Patient autonomy in highly technological care environments from a caring perspective

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Cover photo by Mario Alberto Magallanes Trejo

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Det som förnekar att vårt liv är mottaget
är vår vilja att bli ansedda och få del av makt.
Om sjukdomen förhindrar utvecklandet av förmågor och krafter,
om smärtan utestänger hängivelse i upplevelser,
måste andra människor utgöra en oumbärlig och levande del
av den lidandes liv,
för att livet skall kunna hålla fast vid sin karaktär
av skänkts på trots av alla lidanden.

K. E. Lögstrup

Contents

Abstract

Background

Patients in highly technological care environments are severely ill, and are often suffering from a reduced physical and/or cognitive capacity following their illness and treatment, making them exceedingly vulnerable. The most severely ill patients are cared for in the intensive care unit. These vulnerable persons are cared for in an environment traditionally associated with a paternalistic care culture, which implies that patients are at risk of being overridden in relation to ethical issues, and of having their autonomy compromised. The question is whether it is possible for the patient to be capable and autonomous in this context.

Advanced home care involves an increasing amount of advanced medical technology, and is then to be characterized as a highly technological care context. The advanced home care context is different from the intensive care context in that the patients are not sedated, they are cared for at home, and they are expected to be the masters of their home environment. They recognize their home as private territory which gives them the right to decide what to do and how and when to do it. Their need for technology and care from formal/informal carers points to a vulnerability on the part of the patient, risking a hidden paternalism in terms of overprotectiveness, including excesses of care. These aggravating circumstances may exert an influence on the patient's everyday life, threatening the patient's possibilities of remaining/becoming autonomous.

This thesis is a response to the absence of consensual understanding in nursing of the concept of patient autonomy in a highly technological care context, as well as an answer to the lack of knowledge of the phenomenon of patient autonomy in highly technological care environments from the patient perspective and in a caring context.

Aim

The overall aim of this thesis was to describe and elucidate patient experiences of autonomy in highly technological care environments, and to create an extended understanding of the concept of patient autonomy in a highly technological care context, from a caring perspective.

Methods

In answering to the aim of this thesis, a diversity of qualitative methods for data collection and data analysis was used. Two empirical studies comprising individual patient interviews (n=23) within highly technological care environments were carried out, in intensive care (II) and in advanced home care (III). The patient experiences were analyzed through inductive content analysis (II) and descriptive phenomenology (III). Theoretical development was accomplished through a concept analysis (I) from scientific literature, and a concluding metasynthesis (IV) of the previous studies (I-III).

Findings

The concept analysis (I) revealed that increased vulnerability was the antecedent of patient autonomy in a caring context. It further showed that patient autonomy is not to be understood as absolute but as changing throughout the care episode. The interviews with patients being cared for in intensive care described patient autonomy in this highly technological care environment as a “trajectory towards partnership in care depending on state of health and mutual understanding”. Patient autonomy, in advanced home care including advanced medical technology, was differently described as “befriending everyday life when bringing technology into the private sphere”. The findings of the concept analysis (I) as well as the findings from the empirical studies of patient experiences of autonomy (II-III) resulted in the concluding theoretical framework (IV), adding new knowledge to ameliorate the clarity of the concept. A tentative framework, the Control-Partnership-Transition framework of patient autonomy, was delineated. This framework comprises four strategies, the strategy of control, of partnership, of trust, and of transition, used by patients to preserve or obtain autonomy in highly technological care environments.

To experience autonomy, patients in highly technological care environments want to be considered as capable agents, and not only as a vulnerable person in need of care. Their thoughts and experiences reveal that patient autonomy should be understood as a process, something that changes over time, and is dependent on their health condition as well as on others around them and the care environment. The knowledge obtained could be used to facilitate the adherence of health care professionals to ethical principles and codes related to patient autonomy, hence strengthening the patients’ position in regard to their autonomy.

Keywords: agent, autonomy, capable, caring context, co-determination, concept analysis, concept development, control, descriptive phenomenology, experiences, highly technological care, inductive content analysis, interdependence, patient, metasynthesis, patient autonomy, partnership, qualitative research, vulnerability, theoretical development, transition, trust.

Abbreviations

AHC	Advanced Home Care
AMT	Advanced Medical Technology
EMCA	The Evolutionary Method of Concept Analysis
HC assistant	Health Care assistant
HCP	Health Care Professional
HTC	Highly Technological Care
HTCE	Highly Technological Care Environment
ICU	Intensive Care Unit
PCC	Person Centred Care
RN	Registered Nurse
The Nine-Field-Model	The Nine-Field-Model for Evaluation of Theoretical Constructs in Nursing

Definitions

Advanced home care	Care provided at home including advanced medical technology, either managed by the patient, with support from formal/informal caregivers, or fully provided by formal/informal caregivers. Responsible authority is the municipality, or, if the care is linked to the palliative care team or to nurse-led clinics at the hospital, the county councils/regions. Depending on the care needs of the patient, the responsibility could also be divided between these two authorities.
Carer	RNs, specialist RNs, auxiliary nurses, HC assistants, physiotherapist
Formal carer	see *carer*
Home care	Care provided in the home environment by employed caregivers, including Activities of Daily Living (ADL) and health care. Responsible authority is the municipality.
Informal carer	family member, next of kin
Patient	An adult person in need of highly technological care, in the intensive care unit or at home.
24-hour home care	Care provided at home when caregivers, due to care needs and/or needs of surveillance, are required day and night.

Original papers

This thesis is based on following papers referred to in the text by their Roman numerals:

I	Lindberg, C., Fagerström, C., Sivberg, B., & Willman, A. (2014). Concept analysis: patient autonomy in a caring context. *Journal of Advanced Nursing, 70*(10), 2208–2221.
II	Lindberg, C., Sivberg, B., Willman, A., & Fagerström, C. (2015). A trajectory towards partnership in care — Patient experiences of autonomy in intensive care: A qualitative study. *Intensive and Critical Care Nursing, 31,* 294-302.
III	Lindberg, C., Fagerström, C., Willman, A., & Sivberg, B. (2016). Befriending everyday life when bringing technology into the private sphere. *Qualitative Health Research.* Published online. doi: 10.1177/1049732315627428
IV	Lindberg, C., Fagerström, C., & Willman, A. Patient autonomy in a highly technological care context – A theoretical framework. Submitted.

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Preface

My clinical background consists in the main of almost twenty years as an intensive care nurse. In 2006 I decided to develop by taking a supplementary degree course to become a registered nurse teacher. I continued to work parallel to my studies, which enabled me to move back and forth between the clinical context and my studies in pedagogics. In that way I became both a part of and not a part of everyday work at the intensive care unit (ICU). I then became more reflective as concerned the work at the ICU and I gained new insights that previously had been hidden from me as a full time intensive care nurse.

My studies encouraged me to make more ethical reflections related to patient care. This made me realize that we easily care for patients in the ICU with the goal of protecting them from different kinds of threats, no matter whether these are real or not, or whether we have been asked to do this by the patient. I started to think of patient involvement in care in the ICU leading to the field of patient autonomy. I raised questions such as: Is patient autonomy possible in the ICU? and If patient autonomy is possible, what is it and how is it performed? I then turned to the patient perspective in reflecting upon questions such as: Do patients think of being autonomous in the ICU? and if they do so, What are their thoughts and experiences regarding their autonomy when being cared for in the ICU?

In 2011 I was admitted as a doctoral student at Lund University and was employed at Blekinge Institute of Technology, making it possible to address these questions during the work with my thesis. When I started to study the research field of interest, I realized that the patient perspective of autonomy was often neglected in the nursing literature, hence making my research questions related to the patient perspective even more important. Neither was the patient perspective of autonomy frequently addressed in relation to patient care in the ICU. With the purpose of extending the knowledge about patient autonomy in highly technological care contexts, I also turned to advanced home care (AHC), which is expected to expand in the future and to involve to a greater extent different advanced medical technology solutions. The AHC was a new context for me and an additional challenge to the work with my thesis. By involving these two care environments, my expectations were to be able to clarify and define the rather abstract concept of patient autonomy in relation to highly technological care.

Introduction

Patient autonomy is not a matter of course in highly technological care environments as the patients are severely ill, and most often have reduced physical and/or cognitive capacity following their illness and treatment. Intensive care is a traditional highly technological care context that is under rapid development. In 2015, Swedish ICUs had more than 46 000 care occasions, 14 200 longer than 48 hours, and with about 118 000 care days (SIR, 2016). The most severely ill patients are cared for in the ICU and the number of deceased are relatively high. In addition, these vulnerable persons are cared for in an environment traditionally associated with a paternalistic care culture, which risks strongly obstructing their possibilities of autonomy (Beauchamp & Childress, 2009). Consequently, many patients are at risk of being overridden in relation to ethical issues, and having their autonomy compromised. This could be understood as an ethical dilemma and the question is if it is even possible for the patient to be capable and autonomous in this context.

Advanced home care is a care context involving an increasing amount of advanced medical technology, and is then characterized as a highly technological care context. There is a widely spread organization of caregivers and the division of responsibility between different authorities within AHC can be unclear. Accordingly, it is problematic obtaining an overview of the persons cared for in AHC, and an overview of their caregivers, which could rend care planning and patient participation in care more difficult. The AHC can be understood as the opposite to the ICU in that it is outpatient care, the patients are not sedated, and they are expected to be the masters of their home environment. However, they do feel a need for safeguarding when being visited and cared for by nurses, by taking control and securing their territory which at the same time is the nurses' workplace (Öresland, Määttä, Norberg, & Lützén, 2009). They recognize their home as private territory which gives them the right to decide what to do, how and when. However, the need for technology and care from formal/informal carers points to a vulnerability on the part of the patient, risking a hidden paternalism in terms of overprotectiveness, including excesses of care (Delmar, 2012a). These aggravating circumstances occur in a field of ethical tension and may exert an influence on the patient's everyday life, threatening the patient's possibilities of remaining/-becoming autonomous.

The future Swedish/Western health care system will be responsible for the care of a population of an increasing old age (Rechel et al., 2013). At the same time, the medical and technological development of care is exploding and the resources are becoming reduced, which in the end will make people take more responsibility for their health and illness and presumably, and if possible, this care will take place at home. The scientific knowledge of autonomy in highly technological care environments from the viewpoint of the patient is limited. Therefore, if we are to support and strengthen the patient in remaining/becoming autonomous in relation to care in highly technological care environments, we need to know more about the patient's own thoughts and feelings about autonomy in the role of patient, from a caring perspective. In addition, there is a lack of consensus between nurses as regards the meaning of the concept of autonomy (Aveyard, 2000) that could further complicate the realization of the concept in daily patient care situations. This calls for concept development in identifying and clarifying the concept from the patient perspective, to inform the nursing academia and profession, which could lead to improvements in education and care.

Background

The background is divided in two parts and includes the perspective of patient autonomy and the perspective of highly technological care. These two perspectives are partly contradictory in how they regard the role of the patient in highly technological care environments, and this contradiction in perspective represents the overall focus of this thesis.

Patient autonomy as a prerequisite for ethical caring

Patient autonomy, being one of the six most important moral principles of use in nursing practice[1] (Fry & Johnstone, 2008), is to be seen as one of the prerequisites for ethical caring. Therefore, a passage related to nursing ethics and ethical codes in nursing will be addressed. In the following, patient autonomy will be discussed through the subsequent concepts of vulnerability, trust, power, interdependence and patient participation. These concepts illustrate important interrelations with patient autonomy which could be helpful in grasping the complexity and the extent of this concept.

Patient autonomy

Autonomy (*autos* self; *nomos* rule, governance or law) is an ethical concept, including factors such as self-determination and freedom through independence, and has become increasingly important in care over the last thirty years (Beauchamp & Childress, 2009). Patient autonomy is a cornerstone in caring and is often used to describe patients' possibilities to make decisions about their own life situation (Moser, Houtepen, & Widdershoven, 2007), thus claiming respect for individuals as self-determined choosers (Johnstone, 2016).

The principle of respect for autonomy, being one of the important principles in nursing practice, demands the acknowledgment of a person's right to hold views, to make choices, and to act based on the person's own values and beliefs (Beauchamp & Childress, 2009). This means that people should be free to choose and entitled to act

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[1] See p.17.

on their preferences, provided that their decisions and actions do not stand to violate, or impinge on, the significant moral interest of others (Johnstone, 2016, p.37). Nevertheless, every culture has values and beliefs when it comes to health and illness and as to what is morally acceptable behaviour in care (Fry & Johnstone, 2008). In the Anglo-American cultures, for example, the sovereignty of the individual, and the rights of individuals to make choices about their lives free from the interference of others, including family and friends, are highly valued (Johnstone, 2016). This could be compared with other cultures where the interests of the family are put above those of the individual, for example in cultures of indigenous peoples of colonised countries, traditional Greek and Italian cultures, and in many traditional groups in South Asia.

Several problems arise in applying this ethical principle of autonomy in nursing care, as the patients often have different capacities to be autonomous as a consequence of internal or external constraints (Fry & Johnstone, 2008). Internal constraints may consist of mental ability, age, disease status and level of consciousness. The hospital environment, financial resources, the amount of information provided for making informed choices, and the availability of nursing resources, are examples of external constraints. Autonomy should not be seen as equivalent with liberty, power or with control over one's life even if these conditions are necessary to persons in the living of their lives as self-determining individuals (Dworkin, 1988). If a patient is deceived, for example, this could lead to a situation where his/her autonomy is being affected because of misinformation, however this is not restricting the liberty of the person.

An acceptance of responsibility has been shown to be the antecedent of the exercise of autonomy (Keenan, 1999) and could be thought of in both positive and negative terms, depending on the care situation and the patient's health condition. In studies of the attitudes towards patient autonomy from the perspective of patients dying from cancer, the findings revealed a division of the concept into self-determination and shared autonomy, the latter consisting of co-determination and delegation (Sahlberg Blom, 2001). In the light of ethical caring, it could be discussed whether persons delegating their decision-making could be seen as autonomous. Nevertheless, they may have made their judgement of not participating in decision-making related to their own care, which could also be understood as an act of autonomy (ibid.). This is in line with the thoughts of Dworkin (1988) that waivering, that is the possibility of giving up one's independent determination, is also included in autonomy.

However, without a mutual conceptional point of departure among nurses regarding the concept of patient autonomy, there is a risk of an arbitrary outcome if the interpretation of the concept only rests on each nurse's individual interpretation (Aveyard, 2000). If so, this could influence patient care insofar that the patient becomes even more dependent leading to a feeling of uncertainty, or it could result in a responsibility towards care that is far outside the patient's own capacity.

Nursing ethics

Ethical principles are guides to moral decision-making and moral action, as well as the basis for the formation of moral judgments in professional practice (Beauchamp & Childress, 2009). They could be compared to a ruler having a certain standard of measuring what is 'correct', morally right, and what is 'incorrect', morally wrong (Johnstone, 2016). The most important moral principles of use in nursing practice are the ones of beneficence and nonmaleficence, justice, autonomy, veracity and fidelity (Fry & Johnstone, 2008).

Gastmans (2013) points out that nursing ethics have been constantly developing since the beginning of the 1980s and have become a standard discipline in applied ethics. Fowler (2016) stresses that nursing ethics have connections not only to the realm of bedside ethics, but also to the problems of society and the structure of society. Fry (1989) elucidates that the value foundation of nursing ethics derives from the nature of the nurse-patient relationship, which is different from the rights-based autonomy or the social contract of professional practice found in medical ethics. Principle-based ethics asks questions addressing what to do to be ethical, whereas caring ethics asks questions related to how the one given care should interact with the one being cared for (Davis, 2006). Fry and Johnstone (2008) bring out the importance of nurses being able to apply traditional ethical principles in nursing practice along with contextual demands related to the ethic of care, as well as the responsibility in human relationships. Thus, when ethical issues in nursing care are addressed, no one ethical approach should exclude others but instead the approaches should be regarded as complementary (Davis, 2006; Gastmans, 2013; Johnstone, 2016).

Several attempts have been made to present new ethical frameworks as a critique of the principlism approach within medicine, which is historically a" male" approach. This has for example been done by different "female"[2] ethicists, addressing an ethics of care, trust or empathy (Koehn, 1998). Koehn herself offers an ethics of dialogue, as she emphasizes that female ethics does not really take the patient perspective but favours the caregivers, the trustor and empathizer. Another critical viewpoint is nursing ethics as dignity-enhancing nursing care (Gastmans, 2013). This viewpoint advocates a change from considering ethical dilemmas from the view of *one act* to a view from the perspective of a *care process* highlighting the different phases of decision-making as pre-question, question and post-question, all of which involve nurses often being at the patient's side around the clock.

These ethicists share the view of care as relational, stressing the fact of human interdependence as well as confirming the human being as vulnerable when in need of

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[2] Koehn (1998) argues that the differences between the feminine and feminist ethicists are less significant than the large number of similarities. Therefore, she treats them both under the rubric of "female" ethics.

care. However, these ethicists are not the ones making decisions in today's health care, nor are they present at the patient's bedside. The health care sector is very much guided by care production and economic values with the risk of losing both the ethical and the patient perspective. The work of health care professionals (HCPs) is frequently stressful and time for ethical reflection is often lacking. This is alarming as an ethical awareness is important in the daily bedside work and not only when discussing obvious yes/no questions about the patient acceptance or rejection of a suggested medical treatment. Instead, ethical awareness should be about the whole process of caring surrounding such a decision, in recognizing the person behind the patient, hence it concerns all health care professionals. Further, it is crucial that nurses and other HCPs are aware of ethical principles such as the principle of autonomy, because it is of great importance to the relationships between the patient and the carer, if the ethical dimension of caring is to be realized.

Codes of Nursing Ethics

Professional codes of ethics offer important ethical standards of help to professionals when faced with ethical questions during the course of their work (Fry & Johnstone, 2008). Moral guidelines in a code of ethics generally involve three elements: values, duties and virtues (Spicer, 1995). 'Values', in nursing, is about the primary good, which might be the one of patient well-being, 'duties' can be for example respecting human dignity, preserving people's capacity for self-determination, or maintaining confidentiality, while 'virtues' might consist of honesty, compassion, truthfulness and personal integrity (Fry & Johnstone, 2008). The International Council of Nurses offers an international code, the Code of Ethics for Nurses (ICN, 2012), available to nurses and nurse students all over the world. It describes the ethical responsibilities of nurses by stating that the nurse should promote health, prevent illness, restore health and alleviate suffering. It further points out that people requiring care have a right to receive this without being discriminated against on the basis of race, ethnicity, religious beliefs or other personal characteristics. The right to choose, or decline, nursing care as well as the right to accept or refuse medical treatment, the right to waive informed consent and confidentiality, and the right to dignity and to die with dignity are included in this right (Dudzinski & Shannon, 2006).

Nursing codes can be of help in cultivating the moral character of RNs and they can also provide nurses with a reason to think and act ethically, even though codes have a limited legal authority (Johnstone, 2016). Irrespective of this limitation, the codes have to be known by nurses, reflected on and incorporated in nursing care. This is something that falls on academia, when providing nursing education, but it is also something for the health care organization, and the RNs themselves to take responsibility for. Codes of nursing ethics are important statements and guiding principles. However, if they are not taken into account and followed by actions, their purpose will be lost.

The vulnerable human being

Patients in highly technological care environments should be understood as vulnerable because their illness/ill health is either severe, chronic and/or palliative. When somebody becomes a patient, he/she tends to be at a threefold disadvantage related to the health care system (Kristensson Uggla, 2014). First of all the patient is at an *institutional disadvantage* because health care is an organization of strong hierarchy where the patient is located near the bottom. Then the patient is at an *existential disadvantage* connected to the vulnerability of being a patient, i.e. someone suffering from failing health. Lastly, the patient is at a *cognitive disadvantage,* as he/she most often is in a disadvantageous position in regard to knowledge. This threefold weakness is very much a consequence of today's specialized health care built on tremendous success within medicine and care, which risks putting the patient in a position of not being taken seriously as a living human being of age (ibid.). In addition, vulnerability has been argued to be a three-dimensional phenomenon (Gjengedal et al., 2013): an *existential phenomenon* referring to the basic conditions of life; a *contextual phenomenon* referring to its variation dependent on the situation and the cultural context; and a *relational phenomenon* referring to the great importance of the relationships with others, hence determining a person's experience of vulnerability.

Vulnerability is not inflicted but inherent and a part of the human condition, in that it cannot be chosen or rejected (Daniel, 1998). People are vulnerable by the simple fact that they have a body, mind, and spirit, and the body makes them susceptible to pain and injury. Lawler (1991) addresses this vulnerability in what she calls "the problem of the body" by introducing the concept of somology, to be of help in caring for the bodies of others. Martinsen, in her writing about care and vulnerability, refers to the thoughts of Lögstrup, and addresses the idea that all living humans are entitled to a zone of untouchability, with boundaries not to be crossed (Martinsen, 2006). Sometimes, however, due to illness/ill health, these boundaries must be changed for an openness, and then it is the responsibility of the nurse to do this without causing embarrassment or a feeling of invasion.

Vulnerability is related to people's capability of protection and to the exposure of risks, hence it is a consequence of the uncertainty with which we live our lives (Sellman, 2005). Even though people may want to be autonomous and independent, they are limited as individuals in the possibilities of reducing their vulnerability, ultimately depending on the good will of others. Nurses and patients engage one another through vulnerability (Daniel, 1998). The patients' compromised health is the cause of their vulnerable condition. The nurses' work is to ameliorate this condition. In recognizing the vulnerability of another, our own vulnerability is reflected, which gives nurses the opportunity to be authentic, hence true to the discipline of nursing, which has caring as its central foundation (ibid).

Sellman (2005) argues that some people are more vulnerable than others and in more non-everyday ways. Consequently, being a patient implies that the person is more-than-ordinarily vulnerable. The experience of illness adds an additional layer of vulnerability which *has the potential* to restrict the flourishing of an individual (Sellman, 2009, p.221). The experience of a more-than-ordinarily vulnerable body could be painful or frightening to a person, and it may also affect the person's autonomy and agency (Carel, 2009). People react very differently to physical vulnerability and the reaction may change over time, sometimes leading to an opportunity for change or a means for self-development. Carel (2009) argues that vulnerability should not be seen as the opposite of well-being or in the words of Sellman, flourishing (2009), because it is possible to suffer objective ill health and be subjectively well at the same time. Carol suggests that this insight can be used when caring for patients in that they may view themselves and their life situation more positively. If the point of departure is understanding the lived world of the patients from their perspective, this could make their vulnerability bearable or even change it into strength (Gjengedal et al., 2013).

Trust, power and interdependence in care

Asymmetrical relationships are very frequent in health care, as the primary relationships are developed from the fact that some people are in need of help, knowledge and resources that are at the disposal of others, hence the relationship always remains unequal and dependent on trust (Nortvedt & Grimen, 2006). The life phenomenon of trust and power are present in all care situations, and are of significance to the extent of the patient's room for manoeuvre (Delmar, 1999), hence influencing patient autonomy. When someone shows trust in the other, this means that he/she is at the same time at somebody's mercy (Lögstrup, 1992). If the trust is then misused, this creates not only mistrust but also a feeling of being uncovered.

The Danish philosopher and theologian Lögstrup (1992) considered trust to be a fundamental manifestation of life and as such it cannot be created but is given in our lives. Trust belongs to an ethical dimension of life together with other life manifestations, such as openness, honesty, sympathy, compassion, hope, indignation and respect for integrity (Lögstrup, 1988). These life manifestations can also be addressed as ethical life phenomena (Delmar, 2012b). In contrast to needs that could be of physical, social or cultural nature, life phenomena do not explicitly call for satisfaction and they often tend to be invisible. They demand that the nurse be attentive to their occurrence when caring for the ill and vulnerable person. If the nurse is not in the present, or adheres to a more or less instrumental-technical way of nursing, there is a risk that the nurse becomes blind to the existence of these life phenomena with their importance to the patient's life and health as a whole (ibid.).

Caring is something that occurs between the caregiver and the patient and is consequently, in accordance with Martinsen (2012), to be seen from the perspective of interdependence (Lögstrup, 1992). In every relation characterized by dependence, power is to be found, and therefore an ethical attitude is a prerequisite for not abusing this power (Delmar, 2012a). Power thrives in asymmetrical relations, and that is why a person that shows trust also becomes vulnerable (Nortvedt & Grimen, 2006). All care relations are asymmetrical to their nature, consisting of a stronger and a weaker part, where the patient is the frail part because he/she is the one that is dependent. In care situations where the patient is not conscious, or has a reduced cognitive capacity, this becomes even more obvious, and questions about consent to care then turn out to be delicate. The overall purpose with informed consent has to do with morals, in that it aims at protecting the patients from preventable harm, and at improving the quality and safety of health service provision (Johnstone, 2016). In providing care to such vulnerable patients, the nurse/carer can either address consent as *tacit,* that is consent without explicit signs, or as *inferred*, addressing the judgement of what the agent would have agreed to under certain circumstances (Dworkin, 1988).

In a recent systematic review of patients' experiences of trust in the patient-nurse relationship, it was concluded that the patients' trust is dependent on the knowledge of the nurses, on the level of the nurse's commitment in the dialogue to develop the relationship, and on contextual issues (Rørtveit, 2015). Trustful relationships are of importance to care, not only from the perspective of the patient but also from the perspective of the nurses/carers, because if the nurses/carers are not trusted by the patients, they cannot carry out their duties (Nortvedt & Grimen, 2006). This shows the importance of interdependence, being a two-way dependence, which risks creating difficulties if the relationship does not work, in that care will not be provided nor received.

Hence, the connection between trust, power, and interdependence is very much inherent in care. It is therefore important that health professionals never cease to reflect over the two interrelated human activities, needs and life phenomena (Delmar, 2013). Then the interdependence between the patient and the nurse will be more balanced, leading to trustful relationships where patient autonomy may be respected.

Patient participation in care

Active patient participation in care arises from both the worldwide striving for human rights (Rothman, 2001), and social, cultural, ethical and juridical influences (Pierce & Hicks, 2001). It could however, be questioned if and when a patient is actually invited to participate in decision-making although Swedish health legislation, for example, claims that care should be performed through good care relationships and with respect to the patient's integrity and self-determination (SFS 1982:763; SFS 2014:821.

Recent developments related to the Internet and information and communication technology have resulted in people nowadays being better informed about their health and illness, as well as their legal rights. This highlights a somewhat new role for the patient, being not only a care receiver but also a care planner, a care demander and a partner in care (Ekman et al., 2011). In respecting individuals as persons and allowing them to make rational decisions and determine their own ends, there is a shift in thinking about the role of the patient in health care decision-making (McCormack, 2001). In providing conditions for true patient participation, the professionals need to respect the patients and share knowledge with them, in that each patient's description of his/her body and situation becomes acknowledged (Eldh, Ekman, & Ehnfors, 2006; Eldh, Ekman, & Ehnfors, 2008). If the patient through an altered knowledge might pose demands and questions, and take sides with different caring actions, and make active and deliberate decisions according to this knowledge, this might strengthen their autonomy (Keenan, 1999).

Nevertheless, decision-making can be stressful, confusing and can create uneasiness and is therefore not always experienced as positive by the patient (Pierce & Hicks, 2001). Some patients could be characterized as "autonomists", which implies that the patients want to make the important decisions themselves, whilst others prefer to hand over the important decisions to the professionals, being therefore characterized as "delegators" (Flynn, Smith, & Vanness, 2006). Neither do all patients want to be "customers" or "experts" in relation to the health care system (Glasdam, Oeye, & Thrysoee, 2015). Instead they want to be regarded as patients, that is, a person consulting an expert for help and advice, which can lead to a partial resistance to the decision-making process.

Patient participation and non-participation are not experienced in the same way by patients and nurses (Eldh, Ehnfors, & Ekman, 2006). From the view of the patients, participation means "being responsible and accepting responsibility", whereas from the view of the nurses it is about "getting information and security to act". Patients interpreted non-participation as "lacking an equal relationship while being controlled" whereas in contrast, nurses viewed non-participation as "not accepting". Challenging factors to patient participation could be the patients' willingness and the nurses' approach, as well as confusion around expectations and roles (Tobiano, Marshall, Bucknall, & Chaboyer, 2015). In contrast, factors that promote patient participation include information-sharing and patient involvement in assessment and care planning, which is very much in line with the findings from a previous concept analysis of patient participation (Sahlsten, Larsson, Sjöström, & Plos, 2008).

Patient participation in emergency care has been shown to take place under conditions dictated by the staff (Frank, Asp, & Dahlberg, 2009). Additionally, and because of the asymmetrical relationship between laypersons and professionals, the question has been raised whether patient participation in its ideal form can be reached (Angel & Frederiksen, 2015). However, if the paternalistic dominance as a decision-making model is abandoned, and instead a dialogue that focuses on patient participation as shared decision-making is initiated, the violation of human dignity may be prevented (Holm, Lyberg, Berggren, & Severinsson, 2014). This dialogue could be facilitated by adopting a patient-centred approach using bedside handovers for example, to involve the patients in their own care (Bradley & Mott, 2014). In addition, a caring climate where nurses perceive the patient involvement as less of a hindrance in their work, could lead to nurses being more responsive to patient needs (Arnetz & Zhdanova, 2015). This could also lead to an improved information exchange and a discussion of suitable activities post-discharge.

Patient participation in nursing care on medical wards is still passively desired, perceived and enacted by both patients and nurses (Tobiano et al., 2015). This could be expected to be even more prominent in highly technological care environments, these environments being traditionally influenced by a paternalistic viewpoint of the patient. Recent research indicates, however, that the promotion of patient involvement in patient safety while under hospital care, is an important component especially in the management of long-term conditions (Vaismoradi, Jordan, & Kangasniemi, 2015). A need for the patients to understand that they are allowed to inform the nurse of adverse events was discovered, and the researchers concluded that the patients play a significant role related to their in- hospital safety. This involvement could be one way for patients to feel that their role of patient can be acknowledged as participatory, which could have an impact on their future care, which in some cases will be AHC.

Highly technological care

Highly technological care (HTC) is more and more frequent in both inpatient and outpatient care environments. It has traditionally been a context often characterized by paternalism and advocacy as most patients in need of highly technological care are critically ill, often with an impaired physical and/or cognitive capacity, as they suffer from severe illness or long-term conditions. In addition, the technology involves an extra dimension of dependence that sometimes makes it more difficult for the person to preserve or achieve autonomy in the role of patient. The coming passage will shed some light on the concept of technology itself and of paternalism and advocacy, in nursing and caring. Two examples of highly technological care contexts, the inpatient context of intensive care and the outpatient context of advanced home care, being the contextual basis for this thesis, will also be addressed.

The concept of technology in nursing and caring

The concept of technology in the caring and nursing literature has been shown to be multifaceted, referring to modern information technology, high-tech and advanced device technology, simple tool technology and assistive technology (Korhonen, Nordman, & Eriksson, 2015). It is often concealed and not reflected on until failure occurs or if a lack of utility becomes apparent (A. Barnard, 2002). Barnard (1996) illustrates the meaning of medical technology in nursing as seen from three different layers of meaning, with the physical objects such as medical devices being the most obvious. The second layer contains the knowledge about the technology and how it is used and in the final layer, technology could be seen in relation to human activities. The concept of technology, referring to caring science, has also been determined to have a two-dimensional nature, being advanced and progressive and at the same time demanding, difficult and routine (Korhonen, Nordman, & Eriksson, 2014). Thus, the complexity of the concept of technology in nursing and caring leads to different demands on the nurse in highly technological care environments, as he/she is expected to ensure that the use of technology and scientific advances are compatible with security, dignity and human rights (ICN, 2012).

Paternalism and advocacy in caring

The principle of autonomy may be difficult to apply in patient care when the nurse believes that respecting the individual choice made by the patient is not in the patient's best interest (Fry & Johnstone, 2008). Then the nurse may need to consider the criteria for justified paternalism, overriding the individual choice of the patient, in order to provide benefit to him/her (Beauchamp & Childress, 2009). This is in part problematic, as it involves the risk of doing harm instead of good to the patient, who becomes left out of the care decision process. For a long time, paternalism has been a means for HCPs to protect the vulnerable patient from harm in different health care situations, and it is most often performed with acceptance from the health care organization (Beauchamp & Childress, 2009). The nurse's exercising of power in different care situations is often unconscious and unintentional, i.e. to a certain degree hidden, but can, nevertheless result in the harmful exercise of power on the part of the carer, or in sentimental care, i.e. overprotectiveness through misconceived attention to the patient in that the care becomes emotional (Delmar, 2012b).

Paternalism in nursing could also be discussed from the view of the caring function itself being the disempowering phenomenon for the patient (Christensen & Hewitt-Taylor, 2006). This is sometimes referred to as "maternalism", being a more gentle way of doing things for the patient as well as protecting him/her from harm, however with the risk sometimes of resulting in overprotective behaviour. If, in contrast, the nurse works out of sensitive, situation-specific attention, this will prevent intimacy and closeness from standing alone (Delmar, 2013). Instead, the nurse/carer will interpret what is most significant in the actual situation, noticing the life phenomena and acting in response to them. When the nurse/carer shows respect for the uniqueness of the patient as well as the patient's self-determination, accepting his/her interpretation and understanding of life and suffering, the patient is given a different status than the one of the asymmetrical relationship (Schuster, 2006). However, this presumes a care relationship between the nurse and the patient which is less marked by asymmetry and instead focuses on reciprocity.

Advocacy has been used as another way of protecting the vulnerable patient. It is regarded as one of the ethical concepts that, together with accountability, cooperation and caring, provide a foundation for nurses' ethical decision-making (Fry & Johnstone, 2008). Advocacy is also to be found in the ICN Code of ethics for nurses (ICN, 2012). The ICN Code addresses the duty for nurses to advocate for equity and social justice in terms of resource allocation, access to health care, and other social and economic services, yet, as in other codes of ethics for nurses, this is done in an ambiguous way which does not provide an actual definition of the concept (Bu & Jezewski, 2007; Kalaitzidis & Jewell, 2015). From the point of view of the philosophy of the nursing profession, nurses ought to be effective patient advocates (Bu & Jezewski, 2007) well placed to act out this charge as they both have the expert knowledge of their patients and of the care context (Kalaitzidis & Jewell, 2015), providing 24-hour continuity of care and are often regarded as patient ”gatekeepers” (Choi, 2015). Advocacy is understood as inherent in nursing (Bu & Jezewski, 2007; Vaartio, Leino-Kilpi, Salanterä, & Suominen, 2006) although there is no great evidence supporting the presumptions that patients want, need or request nurses to represent them, nonetheless they are aware of activities done in the name of advocacy (Vaartio & Leino-Kilpi, 2005).

Advocacy has many faces and could be seen from at least four viewpoints, the patient's, the nurse's, the health care manager's, and the jurisdiction. Attempts have been made to clarify the concept through concept analysis of patient advocacy (Baldwin, 2003; Bu & Jezewski, 2007), of nursing advocacy in community health nursing (Ezeonwu, 2015), and of the barriers to nursing advocacy (Hanks, 2007). As a consequence of a lack of consensus, Kalaitzidis and Jewell (2015) present what they think is the best candidate for a commonly accepted meaning in nursing so far as, “Speaking on behalf of the patient”. There is still, however, an ongoing discussion of the health care management support of the patient advocacy role in nursing practice (Kalaitzidis & Jewell, 2015; Welchman & Griener, 2005) as well as the legislation support for nurses' whistleblowing (Watson & O'Connor, 2015). The ambiguity connected with this concept indicates that it should be used with caution and not without due reflection, as it has the potential to exclude patient participation and autonomy.

Highly technological care environments

In highly technological care environments (HTCEs) the patient is often connected to a large amount of electronical surveillance equipment and sometimes even to life upholding apparatus such as a ventilator or a dialyzer. Initially this was only an issue for in hospital care but during the last decades there has been a considerable addition of the use of medical technology in advanced home care (National Board of Health and Welfare, 2008; World Health Organization, 2008), circumstances that are predictable to an escalation in the coming years (Rechel et al., 2013). A highly technological care environment could be demanding as it comes to both knowledge and decision making, and the patients often have to put their trust in the staff's specific competence in relation to their illness and to the medical technology at their disposal. Nevertheless, nurses have a primary role in interpreting and influencing the relationships between technology, health care praxis and human experience (Barnard, 2002). Moreover, they have accepted the responsibility for a substantial amount of medical technology in health care in addition to daily nursing care in hospitals and the community. However, it is not the technical device *per se* that is problematic, nor that it determines whether a technology dehumanizes or depersonalizes a patient, but instead how the technology is used related to the interaction between caring and technology (Barnard & Sandelowski, 2001).

Advanced medical technology

Advanced medical technology includes different medical devices that are approved for monitoring, preventing, diagnosing, treating, or alleviating diseases. It could also be used to compensate for an injury or a disability (Council of Europe, 1993). Examples of technological devices related to in-hospital advanced medical technology could be: monitoring devices, invasive or non-invasive ventilators, infusion pumps, drug delivery pumps, pain relief and analgesia devices, enteral feeding pumps, wound healing equipment, dialyzers, and equipment for secretion clearance. Many of these devices can also be used in home care, but then often in a more user-friendly and human-centred design (Lathan, Bogner, Hamilton, & Blanarovich, 1999). Additional devices used in advanced home care are liquid oxygen tanks and oxygen generators, for example.

The context of intensive care

Intensive care units (ICUs) are constructed and equipped for saving the lives of critically ill patients and the development has led to the ICU of today being among the hospital units with the highest concentration of medical-technical equipment, thus the ICU is regarded as a highly technological care environment (Fridh, 2009). In intensive care, the nurse-to-patient ratio is higher than in non-critical wards, 1:1-2, and Swedish ICUs are staffed by specialized RNs and by auxiliary nurses. The patient rooms are usually either single rooms (Figure 1), most often with isolation facilities, or multi-bed rooms for two to four patients with folding screens to help preserve patient integrity. However, the ICU environment is not constructed to encourage privacy, as its main assignment is the provision of critical care. The patients are not physically restrained, they are never left alone, and visitors are allowed at any time, day or night.

Figure 1. Picture from a single-bed patient room in an ICU at a Swedish hospital in 2015.

An ICU-environment should not only be understood as a physical place but also as a lived place, where the design influences not only the patient but also the next of kin, the staff, and the moulding of care provision (Olausson, 2014). It is both a technologically intense and a cognitively intense environment (Almerud, 2007), and includes visual influences such as lightning which have an effect on sleep and security (Engwall, Fridh, Johansson, Bergbom, & Lindahl, 2015). It also has sound-intensive influences which leave the patient with a feeling of aimlessly floating in circles with no possibility of taking control over the situation, leading to uncertainty (Johansson, Bergbom, & Lindahl, 2012, p.113).

Patients being cared for in the ICU sometimes feel restrained by technical apparatus which makes the patient feel passive and shut in (Almerud, Alapack, Fridlund, & Ekebergh, 2007). These care experiences give rise to a dependence on the technology itself but also on its experts, the staff. This dependence puts a demand on the staff in caring to be "standing by", attentive to the patient at all times and having the courage, willpower and knowledge to support the patients in striving for independence and a sense of control (Karlsson, Bergbom, & Forsberg, 2012). In intensive care, the patient is often marginalised by the distance created between the patient and the carer as a result of the technical surveillance focusing on the biological body (Almerud et al., 2007). Therefore, there is a risk that the staff take over not only the patients' vital functions but also their decision-making. If, on the contrary, the staff take the time to communicate about what the patient experiences as important in daily life, this may strengthen and stimulate the patient's inherent joy of life and the will to fight (Wåhlin, Ek, & Idvall, 2006). This way of effectuating nursing care could be understood as "confirming nursing" (Meijers & Gustafsson, 2008). This method also includes the supply of information to the patient, as a form of motivational support for the patient to be involved in and to influence care situations, hence increasing the possibilities for patient participation in intensive care.

The context of advanced home care

Advanced home care not only involves the transfer of a particular technology from the hospital to the home environment (Lehoux, 2004). It also demands a transfer of knowledge and skills to lay people, in making the use of technology at home safe and personally satisfying. People in need of home care, including advanced medical technology, are a heterogeneous and primarily nonprofessional group (Lathan et al., 1999). Their user experiences differ, as well as their background, age, and level of professionalism. Moreover, their physical and mental fitness, dedication, and language knowledge are variable, thus complicating the options of using home health care equipment. Exercising self-care while using advanced medical technology at home requires cognitive capacity and a positive attitude to life (Fex, Ek, & Söderhamn, 2009). It also involves planning and adjusting to technology, as well as a process of learning (ibid.). Advanced home care could be rehabilitative or palliative to its nature, and when patients suffer from long-term or chronic illness, the use of medical technology is often permanent. The patients could be running the technology by themselves, or involving their relatives or HCP, who are sometimes fully operating the equipment for the patient (Lathan et al., 1999).

The use of medical devices at home is different from the use in hospital, as the home is more uncontrolled, unpredictable and changeable (Bitterman, 2011). Each home is unique and there is always a need for an adoption of the technology to the current home environment (Figure 2 and Figure 3). The patient's dependence on technology when cared for at home, is different from the dependence when cared for in hospital, as the patient in advanced home care spends most of the day alone with the technology. The dependence on technology is experienced as dichotomous, involving feelings both of being tied up and of feeling free (Fex et al., 2009), as well as of mastering or of being mastered by the technology (Munck, 2011). It has also been presented by the concepts of unburdening and burdening (Lindahl, Sandman, & Rasmussen, 2005), as well as having been found to be a mixed blessing of life-saving treatment and meaningless exertion (Ingadóttir & Jonsdottir, 2006), hence stressing this ambivalence.

Figure 2. Picture from a home care environment including advanced medical technology.

Figure 3. Picture of a person attached to night mechanical ventilation at home.

The home represents the place where a person dictates and makes decisions to achieve his/her best possible conditions (Lindahl, Sandman, & Rasmussen, 2003). It is also the place where a person acts and pursues his/her interests and where friends visit. Bringing AMT into the home environment also has an influence on family and next of kin, who share the everyday life with the patient. As close relatives to a technology-dependent person, they might experience a feeling of struggling in an inescapable life situation that involves both worries, responsibility and endurance (Bjuresäter, Larsson, & Athlin, 2012). The situation may lead to an increased caregiver burden and uncertainty among the next of kin (Munck, Sandgren, Fridlund, & Mårtensson, 2012), as they take on a substantial responsibility for the care of the relative (Fex, Flensner, Ek, &

Soderhamn, 2011; Munck et al., 2012). The next of kin sometimes experience that the technology restricts and affects the private sphere (Munck et al., 2012), and creates a dependence on HCPs and significant others (Fex et al., 2011). Family activities are often scheduled to fit the treatment, with the relatives' best interest in focus, sometimes leading to the next of kin moving their own needs into the background. The patients and their next of kin often become experts as they are dealing with the technology day and night. This sometimes leads to disagreements with the HCPs, and causes an obscurity surrounding decision-making that complicates the care from and relationships with the HCP (Dybwik, Nielsen, & Brinchmann, 2011).

When advanced medical technology is added to the home environment, there is an addition of anxiety on the part of the patient, concerning potential risks such as infections or oxygen mediated fires, but also a need for balancing treatment with meals and other daily activities (Lehoux, 2004). Patients in 24-hour home care experience that they are at risk of receiving unsafe care and they strive for control and safety by developing compensatory processes (Swedberg, Chiriac, Törnkvist, & Hylander, 2012). This lack of safety could also be experienced by close relatives, who feel relief when they can share the responsibility for the loved one with the palliative advanced home care teams (Brännstrom, Ekman, Boman, & Strandberg, 2007). As the workhours and tasks for the HCP are assigned and allocated beforehand, the HCP are neither allowed nor are able to respond to the immediate situation at home, sometimes making it hard for patient or relatives to approach them (Glasdam, Praestegaard, & Henriksen, 2013).

The conceptualization of technology making the home more hospital-like has been discussed, and instead other alternative ways of understanding have been proposed, e.g. the consideration of technology becoming an incorporated part of the home environment (Nagington, Walshe, & Luker, 2016). This way of naturalization and integration of the technology might facilitate the patients' priorities of being cared for at home, despite illness and disease, as it also offers a possibility of being around their family, preserving the feeling of at-homeness (Lindahl, 2010; Öhlen, Ekman, Zingmark, Bolmsjö, & Benzein, 2014). Nevertheless, being cared for at home with AMT does have the potential to change both the home environment, the relations with the next of kin, and the patients' possibilities to fully take responsibility for everyday life. Consequently, more knowledge is needed from the patients' perspective of how to remain or become an autonomous person in their private home, despite the addition of AMT to their home environment.

Rationale

Patient autonomy is a rather abstract and complex phenomenon in health care. The concept of patient autonomy is unclear, and existing knowledge and experience indicate that a consensus among nurses regarding the meaning of this concept is still missing (Aveyard, 2000). When the concept of autonomy is discussed in health care literature, it frequently involves medical or jurisdictional issues in relation to patient care. It also refers to the professional autonomy of physicians, nurses or other HCP, and the patient perspective becomes more or less invisible. Therefore, there is a need for identifying and constructing the meaning of patient autonomy in a caring context (Study I).

Patients in need of intensive care often have difficulties communicating their needs and wishes as they are in many cases suffering from severe illness/ill health, being in need of mechanical ventilation, sedation or lacking metacognitive capacity. Consequently, they are seen as vulnerable with difficulties in remaining or becoming autonomous in the care situation, even if the person is regarded as an active subject in care, entitled to certain legal rights (Levinsson, 2008). Autonomy implies some kind of involvement on the part of the person, that for patients in ICUs is often expected to be impossible. Therefore, to be able to support the patient's autonomy in intensive care, the HCP needs more knowledge from the patient perspective, describing and elucidating patient experiences of autonomy in an intensive care context from a caring perspective (Study II).

In the years to come a larger number of patients will probably be cared for at home and sometimes with an increased use of advanced medical technology. Such a development may lead the patient into a position inherent with a greater responsibility regarding their own care. However, patients in need of AHC are often suffering from chronic illnesses or palliative conditions, which increase their vulnerability and obstruct their possibilities for responsibility as well as autonomy. When AMT is brought into the home area, this changes the appearance of the home environment and it also creates a dependence on technology and formal/informal carers on the part of the patient. In order to support patients in AHC, nurses and other HCP, using the patient's home as a work place (Öresland et al., 2009) need an extended understanding of the patient perspective of autonomy in AHC. Therefore, there is a need to describe and elucidate the meaning of being an autonomous person while dependent on advanced medical technology at home (Study III).

When HCP are required to protect the respect for patient autonomy in highly technological care environments, they need a knowledge basis to rely on. To further clarify this fairly abstract concept of patient autonomy, which nevertheless is crucial in a caring context, there is a need to bring together available scientific knowledge, making it somehow possible to reach an extended and consensual understanding. One way of doing this could be through a metasynthesis of previous findings within a specific research area. By amalgamating basic concept clarification (I) with empirical studies from the context of intensive care (II) and AHC (III), an attempt at concept development might be possible, with the purpose of developing a theoretical framework of patient autonomy in a highly technological care context (Study IV).

Aim

The overall aim of this thesis was to describe and elucidate patient experiences of autonomy in highly technological care environments, and to create an extended understanding of the concept of patient autonomy in a highly technological care context, from a caring perspective.

Specific aims

- To identify and construct the meaning of patient autonomy in a caring context
- To describe and elucidate patient experiences of autonomy in an intensive care context from a caring perspective
- To describe and elucidate the meaning of being an autonomous person while dependent on advanced medical technology at home
- To develop a theoretical framework of patient autonomy in a highly technological care context

Perspective and viewpoints

This thesis stems from the assumption that a person should be understood as a whole, being more than his/her constituent parts, and from the assumption that the human being is essentially vulnerable. When a person is being cared for in highly technological care environments, this vulnerability is presumed to increase as a consequence of the person's illness/ill health, leading to a dependence on others and on technology to manage everyday life. Care in HTCEs involves situations where the patients have to allow a much more intimate relation with the carer than they would have allowed if they had been well, hence accentuating their vulnerability. Nevertheless, the person should still be recognized as a *homo capax* (Ricoeur, 2011), i.e. capable of health and well-being irrespective of disease and illness. This view of the capable patient should be seen as conceivable even in highly technological care environments, on condition that the right prerequisites are at hand, suggesting that the attitude of the formal/informal carer is of great importance.

The choice of caring as the overall contextual concept was made because the patients do not always distinguish between the different professions within the staff, for example between registered nurses (RNs), auxiliary nurses, physiotherapists and staff belonging to personal assistance services. Patients seem to primarily focus on how care related issues are performed and not by whom, as they expect the staff to be trained and educated for their duties. In that way the context of this thesis, although primarily related to the close encounter with the patient, and from the patient perspective, is not restricted to RNs but involves the work of several professions. Caring is of ubiquitous concern to everybody working in health care. At the same time, there is no other discipline but nursing that has developed knowledge essential to all disciplines in which caring relationships are the practice foundation, of how the quality of relationship facilitates health, healing and the quality of life (Smith, 1999). Caring is recognized by several nursing theorists, such as Leininger, Eriksson and Watson, as being the core of nursing (Finfgeld-Connett, 2008). The discussion related to the ambiguity of the meanings of the concept of caring has not hitherto reached a conclusion within the nursing academia. However, this thesis is in line with the thoughts of Rogers, that nursing is an organized body of knowledge, and that this knowledge about the phenomenon of concern determines the nature of the caring (Rogers, 1994). Consequently, as remarked by Rogers, before we can care, we have to know (Huch, 1995), thus acknowledging caring to be more than doing. In conclusion to this complex issue of the knowledge of the discipline, the standpoint for this thesis is in accordance with the conclusive perspective of Smith (1999), that is, for the nursing profession, the concept of nursing ”is not possible without caring even though caring is possible without nursing”.

The long background as an intensive care nurse might have influenced the author’s preunderstanding of the ICU care context from the nurse perspective. However, this is not only negative as it also includes the familiarity with the care environment and the technology itself that could be of great use in the interview situation, both with patients in need of care in the ICU, and when interviewing persons in need of AMT at home. In contrast, the context of AHC was a blank page to the author, without any possibility of having been influenced by previous experiences, with the exception of the knowledge related to advanced medical technology.

Methods

Design and methods

The epistemological perspective of this thesis was heuristic, in that knowledge is not something fixed but continuously changing over time (Rodgers, 2000). This approach was suitable when addressing the old but current concept of autonomy, in that the meaning of a concept is most often context-dependent and affected by the changes in society. Various designs and methods have been used (Table 1), however all adhere to the approach of qualitative inquiry, as the understanding and the meaning of patient autonomy was the focus. Therefore, all four studies used an inductive approach, with the exception of study IV that in addition was deductive, with the purpose of attaining a transparent structure of the work with the theoretical development of the concept.

In the planning phase of this thesis, a consensual lack of the meaning of the concept was found (Aveyard, 2000), and previous research did not address the concept from the patient perspective nor from a general caring context. Consequently, a concept clarification was needed, thus leading to the choice of methods for study I. The Rodgerian method of concept analysis was chosen because it is evolutionary and adheres to the view of findings as a starting point rather than an end point (Rodgers, 1989; Rodgers, 2000). Two empirical studies (II and III) were carried out to further develop the knowledge from study I in relation to highly technological care environments. One inpatient and one outpatient context were chosen to extend the contextual perspective. Individual interviews were used in order to obtain narratives comprising patient experiences and thoughts on patient autonomy. The methods of analysis differed as a means of keeping the inductive perspective as pure as possible.

The final study aimed at theoretical development through the synthesis of previous findings (I-III), in creating a theoretical framework of the concept of patient autonomy in highly technological care environments. The objective was to reach an extended knowledge of the concept to be of use in care and education, but also as a foundation for future research and development, hence adhering to a heuristic approach.

Table 1. Overview of design and methods of the studies in this thesis.

Study	I	II	III	IV
Design	Qualitative; Inductive, Concept development	Qualitative; Inductive	Qualitative; Inductive	Qualitative; Inductive and deductive, Theoretical development
Methods for data collection	Systematic literature search; Medline, CINAHL, The Cochrane Library, PsycINFO Included articles (n=41)	Individual interviews with patients in need of intensive care; open-ended questions Included patients (*n*=11)	Individual interviews with patients in need of advanced medical technology at home; open-ended questions Included patients (*n*=12)	Amalgamation of the findings from study I-III (*n*=3)
Methods for analysis	Concept analysis (Rodgers 1989; 2000)	Inductive content analysis (Elo & Kyngäs, 2008)	Descriptive phenomenology (Giorgi, 1997)	The approaches for theory development (Walker and Avant, 2011)

Study I

Data collection

A systematic electronic search was undertaken in the four databases CINAHL, Medline, PsycINFO and the Cochrane Library, with the purpose of identifying the most relevant publications related to patient autonomy in a caring context. The search was limited to title/abstract/keyword and peer-reviewed articles in the English language published between January 2005 and June 2013. The keywords were searched through a building block strategy, including three search blocks (Figure 4), to attain a balance of high sensitivity and high precision within the search process (Lefebvre, Manheimer, & Glanville, 2011). In total, 2737 citations were obtained from the search and 1951 articles were retrieved for a more detailed consideration (Figure 5). The selection of articles was performed as a three-level selective process on the title, abstract and full-text level, using a review protocol.

Block autonomy

#1 Autonomy (CH)
#2 Autonomy (free text)
#3 Personal autonomy (Mesh)
#4 “Personal autonomy” (free text)
#5 Patient autonomy (CH)
#6 “Patient autonomy” (free text)
#7 #1 OR #2 OR #3 OR #4 OR #5 OR #6

Block nursing/caring

#8 Nursing (MeSH)
#9 Nursing (free text)
#10 Nurs* (free text)
#11 Caring (CH)
#12 Caring (free text)
#13 Care (free text)
#14 #8 OR #9 OR #10 OR #11 OR #12 OR #13

Block patient

#15 Patient
#16 Patient*
#17 #15 OR #16

Combined block search

#18 #7 AND #17
#19 #14 AND #17
#20 #18 AND #19

Figure 4. Search string.
#=search; CH=Cinahl Headings (search terms used for indexation in the database Cinahl); MeSH=Medical Subject Heading (search terms used for indexation in the databases Medline and The Cochrane Library); *=Truncation

A pilot review was performed on the title level to examine the 25 most recently published articles from each of the four databases. The first and second authors then assessed and discussed these articles in accordance with the review protocol for article inclusion or exclusion and the protocol was then revised. When an acceptable inter-reliability (k = 0,9) was reached, these discussions were discontinued, and the first author completed the selection process for all levels. When selection difficulties were encountered, the other authors were used as discussion partners. The quality assessment was met by using peer reviewed papers only, and with the intention to achieve a high level of quality by involving a multiplicity of perspectives on the concept of interest regarding methods/design and theoretical discussions. The final data set consisted of 41 articles.

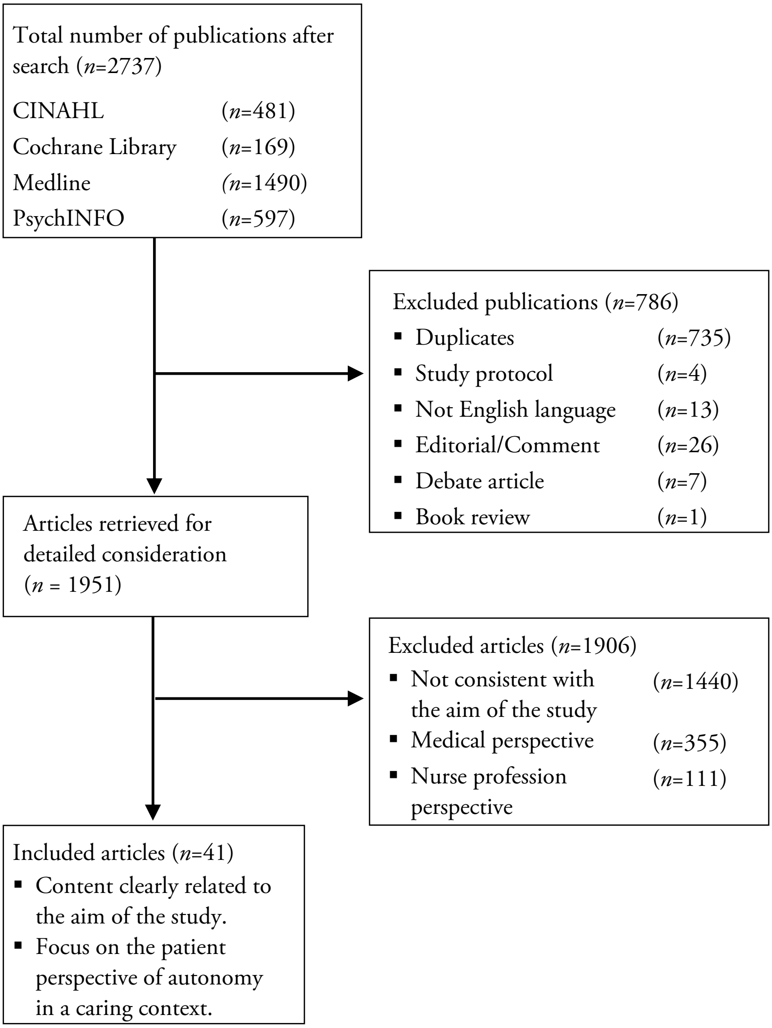

Figure 5. Flow chart of the data selection process.

Data analysis

Concept analysis

The Evolutionary Method of Concept Analysis (EMCA) by Rodgers (1989; 2000) was chosen for the analysis of Study I, in trying to gain an extended understanding of the concept of patient autonomy in a caring context and from the perspective of the patient. Methods for concept analysis are by definition concerned with concepts as clusters of attributes, and there are several methods of use within nursing science (e.g. Chinn & Kramer, 1991; Walker & Avant, 2011; Wilson, 1963). The EMCA has been developed as a means of meeting the criticism of earlier methods (e.g. Walker & Avant, 2011; Wilson, 1963), based on the assumptions that concepts are context-dependent and continuously changing over time, hence to be seen as evolutionary. Although it is not the most frequently used method for concept analysis within nursing, it has been shown to be a relevant method for developing knowledge in nursing science in that it is systematic and focuses on clear phases in the analysis (Tofthagen & Fagerstrøm, 2010).

The philosophical background to this method is foremost to be found in the thoughts of Toulmin (1972), who discusses concepts in relation to the socialization within a discipline. He claims that concepts are important elements in the development of knowledge and a precondition for maintaining continuity and progress in a discipline. Concepts could be regarded as building blocks from which theories are constructed (Rodgers, 2000). Nevertheless, it is important to make the distinction between words and concepts, in that words are manifestations of concepts, and not the concepts themselves (Price, 1953), and that it is a description of, and not the "real" meaning of the concepts that appear through the analysis (Rodgers, 2000).

The analysis was guided by the six steps of the EMCA (Rodgers, 2000, p.85). The *first* step involves an identification of the concept of interest and associated expressions (including surrogate terms), whereas the *second* step contains an identification and selection of an appropriate realm (setting and sample) for data collection. The *third* step involves the collection of data relevant to identify: a) the attributes of the concept, and b) the contextual basis of the concept, including interdisciplinary, sociocultural and temporal (antecedent and consequential occurrences) variations. The analysis of the data regarding the above characteristics of the concept represents the *fourth* step. The *fifth* step comprises the identification of an exemplar of the concept, if appropriate, whereas the *sixth* and last step consists of the identification of implications, hypotheses and implications for further development.

According to the evolutionary nature of the method, the analysis process was followed step by step through reflection, back and forth. In the planning step of the study, the identification of the concept and the appropriate setting was established. An appropriate sample was achieved through the data selection process (Figure 5). Data analysis was performed by gathering single words, sentences or verbatim passages from the articles. These were then entered into a protocol with the predetermined categories:

attributes, surrogate terms and related concepts, references, antecedents and consequences (Rodgers, 2000). During the reading process, notes on withholding reflections were entered into this protocol in a parallel procedure. Repeated discussions took place between the authors before concluding the results. During the analysis, a conceptual understanding of patient autonomy was reached, and a descriptive definition and a tentative model were derived from this work. Two exemplars of the concept were chosen from the data to identify practical demonstrations of the concept. Lastly, implications for further development of the concept were elucidated.

Study II

Setting

Study II was carried out at one thoracic intensive care unit (ICU) and five general ICUs at five county hospitals in south-east Sweden. Each ward could accommodate five or six patients. The nurse-to-patient ratio was 1:1-2, and the wards were staffed by RNs with intensive care specialization and by auxiliary nurses, with the exception of the thoracic ICU that was staffed exclusively by RNs. The ICU rooms were either single rooms with isolation facilities, or multi-bed rooms for two to four patients. The multi-bed rooms were equipped with folding screens to help preserve patient integrity. The patients were not physically restrained, were never left alone and visitors were allowed at any time, day or night.

Data collection

The study was performed with assistance from intensive care RNs, the majority of whom were linked to the intensive care after-care service, and who operated as contact nurses. These RNs identified the informants, provided verbal information about the study and handed over an information letter on behalf of the researcher, as a preventive measure to avoid having the patient feel obliged to participate. For the purposes of short-term memory transition, the interviews took place on the general hospital wards to which the informants had been transferred following discharge from the intensive care unit. The recruitment was dependent on the process of identifying informants as well as on the patients' health condition. The data collection process took place between March 2013 and April 2014. The interviews were carried out within the following post-ICU time ranges: ≤1week (*n*=7), 2 weeks (*n*=1), ~3 weeks (*n*=1), ~4 weeks (*n*=1) and 7 weeks (*n*=1).

The interviews took place in the patient room with only the researcher and the participant present, with one exception when a spouse arrived during the interview. Before the interview began, the participant was once more informed about the study and the voluntariness of participation, and had the opportunity to ask questions. Breaks were taken when the patient needed to recover breath or rest for a while. The following two main open-ended questions constituted the base for the interview guide: *"Could you tell me about your stay at the intensive care unit?"* and *"Could you tell me about the opportunity to participate in and influence decisions about your care?"*

When appropriate, additional questions and probe questions were asked. The interviews were recorded and transcribed verbatim, including remarks on pauses, laughter and so on. The length of the interviews varied from 12 to 97 minutes (median 54).

Participants

The inclusion criteria for partaking in the study were: adult patient (18 years or over); an ICU care episode of two days or more, including a need for various forms of medical technology; recall of the ICU care episode; and being oriented in terms of time and space. Thirteen patients who met the inclusion criteria were asked to participate in the study. Seven men and four women (*n*=11) were included (drop-outs *n*=2, [death prior to interview *n*=1; late withdrawal *n*=1]). They were aged 34-75 years (median 54.5), and had an ICU care episode of 2-28 days (*n*=7), 29-56 days (*n*=2), 57-84 days (*n*=1), 85-112 days (*n*=1), (median 10). The participants had a variety of admission diagnoses, mainly related to major surgery, severe infections and/or respiratory failure. None suffered from a chronic condition prior to the ICU care episode and they had all been admitted to an ICU for the first time.

Data analysis

Inductive content analysis

In study II, qualitative content analysis was used in accordance with the inductive approach of the content analysis model produced by Elo and Kyngäs (2008). This model corresponds to conventional content analysis (Hsieh & Shannon, 2005), which is often used when existing theory or research literature is limited, as was the case in this study. The conventional approach allows the categories to emerge from the data, hence it is inductive, with the advantage of gaining direct information from study participants without imposing theoretical perspectives or predetermined categories. Qualitative content analysis is not a single method but a widely used qualitative research technique (ibid.). It is used to interpret meaning from the content of large amounts of textual data, and with the goal of providing and understanding the phenomenon under study (Downe-Wamboldt, 1992). Content analysis provides a mechanism to yield interesting and theoretically useful generalizations with minimal loss of information from the original data (ibid, p.320).

The method of analysis used consists of the following six steps to organize the qualitative data: making sense of the data and the whole, open coding, coding sheets, grouping, categorization, and abstraction (Elo & Kyngäs, 2008). Each step of the analysis was performed in relation to the aim of the study. First of all, the interviews were repeatedly read by the first author with the purpose of becoming immersed in the data. Then the first author open-coded one of the interviews, and this work was checked by the other authors to validate the coding process. The first author then completed the open-coding process for all the interview texts. The first and second authors worked together on the remaining parts of the analysis. The codes emanating from the process of coding each interview, were compiled into a coding sheet. Then the codes were put into tables and grouped, over and over again, according to similarities and differences in terms of patient autonomy in intensive care. Next step was the categorization, when the codes were put into *subcategories* that described the content. This was followed by an interpretation of these subcategories to reduce their number, as they were subsequently grouped under the higher-order headings of *generic categories.* In the final step of the analysis, the generic categories were grouped and once more reduced through abstraction, to a *main category* that reflected the abstracted findings. Finally, to avoid bias, the last author read all the interviews, checking the categorization and interpretation of the texts, as a validation of the analysis.

Study III

Setting

The care setting of study III was the one of advanced home care, which in this thesis is defined as home care including advanced medical technology. In the context of Swedish AHC, it is the county councils/regions, 20 in all, that are responsible for health care related to hospital care and emergency care. The responsibility for the delivery of home care and the care of the elderly and disabled i.e. for most of the care delivered outside the hospital, lies with the Swedish municipalities.

The AHC involved the introduction and education from RNs related to the new medical device. It consisted of non-institutional care on a daily or weekly basis or sometimes only periodically. The AHC was provided by formal carers such as municipality nurses, RNs from nurse-led clinics, palliative care teams connected to the hospital, HC assistants, or through cooperation between these actors belonging to different organizational units. The care could also be supported by informal carers, that is family members and next of kin. The medical devices used in this study are displayed in Table 2. As the health condition of some patients required more than one device, the total number of devices used (*n*=19) is consequently larger than the number of participants (*n*=12).

Table 2. Overview of advanced medical technology used in study III.

Medical device	Number of users (*n*)
automated peritoneal dialyzers	2
invasive ventilator	1
non-invasive ventilator	3
cough assistance	1
equipment for secretion clearance	2
oxygen concentrator	1
nebulizer	1
intravenous infusion pumps	2
drug delivery pumps	1
pain relief and analgesia devices	4

The home environment sometimes included other supporting technical equipment besides the medical device, for example, lifters, therapeutic mattresses, gliders, wheelchairs, and walking frames. The setting could also include supportive functions such as home care services from once a week to eight times a day, and personal assistance services in terms of full-time, or almost full-time, day and night service.

Data collection

The individual interviews were carried out between May 2013 and October 2014 in two different counties in the south-east of Sweden. The participants were identified with assistance from contact RNs, the majority of whom were linked to nurse-led clinics working with patients in need of advanced medical technology at home. When including participants, the intension of purposeful sampling was used. When AMT is introduced into the patients' homes, they usually need some time to become familiar with the new technology and its influence on daily life. Therefore, the interviews were planned to take place not earlier than two weeks after the implementation of the medical device at home. To avoid the patient feeling obliged to participate, the RNs identified the patients, provided verbal information about the study, and handed over an information letter on behalf of the researcher. When each patient had become acquainted with this information and had given a verbal agreement to being contacted for an interview, the RNs informed the researcher. The contact nurse also supplied the researcher with the patient's telephone number, so that the date, time, and place for the interview could be set through a call to the patient.

The participants were encouraged to choose the environment for the interviews, which in all cases turned out to be their home. The interviews took place within the following post-device introduction time ranges: <1 month (*n* = 2), 1 to 6 months (*n* = 4), 12 to 24 months (*n* = 4), and approximately 96 months (*n* = 2). A total of 12 interviews were carried out. The interview began with small talk about everyday topics and then gradually moved to the participants' current health status and the medical technology in use at home. Then the audio recorder was prepared, and the papers of consent were filled out. Finally, the two open-ended interview questions were raised: *"Could you tell me about your experiences of home care including advanced medical technology?"* and *"Could you tell me about your opportunities to participate in and influence decisions about your care?"*

The focus of the interviews was to obtain narratives about the lived experience of the phenomenon, revealing the meaning of being an autonomous person while dependent on advanced medical technology at home. When appropriate, additional questions and probe questions were asked. The interviews were recorded and transcribed verbatim, including remarks on pauses, laughter, and so on. Their length varied from 21 to 90 minutes (median 53).

Participants

Fifteen patients were asked to participate in the study. They all met the following inclusion criteria: adult person, in need of various forms of advanced medical technology at home, and oriented in terms of time and space. Eight women and four men, in total 12 patients, were included (dropouts *n*=3 [death prior to interview *n*=1; late withdrawal *n*=2]). In addition to the need for AMT, some of them also needed daily personal care, indicating their dependence and the severity of their health condition. The participants were 42 to 78 years old (median 61.5 years), and they were all suffering from a long-term and/or palliative condition. Their diagnoses were mainly related to cancer (*n*=5), kidney failure (*n*=2), muscle disease (*n*=2), respiratory failure (*n*=1), post polio (*n*=1), and rheumatologic disease (*n*=1). Four of the participants lived alone whereas the other eight were cohabiting, and they had children that had either left home or, in two cases, were still living at home.

Data analysis

Descriptive phenomenology

The Husserlian phenomenological theoretical perspective was employed in the analysis of study III. This perspective implies the use of a life-world approach to grasp the whole meaning of an experience, and gives attention to the person's lived situation and social world, thus avoiding reductionism (Dahlberg, Drew, & Nyström, 2001). The Husserlian phenomenological philosophy is descriptive, searches for the essence of the most invariant meaning, uses the phenomenological reduction, and is focused on the intentionality, referring to the intentional act by which every human being is related to the world and objects (Giorgi, 1985).

According to Husserl (2000) the content of mental states and processes are different from what psychologists in general claim. He stresses that the content in mental processes refers to real meaning content possible to describe via a phenomenological reduction of spontaneous meaning units. The descriptive phenomenological human-scientific method of Giorgi (1997) is built on the theses expressed in the major philosophical work of Husserl (2000). Nonetheless, Giorgi claims that phenomenological analysis deals with contents of mind, departing from the Platonic view which sees these as objectively existing (Copleston, 1999), instead claiming that they are presenting themselves to consciousness via perception.

The work with the analysis was made in accordance with the methodological outline by Giorgi (1997), founded in Husserlian phenomenological philosophy, because of its relevance in having been developed to facilitate the analysis of empirical data, and to nursing research (Giorgi, 2000). When adopting descriptive phenomenology, it is essential to minimize the influences of experiences and values held by the researchers.

This is often described as "bracketing", aiming at putting past knowledge related to the phenomenon of interest into brackets, so that it has a chance to present itself in its fullness (Giorgi, 1997, 2009). Throughout the work with the analysis, the researchers kept the language as close as possible to the participants' original expressions. In that way, they preserved the approach of descriptive phenomenology in trying to avoid interpretative influences intruding from their preunderstanding. There was a holding back from theoretical influence, and the divergent experiences and knowledge within the research group were used as an aid to accomplish the task of staying open to the data and to avoid being affected by the group members' preunderstanding of the phenomenon.

The application of the descriptive phenomenological analysis within this study is presented as a step-by-step description in Table 3. It is founded in Giorgi's methodological outlines (1997), applied however in an empirical environment of personal interview texts, not philosophical or theoretical texts discussing methodological or theoretical issues. The first and last author worked together with the analysis, reading the texts separately and reflecting, prior to joint discussions. The other members of the research group were provided with selections of this work as a stepwise validation of the work in relation to the original interview texts.

Table 3. Overview of the analysis process of study III.

Step 1	Collection of verbal data through narrative patient interviews. Prompts were used to deepen the interview person's reflections about his or her situation.
Step 2	A perusal of the transcribed texts from the 12 interviews. The texts were then reread to identify meaning units in relation to the central phenomenon stated in the aim of the study.
Step 3	The phenomenological reduction of the spontaneous meaning units, implying that a scientific perspective should be chosen for the analysis to sustain the language used in the specific discipline, and not everyday language. The scientific perspective of caring science was chosen and the spontaneous meaning units were reformulated, shortened into usages expressed in the third pronominal grammatical form.
Step 4	The 12 interviews were once again reread to get a sense of the whole without stating or looking for themes in the texts. During this thorough reading, four constituents* became apparent emanating from the data itself. These constituents were shown to belong to the essential features of the life world, namely the features of embodiment, sociality, spatiality, and temporality. These interrelated features were then used to organize the phenomenological reduced meaning usages of content, centering the further analysis of themes, describing the participants lived experience. Each interview was analyzed separately and the reduced meaning usages for each constituent were listed. Then a comprehended text was formulated for each one of the four constituents.
Step 5	An integrated text were constructed from the comprehended texts from step 4, to express the essence of each interview. Parallel to this analytical process to describe the structure of essence, the interrelationships between the constituents were analyzed. This part of the analysis was both descriptive and interpretative in its nature as it was the strength of, and not the number of, verbal expressions giving impact to a constituent, that was taken into consideration.
Step 6	Similarities and differences between the 12 single essences and structures were compared to elucidate the meaning and interrelationships between the constituents. Internal themes emerged within the descriptions of each of these constituents. A final text was then constructed describing the most invariant essence of the phenomenon, that is, the general description of the structure, including the essence structure given as the structure of the constituents.

*According to Giorgi (2009), constituents are interrelated parts of the data with a role in the whole and they could be of help in creating a structure within the analysis.

Study IV

Study IV had the design of theoretical development, with the purpose of creating a theoretical framework to be of use to nurses in highly technological care environments to support and defend the patient's autonomy. The role of theoretical knowledge is to enhance thinking and deepen understanding, thus making it intellectual (Sarvimäki, 1994). In a practice discipline such as nursing, theoretical knowledge helps to improve nursing practice because nursing science produces tools for reflection. In the work of clarifying a discipline, the theoretical development is of importance (Pörn, 1985), and therefore prominent in both nursing care and nursing education.

When using qualitative methods, the researcher handles concepts and constructs that are theoretical entities with the purpose of *representing the empirical world as accurately as possible* (Morse, 1997b, p.168). Qualitative theory resembles reality and is pragmatic and tolerant of ambiguity. It is systematically developed from both empirical data and the cognitive analytical practices of synthesizing, theorizing and confirming (Morse, 1997b). It should not be seen as representing pure fact, which could blind the investigator and threaten the validity, but instead be understood as a creative and innovative process of knowledge development.

Most qualitative and quantitative nursing research is descriptive, and does not use the tools for synthesizing results. As a replacement for such a design, researchers are constantly initiating new, single studies. However, there are nursing academics who support and encourage qualitative synthesis in that it facilitates better use of research findings (Morse, 1997a; Sandelowski & Barroso, 2007). In synthesizing related data into a greater whole, such as a theoretical model or a conceptual framework, it is possible to obtain new knowledge of use to both academia and the discipline.

When accomplishing a synthesis, the objective is to gain an interpretive explanation, or an understanding, of a phenomenon and it is therefore interpretative and not aggregative in nature (Jensen & Allen, 1996). As there is no correct view of a phenomenon, the researcher instead searches for the consensus of the nature of the phenomenon, with the goal of obtaining new understanding (Jensen & Allen, 1996; Morse, 1997b). When carrying out a research synthesis project, the data is not original, but rather the findings presented in reports from the included studies. Therefore, it is important to retain the qualitative research attitude of reflexivity and critique, as well as the nature of qualitative research design, to avoid misinterpretation of researchers' findings (Sandelowski & Barroso, 2007).

Metasynthesis

This study was performed as a metasynthesis through the amalgamation of the results from study I-III of this thesis. The studies included have been carried out by members of the same research group, as was this synthesis, using different forms of qualitative analysis and focusing on the phenomenon of patient autonomy from a patient perspective within a caring context (I), to attain a basic understanding of the concept, and then henceforth in a highly technological care context (II-III).

In the work with the analysis, the theoretical model, "The Nine-Field-Model" for Evaluation of Theoretical Constructs in Nursing, hereafter "The Nine-Field-Model", was a source of inspiration (Gustafsson & Andersson, 2001a, 2001b) (Figure 6). The model provided a scaffold structure, deductive in nature, which was used as a means for sorting the inductively revealed data. "The Nine-Field-Model" contains nine fields, adhering to three different comprehensive perspectives that can be useful for organizing the hierarchy in nursing knowledge, which was the intention behind its use in this study (Gustafsson & Andersson, 2001a).

*Process: **Levels:	Model	Hypothesis	Theory
Scientific "episteme"	*Field 1* Scientific model	*Field 2* Scientific hypothesis	*Field 3* Scientific theory
Technological "techne"	*Field 4* Prescriptive model	*Field 5* Prescriptive hypothesis	*Field 6* Prescriptive theory
Technical "phronesis"	*Field 7* Process model	*Field 8* Process hypothesis	*Field 9* Process theory

*The process from abstract to concrete (from model to theory); **The relationship between the levels of knowledge and the intellectual virtues of Aristotle. Reprinted with permission from the authors, Gustafsson & Andersson (2001a, p.14).

Figure 6. Overview of the "The Nine-Field-Model".

"The Nine-Field-Model" for Evaluation of Theoretical Constructs in Nursing

A short description of the different comprehensive perspectives within the "Nine-Field-Model" (Figure 6) will be provided as follows. The "first comprehensive perspective" differs between models and theories, from abstract to concrete, and reserves the term "theory" for the closures of all the assumptions of the model that the theoretical hypothesis involves (Gustafsson & Andersson, 2001a).

The "second" comprehensive perspective refers to the scientific, technological and technical level of knowledge (Gustafsson & Andersson, 2001a). On the *scientific* level of knowledge in nursing, the knowledge is science, i.e. basic nursing research answering to the queries of "knowing what" and "knowing why". The theories generated on this level are theories “of” something and could be seen as scientific maps of propositional statements regarding the matter in question. On the *technological* level of knowledge in nursing, the knowledge concerns clinical nursing research based on successful scientific models trying to resolve a distinct problem through the knowledge of “knowing how”. The theories on this level are prescriptive, that is theories “for”, focusing on a distinct entity in the real nursing practice and with solutions formulated as testable nursing principles that may be tested as being either true or false.

On the *technical* level of knowledge in nursing, the knowledge has to do with clinical practice and not research and answers to the query of “knowing that”, which is applied knowledge based on “knowing why” and “knowing what” on the scientific level, and “knowing how” on the technological level. The theories on the technical level are theories “in” referring to skills and techniques focusing on a distinct entity in the real nursing practice and based on hermeneutic understanding. A theory on the this level is called a process theory and concerns the nursing process with the goal of nursing practice as preserving and supporting the patient’s good life, and is used for planning and performing nursing actions in relation to an individual patient (Gustafsson & Andersson, 2001a).

The “third” and last comprehensive perspective is the one of the intellectual virtues of Aristotle, i.e. episteme, techne and phronesis. *Episteme* should be understood as the knowledge virtue – epistemology – focusing on the knowledge of: understanding, invariability in a holistic view of human concerns, general connections, and of knowledge production (Gustafsson & Andersson, 2001a, p.13). *Techne* is to be seen as a technological virtue – technology – and is context-dependent related to the craft or the art. *Phronesis* has to do with what is good or desirable in relation to the unique individual and is to be understood as a value virtue – ethics – being context-dependent and related to knowledge of ethical qualities.

Theoretical development

In the work with the theoretical development of the concept of patient autonomy in a highly technological care context, the three basic approaches of theory development by Walker and Avant (2011) were adopted. These approaches, derivation, synthesis and analysis, provide an operational structure that also permits the researcher to move back and forth between them during the work, as was done when carrying out this study. In the presentation of information related to the different fields of the “Nine-Field-Model” (Figure 6), they will from now on be announced as (Field 1), (Field 2) etc.

The approach of *derivation* allows the researcher to transpose and redefine a concept, statement, or theory from one field context to another, which in this study initially involved reading through the findings from the three included studies in an attempt to obtain an overall view of the concept. The texts were then reread several times with the purpose of identifying important data and key concepts within the findings that elucidated the most significant features of the concept of patient autonomy. These features were first gathered in a conceptual mind map to provide an overview of the phenomenon. Later these significant features were deductively sorted into levels of knowledge (Table 4), to create a new way of approaching the data and yet adhering to the qualitative research attitude of reflexivity and critique (Sandelowski & Barroso, 2007).

When following the approach of *synthesis,* the researcher is allowed to combine isolated items of information that have not yet been connected (Walker & Avant, 2011). This consisted of reflecting once more on the data within the different levels of knowledge. The *first* level involves being scientific – knowing what/why. The *second* level involves being technological – knowing how, and the *third* level involves being technical – knowing that – to gain an understanding of the interrelationships between the items of information. The interpretation resulted in the creation of triangles containing the meaning of patient autonomy. The triangle representing the first level contained patient experiences and thoughts on autonomy. The triangle representing the second level contained patient experiences and thoughts on how autonomy should be met. The third triangle, representing the third level, contained the prerequisites underpinning patient autonomy. Lastly, these triangles were amalgamated in the creation of a theoretical framework of patient autonomy in a highly technological care context.

In the approach of *analysis* the researcher is allowed to break the whole into its component parts to reach a better understanding of the relationships between each of the parts and the whole (Walker & Avant, 2011). This was made by reflecting once more on the content synthesized above and by examining the different parts and their relationships and attempting to grasp the entirety of the concept of the study. An emerging scientific theory[3] of patient autonomy in a highly technological care context was delineated, and propositional statements were constructed (Field 3). The analysis also resulted in an outline of a premature prescriptive theory and its governing nursing principles (Field 6). Finally, a tentative process theory with underpinned assumptions, hypotheses and propositional statements was delineated (Fields 7-9).

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[3] The term *theory* is used in accordance with the vocabulary of the Nine-Field-Model, even though the theories, delineated on the scientific, technological and technical level of theory, should be seen to be in their infancy, requiring further development.

Table 4. Data related to patient autonomy underpinning different levels of knowledge.

Level of knowledge	Examples of important data and key concept features (I-III)	Expressing (study IV)
Scientific	• illness-related • vulnerability • the lived body • capability of the lived body • control of everyday life: preserving (trust in oneself) or surrendering (trust in others) • the will to continue to live • doing one's utmost • agency vs capability: exercising self-care, managing technology, managing informal/formal careers	Patients' experiences and thoughts about autonomy
Technological	• being recognized by others: noticed, asked, listened to, shown respect, given information • being involved: in care decisions and in care • avoiding too much responsibility: tiresome, demanding, being allowed to be ill • co-determination: participation, being a team member,	Patients' experiences and thoughts about how autonomy should be met
Technical	• autonomy is transformable: adapting, befriending, (re)constructing • spatial influence: the environmental power structures reign; inpatient care vs home care • interdependence: trust, ethical demand, mutuality, partnership, relationships, sociality	Prerequisites underpinning patient autonomy

Ethical considerations

This thesis was guided by the ethical principles for research outlined in the Declaration of Helsinki (World Medical Association, 2013), prescribing research involving people to answer to the prerequisites of being valuable to mankind. They also prescribe the use of informed consent, comprising the possibility to discontinue participation at any time. The two empirical interview studies (II and III) were approved by The Regional Ethical Review Board in Lund (No. 2012/343), and an additional approval (No.2013/832) authorized the inclusion of another hospital/ICU to facilitate the recruitment process (study II). Prior to the applications for ethical approval, the heads of the involved in-hospital and out-hospital clinics received verbal and written information, and consented in writing to the realization of the studies.

As a means to get in touch with possible participants, and to protect them from feeling obliged to participate, the patients were contacted, informed and recruited by special contact RNs who had taken on this task without compensation. There is, however, a risk that these RNs become conscious or unconscious gate-keepers (Polit & Beck, 2012), making the recruitment by selection out of their own values and beliefs and not from the perspective of the patient. Then the gate-keeper function not only protects vulnerable persons from harm, but also prevents those who would have wanted to take part in the study from actually being provided with the question of partaking, thus hindering the patient's benefit of participation (Alexander, 2010; Orb, Eisenhauer, & Wynaden, 2001). This protective attitude could be understood to answer to the medical ethics principles of non-maleficence and beneficence, but not to the principles of autonomy and justice (Beauchamp & Childress, 2009).

The participants were provided with an information letter from the contact RNs in that they had some time for reflection before they, if agreed on, were contacted by the researcher. Then they could ask questions about the study and their participation. They were also verbally informed about the study and their voluntary participation, and their possibility to withdraw consent without being obliged to explain why. Informed consent was signed prior to the interviews, and for those patients who were too frail to sign, or who suffered from paralysis, their consent was received verbally and recorded.

The participants were also promised anonymity and confidentiality in line with good ethical practice (Swedish Research Council, 2011). Their statements, when quoted in the scientific journal (study II) were de-identified both to person and sex. The hospitals were only addressed as A-E to show the variety in settings, and a participant number was used to show the dependence on different medical devices in relation to a specific quote. The confidentiality of the participants was maintained as all original data stayed within the research group, and when reported outside this group the information was de-identified and presented as overall findings.

When performing research involving vulnerable populations, there should always be a profit in knowledge that is not available in other ways (Medicinska forskningsrådet, 2003). This was taken into account when planning the outline of this thesis. However, if we want to know more about and understand the patient perspective of autonomy in highly technological care environments, the patients, and not proxies or caregivers, have to be properly asked about their thoughts and experiences.

The patients involved in these studies (II and III) should be seen as vulnerable because of their serious or long-term illnesses and frailty. Therefore, the researcher always made a phone call on the morning of the planned interview, either to the hospital ward (II) or to their home (III), to see if the interview was still possible to carry out. More than once the interviews were rescheduled as a consequence of death, re-hospitalization or deterioration in illness. During the interviews there were sometimes a break if the patient was too tired and needed for example to regain breath or to go back to bed. Nevertheless, the patients seemed to be interested in sharing their experiences, and they hoped that their stories would do good for others. This has also been shown in previous research, illustrating that there is strong evidence that involving vulnerable populations in research may not only be harm-free, but also of direct benefit to participants (Alexander, 2010).

Efforts were made to do justice to the rich data gained from the interviews, although the word limitation within most international scientific journals could be restrictive. The participants were offered the opportunity to contact the members of the research group at any time after the interviews. They were also offered a copy of the article, to study the contents of the research after it had been published in scientific journals.

Summary of findings

The patient's experiences of autonomy in highly technological care environments were shown to be about different ways to retain control over everyday life. This seemed to be important if the patients were to keep their status as a person. Trust in self or in others was an essential basis for the patients' possibilities of exercising their autonomy. This was also the case regarding the care relationships with formal carers that should preferably be in terms of co-determination, thus acknowledging the patient as a capable agent. Patients cared for in the ICU wanted to be involved in decisions about their care when their health condition so allowed, and when they were too ill they instead wanted to have the possibility to surrender control to the staff. When the patients living at home were able to exercise self-care and manage the technology by themselves, their chances of maintaining autonomy were shown to be good. In those cases when their physical health declined, they could remain autonomous by managing their informal and formal carers, hence keeping control of everyday life. The advanced medical technology complicated the life at home for the patients in AHC as it changed the appearance of the home and created a constant dependence on the technology that also involved a dependence on HCPs, sometimes challenging the patients' autonomy. However, because of the amelioration of everyday life created by the technology, they endured. When cared for in the ICU, the patients found the AMT to be a natural part of the care environment, and only patients who were in constant need of ventilation seemed to have frequent reflections upon it.

In the following a short presentation of the findings from each study will be presented, concluding with a more extensive presentation of the theoretical framework, developed to extend the understanding of the concept of patient autonomy in a highly technological care context, from a caring perspective.

Through the concept analysis of study I, the meaning of the concept of patient autonomy in a caring context was identified and constructed. The findings suggested a tentative model to be of help in explaining this complex concept. Five attributes were identified: to be seen as a person, the capacity to act, the obligation to take responsibility for one's own actions, process and (re-)constructing, leading to the following descriptive definition: *Patient autonomy is a gradual, time-changing process of (re)constructing autonomy, through the interplay of being seen as a person, the capacity to act and the obligation to take responsibility for one's own actions*. The consequences were identified as preserving control and preserving freedom. The concept arose both in somatic and psychiatric inpatient contexts and in situations related to antenatal screening, chronic illness and end-of-life care, for example. Additional references were associated with a lack of decision-making capacity in persons with psychiatric illness or intellectual disability. “Increased vulnerability” was the antecedent of patient autonomy that came forth in terms of a changed interdependence and/or a need of care support. This increased vulnerability was most commonly shown in relation to frail persons, suffering from old age and/or multiple diseases, but also existing in highly technological care environments. In conclusion, patient autonomy in a caring context is not an absolute and does not need to be the same before, during and after a care episode.

The findings of study II described and elucidated patient experiences of autonomy in an intensive care context. Four generic categories were revealed. The first, *acknowledged dependence*, showed that the ICU patients often had a limited interest in exercising autonomy, because of their lack of strength, and a lack of experience and knowledge about being critically ill. They considered technology as a normal aspect of intensive care, and they did not feel vulnerable despite their condition, but instead safe and grateful to be in the hands of others. The second generic category, *being recognized as a person*, showed that the attitude of the staff was of importance if the patients should feel confirmed. To be able to preserve their autonomy the ICU patients wanted to be noticed, asked, and listened to, be shown respect and given information, thus being treated as individual persons and not being objectified.

Invited participation, being the third identified generic category, indicated the importance of the ICU patients being trusted by the staff and also being expected to be a party in care. This involved encouragement from the staff, letting the patient be a part of the care relationship in that they felt confidence in their own ability. The fourth and final generic category, *becoming a co-partner in care*, involved statements of the participatory aspect of care decision making, being expressed as essential for the ICU patient’s recovery. When participating in care, the patients felt a greater degree of control, thus they could avoid being left to the goodwill of the staff.

The main category “A trajectory towards partnership in care depending on state of health and mutual understanding” elucidated that patients in need of intensive care wanted to be involved in decisions about their care as this creates a trusting and healthy care environment. When their state of health did not allow them to participate in the decision-making process, they wanted to be able to surrender control. When recovering, their experiences of patient autonomy were related to different ways of *co-*determination, i.e. being invited to participate, thus leading to a partnership in care. To enhance the autonomy of patients in intensive care, there is a need for greater awareness about the patient not only being a passive care recipient but also being an active agent and where involvement in decision-making and participation in care are crucial.

In study III the lived experience of being an autonomous person while dependent on advanced medical technology at home, was given in the participants’ narratives as

“Befriending everyday life while bringing technology into the private sphere”. Four intertwined but verbally very different articulated constituents were revealed. The first constituent was described as *befriending the lived body*, indicating that the capability of the lived body was given as the limitation for controlling everyday life. The participants described that their dependency on technology and on formal/informal carers providing them with support created a feeling of being vulnerable, sometimes with the extreme fear of death. The technology created conditions for and facilitated their everyday life, which led to mobility and opportunities for further independence. Nevertheless, the technology caused ambivalent feelings because of it being experienced not only as a help but also as a hindrance to their everyday activities. They also felt a fear in realizing that the need for advanced medical technology was an indication of their deteriorating health condition. However, being proactive led to a feeling of greater independence and the intellectual participation was especially valuable for those who did not have the bodily conditions to influence their situation.

Depending on good relationships, being the second constituent, addressed the relationships with the carers and with the family, which were discovered to be important parts in staying autonomous founded on continuity, locality, respect and mutuality. It was also found to be important to recognize patients as persons to be included vis-à-vis their care, and that nursing care, above all from RNs in regard to availability and technical support, can make the patients feel safe and secure. Therefore, good participation and influence on the care process, i.e. planning and executing their care, were shown to be crucial in strengthening patients in relation to their autonomy in being more independent and confident in their care situation.

The third constituent, *keeping the home as a private sphere*, described the possibility to remain at home as an essential part of what was experienced as private in life. The participants expressed a feeling that the technology challenged their private sphere as the equipment changed its physical environment. Being cared for at home created a feeling of freedom when the patients could manage the technology all by themselves. In contrast, when they were dependent on others to manage their everyday life at home, they felt limited. The changes in the home environment were related to the appearance and sounds from the advanced medical technology and to a need for storage of bulky material linked to this technology. The participants experienced their health status and not the technology *per se* as the major hindrance to activities outside the home. They appreciated not having to put up with tiring journeys to the hospital and preferred the home as their care environment when the support from the health care staff was sufficient.

Managing the time, being the fourth and last constituent, described the participants’ experiences of technology in relation to for example day or night time treatment as a means of being able to continue their work or social life. It also involved expressions of the present life seen from the perspectives of the past and the future. These different views on temporality coexisted in daily life. The present was seen as a busy time because of the time-consuming technology, and the past often recognized with gratitude in respect to good family life. The future comprised a life-long dependence on technology, and the participants' underlying illness created an uncertainty about their life span.

In study IV, a synthesis of the findings from study I-III was the basis for theory development of the concept of patient autonomy in a highly technological care context, leading to "The Control – Partnership – Transition Framework". The theoretical reasoning followed the structure of process, level and field according to the "Nine-Field-Model" (Figure 6, p.53), and the inductively obtained data was deductively collected in this structure resulting in a theoretical outline related to the synthesis of study I-III (Table 5). Some fields have a content that has previously been published (study I-III), whereas other fields contain findings that emanate from this synthesis.

The theoretical reasoning related to Field 3, scientific theory, should be seen as being in its infancy, and consists so far of the propositional statements referring to person, relationships, health, environment and transition (Table 6). These statements should be seen as suggestions building on existing knowledge to be further developed.

Table 5. The theoretical outline for study IV via “The Nine-Field-Model”-structure.

***Process** ****Level of Knowledge**	**Model**	**Hypothesis**	**Theory**
Scientific “episteme”	*Field 1* *Scientific model* The tentative model of patient autonomy [Figure 6] (I)	*Field 2* *Scientific hypothesis* Patient autonomy is a gradual, time-changing process of (re-)constructing autonomy through the interplay of being seen as a person, the capacity to act, and the obligation to take responsibility for one’s own actions (I)	*Field 3* *Scientific theory* The incipient scientific theory of patient autonomy [Table 6] (thesis)
Techno-logical “techne”	*Field 4* *Prescriptive models* The structure of the generic categories and the subcategories of patient experiences of autonomy in intensive care [Figure 2] (II) and The constituents: Befriending the lived body, Depending on good relationships, Keeping the home as a private sphere, Managing the time (III)	*Field 5* *Prescriptive hypothesis* A trajectory towards partnership in care depending on the state of health and mutual understanding (II), is how patients experienced autonomy in intensive care Befriending everyday life while bringing technology into the private sphere (III), is the meaning of being an autonomous person while dependent on advanced medical technology at home	*Field 6* *Prescriptive theory* The person-centred-care-prescribing theory of patient autonomy [Table 7] (thesis)
Technical “phronesis”	*Field 7* *Process model* The assumptions of patient autonomy in a highly technological care context [Table 4] (IV)	*Field 8* *Process hypothesis* Transition in everyday life due to illness/ill health, other people and the environment, is patient autonomy in a highly technological care context (IV)	*Field 9* *Process theory* The control-partnership-transition theory [Table 5] (IV) [Figure 2] (IV) [Figure 7] (thesis)

* The process from abstract to concrete (from model to theory)
** The relation between the levels of knowledge and the intellectual virtues of Aristotle
I-III indicate the different studies underpinning the synthesis
IV indicates the present study
The text within [ ] refers to figures/tables within studies marked in ( )

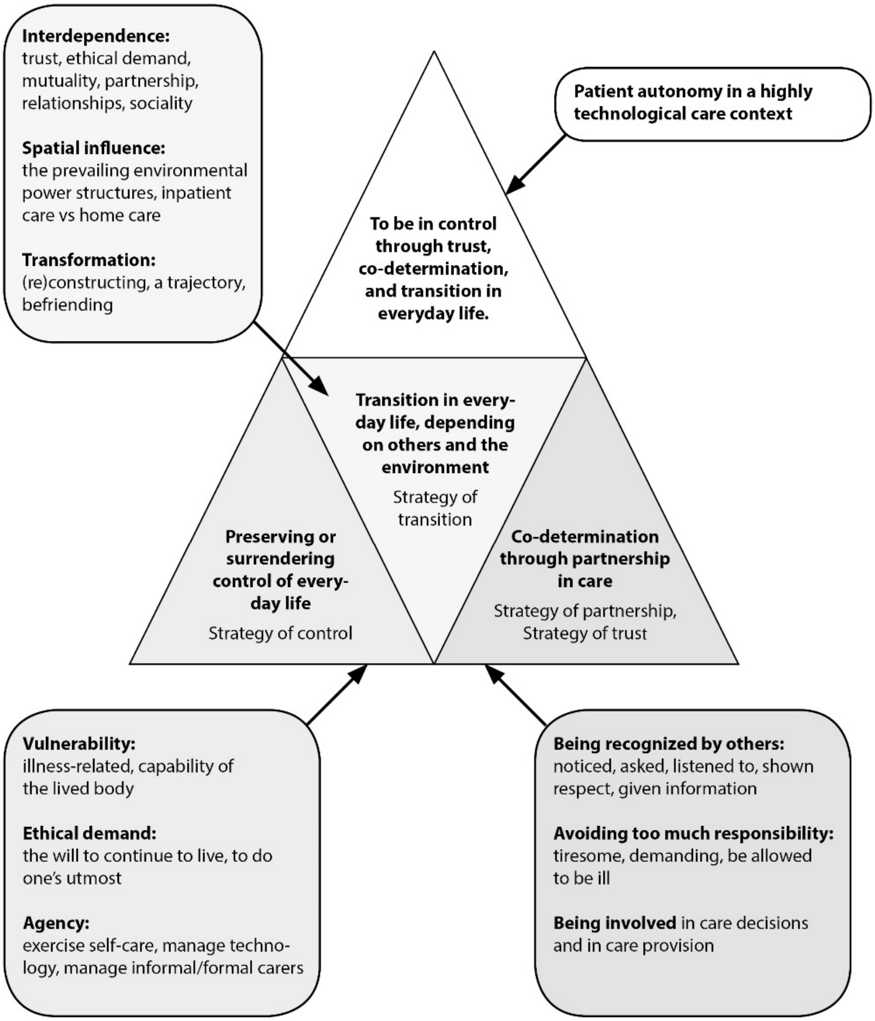
Table 6. Tentative scientific propositions of patient autonomy.

Key concept	Related statement
Person	- The patient/person exists through the lived body, including mental health needs - The patient must be thought of as an individual and an agent - The patient must have self-trust
Relationships	- The interdependence between the patient and the nurse creates the basis for patient autonomy - Patient autonomy is dependent on relationships with the health care staff - A trustful relationship built on person centered care is essential for patient autonomy
Health	- Illness/ill health-related care needs affect and direct the requirements for and the outcome of autonomy - Illness/ill health creates increased vulnerability that challenges patient autonomy - Patient autonomy is possible despite illness/ill health
Environment	- The care context consists of the caring encounter, the caring environment and illness-related care needs - Patient autonomy is contextually dependent - Different care contexts create different forms of responsibility and involvement
Transition	- Patient autonomy is a process with an ever-present time component - Patient autonomy does not have to be the same before, during and after a care episode - Patient autonomy is transformable as it is (re)constructive in nature - Patient autonomy is a transition when 'befriending' everyday life

The theoretical reasoning related to Field 6, prescriptive theory, led to the premature outline for the “person-centred-care-prescribing theory of patient autonomy”. Theoretical development on this level involves general guiding principles that in this study were presented as nursing principles to be used as nursing guidelines related to patient autonomy in highly technological care environments (Table 7).

Table 7. Nursing principles on the technological level of knowledge

Number of guideline	Nursing guidelines of patient autonomy in highly technological care environments
1)	Recognize the patient in terms of noticing, asking, and listening to him/her
2)	Show the patient respect
3)	Provide the patient with information
4)	Involve the patient in care decisions and in care provision
5)	Encourage co-determination by making the patient a team member
6)	Avoid handing over too much responsibility to the patient as this can be demanding when he/she simply wants to be allowed to be ill



The Control – Partnership – Transition Framework

Note: The three coloured triangles represent the prerequisites for patient autonomy in a highly technological care context, and the coloured rectangles contain the key features of each prerequisite.

Figure 7. "The control – partnership – transition framework" of patient autonomy in a highly technological care context.

The most conclusive findings from study IV was the Control – Partnership – Transition Framework (Figure 7), which was delineated from theoretical reasoning on the technical level (Field 9). The synthesis showed the overall understanding of patient autonomy in a highly technological care context to be: *To be in control through trust, co-determination and transition in everyday life*. This control was not necessarily shown to be complete in the sense of absolute. It was rather manageable through trust in oneself and in others, and through co-determination with formal/informal carers. Several prerequisites were needed if the person was to remain in control, i.e. be autonomous in the role of patient, in a highly technological care context. These prerequisites were shown to consist of: *preserving or surrendering control of everyday life*, through the strategy of control; *co-determination through partnership in care*, via the strategies of partnership and trust; and *transition in everyday life depending on others and the environment*, using the strategy of transition. These different strategies, four in number, were understood to comprise the patient strategies to remain/become autonomous, and to which the propositional statements of this level were linked.

The strategy of control showed that people in need of care in a highly technological care environment, most often want to remain in control of their everyday life. This strategy of acting out autonomy comprises an ethical demand, expecting people to assume responsibility for their own actions, which is not always possible or even desirable when a person falls ill. The patient may be guided by the will to continue to live and when possible do his/her utmost, whereas vulnerability in terms of suffering from weakness, fatigue or at worst from being unconscious, may prevent these actions. Patients who are able to preserve control of everyday life can retain their agency by exercising self-care, making informed decisions, handling care-related medical technology, and managing formal/informal carers. If the patients instead lack the capacity to retain control, with a deficient body and needing all the strength available to recover, they might freely and temporarily choose to surrender control to the staff. Therefore, this strategy can be executed either as preserving control of everyday life or in terms of surrendering control.

The interdependence between the patient and the nurse/carer calls for a *strategy of partnership* on behalf of the patient. A person who is in need of care in a highly technological care environment, has some kind of link to the health care staff. This creates a state of mutual dependence constituting the basis for the relationships. It is to be regarded as asymmetrical because the patients, due to their illness/ill health, are frequently vulnerable. Patient needs and wishes regarding partnership were understood to be the capacity to partake in care decisions, preferably in terms of co-determination. This form of patient involvement in the care decision process indicates that the patient is viewed as being capable and responsible and able to act out of reason. Co-determination was shown to be a reasonable arrangement of partnership, as it includes recognition but avoids too much responsibility. *The strategy of trust* was shown to be dependent on the health and care situation. It comprised the patients' need for trust in themselves and/or others if they are to exercise patient autonomy. Self-trust can facilitate participating in care decisions and everyday matters as it underpins self-confidence and self-esteem. Yet, people sometimes need to surrender control or accept dependence on formal/informal carers, which could at worst mean putting one's life in the hands of others, thus making trust in others a necessity.

The strategy of transition was shown to be dependent on other people and the setting, and can be used by the patient to preserve autonomy in a highly technological care context. This strategy involves the requirement that people transform their lifeworld when their interdependence with others changes as a consequence of illness/ill health. The patients need to trust themselves and their relationships with others in making this transformation. The spatial influence also calls for a transitional strategy on the part of the patient. This sometimes involves a change in the care environment, such as inpatient care or home care, or the introduction of medical technology into the patient's present care setting. When the patient is (re)constructing life, so that he/she feels in charge of everyday existence, the transition strategy can result in something new and different but still include elements of recognition.

Discussion of findings

This thesis is a response to the absence of consensual understanding of the concept of patient autonomy, as well as an answer to the lack of knowledge of the phenomenon of patient autonomy from the patient perspective, in a highly technological care context. The purpose was not to compare different HTC contexts, but to obtain several examples of HTCE in order to extend the perspective of the phenomenon of patient autonomy in highly technological care. Through the patient narratives, both the thoughts and experiences of patient autonomy in HTCE, and on the advanced medical technology itself, were revealed.

The overall finding from the amalgamation of the studies (I-III) within this thesis was the following description: "Patient autonomy in a highly technological care context consists of being in control through trust, co-determination, and transition in everyday life". In the suggested framework, several strategies were put forward that involve the prerequisites for remaining or becoming autonomous in HTCE. These strategies will be discussed in part under the following headings: Being dependent on technology and striving for control, Interdependence and the sharing of power, and Transition from a vulnerable to a capable person. The headings refer to the vulnerable and dependent patient in HTCE who struggles with others and with technology in order to obtain control of everyday life.

Being dependent on technology and striving for control

The patients in need of AMT most often reflected on their dependence on technology, although this was expressed in different ways depending on their care context (II-III). A technological dependency, as an effect of a need for medical technology, is "a short- or long-term reliance on devices and techniques to evaluate or to satisfy or resolve health-related needs or problems" (Sandelowski, 1993, p.37). This reliance becomes an absolute when required for survival, which was the case for many of the participants included in the studies in this thesis. The intended consequences of technological dependency are most often judged as positive, including the maintenance of good health, amelioration of discomfort, restoration of function, extension of life, and improvement in the quality of life (Sandelowski, 1993). These intended positive consequences of technological dependency were all shown in the participants' narratives

(II-III). The patients in the ICU expected their need for technology to be a temporary situation, and they did not question the technology, which they found to be a predictable part of the care environment (II). They did not find the technology itself to be problematic, which is well in line with the assumptions of Barnard and Sandelowski (2001), who instead put forward the problems related to the interaction between caring and the technology. However, when the patients were suffering from ill health conditions that created a long-term need for treatment with AMT and a lengthy stay in the intensive care unit, the dependence and the striving for control were more often articulated (II).

Unintended outcomes, involving further morbidity and mortality as well as an anatomization of body and experience, could be by-products of technological dependency (Sandelowski, 1993), but these negative consequences were more seldom expressed (II-III). Yet, the technology was much more apparent and questioned by the patients in need of AMT at home, as it changed the appearance of their home environment (III). In addition, the patients knew that their need for advanced medical technology was life-long, which complicated their control over everyday situations that made a large change to their ordinary life. Some of the participants suffered from conditions that implied that they could be under consideration for an organ transplant, and then the technology did not bother them so much, because they thought of their dependence as something temporary.

Striving for control was a frequent topic when patient autonomy was addressed within the nursing literature (I) as well as in previous empirical studies (II, III), hence leading to “the strategy of control” (IV). However, it is not always feasible to remain in control as illness/ill health moves into people’s lives, which has previously been shown in relation to patients in 24-hour home care and their feeling of getting unsafe care (Swedberg et al., 2012). In this thesis, the control of everyday life was shown to be associated with joy of life and life courage (II-III), which is well in line with previous findings from the context of intensive care (Wåhlin et al., 2006) and the context of AHC including advanced medical technology (Fex et al., 2009). This could be understood as the life phenomenon of “to live”, which is to be compared with “to be alive” referring to survival and needs (Delmar, 2012b). “To live” could be paralleled to the findings of preserving control through different forms of agency leading to control through transition (IV). On the contrary, “to be alive” was shown to be an important underlying condition in surrendering control when the patient needed all the strength to recover (II). Nevertheless, it was shown that a person is dependent on trust in others to feel comfortable in the surrendering of control. This trust in others was also a prerequisite for moving further in the recovery process, for example by venturing to get out of bed, or to visit the toilet (II), which could be compared to the support that people in the ICU need in their striving for independence and a sense of control (Karlsson et al., 2012). This is somewhat complicated, as trust at the same time makes people vulnerable, and if it becomes undermined mistrust takes its place (Lögstrup, 1992; Martinsen, 2003), hence addressing a vicious circle of actions referring to the strategy of control. Therefore, the patients' dependent situation and need for trust must never be misused by the staff, but instead be a constant reminder of the patients' vulnerability and their need of support in their striving for control.

Interdependence and the sharing of power

The findings support the relational and well-known phenomenon of interdependence being an overall factor influencing care (Lögstrup, 1992; Martinsen, 2012), also in HTCE. In addition, the results revealed that patients in HTC want to share the power related to their care, although in different ways, irrespective of whether they are cared for in an intensive care unit (II) or in need of AHC (III). Because of their continuous dependence on health care, caused by their illness/ill health and of the related asymmetrical relationships, the participants did not address patient autonomy in terms of self-determination. Instead, they expressed their autonomy as the sharing of power, and then often in terms of co-determination, indicating that they wanted a partnership in care (II-III).

The asymmetrical relationships were quite often expressed by patients in the ICU and then addressed in relation to trust, such as "I trust them, they know what they are doing" or "I leave the technology to them, they know best. It's their job" (II), referring to the knowledge of the staff. They did not speak of the surveillance linked to the AMT, unless there had been problems related to the technology, and they had been left without information. Previous research addressing ICU care and vigilance showed dissimilar results (Almerud et al., 2007), however the fact that patient autonomy was the focus of this thesis, and not the technology *per se*, might have influenced the outcome of the findings (II).

The desired partnership from the point of perspective of the patients was shown to belong to one of the strategies underpinning patient autonomy in HTCE, and comprised the importance of recognition and involvement, and of not being given too much responsibility (IV). These could be interpreted as dichotomous conditions, not adhering to the above mentioned co-determination, but it should not be forgotten that most people cared for in HTCE are vulnerable in consequence of their ill health. Accordingly, they sometimes have to be allowed to be ill and temporarily leave some of the power to their formal/informal carer. The point here, in line with the findings of this thesis, is that this should be effectuated in respect to the wish of the patient, and not in a paternalistic or representative way of caring without listening to the patient.

The strategy of partnership has connections to trust and vulnerability together with the condition of interdependence. Vulnerability is usually seen as something problematic for a person, but Malterud (2016) and Carel (2009) provide a different way of looking at vulnerability, suggesting that it should also be recognized as something positive, a strength, sometimes leading to personal growth. They refer to strong empirical evidence that proposes that illness does not negatively correlate with well-being, which was also shown in some of the narratives of the patients in need of care in HTCEs (III). This view of well-being not necessarily being the opposite of illness, somehow confirms the individuality in the response to illness and shows that there is no specified pattern of how people react to illness/ill health. In that way, the strategy of partnership could be facilitated if the patient is also recognized as a person when cared for in a HTCE. This could be possible if attention is given to the thoughts of person-centred care (PCC) (Ekman, 2014; McCormack & McCance, 2010).

PCC implies working towards an integration of "being with", the relational part, and "doing for", being the task-based part in nursing (Edvardsson, 2015). According to Edvardsson, PCC means bringing back the person into care and in that way reinforcing the ever-present ethical demands to uphold dignity, to provide autonomy, choice and control, respecting decision making and doing good. Research that refers to the sharing of power in care in terms of patient participation, such as Bradley and Mott (2014), most often express, either explicitly or implicitly, the importance of patient-centred care in fostering the possibilities of patient participation. The distinction between patient-centred and person-centred care is not without importance, as in the latter case it highlights that the patient is not only someone in need of care, but also a person of great knowledge related to their own health and illness (Ekman et al., 2011; McCormack & McCance, 2010). By this means, PCC is to be seen as holistic, flexible, creative, personal and unique, and thus avoids being reductionist, standardized, detached and task-based, unless the person wants it to be (Edvardsson, 2015, p.66). These thoughts highlight the importance of how to encounter the other that corresponds well with the suggestion of the premature person-centred-care-prescribing-theory of patient autonomy (IV).

Being involved in care, and sharing the power as a person, also comprises the task of "acceptance of the responsibility", which was offered as an antecedent of the exercise of autonomy in a previous concept analysis (Keenan, 1999). The patient experiences of responsibility towards their care in HTCE was shown both as being an important way of being in control, but also sometimes tiresome and demanding (II-III). The patients then wanted to share this responsibility with formal/informal carers, addressing the interdependence ever present in care relations irrespective of the care environment. However, the sharing of power and responsibility should not be understood as something static but instead as something changing according to the different phases of the care/recovery process. If this is to lead to trustful HTCE, where the patient's sharing of power in care is taken into account, the starting point for caring must be the patient perspective, where the patient is looked upon as a person, a resource, and a partner in care.

Transition from a vulnerable to a capable person

Autonomy assumes capable agents and becomes challenged when people have an increased vulnerability as a result of a changed interdependence and/or a need of care support (I). This could lead to problems in applying the ethical principle of autonomy in nursing care, as the patients often have different capacities to be autonomous as a consequence of internal or external constraints (Fry & Johnstone, 2008). Consequently, in HTCE the patient's autonomy is at great risk of being challenged and the patient is not necessarily looked upon as an agent or as a capable person. Instead the patient is often viewed from the perspective of a vulnerable person and reduced to being a *patient* in the original Latin meaning of "the one who suffers".

Some of the participants talked about their memories related to the time during their hospital stay when they were fighting for life and recovery (II). They were unconscious at times, and as a consequence of mechanical ventilation or extreme fatigue, deprived of their possibilities of communicating. Accordingly, they were to some extent reduced to a vulnerable body that could not actively participate in daily communication about their care. Lawler (1991) addresses vulnerability and the problem of the body through her thoughts of somology, providing nursing with a language to describe the crucial social components of skilled nursing care. She addresses among other things, the temporal dimension that controls the body, and that leads to "handing over" from patient to nurse during illness, and dying and "handing back" from nurse to patient in recovery. This temporal feature is also addressed as a situated dependence, in that the nurse and patient negotiate when the patient is in need of short term assistance with body care, which could very much be an issue in HTCE. Consequently, this clearly announces the temporal feature influencing the care of the vulnerable person, hence influencing his/her autonomy, which was shown to be evident in the context of highly technological care (II-III).

Yet, if the patient should remain or become autonomous in the role of patient, there is a need for a transition to a view of the patient as a *homo capax*, that is, a person capable of health and well-being irrespective of disease and illness (Ricoeur, 2011). This is not always fully possible in the context of HTC, however the intention to think of the patient in this way is of importance. The patient's recovery and (re)gaining of autonomy has been shown as "a trajectory towards partnership in care depending on state of health and mutual understanding", between the patient and the staff (II), indicating that autonomy is not a state but a process that requires the carer to be attentive to the patient's needs and wishes, thus looking for occasions when the patient is capable of taking a somewhat active part in the care relationship.

The strategy of transition, being one of the findings from this thesis (IV), could very much be understood as a passage or movement from one state, condition, or place to another, thus linking change with experienced time (Chick & Meleis, 2010, p.25). This strategy contains a type of transition related to the health-illness transition, although here discussed in the terms of capable person-vulnerable person, and refers to both the process and the outcome of complex person-environment interactions. The health–illness transition among persons using AMT at home has previously been described in terms of a learning process (Fex, Flensner, Ek, & Söderhamn, 2011). This process referred to accepting, managing, adjusting and improving daily life with technology. The health-illness transition was also described as being facilitated by realizing the gain from technology at home. It was furthermore interpreted as contentment with being part of the active and conscious process where the person progressed towards a new state of living, in which the individual and the technology were in tune. This corresponds in parts to the findings within this thesis adhering to the description of "befriending everyday life when bringing technology into the private sphere" (III).

Meleis (2010) describes transitions as something essentially positive that could be said to count for the findings from this thesis, involving descriptions like a trajectory (II), befriending (III), and (re)constructing (I). These positive descriptions also count for the transition reported by Fex et al. (2011), hence giving some weight to the positive transition-related findings within HTCE, emanating from this thesis.

The strategy of transition indicates some kind of increased stability compared to a previous state (Meleis, 2010). Two of the characteristics of transitions theory, disconnectedness and awareness, are also to be addressed in association to autonomy. The first, dealing with disruption of linkages of importance to a person's feelings of security, is very much connected to vulnerability and trust within patients trying to be in control of their everyday life (II-III). The second, announcing that transition is not a structural but a personal phenomenon and that to be in transition a person must have some awareness of the ongoing changes, also has implications for patient autonomy. A patient trying to remain or become autonomous needs awareness to be capable of agency and transformation leading to changes in everyday life. If, however, the patient is still in a pre-transition phase, he/she might need help from the nurse/carer to advance into transition.

In conclusion, the transition from a vulnerable to a capable person within HTCEs, related to everyday life, depends on both others and the environment. The organization ideal of the health care system has gradually evolved from a system responding to unexpected situations of dependency, sickness and death that vary from patient to patient, into one of complete managerial control (Kohlen, 2015). According to Kohlen, this change has its ground in the use of technical devices such as scales and assessment instruments for the determination of others' needs. There is a need for an attitude toward the patient in HTCE which understands the patient as more than a vulnerable person, in that the transition into a capable person can be healthy, making patient autonomy possible.

Methodological considerations

In answering to the two-fold aim of this thesis, addressing the concept of patient autonomy (I, IV) and the phenomenon of patient autonomy (II-III), in a highly technological care context, a theoretical as well as an empirical approach was used, including different qualitative methods for data collection and for data analysis (Table 1, p.37).

The work with the studies of this thesis has been highly systematic, structured and transparent in trying to adhere to the quality criteria of credibility, dependability, and transferability (Lincoln & Guba, 1985). The data collection of study I aimed at reaching both high sensitivity and high precision by using one search string, divided into search blocks, for all four databases (Lefebvre et al., 2011). The textual data from the work with the analysis (I-IV) has been digital, collected in different charts, hence facilitating the audit trail, and making the work transparent and available for sharing by all of the researchers involved. The methods chosen for the analysis of the different studies all contain different steps, allowing the researcher to move back and forth between these steps during the analysis process which provides a structure to the work and hence is of help in making the work systematic. In addition, providing enough information and making the analytic process clear makes it easier for the reader to judge the possible transferability of the findings to other settings. Findings from qualitative research are most often not possible to generalize, as they primarily serve the purpose of understanding from the viewpoint of variation. However, they are still useful for clinical praxis as they can provide new and/or extended knowledge of use in facilitating important clinical reflections.

To adhere to this important feature of variation, used within qualitative research as a means of reaching a higher truth value of the findings and hence a higher degree of credibility (Lincoln & Guba, 1985), the studies varied both in relation to the data collection and to the data analysis. The variation referring to the data collection process consisted of the use of four different but relevant data-bases (I), of two different HTC contexts (II-III), and of settings within these contexts (II-III). An extended use of databases and of grey literature might have extended the variation (I), nevertheless at the same time this might risk obscuring the overview of the data. The settings (II-III), were all in less populated areas, hence they do not represent a variety in population with regard to areas of more urban character. This can have an effect on the distance from home to hospital, or to the outpatients' department, which might influence the patients' feelings of safety, control and autonomy (III).

The variation also consisted of a heterogeneous sample when referring to demographic characteristics such as gender, age, illness and state of health, as well as of the AMT of use, and of the length of stay in the ICU or the length of post-device introduction time at home. The recruitment of participants was done with the intention of purposeful sampling to obtain information-rich narratives, in order to be able to learn about the phenomenon (Patton, 2002), thus adhering to the aim of the studies and to the inclusion criteria. The outcome of the sampling was more in line with convenience sampling. Nevertheless, a satisfactory variation was obtained, however it was unpredictable and was not possible to manoeuvre because of the most restricted number of potential participants. The possibility of using other methods for data collection of the phenomenon of patient autonomy was considered, for example video-recording of actual patient/nurse situations, but as a cause of ethical difficulties regarding patient and nurse/carer integrity, this method was not selected.

The thesis also includes a variety of methods for analysis that have had the advantage of allowing the essence of the data to be shown to the analyst in different ways. This might create a greater variation of descriptions of the phenomenon of interest (II-III) as well as being used as different lenses on the data in the development of theoretical understanding (I, IV). It also prohibits the analyst from being deadlocked in predetermined categories as it continuously opens up for new perspectives on the data, adhering to a greater believability of the findings and thus to a greater credibility (Lincoln & Guba, 1985). The choice of methods for analyses of study II was made prior to the interviews, and with the assumption of getting short and not very deep interviews because of the participants' severe illness/ill health. However, subsequently, the method of descriptive phenomenology, as used in study III, seemed to be applicable to the fairly rich narratives. Nevertheless, the content analysis provided interesting findings that gave utterance to the patients' narrated experiences.

The authenticity of a study refers to the extent to which the researchers may fairly and faithfully show a range of realities that convey a feeling tone of the participants' lives (Guba & Lincoln, 1994). This was made through the provision of exemplars of the concept (I), of direct citations from the participants' narratives (II), and of a general description of the structure, including the essence structure given as the structure of the constituents (III). The question of confirmability, referring to objectivity and being true to the information provided by the participants (Lincoln & Guba, 1985), was addressed within the research group (II-III). These researchers were the only persons to have access to the original data from the patient narratives, as a matter of respecting confidentiality (Swedish Research Council, 2011).

The accomplishment of qualitative inquiry involving patients in highly technological care environments poses a number of challenges to the researcher. The context itself, in this thesis represented by intensive care (II) and advanced home care (III), is delicate in not being easily accessible for empirical research, either being constantly shared with others, patients and staff (II), or not being an exclusively private environment (III). In addition, the patients' severe illness and/or suffering from chronic or palliative conditions led to several cancellations of interviews due to a decline in health, death, or readmission to the ICU (II) or to in hospital care (III). Furthermore, most patients in need of intensive care have a length of stay that is shorter than two days (SIR, 2016), which was the limit of one of the inclusion criteria. This limitation was decided on as a means of facilitating the possibility of including patients who had stayed long enough in the ICU to have had time when awake to experience care, that they later could reflect on in relation to their own autonomy (II). Additionally, the patients cared for at home using AMT were difficult to find, as the organizational context of Swedish AHC does not rely on a single authority but includes several responsible authorities (III). All these circumstances addressed above led to a long process of data collection, 14 (II) and 18 months (III) respectively. Nevertheless, as there were no organizational changes within this time frame or other changes related to the above data collection circumstances, this should not have affected the outcome of the studies.

When the data collection was shut, 12 women and 11 men, in total 23 patients, had been interviewed with a median interview length of 53.5 minutes (II-III). This resulted in extensive and rich descriptions of patient experiences of autonomy in highly technological care environments (HTCE), which had been desired but not fully expected due to the patients' ill health, and which can be seen as a strength of these studies.

All of the interviews (II-III) were performed by the author of this thesis, which could be seen as a strength as this led to a possibility of developing vital skills related to the specific interview context. The study interviews were preceded by a pilot interview with a person who had experience from both the ICU and the AHC context. The two interview questions were found to be adequate to help the interviewee to grasp the focus of the subject of reflection. The pilot interview was also useful to the interviewer in becoming acquainted and confident with the interview situation in regard to this specific research field. During the interviews, the interviewer had good use of previous experience of interviewing, as well as of long-term experience as an intensive care nurse, in that it facilitated attendant questions when obscurities arrived in the patients' narratives. This could be about the care environment itself (II) or about the advanced medical technology (II-III). The interviewer tried to be sensitive to the patient's actual health condition, which resulted in cancellations of planned interviews as well as breaks being taken during the interviews.

To avoid misunderstanding the participants' narratives, as they sometimes were extremely tired or had difficulties in communicating, the interviewer made short summaries during the performance of the interviews, which is one way of obtaining good interview quality in terms of credibility (Kvale & Brinkmann, 2009). The meaning of the abstract concept of autonomy was not obvious to all participants, but they could reflect on the related questions of participation and influence, thus this was an adequate way of approaching the field of interest. Although the patients sometimes found the subject of the interview difficult to reflect on, they were happy to try. They wanted to tell their stories, notwithstanding their sometimes fairly restricted life span, as they thought that their experiences and thoughts could be of use to other patients in the future.

When performing interviews at the hospital, in spite of the choice of carrying out the interviews on the post-ICU ward, interruptions or disturbances occurred when the staff arrived with food or medicine, for example. On one occasion, the interview environment was changed at the time of the arrival of the interviewer, as the patient had to be moved for urgent treatment. However, the patient wanted to carry out the interview and found it even more positive as it helped to pass the time during the time-consuming treatment on the dialysis ward. In two cases, one in hospital and one an out of hospital interview, a spouse was present. One spouse arrived during the visiting time, and the other as a request from the participant to be of help in remembering points of time during the long period of AHC, thus facilitating the sequences of the narration of the experiences. However, the interviewer does not believe that the conditions referred to above have affected the contents of the narratives, seeing that the participants seemed relaxed and focused on the interview situation.

The concept clarification emerging from the concept analysis (I) constituted a baseline for the understanding of the concept that was fruitful for the outline of the coming studies within this thesis. It was of use in creating the interview questions and of facilitating probe questioning throughout the interviews. The analysis was performed from a patient perspective and in the context of caring, thus carefully attending to a specific context, in order to minimize the risk of being deprived of its power to justify a nuanced analysis (Risjord, 2009). The concept analysis (I) could be said to be “theoretical” as it was restricted to scientific literature that is primarily useful for making the content of an existing theoretical concept explicit. Theoretical concept analysis contributes to theory development by clarifying conceptual materials that nurse theorists can rework for their own ends (Risjord, 2009).

The theory development (IV) was founded on only three studies, the concept analysis (I) and two empirical studies (II-III), and is therefore to be understood as tentative. The fact that the researchers themselves had performed the included studies (I-III) allowed them to be well acquainted with the original data, as well as with the findings, so that misinterpretations ought to be rare. However, the risk of bias, of being too immersed in the work, could not be eliminated even though the researchers have not actively used their preunderstanding but instead tried to keep it in full view in discussions with one another.

The data analysis (I-IV) was performed in collaboration with the research group. The first author led the work and the co-authors acted as co-analysers. This was a fruitful work arrangement, leading to a greater credibility of the findings, as it made possible both first order and second order reflections on the data itself and on the descriptions, and, where appropriate, interpretations. However, there is still a risk of not being conscious about one's own preunderstanding, and when the findings of several studies made by the same group of researchers (IV) are put together, the misinterpretations from previous findings could be transferred into coming studies. If so, this can reduce the dependability of the findings (Lincoln & Guba, 1985). To try to minimize this influence, the researchers worked close to the texts with the prior goal of description, adhering to the traditional phenomenological attitude of "bracketing" (Husserl, 2000) that was most explicit in study III using the method of Giorgi, but nonetheless of importance in parts of the work with study II. Giorgi (1997, 2009) claims however, that interpretation is somehow inevitable, but should be used with due reflection to reveal the meaning of the text, hence it was primarily used through the step of imaginative variation.

However, in the attempt to amalgamate studies on the same topic (patient autonomy in a caring context and from a caring perspective), and in the same context (HTCE), the availability of previous research has been sparse. To further strengthen the study, an additional recently updated database search related to the HTC context *per se* could have added important studies to the data in bringing an extended understanding of the concept in HTCE, which could have affected the outcome of the metasynthesis.

A new method of assessing the Confidence in the Evidence from Reviews of Qualitative research (CERQual) is under development (Lewin et al., 2015). This method addresses different forms of synthesis of qualitative data, hitherto using framework and narrative synthesis approaches that have provided largely descriptive findings. In accordance with the CERQual method, the assessment of the confidence for review findings should be based on the following four components: the methodological limitations of the included studies, the relevance to the review question, the coherence of the review finding, and the adequacy of the data supporting a review finding.

If this reasoning is applied to the metasynthesis (IV) within this thesis, despite it not being a review but a synthesis of single studies, not primarily aimed at providing evidence but at extending understanding, the findings arrives at the level of moderate confidence. In regard to *relevance*, the included studies clearly answer to the aim of the synthesis. The *coherence* of the findings within the different studies was good, as was the *adequacy* of the data supporting the findings within the synthesis. The critical component was the *methodological limitations*, essentially consisting of the fact that the studies were few and small (II-III) in regard to building evidence. Nevertheless, the assessment indicates that it is likely that the findings from this synthesis are a reasonable representation of the concept of interest.

The texts and the analysis have continuously been subjected to external scrutiny, and through the peer-review process adapted to the published studies (I-III), including a review of both content and methods, a further layer reflecting both credibility and dependability of the studies was added (Lincoln & Guba, 1985). In conclusion, despite the small amount of data underpinning the theoretical development (IV), the researchers believe that the metasynthesis has captured the key features of the concept to some extent, and that the findings from the metasynthesis could be of use to practice and education. None the less, in adhering to a heuristic approach, the findings need to be further tested and developed.

Conclusions and clinical implications

When a person becomes a patient, his/her autonomy risks being challenged by the increased vulnerability and the need for care support that is caused by the illness/ill health. The dependence stemming from the patient's vulnerability in highly technological care environments (HTCE) is care-related, and associated with the need for support from both health care professionals (HCPs) and technology. The interdependence between the patient and the HCP, caused by the patient's vulnerability, calls for an extended knowledge on the part of the HCP of knowing why, what and how to support and strengthen patient autonomy. As a result of this thesis, a tentative framework for patient autonomy in HTCE has been developed to be of use in educational and clinical reflections regarding patient autonomy, as well as in future research within this field. Four strategies for achieving patient autonomy were proposed, namely the strategy of control, of partnership, of trust and of transition, which will partly be addressed below.

A difference was shown concerning the expectations of patient autonomy in different kinds of HTCEs. Patients cared for in intensive care units (ICUs), as a consequence of critical/severe illness, were surrounded with professionals taking a large responsibility for their care and care-related decisions round the clock. The ICU-patients did not pay so much attention to the technology, which they found to be a natural part of the care environment. They felt trust in professionals and did not question the technology unless there were some problems related to the advanced medical technology (AMT) equipment, thus adhering to the strategy of trust. This could be compared to patients in need of AMT at home, where the patients were expected to, and most often wanted to, take major responsibility for their AMT device, although they did have various kinds of back-up from HCP. Besides, the patients in advanced home care wanted to be in charge of their decisions, adhering to the strategy of control, related to everyday life as the long-term treatment with AMT caused a dependence on technology that affected their daily life conditions. However, patients in HTCE strived for control of their everyday life, although in different ways depending on their health condition, as a means of remaining autonomous in the role of the patient.

Patient autonomy in terms of self-determination was not shown to be the goal for patients in need of care in HTCE. Instead they wanted to be partners in care, in accordance with the strategy of partnership, and share the power related to their care and perform care-related decision-making through co-determination. Although vulnerable as a consequence of illness/ill health, they wanted to be seen as capable agents, and expected to take responsibility in relation to their present health condition. They were more or less dependent on others. These other persons could, depending on the care environment and the patient's health condition, consist of formal and/or informal carers.

In conclusion, the findings reveal a clear desire on the part of the patients in HTCE to be partners in care. This highlights the need for an increased consciousness among HCP about this desire for co-determination. A change in the perception of the patients as vulnerable persons towards a view of them as capable, could be of help in the patients' accomplishment of the strategy of transition towards autonomy. One way to achieve this change of view of the patient, seems to be possible if the thoughts of person centred care (PCC) are adhered to. The Control- Partnership-Transition framework of patient autonomy, developed from the studies within this thesis, can be used as a basis for ethical reflections among HCPs, as well as for people within education and academia, about patient autonomy in HTCE. The proposed guiding nursing principles could easily be used by HCPs in everyday practice. In addition, this tentative framework and its related theoretical development could be used as a point of departure in future research, aiming at extending the knowledge about patient autonomy in HTCE.

Concluding points about patient autonomy in highly technological care environments:

- Patient autonomy is not an absolute and does not need to be the same before, during and after a care episode.
- Patients in need of intensive care want to be involved in decisions about their care in relation to their health condition, as this creates a trusting and healthy care environment.
- An addition of advanced medical technology to the home environment leads to a change of autonomy in everyday life in relation to body, relationships, space and time.
- Sharing of power between the patient and the health care professional is important in highly technological care environments and preferably performed through co-determination.
- Patient autonomy in highly technological care environments requires a transition of the view of the patient from a vulnerable to a capable person.
- Person centred care can be an important prerequisite for patient autonomy in highly technological care environments.

Further research

This thesis has shown that there are several prerequisites for patient autonomy to be realized within highly technological care environments (HTCE). Guiding nursing principles have been suggested and propositional statements of patient autonomy have been provided that could be of use in creating an instrument for measuring patient experiences of autonomy. Such an instrument could be of use to health care professionals in evaluating a patient's experiences of his/her autonomy during a care episode, and hence in adapting practice to the actual needs and wishes of a patient. In addition, if used from a more general point of view including the answers from several patients, this could be one way of evaluating the care process on a specific ward or clinic, regarding the adherence to the principle of patient autonomy.

The findings are based on empirical data from small studies and the framework could profit from more empirical studies addressing other HTCEs, emergency care and operating theatres, for example. It could also be interesting to test the results adhering to the framework in other care contexts with frail and vulnerable persons such as in mental care and dementia care, as these contexts are often present in the scientific literature related to patient autonomy.

Finally, nurses or other health care professionals could be involved in research about patient autonomy in a caring context. In using the previous studies from this thesis to construct fictive patient cases of moral dilemma that health care professionals could reflect upon in terms of "moral judgement", a representation of their ethical judgements and ethical awareness could be revealed. Such an approach could open up a dialogue on the issue of patient autonomy in academia, but also when referred back to the health care professionals in practice, letting this ethical principle not only be present in professional codes and educational documents but also "coming alive".

Svensk sammanfattning

I en tid när hälso- och sjukvården blir alltmer specialiserad, och det ständigt görs nya teknologiska landvinningar, blir det nödvändigt att reflektera över den enskilda människan och hennes autonomi. När autonomibegreppet belyses i förhållande till hälso- och sjukvård så handlar det oftast om medicinska eller juridiska frågor i förhållande till patientvård, eller om olika vårdprofessioners autonomi, och patienten själv blir mer eller mindre osynlig. Begreppet autonomi, som står för självständighet eller oberoende, användes ursprungligen i politiska sammanhang om de grekiska stadsstaterna under antiken. Det har sedan införlivats i allt fler sammanhang och är idag en del av den rättsvetenskapliga, forskningspolitiska och vetenskapsteoretiska debatten. Respekten för autonomi utgör tillsammans med principen att inte skada, principen att göra gott samt rättviseprincipen, en av de fyra praktisk-etiska principerna inom medicin och omvårdnad. Den avspeglas också på olika sätt i den internationella etiska koden för sjuksköterskor.

I stora delar av västvärlden lever vi i ett samhälle som bygger på individualism och där individen förväntas ta ett stort ansvar för sitt liv och för sin hälsa. Detta hamnar i konflikt med det beroende som patientrollen ofta innebär liksom med vårdens paternalistiska förhållningssätt. Denna förmyndarmentalitet, som har blivit tradition inom hälso- och sjukvård, har länge försvårat patienternas möjligheter till självbestämmande, och den enskilda personens delaktighet har företrädesvis skett på vårdpersonalens villkor. Autonomi förutsätter såväl kunskap, självinsikt som kapacitet att fatta beslut, vilket ibland inte är möjligt för en person som är svårt sjuk och det finns därför begränsningar för när, var och hur patientautonomi är möjlig och önskvärd.

I förhållande till sjuksköterskans kunskapsområde omvårdad, så handlar patientautonomi inte enbart om övergripande medicinska beslut utan också om alla de små beslut som dagligen ska fattas i samband med olika omvårdnadsåtgärder. Aktuell forskning lyfter fram behovet av att se personen bakom patientrollen för att på så sätt göra det möjligt för personen ifråga att vara delaktig i vården utifrån hans eller hennes förutsättningar och önskemål. Detta har också visat sig vara av stor betydelse för den fortsatta vården i hemmet där den enskilda personen har ett tydligare egenansvar för sin hälsa. Alltfler personer med allt mer komplexa vårdbehov vårdas idag på sjukhus och avancerad medicinsk teknik har blivit en del av vardagen inte bara inom akutsjukvård utan även på traditionella vårdavdelningar. För att lösa ekvationen mellan resurser och behov kommer allt fler av dessa personer i framtiden att vårdas i hemmet.

Därmed kommer även den medicinska teknologin i allt högre utsträckning att ”flytta hem”. Detta innebär att det kommer att ställas nya krav på morgondagens patienter. Krav kommer också att ställas på hälso- och sjukvårdens organisation och på dess utövare vilka kommer att behöva ha en större medvetenhet om hur patienter ser på det egna behovet av autonomi, samt hur detta kan tillvaratas och främjas i förhållande till varje enskild person.

Idag sker även en snabb utveckling av informations- och kommunikationsteknologin, bland annat via Internet, och människor har därför större möjligheter att hålla sig informerade om sin hälsa och ohälsa men också om sina lagstadgade rättigheter. Detta kan tänkas leda till en förändring av patientens roll från att vara en vårdmottagare till att istället bli en vårdbeställare, vilket också innefattar ett ökat ansvarstagande för den enskilda personen. För att möta dessa kommande behov och samtidigt stärka patients roll i en alltmer högteknologisk vårdmiljö behövs mer forskning om autonomi som tar sin utgångspunkt i patientens perspektiv.

Denna avhandling består av fyra delstudier vars övergripande syfte har varit att utifrån patientens perspektiv, beskriva och belysa patienterfarenheter av autonomi i högteknologiska vårdmiljöer (II, III), och att skapa en utvidgad förståelse för begreppet patientautonomi i en högteknologisk omvårdnadskontext (I, IV).

Den första delstudien var en teoretisk studie som genomfördes som en begreppsanalys (Rodgers, 1989, 2000) med syfte att identifiera och konstruera innebörden av patientautonomi inom omvårdnad ur ett patientperspektiv. En systematisk sökning genomfördes i de fyra databaserna Medline, CINAHL, The Cochrane Library och PsycInfo. Denna sökning tillsammans med efterföljande urvalsprocess, ledde fram till att 41 artiklar, publicerade mellan januari 2005 och juni 2013, valdes ut. Resultatet från begreppsanalysen mynnade ut i en beskrivande definition och en tentativ modell av begreppet, vilka är möjliga att använda i kliniskt arbete och inom utbildning för att sammanföra etisk reflektion och klinisk praktik.

De fem ”kännetecken” som karaktäriserar patientautonomi visade sig vara: att bli sedd som en person, att ha kapacitet att agera, ett åtagande att ta ansvar för sina egna handlingar, en process och ett (åter-)konstruerande. Det som föregick att patientens autonomi utmanades var den ökade sårbarhet som en person kan uppleva när han eller hon blir sjuk och i behov av vård. Detta kunde handla om att överlämna sig i andras händer till följd av en nedsatt funktionsförmåga eller i samband med exempelvis narkos. För att kunna stödja patienters autonomi är det därför av stor betydelse att den som vårdar har en medvetenhet om den ökade sårbarhet som uppkommer när det ömsesidiga beroendet, interdependensen, mellan patient och sjuksköterska förändras.

Konsekvenserna av patientautonomi visade sig som möjligheten att dels bevara kontroll dels bevara frihet. Begreppet patientautonomi förekom företrädesvis i vårdmiljöer som inkluderade personer som var sköra eller äldre, som led av psykisk ohälsa eller av ett flertal fysiska sjukdomar, och som kunde sammankopplas med en ökad sårbarhet.

Denna sårbarhet visade sig även hos personer som vårdades i högteknologiska vårdmiljöer men dessa miljöer fanns inte representerade i samma omfattning i data.

Studien visade vidare att patientautonomi inte skall ses som något absolut, utan att den skall förstås som individbunden och relaterad till såväl personlig karaktär som till variationen av vårdsituationer. Patientautonomi kan förstås som en process av gradvis förändring, ett kontinuum från beroende till oberoende, i relation till kontext, tid, relationer och mental och fysisk kapacitet. Den (åter)konstrueras genom företeelser såsom identifikation av den rådande situationen, förändring över tid, att åter kunna uppleva inre kraft och styrka samt förhandling mellan patient och sjuksköterska, och behöver inte vara detsamma före, under och efter en vårdepisod.

För att utvidga kunskapen kring patientautonomi i högteknologiska vårdmiljöer blev valet att i de kommande två delstudierna vända sig dels till intensivvård, vilken är en vårdmiljö som traditionellt är förknippad med avancerad medicinsk teknik, dels till avancerad sjukvård i hemmet, som är en vårdmiljö där en stor del av framtidens vård kommer att ske och där avancerad medicinsk teknik blir allt vanligare.

Den andra delstudien genomfördes som en intervjustudie med elva patienter, sju män och fyra kvinnor, som tidigare varit i behov av intensivvård under minst två dygn. Intervjuerna var individuella och ägde rum på den vårdavdelning dit patienterna förflyttats efter utskrivning från intensivvårdsavdelningen (IVA). Två öppna frågor kring intensivvård, patientdelaktighet och patientinflytande ställdes med syfte att beskriva och belysa patienters erfarenheter av autonomi inom intensivvård från ett omvårdnadsperspektiv. Alla intervjupersonerna var vuxna och hade varit i behov av olika former av medicinskteknisk utrustning under sin vårdtid. De hade alla minne från vårdtiden på IVA och var orienterade till tid och rum. Deltagarna var mellan 34 och 75 år gamla (median 54,5), hade en vårdtid av 2-28 dagar (n=7), 29-56 dagar (n=2), 57-84 dagar (n=1), och 85-112 dagar (n=1), och med olika intagningsdiagnoser främst relaterade till stor kirurgi, allvarliga infektioner och/eller nedsatt lungfunktion. Ingen av de intervjuade hade något tidigare vårdtillfälle på IVA. De hade heller inte någon kronisk sjukdom innan de skrevs in för vård. Intervjudata transkriberades ordagrant och analyserades med induktiv innehållsanalys enligt Elo och Kyngäs (2008).

Patienterfarenheter från intensivvård visade att autonomi ur ett omvårdnadsperspektiv kunde ses som ”En väg i riktning mot ett partnerskap i vården, beroende av hälsotillstånd och ömsesidig förståelse”. Patienter som vårdats på en intensivvårdsavdelning visade sig vilja vara involverade i beslut som rörde deras egen vård, men i förhållande till den egna förmågan. De fann att detta skapade en tillitsfull och hälsofrämjande vårdmiljö. När patienterna var alltför sjuka, och därför inte kunde vara delaktiga i beslutsprocessen, ville de ha möjligheten att lämna över kontrollen till vårdpersonalen. I takt med att de blev friskare upplevde de att deras autonomi hade varit relaterad till olika aspekter av medbestämmande. Den kommunikativa förmågan hos personer som vårdas inom intensivvård är ofta nedsatt, och det visade sig att patienterna istället är hänvisade till en ständig ström av information för att känna sig involverade i den egna vården. Det framkom även att kontinuiteten bland personalen var grundläggande för att säkra det tysta samförstånd som skapar en god vårdrelation. Patienterna uttryckte en önskan om att få stöd och uppmuntran till att vara aktiva i förhållande till sitt hälsotillstånd eftersom detta byggde upp tilliten till den egna förmågan. Genom att som patient bli inbjuden att på olika sätt delta i den egna vården kunde ett partnerskap så småningom växa fram.

Sammanfattningsvis visade studien att personer som vårdas på IVA kan befinna sig i ett starkt beroende, och samtidigt vara oberoende, och det är därför viktigt att hantera varje omvårdnadsåtgärd på ett anpassat sätt så att patienten känner sig inkluderad. För att förbättra autonomin hos patienter som vårdas inom intensivvård krävs en högre medvetenhet om att patienter inte enbart ser sig själva som passiva vårdtagare, utan också som aktiva agenter, och att det därför är av yttersta vikt att de blir involverade i beslut och får möjlighet att vara delaktiga i den egna vården.

I *den tredje delstudien* genomfördes individuella intervjuer med syfte att beskriva och belysa innebörden av att vara en autonom person och samtidigt beroende av avancerad medicinsk teknik i hemmet. Tolv personer, 42-78 år gamla (median 61,5), åtta kvinnor och fyra män, intervjuades i sina hem. Intervjuerna genomfördes med öppna frågor och med målet att locka fram personernas egna berättelser. Förutom behov av olika former av avancerad medicinsk teknik var vissa av deltagarna också i behov av hjälp med daglig personlig omvårdnad, vilket visade på deras beroende och allvarliga sjukdomstillstånd. Deltagarna led av antingen långvarig sjukdom och/eller palliativa tillstånd kopplade till cancer, njursvikt, muskelsjukdom, nedsatt lungfunktion, reumatologisk sjukdom, eller tidigare poliosjukdom. De var alla orienterade till tid och rum och hade ett behov av antingen andningssupport, dialys, sondmatning eller smärtlindring. Den medicinska tekniken hade introducerats i hemmet inom allt från <1månads tid (n=2), 1-6 månader (n=4), 12-24 månader (n=4), till ca 96 månader (n=2) före intervjutillfället.

Intervjuerna transkriberades ordagrant och data analyserades med deskriptiv fenomenologi (Giorgi, 1997). Innebörden av fenomenet visade sig som ”Att bli vän med vardagen när teknologin tas in i den privata sfären”. Följande fyra inbördes beroende konstituenter identifierades: Att bli vän med den levda kroppen, Att vara beroende av goda relationer, Att behålla hemmet som en privat sfär, och Att styra över tiden. Resultatet visade att det var kapaciteten hos den levda kroppen som utgjorde begränsningen för kontrollen av vardagen. När patienterna kunde utöva egenvård och sköta teknologin på egen hand var deras förutsättningar goda för att ha fortsatt autonomi. I de fall deras fysiska hälsa försämrades kunde de bevara autonomi genom att styra sina informella och formella vårdare, och på det sättet behålla kontrollen över det dagliga livet. Relationerna med vårdare och med familj visade sig vara viktiga delar i att fortsätta att vara autonom vilket grundade sig i kontinuitet, närhet, respekt och ömsesidighet. Det visade sig också vara viktigt att patienterna blev erkända som personer att räkna med i förhållande till den egna vården. Omvårdnad, särskilt från sjuksköterskor med avseende på tillgänglighet och teknisk support, kunde göra att patienterna kände sig trygga och säkra. Således visade sig god delaktighet och möjlighet till påverkan av vårdprocessen, vara nödvändiga förutsättningar för att stärka patienternas autonomi.

Många forskare inom omvårdnad, medicin och utbildningsvetenskap lyfter idag betydelsen av att inte bara genomföra nya studier utan betonar också vikten av att sammanställa tidigare studier för att utnyttja forskningsresultat på ett bättre sätt. *Den fjärde och avslutande delstudien* genomfördes som en form av teoretisk utveckling genom en tolkande sammanslagning, syntes, av resultaten från de tre första delstudierna. Syftet var att presentera ett teoretiskt ramverk för begreppet patientautonomi inom högteknologiska vårdmiljöer med målsättning att nå en fördjupad förståelse av begreppet. Arbetet med att syntetisera och organisera induktiv data inom ramen för studien genomfördes med inspiration av ”Nio-fälts-modellen” (Gustafsson & Andersson, 2001a, 2001 b). Detta är en modell för utvärdering av existerande omvårdnadsteorier som kan fungera som ett stöd för att organisera omvårdnadskunskap hierarkiskt. Arbetet följde det inom teoriutveckling vanligt förekommande tillvägagångssättet med de tre stegen härledning, syntes och analys (Walker & Avant, 2011).

Studien ledde fram till utvecklandet av ett teoretiskt ramverk för patientautonomi i samband med omvårdnad i högteknologisk vårdmiljö, ”Kontroll – partnerskap – transitions ramverket”. De underliggande förutsättningarna för patientautonomi visade sig utgöras av tre komponenter. Dessa innefattade i sin tur totalt fyra olika strategier som personer använder sig av för att bevara eller uppnå autonomi i sin roll som patient. Den första komponenten, ”Att bevara eller ge upp kontrollen över vardagen”, innefattade strategin för kontroll. Resultatet visade att personer i behov av vård oftast vill behålla kontrollen över sin vardag. Bakom denna strategi finns en etisk fordran att människan skall ta ansvar för sina egna handlingar. Detta kan ske via en stark vilja att leva vidare och genom att göra sitt yttersta, vilket inte alltid är möjligt eller ens önskvärt för en person som är allvarligt sjuk. Strategin för kontroll kan därför utövas antingen som att bevara kontroll genom egenvård, genom att leda formella/informella vårdare, genom att fatta informerade beslut eller genom att ta hand om vårdrelaterad medicinsk teknik. Ibland förväntar sig patienten professionellt stöd och rådgivning från sjuksköterskan vilket hon/han behöver vara uppmärksam på. Strategin för kontroll kan också utövas genom att avstå kontroll över vardagen. I de fall patienten saknar kapaciteten att bevara kontroll, eftersom den levda kroppen behöver all kraft för återhämtning, kan han/hon frivilligt och tillfälligt lämna över kontrollen till personalen. Om detta beslut är uttalat av patienten själv så är det också ett uttryck för autonomi.

Den andra komponenten, ”Medbestämmande genom partnerskap i vården”, innefattade två strategier. Strategin för partnerskap som har sitt ursprung i det faktum att patienten alltid har en koppling till vårdpersonal, vilken leder till att ett ömsesidigt beroende skapas mellan patient och vårdare. För att kunna behålla sin autonomi måste patienten bli inbjuden att delta i vården som en fullvärdig medlem av vårdteamet.

Patientdelaktighet genom medbestämmande visade sig vara en möjlig väg att involvera patienten i vården då den innefattar ett erkännande men undviker att ett alltför tungt ansvar läggs på patientens axlar. Den andra strategin var strategin för tillit. Denna lyfte fram att en person behöver känna tillit till sig själv och/eller andra för att kunna utöva sin autonomi. Tillit visade sig vara viktig för att kunna ta del i beslut om vård och vardagsaktiviteter då denna understödjer personens självkänsla och självförtroende. Den var också en nödvändig förutsättning när en person måste ge upp kontrollen till förmån för formella/informella vårdare liksom när personen tvingades acceptera ett beroende till dessa personer.

Den tredje komponenten, ”Transition i vardagen beroende av andra och den omgivande miljön”, innefattade strategin för transition. Det förändrade ömsesidiga beroendet i förhållande till andra, som uppkommit genom illabefinnande/ohälsa, ledde fram till att personen behövde transformera sin livsvärld för att kunna bevara sin autonomi. Denna strategi innebar att patienten kunde bli vän med sin situation genom att (åter)konstruera livet så att han eller hon fortfarande upplevde sig leda och ha ansvaret för vardagen. För att kunna genomföra detta behövde patienten känna sig trygg i sig själv och i de relationer som han/hon omgavs av. Den omgivande miljön, oavsett om vården skedde i sjukhusmiljö eller i hemmiljö, kunde också skapa ett behov av transition. Transitionen kunde leda till någon nytt och annorlunda men samtidigt vara anpassad till den enskilda personen och innefatta element av igenkänning. Slutsatsen från denna avslutande studie var att när sjuksköterskan/vårdaren har kunskap om patientens strategier för att bevara sin autonomi blir det lättare att undvika ett förhållningssätt präglat av paternalism eller maternalism och istället bjuda in patienten som en partner med makt över den egna vården.

Slutsatsen från denna avslutande studie var att när sjuksköterskan/vårdaren har kunskap om patientens strategier för att bevara sin autonomi blir det lättare att undvika ett förhållningssätt präglat av paternalism eller maternalism och istället bjuda in patienten som en partner med makt över den egna vården.

Sammanfattningsvis och med utgångspunkt i hittills framkomna resultat, handlar främjande av patientautonomi om att skapa en medvetenhet om att begreppet inte står för något absolut utan att patientautonomi måste förstås utifrån varje enskild persons förmåga och önskemål. De som arbetar inom hälso- och sjukvård måste ha ett personfokus och anpassa vården så att den kapacitet som patienten/personen besitter kan tas tillvara. När han/hon inte kan, eller vill, utöva sin autonomi till följd av illabefinnande/ohälsa måste vi, sjuksköterskor och andra vårdare, respektera detta och avvakta en förbättring av hälsotillståndet för att sedan på nytt försöka att motivera och pusha honom eller henne. Relationen mellan patient och vårdare är av avgörande betydelse i den dagliga omvårdnaden och då många svårt sjuka patienter tvingas överlämna sig i vårdarnas händer är en god vårdrelation, där patienten ses som kapabel och med en önskan att vara delaktig efter förmåga, en förutsättning för tillit.

Det är dags att på ett tydligare sätt lyfta in det omvårdnadsetiska perspektivet i hälso- och sjukvård där frågorna inte bara skall handla om ja/nej till olika behandlingsformer utan också om att på större allvar fundera över hur processen kring dessa frågor ser ut. Denna process innefattar alla tankar, frågor och ställningstaganden som patienten skall förhålla sig till både före, under och efter att de stora frågorna ställts. Detta utgör, tillsammans med delaktighet i beslut direkt kopplade till olika omvårdsåtgärder, en viktig del i mötet med patienten i samband med den dagliga omvårdnaden. Det är därför nödvändigt att också patientens/personens perspektiv beaktas - för hur ska vårdpersonal annars veta vilka frågor, stora som små, som är avgörande för den enskilda personen i olika omvårdnadssituationer. Inom hälso- och sjukvård måste vårdpersonalen bli bättre på att inte enbart se patienten som en person utan också på att agera därefter med respekt för patientens autonomi så att integritet och värdighet bevaras. Eftersom patientens tillit till den egna förmågan, liksom tilliten i relationen med samarbetspartners inom hälso- och sjukvård, är avgörande för att stödja patientautonomin måste patienten ses som en person kapabel till hälsa och välbefinnande oberoende av sjukdom eller illabefinnande. Detta är ett viktigt led i att skapa förutsättningar för patienten att återfå och bibehålla hälsa samt för att bevara kontroll över den egna vardagen.

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