Caring in research and practice
- some nursing aspects

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ABSTRACT

This thesis has a caring science perspective (caring in nursing). The general aim was to gain a deeper understanding of important aspects of caring in clinical practice from both the patients' and nurses' perspectives and to illuminate essential aspects of caring for future nursing research. In Study I, aspects of caring important to women (n = 10) suffering from breast cancer and the importance of the outcome of caring for patients' health and wellbeing was illuminated with a descriptive exploratory method. In Study II, caring and its influence on excellent nurses' (n = 5) attitudes, actions and professional growth was studied with a descriptive phenomenological approach. In Study III, caring as described in the medical and nursing records of lower-limb amputees (n = 45) was explored by content analysis. Study IV was conducted to illuminate essential areas in caring for future patient-related nursing research. A three-round Delphi technique was used on 95 nurses within a health care district.

The results highlight the need for health care professionals who are competent, compassionate, courageous and concordant in order to develop caring in health care practice. The results also indicate that caring has a positive impact on vulnerable patients' health and wellbeing and on nurses' professional growth. Furthermore, this thesis explores the problem of documenting patients' suffering and caring needs in nursing records and the risk of inadequately prioritizing or of underestimating these needs. When prioritizing important areas for patient-related nursing research, informed nursing practitioners prioritize research areas that will assure patients' wellbeing and a caring environment. Research areas across the full continuum of care, from wellness to death, are regarded as important. A focus on research aimed at preserving humanistic values and developing collaboration between health care providers across organizational boundaries in the health care system is stressed.

This thesis points out the importance of caring encounters in modern health care practice and the need for investigation and research on connections with the creative use of health care resources in the 21st century.

Keywords: caring in research; caring in practice; patients' perspectives; nurses' perspectives; descriptive exploratory method; descriptive phenomenological method; content analysis; Delphi technique.

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SVENSK SAMMANFATTNING

Denna avhandling belyser några grundläggande aspekter av mänsklig omsorg (caring) inom professionell omvårdnad. Det övergripande syftet var dels att få en djupare förståelse för vilka aspekter av mänsklig omsorg i omvårdnaden (caring in nursing) som är väsentliga för både patienter och sjuksköterskor och dels att klargöra vilka områden inom mänsklig omsorg som sjuksköterskor prioriterar för framtida forskning. Avhandlingen har en vårdvetenskaplig ansats och är en sammanläggning av fyra delarbeten. Delarbete I och II belyser betydelsen av mänsklig omsorg från patienters och sjuksköterskors perspektiv. Delarbete III beskriver hur mänsklig omsorg dokumenteras i medicinska - och omvårdnadsjournaler. Delarbete IV visar på att mänsklig omsorg är ett prioriterat forskningsområde för framtiden.

Delarbete I

Mänsklig omsorg är viktig för patienternas välbefinnande

Kvinnor som drabbats av bröstcancer utgör en stor grupp bland de cancersjuka. De utsätts för ingrepp och behandlingar som påverkar såväl kropps- som självuppfattningen. Dessa patienter antas vara i särskilt behov av en mänsklig omsorg och personlig omvårdnad. För att få en fördjupad kunskap om vilka aspekter av mänsklig omsorg i omvårdnaden som påverkar patienters hälsa och välbefinnande i positiv riktning genomfördes intervjuer med tio (n=10) bröstcanceropererade kvinnor. I en av frågorna ombads patienterna att berätta om en sjuksköterska som genom sitt förhållningssätt visat prov på mänsklig omsorg och att beskriva en situation där sjuksköterskans agerande hade haft en avgörande positiv betydelse för dem. Intervjuerna spelades in på band och skrevs ut ordagrant och analyserades med en deskriptiv exploratorisk metod. För patienterna innebar ett omsorgsfullt möte att sjuksköterskorna uppvisade kompetens, medkänsla, civilkurage och kongruens i omvårdnadssituationen. Särskilt betydelsefullt var att sjuksköterskan snabbt kunde etablera en kontakt och komma på samma våglängd som patienten. Att vara närvarande i mötet ansågs som särskilt viktig för att en vårdrelation skulle utvecklas. Genom sin kompetens identifierade sjuksköterskan patientens individuella behov, vilket resulterade i att patienten upplevde trygghet, välbefinnande och styrka i att klara av livets dagliga aktiviteter. Genom sjuksköterskans medkänsla och äkta engagemang upplevde patienten sig respekterad som person. När sjuksköterskan vågade möta patientens oro och frustration kunde en känsla av hopp och mening framkallas. Att våga förmedla ett svårt besked på ett omsorgsfullt sätt ansågs mycket viktigt för patienterna. Genom sjuksköterskans omsorg utvecklades en

tillitsfull interpersonell relation som kännetecknades av vänskap, samförstånd och balans. De sjuksköterskor som hade förmågan att vara på samma våglängd betraktades av patienterna som excellenta (hade gröna fingrar för vård). Att få kontakt, att vara på samma våglängd och att sjuksköterskorna gjorde ”det lilla extra” beskrevs som det viktigaste för att patienterna skulle uppleva mänsklig omsorg i kontakten med sjuksköterskorna.

Delarbete II

Mänsklig omsorg påverkar sjuksköterskors attityder, handlingar och professionell utveckling

Betydelsen av mänsklig omsorg i patient-sjuksköterskerelationen bedömdes bäst kunna beskrivas av sjuksköterskor som var ansedda som särskilt omsorgsfulla i sitt yrkesutövande. Klinikchefer och klinikföreståndare inom sluten somatisk vård i ett landsting valde ut 32 sjuksköterskor som lämpliga informanter. Dessa sjuksköterskor ombads bland annat att beskriva en situation där deras handlande hade haft en avgörande positiv betydelse för patienterna. Fem (n=5) av intervjuerna innehöll beskrivningar av situationer som bedömdes som så innehållsrika att de kunde åskådliggöra fenomenet i sin helhet. Intervjuerna skrevs ut ordagrant och analyserades med hjälp en deskriptiv fenomenologisk metod. Gemensamt för de situationer som hade haft en avgörande positiv betydelse för patienterna var att sjuksköterskorna hade blivit djupt berörda av att bevittna patienters lidande, utsatthet och öde. Genom att låta sig beröras väcktes en känsla av närhet, förståelse och engagemang för patienten som person. Samtidigt som sjuksköterskorna upplevde frustration och indignation i en sådan situation, väcktes en moralisk förpliktelse att göra gott för patienten och att agera omsorgsfullt för patientens räkning, i enlighet med det humanistiska värderingssystem som utgör fundamentet i omvårdnaden. Sjuksköterskornas förmåga att visa medmänsklighet i omvårdnaden utvecklades och genom dessa möten växte de som yrkesmänniskor.

Delarbete III

Mänsklig omsorg är ofullständigt beskriven i omvårdnadsjournalen

För att studera hur mänsklig omsorg uttrycks i journalhandlingar genomfördes en retrospektiv studie av medicinska - och omvårdnadsjournaler för patienter som amputerades vid ortopedkliniken, Uddevalla sjukhus, 1997 (n=45). Förutom uppgifter om demografi, vård, behandling och rehabilitering studerades omvårdnadsrelaterade uppgifter. Informationen i omvårdnadsjournalerna

analyserades med hjälp av innehållsanalys. Under analysen användes sökorden i VIPS dokumentationsmodell som ett kategoriseringsraster. Analysen visade att äldre benamputerade hade stora och svåra medicinska problem såväl före som efter amputationen vilket antogs vara förenat med stort lidande.

Av dokumentationen framgår att de som överlevde amputationen hade problem som var relaterade till smärta/smärtlindring, nutrition, elimination, cirkulation, sår och sömn. Smärtproblemen hänfördes till tre specifika områden nämligen smärta orsakad av bakomliggande sjukdom, smärta som komplikation av amputation och smärta utan angiven orsak. Fantomsmärtor fanns noterade i nio av omvårdnadsjournalerna. För att beskriva smärtan användes termen ”ont” utan närmare förklaring, typ eller specifik lokalisering. Alla patienter som avled (n=8) i samband med sjukhusvistelsen hade förutom problem med smärta och smärtlindring också problem med nutrition, elimination, sårläkning, kommunikation, välbefinnande och psykisk tillstånd. Sökorden användes inte konsekvent i omvårdnadsjournalen. Objektiva symtom och problem var relativt klart beskrivna, även om de presenterades osystematiskt. Anteckningar som berörde samma problem fanns noterade under olika sökord. Störst variation återfanns i formuleringar som berörde patienternas problem med elimination, smärta, hud och välbefinnande. Välbefinnande, psykiskt tillstånd och kommunikation användes synonymt i flera av journalerna. Endast enstaka noteringar fanns som berörde patienternas önskemål, värderingar, subjektiva upplevelser, behov av omsorg och delaktighet i omvårdnaden.

Delarbete IV

Mänsklig omsorg är en viktig aspekt för framtida omvårdnadsforskning

Det övergripande syftet med denna studie var att identifiera angelägna områden för framtida patientnära omvårdnadsforskning. Studien genomfördes med den s.k. Delfi-metoden under tre ronder. Av resultatet framgår att forskning om mänsklig omsorg prioriteras högt av expertpanelen. I synnerhet betonades vikten av forskning som kan bidra till att säkra patientens välbefinnande, integritet och en vårdmiljö som genomsyras av mänsklig omsorg. Expertpanelen (n=95) prioriterade forskning om hur man etablerar en relation som bevarar människans värdighet, skapar omsorgsfulla möten, utvecklar attityder och värderingar samt får patienten att känna sig respekterad och lyssnad till. Forskning kring betydelsen av beröring, näring, tröst, hopp, sömn, stimulans för tillfrisknandet prioriterades också. Likaså betonade expertpanelen betydelsen av forskning kring mänsklig omsorg för utveckling av olika samverkansformer och utifrån den berörda individens perspektiv.

Implikationer

Mänsklig omsorg framstår i denna avhandling som mycket viktig i alla möten inom hälso- och sjukvården. För att visa mänsklig omsorg krävs en betydande kunskap om hur man möter patienten som en unik person. Resultaten tyder på att mänskliga omsorgsmöten främjar patientens aktiva medverkan, stärker människovärdet och minskar missnöje med hälso- och sjukvården. Av denna anledning föreslås:

- framtida studier som belyser sambandet mellan patienternas uppfattning av mänsklig omsorg och graden av tillfredsställelse med vårdresultatet, liksom hur mänsklig omsorg kan användas som en kvalitetsindikator
- studier som belyser upplevelsen av mänsklig omsorg. Det behövs forskning som klargör vilka professionella, organisatoriska och sociala faktorer som påverkar attityder och beteenden av mänsklig omsorg
- studier i hur man utvecklar en begreppsmässig struktur för dokumentation av mänsklig omsorg, den mänskliga omsorgens värden, problemlösning och patienttillfredsställelse
- forskning som bevarar och stärker människovärdet i morgondagens hälso- och sjukvård.

Slutsatser

Resultatet av denna avhandling visar att mänsklig omsorg är viktig, men hittills en alltför osynlig och outforskad aspekt i dagens hälso- och sjukvård. Mänsklig omsorg har inte bara betydelse för läkningsprocessen utan också för att utveckla en trygg och effektiv vårdmiljö. Ju mer avancerad och sofistikerad vård och behandling som införs desto viktigare är det att alla som arbetar inom vården kan skapa mänskliga omsorgsmöten där patienternas integritet och värdighet bevaras.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals (I-IV):

I. Jensen KP, Bäck-Pettersson SR, Segesten K. Catching my wavelength - perceptions of the excellent nurse.
Nurs Sci Q 1996;9:115-20

II. Bäck-Pettersson S, Jensen KP, Segesten K. The meaning of being touched deeply inside in a nurse-patient encounter - excellent nurses' experiences.
Int J Hum Caring 1999;2:16-23

III. Bäck-Pettersson S, Björkelund C. Care of elderly lower-limb amputees, as described in medical and nursing records.
Scand J Caring Sci 2005;19: 1-7

IV. Bäck-Pettersson S, Hermansson E, Sernert N, Björkelund C. Research Priorities in Nursing - a Delphi Study among Swedish nurses.
Submitted for publication

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Contents

ABBREVIATIONS

CVD	CardioVascular Disease
NANDA	North American Nursing Diagnosis Association
NIC	Nursing Interventions Classification
NOC	Nursing Outcomes Classification
IPW	Importance to Patient Welfare
LLA	Lower Limb Amputation
SNBHW	Swedish National Board of Health and Welfare
UGH	Uddevalla General Hospital
ULF	Survey of Living Conditions [Undersökning om levnadsförhållanden i Sverige]
VIPS	Wellbeing, Integrity, Prevention and Security
VHCO	Value to the Health Care Organization
VNP	Value to the Nursing Profession

DEFINITIONS

Care (http://wordnet.princeton.edu/perl/webwn)
As a noun, care is used to describe the work of providing treatment for or attending to someone or something; judiciousness in avoiding harm or danger; an anxious feeling; a cause for feeling concern; attention and management implying responsibility for safety; activity involved in maintaining something in good working order. As a verb, care means to feel concern or interest; to provide care for; to prefer or wish to do something; to be in charge of, act on, or dispose of; to be concerned with.

Caring (http://wordnet.princeton.edu/perl/webwn)
As a noun, caring is used to describe a loving feeling. As a verb, caring is defined as feeling concern or interest; providing care for; preferring or wishing to do something; being in charge of, acting on, or disposing of; being concerned with. As an adjective, caring means showing a care; having or displaying warmth or affection; feeling and exhibiting concern and empathy for others.

Nursing (http://wordnet.princeton.edu/perl/webwn)
As a noun, nursing is used to describe the work of nurses for the sick or, injured or infirm; the profession of a nurse; nourishing at the breast. As a verb, nursing is to try to cure by special care of treatment, of an illness or injury; to maintain a theory, thoughts or feelings; to care for sick or handicapped people; to treat carefully: to give suck to.

INTRODUCTION

"Good-bye", said the fox, "and now I am going to entrust you with my secret. It is quite simple: only with the heart can you see properly. The essential thing is invisible to the eye."
"The essential thing is invisible to the eye", repeated the little prince, the better to remember it.
"It is the time you have spent on the rose that makes it so meaningful."
"It is the time I have spent on my rose", said the little prince, the better to remember it.
"Mankind has forgotten that truth", said the fox. "But you must not forget it. You are for ever responsible for what you have tamed. You are responsible for your rose."
"I am responsible for my rose", repeated the little prince, the better to remember it.

Antoine de Saint-Exupéry

This excerpt from "The Little Prince" is used here to illuminate some more or less visible aspects of human caring that are infrequently explored in modern health care practice. Caring with the heart make us see properly, according to the Little Prince. What essential aspects of caring are more or less visible to the eye but easy to feel in our hearts?

We all see when caring is present and we also know when caring is absent. We can immediately experience caring when we meet another human being without even speaking. Caring can manifest itself in a gentle touch, a tender look or a serene tone of voice, like an exchange of emotions between people. We can recall caring memories just by looking at a picture or listening to an old song. As an expression of the human heart, caring seems to play an important role in the modern scientific, technological and bureaucratic health care systems.

Internationally, Swedish health care standards are reportedly relatively high and residents of Sweden are entitled to health care services of good quality on equal terms, easily accessible to all and with respect for the patient's integrity and his/her right to make his/her own decisions. The services are to be organized and offered in dialogue with the patient and close relatives and the patient should be empowered and participate in his/her care at all levels of the health care organization (Health and Medical Act, 1982).

Few sectors are as dependent on their staff as the health care services, which involve human interaction in every encounter. This interaction between patient and caregiver is governed partly by the dimension, capacity and availability of

the services but there are also qualitative aspects, depending on how the interaction functions. The outcome of these encounters is, to a great extent, determined by the staff's knowledge and skill as well as by their attitudes and personal characteristics (1).

Discussions have been ongoing, not least in the Nordic countries, regarding how nursing care should be developed in order to preserve human caring while satisfying society's demands for high-quality, efficient and effective health care. In Sweden, the National Board of Health and Welfare (SNBHW) has suggested more than 60 overall quality indicators for health care service. They conclude that most registers focus on technical data, while aspects of caring in nursing and patients' experiences of care were less frequently described (2).

Moreover, data from the recurrent Surveys of Living Conditions (ULF) indicates that attitudes toward the health care services have become somewhat less positive during the past ten years, especially expressed as conceptions about poor accessibility and lack of continuity and coordination between units and care levels in the health care organization as a whole (3).

A recent (Spring, 2006) study of written complaints about the provision of health care in the Västra Götaland region in Sweden, revealed that patients felt that caregivers gave them insufficient time, that the staff did not listen to them and had nonchalant and sometimes hostile attitudes. Even indignities were experienced in encounters with health care professionals (unpublished report).

It was assumed in this thesis that caring plays an important role in health care practice, in preserving individuals' dignity, integrity and wholeness. It was also assumed that caregivers, as well as care recipients, benefit from a caring contact and that a caring relationship is needed in times when health care practice becomes more product-oriented, mechanistic and technical. In other words, the time has come to focus more on the "quality of caring" in conjunction with discussions about the "quality of care".

BACKGROUND

Caring as a human mode of being

Caring is the human mode of being in every relationship. Caring is far more than wishing another person well, liking, comforting, maintaining or having an interest in what happens to the other (4).

Mayeroff (4) states that the more deeply we understand the central role of caring in our own lives, the more we realize its centrality as a human condition within human relations. In the case of a parent, caring in its most profound sense is to patiently and respectfully enable the child to grow in his or her own time and way. It is trusting the child to let go, showing devotion grounded in the

worth of the other, being humble in learning from the other, being honest and showing genuine concern, having hope for the realization of the other, alternating between doing or not doing for the other and having the courage to go into the unknown with the other, respecting the primacy of the process of becoming. Caring is to truly see the other, as he/she is, not how one would like him/her to be, to have a genuinely humble attitude towards the other and to understand that person's world as if one were inside it. Helping other people grow also entails encouraging and assisting them to care for something or someone other than themselves, as well as for themselves (4).

When caring for another person, one must consider his/her nature, way of living and needs and desires (5). Knowing another person requires openness, participation and empathy. To Buber (6), the "I-it" relationship is necessary for human life and progress to understand and order the world. But he claims that such a relationship is a purely subjective process, lacking any mutuality, and marked by the subject – object dichotomy. In an "I-it" relationship, both parties experience, but experiencing takes place within the person and not between individuals. The "I-Thou" relationship involves a real encounter and genuine mutuality, an encounter in which confirmation of both is established; caring connectedness is rooted in such a relationship by affirming and encouraging the best in others. Caring connectedness and authentic communication occurs when the "self," or the "I," of each person interacts in the "I-Thou" relationship. The togetherness in Buber's "I-Thou" encounter is essential in that it facilitates spiritual growth, creates meaning for the experience and potentiates transcendence. According to Buber (6), all living is meeting in a real sense, a meeting of souls where the heart is the core issue and this "I-Thou" relationship serves as the basis for a warm and relational human understanding of caring.

In health care practice, all professionals are expected to be humane and sensitive and to believe in and understand the meaning of values, choices and priority systems in relation to their patients (7). Solidarity between people in a society is built on the fact that all humans potentially require high-quality medical and nursing care and a health care system that satisfies a diversity of needs (8).

In professional caring, the patient/person is always in a situation of risk and vulnerability because caring highlights what matters to the individual. This means that relationships, things and events that matter in a person's life affect his/her reactions to and experiences of caring. By caring, professionals attend to the "objectness" of people without reducing them to the moral status of objects, according to Gadow (9). Both Mayeroff and Noddings describe uncaring behaviours such as possessing, manipulating, dominating (4), fighting, killing, vandalism and inflicting psychological pain (5). When planning this study, it was assumed that it is of the utmost importance, in the moment of a clinical face-to-face encounter, that health care practitioners firmly understand the

meaning of values, choices and priority systems within which a patient's/person's values are expressed. This is essential in order to be able to positively influence the outcome for human beings seeking help as well as to preserve human caring in clinical practice (7, 9-11). All members of the health care team who directly encounter patients are engaged in a special kind of human relationship characterized by a vulnerable human being in distress and another human being who has declared and professed that he/she is competent to heal. This relationship is different from a commercial or legal relationship, according to Pellegrino (12).

Caring in the discipline of nursing

Nursing as an academic discipline is derived from the same concept of science as medicine, since all caring actions are based on the intent to do "good" in a broader sense (13). Roach (14) regards caring as "unique *in* nursing as the concept which subsumes all the attributes descriptive of nursing as a human helping discipline" (p. 8-9).

Caring is not regarded as one of the core concepts in the discipline of nursing. However, some nursing scholars assert that caring is central to the science and art of nursing (14-17), as no other profession is so totally concerned with caring behaviours, caring processes and caring relationships (18). This author sympathizes with Smith's (19) statements that nursing is not caring, but that nursing cannot exist without caring.

The theoretical concept of caring has been explored by Boykin (20) from five different perspectives: ontological (the being of caring), anthropological (the meaning of being a caring person), ontical (caring attitudes), epistemological (development of personal, empirical, ethical and aesthetical knowledge), and pedagogical (teaching and learning).

In this thesis the being of caring, the meaning of being a caring person and caring attitudes served as areas to explore in relation to nursing practice as well as nursing research.

In the ontological perspective, the focus is on the 'being of caring' as an intrinsically human expression, inseparable from our nature as human beings, (21) and a way of living. Caring is the active engagement in the person-to-person process of being and becoming (17) and the "risking of being with someone toward a moment of joy" (22) p.130. The being of caring is not merely a strategy, procedure or action but the ethical foundation of nursing action and a moral principle or ideal (9) (23, 24). Caring as the moral ideal means that nurses have a moral commitment to protect, enhance and preserve human dignity in the intersubjective human process (17) and a sensitivity to the moral meaning of actions in an asymmetric encounter (24). Caring as a will, a commitment, an

intention, as well as an ideal, is grounded in humanism. Nursing as a caring profession bears a responsibility for safeguarding "a holistic and personalized approach to individual, family and community" (25) p.11. The preservation and safeguarding of life and health can only occur through genuine caring (8, 23, 26-29). In Watson's (30) opinion, both nursing and medicine are moving from a cure-dominated paradigm to a paradigm in which caring takes precedence.

The anthropological perspective, on the other hand, addresses caring in nursing as being a caring person in relation to cultural beliefs, practices and the survival of all human beings. According to Watson (17), caring-healing moments are created when both patient and nurse transcend self, time and space and share a common energy field. If the caregiver has the courage to be authentic in an encounter, reciprocity and togetherness are experienced by both the caregiver and the cared for. Transpersonal caring represents what happens when nurses pay attention to the process of being human, the care activity, the intersubjective feelings between nurses and patients and the individuality of each nurse and patient (31).

The third perspective (ontical) relates to the caring obligations inherent in nursing, e.g. caring attitudes (20). Caring is best accomplished through the nurse's compassion in demonstrating respect for human life and expressing nonpaternalistic values; through competence, by having the knowledge, skill, energy, motivation, judgment and experience necessary to respond appropriately to the call of the patient; through confidence, by showing trust, hope and courage; through conscience, by being humble; and through commitment, by serving humankind and affirming personhood. By involvement in others and concern about their everyday experiences, nurses facilitate the preservation of human caring in the health care system (14). Paradoxically, caring is often more obvious by its absence than by its presence, not only in human affairs in general but also in health care practice.

Caring in nursing practice

The overall aim of nursing is to preserve and promote the health and wellbeing of the patient/person. The nurse identifies a need for care and chooses and implements an action intended to serve as a mean for positive change in the patient (26). In nursing practice, the caring nurse is guided by the moral motivation to do good for the patient (24). Whether an action is caring or not is to be judged solely by the person being cared for (26). Valentine (32) has explored the relationship between caring and cost and concludes that caring is related to satisfaction with the hospital, health outcomes, readiness to leave the hospital, satisfaction with nurses and rating of the hospital. Quality of caring

also predicts patients' knowledge of medications at the time of discharge, clinical condition, and length of stay.

Patients' perspective

Riemen (33), a pioneer in studying caring from patients' perspective, was the first to notice that when patients were asked to describe caring in nursing actions, they initially responded by describing nursing actions that were not caring.

Patients' perceptions of caring have been reported as being strongly related to "what the nurse is like", "what the nurse does" and "how she does it" (34). When studying patients' experiences of being cared for by a nurse, Brown (35) claims that meeting treatment needs in a manner that protects and enhances the unique needs of the individual was regarded as important because the nurse became "a reassuring presence to the patient" in this situation (p.60). Moreover, the importance of making the patient a decision-making participant in the treatment was stressed. Validating the effect of caring on patients' wellbeing in relation to the reduction of time spent with them was regarded as important. This is confirmed in a recent study of outcomes of caring in nursing. Werner *et al.* (36) reported that emotional wellbeing, emotional comfort, reassurance/ security, hope, satisfaction with nursing and with the hospital, nurse-patient relationship and healing were positively influenced by nurses' caring.

In her phenomenological study, Riemen (37) found that professional caring, from the patients' perspective, is not only what the nurse does in terms of physical acts of assistance but also what the nurse is. Based on three empirical studies in different perinatal contexts, Swanson (38) developed a theory of caring in which caring was defined as "a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility" (p. 165). This way of relating included knowing, being with, doing for, enabling and maintaining belief.

Lövgren *et al.* (39) examined patients' accounts of good and bad caring. Bad caring from the patient's viewpoint was expressed as not being respected, not being listened to, not being treated as a whole human being and the staff being inattentive. Inadequate pain relief, having to wait, forced treatment and staff forgetting a care task were also reported examples of bad caring.

In her thesis on caring and uncaring patient encounters, Halldórsdóttir (40) describes a caring nurse as an indispensable companion. In professional encounters, the patient experienced a caring connection and perceived solidarity, empowerment, wellbeing and healing. Participants in her studies acknowledged a need for a nurse-patient connection characterized by openness, genuine concern, moral responsibility, presence and appropriate involvement (40).

Some studies have indicated that there is a difference between patients' and nurses' perceptions of caring in that nurses overestimate patients' emotional and physical needs (41, 42). Nursing staff considered expressive or affective behaviours to be most important while patients identified competent technological knowledge and physically based caring behaviours as most important. These discrepancies were found among the rankings of behaviours in other studies as well (43-48). Caregivers' openness to patients' perceptions of important caring behaviours as well as the need for validation of staff perceptions of patient needs and concerns is stressed (49).

Nurses' perspective

It is regarded as important for a caring nurse practitioner to create a caring environment in which the dignity and worth of the patient/person is safeguarded. One of the nurse's greatest responsibilities is to welcome the patient and to make him/her feel respected, cared for and entitled to be a patient (50).

Halldórsdóttir (51) described five aspects of caring that are especially important from the professional nurse perspective, i.e. being open and perceptive of others; being genuinely concerned for the patient; being morally responsible; being truly present for the patient; and being dedicated and having the courage to be appropriately involved.

In a cardiac care context, Ford (52) developed six important themes in characterizing caring encounters from the nurses' perspective: sensing the patient's vulnerability; beyond the call of duty; being in tune with the patient's world; being attentively present; centring on the patient; and being comfortable with the patient. She concludes that "caring for" is a way of doing, while "caring" is a way of being.

The meaning of caring from hospital nurses' perspective was described by Forrest (53) as involvement and interacting. Involvement entailed being there, respect, feeling with and for and closeness. Interacting entailed touching and holding, picking up cues, being firm, teaching and knowing the patients well.

To be caring, a nurse must believe in the dignity and worth of the patient/person and be able to identify specific clinical situations in which values influence the outcome for human beings seeking help (54). Nurses who demonstrate excellence in their everyday activities change their practice with each patient and situation (55, 56). Gadow (57) pictures such a relationship as a safe haven - a moral space - where values, roles, actions and desired outcomes are created. She regards such a relationship, like the morality it creates, as a patient-nurse ontology or a way of being as a person, patient or nurse and as part of a professional relationship (57).

The caring encounter

In health care practice, the encounter between the patient and the caregiver should be caring. In a study of nurses with a special gift for caring (i.e. excellent in clinical practice), Jensen and Bäck-Pettersson (58, 59) found that the ability to intentionally create caring moments was imperative. By analyzing caring situations important to patients, the nurses created caring moments through their consciousness and way of being, using their competence, compassion and courage. In these moments, mutual attention, harmony and trust was established. In the caring moment, authentic presence and connectedness were demonstrated and affirmation as well as meaning and hope for the future were experienced. These caring moments often resulted in a practical down-to-earth solution to an identified problem.

This view of caring moments is congruent with that of Wolf (60), who describes caring occurring during moments of shared vulnerability between nurses and patients, benefiting both, and occurring when nurses respond to patients in a caring situation. In these caring situations, connectedness between the patient and the nurse is established. The caregiver participates in the patient's struggling with suffering and when the patient's suffering evokes the caregiver's compassion, the patient is invited into a caring relationship (27). Several other studies have revealed the necessity of creating such caring encounters in order to protect humanistic values and prevent humiliation within the health care system (27, 35, 37, 40).

In conclusion, research confirms the importance of caring and its significance for human life and existence. Caring is needed in all relationships between human beings. In general, caring is a concern for all health care professionals in asymmetrical health care encounters. In nursing, the characteristics of caring encounters from the nurses' perspective are relatively well described. The meaning and outcome of caring encounters from the patients' and nurses' perspectives do, however, require further investigation.

AIMS

The general aim of this thesis was to gain a deeper understanding of important aspects of caring in clinical practice from both the patients' and nurses' perspectives and to illuminate essential aspects of caring for future nursing research.

Specific aims

- to explore aspects of caring important to vulnerable patients' health and wellbeing (I)
- to describe how caring influences nurses´ attitudes, actions and professional growth (II)
- to explore caring as described in medical and nursing records (III)
- to illuminate essential areas for future patient-related nursing research (IV)

MATERIAL AND METHODS

An overview of research design and methodologies included in the thesis are presented below (Table 1).

Study	Design	Data analysis	Subjects
I	Inductive Descriptive	Qualitative Descriptive exploratory	10 patients
II	Inductive Descriptive	Qualitative Phenomenological	5 expert nurses
III	Deductive Descriptive	Retrospective cohort study	45 medical and nursing records
IV	Inductive Descriptive	Delphi technique	95 nurses

Table 1. Overview of design, approaches and methodologies.

Subjects

Ten women participated in Study I. The Danish Cancer Society helped locate the subjects, who were all members of a breast cancer support club. The women had undergone breast cancer surgery more than one year ago and were still in secondary treatment; none of them were hospitalized. Their mean age was 50 (41-60) years, the mean interval since the surgery was 6 (1.5-17) years. Eight women were married and all but one were employed outside the home.

In Study II, essential narratives were recorded from five female nurses (of 32) in head nurse and staff nurse positions in in-patient wards at three general

hospitals. Their mean age was 43 (24-60) years, and their mean duration of professional experience was 18 (3-39) years. Purposive sampling was used to deliberately seek out subjects with distinctly differing opinions and understanding of the phenomenon under investigation (61).

In Study III, data from medical and nursing records was examined. There were 90 lower limb amputations (LLA) in the Uddevalla General Hospital (UGH) district in 1997; 48 patients were >60 years of age. The medical records of these patients were retrospectively scrutinized. As the records of three patients were missing, the study population consisted of the medical and nursing records of 45 patients.

A panel of 95 (4 male) nurses, head nurses, staff nurses, teachers/researchers and administrators participated in Study IV. The subjects' ages ranged from 25-67 (mean 49) years and they had an average of 23 (1-40) years in nursing. The panel consisted of nurses from hospitals (42%), primary health care centres, community care (44%) and administration/education (14%). The nurses were educated during different periods; 66% had graduate diplomas and 34% had an academic education ranging from Bachelor's to doctoral degree.

Study design and analysis

Scientific research is defined by paradigms or conceptual world views. Kuhn (62) uses the concept of paradigm to describe existing theoretical positions, aims and methods within an established discipline. Scientists in the discipline agree to stay within the existing paradigm in their day-to-day work as they seek to extend and refine derived theories, explain puzzling data and establish more precise measures of standards and phenomena. The shared constellation of concepts, values, perceptions and practices of this scientific community forms a particular vision of reality for organizing and sharing the focus for research, theories and goals.

The concept of paradigm is also related to the researchers' world view, view of science, interests and competence. The researcher paradigm is developed during doctoral education but the paradigm is also related to the researcher's professional paradigm and the profession to which he/she belongs (63, 64).

Both quantitative and qualitative research methods have been applied in this thesis. This means that caring has been studied within two distinctly different paradigms: natural science and human science. This distinction relates to both the production of knowledge and the research process (65).

As an academic discipline, nursing is expected to produce knowledge that is relevant and meaningful to nursing practice. It is thus essential to take people's experiences, feelings and values into account when investigating human

phenomena (13). In the discipline of nursing there is an ongoing discussion of paradigm, focusing on whether the paradigm of natural science and the paradigm of humanities can be combined, can exist parallel to each other or are mutually exclusive in nursing research (66).

The choice of methods depends on the nature of the phenomenon, the type of questions asked and the aim of the study. The combination of research approaches – different questions, different sources and different methods – is recommended as it helps us to understand complex phenomena more fully (61).

In this thesis, triangulation has been used in designs, research questions, data collection and methods as it is based on data on caring from the perspectives of patients, nurses and medical and nursing records. Thus, using qualitative and quantitative approaches, data has been dealt with both inductively and deductively.

The purpose of methodological triangulation is to obtain different and complementary data, according to Morse (67). The notion of triangulation is drawn from the idea of "multiple operationalism" which suggests that the validity of findings and the degree of confidence in them will be enhanced by the deployment of more than one approach in data collection (67).

Study I

A variety of qualitative methods can be used to explore the meaning of human experiences. In this study, content analysis was used to understand and describe patients' experiences of the excellent nurse. A descriptive, exploratory method was used. The purpose of this method is to investigate the meaning of a particular life event for a group of subjects who have shared the event (68, 69).

The subjects participated in a semi-structured interview. The overall object was to describe the characteristics of an excellent nurse and a caring situation in which the nurse was involved. The researchers focused on discovering the meaning of these experiences. The subjects were encouraged to give as detailed answers as possible, including feelings, reactions and reflections. They were asked to tell the interviewer everything they had to say on the matter, leaving nothing out. The interview was tape-recorded and transcribed verbatim into Danish and subsequently translated into English since the researchers spoke different languages. The data analysis procedure was conducted in English and included the following six steps: (a) transcripts were read to achieve a sense of the whole, (b) transcripts were analyzed and the essential points were summarized in paraphrases, (c) major themes were extracted, (d) the import of these themes was formulated and organized into theme clusters, (e) theme clusters were formed as concepts and (f) the essence of the studied phenomena was described.

Study II

Phenomenology was the research strategy in Study II. Phenomenology is a philosophy as well as an approach and a method, based on the three main concepts of lifeworld, intentionality and reduction. It is in the concrete, lived existence of the world that phenomenology begins (70). The concept of lifeworld is to be understood as the place in which concrete experiences of everyday life, taken for granted in all human activities, occur. According to Husserl (71) intentionality is the essential feature of consciousness. He refers to the fact that consciousness is always directed towards some object that is not itself consciousness, although it may be, e. g. in the case of reflective acts. When conducting phenomenological research, one is interested in how consciousness grasps an object or event in terms of its meaning to the subject. Intentionality is defined as making the experiences into a full, concrete or abstract picture. In this sense, consciousness completes the experiences of seeing a situation, an object or the object's inner horizons integrated in the actual presentation (70). Phenomenological reduction is a methodological device used to make research findings more precise in searching for the essence.

To seek the essence of the investigated phenomenon, research with a method called free imaginative variations has been suggested by Giorgi (72). The overall aim of this phenomenological method is the description and exploration of the everyday world in a way that expands our understanding of human experiences. The purpose of this method is to obtain knowledge that is systematic, general, critical, methodological and verifiable (73). The method incorporates the rigorous processes of being present to and dwelling with the data, analyzing, and describing the unfolding of the meaning. The lifeworld perspective in turn demands a research methodology in which openness is the central concept. Phenomenology is one possible approach in nursing research (70).

The descriptive phenomenological method was regarded as appropriate to understand the meaning of the phenomenon of being touched deeply inside (73). The data analysis procedure included the following steps: (a) the narratives were read and reread to get a sense of the whole; (b) the subject's naive description in everyday language was discriminated into meaning units, within a nursing perspective and with focus on the phenomenon being investigated; (c) the meaning units were transformed into nursing language in a manner that captured the intuited essence; and (d) the transformed meaning units were synthesized into a general structure of being touched deeply inside by a patient in a nurse-patient encounter (73).

Study III

A retrospective cohort study of medical and nursing records of elderly lower limb amputees was conducted in order to explore caring as described in these

records. Demographic data, hospitalization, rehabilitation and nursing-related data were collected and compared. Data were cross-checked with the SNBHW to ensure that all subjects undergoing surgery in the catchment area during 1997 were included. Data from a demographically corresponding region were obtained in order to enable national comparison.

The information obtained from the medical records was entered into computer files, verified and analysed by descriptive analysis, using SAS statistical systems (74). The chi-square test was used to compare frequencies. When comparing means, the Student's t-test was used and a logistic regression model was used to compare amputation frequencies between populations.

The information obtained from the nursing records was processed with a qualitative content analysis method in which both manifest and latent meanings were sought (75, 76). The analysis was conducted by data reduction. The Swedish documentation model, based on Wellbeing, Integrity, Prevention and Security (VIPS) with keywords on two levels corresponding to the nursing process and relevant concepts for patient care, was used as a scheme for categorizing during the analysis process (77). Frequencies of descriptive statements were calculated and qualitative aspects of statements were organized into categories by themes, indicators and tables. The data were re-examined and re-assessed several times by the two authors to obtain interrater reliability. The analysis and interpretation process involved a rigorous re-contextualization of the information in the hospital records in order to obtain external validity (78).

Study IV

In study IV, a three-round Delphi technique was used to involve professional nurses in illuminating essential areas for future nursing research (79-82).
The Delphi technique can be briefly described as a series of sequential questionnaires or "rounds", interspersed by controlled feedback, aimed at gaining the most reliable consensus of opinion within a group of experts (83).

The Delphi process can be described as multi-stage, with each stage building on the results of the previous one (84). Some common features that characterize the basic Delphi procedure are: sampling and the use of experts, anonymity that provides an equal chance for each panel member to present and react to ideas unbiased by the identities of other participants (81) and a number of rounds in which questionnaires are sent out and used until consensus is reached (85, 86). In each round, a summary of the results of the previous round is included and evaluated by the panel members (87).

The study design (Table 2) and invitation to participate were simultaneously conveyed verbally and online to executives of the participating health care organizations in Fyrbodal in the Västra Götaland region of western Sweden. One hundred and eighteen nurses responded positively to the invitation; all health care institutions in the area were represented. These respondents were

regarded by the researchers as a convenient group of informed individuals and specialists, thus qualifying them as panel members (83, 87, 88).

	Nurse Panel	Questionnaire	Measures	Research Areas
Round I (Creating)	118	Five priority topics in nursing research	Content analysis	380 primary areas
▼				7 main categories 41 sub-categories
Round II (Categorizing)	103	Important to Patient Welfare (IPW)	Statistical analysis	40/137 (IPW)
▼		Value to the Health Care Organization (VHCO)		15/74 (VHCO)
		Value to the Nursing Profession (VNP)		28/86 (VNP)
Round III (Prioritizing)	95	Important to Patient Welfare (IPW)	Statistical analysis	15/40 (IPW)
		Value to the Health Care Organization (VHCO)		15/15 (VHCO)
		Value to the Nursing Profession (VNP)		15/28 (VNP)
		In relation to professional and educational background		The highest ranked areas

Table 2. Overview of the Delphi process.

Round I (creating). Information about the study, including assurance of confidentiality, was distributed by e-mail or fax to the 118 head and staff nurses, teachers/researchers and administrators. They were asked to identify five primary areas/questions of importance to patient-related nursing research, and to provide demographic and educational data. The panel members identified 380 primary areas/questions. The data was subjected to content analysis in order to describe and quantify specific phenomena systematically and objectively (75, 76) and to make valid inferences from verbal, visual or written data which provides interpretations based on systematic and objective scrutiny of the phenomena of interest (78). The review, content analysis and categorization of data resulted in a thirteen-page questionnaire organized in 7 main categories and 41 sub-categories.

Round II (categorizing). The questionnaire from Round I was sent to all 118 panel members for evaluation. Fifteen did not complete Round II due to lack of time. In the questionnaire, the response scales were graded from 1-7 (with 1 for low importance and 7 for high). Each item (research area) was to be evaluated from three different perspectives: *Importance to Patient Welfare* (IPW), *Value to the Health Care Organization* (VHCO) and *Value to the Nursing Profession* (VNP). Data were analyzed using SPSS® descriptive statistics and mean, standard deviation, median and range were calculated when applicable. The mean value was calculated for every item with a median score of ≥6. Ranking lists of items with mean scores ≥ 5.5 were created for each perspective in three different questionnaires, a total of 40 items in the IPW perspective, 15 items in the VHCO perspective and 28 items in the VNP perspective.

*Round III (prioritizing).*The three questionnaires from Round II were sent to all 103 panel members. Three panellists did not complete Round III, four questionnaires were incomplete and were excluded and one panel member responded too late. The 95 remaining panel members were asked to rank, from each perspective, the fifteen most important areas for patient-related nursing research. The highest rank was given 15 points and so forth, on a descending scale, in order to facilitate mean value calculation. Finally, the mean values were re-calculated and re-ranked. The instructions and questionnaires were distributed to each panel member (n=95). Three weeks after the questionnaires had been distributed, an e-mail/fax was sent to thank the participants and remind non-respondents.

ETHICAL CONSIDERATIONS

The Danish Cancer Society approved Study I. Measures were taken to protect confidentiality of the subjects, who were informed that participation was voluntary and about the possibility of dropping out. For Study II, approval was obtained from each participating health care organization. Measures were taken to protect confidentiality of the subjects, who were informed that participation was voluntary and about the possibility of dropping out. The Ethics Committee of Göteborg University approved Study III. For Study IV, approval was obtained from each participating health care organization in the Västra Götaland region of western Sweden. Measures were taken to protect confidentiality of the subjects, who were informed that participation was voluntary and about the possibility of dropping out.

RESULTS

Study I

Caring important for wellbeing of patients

The principal findings in this study were that the patients regarded the excellent nurses as competent, compassionate, courageous and concordant in the caring relationship with them.

In this study, the patients regarded nurses as *competent* when demonstrating knowledge of human beings as well as being able to react and act appropriately in response to individual needs, while preserving autonomy in traumatic situations. Communication skills were demonstrated when individual needs were identified and relevant information was provided. The technically skilled nurse also applied nursing and medical knowledge, creating feelings of continuity and wellbeing. When caring, the excellent nurse used humour, timing and creativity to help the patient find valuable solutions to health problems and the power to manage her activities of daily living.

Furthermore, the patient perceived the nurse as being *compassionate* when she expressed altruism, adopted a genuinely positive approach and showed respect and genuine concern. In that encounter, patients felt that these nurses were really caring. The nurses approached them with constant, unconditional affection by being warm and friendly people, who were openly, honestly and genuinely interested in the patient/person and treated her as one human being treating another. The excellent nurse was regarded as caring when he/she was really interested in how the patients managed in their life situation, was anxious to help them through pain and suffering and was making an extra effort to be supportive.

Patients perceived the nurse as *courageous* when he/she was totally present in a crisis and when he/she transmitted hope and meaning in critical situations. These nurses were regarded as people who were present in chaos, faced death together with their patients and who were able to communicate hope and meaning. When caring, the excellent nurse had the courage to come close and remain in a crisis, steady as a rock when the patients lost control. Finally, the patients reported that the excellent nurse was able to transmit hope and meaning when facing difficult situations by daring to be present and to convey even the most negative messages in a way that made the patients revalue life from another perspective.

In this study, concordance appeared to be more important to the patients than expected and was described as directly related to their perception of excellence in nursing. Patients perceived the excellent nurse as *concordant* in the relationship when he/she inspired confidence, easily obtained a sense of

congruity, acted according to patients' preferences and constructed and maintained a caring connectedness, leading to a trustful and harmonious interpersonal relationship. Patients stated that the nurse, by his/her way of being, immediately became that trustworthy person with whom they would like to keep in contact, that the nurse rapidly caught their wavelength, understood their situation and treated them as they wanted. Patients reported that the nurse made them feel as if they were the primary patient. In this patient-nurse friendship, the patient experienced equality, understanding, faithfulness and that the excellent nurse was willing to do more than was expected of him/her, "to do that little extra bit" when caring.

Study II

Caring influences nurses' attitudes, actions and professional growth

When the nurses were asked to describe the meaning of being touched deeply inside in a nurse-patient encounter, the following general structure emerged from the analysis:

The experience of a nurse being touched deeply inside begins with the nurse's awareness when perceiving the patient's suffering and being exposed to unfairness. In this encounter, the nurse has a sense of closeness to the patient/person and becomes more aware and sensitive to the meaning of the situation for him/her. The nurse experiences extreme demands and extreme distress which she perceives as a challenge to act on behalf of the patient. She recalls this as a situation resulting in her professional growth.

In the above-mentioned structure, four key constituents were identified as capturing the essence of the general structure of the phenomenon: (1) witnessing patient suffering and being exposed to unfairness; (2) sensing closeness, understanding and involvement in the patient/person; (3) perceiving extreme distress as a challenge to act accordingly; and (4) growing professionally. The key constituents presenting each subject's common central ideas were then linked into the general structure of the phenomenon of being touched deeply inside in a nurse-patient encounter (Table 3). The varied embodiments were substantiated by meaning units transformed from the nurses' naive description of situations of being touched deeply inside in a nurse-patient encounter.

The results showed that being deeply touched in a nurse-patient encounter fostered the nurses' caring abilities and professional growth. The relationship with the most vulnerable and defenseless patients brought forth the nurses' moral obligation to do good and to act based on the caring value system inherent in nursing.

Key constituents	Varied embodiments
Witnessing patient suffering and exposed to unfairness	– less than optimal treated – exposed to professional uncaring – bad fate (e.g. seriously ill, highly dependent, vulnerable to humiliation and neglect, early death)
Sensing closeness, understanding and involvement in patient/person	– succeeds in reaching out to neglected patient – becomes special for patient/person – experiences human to human relationship and discovers the authentic person the patient is – is impressed by the patient/person's ability to dwell with suffering and to bear the situation – patient forever carved in nurse's mind – identify with patient
Experiencing extreme distress as a challenge to act accordingly	– gets frustrated and acts immediately when patient is exposed to indignities – gets involved and feels a moral obligation to do good for the person and to safeguard human dignity
Growing professionally	– more open to protect humanistic values – more aware of professional obligations to alleviate suffering, and to help patient find ease – more sensitive to what is good and bad nursing practice and to promote good nursing care

Table 3. All key constituents of structures and their varied embodiments of the phenomenon of being touched deeply inside in a nurse-patient encounter.

Study III

Caring, an infrequently mentioned subject in nursing records

Studying nursing records showed that LLA patients had several severe pre- and post-amputation problems which may be assumed to cause great suffering. Problems related to the following areas were recorded in nursing records: breathing, circulation, nutrition, elimination, skin, sleep, activity, mobilization, pain, pain alleviation, communication, mental condition, wellbeing and psychosocial status. Administrative data were also recorded.

The most frequently reported problems pre- and post-amputation were related to pain/pain alleviation, nutrition, elimination, circulation, ulceration and sleep. All patients were reported as suffering from severe pain and/or having problems with pain alleviation. The analysis indicated three specific categories of pain: pain related to underlying illness, pain as a complication of amputation and pain without cause. The patients' suffering from phantom pain was only recorded in nine of the nursing records. The Swedish word "ont" (pain) was used in several records without explanation, characterization or specific localization.

In addition to severe pain and problems with pain alleviation, all amputees who died (n= 8) while hospitalized had problems with nutrition, elimination, wound healing, sleep, communication, wellbeing and mental condition.

Standard keywords were not used consistently in the nursing records. Objective symptoms and problems were relatively clearly described, although non-systematically presented. Several notations relating to the same problem were found. The most varied notations were used when formulating the patients' problems related to the elimination, pain, skin and wellbeing keywords. The wellbeing, mental condition and communication keywords were used synonymously in several of the nursing records. Patient wishes, values, subjective experiences and participation were only occasionally noted.

Study IV

Caring, an essential aspect of future nursing research

When informed nursing practitioners were asked to identify essential issues for future nursing research, they prioritized areas that will assure patients' wellbeing and a caring environment. More specifically, research areas across the full continuum of care, from wellness to death, were regarded as important, with a focus on research needed to preserve humanistic values and develop collaboration between health care providers across organizational health care system boundaries.

The ranking procedure reveals that nurses gave highest priority to research concerning caring values, caring encounters and communication. Below, the ten highest-ranked research areas concerning IPW, VHCO and VNP are presented (Table 4-6).

Important to Patients' Welfare (IPW)	Rank	Mean
Establish relationships that preserve human dignity at all levels in geriatric care	1	8.9
Explore the meaning of a caring encounter	2	7.5
Describe attitudes and actions that make the patient feel respected and listened to	3	6.6
Explore the meaning of therapeutic touch, nurturing, comfort and sleep in relation to healing and wellbeing	4	5.4
Establish caring relationships when organizing health care	5.5	5.1
Explore the meaning of empowerment dialogue and its implications for healing power and health	5.5	5.1
Examine the meaning of communication skills when presenting unpleasant information	7	4.9
Explore the meaning of efficiency in continuity of patient care	8	4.8
Explore how transfer from hospital care to primary care can be effected with dignity	9	4.6
Explore the meaning of compassion in patient-related nursing	10	4.1

Table 4. Research areas given the highest mean IPW scores by the nurse panel (n=95).

The nurse panel gave highest priority to research concerning the exploration of caring attitudes and actions and its impact on patients' welfare as well as on the health care organization as a whole.

Value to the Health Care Organization (VHCO)	Rank	Mean
Access the relationship between good nursing practice and the nursing staff ‘s wellbeing	1	12.2
Determine means for utilization of research in clinical practice	2.5	10.0
Determine effective means of communicating and implementing nursing knowledge in clinical practice and evaluating the beneficence to the patient	2.5	10.0
Establish relationships that preserve human dignity at all levels in geriatric care	4	9.6
Explore the meaning of efficiency in continuity of patient care	5	9.0
Determine means to evaluate the relationship between supervision of nurses and quality improvement in nursing	6	8.9
Explore the meaning of coordination and continuity in care when several caregivers are involved	7	8.2
Describe the characteristics of a caring encounter	8	7.9
Explore how transfer from hospital care to primary care can be effected with dignity	9	7.5
Establish a common value system in the interaction between caregivers	10	7.4

Table 5. Research areas given the highest mean VHCO perspective scores by the nurse panel (n=95).

The nurse panel prioritized research concerning staff wellbeing and the utilization, implementation and evaluation of research in clinical practice. Research concerning caring values was also ranked high in the VHCO perspective.

Value to the Nursing Profession (VNP)	Rank	Mean
Explore the meaning of a caring encounter	1	8.4
Determine means for utilization of research in clinical practice	2	7.2
Explore means of improving quality of nursing care through supervision of nurses	3	6.7
Determine means of preserving the nursing paradigm in the medically oriented organization	4	6.6
Explore the meaning of supervision, collegial support and cooperation/ interaction	5	5.9
Access relationship between nurses' documentation and patient safety, wellbeing and continuity of patient care	6.5	5.7
Describe attitudes and actions that make the patient feel respected and listened to	6.5	5.7
Determine the role of the nurse in the health care team	8	5.0
Establish relationships that preserve human dignity at all levels in geriatric care	9	4.6
Explore the characteristics of a professional nurse, an expert nurse	10	4.3

Table 6. Items given the highest mean VNP perspective scores by the nurse panel (n=95).

The nurse panel prioritized research concerning the meaning of a caring encounter as well as professional issues. Determining means for utilization of research in clinical practice, improving quality of nursing care through supervision and preserving the nursing paradigm in the medically oriented organization were ranked the highest.

GENERAL DISCUSSION

Issues relating to the results

The general aim of this thesis was to gain a deeper understanding of important caring aspects in clinical practice from both the patients' and nurses'

perspectives and to illuminate essential aspects of caring for future nursing research.

As indicated in the literature, caring is essential in the healing process as well as for patients' wellbeing and outcome (36). The ability to provide care, presence and connectedness seem to be imperative (40).

Caring as presence

The need for authentic presence in the caring relationship was emphasized by both patients and nurses in this thesis. The patients expressed the need for nurses who could create a caring contact, establish caring connectedness and develop a caring relationship. By being open and perceptive and truly present, the nurse immediately caught the patient's wavelength, understood the situation and treated the patient accordingly (89).

To be truly present, physically and emotionally, is regarded as crucial to create a caring contact (40). Authentic presence, while defined in various ways in the literature, seems to have similar connotations: "presencing" (90), "the irreducible presence" (91), "existential presence" (37), "living a caring presence" (92), caring communion (93), co-presence (94) and "authentic quality of presence" (28). Parse (22) adds having courage to being authentically present as important in the caring relationship.

Presence involves putting everything aside and focusing completely on the individual. It involves a deep connection and a shared vulnerability which goes beyond the task at hand and being physically present (94-96). Being mindfully present is regarded as an important element of the caring moment (97). This corresponds with the results of Study II. When witnessing patients' suffering and unfairness, the caring nurse was mentally and emotionally present when touched deeply inside in the encounter (98). By her being touched deeply inside, the nurse's own ethical reality was strongly affected by the patient's ethical reality. The nurse refrained from fleeing, both physically and emotionally. In this situation, the distress and uneasiness was endured, sensitivity to the moral meaning was activated and both patients and nurses regarded the courage to be there all the way through as of the utmost importance (99). These findings are congruent with Lützén's (24) notion of the development of moral sensitivity. In order to generate caring, Noddings (5) suggests a realignment of education to encourage and reward not just rationality and trained intelligence, but to enhance sensitivity in moral matters. According to Gilligan (100), connectedness in this sense is essential to women's sense of morality and ethics.

Caring moments as connectedness

In this thesis, being mindfully present and being able to catch the patient's wavelength was regarded the first step towards a caring connectedness, important for both patients and nurses. By using competence, compassion,

courage and concordance, the nurses caught the patient's wavelength and created caring moments (58). In these caring moments, both patients and nurses realized their intersubjective connectedness and mutual attention and trust. In this trustful and harmonious intersubjective relationship, dignity, wholeness and integrity were preserved (101). The caring nurse maintained this connectedness by being concordant. In the caring moment, this nurse made the patient take responsibility for her own situation and inspired her to work actively on the healing process (89). The nurse was regarded as caring when using herself and her entire capacity, including knowledge from nursing and medicine and knowledge about human beings and communication skills, in the interaction. The nurse approached the patients with a genuinely positive attitude, respected and acknowledged personhood and showed a constant and genuine concern for the patient/person. The nurse dared to come close to the patients in chaos and stayed there, steady as a rock. This caring connectedness influenced nurses' attitudes, actions and professional growth (89). Halldórsdóttir and Pellegrino (40) argue that human contact, dialogue, receptiveness, spending time and meeting the patient are important parts of and inherent in the healing process as well as in curing acts (12). The nurse's personal talents, skills and open mind thus affect both reflections in action and outcomes for the patient (40, 50, 51, 102, 103). In this context it is important to point out that connecting with a patient does not take extra time, provided the nurse has this caring competence, intentionality and good communication skills (96).

In Study I, concordance, a neglected phenomenon not described previously in nursing, appeared to be an essential aspect of caring from the patients' perspective. The patient was encouraged by the nurses' caring attitudes and behaviours. Åström (104) stresses the importance of really making room for dialogue and reflections concerning how to do just and good things in everyday health care practice in order to let caring make a difference to the patients.

The most significant elements of caring – being mindfully present, being with, being there, quality of life and wellbeing – are seldom recognized, rewarded or taught because they constitute the invisible aspect of professional caring (97, 105). To protect a person's integrity and dignity, especially in stressful caregiving situations, is considered an example of a hidden dimension of caring (106).

Most nurses are aware of the secret that caring is fundamental to human life. Interviews with patients and nurses in Studies I and II illuminated some less visible aspects of caring situations. It takes involvement and insight to identify caring moments. Professionals who are able to create caring moments in health care practice should be rewarded. Maybe focusing more on these less visible aspects of nursing could increase the "quality of caring" in health care practice, as suggested by Gramling (107).

Responses and outcome of nurses' caring

When patients were asked about the characteristics of an excellent, caring nurse ("with a green thumb"), some outcome aspects of the interaction with the nurse emerged (89). Patients' individual needs were met through the nurses' skilful communication, wellbeing was promoted by technical competence and by a compassionate attitude and patients were affirmed as individuals in a trustful, harmonious relationship. They also experienced comfort, relaxation, security, hope and empowerment (89).

These findings are in line with a phenomenological study by Sherwood (108) on patient outcome of caring. She asked ten adult hospitalized patients about their response to demonstrations of nurses' caring. The following eight themes and descriptive elements emerged from the analysis: 1) a positive mental attitude, increasing the ability to cope while enhancing physical wellbeing; 2) movement toward recovery and healing or rehabilitation as a result of a personalized coordinated care plan; 3) physical comfort brought about by competent personalized intervention; 4) gratitude for safety, protection and skilful actions; 5) reassurance provided by constant monitoring and attentive presence; 6) dignity and acceptance from being treated like a person; 7) trust developed between nurse and patient; and 8) satisfaction from receiving quality care. Riemen (33) also found that patients needed to experience existential presence, availability, genuine interest in themselves as well as being valued individually by really being listened to. This is also described by Kasén (27) who states that a caring relationship, in which both parties experience an inner connection, is life-giving and creates enthusiasm, thus promoting the movement toward health and alleviating suffering.

Other studies show that there are described differences in patients' and nurses' perceptions and definitions of caring (44-46, 109-111), but these differences are said to be both rational and expected (112). Ellis (113) states there are no tools that can measure "tender loving care". The question is whether it is at all possible to measure the affective side of nursing. These thoughts were stressed by Lützén and Tishelman (114) who argued that caring as a multifaceted process is difficult to study accurately by using one-dimensional and linear methods.

As suggested by Patistea (105), patients' and nurses' differences in perceptions and definitions of caring should be viewed as complementary rather than contradictory. Interestingly, Wolf (115) found, when developing the Caring Behaviours Inventory for Elders (CBI-E), that relationship-building behaviours were important during caring episodes for both elders and caregivers. These findings are consistent with Watson's theory of human care and her assumption that caring is interpersonally experienced as well as being consistent with the concept of caring ontology (28, 30, 101).

The nurses' professional caring behaviours are regarded as determined by the organizational structure of the health care institutions (116). Moreover, nurses' perceptions of caring are influenced by their personalities, the philosophies of their own lives, educational institutions and professional ethics as well as by the environments in which they provide their services (105).

Outcomes of caring in medical and nursing records

The study of medical and nursing records of LLA patients (Study III) revealed that these patients, in addition to considerable suffering, severe pain and markedly deteriorated general health status, had major problems regaining physical and mental functions. The patients' objective symptoms and problems were relatively clearly described, although non-systematically presented. However, their psychological and mental reactions to interventions were scarcely noted.

But concrete suggestions, actions or behaviours that improved the patients' situations or conditions were not recorded or explained. Moreover, there was no information or notation concerning nurses' caring, e.g. how they protected, enhanced or preserved human dignity, although this might have taken place several times a day. Nor were there any signs of the meaning of presence, the intersubjective response, authenticity and caring moments In fact, no notations on how caring best was accomplished for the individual were found in the studied nursing records (99).

This is congruent with other studies describing nurses' difficulties in integrating and expressing what happens in everyday practice in nursing records (77). Actually, little is known about the extent to which the records accurately reflect the patient's problems, care interventions and outcomes of care, or if the written data corresponds to the actual care performed.

Ehrenberg *et al*. (117) stress the need to further explore whether VIPS and applying this nursing process format accurately reflects the care given and contributes to the quality of care. It is regarded as imperative that the person's experiences and the meaning he/she attributes to a situation are shown in the documentation.

It is also important to include both patients' and nurses' descriptions of reactions and outcome of nurses' caring. Nursing activities and plans should always be described from the individual, family or community perspective (118). Parse maintains that this type of documentation is quite different from standard assessment forms that usually focus on the illness process rather than the meaning of the situation from the person's own viewpoint (119).

As the nursing records revealed, the patients' responses to professionals' attitudes and interventions were not clearly documented. This might imply a risk that patients' individual needs will be unmet or inappropriately addressed. Furthermore, the patients' participation in the healing process might be

disrupted and professional caring inadequately prioritized. In times of increasingly shorter stays in hospitals and decreasing resources in primary and municipal care, there is a risk of underestimating patients' needs, rendering them more exposed, vulnerable and unsatisfied with the quality of caring.

Caring in future nursing research

In Study IV, when given the opportunity to participate in prioritizing areas for future nursing research, nurses keep emphasizing the urgency of studying the meaning and outcome of caring encounters in health care practice. In Table 7, prioritized areas of nursing research are presented in relation to the three perspectives on caring in the discipline of nursing.

Caring perspectives	Prioritized areas of nursing research		
	Important to patient's welfare	Value to the health care organization	Value to the nursing profession
The being of caring (ontological)	The meaning of caring in preserving human dignity	The meaning of caring in preserving human dignity	The meaning of caring in preserving human dignity
	Preserving human dignity in transfer	Preserving human dignity in transfer	Preserving human dignity in transfer
	Caring encounters	Caring encounters	Caring encounters
The meaning of being a caring person (anthropological)	Caring in nurses' intervention	Caring relationships and staff's wellbeing	Caring and professionalism
	Caring in organizing health care	Coordination and continuity across organizational boarders	Caring supervision, collegial support and interaction
	Caring in communicating Caring and compassion		
Caring attitudes (ontical)	Caring attitudes and respect	Caring attitudes – efficiency – continuity	Caring attitudes and respect
	Caring attitudes and continuity		

Table 7. Prioritized areas of nursing research in relation to caring perspectives.

The importance of studying lived experience of caring encounters, as well as the role of caring in preserving humanistic values when developing collaborations between health care providers across organizational boundaries, is stressed. The need for more research about caring communication, attitudes and behaviours in nursing has also been brought up elsewhere (120-122).

Methodological considerations

The knowledge emanating from this study was obtained by triangulation. By combining methods, a deeper understanding of caring as an important phenomenon in nursing practice and research was achieved. The findings in each of the four studies have illuminated the concept and thereby shown a well integrated picture of the phenomenon, leading to mutual validation. This synthesis of methodological approaches has been productive in order to gain knowledge about how to visualize and develop caring in research and practice.

Quantitative and qualitative research may be combined for the purposes of triangulation, but this is not as unproblematic as it might seem. Bryman (123) states that the same concepts have different connotations in the respective research traditions. Moreover, quantitative and qualitative research have different preoccupations and highly contrasting strengths and weaknesses. The quantitative approach emphasizes causality, variables and a highly pre-structured approach while qualitative research is concerned with elucidation of subjects' perspectives, process and contextual detail (123).

In Studies I and II, the data was collected by interviews. The interviewer stayed present to patients' experiences and encouraged them to say everything they had to say about the subject, leaving nothing out. The interview lasted as long as necessary to permit the patients to explore the entire meanings of their experiences.

Trustworthiness is partly indicated by the chosen quotations that represent the atmosphere during the interview, and the concepts supported by qualities that are close to the participants' description. The qualitative analyses were carried out from the nursing and the patients' perspectives and discussed and examined by the authors.

There are weaknesses in the methods when it comes to selection of the participants in Studies I and II. The selection of breast cancer patients may have been influenced by preferences and opinions within the Danish Cancer Society. The nursing superiors' choices might have been supplemented by enquiring after the patients' choices, in order to ensure that the "right" professionals were chosen. Nevertheless, even if some valuable informants were not selected, the interviews indicated that the data obtained were as rich and informative as they should be.

The fact that most participants in this thesis, who have defined caring are women, may be another weakness. Perhaps men would have expressed the meaning of caring differently.

Generalization in a qualitative research study entails obtaining the essence of the phenomenon under study. By using imaginative variations in the analyses of the interviews with the nurses, an eidetic understanding and a general structure were obtained. Because this structure is based on empirical data and imaginative variations, it is generalizable to the extent that it can be extrapolated beyond these five nurses. The results present one image of the phenomenon studied. Future research would possibly yield more images that together might cover the experiences of most excellent nurses. The method is not supposed to mirror but to describe and explore the subjective reality. Therefore, it is impossible to assert that these experiences are right or wrong. Instead, it is interesting to know of their existence and to understand their inherent meaning (73).

In Study III, medical and nursing records of 45 patients (a total population of LLA patients aged over 60) were retrospectively scrutinized. As in all retrospective studies, the problem of finding the relevant information is obvious. Moreover, the researcher is dependent on the information given. As the records were collected from five different departments, the information given was somewhat diverse, reflecting clinical speciality and the care focus. This problem was especially evident in records from patients who had undergone multiple interventions at various departments. The strength of the results was that the data were re-examined and re-assessed several times by the two authors, leading to interrater reliability. External validity was obtained by the rigorous re-contextualization process. The problem in identifying caring modalities, the caring process and outcome of caring may have something to do with the VIPS model's lack of ability to capture caring in nursing/patient records, as emphasized by von Krogh *et al.* (124). But this problem can also be related to unspecific data in the records (117).

When interpreting the results of the Delphi study (Study IV), it is important to bear in mind that a minority of the target population was reached by the invitation to participate in the study. Nonetheless, 81% of the originally responding nurses completed the study. The participants seem to represent the target population in terms of age, clinical settings, working area, years in nursing and level of education; they thus present a variety of opinions and perspectives which in turn help increase content validity (81). Moreover, all suggested research areas analysed in the first round represent several important perspectives in clinical practice, traversing organizational boundaries.

In a Delphi study the communication between the researcher and the panel members is dependent on the communication channels (83). Using computerized communication presupposes that everyone has access to a

computer and can use the software properly. In the case of panelists that lacked access to a computer, communication occurred by mail or fax.

Implications

Caring is significant in all health care practice encounters. The findings in this thesis show that all caregivers must have significant knowledge of how to treat the patients as unique individuals in order to promote humaneness in the health care sector (125).

Nursing literature emphasizes the value of investigating caring, how it is expressed and dealt with in caring relationships and the outcome for the patients' health and wellbeing. Establishing caring relationships that encourage active patient participation will improve compliance, enhance human dignity (126) and diminish patients' dissatisfaction with the health care system (127).

Therefore:

- Future studies of caring are required, aimed at establishing the association between patients' perceptions of caring and the satisfaction with care outcome (115), as well as of caring as a quality indicator
- The lived experience of caring is an area for further investigation. Research is needed to illuminate which health care professionals, organizational and social factors shape perceptions and behaviors of caring and how this occurs (105)
- Future studies on developing a conceptual framework for documentation that is capable of recording caring values, problem solving and patient satisfaction are highly recommended
- And finally, further studies are recommended to preserve and develop caring in the health care organization of today.

SUMMARY AND CONCLUSIONS

The findings in this thesis suggest that caring is an important and an inadequately visible aspect of current health care practice in which caring seems to be more obvious by its absence than by its presence.

Humaneness in health care practice is desirable. The more advanced sophisticated and technological care and cures become, the more health care practice needs professionals who treat patients and each other with respect. All human beings need caring contact, connectedness and encounters, especially during episodes in our lives when we are vulnerable and exposed to illness and suffering. There is more advanced technical support now than ever before, but a

patient suffering from breast cancer is still a patient suffering from breast cancer and she will need human caring in the healing process.

Safety and effectivity in health care practice require competence and knowledge. Caring must be present in order for healing to occur. Caring opens up the opportunity to give and receive as well as to listen and respond. Caring directs attitudes and behaviours and in these relational activities manifestations of caring are apparent.

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REFERENCES

1. Ottosson J-O, redaktör. Patient-läkarrelationen: Läkekonst på vetenskaplig grund (The patient-physician relationship). Stockholm: Natur och Kultur i samarbete med Statens beredning för utvärdering av medicinsk metodik (SBU); 1999.

2. The National Board of Health and Welfare. Sweden's Health Care Report 2001. Stockholm: The National Board of Health and Welfare; 2002.

3. Vogel J, Statistiska centralbyrån. Associational life in Sweden: general welfare, social capital, training in democracy. Stockholm: Statistics Sweden (Statistiska centralbyrån) (SCB); 2003.

4. Mayeroff M. On caring. New York: Harper & Row; 1971.

5. Noddings N. Caring: a feminine approach to ethics & moral education. Berkeley: University of California Press; 1984.

6. Buber M. I and Thou. New York: Charles Scribner's Sons; 1958.

7. Pellegrino E. The caring ethic: The relationship of physician to patient. In: Bishop A, Shudder J, editors. Caring, curing, coping: Nurse, physician, patient relationship. Tuscalosa: The University of Alabama Press; 1985. p. 8-30.

8. Martinsen K. Omsorg, sykepleie og medisin. Oslo: Tano; 1989.

9. Gadow S. The caring relationship. In: Bishop A, Shudder J, editors. Caring, curing, coping: nurse, physician, patient relationship. Tuscalosa: University of Alabama Press; 1985. p. 31-43.

10. Pellegrino ED. The commodification of medical and health care: the moral consequences of a paradigm shift from a professional to a market ethic. J Med Philos 1999 Jun;24(3):243-66.

11. Watson J. Love and caring: ethics of face and hand - an invitation to return to the heart and soul of nursing and our deep humanity. Nurs Adm Q 2003 Jul-Sep; 27(3): 197-202.

12. Pellegrino ED. The internal morality of clinical medicine: a paradigm for the ethics of the helping and healing professions. J Med Philos 2001 Dec;26(6):559-79.

13. Kalkas H. Nursing as a scientific discipline. Scand J Caring Sci 1990;4(1):5-7.

14. Roach MS. The call to consciousness: Compassion in today's health world. In: Gaut DA, Leininger MM, editors. Caring: The compassionate healer. New York: National League for Nursing; 1991.

15. Leininger MM. Caring: An essential human need. Proceedings of the third caring conference; 1981; Thorofare, NJ: Slack; 1981.

16. Roach M. Caring: The human mode of being: Implications for nursing. Toronto: University of Toronto Press; 1984.

17. Watson J. Nursing: Human science and human care. A theory of nursing. Norwalk, CT: Appleton: National League for Nursing; 1985.

18. Leininger MM. Leininger's theory of nursing: cultural care diversity and universality. Nurs Sci Q 1988 Nov;1(4):152-60.

19. Smith MC. Caring and the science of unitary human beings. ANS 1999 Jun;21(4):14-28.

20. Boykin A, Schoenhofer S. Caring in nursing: analysis of extant theory. Nurs Sci Q 1990;3(4):149-55.

21. Roach MS, editor. Caring from the heart: the convergence of caring and spirituality. New York: Paulist Press; 1997.

22. Parse R. Caring from a human science perspective. In: Leininger MM, editor. Caring an essential human need. Thorofare, NJ: Slack; 1981.

23. Lindholm L, Eriksson K. To understand and alleviate suffering in a caring culture. J Adv Nurs 1993 Sep;18(9):1354-61.

24. Lützén K. Moral sensitivity: a study of subjective aspects of the process of moral decision making in psychiatric nursing [dissertation]. Stockholm: Karol.inst; 1993.

25. Lanara VA. Heroism as a nursing value: a philosophical perspective. Athens, Greece: Sisterhood Evniki; 1981.

26. Gaut DA. Development of a theoretically adequate description of caring. West J Nurs Res 1983;5(4):313-24.

27. Kasén A. Den vårdande relationen. Åbo: Åbo akademi; 2002.

28. Watson J. Nursing: human science and human care: a theory of nursing. New York: National League for Nursing; 1988.

29. Watson J. What, may I ask is happening to nursing knowledge and professional practices? What is nursing thinking at this turn in human history? J Clin Nurs 2005 Sep; 14(8): 913-4.

30. Watson MJ. New dimensions of human caring theory. Nurs Sci Q 1988 Nov; 1(4): 175-81.

31. Watson J. Caring science as sacred science. Philadelphia: F.A. Davis; 2005.

32. Valentine KL. Exploration of the relationship between caring and cost. Holist Nurs Pract 1997 Jul;11(4):71-81.

33. Riemen D. The essential structure of a caring interaction: doing phenomenology. In: Munhall PO, Oiler CJ, editors. Nursing research: a qualitative perspective. Norwalk, CT: Appelton-Century-Crofts; 1986.

34. Brown L. Behaviors of nurses percieved by hospitalized patients as indicators of care [Dissertation abstracts international, 43, 4361b]; 1981.

35. Brown L. The experience of care: patients perspective. Top Clin Nurs 1986;8(2):56-62.

36. Werner JS, Wendler MC, McCormick J, Paulus-Smith S, Jackson C, Nie J. Human response outcomes influenced by nursing care. Int J Hum Caring 2002; 6(3): 15-23.

37. Riemen DJ. Noncaring and caring in the clinical setting; patients' descriptions. Top Clin Nurs 1986 Jul;8(2):30-6.

38. Swanson KM. Empirical development of a middle range theory of caring. Nurs Res 1991 May-Jun;40(3):161-6.

39. Lövgren G, Engström B, Norberg A. Patients' narratives concerning good and bad caring. Scand J Caring Sci 1996; 10(3): 151-6.

40. Halldórsdóttir S. Caring and uncaring encounters in nursing and health care: developing a theory [dissertation]. Linköping: Linköping University; 1996.

41. Larson PJ. Important nurse caring behaviors perceived by patients with cancer. Oncol Nurs Forum 1984 Nov-Dec;11(6):46-50.

42. von Essen L. What is good caring? [Doctoral dissertation]. Uppsala: Uppsala University; 1994.

43. Scharf L, Caley L. Patients', nurses', and physicians' perceptions of nurses' caring behaviors. Nursingconnections 1993 Spring; 6(1): 3-12.

44. von Essen L, Sjödén P. The importance of nurse caring behaviors as perceived by Swedish hospital patients and nursing staff. Int J Nurs Stud 1991; 28(3): 267-81.

45. von Essen L, Sjödén P. Patient and staff perceptions of caring: review and replication. J Adv Nurs 1991;Nov;16(11):1363-74.

46. von Essen L, Sjödén P. Perceived importance of caring behaviors to Swedish psychiatric inpatients and staff, with comparisons to somatically-ill samples. Res Nurs Health 1993 Aug; 16(4): 293-303.

47. Larsson G, Widmark V, Lampic C, von Essen L, Sjödén P. Cancer patient and staff ratings of the importance of caring behaviours and their relations to patient anxiety and depression. J Adv Nurs 1998 Apr; 27(4): 855-64.

48. Gardner A, Goodsell J, Duggan T, Murtha B, Peck C, Williams J. "Don't call me sweetie!" Patients differ from nurses in their perceptions of caring. Collegian 2001 Jul; 8(3): 32-8.

49. Widmark-Petersson V, von Essen L, Sjödén P. Perceptions of caring among patients with cancer and their staff: differences and disagreements. Cancer Nurs 2000 Feb; 23(1): 32-9.

50. Eriksson K. Den lidande människan [The suffering of the human]. Stockholm: Liber utbildning; 1994.

51. Halldórsdóttir S. "Caring or uncaring?" An important question from the perspective of the recipient of nursing and health care. Nordiskt jubileumsymposium "To care or not to care - The key question in nursing"; 1993; Wasa: Åbo Akademi; 1993. p. 1-15.

52. Ford JS. Caring encounters. Scand J Caring Sci 1990; 4(4): 157-62.

53. Forrest D. The experience of caring. J Adv Nurs 1989 Oct;14(10):815-23.

54. Carper BA. The ethics of caring. ANS 1979 Apr;1(3):11-9.

55. Benner P, Wrubler J. The primacy of caring: stress and coping in health and illness. Menlo-Park, CA: Addison-Wesley; 1989.

56. Wolf ZR. Making nursing work visible inside and outside the profession. Pa Nurse 1999 Jan;54(1): 21-4.

57. Gadow S. Relational narrative: the postmodern turn in nursing ethics. Sch Inq Nurs Pract 1999 Spring;13(1):57-70.

58. Jensen KP, Bäck-Pettersson SR, Segesten KM. The caring moment and the green-thumb phenomenon among Swedish nurses. Nurs Sci Q 1993 Summer; 6(2): 98-104.

59. Bäck-Pettersson S, Pryds Jensen K. She dares: An essential characteristic of the excellent Swedish nurse. In: Gaut DA, editor. A global agenda for caring. New York: National League for Nursing Press; 1993. p. 257-265.

60. Wolf ZR, Giardino ER, Osborne PA, Ambrose MS. Dimensions of nurse caring. Image J Nurs Sch 1994 Summer;26(2):107-11.

61. Erlandson D, Harris E, Skipper B, Allen S. Doing naturalistic inquiry: A guide to methods. Newbury Park, CA: SAGE Publications; 1993.

62. Kuhn T. The structure of scientific revolutions. 2nd ed. Chicago: Chicago University Press; 1970.

63. Törnebohm H. Att forska över paradigm. Göteborg: Göteborgs Universitet, Institutionen för vetenskapsteori; 1982. Report No.: 136.

64. Törnebohm H. Livsparadigm och livsvärldar. Göteborg: Göteborgs Universitet, Institutionen för vetenskapsteori; 1989. Report No.: 95.

65. Brannen J. Combining qualitative and quantitative approaches: an overview. In: Brannen J, editor. Mixing methods: qualitative and quantitative research. Aldershot: Avebury; 1992. p. 3-37.

66. Leininger MM, editor. Ethnography and ethnonursing: models and modes of qualitative data analysis. Orlando, Florida: Grune & Stratton; 1985.

67. Morse JM. Approaches to qualitative-quantitative methodological triangulation. Nurs Res 1991 Mar-Apr;40(2):120-3.

68. Taylor SJ, Bogdan R. A qualitative approach to the study of community adjustment. Monogr Am Assoc Ment Defic. 1981(4):71-81.

69. Parse R, Coyne A, Smith M. Nursing research: qualitative methods. Bowie, MD: Brady; 1985.

70. Dahlberg K, Drew N. A lifeworld paradigm for nursing research. J Holist Nurs 1997 Sep; 15(3): 303-17.

71. Husserl E. The crisis of European science and transcendental phenomenology. Evanstone, IL: North Western University Press; 1970.

72. Giorgi A. The theory, practice, and evaluation of phenomenological method as a qualitative research procedure. Journal of Phenomenological Psychology 1997;28(2):235-60.

73. Giorgi A. Phenomenology and psychological research. Pittsburg, PA: Duquesne University Press; 1994.

74. SAS User's Guide. Statistics. Version 5 Edition. Cary, NC: SAS Institute Inc; 1985.

75. Krippendorff K. Content analysis: An introduction to its methodology. 2 ed. Thousand Oaks, CA: Sage; 2004.

76. Weber R. Basic Content Analysis. Beverly Hills, CA: Sage; 1985.

77. Ehrenberg A, Ehnfors M, Thorell-Ekstrand I. Nursing documentation in patient records: experience of the use of the VIPS model. J Adv Nurs 1996 Oct;24(4):853-67.

78. Downe-Wamboldt B. Content analysis: method, applications, and issues. Health Care Women Int 1992 Jul-Sep;13(3):313-21.

79. Lindeman CA. Delphi survey of priorities in clinical nursing research. Nurs Res 1975 Nov-Dec;24(6):434-41.

80. Bond S, Bond J. A Delphi survey of clinical nursing research priorities. J Adv Nurs 1982;7(6):565-75. 1987.

81. Goodman CM. The Delphi technique: a critique. J Adv Nurs 1987 Nov;12(6):729-34.

82. MacMillan M. A Delphi survey of priorities for nursing research in Scotland. Edinburgh: University of Edinburgh; 1989.

83. Powell C. The Delphi technique: myths and realities. J Adv Nurs 2003 Feb;41(4):376-82.

84. Sumsion T. The Delphi technique: an adaptive research tool. Brit J Occup Ther 1998 Apr; 61(4): 153-6.

85. Beretta R. Issues in research. A critical review of the Delphi technique. Nurs Res 1996 Jun; 3(4): 79-89.

86. Green B, Jones M, Hughes D, Williams A. Applying the Delphi technique in a study of GPs' information requirements. Health Soc Care Community 1999 May; 7(3): 198-205.

87. McKenna HP. The Delphi technique: a worthwhile research approach for nursing? J Adv Nurs 1994 Jun;19(6):1221-5.

88. Keeney S, Hasson F, McKenna HP. A critical review of the Delphi technique as a research methodology for nursing. Int J Nurs Stud 2001 Apr;38(2):195-200.

89. Jensen KP, Bäck-Pettersson S, Segesten K. "Catching my wavelength": perceptions of the excellent nurse. Nurs Sci Q 1996;9 (3):115-20.

90. Benner P. From novice to expert: excellence and power in clinical nursing practice. Menlo Park, CA: Addison-Wesley; 1984.

91. Martinsen K. Fra Marx til Løgstrup: Om etikk og sanselighet i sykepleien. København: Munkgaard; 1994.

92. Nelms TP. Living a caring presence in nursing: a Heideggerian hermeneutical analysis. J Adv Nurs 1996 Aug;24(2):368-74.

93. Eriksson K. Nursing: the caring practice "being there". NLN Publ 1992 Apr(15-2465):201-10.

94. Leners DW. Nursing intuition: the deep connection. In: Gaut DA, editor. A global agenda for caring: Fourteenth Annual Caring Research Conference, Melbourne, Australia, July 1992. New York: National League for Nursing; 1993. p. 223-40.

95. Montgomery CL. The spiritual connection: nurses' perceptions of the experience of caring. In: Gaut DA, editor. The presence of caring in nursing. New York: National League for Nursing; 1992. p. 39-52.

96. Wilde MH. The caring connection in nursing: a concept analysis. Int J Hum Caring 1997 Spring; 1(1): 18-24.

97. Euswas P. The actualized caring moment: a grounded theory of caring in nursing practice. In: Gaut DA, editor. A global agenda for caring Fourteenth Annual Caring Research Conference, Melbourne, Australia, July 1992. New York: National League for Nursing; 1993. p. 309-26.

98. Bäck-Pettersson S, Jensen KP, Segesten K. The meaning of being touched deeply inside in a nurse-patient encounter-excellent nurse experiences. Int J Hum Caring 1998;Fall;2(3):16-23.

99. Bäck-Pettersson S, Björkelund C. Care of elderly lower limb amputees, as described in medical and nursing records. Scand J Caring Sci 2005 Dec; 19(4): 337-43.

100. Gilligan C. In a different voice. Camebridge, MA: Harward University Press; 1982.

101. Watson J. Nursing: The philosophy and science of caring. Boston: Little, Brown; 1979.

102. Kiikkala I. Professional expertice and nursing practice. In: Krause K, Åstedt-Kurki P, editors. International perspectives on nursing: a joint effort to explore nursing internationally. Tampere: Tampere University, Department of Nursing; 1992. p. 51-5.

103. v Rosén A. Idealsjuksköterskan. [The ideal nurse]. Tidskrift för Sveriges Sjuksköterskor 1939(6):155-62.

104. Åström G. The meaning of caring as narrated, lived, moral experiences [dissertation]. Umeå: Umeå University; 1995.

105. Patistea E. Nurses' perceptions of caring as documented in theory and research. J Clin Nurs 1999 Sep; 8(5): 487-95.

106. Roberts JE. Uncovering hidden caring. Nurs Outlook 1990 Mar-Apr; 38(2): 67-9.

107. Gramling K. Photography and music give expression to caring from the heart. In: Roach MS, editor. Caring from the heart: The convergence of caring and spirituality. New York: Paulist Press; 1997.

108. Sherwood G. The responses of caregivers to the experience of suffering. In: Starck PL, MacGovern JP, editors. The hidden dimension of illness: human suffering. New York: National League for Nursing; 1992. p. 105-13.

109. von Essen L, Carlsson M, Sjödén P. Nursing behaviors that make patients feel cared for: views of cancer patients, oncology nurses, and "others". J Psychosoc Oncol 1995; 13(3): 67-87.

110. von Essen L, Burström L, Sjödén P. Perceptions of caring behaviors and patient anxiety and depression in cancer patient-staff dyads. Scand J Caring Sci 1994; 8(4): 205-12.

111. Rosenthal KA. Coronary care patients' and nurses' perceptions of important nurse caring behaviors. Heart Lung 1992 Nov-Dec;21(6):536-9.

112. Meleis AI. Theoretical nursing: development and progress. 2. ed. Philadelphia: Lippincott; 1991.

113. Ellis R. The practitioner as theorist. Am J Nurs. 1969 Jul;69(7):1434-8.

114. Lützén K, Tishelman C. Patients' perceptions of nursing practice. A rationale for a qualitative research approach. Scand J Caring Sci 1991;5(4):179-86.

115. Wolf ZR, Zuzelo PR, Goldberg E, Crothers R, Jacobson N. The Caring Behaviors Inventory for Elders: development and psychometric characteristics. Int J Hum Caring 2006;10(1) 49-59.

116. Valentine K. Caring is more than kindness: modeling its complexities. J Nurs Adm 1989 Nov; 19(11): 28-35.

117. Ehrenberg A, Ehnfors M, Smedby B. Auditing nursing content in patient records. Scand J Caring Sci 2001;15(2):133-41.

118. Parse RR. Nursing: the discipline and the profession. Nurs Sci Q 1999 Oct;12(4):275-6.

119.Parse RR. Nursing science: the transformation of practice. J Adv Nurs 1999 Dec;30(6):1383-7.

120.Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. J Adv Nurs 2000 Oct;32(4):1008-15.

121.Hinshaw AS. Building excellence in science: setting priorities for knowledge development. In: Hamrin E, Lorensen M, editors. Perspectives on priorities in nursing science; 1995 Oct 23-24; Nordic Symposium in Vadstena, Sweden, Stockholm: Vårdalstiftelsen; 1997. p. 15-28.

122.Ross F, Smith E, Mackenzie A, Masterson A. Identifying research priorities in nursing and midwifery service delivery and organisation: a scoping study. Int J Nurs Stud 2004 Jul;41(5):547-58.

123.Bryman A. Quantitative and qualitative research: further reflections on their integration. In: Brannen J, editor. Mixing methods: qualitative and quantitative research. Aldershot: Avebury; 1992. p. 57-78.

124.von Krogh G, Dale C, Nåden D. A framework for integrating NANDA, NIC, and NOC terminology in electronic patient records. J Nurs Scholarsh 2005;37(3):275-81.

125.Wilde B, Starrin B, Larsson G, Larsson M. Quality of care from a patient perspective-a grounded theory study. Scand J Caring Sci 1993;7(2):113-20.

126.Kalisch BJ. Of half gods and mortals: Aesculapian authority. Nurs Outlook 1975 Jan;23(1):22-8.

127.Manthey M. A theoretical framework for primary nursing. J Nurs Adm 1980 Jun;10(6):11-5.

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