. Having a social network to confide in, who understood and accepted the situation with technology, felt supportive. This also involved people who allowed the participants to adapt their working life to the technology in some way. The participants strove to maintain their social life, and a new friend in a similar situation was also a valued source of support.

DISCUSSION

Description of self-care in relation to advanced medical technology

Orem (2001) defined self-care as activities performed in order to maintain life, health and well-being. In this thesis the phenomenological meaning of self-care (I) besides activities, also involved prerequisites for and consequences of self-care. Further, self-care in a high-tech home context was more than simply mastering the technology. It also involved daily life activities for healthy living, planning in advance of using the equipment and doing so in relation to various activities, knowledge about bodily signs of good and ill health, and adjusting the treatment according to the circumstances.

Considering the demands and risks involved with this kind of technology, one may find it impressive that ordinary people - some of whom had comparatively low levels of formal education, were older people, or living alone - were able to manage self-care in such an advanced context. However, five of 180 participants (3%) answered that they did not have the knowledge to manage technology safely. Ninety-five percent of the participants felt content with the support they received from the healthcare professionals (IV). The questionnaire study was not designed with permission to identify and return to certain participants for supplemental information. The nurses might, however, consider patients' knowledge as an area worth further investigation. Early on, Arras (1995) highlighted the fact that home care in a technology context raises special challenges for quality-assurance activities.

In the interviews (I-II, III) the participants described the technology as heavy, conspicuous and bulky, with a negative influence on the home environment. This is in line with previous research (Ring & Danielson 1997; Lehoux 2004; Ingadóttir & Jonsdóttir 2006) elucidating needs for design improvements to medical technology for use in the home. Also, the WHO (2010b) has highlighted the consequences of advanced medical technology on patients and healthcare professionals, claiming that the equipment is often not well designed for the environment in which it is used. But in the questionnaire study (IV), only five of 179 patients perceived the technology as uneasy to manage, and negative technology impact on the home environment was experienced to quite a low extent. The 40% of participants who did not find the equipment easy to bring along when leaving home (IV) is not explained by the seven participants who performed haemodialysis; Equipment for HD is almost impossible to bring along, due to demands for water and plumbing. Feelings of being tied up due to the situation with technology was a constituent for self-care in this context in the first interview study (I), partly in space, due to difficulties in carrying technology. These feelings were confirmed to

quite a high extent in the questionnaire study (IV). Even though participants considered themselves to have an active life to quite a high extent (IV), they were still restricted in reaching their vital goals (Nordenfelt 2000) away from home. In conclusion, this thesis points out needs for design improvements to medical technology for use in the home.

The phenomenological study (I) showed that there were self-care advantages, such as the experience of freedom, and opportunities for adjusting the technology to suit the user's state of health and activities. Similarly, a sense of freedom was perceived to a very high extent in the questionnaire study (IV), in line with research on patients performing home HD (Ageborg *et al.* 2005). Knowledge to make correct, safe adjustments ought to be considered high self-care ability. Previous studies by Polashek (2005) and Ingadóttir and Jonsdóttir (2006) show that patients in this home context sometimes depart from the ordinary technology routine, for health and social activity reasons. The participants in Study IV, however, answered that their daily routine with technology was seldom adjusted. Perhaps they were not familiar with the researchers' meaning of 'adjust' in this context.

Factors that influence self-care and perceived health

In Study I, participants expressed the challenge of managing self-care with technology as mainly related to the cognitive capacity of memory. Increased age may negatively influence cognitive as well as physical capacity among some older persons. The mean ASA-A sum in the total study group (IV) was 88 of a maximum of 120 points, and the mean age was 67 years, the oldest being 87. One might wonder what ASA-A sum is to be expected. A negative relationship between ASA-A sum and age has been found among patients who were preparing to start home HD (Pagels *et al.* 2008), and among cohorts of home-dwelling persons aged 65-74 years, 75-84 years, and 85+ years (Söderhamn *et al.* 2000). Compared to this thesis (IV), the youngest cohort in Söderhamn *et al.*'s (2000) study scored higher (mean ASA-A=94). This may be because they were 'ordinary' old people in a better physical state, not technology-dependent patients. In a study among dialysis patients mean ASA-A sum was 92, not significantly related to age (Morgan 1998). No study has been found measuring ASA-A among patients on LTOT or ventilator treatment. In this thesis (IV), the regression analysis showed no significant relationship between ASA-A sum and age. However, other studies have shown a negative correlation between ASA-A sum and advanced (65+ years) age (Evers 1989).

The positive linear relationship between self-care agency and sense of coherence that was found in this thesis (IV) was also implied among home HD patients in a study by Ageborg *et al.* (2005). Although not statistically significant, a small group of patients performing home HD scored higher in ASA-A and SOC-29, compared with those performing self-care or being dialysed in hospital.

Health was perceived to quite a high extent to be good among participants (IV), but patients on LTOT rated perceived health significantly lower, compared to the other technology groups. COPD-related hypoxia, which is a common indication of LTOT (Swedevox 2010), involves a general decreased physical capacity, which may negatively influence perceived

health. Patients on LTOT also use (and are thus tied up to the equipment) for 16 to 24 hours a day (Swedevox 2010), compared to the other groups who mainly use it during shorter periods of the day or night. The regression analysis showed a negative relationship between perceived health and advanced age (IV). This relationship was not found in the study by Söderhamn *et al.* (2000). Again, the participants in study IV were not ‘ordinary’ old people.

Antonovsky (1987; 1993) postulated that a person’s sense of coherence should be stabilized by the end of young adulthood, and should then only be affected to a minor degree. However, in some studies SOC has been shown to increase with advanced age (Larsson & Kallenberg 1996; Eriksson & Lindström 2005b; Nygren *et al.* 2005). A recent study of cohorts aged 20, 30, 40, 50, 60, 70 and 80 years, equal numbers of women and men in total, showed that the 20-year-olds had a statistically significant lower SOC-13 sum compared with the other age groups. Fifty-five percent of the 20-year-olds had a SOC-13 sum of 66 point or less of a maximum of 91 points, compared with 17% of the 80-year-olds. It was also found that men aged 60 or 70 years had statistically significant higher mean SOC-sums than did women of the same ages (Lindmark *et al.* 2010). Antonovsky’s (1987; 1993) hypothesis that SOC remains quite stable when the personal level has been reached was confirmed in a recent study by Söderhamn & Söderhamn (2010). They found no differences in median SOC-29 scores between home-dwelling physically active older people and in-patients of the same age and sex.

Even though sense of coherence has been shown to be strongly related to perceived health (Eriksson & Lindström 2005a), it is questionable what interventions might increase adult patients’ SOC. Besides SOC-sum, close contact with others and sufficient knowledge for using technology were factors that contributed to higher self-care agency (IV). Being satisfied with life and having an active life contributed to good perceived health, and not feeling helpless was a contributing factor to both ASA-A and perceived health. Polashek (2003), who has elucidated daily life for persons on home HD, claims that the nursing role in this context lies beyond the performance of a range of technical tasks. Rather, nursing concerns responding to the patient’s experience as a person, living on dialysis. Accordingly, supporting chronically ill persons who are in need of knowledge to manage daily life and feel tied up by technology would be possible, relevant nursing actions. Such interventions might decrease patients’ feelings of helplessness and increase their action ability. This would be in line with Pörn’s (1984) and Nordenfelt’s (2000) view of health as the ability to act.

Meanings of health-illness transition

The structural analyses, aimed at validating the naïve understanding (Lindseth & Norberg 2004) of the health-illness transition experience among adult persons using advanced medical technology at home (II), confirmed four themes involving a learning process of 1) accepting, 2) managing, 3) adjusting and 4) improving daily life with technology. This learning process was facilitated by realizing the gain from technology at home. The themes can be transferred to the steps of an endpoint, passage and new beginning constituting a transition (Chick & Meleis 1986; Bridges 2004), and to the properties of the transition experience in the middle-range transition nursing theory (Meleis *et al.* 2000; Meleis 2010).

Learning to accept technology; the end of an earlier life situation

This thesis focuses on the mastery of daily life among chronically ill adult persons in a home technology context (II). Most often, the participants' medical diagnoses were issued long before their technical needs at home surfaced. Thus, they had already experienced the transition from health to illness, and to chronic illness. All participants were experienced with advanced medical technology in the hospital, and were trained by nurses in how to use it at home. One concrete endpoint (Chick & Meleis 1986; Meleis *et al.* 2000) was when the technology arrived at the home. But, being chronically ill, the participants were mentally prepared for their coming technology needs. The critical endpoint (Meleis *et al.* 2000) was rather the moment when they realized and accepted that the time had come to use the technology at home. The accepting step is, to my knowledge, not previously focused on within health-illness transitions. Being chronically ill rarely involves a choice. It is not obvious that all patients in need of medical technology for long-term survival have the choice to accept it or not. However, they might have some influence on when the technology is brought home, and patients on HD, for example, still have an option to receive dialysis at the hospital. This thesis shows that nurses have an assignment to help patients gain insight into how the situation with home technology can be dealt with (I, II). These insights would be prerequisites for accepting it.

Learning to manage daily life with technology; the passage

Managing daily life was an active action that presupposed total awareness, even though the participants did not inevitably reflect on the fact that they were in transition. The awareness and active engagement (Meleis *et al.* 2000) were shown in efforts towards advanced planning and adjusting the technology to activities in daily life. Transitions are the result of a change, and result in a change (Meleis *et al.* 2000). Besides practical procedures involving the equipment, bringing the technology home also influenced the participants' social life and home environment, which had to be adjusted. Family roles could change, and new interests and friends were found. Growing faith in one's personal abilities in handling daily life with technology was another sign of change in the transition process. Participants could feel restricted in time and space because of the daily self-care routine. But by recognizing the opportunity to be at home, adjust the technology to fit social activities, and be less dependent on others, they also experienced feelings of freedom.

Personal meanings, cultural beliefs and attitudes, socioeconomic status, preparation and knowledge, like community or societal conditions, can facilitate or inhibit the transition process (Meleis *et al.* 2000). Participants' positive attitudes to life in general, and to technology as a means of facilitating life, were essential to the transition process. Even though socioeconomic status did not seem to influence the transition process, regular fees for care and medicine as well as increased costs for equipment, electricity, garbage removal and transportation, were noticeable economic consequences. Concerning preparation and knowledge (Meleis *et al.* 2000), most participants experienced themselves as so well trained from their time spent in the hospital that there was nothing dramatic about their first time using technology at home. However, permanent access to support from professionals was a crucial facilitator for transition.

Learning to adjust and improve daily life with technology; the new beginning

A healthy transition is characterized by process indicators of feeling connected, interacting, being situated and developing confidence and coping (Meleis *et al.* 2000). Seeing family and friends was a vital goal for all participants, who deeply appreciated support in adjusting social events in time and space to the treatment, and provided someone to talk to in a mutual friendship. Participants also felt connected by support from, and even friendship with, the health-care professionals. This positive interaction facilitated transition as well as self-care. The benefits of using technology at home were expressed as increased freedom, an ability to depart from the hospital routine, and decreased patient identity. Self-care now constituted actions integrated into daily life. Participants developed confidence in managing life with technology, even in unexpected situations, and knew the circumstances for temporarily departing from daily routines and restrictions. This is in line with the developmental process that has been described among nurses (Benner 1984). From being limited and rule-dependent novice nurses, through practice they became able to grasp situations in their entirety and act beyond rules. Through experience, patients in this thesis (II) became able to modify the plan to the circumstances, just like the nurses did. Offering their support to less experienced fellow patients was another sign of a cumulative knowledge and coping ability.

Phases in a transition are more likely to merge into one another than to be discrete (Chick & Meleis 1986). The process of accepting technology at home was most focused on at the end of the earlier life situation, when the need for technology became obvious. However, participants occasionally reconsidered their choice of using the technology at home, in moments of aversion to the situation as well as when experiencing the gain. Learning to manage daily life with technology was focused on in the same way; not only in the passage, but also at the new beginning, when new goals for things like travelling were set.

The meaning of the health-illness transition experience among persons using advanced medical technology at home was interpreted as contentment at being part of the active and conscious process towards transcending into a new state of living, in which the individual and the technology were in tune. The successful and healthy transition experience was characterized by human growth and becoming. This meaning is in line with the properties of healthy transitions (Meleis *et al.* 2000; Meleis 2010).

Meanings of living with a family member using advanced medical technology at home

The analysis of the next of kin interviews (III) resulted in ten interpretations illuminating different meanings of living with an adult person using advanced medical technology at home. These interpretations were followed by a main interpretation, inspired by Parse (1998). According to her, a constant flow of paradoxical patterns co-exist as rhythms within two dimensions. Whilst one is at the front, the other is in the background, but they are still both simultaneously present. Meanings of connectedness versus separation, and grief versus reconciliation, were interpreted in this way.

Sorrow is defined as pervasive sadness that follows loss (Burke *et al.* 1999). Due to patients' impairments and technology dependency, next of kin in this thesis (III) experienced loss in

their earlier hopes for mutual activities, and loss of the patient, when the former closeness to him/her was broken. This might be interpreted as chronic sorrow, i.e., a periodic recurrence of permanent, pervasive sadness. This phenomenon has been widely addressed in nursing literature, as well as in studies on family caregivers. Comparison with social, developmental or personal norms are most often the triggers, but management crises like the need for additional treatments (Burke *et al.* 1999), in this context the need for advanced technology at home (III), can also trigger it.

Even though the concept of reconciliation is quite unexplored within nursing research, it has been found to mean a process and movement, and a desire that can never be fully saturated, or final (Gustafsson 2008). This would be in line with the rhythmical patterns of reconciliation and grief found in this thesis (III). Further, reconciliation is involved with a new understanding for the past, present and future (Gustafsson 2008). In this thesis (III), next of kin learned that when the technology-dependent family member occasionally had some bad days, this was not a sign of permanently declined health. By seizing the day and making efforts to make the best of life now, despite technology, next of kin also redefined what the most important things in life were.

No paradox of dependency was found, however, which might be in line with the famous statement by the English poet John Donne (1624): *No man is an island*. We are all interconnected to and dependent on other persons.

Orem's (2001) self-care deficit theory comprises some aspects of dependent-care. According to Orem, dependent-care agency involves a continuing dependent-care system of knowing and meeting the dependent person's therapeutic self-care demand, and exercising and developing one's dependent-care abilities. But it also involves a continuing self-care system to meet one's own self-care demands and to exercise and develop one's self-care abilities. Dependent-care agency thus relies on the good health of the next of kin. In this thesis (III), striving to maintain an active social life may be one way to maintain one's health. But, being in their 60s or 70s, the next of kin worried about the future when their strength would decline more.

Like nursing- systems (Orem 2001), dependent-care systems may be partly compensatory when the patient is able to perform some self-care moves, or supportive-educative when he/she meets the self-care requirements and continues to learn and develop self-care abilities, in regular interaction with professional caregivers (Taylor *et al.* 2001). Some patients in this thesis (III) would probably have met their self-care requisites, if they had been living alone. The remaining patients were in a combined system of self-care and dependent-care. One patient was additionally dependent on daily care from professional caregivers. As some patients became increasingly dependent on care from their next of kin as their impairments worsened, there was a movement from self-care to dependent-care, and from a supportive-educative to a partly compensatory dependent-care system. This progress may be a potential problem to be aware of. The patient and next of kin might have sufficient ability for self-care and dependent-care at the beginning of the self-care period, but may experience changes in this ability over time. This may raise a need for added nursing support, while taking the decision regarding self-care at home under reconsideration.

Meeting patients' self-care demands means getting knowledge and exercising and developing one's dependent-care abilities (Orem 2001; Taylor *et al.* 2001). In this next of kin study (III), knowledge and skills concerned the capability to understand and to various extents manage the medical technology, and to adapt the home environment and daily activities to the technical treatment. Some caring activities did not seem to be much of a challenge, like bringing things to the patient during treatment and performing domestic duties, even if this could be a burden and cause the next of kin feelings of being tied up in time and space. However, abilities like handling the technology and recognizing the patient's signs of ill health and deciding when to call for professional support, require specialist knowledge. Next of kin learnt from patients as well as from professionals. But even though the participants prized good relationships with the patient's nurses and physicians, the supportive-educative nursing system (Orem 2001) seemed to focus on the patient's needs.

Methodological considerations

This thesis aimed to develop knowledge of self-care and transition in a group of patients using different kinds of advanced medical technology at home. For validity, an ideal situation would be that the same number of persons using LTOT, or a ventilator, or HD or PD, participated. While factors like age were fairly evenly distributed in the qualitative studies, only one person using a ventilator was able to participate in Studies I-II, and only one patient was performing HD in Study III. However, self-care and transition involving a ventilator were shown to have similarities with the other forms of technology, as did being next of kin to a person performing HD, compared with other next of kin. The higher frequency of female next of kin (III) and male patients (IV) may be due to the fact that renal failure is more common among men (SNR/SRR 2009). The group of patients performing HD (IV) is a small yet interesting group in this context, and it would not have been appropriate to combine it with the PD group.

The question of variation in samples also involves rich variation in data (Dahlberg *et al.* 2008). The participants in Study group 1 (I-II) gave an overall positive view of the meaning of self-care, and all showed patterns of healthy transitions. Perhaps the nurses who invited appropriate patients showed consideration to those who may have fulfilled inclusion criteria but were still in an unstable phase, by refraining from giving them an invitation. However, the next of kin (III) balanced the positive view by also expressing meanings of separation and grief. Looking at a phenomenon from different perspectives is one form of triangulation that supports validity (Patton 2002).

Questions are raised about how it might be possible to bracket one's former knowledge of a phenomenon, which is central in Giorgi's (1985; 2009) phenomenological method. According to Merleau-Ponty (2001), there is no thought which embraces all of our thoughts. Since we are not all mind, but are in the world and are reflective persons, a complete reduction is never possible. Strategies for bracketing, e.g., openness to the phenomenon (I-III) and avoidance of theoretical influence (I), can never be correctly measured, but rather simply strived for.

A question in qualitative research concerns the necessity to go back to participants for more data. According to Dahlberg *et al.* (2008), a complex phenomenon has to be approached slowly and very flexibly. It is possible that a first round of data gathering ought to be followed by a second one, focusing on new illuminated aspects of the phenomenon. However, lifeworld research holds the idea that meanings are infinite and always expanding themselves. Thus, no meaning saturation can exist. Fleming *et al.* (2003), on the other hand, more generally recommend that researchers go back to participants for a second or third talk. Their opinion is based on Gadamer's (2004) view that understanding depends on the particular historic situation, i.e., the participants' as well as researchers' understanding will develop over time. In this thesis, all interviewed participants (I-III) gave rich data, and I found no need for follow-up interviews. However, all participants received an invitation to contact me if they had something to add, or if the interviews raised any questions in their minds. No one made this second contact.

Giorgi claims that neither the use of researcher judges in the analysis part, nor going back to the participants for verification of the findings, is an action for increasing the validity of a phenomenological study. Even several researchers analysing a text may still make the same mistake. Further, the participants' perspective is not the same as the meaning in the researcher's discipline (Giorgi 1989), and by asking for participant approval the analysis risks being kept on too low an abstraction level. Instead, through following the verification strategies that are integral and self-correcting in the psychological phenomenological method (Giorgi 1985; 2009), i.e., phenomenological reduction and the search for essences, Giorgi (1989) claims that the method is valid.

Triangulation strengthens a study by combining methods (Patton 2002). In this thesis, naturalistic inquiries with qualitative data based on interviews (I-III) were followed by a statistically analysed questionnaire-study. The questions concerning daily life with technology were based on findings from Studies I-III. The naturalistic approach allows researchers and participants to understand each other (the answers and questions, respectively), which strengthens validity. This thesis showed some incongruence between the qualitative and quantitative studies. The interviewed patients (I-II) as well as next of kins (III) expressed that the technology was noisy, heavy and bulky, whereas almost all patients who answered the questionnaire (IV) expressed that it was easy to manage and that it negatively influenced the home environment only to a low extent. The different opinions on whether the daily routine with technology was adjusted (I-II) or not (IV) might be another example of difficulty in communication in a mailed questionnaire-study. A limitation in this thesis is that the clarity of questions concerning daily life with technology (IV) was not tested in a pilot study among persons in this context. Unanswered questions highlight another difficulty in data collection via mailed questionnaires. Self-care in this context requires medical knowledge and technical skills, and it would have been valuable to look for a relationship between profession and self-care agency. However, a great number of participants refrained from answering the question about profession, so it was not analysed.

Transferability concerns the extent to which findings can be generalized (Patton 2002). The findings from the qualitative studies (I-III) are based on a general level, despite the specific

technology that is used. Even though phenomenological reduction (I) involves the prohibition of existential claims about the phenomenon, i.e. saying that the given is factually what it appears to be (Giorgi 1985), and the fact that a text never has only one meaning (II) (Lindseth & Norberg 2004), it is likely that the qualitative findings from this thesis can be transferred to other home settings, in which persons are using the same types of technology. Further research is needed to show possible transferability to other types of advanced medical technology, like intravenous cannula for analgesic or nutritional treatment, and tubes for enteral feeding.

The group who refrained from participating in the questionnaire- study (IV) consisted of 143 (44%) of the 323 invited persons. Besides hospital affiliation, only age, sex and technology were known in this group. Since it was not possible to determine whether the non-participants further differed from the participants, caution should be observed in interpreting the results and generalizing to other groups.

Clinical implications

The tendency of transferring advanced medical technology from the hospital to the patient's home raises challenges for planning and quality-assurance activities; for healthcare professionals as well as politicians. This issue might be on a level above the specific nephrology or lung medicine unit, and instead may be on a clinical and political overriding level. This thesis makes some implications, based on the experiences of patients' and next of kin' in this context:

Nurses have an assignment to help patients gain insight into how the situation with home technology can be dealt with, which can help patients to accept it. Educating and supporting patients practically and emotionally, such as helping them adopt a positive attitude towards technology, is relevant nursing in this context. Such interventions might decrease patients' feelings of helplessness and increase their action ability, in line with the view of health as the ability to act. Further, permanent access to competent nursing support is a crucial facilitator for transition, and is central in continuously managing daily life. This could be considered in times of reducing costs of medical service.

A few, but still some patients felt that they did not have the sufficient knowledge to manage the technology safely. Further quality-assurance activities are thus required.

Self-care may involve a movement from self-care to dependent-care and from a supportive-educative to a partly compensatory dependent-care system, due to patients' age and progress of impairment. Both patient and next of kin might experience changes in abilities over time, and the next of kin worried about the future, when their strength would decrease. The movement of care- system and the changes in patients' and next of kin's abilities may raise the need for added nursing support.

Regular, practical support from next of kin may be a prerequisite for self-care. Even though the next of kin valued good relationships with the healthcare professionals, the professionals still focused on the patient's needs. A possibility to meet with nurses and physicians in priva-

cy, allowing intricate questions to be raised, was articulated among the next of kin. Further, arranged meetings with others in similar situations and manuals offering advice on many issues concerning daily life with medical technology may be ways to further improve the home technology area.

Patients on LTOT rated their perceived health as significantly lower than did the other technology groups who perceived their health as good to quite a high extent. This implies an importance of focusing on the needs of the LTOT patients.

This thesis showed overriding, general similarities in self-care in a home technology context, irrespective of the specific technology used. Thus, healthcare professionals caring for patients on LTOT, for example, might gain insight by reading research on other types of technology. As with intensive care or cancer care, etc., nurses and other healthcare professionals involved with patients in an advanced home technology context might realize professional advantages in viewing this as one area: the self-care home technology area.

CONCLUSIONS

The main conclusions of the thesis are as follows:

- Self-care among persons using advanced medical technology at home can be described on a general, overriding level and, thus, can contribute to the development of self-care.
- The phenomenological meaning of self-care involves prerequisites for, activities for and consequences of self-care. Further, self-care in a high-tech home context means more than simply mastering the technology. It also involves daily life activities for healthy living, planning in advance of using the equipment and doing so in relation to various activities, knowledge about bodily signs of good and ill health, and adjusting the treatment according to the circumstances.
- Daily life seems to be manageable for patients using this kind of technology at home.
- Having close contacts with other persons, not feeling helpless, and having sufficient knowledge for using technology are factors that positively contribute to self-care agency. Further, a positive relationship between self-care agency and sense of coherence is confirmed. Factors that positively contribute to perceived good health are being satisfied with life, having an active life, and not feeling helpless, but advanced age is a negative contributing factor.
- The health-illness transition in this context means a learning process of accepting, managing, adjusting and improving daily life with technology, facilitated by realizing the gain from technology at home. Further, the meaning of the health-illness transition experience is interpreted as contentment with being part of the active and conscious

process towards transcending into a new state of living, in which the individual and the technology are in tune. The healthy transition experience is characterized by human growth and becoming.

- Living with a family member who is using advanced medical technology at home means rhythmical patterns of being closely connected to, but also separated from, him/her, as well as patterns of sorrow versus reconciliation. Dependence on others is reflected in a need for support from healthcare professionals and significant others.

SAMMANFATTNING (SUMMARY IN SWEDISH)

En allt äldre befolkning, med ökad frekvens av sjukdomar som kan medföra kronisk nedsättning av exempelvis lung- eller njurfunktionen, leder till att allt fler personer använder syrgas, en respirator, eller dialysutrustning hemma. Vanligtvis hanteras dessa typer av avancerad medicinsk-teknisk utrustning av sjukvårdspersonal med särskild utbildning och träning. Möjligheten att använda utrustningen hemma har visat sig innebära fördelar i form av ökad hälsa och livskvalitet för patienten. Men också nackdelar har rapporterats, då utrustningen inte alltid varit användarvänlig, har påverkat hemmiljön negativt genom att vara skrymmande och föra oväsen, och inneburit begränsningar av dagliga livets aktiviteter. Också patientens närstående kan påverkas då utrustningen används hemma.

För flertalet människor har det vi idag kallar för egenvård varit den vanligaste och oftast enda tillgängliga vårdformen. Florence Nightingale bidrog på 1800-talets senare hälft till ökad folkhälsa, genom att erbjuda såväl mödrar som professionella vårdgivare sina professionella, skriftliga råd om hur de skulle vårda sina familjemedlemmar respektive patienter. Dorothea Orem presenterade 100 år senare en omvårdnadsteori för egenvård, riktad till studenter och yrkesverksamma sjuksköterskor. Trots 1900-talets stora medicinska framgångar hade patienter ofta lämnats till korta avseende att själva tillåtas ta ansvar för sin hälsa, eller att lära sig hantera symtom till följd av långvarig sjukdom. Orem menade att egenvård ska vara basen i all vård, men att den i olika omfattning kan kompletteras med annan vård. Utifrån Orems egenvårdsteori vårdas en person, som genomför egenvård genom att använda avancerad medicinsk-teknisk utrustning hemma, inom det delvis kompenserade egenvårdssystemet. Det innebär att vården sker i samråd med de professionella vårdgivarna, och eventuellt med hjälp av de närstående.

I relation till hälsa/sjukdom innebär begreppet transition passagen från ett stabilt läge, genom ett ostabilt, till ett åter stabilt. Målet för transition är ökad hälsa i form av välbefinnande och aktivitet. För den som exempelvis ska börja använda syrgas hemma handlar transitionen om att lära sig att använda och integrera syrgasutrustningen och dess konsekvenser i dagliga livets aktiviteter; att upprätthålla ett socialt och aktivt liv trots behovet av extra syrgas. Transitionen har därför samband med syrgasanvändarens egenvårdskapacitet.

Det förhållandevis sparsamt belysta området egenvård med medicinsk-teknisk utrustning hemma har tidigare beskrivits med fokus på specifik teknik, som att använda syrgas eller genomföra bloddialys. Forskningen har emellertid visat på likheter i patienters erfarenheter av denna typ av egenvård, oavsett vilken specifik utrustning som använts. Det övergripande syftet i denna avhandling var att utveckla kunskap om egenvård och transition, och om faktorer som påverkar dagligt liv och hälsa bland personer som använder avancerad medicinsk-teknisk utrustning hemma.

Delarbete I är en beskrivande fenomenologisk studie, baserad på intervjuer av tio personer som använde syrgas, respirator, eller utrustning för peritoneal- eller bloddialys hemma. Syftet var att beskriva innebörden av egenvård utifrån deltagarnas levda erfarenhet. Analysen visade att egenvård i denna kontext kan beskrivas på en generell nivå, oavsett vilken typ av specifik

teknik som användes. Förutsättningar för denna typ av egenvård påvisades, liksom aktiviteter för ett hälsosamt liv, för planering och justering av tekniken i förhållande till hälsa och aktivitet, vidare en lärandeprocess, och känslor av både frihet och bundenhet. Hemmiljön påverkades. Egenvård innebar något utöver att hantera den tekniska utrustningen; det innebar också en hälsosam livsföring, planering i förhållande till tekniken och dagliga livets aktiviteter, att skaffa sig kunskap om kroppliga tecken på hälsa/ohälsa, och anpassa behandlingen därefter.

I delarbete II analyserades intervjuerna från delarbete I igen, nu utifrån fenomenologisk hermeneutisk (tolkande) metod. Den genomfördes först induktivt utan stöd av någon teori, och sedan deduktivt med hjälp av Pörns hälsoteori. Studiens syfte var att belysa innebörder av transition relaterad till hälsa/sjukdom bland personer som använder avancerad medicinsk-teknisk utrustning hemma. Transitionen innebar en lärandeprocess för att acceptera, hantera, justera och förbättra dagligt liv med tekniken. Lärandeprocessen underlättades av att inse fördelarna av att ha utrustningen hemma. Vidare tolkades transition i denna kontext som tillfredsställelse över att vara delaktig i en medveten process mot ett nytt livsstadium, i vilket människan och tekniken är i samklang. Erfarenheten av hälsosam transition karakteriserades av personlig växt och utveckling.

Delarbete III är en hermeneutisk studie, baserad på intervjuer av elva närstående till vuxna som använde samma typer av medicinsk utrustning som deltagarna i delarbete I-II. Syftet var att nå fördjupad förståelse för innebörden av närståendes situation. Innebörden av att leva med en närstående i denna kontext förklarades som rytmiska mönster av förenande kontra separation, och sorg kontra försoning. Beroendet av andra visade sig i behov av stöd från de professionella inom hälso- och sjukvården, och av familj och vänner. Alla närstående var positiva till att utrustningen flyttats hem, trots att deras egna behov kunde komma i skymundan, i syfte att fokusera "patientens" bästa. Studien visade behov av att ytterligare fokusera närståendes situation.

Delarbete IV är en beskrivande och jämförande enkätstudie. Syftet var att beskriva egenvårdskapacitet och upplevd hälsa, och att finna faktorer som påverkar dessa hos en större grupp av vuxna som använde samma typer av avancerad medicinsk teknik som i delarbete I-III. Enkäten fokuserade dagligt liv med avancerad medicinsk teknik och upplevd hälsa, och inkluderade svenska versioner av instrument som mäter egenvårdsförmåga (ASA-A) och känslan av sammanhang (SOC). Etthundraåttio av 323 tillfrågade personer besvarade enkäten. Både hälsorelaterade och teknikrelaterade faktorer i dagligt liv skattades som tillfredställande i hög omfattning. Upplevd hälsa skattades lägre bland personer som använde syrgasutrustning. Tillräcklig SOC, kunskap för att använda utrustningen på ett säkert sätt, nära kontakter med andra personer, och att inte känna sig hjälplös var positiva faktorer för god egenvårdskapacitet. Positiva faktorer för upplevd god hälsa var att känna sig tillfreds med livet, att upprätthålla ett aktivt liv, och att inte känna sig hjälplös, medan hög ålder var en negativ faktor. Det dagliga livets aktiviteter visade sig vara hanterbara för personer i denna kontext.

Några slutsatser kan nämnas: Egenvård i denna teknikkontext kan beskrivas på en generell nivå. Med kunskap och stöd från professionella vårdgivare kan patienter och deras närstående ta avsevärt ansvar för sin egen/närståendes egenvård. Skärpt uppmärksamhet bör riktas mot

dem som använder syrgasutrustning, och/eller är i hög ålder. Den tekniska utrustningen önskas bättre designad för patienters hemmiljö, inklusive vara lättare att ta med sig utanför hemmet. Patientens närstående är ofta viktiga stöttepelare för att patienten ska klara att genomföra denna typ av avancerad egenvård, och de närstående kan ha behov av att också få samtala enskilt med patientens professionella vårdare.

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