

TURUN YLIOPISTON JULKAISUJA  
ANNALES UNIVERSITATIS TURKUENSIS

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*SARJA - SER. D OSA - TOM. 826*

MEDICA - ODONTOLOGICA

**NURSING ADVOCACY:**  
**A concept clarification**  
**in context of procedural pain care**

by

**Heli Vaartio**

TURUN YLIOPISTO  
Turku 2008

From the Department of Nursing Science, University of Turku, Finland

### **Supervised by**

Professor and Chair Helena Leino-Kilpi, PhD, RN  
Department of Nursing Science  
University of Turku, Finland  
and Nurse Manager  
Turku, South-Western Hospital District, Finland

Adjunct Professor Tarja Suominen, PhD, RN  
Department of Nursing Science  
University of Turku, Finland  
and Professor  
Department of Nursing Science  
University of Kuopio, Finland

### **Reviewed by**

Professor Terese Bondas, PhD, RN  
University College of Borås  
School of Health Sciences, Sweden  
and Docent in University of Kuopio, Finland

Docent Tarja Pölkki, PhD, RN  
Department of Health Sciences  
University of Oulu, Finland

### **Opponent**

Professor Katie Eriksson, PhD, RN  
Department of Nursing Science  
Åbo Akademi, Finland  
and Nurse Manager  
Helsinki, Hospital District of Helsinki and Uusimaa, Finland

ISBN 978-951-29-3719-6 (PRINT)

ISBN 978-951-29-3720-2 (PDF)

ISSN 0355-9483

Painosalama Oy – Turku, Finland 2008

Et voi kahdesti astua samaan jokeen,  
uudet vedet siinä jo virtaavat  
Herakleitos

Heli Vaartio

**Nursing Advocacy: A concept clarification in context of procedural pain care**

Department of Nursing Science, Faculty of Medicine, University of Turku, Finland, 2008.

**ABSTRACT**

The purpose of this study was to clarify the concept of advocacy in context of procedural pain care and to investigate the implementation of advocacy in that context.

First, the concept of advocacy was described on the basis of a literature review (n = 89 empirical studies from 1990 to 2003). Then, the concept was described in the context of procedural pain care on the basis of interview data (n = 22 patients, 21 nurses) in a medical and surgical context. In the second phase, an instrument exploring the content of advocacy and the implementation of advocacy in context of procedural pain care was developed and validated. Then, the content of advocacy and implementation of it was explored in a sample of otolaryngeal patients (n = 405) and nurses (n = 118) in 12 hospitals. In the third phase, an update literature review (n = 35 empirical studies from 2003 to 2007) was conducted, and all data from phases one and two were reviewed in order to refine the elements the concept of advocacy, and the relationships between these elements.

As a result of this study, advocacy in context of procedural pain care was defined as consisting of the dual aspects of patient advocacy and professional advocacy, and called nursing advocacy. It was divided into dimensions and subdimensions in which patient and nurse empowerment seems to play a vital role. All the data obtained lend support to this definition of nursing advocacy. Patients and nurses felt that nearly all of the activities that they considered as advocacy were implemented.

**Keywords:** nursing ethics, advocacy, procedural pain care, empowerment

Heli Vaartio

## **Edunvalvonta hoitotyössä: käsitteen selkeyttäminen proseduraalisen kivunhoidon kontekstissa**

Hoitotieteen laitos, Lääketieteellinen tiedekunta. Turun yliopisto, Suomi, 2008.

### **TIIVISTELMÄ**

Tämän tutkimuksen tavoitteena oli selkiyttää edunvalvonnan käsitettä proseduraalisen kivunhoidon kontekstissa sekä selvittää edunvalvonnan toteutumista tässä kontekstissa.

Tutkimuksen ensimmäisessä vaiheessa edunvalvonnan käsitettä kuvailtiin kirjallisuuskatsauksen pohjalta (n = 89 empiiristen tutkimusten raporttia vuosilta 1990-2003). Seuraavaksi edunvalvonnan käsitettä kuvailtiin proseduraalisen kivunhoidon kontekstissa haastatteleamalla sisätauti- ja kirurgisten osastojen potilaita (n = 22) sekä hoitajia (n = 21). Tutkimuksen toisessa vaiheessa kehitettiin ja validoitiin mittari, jonka avulla kartoitettiin 12 sairaalassa korva-, nenä- ja kurkkutautien yksiköiden potilaiden (n = 405 potilasta) ja hoitajien (n = 118) näkemyksiä edunvalvonnan sisällöstä ja toteutumisesta. Tutkimuksen kolmannessa vaiheessa tehtiin päivitetty kirjallisuuskatsaus analysoimalla edunvalvonta-käsitteeseen liittyviä tutkimusraportteja (n = 35) vuosilta 2003-2007; ja yhdistettiin tutkimuksen aikaisemmissa vaiheissa koottu aineisto ja niiden osatulokset, jotta edunvalvonnan käsitteen osa-alueet ja niiden suhde toisiinsa voitiin määritellä.

Tämän tutkimuksen tuloksena edunvalvonta proseduraalisen kivunhoidon kontekstissa määriteltiin koostuvan sekä potilaan edunvalvonnasta että hoitajien ammatillisesta edunvalvonnasta, joita yhdessä kutsutaan hoitotyön edunvalvonnaksi. Se koostuu tietyistä sisältöalueista ja osioista, joihin potilaiden ja hoitajien valtaistumisella näyttää olevan yhteyttä. Kaikki aineistot tukivat tätä edunvalvonnan määritelmää. Potilaat ja hoitajat kokivat myös, että lähes kaikki edunvalvontatoimet toteutuivat heidän kohdallaan.

**Avainsanat:** hoitotyön etiikka, edunvalvonta, proseduraalinen kipu, kivunhoito, valtaistuminen

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## **LIST OF ORIGINAL PUBLICATIONS:**

- I Vaartio, H. & Leino-Kilpi, H. 2005. Nursing advocacy – a review of the empirical research 1990-2003. *International Journal of Nursing Studies* 42, 705-714.
- II Vaartio, H., Leino-Kilpi, H., Suominen, T. & Salanterä, S. 2006. Nursing advocacy: how is it defined by patients and nurses, what does it involve and how is it experienced? *Scandinavian Journal of Caring Sciences* 20(3), 282-291.
- III Vaartio, H., Leino-Kilpi, H., Suominen, T. & Puukka, P. 2008. Measuring nursing advocacy in procedural pain care - development and validation of an instrument. *Pain Management Nursing*. Accepted for publication 2/2008.
- IV Vaartio, H., Leino-Kilpi, H., Suominen, T. & Puukka, P. 2008. The content of advocacy in procedural pain care – patients’ and nurses’ perspectives. *Journal of Advanced Nursing*. Accepted for publication 7/2008.
- V Vaartio, H., Leino-Kilpi, H., Suominen, T. & Puukka, P. 2008. Nursing advocacy in procedural pain care. *Nursing Ethics*. Accepted for publication 6/2008

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## 1. INTRODUCTION

The philosophy of nursing requires that nurses act for, i.e. advocate for patients. This ethical principle is central to the nurse-patient relationship and reflects an attitude of respect towards patients as individuals (Gadow 1980, Hem & Heggen 2004) and towards patients' rights (Webb 1987, Snowball 1996), particularly their right to self-determination. Advocacy is recognized as a duty of the professional nurse (Chafey et al. 1998, Blondeau et al. 2000, Schroeter 2000) and as an important aspect of good care (Leino-Kilpi 1990, Gaylord & Grace 1995). It has even been suggested (Woodrow 1997) that if the nursing profession fails to advocate for patients, it has little purpose beyond its technical role. Some commentators, however, have suggested that the whole concept of patient advocacy is merely an attempt to raise the professional status of nurses (Gates 1995, Gould 2001).

Advocacy has continued to attract increasing theoretical and empirical research interest up to the present day. The main focus of this research has been on identifying those patients that are most in need of advocacy, and on the other hand on identifying those people who should provide that advocacy. Most of the existing literature is concerned with the health care personnel's point of view, in which advocacy is seen mainly as a duty of nurses, although no work has been done to explore to what degree individual, collegial or organizational ties have impact on that duty.

The increasing awareness of patients about their rights (Act on the Status and Rights of Patient 1992:785) places increasing demands both on the organization providing care and on the clinical and ethical competence of those seeking to respond to these demands. Indeed in Finland at least the number of patient complaints has increased during the past decade. At the same time, growing numbers of nurses are leaving the job because of feelings of professional and/or moral distress (Millette 1993, Biton & Tabak 2002), because of a perceived lack of organizational support (McDonald & Ahern 2000), and because of a sense of poor professional autonomy (Wilkinson 1997, Georges & Grypdonck 2002, Laine 2005). In other words, effective patient advocacy also requires advocacy for the nursing profession. It is important that nurses understand and can demonstrate their scope of practice, for that very much shapes and determines their professional autonomy in the health care team, in the organization, and in society at large. If nursing professionals are to empower their clients, they must first of all empower themselves (Ryles 1999), i.e. to have the opportunity and the ability to make choices (Kuokkanen & Leino-Kilpi 2000).

Despite the obvious importance of the concept, advocacy is rarely measured, documented or evaluated in nursing practice. One possible reason for this lies in the difficulty of adequately interpreting or applying general ethical principles in a particular situation (Edgar 2004). This, in turn, may have to do with the conceptual immaturity of the term advocacy, which was imported into nursing science from law jurisprudence in the 1970s, but not properly re-explored with respect to its meaning, application and appropriateness (Hupcey et al. 2001) in nursing science. If we are

unable to define and agree on the central concepts of nursing, then we cannot be held accountable in relation to those concepts, nor will we have any evidence to support our nursing diagnoses, interventions and outcomes. Importantly, too, we will not be in the position to call for changes in resource allocation, for example. It is vital to analyse the role that nurses have occupied in their profession and health care team, and how they express that role in interactions with their patients, the health care team, and society.

In this study, the concept of patient advocacy is integrated with that of professional advocacy to form what is referred to as nursing advocacy. Patient advocacy is here defined in terms of how patients' needs and interests (such as care preferences) and their rights to information and self-determination in care are taken into account. The principle of self-determination is based on the belief that each person is the best expert of his/her own life, and in order to make informed decisions about their own treatment they need to receive sufficient information about different services, alternative treatments and their effects (Leino-Kilpi et al. 2000). The concept and process of advocacy is here explored in the context of procedural pain care, i.e. pain due to a diagnostic or medical intervention or a surgical procedure. Pain is always a subjective experience, and each patient's own assessment should carry the most weight in effective pain management. Nonetheless pain care often involves ethical dilemmas with respect to resource allocation and the decision on whose experience or expertise of pain is prioritized, for example.

This study was conducted as part of a research project at the University of Turku Department of Nursing Science concerning patients' rights and professional codes of nursing ethics. Its aim was to clarify the concept of advocacy in the nursing science context and to explore its practical relevance from the point of view of both patients and nurses. The concept clarification offered in this study should provide important clues for empirical research on nursing ethics and particularly on advocacy, pain care and empowerment. The instrument developed will provide a useful tool for all these studies. In addition, the model of the concept of nursing advocacy developed in this study can be used in nursing education and in quality assurance projects. This model can be seen as a first step in the process of generating practice theory (Walker & Avant 1995) or situation-specific theory (Im & Meleis 1991) that focuses on a specific nursing phenomenon in clinical nursing practice.

## 2. LITERATURE REVIEW

### 2.1 The concept of advocacy

In order to understand the concept of advocacy, we need first of all to describe its different uses and meanings (Rodgers 1989, Schwartz-Barcott & Kim 1993). This analysis started with an examination of the etymological origins of the word and of how the concept is defined and understood in nursing science (Paper I). This was followed by an investigation of how the concept is used and defined in professional codes of nursing ethics and in closely related disciplines. Since the existing research on advocacy was quite limited, empirical studies were also conducted to obtain thicker materials for the definition of advocacy. The definition produced was then analysed, revised, operationalized and validated in three stages (Papers II-IV).

#### 2.1.1 Origin and dictionary definitions

The concept of advocacy derives from the Latin *advocatus*, meaning the function of an advocate, one who is summoned to give evidence, to support verbally or make arguments for a cause (cf. Woodrow 1997). Here, the term evidence may include information about the clinical or existential needs or preferences of a patient, information about patient's rights, but also knowledge on evidence based care in a certain situation. The verb *advocare*, then, means 'to call'. In the legal system, the role of advocate is that of a counsellor, initiated by a client (cf. Mallik 1997a) or the profession (Oxford English Dictionary 2006). In the legal system the role of advocate is clearly defined as one whose profession is to plead the cause of any one in a court of justice (Evans 1999), to intercede, or speak for, or defend on the behalf of another (Concise Oxford English Dictionary 2007). Advocacy describes the act of pleading for, supporting, urging by argument and active espousal (The Random House Dictionary of the English Language 1979), or raising one's voice in favour of, defending or recommending (Oxford English Dictionary 2006). In nursing dictionaries, advocacy is defined as an integral part of the professional health care practitioner's role (Oxford Dictionary of Nursing 1998), or as the role of a practitioner, usually a nurse, who utilizes her role to promote and safeguard the well-being and interests of her patients by ensuring that they are aware of their rights and have access to the information they need to give their informed consent (Oxford Dictionary of Nursing 1998, Oxford Reference Online 2007). In these definitions the initiator of advocacy is not the patient but a nurse, who either makes the active choice to take on the role of advocate or upon whom that role is bestowed.

In Finland, dictionary definitions of advocacy focus on the role of the advocate in the legal system. An English-Finnish dictionary describes it as either 'providing support, approval' or 'the actions of a lawyer or solicitor' (MOT 2007). The Ministry of Justice defines the role of an advocate as a trustee, as one who defends and represents the interests of the client and represents him/her. This role is governed by the Guardianship Services Act (442, 443/1999) and presupposes that a District Court has issued an order stating that the client is unable to protect their own interests or to represent themselves

for reasons of age, illness, absence, etc. (Facta 2006, Ministry of Justice 2007). This definition is also familiar in the field of sociology. The Finnish nursing dictionary (Hervonen & Nienstedt 2000) does not offer any definitions for advocate or advocacy.

### **2.1.2 Other definitions**

Patient advocacy became a subject descriptor in the International Nursing Index in 1976. Before that, articles related to advocacy were cited under the ethico-legal heading (Mallik & Rafferty 2000). This dual perspective on advocacy is still reflected in many current definitions of advocacy.

Human advocacy (Curtin 1979) is based on the idea that both the patient and nurses are human beings: this common ground forms the basis for the patient-nurse relationship. Human advocacy is defined simply as the exploration of patients' altered human needs during illness and institutionalization. Existential advocacy (Gadow 1980, 1990) goes one step further in that it also involves nurses' active participation: it is defined as active assistance to patients in their self-determination concerning health alternatives, efforts to help patients become clear about what they want in a situation, and to assist them in discerning and classifying their values and examining available options. These definitions are grounded in basic human rights, particularly that of self-determination. Other definitions of advocacy are based on the patient's right to information and informed consent; this is sometimes described as proactive advocacy (Snowball 1996). The purpose of advocacy is defined as making sure that patients have enough information to exercise autonomy (Webb 1987), or as informing the client and then supporting them in whatever decision they make (e.g. Kohnke 1982, Mallik 1997a). Furthermore, definitions that are based on the right to personal safety presuppose even more active participation on the part of the nurse. In those, advocacy has been defined as alleviating suffering (Gaylord & Grace 1995), safeguarding the well-being and interests of patients (Willard 1996), representing the patient, and as defending patients' rights, even after death (Watt 1997).

The most active role for the nurse as an advocate is that of a culture-broker (Jezewski 1993) or whistleblower, i.e. disclosing information about misconduct in the workplace that they feel that violates the law or endangers the welfare of others. This may involve the violation of rights, inadequate staffing, or misuse of public money, i.e. advocacy both on the patient, professional and societal level. (McDonald & Ahern 2000.) However, it has also been argued that whistleblowing does not amount to advocacy at all, since it is a form of public advocacy that tends to be done outside an organization when an advocate is ignored by that organization (Gates 1995). This perspective can be traced back to Fowler's social advocacy model (1989), which calls upon nurses to participate in social criticism and social change beyond institutional walls, and beyond individual patients.

Advocacy in everyday nursing practice is guided and governed by various codes of nursing ethics. In the 1970s, the International Council for Nurses (ICN 1973) defined advocacy as 'the nurse's appropriate action to safeguard the individual where care is endangered'. The ICN Code has influenced the development and substance of many

national codes worldwide. The introductory paragraph of the Code of Professional Conduct (United Kingdom Central Council for Nursing, Midwifery and Health Visiting 1992) identifies advocacy as 'a central role for nursing staff on behalf of patients who do not have the support of family or friends, and recommends that the best interests of patients ought to inform every act by practitioners'. The Irish Code states that 'the therapeutic relationship between nurse and patient serves to empower the patient to make life choices, and nursing practice involves advocacy for the individual patient and for his family, as well as advocacy on behalf of nursing in the organizational and management structures within which care is delivered' (Hyland 2002). The American Nurses Association's Code of Ethics (2001) states that 'the nurse promotes, advocates for, and strives to protect the health, safety and rights of the patient, especially if care and safety are affected by the incompetent, unethical or illegal practice of any person'. The American view on advocacy seems to be chiefly concerned with empowering clients to self-advocacy, while the emphasis in the UK is on influencing a third party on behalf of clients. Closely aligned with this latter view, the Norwegian Nurses' Association, for example, defines advocacy as the prevention of incompetent or unethical nursing practice, treatment and/or research. The Finnish Federation of Nurses (Assembly of the Finnish Nursing Association 1996) does not directly employ the concept of advocacy. However, its codes say that 'a nurse carefully evaluates her own and others' competence when receiving assignments and when giving assignments to others', and 'ensures that no professional involved in care acts unethically towards patients'. These definitions can be seen as instances of patient advocacy with a protective aspect. Further, the Finnish code goes on to say that, 'the nurse participates in discussion and decision-making concerning the health and well-being of people, both on national and international levels'. This refers to advocacy on both a societal and professional level.

There are also several different types of advocacy: the independent professional, the service professional, family, self, citizen, peer and collective advocacy (Brandon 1995). Advocacy thus also includes political and group action, a call for nurses to become involved in policy-making at the organization level and more generally (Snowball 1996), for example by ensuring that health care resources allow for the provision of appropriate quality and quantity of care (Webb 1987). This can involve the assessment and identification of individual, group or community characteristics that, when supported, enhanced or reversed, result in a better quality of life, and also the identification and transformation of social and/or environmental conditions that obstruct or preclude necessary and vital changes in people's lives (Zebrack 2001). Curtin and Mapes (2001) found that self-advocacy was one of the key self-management strategies of long-term survivors of dialysis (n = 18). However, they did not analyse this definition of self-advocacy any further. In the study by Davis, Salo and Redman (2001), oncology patients (n = 51) were found to have developed self-advocacy skills after attending an advocacy training programme by cancer organizations. This advocacy was defined as serving as a member on a committee or board, working on clinical trial recruitment issues or on patient resources, i.e. advocating at the societal level. The results of another cancer patient advocacy training programme on the Internet and involving interactive groups (n = 569 patients and 833

cancer professionals) indicated increased self-advocacy skills of communication, information seeking, problem-solving, decision-making and negotiating (Walsh-Burke & Marcusen 1999).

To conclude, advocacy can be seen as the duty of nurses to verify patients' human rights to self-determination and to personal safety, or patients' rights to information and informed consent. As a rule, advocacy takes place in direct patient contact, but it can also happen without that contact, i.e. as the action of highlighting the risks to the welfare of an individual or group in society. The same is applicable to members of a professional group. In these definitions, advocacy takes place on behalf of someone else. However, advocacy can also take the form of self-activity by empowered individuals. Earlier research has not clearly explicated whether this self-advocacy is an individual personality trait or a consequence of some catalyst experience.

## **2.2 The concept of advocacy in nursing science**

### ***2.2.1 Overview of the nursing literature***

Literature reviews were conducted at the first and last phases of this study to describe, clarify and define the concept of advocacy. Paper I offers a critical review and summary of empirical research derived from CINAHL and Medline from 1990 to 2003 as a basis for the later phases of the study. Furthermore, the purpose at the first stage was to explore the various perspectives applied in researching the concept of advocacy, to list existing definitions, define the dimensions and subdimensions of advocacy, and to identify its antecedents and consequences (see sections 2.2.3.1 and 2.2.3.3). The review indicated that advocacy was rarely used as a key term in titles or abstracts, but the verb advocate did appear frequently in different meanings.

An update was conducted using the same databases in February 2007. The aim here was to examine the definitions and dimensions of advocacy as well as the contexts of advocacy studies in the nursing science field since 2003 in order to ascertain the fit between the hypothetical definition of the concept and its clinical application (Morse et al. 1997). It seems there was no significant development in defining this concept in nursing literature after the first review (see section 5).

### ***2.2.2 Applications of the concept of advocacy***

In the nursing literature, the concept of advocacy has got several applications. Advocacy has been approached in the literature from a variety of different perspectives. Usually, advocacy is approached as a human right or as a patient's right or on the other hand as a nurse's professional role and moral duty. Furthermore, it is sometimes seen as a philosophical basis of nursing, as ethical decision-making, as nursing practice, as competent care, or as an outcome of quality care. However, advocacy has also been interpreted as a professionalization strategy; or as a role outside the patient-nurse relationship, and thus as a role that is not suitable for nurses. Most of these perspectives have been applied in empirical studies (Appendix 1).

These applications of the concept of advocacy indicate that the attributes of the concept have been inferred deductively from legal and moral rights and inductively from nursing practice as the concept has matured. There are no obvious theoretical or empirical trends in the development of advocacy perspectives. However, since the beginning of this decade it seems there has been a growing tendency to approach nurses' advocacy role as a stance on professional empowerment – or disempowerment – in connection with liberalistic care practice, stressing the autonomy of nursing professionals.

### ***2.2.3 Dimensions of advocacy***

Most of the existing research on advocacy has been conducted from the point of view of nurses, focusing on the triggers of advocacy and advocacy experiences in different nursing contexts rather than on definitions of advocacy. In order to extract a definition that has true practical value, the concept of advocacy should be examined from several different points of view, i.e. that of patients and their relatives, other health care team members than nurses, administrators, organizations, and nursing educators. However, the different perspectives on advocacy (Appendix 1) helped to distinguish advocacy as a process, which is preceded by certain antecedents and followed by certain consequences.

#### *2.2.3.1 Antecedents of advocacy*

There are many different personal or situational characteristics that serve as antecedents of advocacy, in other words, as conditions or catalysts for the initiation of advocacy (Rodgers 1989, Morse et al. 1996). These antecedents help to shed light on the context in which the concept is generally used (Appendix 2).

Most antecedents of advocacy seem to be related to the individual nurse's characteristics and skills. In order to be able to advocate, nurses need to have a professional training, clinical experience and competence, as well as ethical and interactional skills. Furthermore, they should be reflective and have the emotional strength and willingness to serve as patients' advocates. It has been suggested that the development of advocacy skills requires the acknowledgment of one's own professional role, observation of other nurses advocating, and having the necessary confidence (Foley, Minick & Kee 2002). All this requires practical work experience (Kieffer 2000, Seal 2007) and systematic feedback. Furthermore, nurses need to take account of ethical principles, standards and values (Millette 1993) as well as patients' rights as triggers to advocacy. Some authors have even argued that advocacy presupposes baccalaureate (Helton & Evans 2001) or doctoral nursing education (Howell & Coates 1997). Other results have shown that regardless of educational level ( $n = 879$  nurses), advocacy acts predict proficiency in non-acute care settings (Bryan et al. 1997).

The existence of a patient-nurse relationship and the quality of that relationship is also taken as an antecedent of advocacy. In order to be therapeutic and to have continuity, this relationship should be based on nurse's 'presence' (Eriksson 1992), mutual

understanding and trust (Donnelly 2000, Hyland 2002). It is necessary for the patient to be able to express his or her needs and interests, to be actively involved in information exchange (Buetow 1998) and not just to wait for nurses to ask questions. However, patient-nurse interaction may also be influenced by patient characteristics such as type of illness and age. Patient vulnerability is the most frequently cited antecedent of advocacy, although it does not always receive sufficient research attention. It should be analysed in relation to all patients' rights and needs, not as a flag signalling the advocacy needs of only aged, anaesthetized, unconscious or psychiatric patients. For example, patients' limited knowledge of their illness and its treatment is an important factor in the power relation between every patient and health care personnel (Carpenter 1992). These antecedents in the patient-nurse relationship have not been confirmed by patients, and therefore we do not know whether the nurse's power to become the patient's advocate depends on nurses' moral integrity, or on their professional autonomy (Wade 1999).

Intra- and interdisciplinary communication, collaboration, support and collegiality are examples of environmental factors or antecedents that lie outside of the patient-nurse relationship, but that are still vital to that relationship. Nurses as autonomous professionals should stand together on issues that demand an advocacy role, and ask for guidance, acceptance and support both from colleagues and society. A more collegial relationship in the health care team gives nurses and physicians greater powers to protect the best interests of patients, particularly when these interests are potentially threatened by external factors such as cost control exercises. This collaboration can be defined as the act of working in partnership with another, or as a joint communication and decision-making process with the express goal of satisfying the patient's needs while respecting the unique qualities and abilities of each professional (Sundin-Huard 2001). When nurses and physicians collaborate, they educate each other about the patient, and the clinical, physiological, social, and emotional knowledge they gain in this process in turn shapes the care they provide. Increased communication and cooperation will improve the prospects of achieving patient well-being (Willard 1996, Gianakos 1997, Sundin-Huard 2001, Hyland 2002, Eaton 2005, Kendall 2006).

The support of employers is also important to advocacy. Although nursing codes identify who is responsible for advocacy, institutional strains may be placed on nurses practising according to that responsibility, with the result that they lose their empowerment (Chafey et al. 1998, Mallik 1998, Schroeter 2000, Goodman 2003, Davis, Konishi & Tashiro 2003, O'Connor & Kelly 2005). Nursing leaders recognize patient advocacy as an integral part of the moral value system in nursing, but they object to the professionalization of the advocacy role because they feel it intensifies interprofessional conflicts. This is because advocacy or its consequences may conflict with nurses' professional responsibilities. (Mallik 1998.) Therefore, nursing organizations should adopt a positive stance towards reporting misconduct, and national nurse's associations should lobby for legislation to protect nurse whistleblowing (McDonald & Ahern 2000).



Obstacles to advocacy are the opposite of its antecedents. Obstacles include work environment barriers such as time restraints, budget austerity (Willard 1996, Kieffer 2000, Schroeter 2000) and high turnover among both clients and staff (Chafey et al 1998, Negarandeh et al. 2006). All of these factors directly affect the dialogue and relationship between nurse and patient. The shift from caring towards control also limits the ability of nurses to advocate patient autonomy (Svedberg, Hällström & Lutzen 2000). Normative power processes may control, enable or foreclose what identities, including the advocate's role, can be assumed by particular individuals (Sundin-Huard 2001). For example, power hierarchy, line management, specific role responsibilities, lack of professional autonomy, fear, frustration, fatigue and burn-out (Willard 1996, Chafey et al. 1998, Schroeter 2000, Kendall 2006) and a climate of secrecy can make advocacy actions impossible, or very difficult, despite strong moral pressure on the nurse to advocate (Mallik 1997a, Georges & Grypdonck 2002, Manojlovich 2005). Svedberg et al. (2000) found that nurses working in a psychiatric context (n = 9) were unable to advocate patients' best interests because they did not have enough collaboration with other professionals, they were unable to influence patient treatment, and because they had negative feelings towards patients. Sellin (1995) reported that the social stigma of drug abusers and alcoholics made caring about them even more difficult than caring for them, and even the idea of advocating was unrealistic. One major obstacle to advocacy is that often it is not the patient who initiates the role of advocacy to nurses, but rather nurses themselves (Mallik 1997b, Evans 1999). This, in turn, may depend on the skills and abilities of nurses to work with the system both within and outside the hospital (Hellewig et al. 2003).

To conclude, antecedents of advocacy seem to consist of a set of nurses' skills, nurse empowerment, patients' participation in information exchange, the continuity of the patient-nurse relationship, collegial support, and employees support received by nurses from employers to take on the advocate role.

### 2.2.3.2 *Advocacy activities*

Given the wide range of definitions of advocacy as a noun, descriptions of advocacy as an activity are also many and varied. What is more, these descriptions of what goes into advocating are often quite vague and ambiguous, making documentation very difficult.

Advocacy activities may be related to patients' needs, such as gathering information or learning about patients' personal wants and desires (Sellin 1995), or to patient information, described simply as informing (Segesten 1993, Snowball 1996, Schwartz 2002), breaking information (McGrath & Walker 1999), educating, supporting and counselling patients (Maher & Myatt 1995), or as promoting informed consent (Schwartz 2002, Baldwin 2003). These descriptions include both the patient and the advocate. However, advocacy can also consist in doing on the patient's behalf, standing up for the patient and his/her rights, protecting and defending patients' interests, taking direct action by physically standing in the way (Sellin 1995), representing or speaking up for patients who are unable or unwilling to speak up for themselves, ensuring that decisions are approached from the perspective of informing

the patient, protecting patients' dignity or privacy and defending them against interventions that may cause them distress (Snowball 1996, Schwartz 2002).

In these activities the advocate seems to be alone, without a specific patient. Advocacy activities can also be described as taking place over and above specific patient-nurse relationships, in relation to the organization or society: going directly to the source of the problem, going through organizational channels, going to ethical committees, or calling for all-inclusive staff meetings (Sellin 1995), intervening in the system on the client's behalf (Chafey et al. 1998), and ensuring that patients have fair access to available resources (Schwartz 2002). A concept analysis (n = 220 articles) based on a tentative mid-range theory of patient advocacy (Bu & Jezewski 2006) yielded 250 empirical referents of patient advocacy, i.e. contextual patient advocacy actions. These were categorized as safeguarding patient autonomy, acting on behalf of patients, and championing social justice in the provision of health care. Interestingly, the research report by Bu and Jezewski mentions only one antecedent of advocacy: patient vulnerability, which is described as a general antecedent, but not included in their emerging theory.

Advocacy activities can thus be categorized as supporting and protecting patients' rights of autonomy and informed consent, as supporting and protecting patients' interests, and as intermediating for or defending these rights and interests. However, these descriptions lack both subject and object, i.e. by whom and from whom or what patient is to be protected or defended. This shortcoming is addressed by Baldwin, who in a concept analysis of patient advocacy (2003) identifies advocacy as valuing, appraising and interceding in a therapeutic nurse-patient relationship in order to secure patients' freedom and self-determination, promoting patients' rights to be involved in decision-making and informed consent, and acting as an intermediary between patients and their families or significant others, and between them and health-care providers. However, this concept analysis does not include advocacy for the nursing profession, or advocacy on the society level. Nurses are described as agents who are not affected by contextual constraints.

### *2.2.3.3 Consequences of advocacy*

Consequences of concepts are events or incidents that occur as a result of the occurrence of a specific concept, an ability to perform specific behaviours as a result of being clear about that concept (Rodgers 1989, Morse et al. 1996). The consequences of advocacy (Table 1) seem to be related to human and patients' rights, i.e. the patient's sense of dignity, autonomy and self-determination, or self-control of both patients and nurses. Self-control, in turn, is an element of empowerment (Falk-Rafael 1995, Hyland 2002).

**Table 1.** Consequences of advocacy

<b>Consequences of advocacy</b>	<b>Authors</b>
	* empirical evidence
<b>Empowering consequences for patient:</b>	
Sense of personhood, self-worth and dignity	Rushton, Armstrong & McEnhill 1996
Satisfaction with care	Rosenman et al. 2000
General sense of well-being	Maier & Myatt 1997*
Quality of life	Benhamou-Jantelet 2001, Bu & Jezewski 2006
Liberation and release	Woods 1999
Involvement in care	Walsh-Burke & Marcusen 1999, Davis et al. 2001, Valokivi 2004, Harkness 2005
Informed choice	Sellin 1995, Segesten & Fagring 1996, Maier & Myatt 1995*, Hyland 2002
Autonomy	Kohnke 1982
Client empowerment	Chafey et al. 1998*, Schroeter 2000*, Falk-Rafel 2001, Vogt Temple 2002, Bu & Jezewski 2006
Self-advocacy	Kohnke 1982*, Mallik 1997a, Morra 2002, Anderson & Funell 2005
Self-determination	Pearson 1998
Quality care	Zebrack 2001, Ostwald et al. 2003
Prevention of complications	Goodger et al. 1998, Allen 2000
Savings in patient's costs	Rydholm 1997, Little et al. 2002
Increased survival rates	Pullen 1995
<b>Disempowering consequences for patient:</b>	
Being abused	Welchman & Griener 2005
Suffering	Welchman & Griener 2005
<b>Empowering consequences for nurse:</b>	
Increased self-assurance	Berggren, Begat & Severinsson 2000
Improved professional status	Bu & Jezewski 2006
Professional satisfaction	Bu & Jezewski 2006
<b>Disempowering consequences for nurse:</b>	
Frustration and burnout	Sundin-Huard & Fahy 1998*
Professional reprisals	Sellin 1995, Jackson & Raftos 1997, Mallik 1997a, McDonald & Ahern 2000*
Personal and professional risk	Wheeler 2000, Hyland 2002, O'Connor & Kelly 2005, Welchman & Griener 2005

Informed consent, for example, represents both an ethical and legal principle relating to the individual's autonomy and respect for that autonomy (Donnelly 2000). According to the Act on the Status and Rights of Patients (1992:785 Section 5), a patient shall be given information about his/her state of health, the significance of the treatment, various alternative forms of treatment and their effects and about other factors related to his/her treatment that are significant when decisions are made on the treatment given to him/her. Furthermore, even though it is not always easy to determine whether or not the patient has the capacity to make decisions, and even though this is rarely properly assessed (Evans 1999), the right to information cannot be sidelined on grounds on the patient's anticipated incapacity.

As far as nurses are concerned, the consequences of advocacy are hardly such that they encourage them to take on the advocate's role. These consequences seem to lead only to loss of professional control and self-determination: loss of status, job and/or

professional role, and indirect or direct conflict with the collegial group or the organization. The triadic model of advocacy in particular is said to give rise to professional conflicts (Wheeler 2000, O'Connor & Kelly 2005). McDonald and Ahern (2000) found that nurses who reported misconduct (abusive or incompetent carer) often experienced demotion, reprimand, referral to a psychiatrist, rejection, or pressure to resign. Accordingly, in a Taiwanese study (Chaowalit et al. 2002), nurses (n = 40) described advocacy as the opposite to maintaining relationships with colleagues. There is also evidence of clear links between nurses' repeated unsuccessful attempts to advocate and experiences of moral distress and leaving nursing careers (Sundin-Huard 2001).

Self-control and self-determination can be seen as elements of empowerment, i.e. the development of critical consciousness and simultaneous action. According to Irvine et al. (1999) and Suominen et al. (2005), empowerment can assume three different forms, namely verbal (ability to state one's opinion, participation in decision-making), behavioural (ability to work in groups in order to solve problems), and outcome empowerment (ability to determine the causes of problems and to solve them, making improvements and changes). Patient empowerment can be seen as a redistribution of power in favour of the patient (Skelton 1994, cited in Rundqvist 2004, p 40). People surrounding the individual are instrumental in the realization of self-determination either by providing support and creating the necessary preconditions for, or by imposing obstacles to self-determination (Välimäki & Leino-Kilpi 1998), whether psychological or structural. On the other hand, the patient must be an active and equal participant in his or her own empowerment, aware and committed to changing problematic situations, and subjectively transforming his or her own realities (Falk Rafael 1995). At best, empowerment leads to compliance, which is measured by such indicators as self-care behaviour, collaboration, an active and responsible patient role, and the intention of the patient to take part in his or her care (Kynngäs et al. 2000). Having the right to self-determination and to informed consent does not carry the obligation to use that right. This might be the reason why it has been suggested that advocacy may even cause loss of control, helplessness and frustration for patients (Pullen 1995). It has also been stated that patients will suffer unnecessarily if nurses are burdened with the responsibility to advocate (Welchman & Griener 2005). However, all these advocacy consequences for patients have been suggested by others than patients themselves.

#### ***2.2.4 Implementation of advocacy***

Following the different applications of the concept of advocacy (see 2.2.2), there are studies that focus on describing the different situations in which advocacy happens: patients' decision-making process (Johnson, Schwiebert & Rosenmann 1994, Love 1995), the identification of ethical problems in nursing practice (Schroeter 1999, Bosek 2001, McSteen & Peden-McAlpine 2006) and consequently, ethical decision-making (Pinch 1985, Holly 1989, Erlen & Sereika 1997, Ahern & McDonald 2002, Berggren, Begat & Severinsson 2002). Furthermore, advocacy has been taken as synonymous to different reality changing efforts (Picard et al. 2004, Kendall 2006). However, based on the number of titles and keywords extracted from database searches, there is only

limited research into the implementation of advocacy, i.e. in what proportion to everyday nursing practice advocacy activities are implemented. On the other hand, there is some research into the implementation of specific aspects of advocacy, such as promoting and safeguarding patients' rights to information, to informed consent and to self-determination (see 2.1.2).

Nurses do seem to advocate patients' right to information and informed consent, but not systematically. For example, patients are known to attach great importance to information about their illness and its treatment. However, in a sample of 928 patients with different diagnoses, only little information was provided by nurses regarding patients' daily coping with the illness, their prognosis and rights (Suhonen et al. 2005). Similarly, in a sample of 318 adult patients with MS, 75 per cent said they were not happy with the information they had received concerning health services (Somerset et al. 2001), and most epilepsy patients ( $n = 2394$ ) rated the information they had received about their illness as poor (Poole et al. 2000). During shorter care periods, too, such as in surgical care, patients need situational information, information about their role, skills training, psychosocial support and information related to discomfort. However, it seems that this information is inadequate or not planned according to patients' preferences (Young & Schloessler 1991). Several studies have shown that this disregard for patients' preferences is also evident in the context of pain care (Cronin et al. 2000, Blay & Donoghue 2005). For example, 78 per cent of adult patients ( $n = 340$ ) seeking help from emergency rooms had expressed their pain verbally to personnel, 54 per cent of these patients had expressed severe pain and 47 per cent pain due to medical treatments. Only 1 per cent in this sample said they had received pain relief. They received no information about their care or about why medication was not provided. (Tcherny-Lessoty et al. 2003.) The pain jeopardized their rights to personal safety, but even this prompted no reaction.

Once information has been provided to the patient, it becomes possible for him/her to participate in decision-making or to give informed consent. Participation in decision-making concerning one's own care is synonymous with possessing self-determination, being independent (Penney & Wellard 2007), and having power (Nordgren & Fridlund 2001). This participation presupposes ongoing opportunities to talk with health care personnel (Kiessling & Kjellgren 2004, Llewellyn-Thomas 2006, Fraenkel & McGraw 2007, Penney & Wellard 2007), and recognition of patient's knowledge and information based on individual needs accompanied by explanations (Eldh, Ekman & Ehnfors 2006, Länsimies-Antikainen et al. 2007). In a study by Flynn, Smith and Vanes (2006), 96 per cent of 5199 adult patients were found to prefer maximal information exchange and 57 per cent wanted to have personal control over or a shared role in medical decisions. Similar figures have been reported in other studies as well (Doherty & Doherty 2005, Deber et al. 2007, Kremer et al. 2007, Meyer et al. 2007). In particular, younger or female patients, or patients who are in good health, have a greater need for self-determination and self care than others (Ganther, Wiederholt and Kreling 2001,  $n = 3500$ ). In a sample of women aged 18 or over ( $n = 1000$ ), good health and high education were associated with preferring an active role in treatment decision-making (O'Donnell & Hunskaar 2007). A systematic literature analysis on studies ( $n = 145$ ) focusing on patient characteristics as predictors of health care

preferences (Jung et al. 2003) also found that financial status correlated significantly with patients' preferences with different aspects of health care. Furthermore, patients from other cultures and/or with another language than that spoken by health care providers have been shown to need more information in order to be autonomous partners in decision-making (Mouton et al. 1997, Green et al. 2006). The same background characteristics also seem to be associated with relatives' information needs (van der Smagt-Duijnsteet et al. 2001).

Even though they acknowledge patients' right to information and to participate in decision-making, health care practitioners tend to contradict patient empowerment in several ways: by communicating their distrust in patients' experiential knowledge (e.g. by referring to laboratory results and other objective data), by quizzing patients about their knowledge, by communicating expectations of compliance, and by not providing the necessary information for informed consent (Cagle 2002). Another problem is that although health care personnel may intend to promote patients' self-determination, they often fail to ask whether patients actually want to participate in decision-making (Kremer et al. 2007), ask that question in an inappropriate situation (Fraenkel & McGraw 2007), ask it only once, or they do not make it clear to patients that the intention is to seek their opinions about making preference-based choices. All these lead to invalid responses. (Llewellyn-Thomas 2006.) For example, in a group of late-stage cancer patients (n = 720), most of them had expressed pain relief as a treatment goal, but treatment preferences and care practices were linked only in the older patient group (Rose et al. 2004). Even in acute situations such as myocardial infarct, patients (n = 19) were reported to have need for participation in treatment decision-making (Deber et al. 2007). In all clinical situations, then, it is important that patients' participation in decision-making is facilitated (Kettunen et al. 2006). One possible solution could be the use of decision aids aimed at improving patients' knowledge of the options available, incorporating patient preferences and values into decision-making (Fraenkel et al. 2007, McCaffery, Irwig & Bossuyt 2007).

Various instruments have been developed for the measurement of patients' self-determination related needs, one example is the Control Preference Scale (Florin, Ehrenberg & Ehnfors 2006). The use of nursing care specific instruments might also help the nursing profession to explain their role and inform patients and the general public at large about their qualifications (Santo-Novak 1997). For example, in a sample of 141 oncology nurses 59 per cent indicated that they often or frequently advocated for medicine. In the same sample, 43 per cent of the nurses indicated that they often advocated for their patients' needs. (Gosselin-Acomb et al. 2007.) However, neither the type of these needs nor the types of advocacy activities were specified. Also some case studies have been conducted on the implementation of safeguarding aspects of advocacy. Advocacy is taken as synonymous with talking for and educating about socio-economic rights for abused women (Thompson, Curry & Burton 1998), substance abusing patients with HIV (Gorman & Carroll 2000) or cancer patients (Walsh-Burke & Marcusen 1999). However, these ethical decision-making studies or reality changing efforts have not been validated by patients.

To conclude, there has not been enough research into advocacy implementation, only some of its aspects have been covered, and only in isolation from one another. The promotion of patients' needs and rights and safeguarding those needs and rights should always go hand in hand.

### **2.3 Procedural pain care**

This study is conducted in the context of pain care. The context of pain care was chosen because it is shared in common by several health care services, and because it integrates the different theoretical aspects of advocacy as defined in this study. In addition, pain care involves ethical problems and disempowerment (Haddad & Vernarec 2001, Lebovits 2001, Livovich 2001), which are often taken as antecedents of advocacy.

This study focuses to procedural pain, i.e. pain which can be described as an acute increase or sudden onset of pain for a brief duration, experienced during some medical procedure, during exercise, or during nursing care (Pasero & McCaffery 1998). In this study, procedural pain means pain due to diagnostic or medical interventions or a surgical procedure. In procedural pain care there is enough time for patients prior to the medical intervention to express their needs and rights, which is not necessarily the case in acute pain care. In chronic pain care, then, there are several other variables that affect the care process, including advocacy.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) issues standards for pain assessment and management, including the requirement that the health care organization shall plan, support and coordinate activities and resources to assure that the pain of all patients is recognized and appropriately addressed (Haddad & Vernarec 2001). The care organization must establish these policies and standards with appropriate scientific rigour, and the care should meet the test of support in the peer-reviewed literature and/or expert consensus that is subject to peer review (Livovich 2001). Clinical nurse specialists should support and teach ward nurses to make use of science in the validation of practices in pain management (Duncan 1999).

Pain management plans should include at least instructions on how often to assess patients' pain, how to assess it most effectively, how to document the pain, when to inform other health care providers about the patient's status, what to teach the patients about reporting pain, how to intervene effectively, and how to develop quality assurance tools to monitor improvement in pain management (Salladay 2001). However, pain judgement and management are usually guided by the diagnosis, level of patient mobility, and the presence or absence of physical and behavioural signs (Loveman & Gale 2000), i.e. by clinical know-how anticipated by a professional training. A recent study in Finland about the content of pain education for medical students revealed widespread dissatisfaction with that education. Issues of pain management were covered in various different courses, but there still remained large knowledge gaps (Pöyhiä & Niemi-Murtola 2007). A study of theoretical pain care skills among practising nurses (n = 80) found that their pharmacological skills were rather good (Lahti, Nordberg & Ruhtila 2007). However other pain care skills were not

included in the survey. Pain is also either a possible or actual threat to every patient's existential well-being and autonomy. Attention should also be given to the suffering component of pain, i.e. the patient's judgement about pain (Haddad & Vernarec 2001) and its effects (McCabe 1997). Research in this field over the last 40 years has indicated that, when compared with the pain judgements of patients themselves, health professionals tend to underestimate pain (Prkachin, Solomon & Ross 2007).

Consequently, several studies in different contexts have reported insufficient pain care and its consequences to patients and health care organizations (e.g. Drayer, Henderson & Reidenberg 1999, Puntillo et al. 2001, Fries et al. 2003). Patients are often subjected to painful invasive procedures without adequate pain relief (Pasero & McCaffery 1998), for example during medical diagnostics (Tcherny-Lessoty et al. 2003); turning or wound care (Stotts et al. 2004). They are not informed about pain and pain care prior to these interventions, even though structured pain assessment and pain care schemes are known to significantly reduce both average and worst pain scores (Closs, Briggs & Everitt 1999), pain medication use and length of hospital stay (Daltroy et al. 1998). This may have to do with lacking pain care knowledge (Brockopp et al. 1998, Haddad & Vernarec 2001, D'Arcy 2008). For example, in a review of the ethics of pain management (Emanuel 2001), there was no place for ethical analysis either in context of acute or procedural pain, but only in chronic and terminal pain management. Other possible reasons might be indifferent attitudes (Tcherny-Lessoty et al. 2003), poor collaboration (Drayer, Henderson & Reidenberg 1999, Duncan & Pozehl 2001) or the fact that patients are reluctant to express their pain or pain care education needs (Rastinehad 2001, Stotts et al. 2004, Lahti, Nordberg & Ruhtila 2007).

In day-to-day interaction nurses have a key role to play in evaluating the patient's status, responding to patients' requests, and in giving information. Heafield (1999) provides a short but usable method for advocating patients within the context of procedural pain, e.g. with invasive interventions: nursing assessment should be used to achieve optimum pain relief and areas to consider include the patient who is supposed to be able to communicate, the environment and its equipment and the procedure. Salanterä (2008) reminds also about observations of pain signs with patients not able to express their pain verbally. Nurses may also be involved in advocating for good pain and symptom management by developing institutional policies, educating patients and families about their rights and working towards broad-based social policy changes (Christopher 1999).

Pain care standards are obviously important, but they will not in themselves ensure that professionals actually fulfil their obligation, that requires both an individual and a collective commitment. Since pain management is one area where nursing and medical expertise overlap, nurses are qualified to make some judgements about physicians' performance and vice versa. The conflict between patients' wishes and the requirement of loyalty to one's professional duties and colleagues presents a major ethical challenge. Other possible threats include resource allocation within pain management, or the referral of patients to unproven techniques. (Haddad & Vernarec 2001.) Some, but not all ethical theories provide useful guidance for dealing with these ethical challenges. For example, utilitarianism is unable to distinguish between acceptable and



unacceptable consequences of well-intended necessary actions, and between well-intended actions that are not necessary. Kantianism offers no guidance for balancing conflicting obligations, nothing is negotiable, and right-based theories are too individualistic and adversarial. Nursing ethics, therefore, offers a viable alternative to addressing these challenges, given its focus on the patient-nurse relationship, emotional commitment to and willingness to act on behalf of other persons. This challenges the impartiality and detachment implied by the alternative ethical theories and universal principles of ethics: respect for autonomy, nonmaleficence, beneficence, and justice. (Sullivan 2000.)

Nonmaleficence stresses the imperative to do no harm, and beneficence holds the view that the right action generates the greater good for the patient (Thompson, Melia & Boyd 2000). These two principles emphasize the importance of people having the right and the power to make ethical decisions about patient's care (Sullivan 2000). This paternalistic approach can be seen in health care practice in situations where personnel urge the patient to select treatment plans based on their clinical views of what is best for the individual (Gadow 1990, Mitchell & Bournes 2000). Directly antithetical to this approach is consumerism, in which health care professionals act as guides, informing patients about the facts of their condition and the treatment options available. The practice of advocacy can be seen as a compromise between paternalism and consumerism (Chafey et al. 1998, Donnelly 2000), as a case-based supplementation of care ethics (Sullivan 2000). However, because of time constraints it is difficult for nurses to identify ethical issues within pain care (Schroeter 1999). If for this reason the paternalistic approach is taken, there is the risk that pain care is omitted from medical procedures.

To conclude, the role of the nurse advocate is to empower the patient to assert control over their pain management and to personally intervene if that is necessary (Söderhamn & Idvall 2003), or to speak out on behalf of the patient (Loveridge 2000) in the event that the nurse perceives an unsatisfactory situation (Söderhamn & Idvall 2003) or problems with technique (Allen 2000). Furthermore, as an advocate aiming to facilitate patient autonomy in pain care, nurses should be able to identify the institution's policies and procedures, take advantage of all opportunities for advance planning as well as be alert to opportunities for sensitive conversations about the institution's current practices (Tilden 2000). For example, it is often assumed that there is no need to obtain the patient's informed consent for minor procedures, especially if they are provided as part of a wider treatment. However, it is essential to ascertain that the patient's wishes are known every time in unclear cases, particularly if the treatment involves risks or if alternative methods of treatment are available. (Leino-Kilpi et al. 2000.)

## **2.4 Conclusions from the literature review**

This literature review has drawn attention to the complexity of the concept of advocacy in nursing care and nursing science. Although the advocacy role and advocacy actions stem implicitly from nursing philosophy, the concept of advocacy does not capture the

meaning and content of this role and these actions very successfully. Although there is far-ranging knowledge about the topic, the concept and its different uses are a source of much frustration in nursing practice and nursing science. First of all, the same phenomenon is described using a range of different concepts: patient advocacy, client advocacy, self-advocacy, professional advocacy, citizen advocacy, peer advocacy, collective advocacy, and so on. Accordingly, the concept has many different theoretical underpinnings, which makes it difficult to clarify the concept.

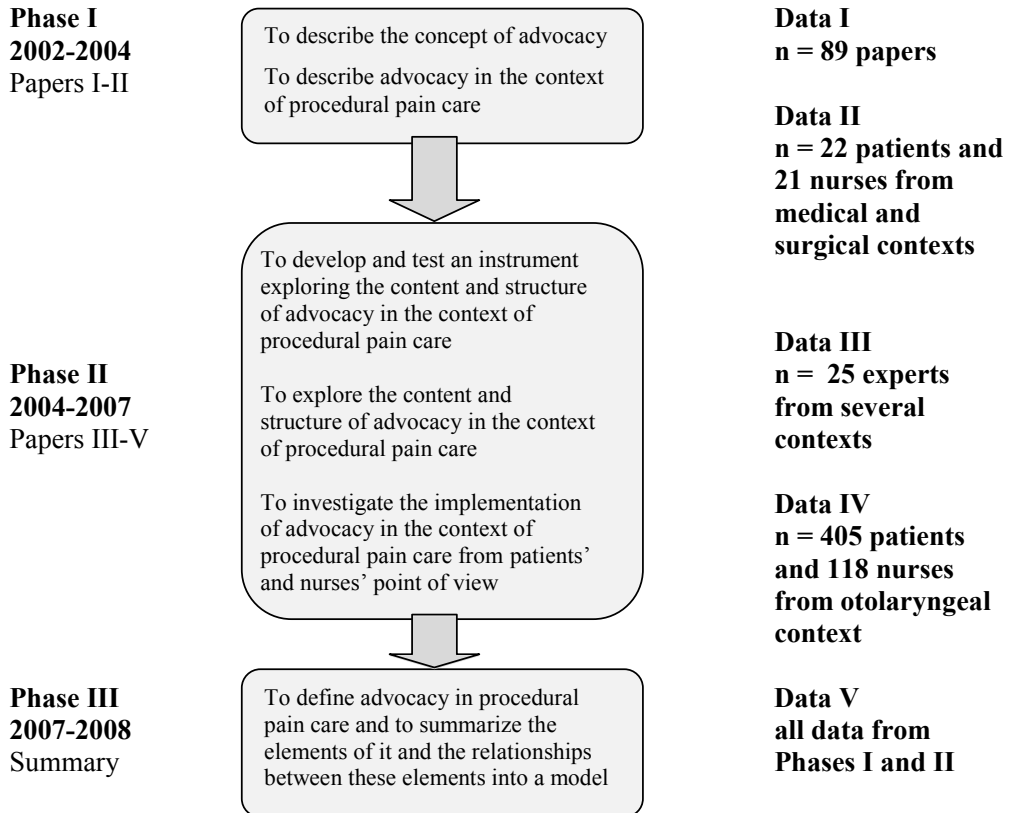
Advocacy can be seen as a patient's legal or moral right or as a nurse's professional or moral duty, as a philosophy, an intervention, an indicator or an outcome. However, it is mostly approached from the point of view of nurses. Furthermore, advocacy can be taken to presuppose nursing education and both clinical and ethical knowledge, or it can be taken as a task of a patient ombudsman outside the health care team. Advocacy can also be defined as an event or as a process, as part of clinically and ethically good nursing care, or as the role of a whistleblower in an ethical conflict situation. These ambiguities certainly affect the identification of advocacy antecedents and consequences, as well as the explication of advocacy activities. This, in turn, adversely affects the operationalization of the concept and research designs concerning advocacy, making verification and measurement of this key nursing concept far too remote an idea to be supported in nursing philosophy, practice, education and research.

Procedural pain care, then, seems to be a relevant context for an explication of the concept of advocacy. Patients have the right to information about their pain care and the right to effective pain care even in minor medical procedures, but according to the literature reviewed these rights are not fully respected.

### **3. PURPOSE AND RESEARCH QUESTIONS**

The purpose of this three-phase cross-sectional study was to clarify the concept of advocacy, to see how it is implemented in procedural pain care, and to summarize the concept as a model. In **Phase I**, the aim was to 1) describe the concept of advocacy and to 2) describe advocacy in the context of procedural pain care. In **Phase II**, the aim was to 1) develop and test an instrument for exploring the content and structure of advocacy in the context of procedural pain care, to 2) explore the content and structure of advocacy in the context of procedural pain care, and to 3) investigate the implementation of advocacy in the context of procedural pain care. Finally, in **Phase III**, the aim was to 1) define advocacy in procedural pain care and to 2) to define the elements and the relationships between these elements into a model of the concept of advocacy in procedural pain care. The phases and goals of the research project are described in Figure 1. More specifically, the following research questions were addressed:

1. What is advocacy in procedural pain care?
  - 1.1 How is advocacy described in the nursing literature? (Paper I)
  - 1.2 How is advocacy described by patients and nurses in procedural pain care? (Paper II)
  - 1.3 What is the content and structure of advocacy in procedural pain care? (Papers III-IV)
2. How are advocacy activities implemented in procedural pain care from patients' and nurses' point of view? (Paper V)



**Figure 1.** The phases and goals of the research project

## 4. METHODOLOGY

### 4.1 Methodological approach

The term concept analysis refers to the study of an existing concept through a synthesis of what is known about a construct at a particular point in time (Finfgeld-Connett 2006), or a process of inquiry that explores concepts for their level of development as revealed by their internal structure, use, representativeness and relations to other concepts (Morse et al. 1997). Concept analysis can also be seen as synonymous with concept clarification. The research strategy chosen depends on the level of maturity of the concept in question (Morse et al. 1997) and on the purpose of the concept development process (Finfgeld-Connett 2006).

The most commonly used methods in concept analyses are the Wilsonian derived methods of Walker and Avant, Chinn and Jacobs, Schwartz-Barcott and Kim, and Rodgers (Morse et al. 1997). These methods are sometimes said to lack intellectual rigour, and qualitative or quantitative methods or a critical analysis of a concept are recommended instead for concept analysis (Hupcey et al. 1997) especially when the aim is to generate new ideas or useful theories (Finfgeld-Connett 2006).

In this study, the aim was to clarify the abstract and immature concept of advocacy by ascertaining the fit between the definition of the concept and its clinical application (Morse et al. 1997) in a certain context. Rather than applying a specific technique of concept analysis, this study set out to accomplish this clarification by a series of approaches to concept development supported by both hypothetical constructions and empirical data. The aim was to combine several sets of data in order to outline the characteristics of the concept of advocacy and the role it plays in explaining reality. The active movement back and forth between the different datasets and between different analysis methods (cf. Schwartz-Barcott & Kim 1993) was intended to overcome the single case study approach that is often used in the literature as a method of conceptual studies. Furthermore, the existence of interrelationships among advocacy and associated concepts was acknowledged (cf. Rodgers 2000a), but the concept was still operationalized so that it can be useful in nursing practice, nursing education and nursing research.

Descriptive, explorative and correlational studies concerning advocacy were conducted in the context of internal medicine and surgical care services among adult hospital patients in 13 hospitals from nine hospital districts in Finland. The work was carried out in three successive, iterative phases between 2002 and 2007 (see Figure 1). In Phase I, the main concern was to define the concept of advocacy (Papers I-II). The etymological and semantic analyses of the concept were not conducted (see Eriksson 1992) for there were no enough dictionary definitions to use as a data. Instead, the previous literature (Data I) was reviewed. The purpose of the review was to study the current use of the concept of advocacy, to clarify its meaning and identify areas of knowledge concerning advocacy (Rodgers 1989, Schwartz-Barcott & Kim 1993, Chinn

& Kramer 1995, Morse 1995). A database search was conducted on CINAHL and Medline in 1990-2003 (for the search strategy, see section 4.3) to examine the theoretical and empirical definitions of the concept, the contexts in which it has been studied, the research methods and samples used, and questions of reliability and validity (Rodgers 2000a,b, Brilowski & Wendler 2005). This can be seen as a critical analysis of the concept in question (Morse et al. 1997), or as a synthesis in which research findings serve as the database, and results from multiple context-bound investigations produce a broad description of the concept (Finfgeld-Connett 2006). The review showed that there has been enough research in this area for an integrative literature review (Polit & Hungler 1995). However, it was also found that the concept of advocacy was not applied coherently and that it lacked a clear definition. The studies reviewed focused on certain acute contexts and on the health care personnel's point of view.

Because of to this obvious epistemological, linguistic, logical and pragmatic immaturity of the concept (cf. Morse et al. 1996, Hupcey et al. 2001), an additional dataset (Data II) was collected for the concept clarification (see Hutchfield 1999) in order to describe the way that nursing advocacy is defined by patients and nurses in the context of procedural pain care (Paper II), i.e. in order to illustrate how the concept is experienced (Eriksson 1997) and how it emerges in a specific practice situation (Brilowski & Wendler 2005). This dataset was analysed inductively until saturation was reached, and until the attributes of the concept could be identified in that specific nursing context (cf. Hupcey et al. 2001). This enabled the description of the concept in analytical terms, to an abstraction beyond a mere description of an experience (Morse et al. 1997).

In Phase II, because there were no existing instruments for the measurement of advocacy from either patients' or nurses' point of view, the preliminary version of the APPC (Advocacy in Procedural Pain Care) instrument was developed and its preliminary validity and reliability tested (Paper III). The dimensions of the concept obtained in Phase I were operationalized into empirical indicators to examine advocacy in the context of procedural pain care (see section 4.3). Then, the content and construct validity of APPC was tested (Data III, IV). Immediately after instrument validation, descriptive and correlational designs (dataset IV) were used to validate the central content of the concept (Paper IV) and to describe the implementation of advocacy from patients' and nurses' point of view (Paper V).

In Phase III, all information was brought together in an attempt to define advocacy. Data were subjected to an abductive review aimed at identifying the central attributes of advocacy (see Wilsonian-derived methods), a model case (Rodgers & Knafel 1993), related concepts, opposite terms (Finfgeld-Connett 2006), and empirical referents (Walker & Avant 2005). Furthermore, the antecedents, consequences and application of the concept were refined (Rodgers 2000a). This process of concept clarification thus integrates several methods of concept analysis: it applies the Hybrid Model of concept analysis (Schwartz-Barcott & Kim 1993) and also integrates elements of Prototype Concept Development (Morse & Doberneck 1995) - the tentative identification of a conceptual prototype from empirical data, deductive verification of this prototype, and

subsequent inductive revising and fine tuning of the conceptualization with the help of raw data. In a subsequent phase of the analysis, the conceptualization is revised and fine tuned. Table 2 summarizes the methods used in this three-phase cross-sectional study.

**Table 2.** Datasets and methods of the three-phase cross-sectional study

Phase	Design	Dataset	Methods of data collection	Data sources	Method of analysis	Paper
I	Descriptive	Data I	CINAHL and Medline databases 1990-2003	Published literature on advocacy (n = 89 empirical papers) and theoretical papers	Critical, integrative review	I
I	Comparative descriptive	Data II empirical	Semi-structured interviews	Internal medical-surgical patients (n = 22) and nurses (n = 21)	Inductive content analysis	II
II	Descriptive and descriptive correlational	Data III empirical	Self-administered questionnaire (content validity of APPC)	Experts in pain care (n = 12), experts in nursing science (n = 9 MNSc, 4 PhD students), altogether n = 25	Statistical analysis	III
II	Descriptive, correlational and explorative	Data IV empirical	Self-administrated questionnaire (APPC)	Otolaryngeal surgical patients (n = 405) and nurses (n = 118)	Statistical analysis	III, IV, V
III	Descriptive, correlational and explorative	Data V	CINAHL and Medline databases 2003-2007, review of all data in previous phases	Datasets in phases I-II	Abductive reasoning, content and statistical analyses	summary

## 4.2 Settings and samples

During the three phases of the study, three empirical datasets (Data II-IV) were collected. The target population was limited to non-acute medical-surgical settings because most studies dealing with nursing advocacy have been carried out in the context of acute nursing care, and it was thought that data from other settings would help to provide a broader insight into the concept in focus. Furthermore, sampling was limited to patients and nurses with experience of procedural pain care, based on the assumption that advocacy could be better explored in connection with some common nursing problem than in isolation. In addition, in the context of pain care there is evidence of ethical problems and disempowerment (Haddad & Vernarec 2001, Lebovits 2001, Livovich 2001), i.e. antecedents of advocacy. In each of these phases eligible patient informants were to 1) have expressed procedural pain during their current hospital stay, 2) be able to answer the interview or questionnaire, and 3)

participate voluntarily. For nurse informants the inclusion criteria were 1) having knowledge of the subject in focus, 2) having a nurse education and 3) voluntary participation. The nurses on the wards in question were to hand out information letters and questionnaires in consecutive order to each patient who fulfilled the criteria specified and to return written informed consent forms or filled questionnaires to the researcher. Patients took the interview or completed questionnaires during their hospital stay, nurse informants completed them during working hours. In each phase the starting-point was determined randomly and the data collection procedures were started at the same time in each hospital. However, patient data were collected prior to nurse data in all phases.

### *Data I*

In Phase I an international literature search was carried out on CINAHL and Medline for 1990-2003 (February), using the keywords patient/client, nursing and advoc\* (to cover advocacy, advocation, advocating, advocate). This was due to the changing nature of the target concept (cf. Morra 2000), as has been indicated by bibliographical analyses (Mallik & Rafferty 2000, Baldwin 2003). The first review was limited to empirical research reports and to adult (18 or over) and aged (65 or over) target groups.

The 134 papers yielded by the database search had to pass a three-stage review process (Paper I). In the first phase, the titles and abstracts of the papers were analysed. The exclusion criteria applied were as follows: not pertinent to the topic, no published abstract and published in other than the English language. In the second stage, the retained papers were analysed and editorials, position papers and descriptions of individual experiences were excluded. In the third stage the examination focused on the remaining 89 papers (see data analysis in section 4.5). A purposive sampling strategy was applied in order to ensure the inclusion of relevant studies only. The papers included in the literature review were thus empirical research articles written in the English language, published in peer-reviewed nursing journals and concerned with questions of advocacy. In addition, the theoretical literature was reviewed during the course of the research project, starting from a manual examination of the lists of references obtained from the empirical research reports and proceeding to manual and database searches concerning theoretical papers on the phenomenon.

### *Data II*

The first empirical dataset was obtained by using convenience sampling among adult patients (n = 22) and nurses (n = 21) on four medical and four surgical wards at one university hospital and one district hospital in Southern Finland. The target population consisted of adult patients who were to have expressed procedural pain during their current hospital stay, and registered nurses at those wards. Recruitment was based on an information letter distributed to and by ward personnel. The data were collected between 17 June and 18 July 2003, until saturation. During this period, the researcher visited the units several times in order to check how many informants had filled in the informed consent form, to negotiate the time and place for the interviews, and then to conduct the interviews. The individual interviews were conducted in a separate room



on the wards concerned. They took 30-70 minutes each (Md 35 minutes) and were tape-recorded with the informants' permission. The questions asked were: "How would you define nursing advocacy? What do nurses do/What do you do in advocacy situations? How do/did you experience nursing advocacy?" (See Paper II). The demographic data for these informants are summarised in Appendix 3.

### *Data III*

The second empirical dataset (see Paper III) was collected by using the stratified random sampling method in 14 clinics at one university hospital, and at one university department of nursing science in October 2006. The target population consisted of people who were presumed to be experts of pain care by virtue of their having provided systematic and continuous pain care education in the organization and by virtue of their having a master's degree in nursing science. A total of 75 questionnaires (Appendices 5a-b) were distributed for instrument content validation (see section 4.4). Only 25 of them were returned, giving a response rate of 33% (pain care nurses  $n = 12$ , response rate 17%, MNSc  $n = 9$ , response rate 45% and PhD students  $n = 4$ , response rate 33%). (Appendix 3). Non-response was found to be associated with employment on a non-acute ward and with variation in nurses' participation in pain care education in that organization, taken as criteria for presumed expertise. Amount of respondents was considered to be sufficient for this phase of instrument development (cf. Penfield & Miller 2004, Polit & Tatano Beck 2006).

### *Data IV*

In this phase the target population was limited to contexts in which patients usually need nursing advocacy for reasons of postoperative communicative inability (Seidman, Shapiro & Shirwany 1999). Thus, in the third empirical dataset (see Papers III, IV, V), the target population consisted of adult otolaryngeal surgical patients and nurses (Appendices 3 and 4) in hospitals that perform more than 400 otolaryngeal non day-surgery operations a year, i.e. 10% of the annual total in Finland ([kela.fi/it/tilastot](http://kela.fi/it/tilastot)). Out of Finland's 20 hospital districts, this criterion was found to be relevant in nine hospital districts, including seven regional hospitals and four university hospitals, and 12 units within them ([Stakes.fi/statistics](http://Stakes.fi/statistics), obtained in November 2006). Cluster sampling was applied here in order to increase the representativeness and generalizability of the findings (Verran et al. 1995).

Data collection procedures with the APPC instrument (Appendices 6a,b) were first piloted in the nearest hospital unit, on two otolaryngeal wards available. The questionnaires accompanied with an information letter were distributed through nurses to all patients meeting the inclusion criteria: adult non day-surgery patients who had experienced procedural pain during hospital admission. Completion of the questionnaire was taken as informed consent, and patients were informed to seal the questionnaires to envelopes enclosed. The envelopes were then collected by nurses, and posted to the researcher. The same procedure was repeated with the nurse dataset. The APPC questionnaire was distributed to 60 adult patients (response rate 80%,  $n = 50$ ) and 25 nurses (response rate 48%,  $n = 12$ ) on two wards between 4<sup>th</sup> December

2006 and 16<sup>th</sup> February 2007. During this period, nurses reported that seven patients refused to participate even before they had seen the questionnaire. Three incomplete patient questionnaires were excluded. The remaining 59 questionnaires (from both patients and nurses) were analysed for purposes of preliminary construct validation and included in the national data collection, which started with the patient datasets from 1<sup>st</sup> February to 31<sup>st</sup> March 2007 and continued with the nurse dataset from 15<sup>th</sup> April to 30<sup>th</sup> April 2007. During this period, one unit announced that they would not be able to proceed with the data collection due to staff shortages, and returned all questionnaires. In addition, another unit from another hospital district announced after six weeks that they would have to discontinue data collection for the same reason as above, but returned 12 questionnaires completed by patients. At the end of March, seven of the remaining 10 units had not managed to collect the planned dataset of 40 patients, and data collection in these units was extended until 30<sup>th</sup> April.

Altogether 405 patient questionnaires were accepted for further analysis (see Table 3), 46 questionnaires were rejected. The overall response rate was 90 per cent ranging from 83 to 97 percent in different units (calculated from questionnaires accepted for analysis in relation to questionnaires returned). Contact persons reported that 64 patients refused to participate, referring to their high age or perceived lack of knowledge about the subject. The patient data represent 10 per cent of the target population (adult otolaryngeal surgical non-day-surgery patients). In the sample of nurses, 153 questionnaires were handed out and 121 were returned; 118 of these were accepted for analysis, giving a response rate of 77 per cent (range from 48 to 100 per cent in different units, calculated from returned questionnaires in relation to total sample available per unit). The nurse data are fairly representative of the nursing staff of otolaryngeal units operating more than 400 patients a year (see Appendices 3-4).

**Table 3.** Response rates per unit, dataset IV

Unit code	Patient questionnaires: accepted for analysis /returned	Response rate (%)	Nurse questionnaires: accepted for analysis/ returned	Nurse questionnaires: total sample available per unit	Response rate (%)
a	50/60	83	12/12	25	48
b	37/38	97	7/7	9	78
c	34/38	89	9/10	10	100
d	34/38	89	10/10	12	83
e	36/37	97	9/9	9	100
f	34/40	85	8/8	10	80
g	34/39	87	9/9	13	69
h	12*	30*	0		
i	36/40	90	22/22	22	100
j	34/40	85	9/9	9	100
k	35/40	87	13/14	18	77
l	31/35	88.5	10/10	12	83
<b>n = 12</b>	<b>n = 405</b>		<b>n = 118</b>		

\* data collection interrupted

### *Data V*

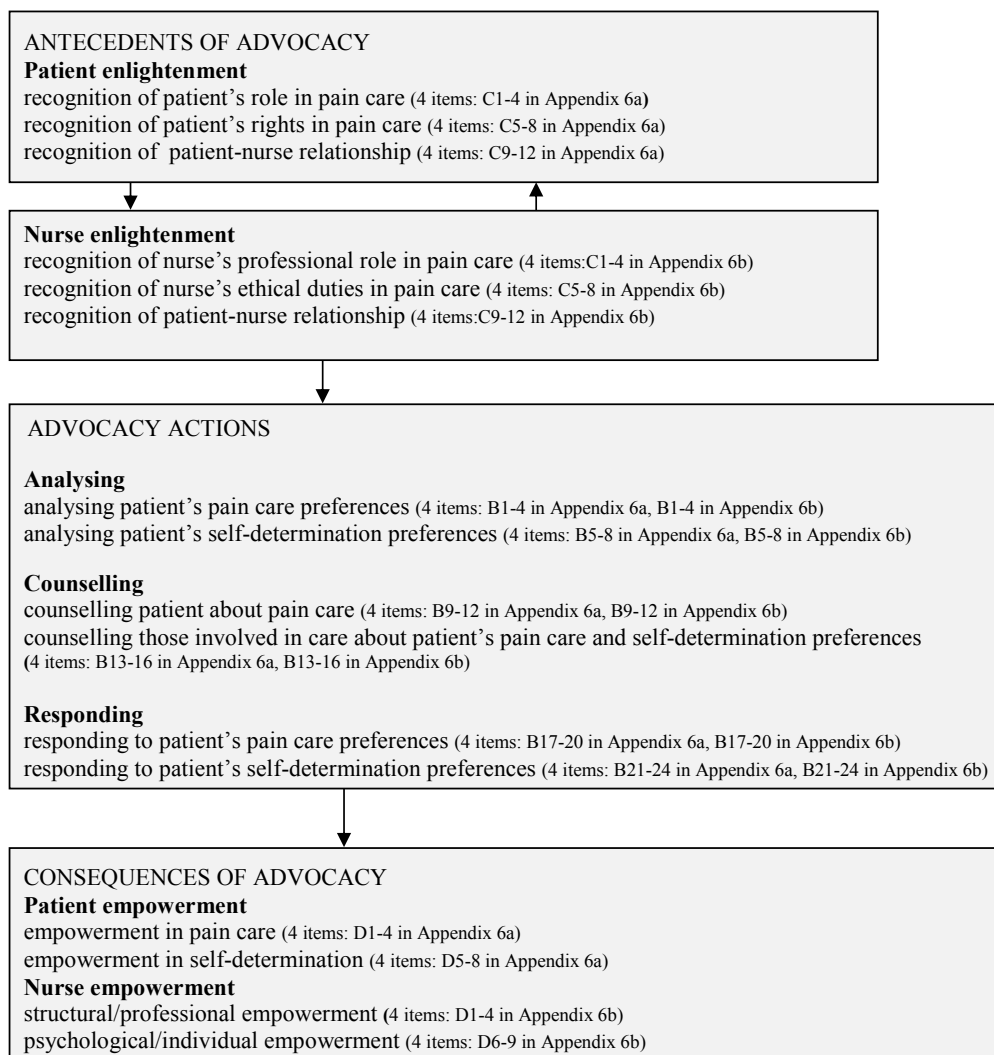
The fifth dataset integrated all previous datasets and was complemented with an international literature search on CINAHL and Medline from February 2003 to February 2007, using the keywords patient/client, nursing/professional and advoc\* (to cover advocacy, avocation, advocating, advocate). The search was limited to empirical research reports written in the English language, published in peer-reviewed nursing journals, and targeting adult (18 or over) and aged (65 or over) patients. The 69 papers yielded by the database search had to pass a three-stage review process as in the literature review in Phase I. As a result of that review process, 34 papers were excluded either because they were not pertinent to the topic (15), because they were named as case studies but were in fact individual statements (11), because they were concerned with paediatric care despite the search limitations (3), or because they did not include an abstract (5). The remaining 35 papers were reviewed (see data analysis in section 4.4). The sampling strategy was purposive to ensure the inclusion of relevant studies only.

### **4.3 Instrument**

There were no existing instruments for the measurement of the phenomenon of advocacy as defined in this study, nor any instruments for exploring component parts of the advocacy process (see Paper III). The instrument developed for this study, APPC (Advocacy in Procedural Pain Care), was designed to explore the content and structure of the advocacy process, i.e. the antecedents, activities and consequences of nursing advocacy, as well as to explore the implementation of advocacy activities.

The development of the APPC involved six methodological phases, i.e. 1) conceptualizing advocacy, 2) choosing dimensions to be measured, 3) describing the subdimensions by which those dimensions were to be measured, 4) formulating the items with which to measure the subdimensions, 5) choosing an appropriate response format and 6) testing the instrument's validity and reliability (cf. Burns & Grove 1997, Kelly & Long 2000, Armstrong et al. 2005). Since the instrument developed in this study serves the purposes of concept clarification and refinement, only one version was needed (Papers III-IV, Appendices 6a, b.)

The conceptualization of advocacy was based on the results of the literature review (Phase I, Data I) and interviews in a specific practice situation where the phenomenon was anticipated to emerge, i.e. procedural pain care (Phase I, Data II). The domains to be measured were outlined on the basis of the characteristics of advocacy as a process. Three dimensions were identified in advocacy: antecedents, activities and consequences. The subdimensions of advocacy were identified (see Figure 2) as enlightenment, i.e. patients and nurses awareness of their rights and roles as well as meaning of the patient-nurse relationship, the recurring process of analysing, counselling and responding, and empowerment (see Paper III). The results in Phase I showed that the antecedents and consequences of advocacy were slightly different for patients and nurses. Therefore two different sets of statements and items with regard to antecedents and consequences of advocacy were produced for the APCC instrument.



**Figure 2.** Dimensions and subdimensions of APPC measuring nursing advocacy in procedural pain care

The APPC consists of a demographic data sheet (part A, 12 items in patient questionnaire, 14 in nurse questionnaire) and four scales designed to measure advocacy activities (part B, 24 items), antecedents of advocacy (part C, 12 items in patient questionnaire, 12 in nurse questionnaire), and consequences of advocacy (part D, 8 items in patient questionnaire, 9 in nurse questionnaire). This order is dictated by the high level of abstraction of the concept of advocacy: before one can make any statements about what happens before or after advocacy, it is necessary to define that concept. The demographic items (see Appendices 3 and 4) include questions related to respondents' background and variables associated with the core attributes of enlightenment, advocacy and empowerment: pain experiences, knowledge of pain care (Brockopp et al. 1998, Drayer, Henderson & Reidenberg 1999, Duncan & Pozehl 2001) and advocacy (Tahan 2005, Esterhuizen 2006), knowledge of one's rights and

duties (Willard 1996, Evans 1999, Benhamou-Jantelet 2001) as well as perceived level of work motivation and power (Söderhamn & Idvall 2003, Holley et al. 2005).

The items in scales B to D were developed using the facet-design approach. Once the subdimensions had been specified, they were linked with a mapping sentence (Guttman 1969 in Armstrong et al. 2005, p 673). For example, when measuring the subdimension named Analysing, all items measuring the analysing advocacy activities (B1-8) start with words Asking the patient... The scales from B to D consisted of five-point Likert-type items. Each item was rated on a scale reflecting the respondents' level of agreement with the statement (5 = fully agree, 4 = agree to some extent, 3 = neither agree nor disagree, 2 = disagree to some extent, 1 = fully disagree). Given the lack of research concerning the implementation of advocacy, each item in the scale measuring advocacy activities (part B) was complemented with follow-up questions: was the activity implemented during hospital care, and in the nurse questionnaire, does the nurse usually carry out this particular activity in her job. These items were rated on a scale reflecting the respondents' level of agreement with the statement using a four-point scale (3 = yes, has been implemented, 2 = no, has not been implemented, 1 = no need, and 0 = don't know).

Two empirical datasets were collected to examine the instrument's content and construct validity. First, the content validity, i.e. appropriateness, quality and representativeness of the content of each item (Tatano Beck & Gable 2001, Winders Davis 2004) was measured in a sample of 25 experts (Data III, Paper III) using a specially developed questionnaire (Appendix 5b). This questionnaire consisted of 120 items measuring accuracy, relevance, clarity, and appearance biases as well as content relevance and completeness (Lockett, Aminzadeh & Edwards 2002, Beaulieu 2003) using a four-point rating scale ranging from not agree (1) to strongly agree (4). From this data, both I-CVI (item level content validity) and S-CVI (scale level content validity) were calculated (cf. Tatano Beck & Gable 2001) with regard to means, and with agreement percentages indicated at interrater level (cf. Polit & Tatano Beck 2006). Intrarater validity, i.e. the accuracy of each expert, was checked by placing three incongruent items in the instrument. As part of the content validation process, raters' comments regarding the need for rewording or additional items were also reviewed.

Questionnaire distribution routines were then tested and preliminary statistical analyses were conducted at the outset of the data collection procedure (Data IV). This piloting focused on assessing how easy it was for the target group to understand and complete the instrument, and on initiating analysis of the construct validity of the APPC instrument (Paper III).

#### **4.4 Data analysis**

In Phase I the first dataset (see Section 4.2) derived from CINAHL and Medline was examined to describe the concept of advocacy and the methods that have been used in studies of that concept. The analysis looked at the theoretical and empirical definitions proposed, the contexts of advocacy studies, the research methods applied, samples, advocacy activities, the consequences of nursing advocacy and issues of reliability and validity. A review of existing uses and definitions of a concept helps to derive a

tentative understanding of that concept and to develop a theoretical framework, methodology and design as well as instrumentation for the study planned (cf. Rodgers 1989, Morse 1995, Morse 2000). The results of this review were described in Paper I.

To illustrate how the concept emerges in a specific practice situation (Hutchfield 1999, Brilowski & Wendler 2005), the second dataset was collected in the context of procedural pain care. The interview themes were drawn from the results of the literature review, with the aim of exploring the way that nursing advocacy is defined by patients and nurses, the activities through which nursing advocacy is accomplished, and the way that nursing advocacy is experienced by patients and nurses. These data were analysed inductively using qualitative content analysis (see Table 4): the aim was to find answers to the research questions and to identify other important parts of data relevant to the advocacy phenomenon, for example a model case (Rodgers & Knafel 1993). Both meaningful single words and whole sentences were included as units of analysis. Relevant units of text (Data II) were then reduced to shorter expressions and clustered into themes based on similar expressions. Next, the themes were named with a code describing the phenomenon, and the codes were combined into categories corresponding to the research questions. (Catanzaro 1988, Miles & Huberman 1994, Burns & Grove 1997, Cavanagh 1997, Polit & Hungler 1999.)

**Table 4.** Example of content analysis, dataset II

Citation from a interview	Code	Category	Subdimension	Dimension
“This morning I had a wash without help... the nurse was also there, to help if needed, but I did it myself...It was possible, cause I did not have pain anymore”	feeling independent	independency	patient empowerment	consequence of advocacy

The analysis was conducted until saturation and until key characteristics of the concept in focus could be identified in that specific nursing context (cf. Hupcey et al. 2001). The analysis was conducted twice at an interval of two months, and some interviews from both samples were analysed by another researcher in order to confirm the coding (see Paper II).

In order to develop an instrument for the measurement of advocacy, it was necessary first of all to define and operationalize the concept. During Phase I (Data I-II) the characteristics of advocacy were analysed using the method of content analysis in order to identify and name the dimensions and the subdimensions of advocacy. The criterion for identifying these dimensions and subdimensions was not how often the characteristics were mentioned in the datasets, but rather the coherence and integrity of the emerging clusters. It was important to consider the perspectives of both patients and nurses, since the aim of the study was to describe advocacy from both these perspectives.

In Phase II the data were analysed using the statistical software packages SPSS 12.0 and SAS 9.1 (see Table 5). First, statistical analyses were conducted (Data III) as part of the psychometrical evaluation of the instrument developed (Paper III). The scores analysed were the values of the Likert number circled, or direct numerical values inquired (e.g. age in years, working experience). To measure internal consistency on both scale, subscale and item level, a CVI (content validity index) was calculated with regard for mean and agreement percentages on interrater level (cf. Polit & Tatano Beck 2006). On the scale level, a CVI of .78 was considered acceptable on grounds that there were more than five raters (Lynn 1986, cited in Polit and Tatano Beck 2006, p 491). Because the sample mean was not normally distributed, it would have been possible to calculate asymmetric confidence intervals. However, this was not done because the sample size exceeded the minimum of ten (Penfield & Miller 2004.)

To describe the subdimensions of advocacy antecedents, activities and consequences, 16 sum variables were formed (Figure 2). One item in the patient questionnaire (Dp 9) and two items from the nurse questionnaire (Dn 5 and 10) were not included in the sum variables because they did not correlate with other sum variable items. The score analysed was the value of the Likert scale number circled, reflecting the respondents' level of agreement with the statement on a scale from 5 (fully agree) to 1 (fully disagree), or a direct numerical value inquired (e.g. age in years, working experience) or obtained from a rating scale (e.g. pain experience on a scale from 0 to 10, work motivation on a scale from 0 to 10). In the analysis of items concerning the implementation of advocacy, response option 0 (Don't know) was labelled as missing, and statistical procedures were applied to answers. In order to analyse which advocacy subdimensions were implemented, negative responses were combined and labelled as zero. The sum variable values thus ranged from 0 (No need for that, or Not implemented) to 1 (Yes, has been implemented), and they were analysed as percentages ranging from 0 to 100. The implementation of all individual items within the different subdimensions were also analysed on all possible answer-levels.

The raw data obtained from the questionnaires were checked and cleaned to assure their accuracy for data analysis. Altogether 49 participants with 10 per cent or more missing data were eliminated, leaving a final sample of 523 participants (Data IV). The inter-item correlations should be above .30 but lower than .70 and the corrected item-to-total correlations high (.35- .80, see Davis 1996) to confirm the structure of the concept to be measured. The construct validity and reliability of the instrument (Paper III) were evaluated by Cronbach's alpha coefficient, the effect of individual items to be deleted and the homogeneity of the subscales and scales (Burns & Grove 1997, Winders Davis 2004) as well as explorative factor analysis with both varimax and promax (oblique) rotation. The standard .30 cutoff point was used for the factor loadings (Zhan & Shen 1994), with the threshold loading of .20 accepted as the lowest value. The factor was thought to correspond to the subdimension if the majority of items had the highest loading on this factor and no item had a loading lower than 0.2 (cf. Knapp & Brown 1995, Potter 1999). Items loading on more than one factor were explored, too.

Next, descriptive statistics (frequencies, percentages, means, standard deviation and range) were used to characterize the variables measured on a sum variable (Papers III-V). The assumption of normal distribution of sum scales was tested with the Kolmogorov-Smirnov test. Both nonparametric and parametric tests (Table 5) were used to reveal statistically significant associations and differences between respondent groups (patients, nurses), respondents' background variables and sum variables, single items and implementation of advocacy. In these analyses an overall significance level of 0.05 was applied.

**Table 5.** Statistical methods applied

<b>Method</b>	<b>Data III content validation</b>	<b>Data IV construct validation</b>	<b>Data IV content of advocacy</b>	<b>Data IV implementation of advocacy</b>
Frequency distribution	x	x	x	x
Mean, standard deviation	x	x	x	x
Kolmogorov-Smirnov test	x	x	x	x
Cronbach's alpha	x	x	x	x
Content validity index on item level (I-CVI)	x			
Content validity index on scale level (S-CVI)	x			
Item analysis (inter-item, item to total)	x	x		
Explorative factor analysis		x	x	
Wilcoxon's two-sample test		x	x	x
Pearson's correlation analysis		x	x	x
Analysis of variances		x	x	x
Chi square		x	x	x
Kruskall-Wallis test		x	x	x

In Phase III, the fifth dataset (see Section 4.2) derived from CINAHL and Medline was examined with a focus on the latest definitions and contexts in advocacy studies, i.e. the updated newest use and applications (Rodgers 2000b, Brilowski & Wendler 2005) of the concept. Between 2003 and 2007, a total of 69 citations were found using the terms nursing or patient advoca\* (to include advocates, advocacy and advocacy), of which 35 were analysed (see section 4.2).

#### 4.5 Ethical questions

The research followed the general principles of research ethics (Burns & Grove 1997, ETENE 2002, World Medical Association Declaration of Helsinki 2002). For every empirical phase, institutional committee reviews were obtained from all the hospital districts concerned, or with the permission of the head of the university department concerned when data was collected in a group of nursing science students (Data III). In addition, prior to data collection in Phase II, ethical boards of the hospital districts concerned reviewed the study plan to make sure that the subjects' human rights were in no way violated (World Medical Association Declaration of Helsinki 2002).



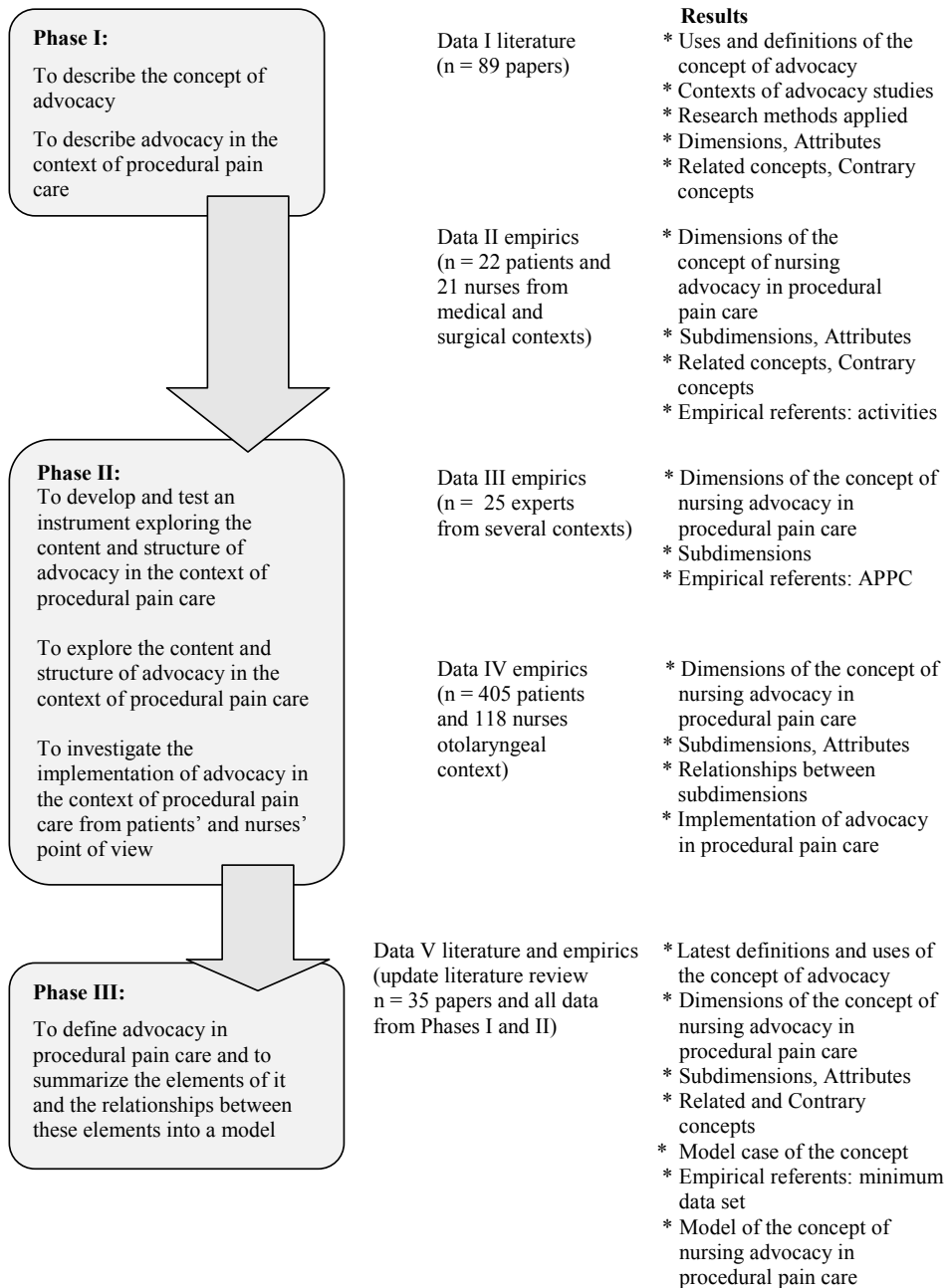
Because of the nature of the research and the possibility that it might cause anxiety among the subjects, either concerning one's own experiences of care or as a witness of care given to other patients, it was important to constantly keep in mind the rights of the research subjects and the ethics of the research process. In Phase I, the researcher met the nursing administrators, staff nurses and other staff prior to data collection on the units. This was done in order to explain the purpose of the study, to discuss procedures of data collection, the sampling criteria and ethical issues – particularly the methods of obtaining the participants informed consent - to make sure they were willing to assist with data collection and to obtain their personal agreement to participate in the study. (Beauchamp & Childress 2001.) Then, a letter including a basic description of the study, principles of anonymity as well as voluntary participation was distributed to the nurses and through them, to the patients. In that letter, patients were also assured that their decision on whether or not to participate would have no effect on their care (Appendices 7a-d). The nurses involved asked the patients to give their voluntary written informed consent to participate. This meant that the researcher only was in contact with patients who were willing to participate in the interview. The same procedure was followed in the samples of nurses, who had permission to take the interviews during working hours. Prior to the interview, which always took place in a single room on the ward, the informant's oral informed consent as well as permission to tape-record the interview were obtained.

In Phase II, which used quantitative methods, the procedure of informed consent negotiation involved various interactions. After obtaining written permission from the institutional committee and ethical board, the researcher mailed a copy of this permission and an information letter to nursing administrators at the units concerned. The administrators were then contacted by telephone in order to discuss the process of data collection and related ethical issues, and in order to get the name of a contact person on the ward. These named contact persons, usually staff nurses, were mailed a package containing an information letter, questionnaires and return envelopes. For reasons of time restraints it was not possible for the researcher to personally visit every participating unit. Therefore, after a suitable period of time, the researcher contacted staff nurses by telephone in order to discuss questions of data collection, sampling criteria and procedures to guarantee informed consent and confidentiality. Again, a letter including a basic description of the study, the principles of anonymity as well as voluntary participation was distributed to the nurses and through them, to the patients. The letter instructed patients who were not going to participate to return the questionnaire to the nursing staff for recycling. The same instruction was included for nurses at the beginning of their data collection.

During the three months of data collection in Phase II, the researcher phoned the staff nurses once a week to discuss any problems that had emerged in data collection. These discussions were highly valued by the staff nurses, and they proved extremely valuable to the researcher as well. During data collection two units announced that they were unable to continue with the process due to staff shortages and high workloads. All units participating in the data collection received copies of Papers IV and V to thank them for their involvement. In addition, all informants during the research process were informed about the publication of the research results.

## 5. RESULTS

The results of this concept clarification process are based on three research phases and altogether five datasets (see Figure 3).



**Figure 3.** The phases and results of the research project

Template verification (Finfgeld-Connett 2006) is used to support and expand the results of this concept clarification. The results from different phases of this research process were placed into a matrix of organizing categories. Furthermore, based on the findings, additional organizing categories were identified as new evidence emerged. The resulting template was used to codify findings from qualitative and quantitative investigations of the concept of nursing advocacy (see Table 6). The matrix explicates a process that is based on interactions among the different categories. This serves not only to triangulate the results of concept analyses, but also to delineate a framework of practice-based phenomena.

**Table 6.** Template verification matrix of concept clarification

<b>Results:</b>	<b>Data I</b> review	<b>Data II</b> interview	<b>Data IV</b> survey	<b>Data V</b> review, all previous data
<b>Dimensions and subdimensions:</b>				
<b>Antecedents:</b>				
recognition of patient's role	-	X	X	-
recognition of patient's rights	X	X	-	X
recognition of patient-nurse relationship	X	X	X	-
recognition of nurse's professional role	X	X	X	-
recognition of nurse's ethical duties	-	X	X	X
<b>Activities:</b>				
analysing patient's (pain) care preferences	-	X	X	-
analysing patient's self-determination pref.	-	X	X	-
counselling patient about (pain) care	X	X	X	X
counselling those involved in care about patient's preferences	-	X	X	X
responding to patient's (pain) care preferences	X	X	X	X
responding to patient's self-determination preferences	-	X	X	X
whistleblowing*	X			X
<b>Consequences:</b>				
empowering in (pain) care	X	X	X	X
empowering in self-determination	X	X	X	X
disempowerment of a patient	X	X	-	-
structural empowerment	-	X	X	X
psychological empowerment	X	X		X
disempowerment of a nurse	X	X		
<b>Attributes:</b>				
ethical principle of nursing care	X	X	X	X
moral duty of a professional nurse	X	X	X	X
right of a patient	X	X	X	X
recognition (see Antecedents above)	-	X	X	-
patient-nurse relationship (see Antecedents)	X	X	X	X
information exchange (see Activities)	X	X	X	X
decision making (see Activities)	X	X	X	X
moral competence (see Antecedents, Activities)	X	X	X	X
clinical competence (see Antecedents, Activities)	-	X	X	-
preparedness (see Antecedents)	-	X	X	X
means (see Antecedents, Activities)	X	X	X	X
autonomy (see Antecedents, Consequences)	X	X	X	X
change (see Consequences)				
<b>Model case of the concept</b>		X		
<b>Related concepts</b>	X	X		X
<b>Contrary concepts</b>	X	X		
<b>Empirical referents (see Dimensions and subdimensions)</b>				
<b>The model of the concept of nursing advocacy in procedural pain care</b>				

\* whistleblowing was integrated into responding activities

The results of this study are organized into three sections according to the aims of the study: the first section describes the concept of nursing advocacy in procedural pain care, the second summarizes the elements of the concept of advocacy and the relationships between these elements into a model, and the third section has focus on the implementation of advocacy in the context of otolaryngeal surgical pain care.

## **5.1 The concept of nursing advocacy in procedural pain care**

This study defines the concept of advocacy by reference to both patients' and nurses' views (Papers I-IV). Patient advocacy is understood as nursing activities aimed at securing patients' legal rights and satisfying their existential needs in the clinical context of procedural pain care, both on the level of the patient-nurse relationship and in the health care team/organization. Professional advocacy is approached as the level of autonomy, competence and collaboration experienced as an antecedent to or consequence of patient advocacy. Thus, the concept of nursing advocacy contains the dual aspects of both patient advocacy and professional advocacy.

### ***5.1.1 Attributes of nursing advocacy***

The defining attributes of a concept are central to its existence. They appear in clusters, situations or phenomena that are assumed to be significant to defining the concept (Rodgers 1989), i.e. they are pure examples of the concept's existence. For research to be reliable, it is necessary to describe rather than simply report the defining attributes identified in the data, and the criteria for deriving these attributes must also be demonstrated (Paley 1996)

The defining attributes of the concept of nursing advocacy are associated with the dimensions and subdimensions identified in datasets I-V. In the update literature review (Data V) there was no significant development in defining this concept in nursing literature after the first review. Several papers were concerned with cultural aspects of the concept: Japanese (Davis, Konishi & Tashiro 2003), Pakistani (Fazil et al. 2004), Hungarian (Fabian 2004), Irish (O'Connor & Kelly 2005) and Dutch (Welie et al. 2005). These studies defined advocacy via rather similar attributes, suggesting that the concept is discussed in largely the same way all over the world. However, the concept remained pragmatically and logically immature. For example, the verb advocate was often taken as synonymous with speaking for or supporting any idea, individual or group. Accordingly, the role of the advocate was not clear at all: volunteer ombudsmen as patient advocates were discussed in several papers (e.g. Long 2002, Tahan 2005), which drew attention to different aspects of this non-professional role. In the literature reviewed, there were indications of a growing research interest in the effects of nursing advocacy and its connections with empowerment, i.e. the consequences of advocacy; examples include studies on patient participation (Valokivi 2004, Harkness 2005), patient self-advocacy (Anderson & Funell 2005), the role of change agent (Picard et al. 2004, Kendall 2006), ethical professionalism in nursing (Nahigian 2003, Kennedy 2004, Kubsch et al. 2004, Corley et al. 2005) and political advocacy by nurses (Long 2005).

However, the focus remained on critical and perioperative care, while elderly care, terminal care and mental care received more marginal attention. There was also some work on advocacy from the case manager's and even nursing students' perspectives, but still no studies that were concerned with patients' or their relatives' points of view.

Based on the necessity and purity of phenomena central to nursing advocacy, the concept is here defined as *ethico-legal nursing decision-making that is based on recognition of the roles, rights and duties of those involved in the patient-nurse relationship, on information exchange, on the nurse's moral and clinical competence as well as having the preparedness, means and autonomy to effect change when considered by means of analysing, counselling and responding activities, even at the society level*. Thus, the defining attributes indicated by this definition are ethico-legal, decision-making, care, profession, recognition, role, rights, patient-nurse relationship, information exchange, moral competence, clinical competence, preparedness, means, autonomy, and change.

Concepts have different theoretical underpinnings, and they can be interpreted differently depending on those underpinnings. In order that a concept can be meaningfully used and measured, it is necessary to explicate its theoretical foundations. If advocacy is taken as nursing philosophy, it is part of clinically and ethically competent nursing care, based on a respect for patients' human and legal rights such as individuality and autonomy. When viewed as an intervention, nursing advocacy has additional attributes that are unique to that perspective: it is a clinical or ethical event related to professional activity, an active attempt to promote or safeguard patients' rights. When viewed as a process, advocacy is dynamic, and its level varies from clinical to ethical. When taken as a right, either a legal or moral right, advocacy is static and its level is fixed, but it must be expected and recognized by the individuals involved. As a professional and moral duty to advocate, the level of involvement and preparedness may vary, because the advocate's role can be either developmental or evolutionary due to the continuous relationship with patients and analysis of their needs and interests. As an outcome, the concept is transitory, but may include experience of change.

### **5.1.2 Related and contrary concepts**

One of the key objects of concept analysis is to demonstrate the characteristics that make the concept unique. Traditionally, this has been done by identifying the defining attributes of the concept and by developing (Walker & Avant 1995), or identifying from data (Rodgers 2000b), different cases. However, in concept analysis process, the relationships and linkages among related concepts need to be uncovered by identifying related concepts and determining their shared attributes in order to generate a theoretical framework (Finfgeld-Connett 2006).

In the process of concept clarification in this study, the analysis of borderline cases, related cases and contrary cases was replaced by an exploration of related and contrary concepts, using data obtained (See Table 6) from the literature and empirical studies (Rodgers 2000b). These related and contrary concepts of advocacy also reflect the other significant concepts concerning patients' rights and professional codes of nursing ethics ([www.med.utu.fi/hoito/nursingbiomed/index.html](http://www.med.utu.fi/hoito/nursingbiomed/index.html)).

### 5.1.2.1 *Related concepts*

Related concepts are those that bear some relationship to the concept in focus, but do not seem to share the same set of attributes (Rodgers 2000a) or the critical attributes of that concept (Walker & Avant 1995). Depending on the theoretical perspective adopted, advocacy in the nursing context is often confused with the terms beneficence, parentalism, caring, client-centred nursing, helpfulness, good care, or empowerment. Furthermore, the role of an advocate can be seen as synonymous with the role of an ombudsman.

On a philosophical level, there is a tendency in the literature to confuse advocacy with beneficence (Falk Rafael 1995, Willard 1996). The principle of beneficence requires that one prevents harm to competent persons, removes harmful conditions, and does well for the benefit of others (Wood 2001). This requires no professionalism on the part of the person in question, nor any information exchange. Advocacy, then, is concerned with representing and promoting the patient's autonomous preferences or interests. Furthermore, beneficence is teleological, while advocacy is a deontological act (Papers II-IV). There is also a tendency to confuse professional accountability with advocacy (Woodrow 1997, Grace 2001, Hewitt 2001). However, although the four areas of accountability (public, patient, employer and profession) are compatible with nursing advocacy, they are recognized in law, while nursing advocacy is not. Another concept sometimes confused with advocacy is that of parentalism (Johns 1999). However, parentalism is concerned with taking action on behalf of another person, while advocacy is about enabling others to take action in matters concerning their health care, resulting in change (Papers III-V).

On the process level, advocacy is related to caring. A concept analysis of caring (Morse et al. 1990) suggests that its attributes are similar to those of advocacy, but it also includes attributes of a human trait and an affect. Caring as such, however, can be provided by non-professionals as well, while nursing advocacy anticipates clinical nursing skills (Papers II-V). On the other hand, Pullen (1995) describes all nursing as advocacy through the delivery of nursing and medically prescribed care using skills of empathy, anticipation and communication. This definition does not include the ethico-legal attribute of advocacy (Papers II-V). Some relatively new and ambiguous terms, client-centred nursing (McGormack & McCance 2006) or person-centred empowering partnering (Brown, McWilliam & Ward-Griffin 2006), are defined as a process where both patients and nurses choose their partnering involvement, in keeping with their knowledge and abilities, as well as preferences and rights in order to engage clients to their optimal potentials as partners in care. This may be seen as synonymous with advocacy in relation to abilities and rights, but no definitions have been offered of how nurses enact this concept.

On a duty or role level, the function of an advocate in nursing is often confused with the function of an ombudsman (Segesten 1993, Segesten & Fagring 1996, Ostwald et al. 2003). The latter, however, is not someone on the nursing staff, an ombudsman has no clinical nursing education, but his or her authority is delegated by hospital management. Ombudsmen deal with patient issues such as complaints, and their job

involves planning projects from patients' perspectives as well as staff education and research to pinpoint problem areas. These patient representatives hold themselves more accountable to hospital administrators than to their occupational reference group, so it is questionable whether they could sustain an enforceable code of ethics. (Mallik 1997c.) Another related role is that of a named nurse, i.e. a named, qualified nurse who is responsible for one's nursing, ensuring that her name and responsibilities are known to the patient and working in partnership with the patient. The role of a named nurse includes accountability as well as patient participation, but patients have little or no choice (Woodrow 1997, Steven 1999), i.e. autonomy.

When advocacy is taken as an intervention based on a nurse's personal traits, the related concepts are helpfulness, caring attitude, interfering, and doing for (Data II). The former two adjectives are either ethico-legal or professional, or involve decision-making. The two verbs share with advocacy only the attributes of preparedness and means, but do not further the autonomy of anyone.

On an outcome level, a concept similar to advocacy is that of empowerment. Advocacy has been said to describe the nurse-patient relationship primarily from the perspective of the nurse, while empowerment describes it from the patient's perspective (Falk Rafael 1995). However, even when explored beyond the patient-nurse relationship, empowerment does not involve an ethico-legal aspect of decision-making in the care profession. Advocacy can also be confused with the meta-concept of good care, in which advocacy is one constituent element (Leino-Kilpi 1990), but which also presupposes an individual experience of satisfaction, as described by one patient in Data II:

“Good care is a collective outcome of this team, the doctor, patient, nurse, and of course it can also have a physiotherapist and these, the whole team together. And advocacy remains for the nurse to look after.”

To conclude, there are many concepts related to advocacy, depending on the perspective adopted. It is therefore necessary to conduct simultaneous concept analyses in order to clarify these central features of nursing practice that were mentioned above.

### 5.1.2.2 *Contrary concepts*

Contrary terms do not incorporate any of the defining attributes of the concept in focus (Walker & Avant 1995). The contrary concepts of nursing advocacy are nouns and verbs stemming from the theoretical premises underpinning the idea of advocacy.

Paternalism means interference with a person's liberty of action justified by the welfare, good, happiness, needs, interests, or values of the person concerned (Dworkin 1971, cited in Evans 1999). For example, information regarding the potential risks of an operation, procedure or medication can be withheld when that is considered to be in the patient's best interests, this therapeutic privilege can be considered to be a paternalistic act (Wheeler 2000). To be kept in a state of ignorance is to be kept in a state of dependence, to be infantilised and controlled. Another example of a paternalistic act is to promote the nurse's own opinion or to manipulate the patient during a discussion in order to achieve the nurse's own preferred outcome (Mallik 1997a). As paternalism does not allow for the

preservation of patient autonomy, it is opposite to advocacy which is grounded in respect for human and legal rights, including autonomy.

Some terms similar to paternalism were identified in Data II, these were labelled as routine care, indifference, arrogance, negligence, enforcement, and nurse offensiveness. These terms were used by both patients and nurses. In fact, many interviewees began by describing what advocacy is not before proceeding to their accounts of what it is.

“I’d to like receive medication when I need it... I mean I can feel it myself when it hurts, that’s when I’d need to have it, not that they just say you’ve had it already, you’re not having any more.”

“And then there was this young man (doctor), he just stood there talking with these people, he said nothing to me. And most of it was in Latin. That really bugged me; I thought this was about me, why aren’t you talking to me!”

”She (nurse) pretty much forced this woman into her bed. And she was screaming her head off, I don’t know whether it was out of pain or fear. So these nurses they put up the rails on her bed and left her all on her own whimpering.”

The relatively new concept of case management, then, is primarily concerned with cost containment, while advocacy is an exercise in brokering arrangements for services in the best interest of patients (Long 2002). This opposite of advocacy was also described in Data II:

“When the patient arrives you don’t have the time straightaway to notice what it is they need. And with all these cutbacks that are going on, it’s possible you won’t have the time later on either, you’re running around like nobody’s business all the time. There’s no way, there’s just not enough time. Not enough nurses.”

At the same time, one other central antecedent of advocacy was confirmed:

“They say they don’t have the time, but often they just let the time pass because they don’t want to.”

To conclude, the contrary concepts of advocacy identified were paternalism, routine care, negligence, enforcement, case management, and nurse arrogance or offensiveness.

### ***5.1.3 Model case describing nursing advocacy***

Based on entity theory, a model case is usually incorporated in concept analysis strategies in order to highlight all attributes of the concept in focus. According to Walker and Avant (1995), a model case is derived from real-life situations documented in the literature reviewed at the beginning of the concept analysis process. In this study, a model case was identified (cf. Rodgers & Knafel 1993) from Data II, on the basis of attributes emerging in a specific practice situation (Brilowski & Wendler 2005). This model case contains all the attributes of advocacy (see 5.1.1).

“I make it clear to the patient that he won’t need to suffer pain (recognition of rights, information exchange, ethico-legal decision-making, counselling), that we have a lots of medicines here on the ward (preparedness, means, responding), if one medicine doesn’t help then we’ll try something else (information exchange, preparedness, clinical



competence), and I also stress that he must let me know immediately when the pain begins (recognition of duty, patient-nurse relationship, preparedness, means, analysing) so that we can intervene.....(care, change) That we don't wait until the patient has to suffer....(ethico-legal, analysing, responding). Patients who have had an operation can experience pain quite suddenly when the local anaesthesia wears off (clinical competence), so that we cannot intervene immediately... My aim is to make sure that the patient gets as much as information about pain care as possible, I tell him that he can get pain killers, I talk to him about the pain medication he uses at home (recognition of rights and duties, patient-nurse relationship, information exchange, analysing, counselling) and that he won't need to suffer any pain (recognition of right, ethico-legal, autonomy, responding)... and I let the doctor know that the patient has been in pain so that we can try to find suitable medication (recognition of duty, profession, information exchange, change, counselling).... so that we can change the dosage or the medication itself if necessary (decision-making, competence, preparedness, means, responding).... Sometimes you have to stand between the patient and doctor because there is no communication (recognition of duty)... When a doctor says that this is what we'll do, you have to say that that won't work! (recognition of duty, clinical and moral competence, analysing) I mean like some exercises, do this and do that, even the patient knows it is impossible (recognition of role, clinical competence), so you can't just say yes, sir. Advocacy, to me, is that there is someone there who will stand up, do things and observe (recognition of duty, preparedness, clinical and moral competence, responding).... Someone who acts as a guardian or watchdog. Often I go over and talk with the patient in advance to say that this is how we'll do this ... it's like a bilateral, mutual contract (information exchange, recognition, autonomy, preparedness)."

#### **5.1.4 Empirical referents**

Empirical referents are the behaviours or conditions whose presence indicates the occurrence of a particular concept (Walker & Avant 1995). They are used for the identification or measurement of the concept both in nursing practice and as a variable in research designs. In this study, the empirical referents of nursing advocacy were identified into Minimum Data Set of nursing practice, operationalized in the APPC scale, and listed as advocacy activities.

##### *5.1.4.1 Minimum Data Set of nursing advocacy*

Many nursing languages have been developed to support the operationalization of nursing care and to describe nursing practice, or to demonstrate or project trends regarding nursing care. One such language is the Nursing Minimum Data Set, which can be defined as the smallest set of items of information required to capture the range of patient problems, nursing interventions and nursing outcomes recorded by nurses on a regular basis (Butler et al. 2006), or items with uniform definitions and categories concerning the specific dimension of nursing. Traditionally, these categories include nursing processes, diagnoses, interventions and outcome elements (Volrathongchai 2003), but new types of indirect interventions and managing or organizing activities have also emerged (Butler et al. 2006). Nurses' everyday practice of ethics is not documented or measured systematically, but it has an obvious influence on clinical and administrative decision-making. The results of this study indicate that nursing advocacy can be identified and documented both within the patient-nurse relationship and outside of it.

The information items needed to identify nursing advocacy as a patient-related process are concerned with patient characteristics, nursing interventions and outcome elements (see Paper II: Table 4). For example, if documented, analysing patient's anamnesis, pain care experiences and preferences as well as coping style will help to set a nursing diagnosis of advocacy alert, i.e. contextual sensitivity reported in Paper II. Furthermore, acknowledging the patient's female gender, her signals of an interest to participate in decision-making concerning her pain care, and having some pain before, during or after the medical intervention (Paper IV) should indicate this advocacy alert in procedural pain care. Then, counselling and responding nursing interventions alternate with analysing interventions, based on outcome elements as pain intensity measurement, observed pain measures, commitment to self care, satisfaction with care and self advocacy (Paper II, IV). These items of care process, when documented, fulfil the legal purposes of documentation and confirm the existing ethical and clinical guidelines of the profession and/or the organization. Furthermore, they help to identify the phenomenon of advocacy, reflecting the complexity of the nursing profession and the intellectual processes underlying nursing practice.

If advocacy for the nursing profession is to be identified as a Minimum Data Set, the items of information needed to demonstrate that advocacy are concerned with processes related to outcomes not only for patients but for nurses and their work. These items include observing the quality of care, reflection on the care processes with the patient and within the team, suggesting changes, questioning pain care procedures on the ward, or questioning the availability of resources in relation to workload, questioning the situation, demanding discussion, declining to accept unclear orders or professional nonchalance (see Paper II Table 4). However, in practice these items are usually discussed unofficially, by those concerned, but not raised on a multidisciplinary, organizational or societal level. In addition, there is no official forum for the documentation of these advocacy items in Scandinavia, as the existing nursing journals are clinically oriented. However, articles are now beginning to appear on matters such as nurses' empowerment and resource allocation (Davis 2007, Tallqvist & Simonen 2007), not in nursing journals but in other literature as well.

#### 5.1.4.2 *The APPC scale*

The Advocacy in Procedural Pain Care scale (APPC) is an 80-item (83-item for nurses) self-report instrument measuring the three main dimensions of nursing advocacy: antecedents (12 items), activities (24 items), and consequences (8 items for patient, 9 items for nurses) as well as the implementation of nursing advocacy (24 items) in relation to demographics (12 items in patient scale, 14 in nurse scale). It was designed for this study for purposes of validating the content and structure of the concept of advocacy (Papers III and IV) and for exploring both patients' and nurses' views on the implementation of advocacy in their own care (Paper V). The APPC was formulated on the basis of a conceptualization derived from the literature (Data I) and from empirical research (Data II). The four-part instrument takes about 30 minutes to complete. In Data IV, high response rates were recorded for both patients and nurses (see Papers IV, V).

The content validity of the APPC scale was evaluated in a sample of 25 experts (Data III) with extensive nursing experience (Md 10 years), knowledge of pain care, or nursing science expertise (Paper III). Using a four-point rating scale ranging from do not agree (1) to strongly agree (4), the experts evaluated the scale for accuracy, relevance, completeness, clarity, and appearance biases as well as content relevance and completeness of items, subdimensions and the content of the instrument in general. All APPC subdimensions and items were found (Appendix 8) to be relevant on interrater level with a threshold of .78 (see Lynn 1986 cited in Polit and Tatano Beck 2006, p 491) and accurate, complete and clear both on item and subdimension level (agreement from 80 to 100% on item level and from 92 to 100% on subdimension level). Intrarater validity, i.e. the accuracy of each expert, was checked by placing three incongruent items in the instrument. The raters were found to have a congruent response pattern. As part of the content validation process, raters' comments regarding the need for rewording or additional items were also reviewed. The few comments received did not lead to any changes in the instrument as they were randomly distributed between the different statements.

The construct validity and reliability of the instrument was established with several statistical methods (see Paper III) with 405 patients and 118 nurses in an otolaryngeal context (Data IV). All subscales were found to have relatively good item-to-item correlations, ranging from 0.15 to 0.86 (see Appendix 9), and good reliability (Cronbach's alpha > .60). In factor analysis, the standard 0.3 cutoff point was used for factor loadings (Zhan & Shen, 1994), with a threshold loading of 0.2 taken as the lowest acceptable value (cf. Knapp & Brown, 1995). Items loading on more than one factor were also explored. Most APPC subdimensions were established as constructively valid (see Paper III). However, some items cross-loaded on more than one factor, or had a relatively low loading. This may be explained by minor differences in the wording of items, which were validated in a sample of nursing specialists only. These items (see Appendix 6a: B16, B17, C8, D9; and Appendix 6b: C5, C10, B3, B11, B17) all occurred in different sum variables, and theoretically vital parts of advocacy, and therefore they were not excluded. In the oblique rotation factor analyses, the correlations between factors showed a logical pattern of relationships. No correlations exceeded the moderate range, indicating that the factors were related but conceptually distinct dimensions of advocacy. The number of factors extracted was the number of corresponding subdimensions, which explained 65 per cent (sample of patients) or 57 per cent (sample of nurses) of the variance in antecedents, 75 or 74 per cent of the variance in activities, and 60 or 56 per cent of the variance in the consequences of advocacy (Paper III). The APPC subscales were thus found to be homogenous and they were confirmed to represent the conceptual dimensions of advocacy based on correlations, alpha coefficients and factor analysis.

#### *5.1.4.3 Advocacy activities*

Behaviours which indicate the occurrence of nursing advocacy in the context of procedural pain care were identified in the first two phases of the research process and verified in dataset IV (see Paper IV). On the subdimension level, these activities cover ethical, legal, existential and clinical perspectives on advocacy (see Table 7). There is

an obvious paradox between certain subdimensions of advocacy when the lowest and highest items are identified.

On the item level (see Table 7), the most highly ranked advocacy activities in procedural pain care seem to be concerned with nurses' clinical behaviours (B1, 3, 18, 19, 20) and counselling acts (B 9, 11, 12, 13). The lowest agreement was found in items measuring patients' preferences with regard to participation in pain care (B6), how patients would like to participate in decision-making concerning pain care (B7) and how patients would like to participate in pain care (B8). However, both patients and nurses also considered some ethico-legal behaviours to represent relevant content of advocacy in procedural pain care, for example the act of monitoring that patients' wishes (B23) and rights (B24) are respected.

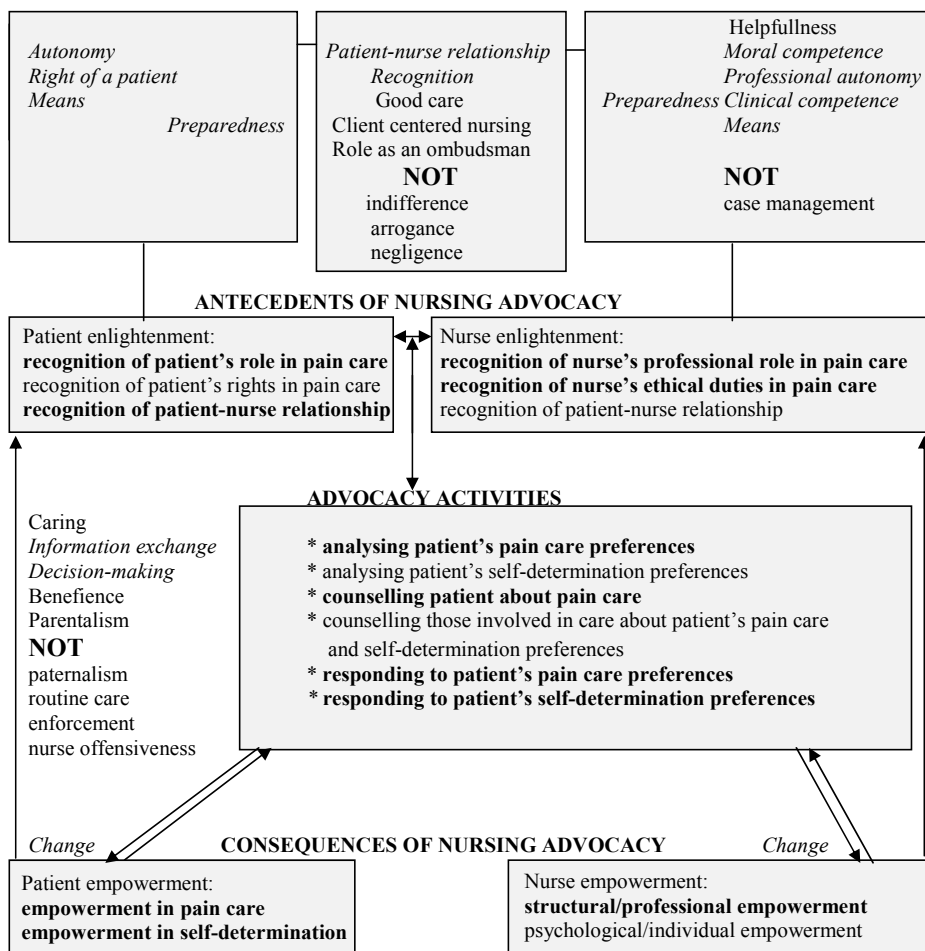
**Table 7.** Content relevance rated by patients and nurses, dataset IV

Subdimension	Item	Patients Mean*	SD	Nurses Mean*	SD
analysing patient's pain care preferences	B1 asking about wishes concerning pain care	4.49	.75	<b>4.56</b>	.64
	B2 asking about wishes concerning pain care methods	3.98	1.00	4.21	.87
	B3 asking for subjective pain intensity evaluation	<b>4.56</b>	.74	<b>4.61</b>	.64
	B4 asking for subjective evaluation of pain care management	4.43	.83	<b>4.70</b>	.49
analysing patient's self-determination preferences	B5 asking about decision-making preferences in pain care	3.62	1.17	3.50	1.06
	B6 asking about participation preferences in pain care	3.51	1.18	3.52	.99
	B7 asking how one would like to participate in decision-making concerning pain care	<u>3.40</u>	1.16	<u>3.29</u>	1.05
	B8 asking how one would like to participate in pain care	3.45	1.14	3.39	1.09
	B9 providing guidance for the expression of one's pain care preferences	4.18	0.98	<b>4.51</b>	.67
counselling patient about pain care	B10 providing guidance for the choice of preferred pain care method	3.58	1.20	3.86	1.09
	B11 providing guidance for the evaluation of pain intensity	4.11	.97	<b>4.60</b>	.68
	B12 providing guidance for the evaluation of care management	4.07	1.04	4.48	.81
	B13 guiding others in health care team concerning one's pain care preferences	3.91	1.17	<b>4.56</b>	.76
counselling those involved in care about patient's pain care and self-determination preferences	B14 guiding others in health care team concerning one's pain care method preferences	3.89	1.18	4.44	.88
	B15 guiding others in health care team concerning one's decision-making preferences	3.75	1.15	4.09	1.10
	B16 guiding others in health care team concerning one's preferences of participation in pain care	3.79	1.16	4.31	.96
	B17 monitoring that pain care is in accordance with patient's wishes	4.29	.94	4.29	.50
responding to patient's pain care preferences	B18 monitoring that pain care methods are relevant to patient	<b>4.59</b>	.74	<b>4.72</b>	.51
	B19 monitoring that patient's pain intensity is evaluated	4.48	.78	<b>4.74</b>	.56
	B20 monitoring that patient's pain management is evaluated	<b>4.50</b>	.77	<b>4.83</b>	.42
	B21 monitoring that patient can participate in decision- making according to his/her preferences	3.97	1.01	4.08	.94
responding to patient's self-determination preferences	B22 monitoring that patient can participate in pain care according to his/her preferences	3.91	1.03	4.15	.95
	B23 monitoring that patients' wishes are respected	<b>4.52</b>	.77	<b>4.65</b>	.70
	B24 monitoring that patients' rights are respected	<b>4.58</b>	.74	<b>4.75</b>	.51

\*1 = fully disagree, 2 = disagree to some extent, 3 = neither agree nor disagree, 4 = agree to some extent, 5 = fully agree  
All items with a mean >4.5 in boldface, lowest and highest values underlined

## 5.2 The model of the concept

The model of the concept of nursing advocacy in procedural pain care (Figure 4) is developed for purposes of explaining, applying and testing the elements (content) and the relationships between those elements (structure) of the concept of nursing advocacy in clinical nursing practice of procedural pain care. The construct is a result of Phases I-III, and it integrates perspectives of both patients and nurses. Dimensions and subdimensions of the concept of nursing advocacy were obtained from datasets I-II and validated in datasets III-V. The core dimensions and subdimensions of this concept remained relatively constant, but were clarified and deepened throughout the research process (see Papers I-V). At every phase of the study, the previous definition was tested and refined with the help of qualitative and quantitative methods as well as logical reasoning (see Table 6).



**boldface:** a subdimension of nursing advocacy validated by empirical data (Data IV) in this study  
 normal text: a subdimension of nursing advocacy not validated by empirical data (Data IV) in this study  
 but not excluded  
*cursive:* attributes of nursing advocacy

**Figure 4.** The model of the concept of nursing advocacy in procedural pain care

The first major concept represents the antecedents of advocacy. This concept was divided into three slightly different subdimensions for patients and for nurses. The second major concept represents the specific nursing activities through which nursing advocacy is identified. This concept was divided into three subdimensions, which are same both for patients and for nurses. The third major concept explains the phenomenon in terms of the consequences of advocacy for patients and nurses.

The model includes also the attributes (see section 5.1.1), and the related and contrary concepts (see section 5.1.2) of the concept in concern. These are significant in defining the concept, and validate the theoretical premises underpinning the idea of advocacy.

The dimensions and subdimensions of nursing advocacy highlight the importance of direct patient contact, the continuity and quality of the patient-nurse relationship, and the ethical and clinical competence of nurses. When advocating, nurses are putting their full expertise to use, not simply working on the basis of patients' medical diagnosis and or implementing interventions based on medical treatments. At the same time, they are moving beyond context-specific knowledge, towards more reflective praxis. The same applies to all those working at the micro, meso and macro levels of health care: it is important that they responsibly collaborate and reflect upon existing practices, even outside clinical care situations.

### **5.3 Implementation of nursing advocacy**

The implementation of nursing advocacy was examined with APPC by looking at both patients' and nurses' views on specific nursing advocacy activities and their experiences of whether that activity was accomplished during the hospital stay, or in the case of nurses, by assessing whether the responding nurse usually accomplishes the activity in her job. The results here are presented as percentages varying from 0 to 100% (all four items in a sum are implemented, see Appendix 10). Furthermore, the associations between respondents' background variables, also at subgroup level in both datasets, and their perceptions of the implementation of nursing advocacy, were examined at both sum variable level and item level (Data IV, Paper V).

Patients were of the opinion that nearly all their advocacy needs had been met during their hospital stay (see Paper V; Appendix 10). The implementation of nearly all summed variables was regarded as quite satisfactory, with mean scores rising above 50% (at least two items in the sum variable were implemented). The highest mean scores were recorded for the sum variable analysing patient's pain care preferences (74%) and responding to patients' pain care preferences (73%). The sum means for responding to patients' self-determination preferences (64%) and counselling patients about pain care (55%) were lower, but still quite satisfactorily implemented advocacy activities. However, certain advocacy activities such as the sum for counselling others about patients' pain care preferences and self-determination preferences (42%) and the sum analysis of patients' self-determination preferences (27%), were either not highly expected, or there may have been need for these kinds of advocacy acts, but it was not felt that these were implemented.

Nurses, then, took the view that all subdimensions of advocacy were more fully incorporated as part of nursing tasks than patients (see Paper V: Figure 1; Appendix 10). Most sum variables reached means of over 80%, indicating that as far as nurses were concerned, at least three items of four in these subdimensions of advocacy were implemented. The highest means were found for the sum variables describing analysis of patient's pain care preferences (89.32%), responding to patients' pain care preferences (89.34%), and counselling patient about pain care (88%). The means for sums counselling others about patients' pain care preferences and self-determination preferences (82%) and responding to patients' self-determination preferences (81%) were slightly lower. The lowest mean was recorded for the sum describing the analysis of patients' self-determination preferences (31%).

Patients and nurses shared quite similar views about the implementation of advocacy acts in procedural pain care. On the sum level, however, their views differed slightly concerning the sum variable of counselling patients about pain care (median in patient data 50%, in nurse data 100%), and the sum of counselling others about patient's pain care and self-determination preferences (Median 25 versus 100%). One possible explanation is that patients do not necessarily know what nurses document or report in the health care team, or they feel that others in the health care team were not aware of their interests. On the item level (see Paper V: Table 3), patients rated all individual items to have been implemented more often (11-56%) than nurses (1-29%). However, if asked which advocacy items were not needed, the ratio was the opposite: the nurses chose the "not needed" response option more often than patients. The same was true for the response option "advocacy needed but not implemented". This was particularly evident in items concerning the analysis of patients' self-determination preferences.

Certain background variables were found to be associated with perceptions of whether or not different subdimensions of advocacy were implemented. For example, age and diagnosis of the patient, his pain level before or during intervention; and working experience, job motivation, and pain care skills of nurse were found to have relationship with perceptions of advocacy implementation. These associations are thoroughly reported in Paper V. In this preliminary version of the instrument, there were no questions concerning the importance of nursing advocacy as such. The aim was first to define and operationalize the concept before proceeding to evaluate its importance. However, the Likert scale items concerning the implementation of nursing advocacy activities also included alternatives that indirectly revealed the respondents' opinion of the importance of each particular act. In addition, during data (Data IV) collection and analysis, it was interesting to talk with the contact nurses and to read the respondents' additional comments about to importance of the concept in focus.

## 6 DISCUSSION

The purpose of this study was to clarify the concept of advocacy and to explore the implementation of advocacy in the context of procedural pain care. This was done by conducting two literature reviews (Data I, Data V) and three cross-sectional studies in three different samples (n = 591).

### 6.1 Discussion of results

Nursing advocacy is a highly complex process concept that has great ethical and clinical importance in health care. However, there has been a marked lack of consistency in how the concept has been used in both theoretical and empirical research. This has also made empirical measurements impossible and by the same token precluded analyses from the health care consumer's point of view.

The literature review carried out at the beginning of this study was aimed at describing different uses of the concept of advocacy, its meaning as well as related areas of knowledge in order to establish a theoretical framework for the study and to provide research design and instrumentation clues (Rodgers 1989, Schwartz-Barcott & Kim 1993, Chinn & Kramer 1995, Morse 1995). Since the concept was found to lack maturity, additional descriptions were obtained in interviews with patients and nurses in a specific practice context (Hutchfield 1999, Brilowski & Wendler 2005). After operationalization and preliminary instrument validation, the dimensions and subdimensions of advocacy were validated by exploring patients' and nurses' opinions concerning the content of nursing advocacy and their experiences of how far it is implemented in practical care.

Advocacy in procedural pain care was found to consist of three dimensions and seven subdimensions: antecedents of advocacy (patient enlightenment, nurse enlightenment), advocacy activities (analysing, counselling and responding), and consequences of advocacy (patient empowerment, nurse empowerment). The evidence accumulated in this research process supports the definition and operationalization of the concept of nursing advocacy as *ethico-legal nursing decision-making that is based on recognition of the roles, rights and duties of those involved in the patient-nurse relationship, on information exchange, on the nurse's moral and clinical competence as well as having the preparedness, means and autonomy to effect change when considered by means of analysing, counselling and responding activities, even at the society level*. This definition integrates human (Curtin 1979) and existential advocacy (Gadow 1980) with advocacy for legal and moral rights (Kohnke 1982, Willard 1996, Mallik 1997a). Defending (Watt 1995) and whistleblowing (McDonald & Ahern 2000) activities were included in responding activities, which were applied if and as necessary, even in public or at the society level (Fowler 1989, Long 2005). Therefore, defending someone is not taken as central attribute of advocacy. The definition obtained in this study allows patients to self-advocate for themselves (cf. Brandon 1995), as well as nurses to



self-advocate for their profession. In other words, there exists both patient advocacy and advocacy outside of the patient-nurse relationship, but even the latter is geared to promoting the patient's best interests rather than simply bolstering the professional status of nurses (cf. Gould 2001). This definition goes to show that advocacy is an integral part of professional decision-making, at both an ethical and clinical level, and recognizes other health care professionals and society as vital antecedents of advocacy. The definition created in this research process is based on descriptions of both health care professionals and consumers, and covers both the concept of patient advocacy and professional advocacy in a certain context. The other integrative definitions (cf. Schwartz 2002, Baldwin 2003) are focused on patient advocacy alone.

The presumed antecedents of advocacy at the micro, meso and macro level (cf. Thompson et al. 2000) were established (see section 4.3, Figure 2) on the basis of the data collected with the APPC instrument (Data III-IV). These antecedents were the nurse's enlightenment of her role and duties and of the existence/meaning of a patient-nurse relationship. The nurse's professional and moral competence, i.e. her theoretical and practical clinical skills, knowledge of ethics, interaction skills with patients, colleagues and the health care team, and her job motivation were all found to be important in relation to advocacy initiation and implementation (Data IV, Papers IV and V). Therefore, the related concepts of professional accountability (cf. Woodrow 1997) and responsibility (cf. Mallik 1997b) can be seen as antecedents of advocacy, especially if the focus is attached to last part of these terms: ability.

However, nurses are not responsible for upholding the advocacy process all by themselves. It was found that their perceptions of communication and collaboration within the team and their ability to influence clinical care plans were of great importance in advocacy process (see Paper V). It seems that nurses' skills relate to the quality of the patient-nurse relationship as antecedents of advocacy, and the nurse's professional empowerment relates to the recognition of her role and duties.

The present results did not confirm earlier findings according to which patient vulnerability or lacking competence to participate in decision-making on one's own care are relevant antecedents of advocacy. Instead, what did emerge as an antecedent was patient enlightenment in their role and rights, i.e. wishes or concerns expressed or observed in the patient-nurse relationship (Data II and IV, Papers II-V). Patient enlightenment takes place via a therapeutic patient-nurse relationship (e.g. Eriksson 1992, Schroeter 2000) and the trust that is built up in that relationship (Mitchell & Bournes 2000). Even where the patient-nurse relationship is based on a sense of mutual respect, it can never be a relationship of complete equality; this is because it is a contractual relationship born out of necessity rather than choice. The nurse enters the relationship for a different reason than the patient. Both parties must acknowledge their respective inequalities, but at the same time value each other's competencies. For example, if patients self-empower themselves by searching for online sources of information about their illness or condition, nurses should value the positive contribution this can have to patient care, but at the same time critically assess that knowledge. (Ronayne 2001.)

This highlights the component of analysing activities in nursing advocacy. However, it must be acknowledged that even these analysing acts can depend on the social and cultural context within which they take place. In procedural pain care this context can be seen as the nurse's pain care competencies, and on her courage to test pain care based on patients' own accounts instead of relying on given pain typologies (cf. Greipp 1992, Lauzon Clabo 2004, Paper II, Paper V) – i.e. antecedents of advocacy in the context of pain care. It follows that nursing advocacy must be interpreted in connection with both professional, duty-based ethics and virtue ethics on the individual and collective level, and within the framework deontological and teleological decision-making. Nursing advocacy is the art of nursing with contextual sensitivity, i.e. balancing between beneficence and autonomy, nonmaleficence and justice. However, the core of advocacy, a *prima facie* obligation, is to show respect for patient dignity, to protect and enhance patients' interests and rights.

Noddings (1984, 1999) argues that local and particular ethical decisions are more valid than universal principles, because for the carer responding to the needs of the cared-for takes priority over the principle of justice. She observes that the caring relation is complete only if the cared-for confirms the value of the care provided. This view on ethical decision-making emphasizes the uniqueness of the patient-nurse encounter and does not take account of the meaning of the structure within which the care takes place. Furthermore, it makes ethical decision-making haphazard, for there is no need for ethical guidance. Kuhse (1997), for her part, integrates nurse's contextual sensitivity and reflection of ethical principles with moral response. However, even she grants that different circumstances and health care settings may require different responses. To conclude, nursing advocacy as ethico-legal decision-making requires collaboration at all levels, i.e. with the patient, with different members of the health care team, and with society. It does not mean blind loyalty to anyone, or to any principles, but reflection – voicing responsiveness.

In this study, one of the consequences of advocacy identified by patients themselves is empowerment (cf. Schroeter 2000, Falk-Rafel 2001, Vogt Temple 2002), especially in the patient's role and in one's own care. On the other hand, in contrast to earlier studies, (cf. Segesten & Fagring 1996, Maher & Myatt 1995, Hyland 2002) informed choice was neither regarded as part of advocacy nor seen as a consequence of advocacy. However, nurses are still expected to respect patients' right to self-determination (Data IV). In order that this respect can be possible, nurses must constantly analyse their patients' needs and respond to their changing needs, including their needs for information. Patients have the right to change their self-determination preferences whenever they so wish. If this right is respected, patients feel empowered and are able to self-advocate (cf. Rosenman et al. 2000, Harkness 2005).

In this study there was no evidence that advocacy causes adverse effects or suffering to patients (Welchman & Griener 2005). Nurses, then, perceived professional empowerment as a consequence of advocacy, i.e. role clarification and better collaboration (cf. Bu & Jezewski 2006), but not personal empowerment, although it has been suggested that empowered nurses are more likely to experience job satisfaction and commit themselves to career and to organization (Nahigian 2003,

Laschinger & Finegan 2005). This lack of individual empowerment might be a simple matter of modesty: nurses certainly can become empowered even individually if they commit themselves engage to the patient-nurse relationship and to good care (cf. Kuokkanen, Leino-Kilpi & Katajisto 2003). In the nurse data (Data II) there were also some references to disempowerment as a consequence of advocacy, such as professional reprisals (cf. Sellin 1995, McDonald & Ahern 2000). These, however, were, mentioned by one informant only. In national nurse data (Data IV) the negative consequences of advocacy (Dn 5, Dn10) did not get support.

This research showed that empowerment is associated with advocacy: the patient's and nurse's structural empowerment enables advocacy initiation, which, in turn, enables individual patient empowerment and structural nurse empowerment. This relationship between advocacy and empowerment can also be interpreted using subject position theory (Butler 1993), a postmodern sociological theory which says that individuals have the capacity to occupy and move between a variety of identities or subject positions within an interaction, and adopt or reject different roles depending on normative power processes. For example, patients continuously move between different roles (client, patient, inpatient, mother/father, spouse), as do nurses (mother, teacher, half-a-doctor, colleague, servant, secretary). This identification with a certain role is explained by role expectations, which are made possible or prevented by patients' and nurses' clothes, nurses' room, doctor's rounds, journals, and perhaps most of all, by the language the health care personnel use in contacts with patients and colleagues. A change of identity is also followed by a change of discourse, the new discourse is used to express that subject position, and the application of that discourse will socially reinforce the chosen discourse. It is vital to analyse what roles are offered by nurses, for example, to patients through their discourses and what assumptions lie behind those discourses. If they consider themselves superior in relation to patients, then they are abusing the power they have by virtue of their education. The abuse of power is reflected in detachment from patients, as a personally disengaged professional role, unnecessary asserted power and control, as well as clinical mismanagement (cf. Fox 2003), such as the decision to withhold analgesia (cf. Loveridge 2000). If the patient is prevented from taking an active role in her own care, she will also remain unaware of the aim of that care and cannot be active or responsible in relation to that goal (Ketola, Kovasin & Suominen 1995).

The evidence from this research lends support to the usefulness of the APPC instrument in exploring opinions about nursing advocacy and its implementation (Papers IV-V). The instrument is relatively easy to administer, and its items have moderate variability. Response rates were high throughout (Data IV). However, closer examination of data that were not valid for analysis showed that older respondents aged 70 or over found the APPC difficult to answer. The choice of a Likert-type scale was based on its frequent use in self-report scales and in the measurement of attitudes (Davis 1996). The response option "don't know" was included in order to minimize the amount of missing data (Polit & Hungler 1999). On the other hand, this forced choice in situations where respondents are unable to make up their minds can negatively affect the reliability of response patterns if percentages are very high. However, as it turned out, the respondents did not opt for this choice very often, and when they did it was

mainly in relation to nurse activities in which patients cannot participate, such as reporting or documentation. There were no existing instruments for the measurement of advocacy from the point of view of patients. The APPC instrument provides a way to quantify the experience of nursing advocacy. It can be used to test and to refine the concept and to develop the theory of nursing advocacy.

The results show that specific nursing activities were applied in procedural pain care in order to support nursing advocacy (Paper V). Patients rate the clinical aspects of advocacy very highly, but the same applies to the continuity of the patient-nurse relationship and the nurse's continuous monitoring of the situation. Nurses, then, seem to follow standardized procedures of pain care, which do not necessarily meet the needs of all patients (cf. Drayer, Henderson & Reidenberg 1999, Duncan & Pozehl 2001). Nurses made only little effort to analyse patients' pain care preferences, whereas patients perceived that the nurses had analysed their pain care preferences. Both patients and nurses gave even less consideration to patients' self-determination preferences (cf. Briggs & Dean 1998, Haddad & Vernarec 2001). Even though patients regarded the analysis of self-determination preferences as a somewhat more important element of advocacy than nurses, that subdimension was not implemented in the majority of the data.

Counselling activities were perceived as relevant to advocacy by both patients and nurses, but they were not always implemented (cf. Sjöling & Nordahl 1998), especially with regard to patients' participation in pain care decision-making or their own pain care. Furthermore, nurses regarded the subdimension of counselling others as an important part of advocacy, and they also said they had engaged in that activity, whereas patients rated counselling others as equally important but had lower assessments of implementation. Responding activities seem to be implemented mainly in relation to pain care interests, not to self-determination. However, most respondents felt that patients' wishes were respected. This is interesting since those wishes were not systematically analysed. At worst this means that patients' autonomy in terms of their competence to think, to will and to act was not systematically analysed or respected, and thus their verbal, behavioural and outcome empowerment (cf. 2.2.3.3, Irvine et al. 1999, Suominen et al. 2005) were inhibited.

## **6.2 Implications of the study**

Systematic data collection combined with relevant analysis and reporting is a crucial tool that can help individual professionals, health care teams, organizations, unit managers, and societies evaluate the quality of care and its different elements. However, these evaluations presuppose conceptual clarity and operationalization. The findings from this study provide a realistic picture of nursing advocacy in the context of procedural pain care, of how nurses carry out their advocacy role and to what extent advocacy is implemented in everyday practice. Furthermore, the findings show that empowerment and advocacy are associated with each other. These results have several implications for nursing education, practice, administration and research. The definition and the instrument developed in this study can help nurses individually and

collectively to reflect on their ethical, clinical and interaction skills, the meaning of their actions in the nurse-patient relationship, and the practice of health care in general.

The results of this study highlight certain ethical areas that need to be given further consideration in nursing education and practice. Nursing education should place greater emphasis on ethical codes of conduct, and with the help of this concept clarification, it might be easier for nursing students to interpret the abstract idea of advocacy in nursing practice. In nursing practice, then, more attention should be given to safeguarding patients' rights in pain care by analysing their pain care and self-determination interests, as well as their possibility to express their informed consent. It seems that patient involvement in pain care is limited either because they are not asked or not informed about their preferences and possibilities, the methods of pain care available or the different methods of pain measurement. In addition, it seems that neither pain management nor the processes of pain care are systematically evaluated, at least not together with the patient. Furthermore, patients' pain care preferences and self-determination preferences are not documented nor reported to other people participating in the care process. All this is liable to give rise to paternalism, the antithesis of advocating patients' rights and interests. Pain care should be an ongoing process of analysing, counselling and responding advocacy activities. This requires strong ethical competence, clinical expertise and good skills of collaboration. It also requires more nursing resources and greater continuity in the patient-nurse relationship, for it is impossible to build trusting relationships with patients and to analyse their needs if contact with them is constantly interrupted.

However, not all the problems related to procedural pain care can necessarily be resolved by increasing the number of nurses on the ward. This study has shown that patients often experience pain even before the medical intervention as well as during the intervention, despite the use of analgesics and anaesthetics. This may be due to poor or lacking pain analysis and poor pain care planning, because there is a tendency to think that medical procedures are, for the most part, quite short, and pain experience minimal. However, the reality for patients is very different, and therefore decisions on pain care provision should be based on their assessments and experiences. The focus of pain care should be on analysing the individual's situation, and this analysis should continue from admission through to discharge, including patients' assessments of how effective the pain care provided has been. Furthermore, these analyses should be documented and reported to other units as well as to aftercare units and patients' significant others. Short hospital stays require the responsible involvement of these instances and people as well. The preliminary version of the Advocacy in Procedural Pain Care instrument can be used in quality evaluations and quality assurance projects in practical everyday care to distinguish between organizations, units or individuals that are competent and those that are not competent in the pain care process and nursing advocacy. Thus, it can also be used as a tool for evaluating staff competencies in pain care or nursing ethics, as part of an introduction to organizational pain care standards, as a tool for evaluating nursing education, including on-the-job training, and even the need for, or outcomes of, on-the-job education.

The results of this study also provide important clues for the development of pain care processes, pain care standards and pain care documentation, including analytical, pedagogical, clinical and ethical decision-making. Furthermore, open debate and discussion about advocacy and systematic documentation and analysis of advocacy situations could pave the way to more effective communication and collaboration among health care professionals. This study may also courage nurses to get involved in their unions and organizations in order to empower their patients and their colleagues. All this could promote the quality of care, but also make nursing interventions more visible and measurable, inspire more public discussion on advocacy and to research designs as well.

This research has helped us gain a deeper knowledge and understanding of the phenomenon of nursing advocacy, its antecedents, activities, implementation and consequences. On this basis we should be able plan and provide nursing education which teaches and evaluates the skills that are needed to advocate, and to plan, provide, document, measure and evaluate pain care which meets both the legal, ethical and clinical requirements of pain care. The framework developed in this study can also be used by nursing administrators as a tool for analysing existing resources for nursing advocacy and pain care, for the development of resource provision, and for following up results related to nursing advocacy and pain care. In addition, this study provides a solid foundation for further research on the issue of advocacy in nursing practice.

### **6.3 Validity and reliability of the study**

#### ***6.3.1 Validity and reliability related to the research design***

In order to produce a broad and comprehensive concept clarification, a set of systematic research methods was applied during the research process rather than any single method of concept analysis (cf. Hupcey et al. 1997, Finfgeld-Connett 2006). First, a descriptive design was applied (Papers I-III), this was complemented by correlational designs (Papers IV-V). Thus, the knowledge base and preliminary hypothesis on the relationships between different elements of the concept obtained in Phase I were tested in Phase II. However, in nursing phenomena it is necessary to take account of their multicausality, which would require more controlled designs (cf. Burns & Grove 1997).

As the concept of nursing advocacy was found to be immature (Paper I), an additional empirical dataset was collected in order to describe major dimensions of advocacy and to explore the patients' perspective (Paper II). Considerable time and effort was invested in developing the instrument to measure the dimensions and implementation of nursing advocacy and to explore the different relationships in the advocacy process in the context of procedural pain care. When a tool is developed on the basis of a concept analysis, the researcher has a start on construct validity (Knafl & Deatrck 1993). Criterion validity could not be established as there were no existing instruments to measure nursing advocacy or its different dimensions as defined in this study. During the statistical analyses the researcher needed the guidance and practical support

of a statistician, particularly in the selection of procedures. Each procedure was selected to resolve a specific question. The results showed no major conflicts or contradictions, even though different statistical procedures were applied.

Data collection and measurement present several validity threats to the research process at both the people, institution, event and researcher level (Burns & Grove 1997). In this study there were no problems with the sampling criteria or sample selection, or passive resistance by personnel at the units. In Data II it was not known whether or to what extent subjects' responses were influenced by other patients, family members or colleagues. In Phases I and II, data were collected in several hospitals in order to get a picture of advocacy not based on specific hospital culture. External influence on subjects' responses was minimized by first collecting the patient datasets and then the nurse datasets. It is impossible to know to what extent patients on the units and nurses discussed the questionnaire, or filled them together. Fatigue, time pressure or the halo effect may also have influenced responses. There were also various institutional problems in the shape of unit closedowns and personnel transfers, but these are all beyond the researcher's control. In order to minimize these problems, administrators and contact persons on the wards were regularly phoned prior to and during data collection.

Researcher problems are often related to role conflict and data collection techniques. In this study the researcher had no other clinical or administrative roles at the units where the datasets were collected. However, in Data II the risk of potential role conflict was recognized during the patient interviews in that some patients sought for clinical answers regarding their care. Another role conflict would have been possible with regard to the information concerning unethical professional behaviours obtained during data collection procedures. In these situations, the role of researcher was kept in mind prior to any other possible roles. Methodological and data triangulation were conducted to control possible biases and to deepen the researcher's skills. Pilot tests were conducted prior to all major empirical data collections (Data II, Data IV), and the whole research process was supervised by senior researchers and a senior statistician.

### ***6.3.2 Validity and reliability related to data***

The integrative review (cf. Polit & Hungler 1999) conducted in this study (Data I) was aimed at synthesizing the existing knowledge about the concept of advocacy. No evidence was available from randomized control designs to indicate the effectiveness of advocacy as an intervention (Evans & Pearson 2001), nor were there any studies on the basis of which the phenomenon could be summarized by reference to statistical values (Burns & Grove 1997). The existing body of research on nursing advocacy was found to be based on descriptive designs from health care personnel's point of view, and its results lacked the coherence necessary for a systematic review (cf. Chinn & Kramer 1995, Morse et al. 1996). Given the qualitative methods and small sample sizes applied in these studies, a proper meta-analysis was also out of the question.

The reviews for this study were conducted on the basis of searches in two major nursing science databases, which were supplemented with manual searches. The

decision to conduct electronic database searches was motivated first and foremost by reasons of efficiency. CINAHL and Medline were chosen because the purpose was to explore the significance, use and applications of the concept of advocacy in the context of both nursing science and nursing practice. The keywords applied in the first search were later found to be ineffective with regard to professional advocacy, but this problem was addressed in the second database search. The papers included in the review were published in international, peer-reviewed journals and the total number of papers was sufficient to identify areas of knowledge concerning advocacy and to develop a theoretical framework for this study (Rodgers 1989, Schwartz-Barcott & Kim 1993, Morse 1995). Some of the studies on advocacy yielded by the database search did not directly define the concept, but only advocacy as a verb for talking for or supporting some idea in common discourse. These studies were excluded from the analysis.

In order to gain a more complete understanding of the concept of advocacy and to approach it from patients' point of view as well, empirical datasets were collected in the context of procedural pain care (Data II), and later in otolaryngeal surgical contexts (Data IV). In order to ensure the validity and reliability of the research process, sampling plans were developed to increase sample representativity and to decrease systematic bias and sampling error. Furthermore, the contact persons at the data collection units were contacted by the researcher on numerous occasions to make sure they understood the criteria and could communicate the details further to personnel and through them to the patients. The samples are considered to be representative of average adult patients and nurses in the surgical context, for the datasets were collected in several hospital districts and in both university and central hospitals across Finland. Response rates were very high. The patient sample (Data IV) represented 10 per cent of the target population (all adult non-day surgical otolaryngeal patients operated in Finland) and over 60 per cent of nurses working on units that operate more than 400 such patients a year. Based on this representativeness, the sampling criteria may be regarded as relevant. However, no data are available on the number of patients who were excluded because staff members did not consider them suitable participants, nor on the exact number of patients who refused to participate. The 49 invalid questionnaires identified and rejected by the researcher together with the valid questionnaires exceed the number of questionnaires distributed to the units. Therefore, the figure of 64 patients who were reported to have refused to participate for reasons of age or perceived lack of knowledge on the subject, may be an estimate offered by personnel involved in data collection.

The sample sizes were planned to meet the requirements of adequate power and cell sizes for the statistical techniques used (cf. Chinn & Kramer 1995, Burns & Grove 1997). Statistical power analysis (cf. Polit & Hungler 1999) was not conducted due to the nature of the process concept measured. Furthermore, the biometric properties of the new instrument developed for this study were not known. However, in order to minimize sampling error, large sample sizes were collected and sample means examined, and random samples were obtained from several units. This proved a successful strategy at all phases of the study, although in the instrument validation process the sample size for determining content validity was smaller than expected



(Data III). However, this was anticipated by distributing the questionnaire to 75 experts, when a sample of at least 10 raters was set as a minimum (cf. Penfield & Miller 2004, Polit & Tatano Beck 2006). Half of the expert sample was recruited from the same context where the qualitative interviews had been conducted in Phase I, aiming to preserve the language and expressions used by the study participants in item construction and validation (Kristjansson, Desroches & Zumbo 2003). Content validation was not conducted with a sample of patients because no experts were available on advocacy as such. In construct validation the sample size was suitable for explorative factor analysis (Nunnally 1978, Knapp & Brown 1995, Goodwin 2002), but the data were not distributed normally enough for confirmational factor analysis, as recommended for the operationalization of a multidimensional concept (Haase et al. 1992, Stoltz, Pilhammer & Willman 2006).

### **6.3.3 Validity and reliability of the results**

The concept clarification offered in this research is based on accumulating evidence from methodological and data triangulation. First, the dimensions of the concept of nursing advocacy were derived deductively from previous research and then complemented by inductive content analysis of empirical data collected from both patients and nurses (Phase I). Then, the concept was operationalized and the preliminary version of the instrument measuring nursing advocacy, its content and structure, and its implementation was developed and validated (Phase II). In Phase III, a model was constructed to describe the concept and its structure. The model of the concept of nursing advocacy in procedural pain care is consistent with earlier theoretical and empirical descriptions of the dimensions and subdimensions of nursing advocacy and their associations with empowerment (Papers I-V). Earlier models of advocacy have concentrated on advocacy as a verb only. In those models advocacy acts has been described as proactive and reactive tasks of nurses (Snowball 1996), as teaching, informing and supporting (Chafey et al. 1998), or as valuing, apprising and interceding (Baldwin 2003). The advocacy activities identified in this study include those verbs, but on more detailed, practical level. The only model of advocacy as process before the one developed in this study stated interpersonal relatedness to be a central feature for advocacy, together with environmental factors such as administration and economics (Chafey et al. 1998). These antecedents of advocacy are synonymous to antecedents identified in this study. However, in this study, the antecedents point out the patient, the nurse and the organization. Appropriate statistical methods such as content validity indices and factor analysis provided support for the model, but much work still remains to be done if a theory is to be developed. However, even as it is now, the model has value in clinical and educational settings. Although the concept clarification and instrument development was based on samples of mainly surgical otolaryngeal patients and nurses, the context of procedural pain care means that the conceptual model has application in several other settings as well.

The structure and content of the concept of nursing advocacy, as it emerges from the present research, is to some extent consistent with the previous literature, even across different cultures. However, some semantic problems especially with regard to the antecedents and the consequences of nursing advocacy may be confusing.

Enlightenment and empowerment are both complex and highly abstract concepts, as are acknowledged rights and ethical duties, self-determination, and the patient-nurse relationship. This is perhaps why the concept of advocacy has been explored mainly as an incident or event like whistleblowing rather than as a process. The findings of this research certainly highlight this complexity, and the accompanying instrument and model are accordingly complex as well. On the other hand, if the concept is integrated to comprise patient advocacy and professional advocacy and all other variants, i.e. advocacy as philosophy, role, intervention, process and outcome, it should be more useful epistemologically, pragmatically, linguistically and logically (cf. Morse et al. 1996, Hupcey et al. 2001).

The preliminary version of the Advocacy in Procedural Pain Care -scale has been tested with all the complementary validation methods that are possible in this phase of concept development, i.e. for its content and construct validity. In Phase II nursing experts in pain care and in nursing science provided content validity ratings for scale accuracy, relevance, completeness, clarity, and appearance biases as well as for content relevance and completeness (cf. Lockett, Aminzadeh & Edwards 2002, Beaulieu 2003). The results of this expert analysis can be regarded as highly positive, both on an interrater and intrarater level, as well as on the item level and scale level (cf. Tatano Beck & Gable 2001). It is recommended (Davis 1996), that also patients might have been used as experts in evaluating the content validity of the instrument developed. Due to difficulties to find a patient population with knowledge on both pain and on measurement of content validity of an instrument this evaluation was not conducted in sample of patients. However, in construct validity assessment a sample of patients was obtained. Patient opinions on instrument item acceptance were encouraged in dataset IV for construct validity. The internal consistency of the subscales was assessed with Cronbach alpha coefficients, which showed that the items were homogenous. The three main parts of the instrument (antecedents, activities and consequences) were then separately submitted to exploratory factor analysis using both varimax and promax (oblique) rotation, which supported the theoretical dimensions and subdimensions of the concept. Convergent and discriminant validity (Burns & Grove 1997) were established by examining the correlations between each sub-scale and the whole APPC, which indicated that the instrument measured the same latent variable. The evidence supporting its content validity was based on literature reviews (Paper I, summary), experts' judgements (Paper III), and empirical datasets (Paper II, Paper IV). For the first time in the context of advocacy research, the content of the concept was defined by integrating the perspectives of both patients and nurses.

#### **6.4 Suggestions for further research**

Concept development is an ongoing process. Further theoretical and empirical work is required to clarify the conceptual parameters of advocacy in order to make it meaningful concept for nursing practice, education and research.

The crucial component of concept clarification is determination of the relationships between concepts. In this study, recognition of one's rights and role was confirmed to

be an antecedent of advocacy, and one's empowerment a consequence of it. These terms need to be further clarified before research designs concerned with these dimensions of advocacy can be planned. For example, does advocacy exist without antecedents of patient, i.e. recognition of rights, role and existence of patient-nurse relationship? Or does advocacy in that situation get different forms compared to advocacy described in this study? With the same manner, some antecedents of advocacy were identified to be linked to nurses' pain care skills, but those skills were also perceived to be improved as consequence of advocacy. Accordingly, recognition of patient-nurse relationship was found to be important antecedent of advocacy, but it was also perceived to become more trustful as consequence of advocacy. Does the nursing advocacy really change patient-nurse relationship and nursing outcomes? In what way are the single nursing advocacy activities related to the single consequences of it? On the other hand, if advocacy is not to take a place, does this non-advocacy have effect on nursing outcomes?

Clinical advocacy activities were preferred as content of advocacy prior to analysis of patients' pain care and self-determination preferences, when evaluated by both patients and nurses in this study. This relationship between clinical nursing interventions and nursing advocacy activities must be clarified deeper. Furthermore, response to patients' pain care and self-determination preferences was still presupposed by both patients and nurses, though they were not analyzed. Does this refer to caring as such, and what is the difference between caring and advocacy? Also other concepts need to be examined and clarified to capture the essence of what nursing advocacy is supposed to be, and to allow the health care professionals to use and communicate the concept appropriately. For example, simultaneous concept analyses could be conducted for advocacy, caring and nursing; self-determination, and empowerment.

The instrument developed during this research process should also need to be improved in terms of content and construct, even though its internal consistency was shown to be good. The feasibility of the instrument including its psychometric properties should be tested in diverse settings and groups of patients and nurses on a less restrictive range in terms of clinical context. Furthermore, a purer, less contextual version of the instrument is needed so that it can be used to measure the implementation of nursing advocacy as such, outside of the pain care context. If we had an instrument that could measure opposite concepts, such as oppression or paternalism, then we could apply statistical methods to demonstrate that they measure opposite sides to the same phenomenon.

The next step in concept development would be a theory of nursing advocacy in order to give insight into essence of nursing advocacy and worthiness of it. The concept of advocacy is here described as linear but also as dynamic, interrelated model (Figure 4), involving the five concepts intertwined. Therefore, covariance analyses and latent variable modelling would enable to account for the various feedback loops suggested by this study, and the shared and unique variances of the concept in concern. Then, the theory would need to be implemented and evaluated in practise. A theory of nursing advocacy would help health care professionals and researchers to generate questions

that explore each of the dimensions of advocacy and lead to more focused interventions and ethically and clinically valid nursing practises.

The results of this study may be stated to fit only one nursing situation, i.e. nursing advocacy in procedural pain care. From this point of view, the concept should be examined from several different perspectives and in several different contexts in order to see how it is impacted by those changes of perspective and environment. These perspectives could include patients' relatives, other health care team members, administrators, whole organizations, nursing students and teachers. Advocacy should also be explored in non-acute settings such as home health care, maternity care, and in elderly care. In these studies, data collection methods such as document analyses, narratives or observations could be applied in order to get even more enriched picture of nursing advocacy and its variations. The existence and use of nursing advocacy as meaningful concept and its dimensions should also be measured in a longitudinal fashion, and in different social and cultural contexts.

However, this concept clarification can also be seen as rich enough to encompass all nursing contexts. According to dispositional view to concept development, concepts are habits and capacities for certain behaviours. In this study, the evolutionary nature of the concept of advocacy is identified, and a generic model case is presented. Thus, health care personnel being able to identify the advocacy activities should have grasp on the concept of nursing advocacy also, despite the context.

## 7. CONCLUSIONS

The purpose of this study was to explore the patient advocate role that nurses have by virtue of their profession, and to describe how they express that role in interactions with patients and the health care team. The ultimate goal was to clarify this very central concept of nursing ethics and to make it more understandable, visible and measurable in everyday nursing practice, education and administration.

According to the results of this research process, the ultimate motive for advocacy is to promote the patient's well-being and rights. Advocacy in procedural pain care integrates clinically, ethically and legally proactive nursing activities into reactive ones. It is taken as a right of all patients, and as a duty of all nurses. However, the results also indicate that patient advocacy may not be possible without advocacy for and empowerment of a professional group of nurses. Advocacy presupposes both means and power, i.e. skills, motivation and the possibility to make a difference. Therefore, this concept clarification process lead to a new term, named as nursing advocacy.

Furthermore, the aim was to explore how advocacy is implemented in procedural pain care, i.e. how nurses apply the general ethical principle of advocacy in everyday nursing practice. The results indicate that advocacy is a natural part of nursing care, although not all of its subdimensions are systematically applied.

Advocacy has earlier been defined in nursing literature mainly by health care personnel. The results of this research are based on experiences and opinions of both patients and nurses.

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## ACKNOWLEDGEMENTS

Over these past years I have received invaluable help, advice and support from many people. I wish collectively to thank everyone who has helped me with this project, because it is impossible to name them all.

This study was carried out at the Department of Nursing Science, University of Turku. I wish to express my gratitude to my supervisors, Professor, PhD Helena Leino-Kilpi, and Professor, PhD Tarja Suominen, for their constructive criticism. I also wish to thank Professor, PhD Sanna Salanterä for her assistance at the very beginning of the project.

I am very grateful to Professor Therese Bondas-Salonen and Docent Tarja Pölkki, who have reviewed this dissertation. Their valuable comments helped greatly to clarify and improve the manuscript.

I also wish to thank Mr Pauli Puukka, MSocSc, for teaching me the principles of statistics, for his expertise and guidance in search for appropriate methods of statistical analyses, and his patience during the project.

I have received invaluable help with English language from MA David Kivinen, who has not only revised this thesis and all five papers, but also taught me to critically review my manuscripts.

I owe my sincere thanks to all the people who took part in my study and made it possible at its various stages: the patients and nurses from 12 hospitals in nine hospital districts all over Finland, ward sisters and other collaborating professionals involved in data collections procedures at different units, the pain nurses at South-Western hospital district, as well as master-students and doctoral co-students at Department of Nursing Science. Without your co-operation and time this study would not have been possible.

My thanks are further due to all colleagues at university of applied sciences Sydväst, now called Novia, who have supported and encouraged me throughout years. In particular, I wish to thank my principal chief Inger Westerlund of the practical working arrangements making it possible for me from time to time to concentrate on this study only. I have also received invaluable assistance by librarian Gunilla Jansson, who taught me to conduct effective database searches.

I extend my deepest gratitude to my friends and family. Lea Hautala, Marina Gruner, Bodil Julin and Mervi Raita, I will thank you for many long discussions, good laughs, warm hugs, and your optimism. My parents Anja and Harri Vaartio, you have supported me both instrumentally and with your ever-lasting belief in me. My dear husband Jari, you have made this study possible by loving me and showing unbelievable tolerance.

This project was financially supported by the Finnish Federation of Nurses (2003), Finnish Foundation of Nursing Education (2003, 2004), University of Turku (2005,

2008), Finnish Association of Nursing Research (2004, 2006), Finnish Association for the Study of Pain (2006), and Finnish Work Environment Fund (2008).

Kaarina, 30th September 2008

Heli Vaartio



**Appendix 1.** Perspectives on advocacy in the nursing literature

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<b>antecedent</b>	<b>Perspectives</b>	<b>Definitions</b>	<b>Authors and year</b> * empirical evidence
	<b>Right of patient</b>	The human right of self-determination	Curtin 1979, Maher & Myatt 1995 *, Hyland 2002
		Patient's right to information and decision-making	Grace, Fry & Schultz 2003* Gadow 1980, Kohnke 1982 Corcoran 1988, Segesten & Fagring 1996*, Ambler et al 1999*, Schroeter 2000 * Altun & Ersoy 2003 *
	<b>Role and duty of nurse</b>	Role of a professional nurse	Kuhse 1999, Millette 1993 * Mallik 1997a, b, c* Mallik & Rafferty 2000 Allen 2000, Grace 2001 Breeding & de Sales Turner 2002* Pullen 1995
		Role of a specialist practitioner	
		Role of change agent Nurse's moral duty	Picard et al. 2004, Kendall 2006 Crockford, Holloway & Walker 1993*, Manton 1998 McGrath & Walker 1999* Lillibridge, Axford & Rowley 2000*, Ahern & McDonald 2002* Gaylord & Grace 1995 Falk-Rafael 1995 Watt 1997 * Allen 2000
<b>Philosophical basis of nursing</b>	Nursing philosophy	Davis, Konishi & Tashiro 2003* Sherblom, Shippis & Sherblom 1993, Erlen & Sereika 1997* Schroeter 1999* Benhamou-Jantelet 2001* deWolf Bosek 2001* Berggren, Begat & Severinsson 2002, McSteen & Peden-McAlpine 2006* O'Connor & Kelly 2005* Sellin 1995*, Snowball 1996* Chafey et al. 1998* Chase-Ziolek & Iris 2002* Gregg 2004* , Boyle 2005*	
<b>activity</b>	<b>Competent care</b>	Ethical decision-making	
		Nursing practice Attribute of care	
<b>consequence</b>	<b>Perspectives</b>	<b>Definitions</b>	<b>Authors and year</b> * empirical evidence
	<b>Outcome of quality care</b>	Indicator of excellence in nursing care	Gadow 1980, Benner 1984 Chafey et al. 1998* Yonge & Molzahn 2002*
		Part of outcome management	Ley 1998, Allen 2000 Söderhamn & Idvall 2003* Long 2002*
Role of case manager		Hellwig, Yam & DiGiulio 2003* Anderson, Helms & Kelly 2004* Tahan 2005*, Carr 2005* Davenport-Ennis et al 2002	
<b>A role outside patient-nurse relationship</b>	Professionalization strategy of nurses	Hewitt 2001, Hyland 2002 Long 2005* Gates 1995 Willard 1996 Mallik 1998* Mitchell & Bournes 2000 Wheeler 2000 Gould 2001 Welchman & Griener 2005*	
	A role not suitable for nurses		

## Appendix 2. Antecedents of advocacy

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Antecedents	Authors
<b>Antecedents for nurse's role as advocate:</b>	* empirical evidence
Nursing education	Schauer 1995, Mallik 1997a
Nursing training	Schauer 1995*, Mallik 1997a*, Mallik 1998
Nursing experience	Mallik 1997a*, McGrath & Walker 1999, Schroeter 2000*, Foley, Minick & Kee 2002
Observation of others	Foley, Minick & Kee 2002
Clinical competence	Sellin 1995, Eaton 2005, Vallerand, Anthony & Saunders 2005,
Nursing expertise	Segesten 1993, Bryan et al. 1997, Chafey et al. 1998, Woods 1999, Robichaux & Clark 2006
Nursing knowledge	Chafey et al. 1998, Mallik 1998
Nursing science education	Howell & Coates 1997, Helton & Evans 2001
Communication skills	Schroeter 2000
Organizational skills	Hellewig, Yam & DiGiulio 2003
Understanding advocacy	Schroeter 2000
Moral development	Millette 1993
Self reflection	Rushton, Armstrong & McEnhill 1996*, Foley, Minick & Kee 2002
Moral obligation	Mallik 1997a*, McGrath & Walker 1999
Moral distress	Sundin-Huard & Fahy 1999, Nahigian 2003
Moral competence	Woods 1999, Kubsch et al. 2004
Personal and professional imperatives	Crockford et al. 1993, Fall-Dickson & Rose 1999
Conviction	Segesten 1993, Chafey et al. 1998
Education in reasoning skills	Schroeter 1999
Integrity	Pullen 1995
Coherence between theories and intentions to be helpful	Mitchell & Bournes 2000
Ethical professionalism	Nahigian 2003, Kennedy 2004, Kubsch et al. 2004, Corley et al. 2005
Acknowledgement of human rights	Mallik 1997a, Watt 1997, Grace, Fry & Schultz 2003
Respect for the person	Falk-Rafael 1995*, Watt 1997, Altun & Ersoy 2003
Respect for patient autonomy	Blondeau et al. 2000
Knowing the patient	Watt 1997, McGrath & Walker 1999
Self-confidence of nurse	Sellin 1995, Snowball 1996, Chafey et al. 1998, McGrath & Walker 1999, Goodman 2003
Sensitivity of nurse	Woods 1999
Commitment to patient	Woods 1999, Seifert 2002
Willingness	Sellin 1995, Mallik 1998, McGrath & Walker 1999, Schwartz 2002*, Baldwin 2003
Emotional strength	Sellin 1995, Mallik 1997a
Accountability	Mallik 1998
Responsibility	Schroeter 2000
<b>Antecedents for patient-nurse relationship:</b>	
Therapeutic relationship	Snowball 1999, Mallik 1998, Woods 1999, Schroeter 2000*, Wheeler 2000*
Therapeutic use of self	Rushton, Armstrong & McEnhill 1996
Interpersonal relatedness	Chafey et al. 1998*
Understanding	Schroeter 2000
Trust	Schroeter 2000, Mitchell & Bournes 2000
Excellent interpersonal skills	Mallik 1998
Continuous observation of the patient	Blondeau et al. 2000, Schroeter 2000
Continuity of care	Hyland 2002
Empathy	Chafey et al. 1998

## Appendix 2 2/2

**Antecedents for patients to require advocacy:**

Vulnerability of patient	Cameron 1996*, Mallik 1997a, Chafey et al. 1998, Sundin-Huard & Fahy 1999, Wheeler 2000*, Schwarz 2002*, Baldwin 2003
Powerlessness of patient	Segesten 1993, Watt 1997
Incompetence of patient	Schwartz 2002
Expression of concerns by patient	Segesten 1993, Mallik 1997a, Mallik 1998, Harris 1999
Patient's wishes	Schroeter 2000
Trigger situation	Segesten 1993, Jezewski 1994, Sellin 1995, Mallik 1997a, McGrath & Walker 1999
Abuse	Allen, Kellett & Gruman 2003
Perception of unsatisfactory situation	Söderhamn & Idvall 2003

**Environmental antecedents:**

Communication	Schroeter 1999, Hyland 2002*
Collaboration with others	Chafey et al. 1998, Svedberg et al. 2000, Hewitt 2001*, Eaton 2005
Support from co-workers	Holly 1989, Rushton, Armstrong & McEnhill 1996*, Chafey et al 1998, deWolf-Bosek 2001
Support from physicians	Holly 1989, Chafey et al. 1998, Mallik 1998, Svedberg et al. 2000, deWolf-Bosek 2001, Kendall 2006
Good interdisciplinary relations	Hyland 2002, Goodman 2003
Nursing collegiality	McDonald & Ahern 2000
Support from employers	McDonald & Ahern 2000
Support from nursing administrators	Holly 1989, Sellin 1995, Mallik 1998, Svedberg et al. 2000, Schroeter 2000*, deWolf-Bosek 2001, Davis, Konishi & Tashiro 2003
Support from hospital administration	Holly 1989, deWolf-Bosek 2001
Higher nursing autonomy	Erlen & Sereika 1997, Jackson & Raftos 1997, Chafey et al. 1998, Hart et al. 1998, McDonald & Ahern 2000, Schroeter 2000*, Chase-Ziolek & Iris 2002, Hyland 2002*, Vallerand, Anthony & Saunders 2005
Nursing empowerment	Schauer 1995*, Schroeter 2000, Hewitt 2001
Consumer-directed approach	Watt 1997, Chafey et al. 1998, Mallik 1998

## Appendix 3. Demographic data of informants, datasets II-IV

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<b>Dataset</b>	<b>Data II</b>		<b>Data III</b>	<b>Data IV</b>	
<b>Variable</b>	<b>patients</b>	<b>nurses</b>	<b>experts</b>	<b>patients</b>	<b>nurses</b>
	<b>n = 22</b>	<b>n = 21</b>	<b>n = 25</b>	<b>n = 405</b>	<b>n = 118</b>
<b>Age in years</b>	34-90	24-57		14-86 Md 44	20-60 Md 41
<b>Gender</b>					
female	11	20		195	114
male	11	1		210	4
<b>Education</b>					
primary school	14			92	
secondary school	5			55	
vocational school	2			162	
college	1			95	
<b>Occupation</b>					
student				23	
blue-collar	5			139	
white-collar	1			186	
self-employed	1			13	
pensioner	15			44	
<b>Professional education</b>					
RN		15	4		74
RN + specialization		5	6		5
RN polytechnic		-	2		37
MNSc or student		1	9		2
PhD or student		-	4		0
<b>Work experience in nursing</b>					
min		6	2		3 months
max		27	29		39 years
Md		Md 11			Md 15 years
<b>Work experience at current clinic</b>					
min		1	1		2 months
max		26	26		34 years
			Md 12		Md 9 years
<b>Diagnosis of chronic disease</b>					
yes	14			256	
no	8			149	
<b>Hospital admissions during past 12 months</b>					
none				280	
once				75	
twice				24	
three times				9	
four to seven times				5	
more than seven times				1	
<b>Number of days in hospital</b>	2-60				
	Md 5				

## Appendix 3 2/2

<b>Dataset Variable</b>	<b>Data II patients n = 22</b>	<b>Data IV patients n = 405</b>	<b>nurses n = 118</b>
<b>Reason for hospitalization</b>			
cardiological	3		
orthopaedic	10		
gastroenterological	5		
oncological	2		
haematological	2		
nasal disorders		84	
laryngeal disorders		97	
otolaryngeal disorders		74	
combinations		59	
other		91	
<b>Current work motivation on scale from 0 to 10:</b>			
0-3			2
4-6			22
7-10			90
<b>Opinion about theoretical advocacy education during professional training:</b>			
very sufficient			2
rather sufficient			25
rather insufficient			54
very insufficient			36
<b>Perceived knowledge about patients' rights:</b>			
very good		12	11
quite good		77	65
rather poor		165	40
very poor		151	1
<b>Perceived knowledge about nurses' ethical duties:</b>			
very good		24	19
quite good		98	73
rather poor		156	24
very poor		127	1

**Appendix 4.** Pain-related background data of informants, dataset IV

<b>Variable</b>	<b>Patients n = 405</b>	<b>%</b>	<b>Nurses n = 118</b>	<b>%</b>
<b>Earlier chronic pain diagnosis</b>				
yes	79	19	13	11
no	293	72	102	86
<b>Pain intensity before intervention on scale from 0 to 10:</b>				
0-3	295	65		
4-6	51	12		
7-10	52	13		
<b>Pain intensity during intervention on scale from 0 to 10:</b>				
0-3	288	71		
4-6	59	14		
7-10	46	11		
<b>Pain intensity after intervention on scale from 0 to 10:</b>				
0-3	174	43		
4-6	148	36		
7-10	79	19		
<b>Worst pain experience on scale from 0 to 10:</b>				
0-3				
4-6			3	2
7-10			30	25
			85	72
<b>Opinion about theoretical pain care education during professional training:</b>				
very sufficient			2	1
rather sufficient			33	28
rather insufficient			61	52
very insufficient			21	18
<b>Participation in pain care education during past 24 months:</b>				
organizational education			68	58
national education			9	7
international education			0	0
not participated			52	44
<b>Perceived pain care skills:</b>				
very good			5	4
rather good			99	83
rather poor			13	11
very poor			1	<1

**Appendix 5a.** Instructions for survey measuring content validity of APPC

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2.10 2006

**Hyvä kivunhoitotyön asiantuntija**

Pyydän Teidän apuanne laatimani kyselylomakkeen sisällön suhteen. Tavoitteena on kehittää mittari, jolla kerätään aineistoa tutkimuksen, toimenpiteen tai leikkauksen aikaisen kivun hoitoon liittyvästä potilaan edunvalvonnasta. Mittari on osa Turun yliopistossa tehtävää väitöskirjaani, jonka tarkoituksena on selvittää potilaan edunvalvonnan (*nursing advocacy*) käsitettä ja prosessia sekä tutkia edunvalvonnan ja potilaiden sekä hoitajien valtaistumisen (*empowerment*) välisiä yhteyksiä.

Kyselylomake pohjautuu aikaisempien tutkimustulosten sekä potilaiden ja hoitajien yksilohaastatteluiden (n = 43) sisällönanalyysin tuottamiin kuvauksiin hoitotyön edunvalvonnasta kivunhoidon yhteydessä.

Ennen kyselylomakkeen täyttämistä tutustukaa huolella oheisiin ohjeisiin.

Kyselylomake pyydetään palauttamaan välittömästi tai viimeistään 16.10 palautuskuoressaan.

Tutkimuksen ohjaajina toimivat THT, professori Helena Leino-Kilpi; TtT, dosentti Sanna Salanterä; sekä THT, dosentti (ja professori Kuopion yliopisto) Tarja Suominen Turun yliopiston hoitotieteen laitokselta, puh xxxx.

**YHTEISTYÖSTÄ ETUKÄTEEN KIITTÄEN**

Heli Vaartio

Sh, TtM, lehtori, TtT-opiskelija

Turun yliopisto

Hoitotieteen laitos

Puh xxxx

[heli.vaartio@](mailto:heli.vaartio@utu.fi)

Turun yliopisto  
Lääketieteellinen tiedekunta  
Hoitotieteen laitos

## ARVIOINTIOHJEET

Tarkasteltavan mittarin tarkoituksena on selkeyttää potilaan edunvalvonnan käsitettä ja edunvalvontaprosessia: mitkä ovat edunvalvonnan ehdot, toteuttamistavat, sekä edunvalvonnan seuraukset. Arvioitava mittari koostuu taustatietojen kartoituksen lisäksi kolmesta eri osiosta, jotka sisältävät yhteensä 64 väittämää. Arviointitapa pohjautuu Perälän (1997) kehittämään mittarin sisällön arviointimenetelmään.

Tässä kyselyssä mittaria tarkastellaan sekä kategorioittain, osioittain että väittämittäin.

**KATEGORIA** Kategorian nimi on kirjoitettu isoilla, tummennetuilla kirjaimilla taulukon vasempaan yläreunaan.  
Esimerkiksi kategoria 1: **EDUNVALVONNAN EHDOT**

**OSIO:** Osiot ovat taulukon vasemmassa reunassa numeroituina.  
Kukin osio esimerkkeineen on erotettu muista osioista katkoviivalla.  
Esimerkiksi osio 1: **1 Potilaan roolin tiedostaminen kivun hoidossa**

Väittämä Kukin osio sisältää sen sisältöä täsmentäviä väittämiä.  
Väittämät ovat lomakkeen vasemmassa reunassa, pienin kirjaimin.  
Esimerkiksi osion 1 ensimmäinen väittämä:  
tiedän miten kipujani voidaan hoitaa

## I KATEGORIAKOHTAINEN TARKASTELU

Tarkastelkaa kutakin kategoriaa erikseen tutustumalla kategorian nimeen ja sen sisältöön osioiden ja esimerkkien avulla.

### 1. Miten hyvin tämän kategorian osiot kattavat kategorian tarkoittaman ilmiön?

- arvioikaa miten hyvin kategorian osiot (**EDUNVALVONNAN EHDOT, EDUNVALVONTA, EDUNVALVONNAN SEURAUKSET**) kattavat kategorian nimeämän ilmiön

- vastatkaa ympyröimällä mielipidettänne vastaava vaihtoehto käyttämällä viisiportaista arviointiasteikkoa: osiot kattavat kategorian nimeämän ilmiön 5 (erittäin hyvin), 4 (hyvin), 3 (tydyttävästi), 2 (välttävästi), 1 (ei ollenkaan)

### 2. Mitkä kategoriat puuttuvat mittarista?

- nimetkää ilmiöön kuuluvia kategorioita, jotka mielestänne puuttuvat mittarista

### 3. Mitkä osiot puuttuvat kategoriasta?

- nimetkää osioita, jotka mielestänne puuttuvat kategoriasta



## II OSIOKOHTAINEN TARKASTELU

Tarkastelkaa kutakin osiota erikseen (**Potilaan roolin tiedostaminen kivunhoidossa; Potilaan kivunhoitotoiveiden analysoiminen; Potilaan valtaistuminen kivunhoitoonsa** jne.). Kuhunkin osioon liittyen kyselylomakkeessa on 5 kysymystä, jotka esitellään seuraavassa yksityiskohtaisesti. Vastauksenne perustelun voitte kirjoittaa kysymysten alle (tai lomakkeen taakse, selvästi numeroituina).

### 1. Mittaako osio edunvalvontaa?

- arvioikaa, kuuluuko osion kuvaama asia potilaan edunvalvontaan
- vastatkaa ympyröimällä joko a (Kyllä ) tai b (Ei)
- jos osio ei mielestänne kuulu edunvalvontaan, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

### 2. Kuuluuko osio tähän kategoriaan?

- arvioikaa, kuuluuko osio mielestänne tarkasteltavana olevaan kategoriaan
- vastatkaa ympyröimällä joko a (Kyllä ) tai b (Ei)
- jos osio ei mielestänne kuulu tähän kategoriaan, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

### 3. Miten tärkeä osio on edunvalvonnan kannalta?

- arvioikaa miten tärkeä osion sisältämä asia on edunvalvonnassa
- vastatkaa ympyröimällä mielipidettänne vastaava vaihtoehto käyttämällä neliportaista arviointiasteikkoa: osion sisältämä asia ei ole tärkeä (1) – on tärkeä (4)
- jos osio ei mielestänne ole tärkeä edunvalvonnan kannalta, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

### 4. Mittaako joku muu osio samaa?

- arvioikaa, mittaako joku toinen osio samaa asiaa
- vastatkaa ympyröimällä joko a (Kyllä ) tai b (Ei)
- jos joku muu osio mittaa mielestänne samaa, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

### 5. Onko osio selkeä?

- arvioikaa osion yksiselitteisyyttä ja ymmärrettävyyttä
- vastatkaa ympyröimällä mielipidettänne vastaava vaihtoehto käyttämällä neliportaista arviointiasteikkoa: osion sisältämä asia ei ole selkeä (1) – on selkeä (4)
- jos osio ei mielestänne ole selkeä, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

### III VÄITTÄMÄKOHTAINEN TARKASTELU

Tarkastelkaa kutakin väittämää erikseen.

#### 1. Mittaako väittämä edunvalvontaa?

- arvioikaa, onko väittämän kuvaama asia potilaan edunvalvontaa
- vastatkaa ympyröimällä joko a (Kyllä ) tai b (Ei)
- jos väittämä ei mielestänne mittaa edunvalvontaa, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

#### 2. Kuuluuko väittämä tähän osioon?

- arvioikaa, kuuluuko väittämä mielestänne tarkasteltavana olevaan osioon
- vastatkaa ympyröimällä joko a (Kyllä ) tai b (Ei)
- jos väittämä ei mielestänne kuulu tähän osioon, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

#### 3. Miten tärkeä väittämä on osion kannalta?

- vastatkaa ympyröimällä mielipidettänne vastaava vaihtoehto käyttämällä kolmeportaista arviointiasteikkoa: väittämä on osiossa  
3 (erittäin tärkeä), 2 (melko tärkeä), 1 (tarpeeton)

#### 4. Mittako joku muu väittämä samaa asiaa?

- arvioikaa, mittaako joku toinen väittämä samaa asiaa
- vastatkaa ympyröimällä joko a (Kyllä ) tai b (Ei)
- jos joku muu väittämä mittaa mielestänne samaa, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

#### 5. Onko väittämä selkeä?

- vastatkaa ympyröimällä mielipidettänne vastaava vaihtoehto käyttämällä neliportaista arviointiasteikkoa: väittämä ei ole selkeä (1) – on selkeä (4)
- jos väittämä ei mielestänne ole selkeä, perustelkaa mielipiteenne kysymyksen alla olevaan tilaan

### IV MUITA KOMMENTTEJA

Nimetkää asioita, jotka kussakin kategoriassa, osiossa tai väittämässä ovat sisällön kannalta häiritseviä ja miten

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Hoitotieteen laitos

### VASTAAJAN TAUSTA

Seuraavassa muutamia asiantuntija-asemaanne liittyviä kysymyksiä. Olkaa hyvä ja vastatkaa ympyröimällä mielestänne sopivin vaihtoehto tai kirjoittamalla vastauksenne viivalle.

1. Mikä on koulutuksenne?
  - a. sairaanhoitaja (opistoasteen koulutus)
  - b. sairaanhoitaja (ammattikorkeakoulu)
  - c. erikoissairanhoitaja
  - d. bioanalytikko
  - e. röntgenhoitaja
  - f. terveystieteiden maisteri – opiskelija
  - g. terveystieteiden maisteri
  - h. muu, mikä?
  
2. Mikä on työkokemuksenne käytännön hoitotyössä ammattitutkinnon suorittamisen jälkeen
 

erikoisala-----	työkokemus vuosina-----	tai	-----kk
erikoisala-----	työkokemus vuosina-----	tai	-----kk
erikoisala-----	työkokemus vuosina-----	tai	-----kk
erikoisala-----	työkokemus vuosina-----	tai	-----kk
  
3. Mikä on nykyinen työpaikkanne?
  - a) sisätautien klinikka
  - b) kirurgian klinikka
  - c) synnytys- ja naistentautien klinikka
  - d) lastentautien klinikka
  - e) muu, mikä
  
4. Mikä on työkokemuksenne nykyisellä klinikalla?
 

----- vuotta tai ----- kk
  
5. Mistä olette saanut pääasialliset tietonne hoitotyön edunvalvonnasta (engl. *nursing advocacy*)?
  - a) hoitoalan peruskoulutuksesta
  - b) hoitoalan erikoistumiskoulutuksesta
  - c) hoitotyön etiikan koulutuksesta
  - Järjestäjä:-----
  - d) itseopiskelun kautta (tutustumalla kirjallisuuteen, Internet)
  - e) työkokemuksen kautta (muiden hoitajien toimintaa tarkkailemalla)
  - f) hoitotieteen koulutuksesta
  - g) muualta, mistä -----
  - h) en mistään

Turun yliopisto  
Lääketieteellinen tiedekunta  
Hoitotieteen laitos

6. Mistä olette saanut pääasialliset tietonne kivunhoidosta?

- a) hoitoalan peruskoulutuksesta
- b) hoitoalan erikoistumiskoulutuksesta
- c) hoitotyön etiikan erilliskoulutuksesta  
Järjestäjä -----
- d) itseopiskelun kautta (tutustumalla kirjallisuuteen, Internet)
- e) työkokemuksen kautta (muiden hoitajien toimintaa tarkkailemalla)
- f) hoitotieteen koulutuksesta
- g) muualta, mistä -----
- h) en mistään

7. Millaisia kokemuksia Teillä on potilaan edunvalvonnasta?

---

---

---

8. Millaisena pidätte omaa asiantuntemustanne potilaan edunvalvonnasta?

- a) heikko asiantuntemus
- b) melko heikko asiantuntemus
- c) keskimääräinen asiantuntemus
- d) melko hyvä asiantuntemus
- e) erittäin hyvä asiantuntemus

Perustelut:-----

9. Millaisena pidätte omaa asiantuntemustanne kivunhoidosta?

- a) heikko asiantuntemus
- b) melko heikko asiantuntemus
- c) keskimääräinen asiantuntemus
- d) melko hyvä asiantuntemus
- e) erittäin hyvä asiantuntemus

Perustelut:-----

## Appendix 5b. Instrument measuring content validity of APPC

1/5

Turun yliopisto, hoitotieteen laitos

Potilaan edunvalvontaa kivun hoitotyössä/Advocacy within Procedural Pain Care (APPC) -mittarin sisältövaliditeetin testaus. © Heli Vaarrio 2006

Olkaa hyvä ja vastatkaa kullakin rivillä sen yläpuolella oleviin kysymyksiin ympyröimällä mielestänne sopivin vaihtoehto.

KATEGORIA:

**EDUNVALVONNAN EHDOT**

huom: potilaat vastaavat osioihin 1-3  
hoitajat vastaavat osioihin 4-6

**OSIO**

	1 Mittaako osio edunvalvonnan ehtoa a) kyllä b) ei	2 Kuuluuko osio tähän sisältöluokkaan? a) kyllä b) ei	3 Miten tärkeä osio on? ei tärkeä 1 erittäin tärkeä 4	4 Mittaako joku muu osio samaa? a) kyllä b) ei	5 Miten selkeä osio on? ei selkeä 1 selkeä 4
<b>1 Potilaan roolin tiedostaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4
<b>2 Potilaan oikeuksien tiedostaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4
<b>3 Potilas-hoitajasuhteen tiedostaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4
<b>4 Hoitajan ammatillisen roolin tiedostaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4
<b>5 Hoitajan eettisten velvollisuuksien tiedostaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4
<b>6 Hoitaja-potilassuhteen tiedostaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4

**Osiot ja väittämät:**

huom: potilaat vastaavat väittämiin 1-12  
hoitajat vastaavat väittämiin 13-24

**1 Mittaako väittämä**

kyseistä osiota  
a) kyllä b) ei

**4 Mittaako joku**

muu väittämä samaa?  
a) kyllä b) ei

**5 Miten selkeä**

väittämä on?  
ei selkeä 1  
selkeä 4

**Potilaan roolin tiedostaminen kivunhoidossa**

1 tiedän miten kipujani voidaan hoitaa.	a	a	1 2 3 4	a	1 2 3 4
2 tiedän voivani itse vaikuttaa kivunhoitooni	a	a	1 2 3 4	a	1 2 3 4
3 tiedän voivani osallistua kivunhoitoani koskeviin päätöksiin	a	a	1 2 3 4	a	1 2 3 4
4 tiedän miten voin itse hoitaa kipujani	a	a	1 2 3 4	a	1 2 3 4

**Potilaan oikeuksien tiedostaminen kivunhoidossa**

5 tiedän oikeuteni kivunhoidossa	a	a	1 2 3 4	a	1 2 3 4
6 ymmärrän oikeuteni kivunhoidossa	a	a	1 2 3 4	a	1 2 3 4
7 tiedän hoitajan voivan toimia etujeni valvojana kivunhoidossa	a	a	1 2 3 4	a	1 2 3 4
8 tiedän miten voin osallistua kivunhoitoani koskeviin päätöksiin	a	a	1 2 3 4	a	1 2 3 4

**Potilas-hoitajasuhteen tiedostaminen kivunhoidossa**

9 koen voivani kysyä kivunhoidostani hoitajalta	a	a	1 2 3 4	a	1 2 3 4
10 koen voivani kertoa kivunhoitoa koskevat toiveeni hoitajalle	a	a	1 2 3 4	a	1 2 3 4
11 koen voivani luottaa hoitajaan kivunhoidossani	a	a	1 2 3 4	a	1 2 3 4
12 koen että hoitaja toimii etujeni valvojana kivunhoidossani	a	a	1 2 3 4	a	1 2 3 4

Turun yliopisto, hoitotieteen laitos  
 Potilaan edunvalvontia kivun hoito-työssä / Advocacy within Procedural Pain Care (APPC) -mittarin sisältövalitieditein testaus. ©Heli Vaartio 2006

### Ostot ja väittämät:

uom: potilaat vastaavat väittämiin 1-12  
 hoitajat vastaavat väittämiin 13-24

#### **Hoitajan ammatillisen roolin tiedostaminen kivunhoidossa**

	1 Mittaako väittäjä kyseistä osiota a) kyllä b) ei	2 Kuuluuko väittäjä tähän sisältöluokkaan? a) kyllä b) ei	3 Miten tärkeä väittäjä on? ei tärkeä 1 erittäin tärkeä 4	4 Mittaako joku muu väittämä samaa? a) kyllä b) ei	5 Miten selkeä väittäjä on? ei selkeä 1 selkeä 4
13 tiedän, miten potilaan kipuja voidaan hoitaa	a	a	1 2 3 4	a	1 2 3 4
14 tiedän voivani vaikuttaa potilaan kivunhoitoon	a	a	1 2 3 4	a	1 2 3 4
15 tiedän voivani toimia potilaan edunvalvojana kivunhoitoon liittyvissä päätöksissä	a	a	1 2 3 4	a	1 2 3 4
16 tiedän miten voin tukea potilasta itse hoitamaan kipujaan	a	a	1 2 3 4	a	1 2 3 4

#### **Hoitajan eettisten velvollisuuksien tiedostaminen kivunhoidossa**

17 tiedän eettiset velvollisuuteni potilaan kivunhoidossa	a	a	1 2 3 4	a	1 2 3 4
18 ymmärrän eettiset velvollisuuteni potilaan kivunhoidossa	a	a	1 2 3 4	a	1 2 3 4
19 tiedän velvollisuuteni osallistua potilaan kivunhoitoa koskeviin päätöksiin	a	a	1 2 3 4	a	1 2 3 4
20 tiedän miten voin osallistua potilaan kivunhoitoa koskeviin päätöksiin	a	a	1 2 3 4	a	1 2 3 4

#### **Hoitaja-potilaassuhteen tiedostaminen kivunhoidossa**

21 koen voivani vastata potilaan kysymyksiin hänen kivunhoidostaan	a	a	1 2 3 4	a	1 2 3 4
22 koen ymmärtäväni potilaan yksilölliset kivunhoitotoiveet	a	a	1 2 3 4	a	1 2 3 4
23 koen potilaan luottavan minuun kivunhoidossaan	a	a	1 2 3 4	a	1 2 3 4
24 koen että potilas odottaa minun toimivan hänen etujensa valvojana kivunhoidossa	a	a	1 2 3 4	a	1 2 3 4

#### **KATEGORIA: EDUNVALVONTA TOIMINTA**

	1 Mittaako osio edunvalvontaa a) kyllä b) ei	2 Kuuluuko osio tähän sisältöluokkaan? a) kyllä b) ei	3 Miten tärkeä osio on? ei tärkeä 1 erittäin tärkeä 4	4 Mittaako joku muu osio samaa? a) kyllä b) ei	5 Miten selkeä osio on? ei selkeä 1 selkeä 4
<b>Potilaan kivunhoitotoiveiden analysoiminen</b>	a	a	1 2 3 4	a	1 2 3 4
<b>Potilaan itsenäisyyttä koskevien toiveiden analysoiminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4
<b>Potilaan ohjaaminen kivunhoitoonsa liittyen</b>	a	a	1 2 3 4	a	1 2 3 4
<b>Potilaan toiveiden välittäminen muille kivunhoitoon osallistuville</b>	a	a	1 2 3 4	a	1 2 3 4
<b>Potilaan kivunhoitotoiveisiin vastaaminen</b>	a	a	1 2 3 4	a	1 2 3 4
<b>Potilaan itsenäisyyttä koskevien toiveiden vastaaminen kivunhoidossa</b>	a	a	1 2 3 4	a	1 2 3 4

Osiot ja väittämät:**Potilaan kivunhoito-ohjeiden analysoiminen**

	1 Mittaako väittämiä kyseistä osiota? a) kyllä b) ei	2 Kuuluuko väittämä tähän sisältöluokkaan a) kyllä b) ei	3 Miten tärkeä väittämä on? ei tärkeä 1 erittäin tärkeä 4	4 Mittaako joku muu väittämiä samaa? a) kyllä b) ei	5 Miten selkeä väittämä on? ei selkeä 1 selkeä 4
1 hoitaja kysyy potilaan kivunhoitoa koskevia toiveita	a b	a b	1 2 3 4	a b	1 2 3 4
2 hoitaja kysyy potilaan toiveita kivun hoitomenetelmien suhteen	a b	a b	1 2 3 4	a b	1 2 3 4
3 hoitaja kysyy potilaan arviota kipunsa voimakkuudesta	a b	a b	1 2 3 4	a b	1 2 3 4
4 hoitaja kysyy potilaan arviota kivun hoidon riittävyydestä	a b	a b	1 2 3 4	a b	1 2 3 4

**Potilaan itsemääräämisoikeuteen liittyvien toiveiden analysoiminen kivunhoidossa**

5 hoitaja kysyy haluaako potilas osallistua päätöksentekoon kivunhoidossaan	a b	a b	1 2 3 4	a b	1 2 3 4
6 hoitaja kysyy haluaako potilas osallistua kivunhoitoonsa	a b	a b	1 2 3 4	a b	1 2 3 4
7 hoitaja kysyy miten potilas haluaa osallistua päätöksentekoon kivunhoidossaan	a b	a b	1 2 3 4	a b	1 2 3 4
8 hoitaja kysyy miten potilas haluaa osallistua kivunhoitoonsa	a b	a b	1 2 3 4	a b	1 2 3 4

**Potilaan ohjaaminen kivunhoitoonsa liittyen**

9 hoitaja ohjaa potilasta ilmaisemaan kivunhoitoa koskevia toiveitansa	a b	a b	1 2 3 4	a b	1 2 3 4
10 hoitaja ohjaa potilasta valitsemaan mieleisensä kivun hoitomenetelmän	a b	a b	1 2 3 4	a b	1 2 3 4
11 hoitaja ohjaa potilasta arvioimaan itse kipunsa voimakkuutta	a b	a b	1 2 3 4	a b	1 2 3 4
12 hoitaja ohjaa potilasta arvioimaan itse kivunhoitoonsa riittävyyttä	a b	a b	1 2 3 4	a b	1 2 3 4

**Potilaan toiveiden välittäminen muille kivunhoitoon osallistuville**

13 hoitaja kertoo potilaan yleisistä kivunhoitotoiveista muille hoitoon osallistuville	a b	a b	1 2 3 4	a b	1 2 3 4
14 hoitaja kertoo potilaan kivunhoitomenetelmiä koskevat toiveet muille hoitoon osallistuville	a b	a b	1 2 3 4	a b	1 2 3 4
15 hoitaja kertoo potilaan halakkuudesta osallistua päätöksentekoon muille kivunhoitoon osallistuville	a b	a b	1 2 3 4	a b	1 2 3 4
16 hoitaja kertoo potilaan halakkuudesta osallistua kivunhoitoonsa muille kivunhoitoon osallistuville	a b	a b	1 2 3 4	a b	1 2 3 4





Turun yliopisto, hoitotieteen laitos  
Potilaan edunvalvontia kivun hoitotyössä/APPC-mittarin sisältövalitettiin testaus. ©Hei Vaarrio 2006

Osiot ja väittämät:	1 Mittaako väittä- mä kyseistä osiota? a) kyllä b) ei	2 Kuuluuko väittä- mä tähän sisälty- luokkaan? a) kyllä b) ei	3 Miten tärkeä väittä- mä on? ei tärkeä 1 erittäin tärkeä 4	4 Mittaako joku muu väittä- mä samaa? a) kyllä b) ei	5 Miten selkeä väittä- mä on? ei selkeä 1 selkeä 4
<b>Potilaan valtaistuminen kivunhoitoonsa</b>					
1 koen voivani vaikuttaa kivunhoitooni	a	b	1 2 3 4	a	1 2 3 4
2 koen saavani hyvää kivunhoitoa	a	b	1 2 3 4	a	1 2 3 4
3 koen voivani hällutessani itsekin hoitaa kipujani	a	b	1 2 3 4	a	1 2 3 4
4 koen hallitsevani kivunhoitoani	a	b	1 2 3 4	a	1 2 3 4
<b>Potilaan itsemääräämisoikeudellinen valtaistuminen</b>					
5 koen osallistuvani hoitoani koskevaan päätöksentekoon	a	b	1 2 3 4	a	1 2 3 4
6 koen olevani itsenäinen, vaikka tarvitsen hoitajien apua	a	b	1 2 3 4	a	1 2 3 4
7 koen voivani itse vaikuttaa terveytykseeni	a	b	1 2 3 4	a	1 2 3 4
8 koen voivani vaikuttaa hoitooni	a	b	1 2 3 4	a	1 2 3 4
9 koen että asioitini puuttuaan	a	b	1 2 3 4	a	1 2 3 4
<b>Hoitajan ammatillinen valtaistuminen kivunhoitossa</b>					
10 koen roolini kivunhoitossa selkeäksi	a	b	1 2 3 4	a	1 2 3 4
11 koen ammattitaitoni kivunhoitossa hyväksi	a	b	1 2 3 4	a	1 2 3 4
12 koen että yhteistyö lääkärin kanssa toimii kivunhoitossa hyvin	a	b	1 2 3 4	a	1 2 3 4
13 koen että yhteistyö osastojen välillä kivunhoitossa toimii hyvin	a	b	1 2 3 4	a	1 2 3 4
14 koen ettei minulla ole sananvaltaa potilaan kivunhoitossa	a	b	1 2 3 4	a	1 2 3 4
<b>Hoitajan yksilöllinen valtaistuminen</b>					
15 koen potilaan luottavan minuun kivunhoitossaan	a	b	1 2 3 4	a	1 2 3 4
16 koen onnistuneen työssäni	a	b	1 2 3 4	a	1 2 3 4
17 koen työmotivaationi kasvavan	a	b	1 2 3 4	a	1 2 3 4
18 koen saavani toimmassani positiivista palautetta työtovereiltani	a	b	1 2 3 4	a	1 2 3 4
19 koen että potilas odottaa minulta liikaa hoitajana	a	b	1 2 3 4	a	1 2 3 4

Kiitoksia osallistumisestanne!

**Appendix 6a.** APPC for patients

6a 1/6

Hyvä vastaaja

Selvitän potilaiden kokemuksia kivun hoidosta. Tutkimuksen tarkoituksena on selvittää mitä tarkoittaa hoitotyön edunvalvonta ja miten se tapahtuu käytännön hoitotyössä. Edunvalvojuudella tarkoitetaan potilaiden hyvinvoinnin edistämistä ja heidän etujensa turvaamista.

**Pyydän Teitä kohteliaimmin osallistumaan kyseiseen tutkimukseen** ennen kotiutumistanne. Jokaiselta tutkimukseen valitulta osastolta valitaan 1.2 - 31.3 2007 aikana ensimmäiset 40 potilasta. Tutkimusaineisto kerätään kyselylomakkeiden avulla. Lomakkeen täyttäminen kestää noin 20 minuuttia.

Aineistonkeruulle on myönnetty asianmukaiset tutkimusluvut. Tutkimukseen osallistuminen on täysin vapaaehtoista eikä siihen suostuminen tai siitä kieltäytyminen vaikuta mitenkään hoitoon. Henkilöllisyytenne ei tule missään vaiheessa tutkimusta ilmi. Mikäli ette halua osallistua tutkimukseen, pyydän Teitä ilmoittamaan siitä hoitajalle. Mikäli päätätte vastata kyselylomakkeeseen, pyydän Teitä sulkemaan sen sitten oheiseen kirjekuoreen ja antamaan hoitajalle ennen kotiin lähtöänne

Tämä hoitotieteen väitöskirjaan tähtäävän tutkimuksen ohjaajina toimivat THT, professori Helena Leino-Kilpi ja THT, dosentti (ja professori Kuopion yliopisto) Tarja Suominen sekä TtT, yliassistentti Sanna Salanterä; Turun yliopiston hoitotieteen laitokselta, puh xxx.

Tutkimuksen oletetaan valmistuvan vuonna 2008 minkä jälkeen se on luettavissa Turun yliopiston hoitotieteen laitoksen julkaisusarjassa.

**KIITOS OSALLISTUMISESTANNE**

Tutkija:

Heli Vaartio

Sh, TtM, lehtori, TtT-opiskelija

Turun yliopisto

Puh xxx

[heli.vaartio@](mailto:heli.vaartio@utu.fi)

Arvoisa vastaaja

ID:

Tämän kyselylomakkeen tarkoituksena on kerätä tietoa siitä, mitä potilaan edunvalvonta on ja miten se toteutuu kivunhoidon yhteydessä. Edunvalvonnalla tarkoitetaan tässä kaikkea sitä toimintaa, jonka avulla hoitajat ajavat potilaiden etuja. Kivunhoito puolestaan tarkoittaa tässä yhteydessä Teidän kokemanne tutkimuksiin, toimenpiteisiin ja leikkauksiin liittyvän kivun ennaltaehkäisyä ja hoitoa.

### A. Taustatiedot

Olkaa hyvä ja rastittakaa sopiva vaihtoehto tai kirjoittakaa vastauksenne sille varattuun tilaan

1 Sukupuoli: Nainen

Mies

2 Ikä: \_\_\_\_\_

3a) Koulutus:

kansakoulu/oppikoulu/peruskoulu

lukio

kouluasteen ammattitutkinto

opistoasteen ammattitutkinto

yliopistokoulutus

3b) ammatti: \_\_\_\_\_

3c) jos olette eläkkeellä, mikä oli ammattinne ennen eläkkeelle jäämistä: \_\_\_\_\_

4 Onko Teillä jokin pitkäaikainen sairaus, mikä? \_\_\_\_\_

5 Kärsittekö kroonisesta (yli 6 kk) kivusta?

kyllä

en

6 Kuinka monta kertaa olette olleet sairaalahoitossa viimeisen vuoden aikana?

en ollenkaan

1-5 kertaa

6-10 kertaa

yli 10 kertaa

7 Tämänkertaisen sairaalahoiton syy:

nenäverenvuodon tyrehdyttäminen

korvan mikroskooppitutkimus

nenän, nenänielun tai sivuonteloiden tähyystys

tärykalvoputken asennus

nenän sivuonteloiden paiseen avaus

tärykalvon paikkausleikkaus

poskiontelopunktio

välikorvan kolesteatooma

rinometria tai rinomanometria

korvan epämuodostuman korjaus

nenän polyypin tai kystan poisto

kuulonparannusleikkaus

nenän epämuodostuman korjaus

sisäkorvaproteesin asennus	<input type="checkbox"/>
nenämurtuman korjaus	<input type="checkbox"/>
korva-sylkirauhaskasvaimen poisto	<input type="checkbox"/>
nenän/nenänielun kasvaimen poisto	<input type="checkbox"/>
korvalehden/korvakäytävän kasvaimen poisto	<input type="checkbox"/>
korvalehden/korvakäytävän paiseen avaus	<input type="checkbox"/>
kita- tai nielurisojen poisto	<input type="checkbox"/>
kurkkupaiseen avaus	<input type="checkbox"/>
kuorsausleikkaus	<input type="checkbox"/>
henkitorven tähyystys	<input type="checkbox"/>
henkitorven kasvaimen poisto	<input type="checkbox"/>
kurkunpään kasvaimen poisto	<input type="checkbox"/>
muu, mikä?	<input type="checkbox"/> -----

8 Kuinka kovaa kipua koitte a) **ennen** tutkimusta, toimenpidettä tai leikkausta?

Arvioikaa kokemaanne kipua asteikolla 0-10 (0 = ei lainkaan kipua, 10 = sietämätöntä kipua).

Mikä se oli pahimmillaan? \_\_\_\_\_ (0-10)

9 Kuinka kovaa kipua koitte b) tutkimuksen, toimenpiteen tai leikkauksen **aikana**?

Arvioikaa kokemaanne kipua asteikolla 0-10 (0 = ei lainkaan kipua, 10 = sietämätöntä kipua).

Mikä se oli pahimmillaan? \_\_\_\_\_ (0-10)

10 Kuinka kovaa kipua koitte c) tutkimuksen, toimenpiteen tai leikkauksen **jälkeen**?

Arvioikaa kokemaanne kipua asteikolla 0-10.

Mikä se oli pahimmillaan? \_\_\_\_\_ (0-10)

11 Miten hyvin tiedätte, mitkä ovat potilaan oikeudet Laki Potilaan Oikeuksista (1992) mukaan?

Erittäin hyvin	<input type="checkbox"/>
Melko hyvin	<input type="checkbox"/>
Melko huonosti	<input type="checkbox"/>
Erittäin huonosti	<input type="checkbox"/>

12 Miten hyvin tiedätte, mitkä ovat Hoitajan Eettiset Velvollisuudet?

Erittäin hyvin	<input type="checkbox"/>
Melko hyvin	<input type="checkbox"/>
Melko huonosti	<input type="checkbox"/>
Erittäin huonosti	<input type="checkbox"/>

## B. Edunvalvonta

Appendix 6a 4/6

Seuraavaksi Teiltä kysytään näkemystänne siitä, **mitä edunvalvonta kivunhoidossa tarkoittaa**. Tämän jälkeen Teitä pyydetään arvioimaan, miten edunvalvonta mielestänne on toteutunut Teidän kivunhoidossanne tällä hoitajaksolla. **Ympyröikää** kunkin edunvalvontaa kuvaavan väittämän kohdalla mielestänne sopivinta vaihtoehtoa edustava numero **ja rastittakaa lisäksi** oikealla sopivin vaihtoehto.

Olen väittämän suhteen

Tämä on toteutunut  
hoidossani

	täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä	Potilaan edunvalvonta kivunhoidossa tarkoittaa että:	kyllä	ei, vaikka olisi ollut tarvetta	ei, ei ole ollut tarvetta	en tiedä
5	4	3	2	1	1. hoitaja kysyy potilaan kivunhoitoa koskevia toiveita					
5	4	3	2	1	2. hoitaja kysyy potilaan toiveita kivun hoitomenetelmien suhteen					
5	4	3	2	1	3. hoitaja kysyy potilaan arviota kipunsa voimakkuudesta					
5	4	3	2	1	4. hoitaja kysyy potilaan arviota kivun hoidon riittävydestä					
5	4	3	2	1	5. hoitaja kysyy haluaako potilas osallistua päätöksentekoon kivunhoidossaan					
5	4	3	2	1	6. hoitaja kysyy haluaako potilas osallistua kivunhoitoonsa					
5	4	3	2	1	7. hoitaja kysyy miten potilas haluaa osallistua päätöksentekoon kivunhoidossaan					
5	4	3	2	1	8. hoitaja kysyy miten potilas haluaa osallistua kivunhoitoonsa					
5	4	3	2	1	9. hoitaja ohjaa potilasta ilmaisemaan kivunhoitoa koskevia toiveitansa					
5	4	3	2	1	10. hoitaja ohjaa potilasta valitsemaan mieleisensä kivun hoitomenetelmän					
5	4	3	2	1	11. hoitaja ohjaa potilasta arvioimaan itse kipunsa voimakkuutta					
5	4	3	2	1	12. hoitaja ohjaa potilasta arvioimaan itse kivunhoitonsa riittävyttä					
5	4	3	2	1	13. hoitaja kertoo potilaan yleisistä kivunhoitotoiveista muille hoitoon osallistuville					
5	4	3	2	1	14. hoitaja kertoo potilaan kivunhoitomenetelmiä koskevat toiveet muille hoitoon osallistuville					
5	4	3	2	1	15. hoitaja kertoo potilaan halukkuudesta osallistua päätöksentekoon muille kivunhoitoon osallistuville					

## Olen väittämän suhteen

Tämä on toteutunut  
hoidossani

täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä	Edunvalvonta kivunhoidossa tarkoittaa että:	kyllä	ei, vaikka olisi ollut tarvetta	ei, ei ole ollut tarvetta	en tiedä
5	4	3	2	1	16. hoitaja kertoo potilaan halukkuudesta osallistua kivunhoitoonsa muille kivunhoitoon osallistuville				
5	4	3	2	1	17. hoitaja valvoo, että potilaan kipua hoidetaan potilaan toiveiden mukaan				
5	4	3	2	1	18. hoitaja valvoo, että potilaan kivunhoitomenetelmät ovat potilaalle sopivia				
5	4	3	2	1	19. hoitaja valvoo, että potilaan kivun voimakkuutta arvioidaan				
5	4	3	2	1	20. hoitaja valvoo, että potilaan kivun hoidon riittävyys arvioidaan				
5	4	3	2	1	21. hoitaja valvoo, että potilas voi osallistua kivunhoitoaan koskevaan päätöksentekoon toiveidensa mukaan				
5	4	3	2	1	22. hoitaja valvoo, että potilas voi osallistua kivunhoitoonsa toiveidensa mukaan				
5	4	3	2	1	23. hoitaja valvoo, että potilaan toiveita kunnioitetaan				
5	4	3	2	1	24. hoitaja valvoo, että potilaan oikeuksia kunnioitetaan				

## C. Edunvalvonnan ehdot

Seuraavaksi Teitä pyydetään arvioimaan, **mitä tarvitaan jotta edunvalvonta voisi toteutua**. Olkaa hyvä ja ympyröikää kutakin edunvalvontaa kuvaavaa väittämää kohden mielestänne sopivinta vaihtoehtoa edustava numero.

## Olen väittämän suhteen

Jotta edunvalvonta voisi toteutua, on seuraavien asioiden toteuduttava:	täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä
1. tiedän miten kipujani voidaan hoitaa	5	4	3	2	1
2. tiedän voivani itse vaikuttaa kivunhoitooni	5	4	3	2	1
3. tiedän voivani osallistua kivunhoitoani koskeviin päätöksiin	5	4	3	2	1
4. tiedän miten voin itse hoitaa kipujani	5	4	3	2	1
5. tiedän oikeuteni kivunhoidossa	5	4	3	2	1
6. ymmärrän oikeuteni kivunhoidossa	5	4	3	2	1
7. tiedän hoitajan voivan toimia etujeni valvojana kivunhoidossa	5	4	3	2	1

## Olen väittämän suhteen

Jotta edunvalvonta voisi toteutua, on seuraavien asioiden toteuduttava:	täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä
8. tiedän miten voin osallistua kivunhoitoani koskeviin päätöksiin	5	4	3	2	1
9. koen voivani kysyä kivunhoidostani hoitajalta	5	4	3	2	1
10. koen voivani kertoa kivunhoitoa koskevat toiveeni hoitajalle	5	4	3	2	1
11. koen voivani luottaa hoitajaan kivunhoidossani	5	4	3	2	1
12. koen että hoitaja toimii etujeni valvojana kivunhoidossani	5	4	3	2	1

## D. Edunvalvonnan seuraukset

Seuraavaksi Teitä pyydetään arvioimaan, **mitä seurauksia edunvalvonnalla on**. Olkaa hyvä ja ympyröikää kutakin edunvalvontaa kuvaavaa väittämää kohden mielestänne sopivinta vaihtoehtoa edustava numero.

## Olen väittämän suhteen

Mikäli edunvalvonta kivunhoidossa toteutuu, niin:	täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä
1. koen voivani vaikuttaa kivunhoitooni	5	4	3	2	1
2. koen saavani hyvää kivunhoitoa	5	4	3	2	1
3. koen voivani halutessani itsekin hoitaa kipujani	5	4	3	2	1
4. koen hallitsevani kivunhoitoani	5	4	3	2	1
5. koen osallistuvani hoitoani koskevaan päätöksentekoon	5	4	3	2	1
6. koen olevani itsenäinen, vaikka tarvitsen hoitajien apua	5	4	3	2	1
7. koen voivani itse vaikuttaa tervehtymiseeni	5	4	3	2	1
8. koen voivani vaikuttaa hoitooni	5	4	3	2	1
9. koen että asioihini puututaan	5	4	3	2	1

Arvoisa sairaanhoitaja

Selvitän sairaanhoitajien näkemyksiä **hoitotyön edunvalvonnasta kivun hoitotyöhön liittyen**. Tutkimuksen tarkoituksena on selvittää edunvalvojuuden käsitettä ja prosessia. Kyseessä on monivaiheinen tutkimus. Aluksi selvitettiin kivun hoitotyön edunvalvonnan sisältöä ja laadittiin kivun hoitotyön edunvalvontaan liittyvä kyselylomake, jolla selvitetään kivun hoitotyön edunvalvojuuden ydintekijöitä ja toteutumista. Lopuksi kehitetään kivun hoitotyön edunvalvontaa selittävä teoreettinen malli.

Tutkimuksen kolmannen vaiheen aineisto kerätään kyselylomakkeella. Jokaisen tutkimukseen valitun osaston **kaikkia sairaanhoitajia** pyydetään täyttämään oheinen kyselylomake. **Pyydän Teitä kohteliaimmin osallistumaan kyseiseen tutkimukseen**. Lomakkeen täyttäminen kestää noin 20 minuuttia.

Aineistonkeruulle on myönnetty asianmukaiset tutkimusluvut. Tutkimukseen osallistuminen on täysin vapaaehtoista, eikä Teidän henkilöllisyytenne tule missään vaiheessa tutkimusta ilmi.

Täytetty kyselylomake pyydetään jättämään oheisessa kirjekuoressa kansliaan. Tavoitteena on saada aineisto kokoon 31.5.2007 mennessä.

Tämän hoitotieteen väitöskirjaan tähtäävän tutkimuksen ohjaajina toimivat THT, professori Helena Leino-Kilpi ja THT, dosentti (ja professori Kuopion yliopisto) Tarja Suominen sekä TtT, yliassistentti Sanna Salanterä; Turun yliopiston hoitotieteen laitokselta, puh xxx.

Tutkimuksen oletetaan valmistuvan vuonna 2008 minkä jälkeen se on luettavissa Turun yliopiston hoitotieteen laitoksen julkaisusarjassa.

#### KIITOS OSALLISTUMISESTANNE

Tutkija:

Heli Vaartio

Sh, TtM, lehtori, TtT-opiskelija

Turun yliopisto

Hoitotieteen laitos

Puh xxx

[heli.vaartio@](mailto:heli.vaartio@utu.fi)





8 Miten arvioitte kivunhoitotaitojanne tällä hetkellä?

- |                          |                          |
|--------------------------|--------------------------|
| 1 Erittäin hyvät taidot  | <input type="checkbox"/> |
| 2 Melko hyvät taidot     | <input type="checkbox"/> |
| 3 Melko huonot taidot    | <input type="checkbox"/> |
| 4 Erittäin huonot taidot | <input type="checkbox"/> |

9 Oletteko osallistunut kivunhoitokoulutukseen kahden viimeisen vuoden aikana:

- |   |                          |
|---|--------------------------|
| 1 organisaation sisäiseen koulutukseen, kyllä | <input type="checkbox"/> |
| 2 kansalliseen koulutustapahtumaan, kyllä     | <input type="checkbox"/> |
| 3 ulkomailla, kyllä                           | <input type="checkbox"/> |
| 4 en ole osallistunut                         | <input type="checkbox"/> |

10 Miten arvioitte keskimäärin vaikutusmahdollisuutenne hoitajana potilaan kivunhoidossa asteikolla 0-10? \_\_\_\_\_

0 = erittäin vähäiset vaikutusmahdollisuudet, 10 = erittäin hyvät vaikutusmahdollisuudet

11 Oletteko kärsineet kroonisesta (yli 6 kk) kivusta

- |                                  |                                  |
|----------------------------------|----------------------------------|
| a) aikaisemmin?                  | b) tällä hetkellä                |
| 1 kyllä <input type="checkbox"/> | 1 kyllä <input type="checkbox"/> |
| 2 en <input type="checkbox"/>    | 2 en <input type="checkbox"/>    |

12 Arvioikaa pahinta elämässänne kokemaanne kipua numeroilla 0-10 (0 = ei yhtään kipua, 10 = sietämätön kipu). Millä tasolla kipunne on ollut? \_\_\_\_\_

13 Miten hyvin tiedätte, mitkä ovat potilaan oikeudet Laki Potilaan Oikeuksista (1992) mukaan?

- |                     |                          |
|---------------------|--------------------------|
| 1 Erittäin hyvin    | <input type="checkbox"/> |
| 2 Melko hyvin       | <input type="checkbox"/> |
| 3 Melko huonosti    | <input type="checkbox"/> |
| 4 Erittäin huonosti | <input type="checkbox"/> |

14 Miten hyvin tiedätte, mitkä ovat Hoitajan Eettiset Velvollisuudet?

- |                     |                          |
|---------------------|--------------------------|
| 1 Erittäin hyvin    | <input type="checkbox"/> |
| 2 Melko hyvin       | <input type="checkbox"/> |
| 3 Melko huonosti    | <input type="checkbox"/> |
| 4 Erittäin huonosti | <input type="checkbox"/> |

## B. Edunvalvonta

Appendix 6b 4/6

Seuraavaksi Teiltä kysytään näkemystänne siitä, **mitä edunvalvonta kivunhoidossa tarkoittaa**. Lisäksi Teitä pyydetään arvioimaan, **miten edunvalvonta mielestänne on toteutunut** Teidän työssänne tällä osastolla.

**Ympyröikää** vasemmalla kunkin edunvalvontaa kuvaavan väittämän kohdalla mielestänne sopivinta vaihtoehtoa edustava numero **ja rastittakaa lisäksi** oikealla sopivin vaihtoehto.

Olen väittämän suhteen					Tämä on toteutunut työssäni tällä osastolla				
täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä					
					<b>Potilaan edunvalvonta kivunhoidossa tarkoittaa että:</b>				
5	4	3	2	1	1. hoitaja kysyy potilaan kivunhoitoa koskevia toiveita				
5	4	3	2	1	2. hoitaja kysyy potilaan toiveita kivun hoitomenetelmien suhteen				
5	4	3	2	1	3. hoitaja kysyy potilaan arviota kipunsa voimakkuudesta				
5	4	3	2	1	4. hoitaja kysyy potilaan arviota kivun hoidon riittävydestä				
5	4	3	2	1	5. hoitaja kysyy, haluaako potilas osallistua päätöksentekoon kivunhoidossaan				
5	4	3	2	1	6. hoitaja kysyy, haluaako potilas osallistua kivunhoitoonsa				
5	4	3	2	1	7. hoitaja kysyy, miten potilas haluaa osallistua päätöksentekoon kivunhoidossaan				
5	4	3	2	1	8. hoitaja kysyy, miten potilas haluaa osallistua kivunhoitoonsa				
5	4	3	2	1	9. hoitaja ohjaa potilasta ilmaisemaan kivunhoitoa koskevia toiveitansa				
5	4	3	2	1	10. hoitaja ohjaa potilasta valitsemaan mieleisensä kivun hoitomenetelmän				
5	4	3	2	1	11. hoitaja ohjaa potilasta arvioimaan itse kipunsa voimakkuutta				
5	4	3	2	1	12. hoitaja ohjaa potilasta arvioimaan itse kivunhoitonsa riittävyttä				
5	4	3	2	1	13. hoitaja kertoo potilaan yleisistä kivunhoitotoiveista muille hoitoon osallistuville				
5	4	3	2	1	14. hoitaja kertoo potilaan kivunhoitomenetelmiä koskevat toiveet muille hoitoon osallistuville				
5	4	3	2	1	15. hoitaja kertoo potilaan halukkuudesta osallistua päätöksentekoon muille kivunhoitoon osallistuville				

Olen väittämän suhteen					Tämä on toteutunut työssäni tällä osastolla				
täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä	Edunvalvonta kivunhoidossa tarkoittaa että:	kyllä	ei, vaikka olisi ollut tarvetta	ei, ei ole ollut tarvetta	en osaa sanoa
5	4	3	2	1	16. hoitaja kertoo potilaan halukkuudesta osallistua kivunhoitoonsa muille kivunhoitoon osallistuville				
5	4	3	2	1	17. hoitaja valvoo, että potilaan kipua hoidetaan potilaan toiveiden mukaan				
5	4	3	2	1	18. hoitaja valvoo, että potilaan kivunhoitomenetelmät ovat potilaalle sopivia				
5	4	3	2	1	19. hoitaja valvoo, että potilaan kivun voimakkuutta arvioidaan				
5	4	3	2	1	20. hoitaja valvoo, että potilaan kivun hoidon riittävyttä arvioidaan				
5	4	3	2	1	21. hoitaja valvoo, että potilas voi osallistua kivunhoitoaan koskevaan päätöksentekoon toiveidensa mukaan				
5	4	3	2	1	22. hoitaja valvoo, että potilas voi osallistua kivunhoitoonsa toiveidensa mukaan				
5	4	3	2	1	23. hoitaja valvoo, että potilaan toiveita kunnioitetaan				
5	4	3	2	1	24. hoitaja valvoo, että potilaan oikeuksia kunnioitetaan				

### C. Edunvalvonnan ehdot

Seuraavaksi Teitä pyydetään arvioimaan, **mitä tarvitaan jotta edunvalvonta voisi toteutua**. Olkaa hyvä ja ympyröikää kutakin edunvalvontaa kuvaavaa väittämää kohden mielestänne sopivinta vaihtoehtoa edustava numero.

#### Olen väittämän suhteen

Edunvalvonta voi toteutua:	täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä
1. jos tiedän, miten potilaan kipuja voidaan hoitaa	5	4	3	2	1
1. jos tiedän voivani vaikuttaa potilaan kivunhoitoon	5	4	3	2	1
3. jos tiedän voivani toimia potilaan edunvalvojana kivunhoitoon liittyvissä päätöksissä	5	4	3	2	1
4. jos tiedän, miten voin tukea potilasta itse hoitamaan kipujaan	5	4	3	2	1
5. jos tiedän eettiset velvollisuuteni potilaan kivunhoidossa	5	4	3	2	1
6. jos ymmärrän eettiset velvollisuuteni potilaan kivunhoidossa	5	4	3	2	1
7. jos tiedän velvollisuuteni osallistua potilaan kivunhoitoa koskeviin päätöksiin	5	4	3	2	1
8. jos tiedän, miten voin osallistua potilaan kivunhoitoa koskeviin päätöksiin	5	4	3	2	1
9. jos koen voivani vastata potilaan kysymyksiin hänen kivunhoidostaan	5	4	3	2	1
10. jos koen ymmärtäväni potilaan yksilölliset kivunhoitotoiveet	5	4	3	2	1
11. jos koen potilaan luottavan minuun kivunhoidossaan	5	4	3	2	1
12. jos koen, että potilas odottaa minun toimivan hänen etujensa valvojana kivunhoidossa	5	4	3	2	1

**D. Edunvalvonnan seuraukset**

Lopuksi Teitä pyydetään arvioimaan, **mitä seurauksia edunvalvonnalla on**. Olkaa hyvä ja ympyröikää kutakin edunvalvontaa kuvaavaa väittämää kohden mielestänne sopivinta vaihtoehtoa edustava numero.

Jos edunvalvonta kivunhoidossa toteutuu:	Olen väittämän suhteen				
	täysin samaa mieltä	melko samaa mieltä	en samaa enkä eri mieltä	melko eri mieltä	täysin eri mieltä
1. niin koen roolini kivunhoidossa selkeäksi	5	4	3	2	1
2. niin koen ammattitaitoni kivunhoidossa hyväksi	5	4	3	2	1
3. niin koen, että yhteistyö lääkärin kanssa toimii kivunhoidossa hyvin	5	4	3	2	1
4. niin koen, että yhteistyö osastojen välillä kivunhoidossa toimii hyvin	5	4	3	2	1
5. niin koen, ettei minulla ole sananvaltaa potilaan kivunhoidossa	5	4	3	2	1
6. niin koen potilaan luottavan minuun kivunhoidossaan	5	4	3	2	1
7. niin koen onnistuneeni työssäni	5	4	3	2	1
8. niin koen työmotivaationi kasvavan	5	4	3	2	1
9. niin koen saavani toiminnastani positiivista palautetta työtovereiltani	5	4	3	2	1
10. niin koen, että potilas odottaa minulta liikaa hoitajana	5	4	3	2	1

Palauttakaa vastauksenne nimettömänä oheisessa kuoressa kansliaan.

**Kiitos osallistumisestanne!**

Turun yliopisto  
Hoitotieteen laitos  
Heli Vaartio

Tiedote hoitotyöntekijöille

### **Edunvalvonta kivun hoitotyössä**

Hyvä hoitotyöntekijä

Selvitän hoitotieteellistä väitöskirjatutkimusta varten potilaiden ja sairaanhoitajien kokemuksia proseduraalisen (tutkimus, leikkaus tai muu toimenpide) kivun hoitotyöhön liittyvistä tilanteista, joissa hoitaja tavoitteellisesti on edistänyt potilaan hyvinvointia ja turvannut hänen oikeuksiaan potilaana. Tutkimuksen tarkoituksena on selvittää edunvalvojuuden (*nursing advocacy*) käsitettä ja prosessia käytännön hoitotyössä. Tutkimusvaiheessa I kehitetään kivun hoitotyön edunvalvontaa kuvaava hypoteettinen malli. Vaiheessa II hypoteettinen malli testataan kehittämällä kivun hoitotyön edunvalvontaan liittyvä mittari ja keräämällä sillä aineistot sekä potilailta että hoitajilta. Vaiheessa III kehitetään aikaisempien vaiheiden tulosten perusteella kivun hoitotyön edunvalvontaa selittävä teoreettinen malli.

Nyt kyseessä on ensimmäinen vaihe ja sen aineisto koostuu potilaiden ja hoitajien haastatteluista. Kahden eri sairaalan kahdelta operatiivisen hoidon osastolta ja kahdelta konservatiivisen hoidon osastolta valitaan satunnaisesti **kolme potilasta ja kolme hoitajaa**, jotka **haastatellaan** kukin erikseen sairaalan tiloissa kullekin sopivana ajankohtana. **Teidän osastollanne haastattelut tehdään viikoilla x-y** Haastattelut nauhoitetaan haastateltavien luvalla, mutta tiedonantajien henkilöllisyys jää vain tutkijan tietoon. Haastattelu kestää noin 30-60 minuuttia.

**Tiedote potilaille** (Liite 2) pyydetään antamaan **viikoilla x-y** sellaisille kommunikaatiokykyisille potilaille, joiden tiedetään kokevan/kokeneen kipua tämän hoitajakson aikana ja jotka viipyvät osastolla ainakin seuraavaan päivään. Potilas itse päättää, osallistuuko hän tutkimukseen ja milloin hänelle sopii tulla haastatelluksi, sekä sulkee vastauksensa kirjekuoreen. **Kuoret kerätään kansliaan**, josta tutkija ne hakee ja ottaa yhteyttä potilasiin työvuorossa olevan hoitohenkilökunnan kautta, potilaiden ilmoittamien tietojen avulla. Mikäli kiinnostuneita on enemmän kuin tarvittavat kolme, valitaan haastateltavat ilmoittautuneiden joukosta satunnaisesti. Kun haastattelut on sovittu, ilmoittaa tutkija osastolle, ettei uusia vapaaehtoisia tarvita.

**Tiedote hoitajille** (Liite 3) on jokaisen kiinnostuneen vapaasti luettavissa hoitajien kanslian ilmoitustaululla. Halutessaan hoitaja voi **täyttää ja jättää kirjekuoreessa kansliaan täytetyn suostumusosion**, josta tutkija sen hakee ja ottaa yhteyttä. Mikäli kiinnostuneita on enemmän kuin tarvittavat kolme, valitaan haastateltavat ilmoittautuneiden joukosta satunnaisesti. Kun haastattelut on sovittu, ilmoittaa tutkija osastolle, ettei uusia vapaaehtoisia tarvita.

Tutkimuksen ohjaajana toimii THT, professori Helena Leino-Kilpi Turun yliopiston hoitotieteen laitokselta, puh xxx.

YHTEISTYÖSTÄ ETUKÄTEEN KIITTÄEN

Heli Vaartio  
Sh, TtM, lehtori, TtT-opiskelija  
Turun yliopisto  
Hoitotieteen laitos  
Puh xxx  
[heli.vaartio@](mailto:heli.vaartio@utu.fi)

Turun yliopisto

Hoitotieteen laitos

Heli Vaartio

**Edunvalvonta kivun hoitotyössä**

Arvoisa vastaaja

Selvitän potilaiden kokemuksia kivun hoidosta hoitotieteellistä väitöskirjatutkimusta varten. Tutkimuksen tarkoituksena on selventää hoitotyön edunvalvojuuden käsitettä ja prosessia käytännön hoitotyössä. Edunvalvojuudella tarkoitetaan potilaiden hyvinvoinnin edistämistä ja heidän etujensa turvaamista.

Tutkimuksen ensimmäinen vaihe muodostuu potilaiden haastatteluista. Jokaiselta tutkimukseen valitulta osastolta valitaan satunnaisesti kolme potilasta, jotka haastatellaan kukin erikseen osaston tiloissa. **Pyydän Teitä kohteliaimmin osallistumaan kyseisen tutkimuksen haastatteluun.** Haastattelut nauhoitetaan luvallanne analyysiä varten, mutta Teidän henkilöllisyytenne ei tule missään vaiheessa tutkimusta ilmi. Haastattelu kestää noin 30-60 minuuttia ja se suoritetaan osaston tiloissa Teille sopivana ajankohtana.

Haastatteluun osallistuminen on täysin vapaaehtoista eikä siihen suostuminen tai siitä kieltäytyminen vaikuta mitenkään hoitoon. Voitte myös keskeyttää haastattelun.

**Mikäli suostutte haastatteluun, kirjoittakaa seuraavalle sivulle nimenne ja ajankohta, jolloin haastattelu mielestänne voidaan sairaalassa suorittaa.** Antakaa sitten kirjekuoreen suljettu lomake takaisin hoitajalle. Otan Teihin yhteyttä vielä sairaalassaoloaikanne.

Tutkimuksen ohjaajana toimii THT, professori Helena Leino-Kilpi Turun yliopiston hoitotieteen laitokselta, puh xxx.

YHTEISTYÖSTÄ ETUKÄTEEN KIITTÄEN

Tutkija:

Heli Vaartio

Sh, TtM, lehtori, TtT-opiskelija

Turun yliopisto

Puh xxx

heli.vaartio@

Turun yliopisto  
Hoitotieteen laitos  
Heli Vaartio  
**Edunvalvonta kivun hoitotyössä**

Potilaan suostumuslomake

Tutkimuksen nimi: Edunvalvonta kivun hoitotyössä

Tutkija: Heli Vaartio

#### SUOSTUMUS HAASTATTELUUN JA SEN NAUHOITTAMISEEN

Suostun osallistumaan edellä mainittuun tutkimukseen liittyvään haastatteluun ja sen nauhoittamiseen. Minulle on alustavasti selvitetty tutkimuksen tarkoitus ja haastattelun toteutus. Haastatteluun osallistuminen ei vaikuta mitenkään hoitooni eikä henkilöllisyyteni tule esille tutkimuksen missään vaiheessa. Minulla on oikeus keskeyttää haastattelu niin halutessani.

Päivämäärä----- Allekirjoitus-----

Ehdotus haastattelun ajankohdaksi-----

Osasto ja huoneen numero-----



Turun yliopisto  
Hoitotieteen laitos  
Heli Vaartio  
**Edunvalvonta kivun hoitotyössä**

Tiedote hoitajille

Arvoisa hoitaja

Edunvalvonta eli potilaiden hyvinvoinnin edistäminen ja heidän etujensa turvaaminen on olennainen osa työnkuva. Mutta mitä edunvalvonta tarkoittaa kivun hoitotyön yhteydessä? Selvitän hoitotieteellistä väitöskirjatutkimusta varten sairaanhoitajien kokemuksia **kivun hoitotyöhön liittyvistä tilanteista**, joissa hoitaja on edistänyt potilaan hyvinvointia ja turvannut hänen oikeuksiaan potilaana. Tutkimuksen tarkoituksena on selvittää edunvalvojuuden käsitettä ja edunvalvontaan liittyviä tekijöitä. Tutkimusvaiheessa I kehitetään kivun hoitotyön edunvalvontaa kuvaava hypoteettinen malli. Vaiheessa II hypoteettinen malli testataan kehittämällä kivun hoitotyön edunvalvontaan liittyvä mittari ja keräämällä sillä aineistot sekä potilailta että hoitajilta. Vaiheessa III kehitetään aikaisempien vaiheiden tulosten perusteella kivun hoitotyön edunvalvontaa selittävä teoreettinen malli.

Tutkimuksen ensimmäisessä vaiheessa haastatellaan hoitajia. Jokaiselta tutkimukseen valitulta osastolta valitaan satunnaisesti **kolme hoitajaa**, jotka **haastatellaan** kukin erikseen **sairaalan tiloissa**. Teidän osastollanne haastattelut tapahtuvat viikoilla x-y. Haastattelut nauhoitetaan luvallanne analyysiä varten, mutta Teidän henkilöllisyytenne ei tule missään vaiheessa tutkimusta ilmi. Haastattelu kestää noin 30-60 minuuttia. Haastatteluun osallistuminen on vapaaehtoista ja voitte myös halutessanne keskeyttää haastattelun.

**Mikäli suostutte haastatteluun, kirjoittakaa seuraavalle sivulle nimenne, tarvittavat yhteystiedot sekä ajankohta, jolloin haastattelu voidaan suorittaa.** Tutkija ottaa Teihin yhteyttä ja varmistaa haastattelun ajankohdan ja paikan.

Tutkimuksen ohjaajana toimii THT, professori Helena Leino-Kilpi Turun yliopiston hoitotieteen laitokselta, puh xxx.

YHTEISTYÖSTÄ ETUKÄTEEN KIITTÄEN

Tutkija:  
Heli Vaartio  
Sh, TtM, lehtori, TtT-opiskelija  
Turun yliopisto  
Hoitotieteen laitos  
Puh xxx  
[heli.vaartio@](mailto:heli.vaartio@)

**Appendix 8.** Content validity measures of APPC, dataset III

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<b>Part B: advocacy activities Item number</b>	<b>Abbreviated items (for both patients and nurses)</b>	<b>Mean</b>	<b>SD</b>	<b>Item-total correlation</b>
01	asking about wishes concerning pain care	4.43	0.70	0.40
02	asking about wishes concerning pain care methods	3.82	1.04	0.19
03	asking for subjective pain intensity evaluation	4.53	0.77	0.42
04	asking for subjective evaluation of pain care management	4.50	0.82	0.37
05	asking about decision-making preferences in pain care	3.45	1.20	0.86
06	asking about participation preferences in pain care	3.37	1.31	0.76
07	asking how one would like to participate in decision-making concerning pain care	3.18	1.19	0.88
08	asking how one would like to participate in pain care	3.20	1.21	0.82
09	providing guidance for the expression of one's pain care preferences	4.20	0.95	0.24
10	providing guidance for the choice of preferred pain care method	3.31	1.12	0.51
11	providing guidance for the evaluation of pain intensity	3.89	1.23	0.82
12	providing guidance for the evaluation of care management	3.70	1.24	0.81
13	guiding others in health care team concerning one's pain care preferences	3.79	1.33	0.90
14	guiding others in health care team concerning one's pain care method preferences	3.77	1.37	0.94
15	guiding others in health care team concerning one's decision-making preferences	3.66	1.32	0.89
16	guiding others in health care team concerning one's preferences of participation in pain care	3.66	1.26	0.78
17	monitoring that pain care is in accordance with patient's wishes	4.35	0.76	0.47
18	monitoring that pain care methods are relevant to patient	4.49	0.77	0.59
19	monitoring that patient's pain intensity is evaluated	4.30	0.93	0.62
20	monitoring that patient's pain management is evaluated	4.42	0.87	0.60
21	monitoring that patient can participate in decision-making according to his/her preferences	3.77	1.05	0.54
22	monitoring that patient can participate in pain care according to his/her preferences	3.66	1.04	0.71
23	monitoring that patients' wishes are respected	4.40	0.89	0.64
24	monitoring that patients' rights are respected	4.50	0.83	0.61

(n = 25)

<b>Part C: antecedents of advocacy</b>	<b>Abbreviated items (for patients)</b>	<b>Mean</b>	<b>SD</b>	<b>Item-total correlation</b>
01	if I know how my pain can be managed	4.15	0.75	0.50
02	if I know that I can participate in my pain care	4.10	0.63	0.56
03	if I know that I can participate in decision-making concerning my pain care	3.51	1.38	0.59
04	if I know how to self care for my pain	3.49	1.06	0.84
05	if I know my rights in pain care	4.10	0.73	0.72
06	if I understand my rights in pain carer	4.36	0.67	0.48
07	if I know that a nurse can advocate for me in pain care	4.51	0.65	0.25
08	if I know how to participate in decision- making concerning my pain care	4.00	0.83	0.12
09	if I feel that I can ask a nurse about my pain care	4.77	0.42	0.65
10	if I feel that I can express my wishes concerning pain care to a nurse	4.80	0.40	0.67
11	if I feel that I can trust a nurse in my pain care	4.79	0.55	0.52
12	if I feel that the nurse advocates for me in my pain care	4.49	0.72	0.49
<b>Part D: consequences of advocacy</b>	<b>Abbreviated items (for patients)</b>	<b>Mean</b>	<b>SD</b>	<b>Item-total correlation</b>
01	I feel that I can participate in my pain care	4.43	0.54	0.55
02	I feel that the pain care provided is effective	4.79	0.46	0.23
03	I feel that I can manage my pain by myself if I want to	3.72	0.85	0.57
04	I feel I have control over my pain care	3.62	0.79	0.44
05	I feel I can participate in decision- making concerning my pain care	3.72	0.90	0.45
06	I feel independent even though I need the assistance of nurses	3.63	1.22	0.37
07	I feel I can influence my own recovery	3.85	0.90	0.40
08	I feel I can influence my own care	4.36	0.67	0.02
09	I feel my privacy is interfered with	4.21	1.21	-0.06

(n = 25)

<b>Part C: antecedents of advocacy</b>	<b>Abbreviated items (for nurses)</b>	<b>Mean</b>	<b>SD</b>	<b>Item-total correlation</b>
<b>Item number</b>				
01	if I know how to care for the patient's pain	4.83	0.39	0.57
02	if I know I can influence the patient's pain care	4.66	0.49	0.49
03	if I know I can act as an advocate in patient's pain care	4.50	0.67	0.49
04	if I know how to support the patient's self care	4.08	0.67	0.56
05	if I know my ethical duties in pain care	4.33	0.78	0.79
06	if I understand my ethical duties in pain care	4.33	0.78	0.79
07	if I am aware of my duty to participate in decision-making concerning patient's pain care	4.41	0.69	0.56
08	if I know how to participate in decision-making concerning patient's pain care	4.33	0.65	0.63
09	if I feel I can answer the patient's questions about her/his pain care	4.42	0.67	0.53
10	if I feel I understand the patient's individual pain care preferences	4.33	0.65	0.62
11	if I feel that the patient trusts me in her/his pain care	4.50	0.52	0.71
12	if I feel that the patient expects me to advocate for her/him concerning pain care	4.25	0.75	0.75
<b>Part D: consequences of advocacy</b>	<b>Abbreviated items (for nurses)</b>	<b>Mean</b>	<b>SD</b>	<b>Item-total correlation</b>
<b>Item number</b>				
01	I feel my role in pain care is clear	4.41	0.90	0.69
02	I feel that I have good professional skills in pain care	4.25	0.87	0.86
03	I feel that I have good collaboration with doctors	3.83	0.83	0.51
04	I feel that there is good collaboration between different units	3.58	0.79	0.37
05	I feel that I cannot influence patient's pain care	4.25	0.86	0.34
06	I feel that the patient trusts me in her/his pain care	4.33	0.49	0.12
07	I feel I have been successful in my job as a nurse	4.41	0.51	0.07
08	I feel my work motivation has increased	4.16	0.58	-0.08
09	I feel that I get positive feedback from my colleagues	4.25	0.75	-0.04
10	I feel that patients expect too much from me as a nurse	3.91	0.90	0.40

(n = 25)

**Appendix 9.** Construct validity measures of APPC, dataset IV

<b>Dimension of advocacy</b>	<b>Subscale of APPC</b>	<b>Pearson correlation item to item</b>
Patient enlightenment n = 405	recognition of patient's role in pain care (4 items: Cp1-4)	0.38-0.55
	recognition of patient's rights in pain care (4 items: Cp5-8)	0.33-0.80
	recognition of patient-nurse relationship (4 items: Cp9-12)	0.38-0.75
Nurse enlightenment n = 118	recognition of nurse's professional role in pain care (4 items: Cn1-4)	0.23-0.58
	recognition of nurse's ethical duties in pain care (4 items: Cn5-8)	0.28-0.69
	recognition of patient-nurse relationship (4 items: Cn9-12)	0.30-0.63
Analysing n = 523	analysing patient's pain care preferences (4 items: Bp1-4)	0.28-0.54
	(4 items: Bn1-4)	0.20-0.68
	analysing patient's self-determination preferences (4 items: Bp5-8)	0.66-0.84
Counselling n = 523	(4 items: Bn5-8)	0.57-0.86
	counselling patient about pain care (4 items: Bp9-12)	0.41-0.68
	(4 items: Bn9-12)	0.31-0.57
Responding n = 523	counselling those involved in care about patient's pain care and self-determination preferences (4 items: Bp13-16)	0.62-0.84
	(4 items: Bn13-16)	0.55-0.80
	responding to patient's pain care preferences (4 items: Bp17-20)	0.30-0.75
Patient empowerment n = 405	(4 items: Bn17-20)	0.15-0.57
	responding to patient's self-determination preferences (4 items: Bp21-24)	0.50-0.84
	(4 items: Bn21-24)	0.57-0.82
Nurse empowerment n = 118	empowerment in pain care (4 items: Dp1-4)	0.32-0.68
	empowerment in self-determination (4 items: Dp5-8)	0.45-0.57
	structural/professional empowerment (4 items: Dn1-4)	0.41-0.64
	psychological/individual empowerment (4 items: Dn6-9)	0.33-0.76

**Appendix 10.** Implementation of advocacy activities, dataset IV

Sum variable	Patients n = 405					Mean/ Md	Nurses n = 118					Mean/ Md
	0%	25%	50%	75%	100%		0%	25%	50%	75%	100%	
B1-4 analysing patient's pain care preferences	26	32	50	58	199	74%/ 100%	0	2	10	16	84	89%/ 100%
B5-8 analysing patient's self- determination preferences	227	22	18	8	72	27%/ 0%	55	7	8	3	21	31%/ 0%
B9-12 counselling patient about pain care	89	45	62	33	129	55%/ 50%	2	1	9	23	79	88%/ 100%
B13-16 counselling others about patient's pain care and self- determination preferences	141	18	20	18	93	42%/ 25%	11	3	9	9	83	82%/ 100%
B17-20 responding to patient's pain care preferences	57	20	25	24	218	73%/ 100%	2	1	8	22	84	89%/ 100%
B21-24 responding to patient's self- determination preferences	77	9	60	20	175	65%/ 75%	8	4	18	5	81	81%/ 100%

0%: none of four items in a sum were implemented

25%: one of four items was implemented

50%: two of four items were implemented

75%: three of four items were implemented

100%: all four items were implemented