



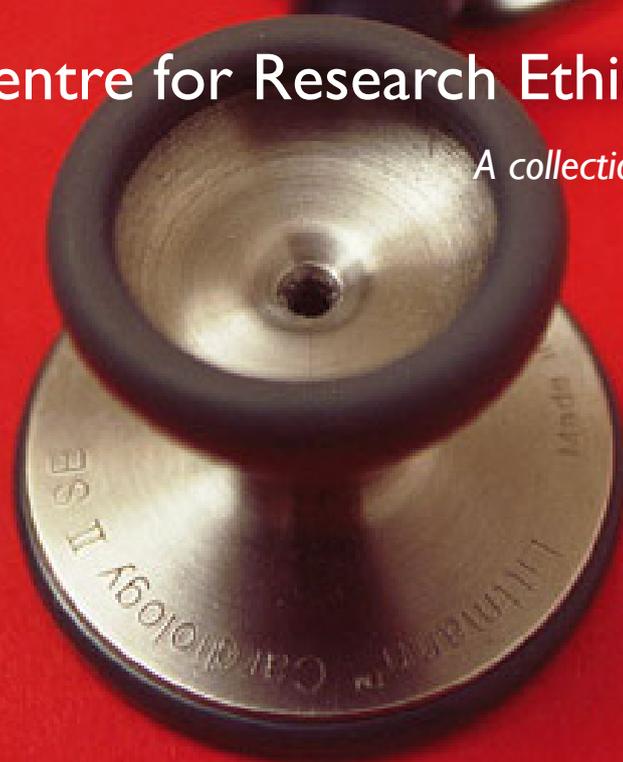
UPPSALA
UNIVERSITET

Benefiting patients and professionals

NURSING ETHICS & ETHICS OF CARE

Centre for Research Ethics & Bioethics

A collection of books and articles



NURSING ETHICS & ETHICS OF CARE

Nursing ethics is concerned with the moral dimensions of nursing practice while the ethics of care is a normative ethical theory. For many years CRB has developed these fields from different angles. We have used qualitative studies to describe and explore the kinds of ethical dilemmas nurses encounter in their day-to-day work and how they solve them. Other studies have investigated the role of ethical guidelines in the building of ethical competence in nursing practice and in priority setting.

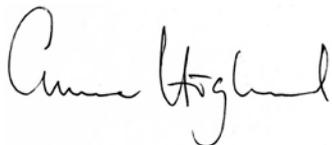
The focus in nursing ethics research is on the relationship between the nurse and the person receiving care. A central question is what the nurse can do for the person in need of care and how a respectful meeting could take place, despite the asymmetry in the relationship between nurse and patient. Nursing ethics focuses more on developing caring relationships than on broader ethical principles. The concept of 'caring' has priority over the concept of 'curing' and how a person should 'be' rather than how they should act is stressed. As a result, virtue ethics have often been elaborated within the framework of nursing ethics.

The concept of 'care' is often defined as a practice, but at the same time as a value and an ideal that can guide normative judgments and actions. This tradition is often contrasted with duty based (deontological) and consequentialist (utilitarian) ethics. It argues for embodied relations and emotions to be part of moral judgments.

Anna T. Höglund is Associate Professor of Ethics and Senior Lecturer in Nursing Ethics and Gender Studies at CRB. She has published extensively on nursing ethics and the ethics of care both by herself and together with her group of PhD students. Apart from her group, several other researchers at CRB are involved in clinical projects that deal with nursing and care in different ways and we are expecting results to be published soon.

This report lists our peer-reviewed publications in the field in chronological order. It also includes abstracts of dissertations, book chapters and monographies.

This report was updated in June 2015.



Anna T. Höglund, Associate Professor of Ethics and Senior Lecturer in Nursing Ethics and Gender Studies
Centre for Research Ethics & Bioethics, Uppsala University

CONTENTS

PEER REVIEWED ARTICLES & DISSERTATIONS	6
Godskesen T, Patients in Clinical Cancer Trials: Understanding, Motivation and Hope, 2014, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation, ISSN 1651-6206;1112.	6
Godskesen TM, Kihlbom U, Nordin K, Silén M, Nygren P, Differences in trial knowledge and motives for participation among cancer patients in phase 3 clinical trials, European Journal of Cancer Care, Article first published online: 21 APR 2015, DOI: 10.1111/ecc.12319	6
Gottvall M, Tydén T, Larsson M, Stenhammar C & Höglund AT, Informed Consent for HPV Vaccination: A Relational Approach, Health Care Analysis, 2015;23(1)50-62.....	7
Jalmsell L, Kontio T, Stein M, Henter JI, Kreicbergs U, On the Child's Own Initiative: Parents Communicate With Their Dying Child About Death, Death Stud. 2015;396(2).....	7
Hakimnia R, Clarsson M, Höglund AT, Holmström IK, Doing gender in the context of telenursing: Analyses of authentic calls to a telenursing site in Sweden, Clinical Nursing Studies 2015;3(2):24-30.....	7
Godskesen T, Hansson MG, Nygren P, Nordin K, Kihlbom U, Hope for a cure and altruism are the main motives behind participation in phase 3 clinical cancer trials, European Journal of Cancer Care, 2015;24(1):133-141.	8
Hakimnia R, Holmström IK, Carlsson M, Höglund AT, Exploring the communication between telenurse and caller - A critical discourse analysis, International Journal of Qualitative Studies on Health and Well-being, 2014;9:24255.....	8
Pettersson M, Hedström M and Höglund AT, Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care, Nursing Ethics published online 9 June 2014, DOI: 10.1177/0969733014533238.....	8
Gottvall M, Introduction of School-Based HPV Vaccination in Sweden: Knowledge and Attitudes among Youth, Parents, and Staff, 2013, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation.	9
Jalmsell L, Forslund M, Hansson MG, Henter JI, Kreicbergs U, Frost BM, Transition to noncurative end-of-life care in paediatric oncology: a nationwide follow-up in Sweden, Acta Paediatrica 2013;102(7):744-748.....	9
Godskesen T, Nygren P, Nordin K, Hansson M, Kihlbom U, Phase 1 clinical trials in end-stage cancer: patient understanding of trial premises and motives for participation, Supportive Care in Cancer, 2013;21(11):3137-3142.	10
Gottvall M, Grandahl M, Höglund AT, Larsson M, Stenhammar C, Andrae B & Tydén T, Trust versus concerns: how parents reason when they accept HPV vaccination for their young daughter, Upsala Journal of Medical Sciences 2013;118(4)263-270.	10
Jalmsell L, Onelöv E, Steineck G, Henter JI, Kreicbergs U, Hematopoietic stem cell transplantation in children with cancer and the risk of long-term psychological morbidity in the bereaved parent, Bone Marrow Transplant, 2011;46(8):1063-70.....	11
Gottvall M, Tydén T, Larsson M, Stenhammar C, Höglund AT. Challenges and opportunities of a new HPV immunization program - Perceptions among Swedish school nurses. Vaccine, 2011;29(28):4576-4583.....	11
Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter JI, Anxiety is contagious-symptoms of anxiety in the terminally ill child affect long-term psychological well-being in bereaved parents, Pediatr Blood Cancer, 2010;54(5):751-7.....	11

Kaminsky E, Carlsson M, Höglund AT, Holmström I. Peadiatric health calls to Swedish telenurses – A descriptive study of content and outcome. <i>Journal of Telemedicine and Telecare</i> . 2010;16:454-457	12
Arnetz JE, Winblad U, Höglund AT, Lindahl B, Spångberg K, Wallentin L et al. Is patient involvement during hospitalization for acute myocardial infarction associated with post-discharge treatment outcome? An exploratory study. <i>Health Expectations</i> . 2010;13:298-311.....	12
Höglund AT, Winblad U, Arnetz B, Arnetz J. Patient participation during hospitalization for myocardial infarction. Perceptions among patients and personnel. <i>Scandinavian Journal of Caring Sciences</i> . 2010;24: 482-489.	12
Gottvall M, Tydén T, Höglund AT, Larsson M. Knowledge of human papillomavirus among high school students can be increased by an educational intervention. <i>International Journal of STD & AIDS</i> 2010; 21:558-562.....	13
Höglund AT, Eriksson S, Helgesson G. The role of guidelines in ethical competence building – Perceptions among research nurses and physicians. <i>Clinical Ethics</i> 2010; 5:95-102.....	13
Gottvall M, Larsson M, Höglund AT, Tydén T. High vaccine acceptance despite low awareness among Swedish upper secondary school students. <i>The European Journal of Contraception and Reproductive Health Care</i> 2009; 14:399-405.....	13
Höglund AT, Helgesson G, Eriksson S. Ethical dilemmas and ethical competence in the daily work of research nurses. <i>Health Care Analysis</i> 2010; 18:239-51.....	14
Höglund AT, Holmström I. Ethical issues in telenursing. <i>International Hospital Equipment and Solutions</i> . 2009; 7:18-19.....	14
Höglund AT, Tydén T, Hannerfors AK, Larsson M. Knowledge of human papillomavirus (HPV) and attitudes to vaccination among Swedish high school students. <i>International Journal of STD & AIDS</i> 2009; 20:102-107. ..	14
Höglund AT, Holmström I. “It’s easier to talk to a woman.” Aspects of gender in Swedish telenursing. <i>Journal of Clinical Nursing</i> 2008; 17: 2979-2986.....	15
Holmström I, Höglund AT. Response to commentary. <i>Journal of Clinical Nursing</i> 2008; 17:3251-3252.	15
Arnetz JE, Höglund AT, Arnetz BB, Winblad U. Development and evaluation of a questionnaire for measuring patient views of involvement in myocardial infarction care. <i>European Journal of Cardiovascular Nursing</i> 2008; 7: 229-238.....	15
Arnetz JE, Winblad U, Arnetz BB, Höglund AT. Physicians’ and nurses’ perceptions of patient involvement in myocardial infarction care. <i>European Journal of Cardiovascular Nursing</i> 2008; 7:113-120.	16
Arnetz JE, Höglund AT, Arnetz BB, Winblad U. Staff views and behaviour regarding patient involvement in myocardial infarction care: Development and evaluation of a questionnaire. <i>European Journal of Cardiovascular Nursing</i> 2008; 7:27-35.....	16
Eriksson S, Höglund AT, Helgesson G. Do ethical guidelines give guidance? A critical examination of eight ethics regulations. <i>Cambridge Quarterly of Healthcare Ethics</i> 2008; 17:15-29.....	16
Eriksson S, Helgesson G, Höglund AT. Being, doing, and knowing: Developing ethical competence in health care practice. <i>Journal of Academic Ethics</i> 2007; 5:207-216.....	17
Holmström I, Höglund AT. The faceless encounter. Ethical dilemmas in telephone nursing. <i>Journal of Clinical Nursing</i> 2007; 16:1865-1871.	17
Källemark Sporrang S, Ethical competence and moral distress in the health care sector. Prospective evaluation of ethics rounds. Dissertation, Acta Universitatis Upsaliensis, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, 2007	17

Kälvemark Sporrang S, Arnetz B, Hansson MG, Westerholm P, Höglund AT. Developing ethical competence in health care organizations. <i>Nursing Ethics</i> 2007; 14:825-837.....	18
Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter JI, Symptoms affecting children with malignancies during the last month of life: a nation wide follow-up. <i>Pediatrics</i> , 2006;117(4):1314-20.	18
Kälvemark Sporrang S, Höglund AT, Arnetz B. Measuring moral distress in pharmacy and clinical practice. <i>Nursing Ethics</i> 2006; 13:416-427.....	19
Kälvemark Sporrang S, Höglund AT, Hansson MG, Westerholm P, Arnetz B. "We are white coats whirling round". Moral distress in Swedish pharmacies. <i>Pharmacy World and Science</i> 2005; 27:223-229.....	19
Kälvemark S, Höglund AT, Hansson MG, Westerholm P, Arnetz B. Living with conflicts. Ethical dilemmas and moral distress in the health care system. <i>Social Science and Medicine</i> 2004; 58:1075-1084.....	19
MONOGRAPHS & BOOK CHAPTERS	21
Höglund AT. Etiska aspekter på att rutinmässigt fråga om erfarenheter av våld i nära relationer. (Ethical aspects on screening for intimate partner violence). I: Att fråga om våldsutsatthet som en del i anamnesen. Uppsala: NCK Rapport 2010:4, s. 95-103.....	21
Höglund AT. Genusperspektiv på att rutinmässigt tillfråga kvinnor om våld i nära relationer. (Gender perspectives on screening for intimate partner violence among women). I: Att fråga om våldsutsatthet som en del i anamnesen. Uppsala: NCK Rapport 2010:4, s. 105-111.....	21
Höglund AT. Gender and Bioethics. In Blomqvist M & Ehnsmyr E (Eds.) Never Mind the Gap! Gendering Science in Transgressive Encounters. <i>Skrifter från Centrum för Genusvetenskap/Crossroads of Knowledge</i> 15. Uppsala: University Printers, 2010, pp. 213-238.	21
Höglund AT. Inga lätta val. Om riktlinjer och etisk kompetens vid prioriteringar i vården. En studie i empirisk etik. (No Easy Choices. On Guidelines and Ethical Competence in Priority Setting in Health Care. A Study in Empirical Ethics). <i>Uppsala Studies in Faiths and Ideologies</i> 15. Uppsala: Acta Universitatis Upsaliensis 2005, 176 pp.....	22
Höglund AT. Reflektioner över etik och prioriteringar i vården – intervjuer med vårdpersonal. (Reflections on Ethics and Priority Setting in Health Care – Interviews with Health Care Providers). Linköping: Prioriteringscentrum, Rapport 7, 2003, 86 pp.....	22
Holmström I, Höglund AT. Det ansiktslösa mötets etik. Sjuksköterskors erfarenheter av etiska dilemman vid telefonrådgivning. (The ethics of the faceless encounter. Nurses' experiences of ethical dilemmas in telephone counselling). Holmström I. (ed.): <i>Telefonrådgivning in hälso- och sjukvård. (Telephone Counselling in Health Care)</i> Lund: Studentlitteratur 2008, pp. 91-105.....	23

PEER REVIEWED ARTICLES & DISSERTATIONS

Godskesen T, [Patients in Clinical Cancer Trials: Understanding, Motivation and Hope](#), 2014, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation, ISSN 1651-6206;1112.

Abstract: The overall aim of this thesis was to study participants' understanding of clinical cancer trials, and their motivation for participation. Of particular interest was the question of whether the patients hoped for a cure resulting from the trial. The thesis was based on four studies and used three methods: interviews, a questionnaire, and empirical bioethics. The results of Study I indicated that the participants in phase 1 trials understood most of the information provided, but were unaware of both the very small potential for treatment benefit, and the risk of harm. Patients in phase 3 trials had a good understanding of the trial, except regarding side effects and their right to withdraw. Some found it hard to ask questions and felt they needed more information (Study III). The participants in phase 1 trials were strongly motivated by the generally unrealistic hope for therapeutic benefit (Study I). When the chances of a cure are minuscule, as for participants with end-stage cancer in phase 1 trials, hope can play an important, positive role and offer meaning to one's remaining life. However, hope for an unrealistic outcome could also deprive patients of an opportunity to spend their remaining lives, as they would otherwise choose (Study II). The participants in phase 3 trials indicated that their motivation for participation was multifaceted; the most common motivations included hope of therapeutic benefit, altruism, access to extra clinical examinations or better care, and a wish to repay society for the help they had received (Study III). After stratifying and analysing the motivation data by gender, age, education and previous experience of trial participation, males and those aged ≥ 65 years were significantly more motivated to participate out of a desire to reciprocate the help they had received, either because of a sense of duty or because their families or friends considered that they should attend (Study IV). In conclusion, the informed consent process seems to work relatively well, with good results within most subgroups. However, patients with end-stage cancer who are participating in phase 1 trials are a vulnerable group as they have very little potential for treatment benefit coupled with a tangible risk of harm.

Godskesen TM, Kihlbom U, Nordin K, Silén M, Nygren P, [Differences in trial knowledge and motives for participation among cancer patients in phase 3 clinical trials](#), *European Journal of Cancer Care*, Article first published online: 21 APR 2015, DOI: 10.1111/ecc.12319

Abstract: While participants in clinical oncology trials are essential for the advancement of cancer therapies, factors decisive for patient participation have been described but need further investigation, particularly in the case of phase 3 studies. The aim of this study was to investigate differences in trial knowledge and motives for participation in phase 3 clinical cancer trials in relation to gender, age, education levels and former trial experience. The results of a questionnaire returned from 88 of 96 patients (92%) were analysed using the Mann–Whitney *U*-test. There were small, barely relevant differences in trial knowledge among patients when stratified by gender, age or education. Participants with former trial experience were less aware about the right to withdraw. Male participants and those aged ≥ 65 years were significantly more motivated by a feeling of duty, or by the opinions of close ones. Men seem more motivated than women by external factors. With the awareness that elderly and single male participants might be a vulnerable group and participants with former trial experience are less likely to be sufficiently informed, the information consent process should focus more on these patients. We conclude that the informed consent process seems to work well, with good results within most subgroups.

Gottvall M, Tydén T, Larsson M, Stenhammar C & Höglund AT, [Informed Consent for HPV Vaccination: A Relational Approach](#), *Health Care Analysis*, 2015;23(1)50-62.

Abstract: The aim of this study was to explore the relational aspects of the consent process for HPV vaccination as experienced by school nurses, based on the assumption that individuals have interests related to persons close to them, which is not necessarily to be apprehended as a restriction of autonomy; rather as a voluntary and emotionally preferred involvement of their close ones. Thirty Swedish school nurses were interviewed in five focus groups, before the school based vaccination program had started in Sweden. The empirical results were discussed in light of theories on relational autonomy. The school nurses were convinced that parental consent was needed for HPV vaccination of 11-year-old girls, but problems identified were the difficulty to judge when a young person is to be regarded as autonomous and what to do when children and parents do not agree on the decision. A solution suggested was that obtaining informed consent in school nursing is to be seen as a deliberative process, including the child, the parents and the nurse. The nurses described how they were willing to strive for a dialogue with the parents and negotiate with them in the consent process. Seeing autonomy as relational might allow for a more dialogical approach towards how consent is obtained in school based vaccination programs. Through such an approach, conflicts of interests can be made visible and become possible to deal with in a negotiating dialogue. If the school nurses do not focus exclusively on accepting the individual parent's choice, but strive to engage in a process of communication and deliberation, the autonomy of the child might increase and power inequalities might be reduced.

Jalmsell L, Kontio T, Stein M, Henter JI, Kreicbergs U, [On the Child's Own Initiative: Parents Communicate With Their Dying Child About Death](#), *Death Stud.* 2015;39(2).

Abstract: Open and honest communication has been identified as an important factor in providing good palliative care. However, there is no easy solution to if, when, and how parents and a dying child should communicate about death. This article reports how bereaved parents communicated about death with their child, dying from a malignancy. Communication was often initiated by the child and included communication through narratives such as fairy tales and movies and talking more directly about death itself. Parents also reported that their child prepared for death by giving instructions about his or her grave or funeral and giving away toys.

Hakimnia R, Clarsson M, Höglund AT, Holmström IK, [Doing gender in the context of telenursing: Analyses of authentic calls to a telenursing site in Sweden](#), *Clinical Nursing Studies* 2015;3(2):24-30.

Abstract: The aim of the present study was to analyze authentic health calls to a telenursing site in Sweden regarding reasons for calling and outcome of the calls with focus on a gender perspective. Background: Telephone advice nursing is an expanding service in many Western countries. In Sweden, all regions are now connected to a national telenursing service. Healthcare in Sweden is stipulated by law to be equitable. This includes the telenursing service, which is a new actor in the Swedish healthcare system, and which often is a citizen's first contact with healthcare. The study had a descriptive and comparative design. 800 authentic calls to SHD were analysed regarding reasons for calling, and outcome of the calls. The results showed that men, and especially fathers, received more referrals to general practitioners than women. The most common caller was a woman fluent in Swedish (64%), and the least likely caller was a man non-fluent in Swedish (3%). All in all, 70% of the callers were women. When the calls concerned children, 78% of the callers were female. In total, 9% of the calls were made by a man calling for another person. Callers were predominately young (mean age 29 years for women and 33 for men). It is important that telenursing does not become a "feminine" activity, only suitable for young callers fluent in Swedish. Given the telenurses' gatekeeping role, there is a risk that differences on this first level of health care can be reproduced throughout the whole healthcare system. In striving for more equitable telenursing services, future research might investigate if campaigns encouraging men to call, and more frequent use of translators could enhance access to telenursing services.

Godskesen T, Hansson MG, Nygren P, Nordin K, Kihlbom U, [Hope for a cure and altruism are the main motives behind participation in phase 3 clinical cancer trials](#), *European Journal of Cancer Care*, 2015;24(1):133-141.

Abstract: It is necessary to carry out randomised clinical cancer trials (RCTs) in order to evaluate new, potentially useful treatments for future cancer patients. Participation in clinical trials plays an important role in determining whether a new treatment is the best therapy or not. Therefore, it is important to understand on what basis patients decide to participate in clinical trials and to investigate the implications of this understanding for optimising the information process related to study participation. The aims of this study were to (1) describe motives associated with participation in RCTs, (2) assess if patients comprehend the information related to trial enrolment, and (3) describe patient experiences of trial participation. Questionnaires were sent to 96 cancer patients participating in one of nine ongoing clinical phase 3 trials at the Department of Oncology, Uppsala University Hospital in Sweden. Eighty-eight patients completed the questionnaire (response rate 92%); 95% of these were patients in adjuvant therapy and 5% participated in clinical trials on palliative care. Two main reasons for participation were identified: personal hope for a cure and altruism. Patients show adequate understanding of the information provided to them in the consent process and participation entails high patient satisfaction.

Hakimnia R, Holmström IK, Carlsson M, Höglund AT, [Exploring the communication between telenurse and caller - A critical discourse analysis](#), *International Journal of Qualitative Studies on Health and Well-being*, 2014;9:24255

Abstract: Telenursing is an expanding service in most Western societies. Sweden is a front-line country, with all of its 21 counties connected to Swedish Healthcare Direct (SHD) 1177. The intention of the service is twofold: to make health care more efficient, while also making it more accessible and safe for patients. Previous research has shown, however, that the service is not used equitably. Gender, age, socio-economic, and ethnicity differences have been reported as determining factors for the use of the service and the advice given. The aim of the study was to explore the communication between telenurses and callers in authentic calls to SHD 1177. A qualitative method, using critical discourse analysis (CDA), was chosen. The approach was deductive, that is, the analysis was made in view of a predetermined framework of theory. Twenty calls were strategically chosen and included in the study. The CDA resulted in five types of calls, namely a gatekeeping call, a gendered call, a call marked by impersonal traits, a call with voices of the life world, and finally a counter discourse call. The dominating patterns in the calls were of gatekeeping and biomedical character. Patterns of the societal gender order were found, in that representations of the reluctant male caller and the ideal female caller were identified, but also a call representing a counter discourse. The service seemed difficult to use for patients with low language proficiency. Telenursing could potentially challenge inequalities in health care. However, the discourse of telenursing is dialectically related to neoliberal ideology and the ideology of medicine. It is also situated in a gendered context of ideal femininity and hegemonic masculinity. Through better awareness of gender biases and the callers' different resources for making themselves heard, the communication between telenurse and caller might become more equal and thereby better suitable for all callers.

Pettersson M, Hedström M and Höglund AT, [Striving for good nursing care: Nurses' experiences of do not resuscitate orders within oncology and hematology care](#), *Nursing Ethics* published online 9 June 2014, DOI: 10.1177/0969733014533238

Abstract: *Background:* Within oncology and hematology care, patients are sometimes considered to have such a poor prognosis that they can receive a do not resuscitate order from the physician responsible, stipulating that neither basic nor advanced coronary pulmonary rescue be performed in the event of a cardiac arrest. Studies on do not resuscitate decisions within oncology and hematology units, focusing on the specific role of the nurse in relation to these decisions, are scarce. *Objective:* The aim of this study was to investigate hematology and oncology nurses' experiences and perceptions of do not resuscitate orders, in order to achieve

a deeper understanding of the nurses' specific role in these decisions. *Research design:* A qualitative, descriptive methodology with individual semi-structured interviews was used. *Participants and research context:* A total of 15 nurses from eight hematology/oncology wards in four hospitals in Sweden were interviewed individually. *Ethical considerations:* In accordance with national regulations, an ethical review was not required for this study. The research followed international guidelines for empirical research, as outlined in the Helsinki Declaration. *Findings:* The nurses strived for good nursing care through balancing harms and goods and observing integrity and quality of life as important values. Experienced hindrances for good care were unclear and poorly documented decisions, uninformed patients and relatives, and disagreements among the caregivers and family. The nurses expressed a need for an ongoing discussion on do not resuscitate decisions, including all concerned parties. *Conclusion:* In order to provide good nursing care, nurses need clear and well-documented do not resuscitate orders, and patients and relatives need to be well informed and included in the decisions. To increase the understanding for each other's opinions within the medical team, regular ethical discussions are required.

Gottvall M, [Introduction of School-Based HPV Vaccination in Sweden: Knowledge and Attitudes among Youth, Parents, and Staff](#), 2013, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, doctoral dissertation.

Abstract: The overall aim of this thesis is to provide a better understanding of knowledge, attitudes, consent, and decision-making regarding Human papillomavirus (HPV) vaccination, seen from the perspectives of concerned parties – high school students, school nurses, and parents. Two quantitative studies were performed: one descriptive cross-sectional study and one quasi-experimental intervention study. Qualitative studies using focus group interviews and individual interviews were also performed. High school students' knowledge about HPV and HPV prevention was low but their attitudes toward HPV vaccination were positive. An educational intervention significantly increased the students' knowledge regarding HPV and HPV prevention. Their already positive attitudes toward condom use and HPV vaccination remained unchanged. The students wanted to receive more information about HPV from school nurses. The school nurses were also positive to HPV vaccination but identified many challenges concerning e.g. priorities, obtaining informed consent, culture, and gender. They saw an ethical dilemma in conflicting values such as the child's right to self-determination, the parents' right to make autonomous choices on behalf of their children, and the nurse's obligation to promote health. They were also unsure of how, what, and to whom information about HPV should be given. Parents, who had consented to vaccination of their young daughters, reasoned as follows: A vaccine recommended by the authorities is likely to be safe and effective, and the parents were willing to do what they could to decrease the risk of a serious disease for their daughter. Fear of unknown adverse events was outweighed by the benefits of vaccination. Parents also saw the school nurse as an important source of HPV information. **Conclusions:** Positive attitudes toward HPV vaccination despite limited knowledge about HPV, are overarching themes in this thesis. School nurses have a crucial role to inform about HPV prevention. It is important that the concerned parties are adequately informed about HPV and its preventive methods, so that they can make an informed decision about vaccination. A short school-based intervention can increase knowledge about HPV among students. From a public health perspective, high vaccination coverage is important as it can lead to a reduced number of HPV-related disease cases.

Jalmsell L, Forslund M, Hansson MG, Henter JI, Kreichbergs U, Frost BM, [Transition to noncurative end-of-life care in paediatric oncology: a nationwide follow-up in Sweden](#), *Acta Paediatrica* 2013;102(7):744-748.

Abstract: The aim of this study was to estimate whether and when children dying from a malignancy are recognized as being beyond cure and to study patterns of care the last weeks of life. A nationwide retrospective medical record review was conducted. Medical records of 95 children (60% of eligible children) who died from a malignancy 2007–2009 in Sweden were studied. Eighty-three children (87%) were treated without curative intent at the time of death.

Children with haematological malignancies were less likely to be recognized as being beyond cure than children with brain tumours [relative risks (RR) 0.7; 95% confidence interval (CI) 0.6–0.9] or solid tumours (RR 0.8; 0.6–1.0). The transition to noncurative care varied from the last day of life to over four years prior to death (median 60 days). Children with haematological malignancies were treated with a curative intent closer to death and were also given chemotherapy (RR 5.5; 1.3–22.9), transfusions (RR 2.0; 1.0–4.0) and antibiotics (RR 5.3; 1.8–15.5) more frequently than children with brain tumours the last weeks of life. The majority of children dying from a malignancy were treated with noncurative intent at the time of death. The timing of a transition in care varied with the diagnoses, being closer to death in children with haematological malignancies.

Godskesen T, Nygren P, Nordin K, Hansson M, Kihlbom U, [Phase I clinical trials in end-stage cancer: patient understanding of trial premises and motives for participation, Supportive Care in Cancer, 2013;21\(11\):3137-3142.](#)

Abstract: In cancer, phase 1 clinical trials on new drugs mostly involve patients with advanced disease that is unresponsive to standard therapy. The purpose of this study was to explore the difficult ethical problems related to patient information and motives for participation in such trials. A descriptive and explorative qualitative design was used. Fourteen cancer patients from three different phase 1 trials in end-stage cancer were interviewed. The interviews were analysed using qualitative content analysis. The patients expressed unrealistic expectations of therapeutic benefit and inadequate understanding of the trials' purpose, so-called therapeutic misconception. However, they reported a positive attitude towards participation. Thus, the patients valued the close and unique medical and psychological attention they received by participating. Participation also made them feel unique and notable. **Conclusions:** Patients with end-stage cancer participating in phase 1 clinical trials are unaware of the very small potential for treatment benefit and the risk of harm. Trial participation may offer hope and social-emotional support and a strategy for coping with the emotional stress associated with advanced cancer and may, consequently, improve emotional well-being.

Gottvall M, Grandahl M, Höglund AT, Larsson M, Stenhammar C, Andrae B & Tydén T, [Trust versus concerns: how parents reason when they accept HPV vaccination for their young daughter, Upsala Journal of Medical Sciences 2013;118\(4\)263-270.](#)

Abstract: *Background.* From spring of 2012, human papillomavirus (HPV) vaccine against cervical cancer is offered free of charge to all girls aged 10–12 years through a school-based vaccination programme in Sweden. The aim of this study was to explore how parents reason when they accept HPV vaccination for their young daughter and also their views on HPV-related information. *Methods.* Individual interviews with parents ($n = 27$) of 11–12-year-old girls. The interviews were recorded, transcribed verbatim, and analysed using thematic content analysis. *Results.* Three themes emerged through the analysis: *Trust versus concern*, *Responsibility to protect against severe disease*, and *Information about HPV and HPV vaccination is important*. The parents expressed trust in recommendations from authorities and thought it was convenient with school-based vaccination. They believed that cervical cancer was a severe disease and felt a responsibility to protect their daughter from it. Some had certain concerns regarding side effects and vaccine safety, and wished for a dialogue with the school nurse to bridge the information gaps. *Conclusions.* Trust in the recommendations from authorities and a wish to protect their daughter from a severe disease outweighed concerns about side effects. A school-based vaccination programme is convenient for parents, and the school nurse has an important role in bridging information gaps. The findings from this qualitative study cannot be generalized; however, it can provide a better understanding of how parents might reason when they accept the HPV vaccination for their daughter.

Jalmsell L, Onelöv E, Steineck G, Henter JI, Kreicbergs U, [Hematopoietic stem cell transplantation in children with cancer and the risk of long-term psychological morbidity in the bereaved parent](#), *Bone Marrow Transplant*, 2011;46(8):1063-70.

Abstract: We have investigated whether hematopoietic stem cell transplantation (HSCT) before the death of children with cancer has a long-term effect on the physical and psychological well-being of the parents. A nationwide questionnaire was sent out to all bereaved parents in Sweden who had lost a child due to a malignancy from 1992 to 1997. Self-reported levels of anxiety, depression and quality of life as well as overall psychological and physical well-being in bereaved parents of children who underwent HSCT were compared with bereaved parents whose children did not receive a transplant. Bereaved parents whose children underwent HSCT had, according to a visual digital scale, an increased relative risk (RR) of long-term anxiety (RR 1.5; 95% confidence interval (CI) 1.0-2.1), poor psychological well-being (RR 1.3; 95% CI 1.1-1.5), low quality of life (RR 1.4; 95% CI 1.2-1.7) and poor physical health (RR 1.3; 95% CI 1.1-1.5), whereas the State-Trait Anxiety Inventory and 'The Göteborg Quality of Life Instrument' were non-significantly increased (RR 1.3; 95% CI 0.8-2.3 and RR 1.7; 95% CI 0.9-3.3, respectively). The risks of these consequences were further augmented in case of multiple HSCT. We suggest that bereaved parents of children undergoing HSCT may be at greater risk of decreased psychological well-being than other bereaved parents of children with cancer.

Gottvall M, Tydén T, Larsson M, Stenhammar C, Höglund AT. [Challenges and opportunities of a new HPV immunization program - Perceptions among Swedish school nurses](#). *Vaccine*, 2011;29(28):4576-4583.

Abstract: *Aim:* To investigate school nurses' perceptions of HPV immunization, and their task of administering the vaccine in a planned school-based program in Sweden. *Method:* Data were collected through five focus group interviews with school nurses (n=30). The interviews were recorded, transcribed verbatim and analyzed using content analysis. *Findings:* The theme *Positive attitude to HPV immunization despite many identified problems and challenges* summarizes the results. The school nurses saw the program as a benefit in that the free school-based HPV immunization program could balance out social inequalities. However, they questioned whether this new immunization program should be given priority given their already tight schedule. Some also expressed doubts regarding the effect of the vaccine. It was seen as challenging to obtain informed consent as well as to provide information regarding the vaccine. The nurses were unsure of whether boys and their parents should also be informed about the immunization. *Conclusion:* Although some positive aspects of the new HPV immunization program were mentioned, the school nurses primarily identified problems and challenges; e.g. regarding priority setting, informed consent, culture and gender. In order to achieve a good work environment for the school nurses, and obtain a high coverage rate for the HPV immunization, these issues need to be taken seriously, be discussed and acted upon.

Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter JI, [Anxiety is contagious- symptoms of anxiety in the terminally ill child affect long-term psychological well-being in bereaved parents](#), *Pediatr Blood Cancer*, 2010;54(5):751-7.

Abstract: We studied the relation between unrelieved symptoms in terminally ill children and the psychological well-being in the bereaved parents 4-9 years after their loss. We contacted parents in Sweden who had lost a child to a malignancy 1992-1997. The parents were asked to assess symptoms affecting their child's well-being during his or her last month of life, and their own current psychological well-being. Altogether 449/561 (80%) eligible parents supplied information on 19 specific symptoms that may occur in children with a malignancy and how each of these symptoms had affected their child's well-being during his or her last month of life (not applicable, none, low, moderate, or severe). These results were linked to questions concerning the parents' self-assessed mental health. Parents of children who were affected by disturbed sleep also had increased risk to develop these symptoms; RR 2.0 [1.4-2.9] for depression, 1.8 [1.3-2.5] for anxiety, 1.5 [1.2-1.8] for decreased psychological well-being, and 1.5 [1.3-1.9] for decreased quality of life. Bereaved parents whose children were affected by

anxiety or disturbed sleep due to anxiety or pain had an increased risk of long-term psychological morbidity. Reducing psychological complications in seriously ill children may also improve the psychological well-being in bereaved parents.

Kaminsky E, Carlsson M, Höglund AT, Holmström I. [Paediatric health calls to Swedish telenurses – A descriptive study of content and outcome](#). *Journal of Telemedicine and Telecare*. 2010;16:454-457

Abstract: We collected data about telephone triage calls concerning children in Sweden. A sample of 110 paediatric calls were recorded. The transcribed data were analysed regarding word count, reasons for calling, results of calls, ages and gender of children, and gender of parents. The median call length was 4.4 min and the median child's age was 3.5 years. Mothers made 73% of calls, but mothers and fathers called to the same extent about daughters and sons, and regardless of age. The most common reasons for calls were ear problems, rash/wound or fever. In nearly half the calls, the telenurses provided self-care advice. Call length, word count or caller's part of word count did not differ according to gender of parents or children. However, mothers were more likely to receive self-care advice while fathers were more often referred to other health services by the telenurses. Telenurses might need to improve their gender competence, and more male telenurses in the service would potentially be beneficial to callers.

Arnetz JE, Winblad U, Höglund AT, Lindahl B, Spångberg K, Wallentin L et al. [Is patient involvement during hospitalization for acute myocardial infarction associated with post-discharge treatment outcome? An exploratory study](#). *Health Expectations*. 2010;13:298-311.

Abstract: *Objective:* To investigate whether patient involvement during hospitalization for acute myocardial infarction (MI) was associated with health and behavioural outcomes 6–10 weeks after hospital discharge. *Background:* Patient involvement has been associated with improved health outcomes in chronic disease, but less research has focused on the effects of patient involvement in acute conditions, such as MI. *Design:* Self-administered questionnaire study. Questionnaire results were run against medical outcome data in a national database of cardiac patients. *Setting and participants:* Cardiac patients (n = 591) on their first follow-up visit after hospitalization for MI at 11 Swedish hospitals. *Main outcome measures:* Patient ratings of three questionnaire scales related to involvement; cardiovascular symptoms, medication compliance, participation in cardiac rehabilitation, and achievement of secondary preventive goals. *Results:* More positive patient ratings of involvement were significantly associated with fewer cardiovascular symptoms 6–10 weeks after hospital discharge. In contrast, patients who attended cardiac rehabilitation and achieved the goals for smoking cessation and systolic blood pressure were significantly less satisfied with their involvement. No association was found between involvement ratings and medication compliance. *Conclusion:* This study represents a first attempt to examine associations between patient involvement in the acute phase of illness and short-term health outcomes. Some significant associations between involvement and health and behavioural outcomes after acute MI were found. However, higher involvement ratings were not consistently associated with more desirable outcomes, and involvement during hospitalization was not associated with MI patient health and behaviour 6–10 weeks after hospital discharge to the extent hypothesized.

Höglund AT, Winblad U, Arnetz B, Arnetz J. [Patient participation during hospitalization for myocardial infarction. Perceptions among patients and personnel](#). *Scandinavian Journal of Caring Sciences*. 2010;24: 482-489.

Abstract: *Background:* Patient participation in healthcare decision-making and illness management has been associated with high patient satisfaction ratings and improved treatment outcomes in chronic diseases. Less is known about patient participation in acute illness, such as myocardial infarction (MI). *Aim:* To explore and describe patient and personnel perceptions of patient participation in care processes and decision-making during hospitalization for MI.

Method: A descriptive qualitative design was used. Five thematic focus group interviews were carried out (n = 25), two with patients and three with personnel, at three Swedish hospitals in 2005. Two researchers were present during the interviews; one as facilitator and one responsible for documentation. The interviews were recorded, transcribed verbatim and analysed through a thematic stepwise method. *Results:* Five themes emerged from the interviews: the meaning of patient participation, positive outcomes, difficult situations, hindrances and facilitating factors. A shared basic assumption in all groups was that patient participation is valuable and desirable in the patient–doctor/nurse encounter in MI care. However, both staff and patients viewed patient participation primarily as information. Active involvement in medical decision-making was less emphasized. Participation was judged as especially difficult to achieve during the initial, emergency phase of MI, although the informants also stressed the need for information in this phase. Positive outcomes of patient participation mentioned were that the patient may feel more secure if involved and that he/she might be more committed to the recovery process. Hindrances were lack of time, staff and, in patients, medical knowledge. Patient characteristics could also influence the level of participation. *Conclusion:* If patient participation is to be achieved in all phases of MI care, patients need to be made aware of their right to participate. Health care professionals need to develop appropriate communication skills for each phase of the MI patient's hospitalization.

Gottvall M, Tydén T, Höglund AT, Larsson M. [Knowledge of human papillomavirus among high school students can be increased by an educational intervention.](#) *International Journal of STD & AIDS* 2010; 21:558-562.

Abstract: The aim of this study was to evaluate the effect of an educational intervention concerning human papillomavirus (HPV) directed at Swedish first year high school students. The intervention consisted of a class room lesson, a website and a folder. Outcome variables were knowledge of HPV and attitudes to preventive methods such as HPV vaccination, condom use and Pap smear testing. An intervention group (n = 92) was matched with two comparison groups (n = 184). At baseline, the median score for HPV knowledge was one out of 10 in both groups. At follow-up, the median knowledge score had increased to six in the intervention group, but was still one in the comparison group (P < 0.001). Attitudes to HPV vaccination, condom use and Pap smear testing remained the same (P > 0.05). In conclusion, a short school-based intervention can greatly increase the students' knowledge about HPV, but attitudes and behaviours are less easy to influence.

Höglund AT, Eriksson S, Helgesson G. [The role of guidelines in ethical competence building – Perceptions among research nurses and physicians.](#) *Clinical Ethics* 2010; 5:95-102.

Abstract: The aim of the present study was to describe and explore the perception of ethical guidelines and their role in ethical competence-building among Swedish physicians and research nurses. Twelve informants were interviewed in depth. The results demonstrated that the informants had a critical attitude towards ethical guidelines and claimed to make little use of them in practical moral judgements. Ethical competence was seen primarily as character-building, related to virtues such as being empathic, honest and loyal to patients. Ethical competence was assumed to be learned through good examples, role models and practical experience, while ethical guidelines were not perceived as valuable in this process. In order to improve the staff's familiarity with and the usability of ethical guidelines, the workplace needs to provide opportunities for ethical dialogues. In such discussions, argumentation can improve, virtues can be developed and guidelines can be usefully invoked.

Gottvall M, Larsson M, Höglund AT, Tydén T. [High vaccine acceptance despite low awareness among Swedish upper secondary school students.](#) *The European Journal of Contraception and Reproductive Health Care* 2009; 14:399-405.

Abstract: *Objective:* To investigate knowledge of human papillomavirus (HPV) and attitudes to HPV vaccination and condom use among Swedish first year upper secondary school students.

Methods: Classroom questionnaire filled in by 608 students from a strategic sample of seven upper secondary schools in Sweden. *Results:* Only 13.5% (n=82) of the students had heard about HPV and 6% (n=35) were aware of HPV vaccination. As many as 84% (n=508) would like to be vaccinated against HPV. The high cost of vaccination was the greatest obstacle (total group 37%, n=227); among girls the second major hindrance was the fear of needles (19%, n=65). Before considering an HPV vaccination 73% (n=443) wanted more information and 36% (n=220) would like to receive such information from the school nurse. The students considered it less likely that they would use a condom when having intercourse with a new partner if they were vaccinated than if they were not ($p < 0.001$). *Conclusion:* Despite intensive marketing directed at potential vaccine consumers, knowledge of HPV and of HPV vaccines was very low among first year upper secondary school students. Their attitude towards vaccination was positive but most of them wanted more information before considering vaccination.

Höglund AT, Helgesson G, Eriksson S. [Ethical dilemmas and ethical competence in the daily work of research nurses](#). *Health Care Analysis* 2010; 18:239-51.

Abstract: In spite of the growing interest in nursing ethics, few studies have focused on ethical dilemmas experienced by nurses working with clinical studies as 'research nurses'. The aim of the present study was to describe and explore ethical dilemmas that Swedish research nurses experience in their day-to-day work. In a qualitative study a purposeful sample of six research nurses from five wards of differing disciplines in four Swedish hospitals was interviewed. The analysis displayed several examples of ethical dilemmas, primarily tensions between the nurses' obligations to the study and to the patients involved. A guiding moral principle for the nurses was patient-centeredness, where the interest of research must not override the interest of the patient. In situations where tensions between research and patient interests occurred, and doctors and nurses disagreed upon the judgement, the nurses sometimes chose to follow the doctors' advice, and thus acted against their own moral judgment. Such situations seemed to create feelings of moral distress among the nurses. They described their profession as being 'invisible' and as lacking opportunities for ethical competence building. The conclusion is that research nurses frequently experience severe and difficult ethical dilemmas in their daily work. They need to be acknowledged as a particular profession in the health care organisation and encouraged to develop their specific ethical competence.

Höglund AT, Holmström I. [Ethical issues in telenursing](#). *International Hospital Equipment and Solutions*. 2009; 7:18-19.

Abstract: Telenursing in healthcare brings advantages for both patients and personnel: for example, the improvement of resource- and time allocation and access for patients. However, this technique might also entail ethical difficulties. In this article a range of ethical aspects that are particularly challenging in telenursing are discussed.

Höglund AT, Tydén T, Hannerfors AK, Larsson M. [Knowledge of human papillomavirus \(HPV\) and attitudes to vaccination among Swedish high school students](#). *International Journal of STD & AIDS* 2009; 20:102-107.

Abstract: The aim of the study was to investigate knowledge of and attitudes to sexually transmitted infection (STI) and STI prevention with special focus on human papillomavirus (HPV) and the new vaccine against HPV, among 16-year-old high school students in a Swedish context. A study-specific questionnaire was distributed to 572 first year high school students from five different high schools in a medium-sized town in Sweden. The students lacked knowledge of HPV and its association with cervical cancer. Similarly, their knowledge of the new vaccine was limited. Their attitude to condom use when having sex with a new partner was positive, but decreased if oral contraceptives were used and if they were vaccinated against an STI. The main source of information was the school, followed by youth clinics and the media. The results highlight the clinical importance for school nurses and personnel at youth clinics to inform adolescents about HPV and its association with cancer.

Höglund AT, Holmström I. [“It’s easier to talk to a woman.” Aspects of gender in Swedish telenursing.](#) *Journal of Clinical Nursing* 2008; 17: 2979-2986.

Abstract: *Aim:* To describe and explore gender aspects in telenursing as experienced by Swedish telenurses. *Background:* Telenurses at call centres in Sweden offer triage recommendations and self-care advice to the general public over the telephone, on a wide range of health problems. The demands on telenurses are multifaceted and competence is needed in many fields such as nursing, pharmacology, psychology and communication. Previous studies have shown that telenurses encounter many ethical dilemmas and that some of these are to do with gender related issues. Most telenurses, as well as most callers, are women. It is, therefore, reasonable to believe that gender plays an important role in the work of telenurses. *Design:* Descriptive and explorative qualitative design. *Methods:* A purposive sample of 12 female telenurses in Sweden participated in in-depth interviews twice during 2004–2005. The transcribed interviews were analysed inductively with a stepwise thematic method. *Results:* Five themes emerged from the interviews, namely: female subordination in the family, disrespect in dialogue with female nurses, distrust in fathers’ competence, reluctant male callers and woman-to-woman connection. *Conclusions:* Gender construction and cultural gender norms seem to be at work in the encounter between Swedish telenurses and callers. Questions of power relations, the picture of the mother/woman as the primary carer for small children and distrusting men in their parental role were particularly highlighted. *Relevance to clinical practice:* Telenurses should be aware of the risk of stereotyping their dialogues with callers in a way that seems to fit better with female callers’ ways of communicating. Clinical supervision based on reflective practice and peer reviews of calls might diminish this risk. Telenurses also need more training in handling overt or covert power messages based on male superiority.

Holmström I, Höglund AT. [Response to commentary.](#) *Journal of Clinical Nursing* 2008; 17:3251-3252.

Response to: Winch, S. Commentary on Holmström I & Höglund AT (2007). The faceless encounter: Ethical dilemmas in telephone nursing. *Journal of Clinical Nursing* 16:1865-1871. *Journal of Clinical Nursing* 2008; 17:3249-3251.

Arnetz JE, Höglund AT, Arnetz BB, Winblad U. [Development and evaluation of a questionnaire for measuring patient views of involvement in myocardial infarction care.](#) *European Journal of Cardiovascular Nursing* 2008; 7: 229-238.

Abstract: *Background:* Patients’ involvement in their healthcare has been associated with improved treatment outcomes in chronic illness. Less is known about the affects of patient involvement on the outcomes of acute illness, such as myocardial infarction. A better understanding of patients’ views and behaviour during hospitalization might improve clinical practice and enhance patient involvement. *Aim:* The aim of this study was to develop and evaluate a questionnaire for measuring patients’ perceptions of their involvement during hospitalization for myocardial infarction care. *Methods:* Focus groups with myocardial infarction patients provided the basis for the construction of the questionnaire. Questionnaire validity and reliability were evaluated in a small pilot study and a larger cross-sectional study among myocardial infarction patients at eleven Swedish hospitals. *Results:* The questionnaire demonstrated good validity and reliability, with six factors measuring patient views and behaviour regarding involvement. *Conclusion:* The questionnaire appears to be a useful tool for evaluating the perceptions and behaviour of patients regarding patient involvement in myocardial infarction care. Use of this questionnaire may provide insight regarding areas of patient–staff interaction that need improvement. Pinpointing such areas may lead to improved patient involvement, satisfaction with care, and treatment outcomes.

Arnetz JE, Winblad U, Arnetz BB, Höglund AT. [Physicians' and nurses' perceptions of patient involvement in myocardial infarction care](#). *European Journal of Cardiovascular Nursing* 2008; 7:113-120.

Abstract: *Background:* Patients' involvement in their healthcare has been associated with better health outcomes. However, few studies have examined whether patient involvement affects the work of healthcare professionals. A better understanding of professionals' views and behaviour is necessary for improving clinical practice and optimizing patient involvement. *Aim:* To measure perceptions and behaviour regarding patient involvement among physicians and nursing staff caring for patients with acute myocardial infarction. *Methods:* A questionnaire study conducted in 2005 among cardiology staff at twelve Swedish hospitals. The questionnaire included six scales measuring staff views and behaviour. *Results:* Physicians, registered nurses, and practical nurses did not differ significantly in their views of patient involvement, but did differ significantly in behaviour ($p < .001$). All three groups felt that an actively involved patient enriched their work, at the same time increasing their work load and taking time from other tasks. Physicians discussed daily activities and lifestyle changes with myocardial infarction patients before hospital discharge to a greater extent than nursing staff ($p < .001$). *Conclusion:* Physicians and registered nurses viewed time constraints as a hinder for patient involvement, while practical nurses felt unsure in communicating with patients. Considering these organizational and professional issues may improve patient involvement and health outcomes in myocardial infarction care.

Arnetz JE, Höglund AT, Arnetz BB, Winblad U. [Staff views and behaviour regarding patient involvement in myocardial infarction care: Development and evaluation of a questionnaire](#). *European Journal of Cardiovascular Nursing* 2008; 7:27-35.

Abstract: *Background:* Healthcare legislation in several nations now dictates the responsibility of health care professionals to involve patients in decisions concerning care and treatment. However, few studies have examined the impact of patient involvement on the work of health care professionals. A better understanding of staff views and behaviour might enhance patient involvement. *Aim:* The aim of this study was to develop and validate a questionnaire for measuring views and behaviour regarding patient involvement among physicians and nursing staff caring for patients with myocardial infarction. *Methods:* Focus groups among cardiology staff provided the basis for the construction of the questionnaire. Questionnaire validity and reliability were evaluated in a small pilot study and a larger cross-sectional study among cardiology staff at twelve Swedish hospitals. *Results:* The questionnaire demonstrated good validity and reliability, with two factors measuring staff views and four measuring behaviour. *Conclusion:* The questionnaire appears to be a useful tool for evaluating the perceptions and behaviour of physicians and nursing staff regarding patient involvement in myocardial infarction care. Use of this questionnaire may provide insight regarding areas of staff-patient interaction that need improvement, as well as implications of patient involvement for the work of each professional group on cardiology wards.

Eriksson S, Höglund AT, Helgesson G. [Do ethical guidelines give guidance? A critical examination of eight ethics regulations](#). *Cambridge Quarterly of Healthcare Ethics* 2008; 17:15-29.

Abstract: The number of legal and non-legal ethical regulations in the biomedical field has increased tremendously, leaving present-day practitioners and researchers in a virtual crossfire of legislations and guidelines. Judging by the production and by the way these regulations are motivated and presented, they are held to be of great importance to ethical practice. This view is shared by many commentators. For instance, Commons and Baldwin write that, within the nursing profession, patient care can be performed unethically or ethically depending on the professional standards the nurses have set for themselves. They also hold that such standards are set when nurses become aware of the ethical codes available. As nurses are often not familiar with the codes, they do not all conform to them. Commons and Baldwin argue that nurses' ability to deal with ethical dilemmas is effectively secured with education on guidelines, creating a "barrier" between personal and professional values (p. 5).

Eriksson S, Helgesson G, Höglund AT. [Being, doing, and knowing: Developing ethical competence in health care practice](#). *Journal of Academic Ethics* 2007; 5:207-216.

Abstract: There is a growing interest in ethical competence-building within nursing and health care practising. This tendency is accompanied by a remarkable growth of ethical guidelines. Ethical demands have also been laid down in laws. Present-day practitioners and researchers in health care are thereby left in a virtual cross-fire of various legislations, codes, and recommendations, all intended to guide behaviour. The aim of this paper was to investigate the role of ethical guidelines in the process of ethical competence-building within health care practice and medical research. A conceptual and critical philosophical analysis of some paragraphs of the Helsinki Declaration and of relevant literature was performed. Three major problems related to ethical guidelines were identified, namely, the interpretation problem (there is always a gap between the rule and the practice, which implies that ethical competence is needed for those who are to implement the guidelines); the multiplicity problem (the great number of codes, declarations, and laws might pull in different directions, which may confuse the health care providers who are to follow them); and the legalisation problem (ethics concerns may take on a legal form, where ethical reflection is replaced by a procedure of legal interpretations). Virtue ethics might be an alternative to a rule based approach. This position, however, can turn ethics into a tacit knowledge, leading to poorly reflected and inconsistent ethical decisions. Ethical competence must consist of both being (virtues) and doing (rules and principles), but also of knowing (critical reflection), and therefore a communicative based model is suggested.

Holmström I, Höglund AT. [The faceless encounter. Ethical dilemmas in telephone nursing](#). *Journal of Clinical Nursing* 2007; 16:1865-1871.

Abstract: This paper aims to present the findings of a study designed to describe ethical dilemmas, in the form of conflicting values, norms and interests, which telenurses experience in their work. *Background:* Telephone nursing is an expanding part of health care. Telephone nurses in Sweden assess care needs, provide advice, support and information, and recommend and coordinate healthcare resources. Lately, ethical demands on healthcare professionals in general have increased. The reasons include new biomedical competence, an ageing population and constrained resources which have made priority setting a primary concern for doctors and nurses. When ethical problems arise, colleagues need open dialogue. Despite this, nurses lack such a dialogue. *Method:* A purposeful sample of 12 female telenurses in Sweden was interviewed twice during 2004 and 2005. The transcribed interviews were analysed thematically. *Results:* Five themes were found: talking through a third party; discussing personal and sensitive problems over the phone; insufficient resources and the organization of health care; balancing callers' information needs with professional responsibility; and differences in judging the caller's credibility. *Conclusion:* The present study has identified five different themes in which Swedish telenurses experience ethical dilemmas in their work. This shows how ethical dilemmas in various forms are present in telenursing. Questions of autonomy, integrity and prioritizing are particularly highlighted by the participating nurses. Telenurses in Sweden also experience new ethical demands due to a multicultural society. Although several of the identified dilemmas also occur in other areas of nursing we argue that these situations are particularly challenging in telenursing. *Relevance to clinical practice:* The work organization should provide opportunities for ethical competence-building, where ethical dilemmas in telenursing are highlighted and discussed. Such a strategy might lead to decreased moral uncertainty and distress among telenurses, with positive consequences for callers.

Kälvemark Sporrang S, [Ethical competence and moral distress in the health care sector. Prospective evaluation of ethics rounds](#). Dissertation, Acta Universitatis Upsaliensis, Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine, 2007

Abstract: Ongoing structural and financial changes in the health care sector have resulted in increased risks for ethical dilemmas and moral distress. It is purported that increased ethical competence will help staff manage ethical dilemmas and hence decrease moral distress. To

enhance ethical competence several approaches may be used – theoretical education, and methods focusing on reflection and decision-making abilities. Ethics rounds are a widespread systematic method hypothesized to improve ethical competence, nurture a reflective climate, and help in ethical decision-making. Despite its popularity, its effects on moral distress have hitherto never been evaluated in a controlled study. The purpose of this thesis was to evaluate the impact of an intervention, including ethics rounds; the hypothesis being that the intervention would decrease perceived moral distress. An additional aim was exploring the concept of moral distress in various health care establishments, including pharmacies. Focus groups were conducted to explore the concept of moral distress. To evaluate the intervention a scale assessing staff-perceived moral distress was designed, validated, and implemented. Results showed that moral distress is evident in diverse health care settings. Some factors associated with this were lack of resources, conflicts of interest, and rules that are incompatible with practice. An expanded definition of moral distress was presented. The training program was much appreciated by participants. However, no significant effects on perceived moral distress were found. Reasons could be that the intervention was too short or otherwise ineffective, there is no association between ethical competence and moral distress, the assessment scale was not sensitive enough, or management was not sufficiently involved. There is a need to further refine the various aspects of ethical dilemmas in clinical settings, and to evaluate the most efficient means to enhance skills for dealing with ethical dilemmas, for the benefit of staff, patients, institutions, and society.

Källemark Sporrang S, Arnetz B, Hansson MG, Westerholm P, Höglund AT.
[Developing ethical competence in health care organizations.](#) *Nursing Ethics* 2007;
14:825-837.

Abstract: Increased work complexity and financial strain in the health care sector have led to higher demands on staff to handle ethical issues. These demands can elicit stress reactions, that is, moral distress. One way to support professionals in handling ethical dilemmas is education and training in ethics. This article reports on a controlled prospective study evaluating a structured education and training program in ethics concerning its effects on moral distress. The results show that the participants were positive about the training program. Moral distress did not change significantly. This could be interpreted as competence development, with no effects on moral distress. Alternatively, the result could be attributed to shortcomings of the training program, or that it was too short, or it could be due to the evaluation instrument used. Organizational factors such as management involvement are also crucial. There is a need to design and evaluate ethics competence programs concerning their efficacy.

Jalmsell L, Kreicbergs U, Onelöv E, Steineck G, Henter JI, [Symptoms affecting children with malignancies during the last month of life: a nation wide follow-up.](#) *Pediatrics*, 2006; 117(4): 1314-20.

Abstract: In a population-based nationwide survey, we aimed to study symptoms in children with malignancies during the last month of their lives. Understanding which symptoms affect children in the terminal phase of disease is crucial to improve palliative care. We attempted to contact all parents in Sweden who had lost a child to cancer during a 6-year period. The parents were asked, through an anonymous postal questionnaire, about symptoms that affected the child's sense of well-being during the last month of life. Information was supplied by 449 (80%) of 561 eligible parents. The symptoms most frequently reported with high or moderate impact on the child's well-being were: physical fatigue (86%), reduced mobility (76%), pain (73%), and decreased appetite (71%). Irrespective of the specific malignancy, physical fatigue was the most frequently reported symptom, and pain was among the 3 most frequently reported. Children who died at 9 to 15 years of age were reported to be moderately or severely affected, by a number of symptoms, significantly more often than other children. The gender of the reporting parent had no significant bearing on any of the symptoms reported. The most frequently reported symptoms in children with malignancies to be aware of and possibly address during the terminal phase are physical fatigue, reduced mobility, pain, and decreased appetite. Children aged 9 to 15 years are reported to be moderately or severely affected by more symptoms than children in other age groups. Mothers and fathers report a similar prevalence of symptoms.

Källemark Sporrang S, Höglund AT, Arnetz B. [Measuring moral distress in pharmacy and clinical practice](#). *Nursing Ethics* 2006; 13:416-427.

Abstract: This article presents the development, validation and application of an instrument to measure moral distress in different health care settings. The concept of moral distress has been discussed and developed for 20 years. A few instruments have been developed to measure it, predominantly in nursing. The instrument presented here consists of two factors: level of moral distress and tolerance/openness towards moral dilemmas. It was tested in four clinics and three pharmacies, where 259 staff members completed a questionnaire. The two factors were found to be reliable. Differences in levels of moral distress were found between pharmacies and clinical departments, and between the youngest and oldest age groups; departmental staff and the youngest age group experienced higher levels of moral distress. Departments reported less tolerance/openness towards moral dilemmas than pharmacies. The instrument needs to be tested further, but its strengths are the focus on every day ethical dilemmas and its usefulness in different health care settings.

Källemark Sporrang S, Höglund AT, Hansson MG, Westerholm P, Arnetz B. ["We are white coats whirling round"](#). *Moral distress in Swedish pharmacies*. *Pharmacy World and Science* 2005; 27:223-229.

Abstract: *Objective:* The extended role of pharmacists has made pharmacy practice more complex and increased the moral responsibility of pharmacy staff. Consequently, ethics has become an important part of their daily work. In health care, ethical dilemmas have been shown to cause distress, usually referred to as "moral distress". Moral distress among hospital personnel has been well described and discussed in numerous studies. There are very few similar studies in pharmacy settings. This article reports on the results of an investigation concerning whether, and in what situations, moral distress is present in pharmacy practice. *Method:* A questionnaire derived from focus group data, covering ethically troubling situations in pharmacy settings, was distributed to all staff of three pharmacies in Sweden. *Results:* The results show that moral distress is experienced in the day-to-day pharmacy practice, and that it is in many ways connected to care providing. For example, prioritizing between customers was reported as very stressful. Younger personnel reported higher moral distress than their older colleagues did. However, there were no differences between pharmacies. A lack of support structures, such as meetings where ethical issues can be discussed, was reported by all the participating pharmacies. *Conclusion:* It is reasonable to assume that moral distress is even more present in pharmacy practice than in other health care areas as it is, in general, much more sensitive and exposed to the modern, demanding customer. The meeting with the customer is on a more neutral ground than in, for example, a hospital setting. Although there are ethical codes for pharmacists, they are not enough. Moral distress is experienced anyway; general codes and personal coping strategies must be supplemented with support from the management and work organization. There is a need to look more closely at specific factors related to the degree and extension of moral distress, going beyond individual coping strategies.

Källemark S, Höglund AT, Hansson MG, Westerholm P, Arnetz B. [Living with conflicts. Ethical dilemmas and moral distress in the health care system](#). *Social Science and Medicine* 2004; 58:1075-1084.

Abstract: During the last decade the Swedish health care system has undergone fundamental changes. The changes have made health care more complex and ethics has increasingly become a required component of clinical practice. Considering this, it is not surprising that many health care professionals suffer from stress-related disorders. Stress due to ethical dilemmas is usually referred to as "moral distress". The present article derives from Andrew Jameton's development of the concept of moral distress and presents the results of a study that, using focus group method, identifies situations of ethical dilemmas and moral distress among health care providers of different categories. The study includes both hospital clinics and pharmacies.

The results show that all categories of staff interviewed express experiences of moral distress; prior research has mostly focused on moral distress experienced by nurses. Second, it was made clear that moral distress does not occur only as a consequence of institutional constraints preventing the health care giver from acting on his/her moral considerations, which is the traditional definition of moral distress. There are situations when the staff members do follow their moral decisions, but in doing so they clash with, e.g., legal regulations. In these cases too, moral distress occurs. Hitherto research on moral distress has focused on the individual health care provider and her subjective moral convictions. Our results show that the study of moral distress must focus more on the context of the ethical dilemmas. Finally, the conclusion of the study is that the work organization must provide better support resources and structures to decrease moral distress. The results point to the need for further education in ethics and a forum for discussing ethically troubling situations experienced in the daily care practice for both hospital and pharmacy staff.

MONOGRAPHTES & BOOK CHAPTERS

Höglund AT. Etiska aspekter på att rutinmässigt fråga om erfarenheter av våld i nära relationer. (Ethical aspects on screening for intimate partner violence). I: [Att fråga om våldsutsatthet som en del i anamnesen](#). Uppsala: NCK Rapport 2010:4, s. 95-103.

Abstract: The chapter deals with some of the ethical issues that are raised by the routine of screening for intimate partner violence in health care. It is argued that if this routine is to be implemented, the staff needs to develop adequate ethical competence. The benefit of the screening may outweigh the risks, as it can result in early detection and help for those who have experienced violence in their intimate relationships and hence improve these patients' quality of life. Screening might also reduce the number of mistreatments and new appointments and can thereby be cost effective for the health care system. Concerning the ethical issue of integrity it is argued that the screening must be done in a well-considered and thoughtful way. Also, the documentation needs to be plain and informative, in order to avoid stigmatizing those who have experienced intimate partner violence. Finally, it is argued that adequate ethical competence is needed if the discussed ethical requirements are to be fulfilled. The responsibility for such a competence development rests not only on the individual care provider, but also on the health care management.

Höglund AT. Genusperspektiv på att rutinmässigt tillfråga kvinnor om våld i nära relationer. (Gender perspectives on screening for intimate partner violence among women). I: [Att fråga om våldsutsatthet som en del i anamnesen](#). Uppsala: NCK Rapport 2010:4, s. 105-111.

Abstract: The chapter deals with aspects of gender in relation to the routine of screening for intimate partner violence in health care settings. It is argued that those who are to ask about experiences of violence need to be well aware of the connection between gender and violence in intimate relationships. A high gender competence can make the screening safer and reduce the risk of improper and insulting treatment of those who have experienced intimate partner violence. High ethical competence also implies a better readiness for how to encounter and support these patients. Concerning the question of whether both women and men should be asked about experiences of violence in intimate relationships it is argued that based on research that has reported a high incidence of men's violence against women, it is reasonable to limit the screening to female patients only, at least in a first step. It is emphasized that the screening must not take place when the woman's partner is in the room. Based on theories of intersectionality and heteronormativity the risk of neglecting violence in same sex relations is discussed, and it is argued that women with immigrant background, disabled women and women from honor cultures might need special attention.

Höglund AT. Gender and Bioethics. In Blomqvist M & Ehnsmyr E (Eds.) [Never Mind the Gap! Gendering Science in Transgressive Encounters](#). Skrifter från Centrum för Genusvetenskap/Crossroads of Knowledge 15. Uppsala: University Printers, 2010, pp. 213-238.

Abstract: The main task for bioethicists has always been to protect vulnerable patients and research subjects from harm and abuses. Likewise, the legal and moral rights of patients and research subjects have also been at the core of this tradition. In spite of this, neither gender, nor ethnicity or class, have been much observed within bioethics. In this article it is argued that the lack of gender perspectives in bioethics mainly depends on two main features of the bioethics tradition, namely, the dominance of principles and the influence of liberal individualism. Groups and their moral interests have not been much explored within traditional bioethics, and hence injustices based on identity constituting factors, such as gender, ethnicity,

age, class, and sexuality have been unobserved. In the article, some examples of recent advances in bioethics with a gender perspective are given; for example, the critique of principle-based ethics and the development of the ethical principle of autonomy from a relational perspective. Finally, one example of bioethics with a gender perspective is presented, namely, a study on how gender, age and ethnicity can influence priority setting in health care. The conclusion is that a gender perspective impacts both topic and method as well as theoretical assumptions in bioethics.

Höglund AT. Inga lätta val. Om riktlinjer och etisk kompetens vid prioriteringar i vården. En studie i empirisk etik. (No Easy Choices. On Guidelines and Ethical Competence in Priority Setting in Health Care. A Study in Empirical Ethics). Uppsala Studies in Faiths and Ideologies 15. Uppsala: Acta Universitatis Upsaliensis 2005, 176 pp.

Abstract: The need for well-informed priorities in the Swedish health care has increased since the 1990s. This development is due to different factors, such as the advanced competence in biotechnology, the demographic changes with an increasing number of old people, and a political and economical development marked by increasing demands and diminishing allocations for health care. According to the ethical platform approved by the Swedish Parliament in 1997, three ethical principles should guide priority setters on all levels, namely the principle of human dignity, the principle of need and solidarity and the principle of cost-efficiency. Following these guide-lines, chronological age, gender and ethnicity are not valid grounds for priority setting, as that would violate the principle of human dignity. In this study the relationship between ethical codes and the health care giver's moral praxis is studied. The investigation is a study in empirical ethics, where both qualitative and philosophical methods are used. A strategic sample of nine doctors, nurses and auxiliary nurses participated in openly conducted interviews. The interviews were transcribed and analysed through categorisation. The results show that the informants are not well aware of the current guide-lines for priority setting in health care. For example, they do set priorities based on chronological age, which they justify through a justice argument, namely that "it is not fair if some people live for only 50 years". It was also made clear that gender and ethnicity could inflict the priority decisions. The conclusion is that we need to make the health care providers' moral competence more conscious, which requires support structures, for example in the form of ethical discussion forum in hospital clinics. Theoretically, this means that the hitherto dominant traditions within medical ethics, principle based ethics and virtue ethics, need to be combined with a communicative ethics approach.

Höglund AT. Reflektioner över etik och prioriteringar i vården – intervjuer med vårdpersonal. (Reflections on Ethics and Priority Setting in Health Care – Interviews with Health Care Providers). Linköping: Prioriteringscentrum, Rapport 7, 2003, 86 pp.

Abstract: This report is part of a larger study on priority setting in health care. The aim was to investigate health care providers' knowledge and use of the ethical guidelines for priority setting adopted by the Swedish Parliament in 1997. Nine doctors, nurses and auxiliary nurses participated in openly conducted interviews. The results displayed that the informants saw the guidelines as vague and therefore not as action guiding. Further, the informants described how they experienced the guidelines to be contradictory. For example, the principle of human dignity was not always compatible with the principle of cost effectiveness. The conclusion is that there is a need for new arenas and open procedures in the decision-making process for priority setting in health care.

Holmström I, Höglund AT. Det ansiktslösa mötets etik. Sjuksköterskors erfarenheter av etiska dilemman vid telefonrådgivning. (The ethics of the faceless encounter. Nurses' experiences of ethical dilemmas in telephone counselling). Holmström I. (ed.): Telefonrådgivning in hälso- och sjukvård. (Telephone Counselling in Health Care) Lund: Studentlitteratur 2008, pp. 91-105.

Abstract: Telenursing in health care can bring advantages for both patients and personnel in the form of resource- and time allocation and improved access for patients. However, this technique might also entail ethical difficulties. In this article, the results of a qualitative investigation of telenurses' experiences of ethical dilemmas in telenursing are presented. The findings display that ethical dilemmas in various forms are present in telenursing. Questions of autonomy, integrity and prioritising were particularly highlighted by the participating nurses. Although several of the identified dilemmas also occur in other areas of nursing, it can be argued that these situations are particularly challenging in telenursing, since the encounter is faceless. The conclusion is that the work organization needs to provide opportunities for ethical competence-building, where ethical dilemmas in telenursing are highlighted and discussed. Such a strategy might lead to decreased moral uncertainty and distress among telenurses, with positive consequences for patients and callers.