

**Annotated Bibliography –  
Patient Centeredness**

**Collaborative and integrated approaches to health 2005:5**

Marie Nilsson



## Forskningsplattformen för utveckling av Närsjukvård är ett samarbete mellan:

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## Patient Centeredness: An Introduction

A key theme under the umbrella of Närsjukvård is the mantra of “putting the patient at the centre”. Over the past thirty years an extensive body of scientific literature has advocated the importance of a patient centred approach to care (Mead and Bowen, 2000). A significant proportion of this literature has focused on the medical profession and particularly on general practitioners, tending to focus on the patient doctor encounter. Not with standing there is little consensus as to the meaning of patient-centeredness. In practice, each profession working in the health care field has developed different meanings of patient centred care, reflecting their own particular background and roles within the health system. Indeed recent research of looking at the perspectives of lay people, health care managers and non medical health professions, including nursing, found that there is a tendency for different groups of professionals to re-brand existing activities within their own areas as patient centred. The study also found that the notion of patient centeredness can cover a broad range of activities beyond individual interactions and shared decision making on treatment (Gillespie et al, 2004). For example it may be seen not so much as listening to the patients’ view and taking a partnership approach to care but rather ensuring individualized care in the context of complex organisational therapeutic and personal constraints. Both perspectives require by the professionals concerned some understanding of an individual’s needs and wants from the wider perspective of a person’s lived experience.

This short annotated bibliography covers literature on patient centeredness in the Swedish context during the period 1993-2005. The criteria for selection have taken one particular slant on patient centeredness namely: are the authors trying to describe/see things from the patient’s point of view. The following databases were used: CINAHL, Diva , HighWire, Google Scholar, Elin Libris. The search terms used were: Patient focused, patient centred, patient perspective; patient near; Sweden, qualitative analysis; nursing; caring; lived experience.

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## References

Mead, N. and Bower, P. (2000 ). Patient centeredness: a conceptual framework and review of the empirical literature *Social Science and Medicine* 51 1087 -1110

Gillespie, R., Florin, D., Gillam, S. (2004). How is patient centred care understood by clinical, managerial and lay stakeholders responsible for promoting this agenda? *Health Expectations* 7 142 -148



**Quality of care from the  
patient's/client's perspective  
(health care setting)**



**Barthelsson, C., Lutzen, K., Anderberg, B. & Nordström, G. (2003). Patients' experiences of laparoscopic cholecystectomy in day surgery. *Journal of Clinical Nursing*. 12(2):253-9.**

Previous research has concentrated mainly on surgical aspects and postoperative complication rates after day surgery laparoscopic cholecystectomy (LC), and less on patients' experiences and nursing care aspects. A qualitative study was conducted aimed at investigating patients' experiences of LC in day surgery. Ten women and two men were interviewed. The material was coded, categorized and analysed using qualitative analysis. The findings demonstrate that individuals with gallstone disease experience limitations in their daily life and feelings of socially handicapped. Prior to surgery, the patients felt anxious and expressed a wish for tranquilizers, and to meet the surgeon responsible. At discharge after day surgery, amnesia was experienced and the respondents did not remember important information about the operation given by the surgeon. Experience of postoperative pain varied greatly. Several respondents had a relapse of pain on the third day lasting up to 1 week. The need for additional pain medication and a bloated feeling were reported. Some respondents reported nausea and vomiting, and most had questions about wound care. The need for additional telephone follow-up was mentioned, as was the fact that it was difficult to come home to small children. However, the great majority felt that returning home on the same day as the operation, was positive.

**Bergström, K., Halling, A. & Wilde, B. (1998). Orthodontic care from the patients' perspective: perceptions of 27-year-olds. *The European Journal of Orthodontics*. 20(3):319-329.**

The aim was to analyse 27-year-olds' perceptions of their own dental arrangement and any orthodontic care they may have received as a child or adolescent. All of the individuals in a sample of young adults in Kronoberg County, Sweden, who had received orthodontic care during childhood or adolescence ( $n = 121$ ) were selected to participate in the study. In addition, 76 orthodontically untreated individuals were randomly selected from the same sample. All participants, both those who had previously had orthodontic treatment and those who had not, were sent a questionnaire. Most of the respondents were satisfied with their earlier decision, whether to choose orthodontic treatment or not. Dental professionals were considered to have had the greatest influence on this decision. This means that the desire for treatment may be guided by the orthodontist. Three out of four individuals considered orthodontic treatment important, even when irregularities of the teeth were minor. A majority of the individuals thought that they would have been able to wear visible braces if needed, even in adulthood. Individuals treated by specialists were more contented than individuals treated by general practitioners. Individuals with malocclusions and treatment need, but who had refused offered treatment, were in general more discontented with their dental arrangement; more than half of them now regretted their decision. They also felt it more difficult to communicate questions, thoughts, and opinions on their own desire for treatment. An increased level of information, especially to these individuals, would have been desirable.

**Björkman, T., Hansson, L., Svensson, B. & Berglund, I. (1995). What is important in psychiatric outpatient care? Quality of care from the patient's perspective. *Int J Qual Health Care*. 7(4):355-62.**

The development of quality assurance programmes for psychiatric care has increased the interest in quality of care and accountability from the patient's perspective. The aims of this study were threefold. First, to map descriptive characteristics of ideal outpatient psychiatric care through open-ended patient interviews, using a sample of 94 psychiatric outpatients, second, to have another sample of 84 outpatients rank the importance of 57 treatment characteristics extracted from the qualitative analysis of the interviews, and third to make comparisons with a previously performed investigation on quality of care of psychiatric inpatients. Results of the content analysis showed that characteristics of ideal outpatient treatment could be classified in eight content categories: accessibility of care, treatment content, staff-patient relationship, continuity of care, staff's professionalism, patient information/co-influence, treatment environment and cost of care. Results from the patients' rating of the importance of treatment characteristics showed that patients put the highest emphasis on staff's empathetic qualities in being interested, understanding, listening and respecting patients. Comparisons with the previously studied inpatient sample, showed great similarities in what was considered important to reach a satisfactory care situation. It is concluded that in order to secure content validity of investigations of the quality of psychiatric care from the patient's perspective, effort should be put into including the areas of staff-patient relationship and patient information and co-influence.

**Boman, L., Andersson, J. & Björvell, H. (1997). Needs as expressed by women after breast cancer surgery in the setting of a short hospital stay. *Scandinavian Journal of Caring Sciences*. 11(1):25-32.**

The aim of this study was to describe needs as expressed by a group of women after surgery for breast cancer in the setting of a short hospital stay. Ten days after surgery, 97 women answered an open-ended question about their perception of the care given. A content analysis inspired by the method of Grounded Theory was used. Satisfaction with the personal treatment and feelings of abandonment were identified as the two main themes. Expressed needs (n=113) were classified in five categories: Trust, Information, Practical Assistance, Personal Treatment and Emotional Support, of which Trust appeared to be the core concept. In addition, time and space emerged as two dimensions that were interwoven with the categories of needs. The patients' perception of trust in the staff was interpreted as depending on whether the needs in the other categories were satisfied or not. It is hypothesized that, to fulfil the patients' need of trust, the patients have to be satisfied at least with information, practical assistance, personal treatment and emotional support. We consider that, in an organization with a high degree of continuity, when the patients are aware of the physician and nurse responsible, the possibilities for trust are increased, especially in short hospital stays.

**Ekwall, E., Ternstedt, B. & Sorbe, B. (2003). Important aspects of health care for women with gynaecologic cancer. *Oncology Nursing Forum*. 30(2 part 1):313-9.**

*Purpose:* To describe what women diagnosed with primary gynaecologic cancer reported to be important during their interaction with the healthcare system.

*Design:* Qualitative.

*Setting:* A specialized gynaecologic cancer care unit in central Sweden.

*Sample:* 14 women diagnosed with primary gynaecologic cancer were recruited. The women had been referred to the specialized care unit for radiation or cytostatic therapy.

*Methods:* Tape-recorded interviews were transcribed, coded, categorized, and analyzed.

*Main research variables:* Primary diagnosed women with cancer and their experience with quality of care during diagnosis and treatment.

*Findings:* Three partly overlapping categories (i.e. optimal care, good communication, and self-image and sexuality) were found to be of central importance in quality of health care. Participants stated that health care should be based on their own perceptions of the need for information and dialogue and how the disease and treatment would affect their health, self-image and sexuality. Everyday conversations also were very important.

*Conclusions:* Central importance in health care for the women included both rational and human aspects. The primary need of participants was to achieve a rapid cure, which necessitated health care that was available, competent and coordinated.

*Implications for nursing:* Women with gynaecologic cancer should be given individualized information and care to satisfy their individual needs and reinforce their self-image. Nurses have an important role in strengthening women's feelings of hope and supporting them in maintaining as positive a self-image as possible. Information-and everyday conversation are of great significance. Sexuality should be an integral part of holistic care; to this end, inclusion of each woman's sexual partner may be helpful when discussion concerning sexuality occur.

**Erlandsson, K. & Fagerberg, I. (2004). Mothers' lived experiences of co-care and part-care after birth, and their strong desire to be close to their baby. *Midwifery*. 21(2):131-138.**

*Objective:* To describe how mothers of premature or sick mature babies, experienced the care and their own state of health after birth in postnatal care in a neonatal co-care ward.

*Design:* a Husserlian phenomenology method by Giorgi was used. Six mothers were interviewed using a semi-structured, open-ended interview guide.

*Setting:* A neonatal ward using a concept of co-care for premature or sick mature babies and their mothers.

*Findings:* In essence, mothers felt that, whatever the circumstances, they wanted to be close to their babies. It was the mother's experience that the organisation, staff or other circumstances prolonged the separation from her baby. The mother experienced the separation from the baby intensely during the first days after birth (even for a short period of time); after returning home, they had still not come to terms with it. The mothers regarded the entire stay in hospital as one event: they did not differentiate between wards or ward staff in the delivery, maternity or neonatal wards. All mothers in the study had, therefore, also experienced part-care for shorter or longer periods when separated from their baby, being then later reunited in co-care.

*Conclusion:* This study can be used as a basis for discussion on more individualised care through co-operation and organisation between delivery, maternity and neonatal wards, on order to reduce the amount of time mother and baby are separated.

**Fossum, B. & Arborelius, E. (2004). Patient-centred communication: videotaped consultations. *Patient Education and Counseling*. 54:163-169.**

The aim of this study is to analyse the way in which orthopaedic physicians manage consultations, and to identify those factors associated with patient-experienced

satisfaction/dissatisfaction. This was explored both using a descriptive method and by analysing comments from patients. Consultations were videotaped: 18 physicians and 18 patients participated. Approximately 1 week after the consultation, the patient was shown the video recording and asked for his/her points of view and spontaneous reactions. Each time, the patient wished to say something, the video was stopped and the comments recorded. According to the patients' comments of the videotaped consultations four consultations were mainly positive, seven negative and seven neither completely positive nor completely negative. We analysed the positive and negative consultations using the Consultation Map (CM) method. The pattern in the positive consultations shows a greater flexibility. Statements regarding initial history and aetiology often move to and fro between other items, and the consultation as a whole was often characterised by this rapid change between items. The pattern in the negative consultations seems to indicate a slower motion; with longer time spent with few items covered. The positive consultations were characterised by a greater prevalence of the items 'Sharing Understanding' and 'Involving the Patient in Management'. On the other hand, the negative consultations were characterised by more time spent with the items 'History of problems' and 'Patient Ideas'. This might be due to the patient having tried to express him/herself in order to present his/her views but the physician not following them up. In this study, The CM has been helpful in clarifying the difference between encounters experienced as satisfactory or dissatisfactory.

**Friedrichsen, M.J., Strang, P.M. & Carlsson, M.E. (2000). Breaking bad news in the transition from curative to palliative cancer care – patient's view of the doctor giving the information. *Supportive Care in Cancer*. 8(6):472-478.**

In the transition from curative to palliative cancer care, communication is of special importance. The aim of this study was to explore who patients with a disseminated cancer disease experienced the information about their incurable stated, focusing on the physician. The persons taking part were 30 patients admitted to a hospital-based home care unit in Sweden. Semi-structured interviews were conducted and analysed using a qualitative method. All patients described their doctors as experts, despite different qualities. Six subcategories were identified: (1) the inexperienced messenger, (2) the emotionally burdened, (3) the rough and ready expert, (4) the benevolent but tactless expert, (5) the "distanced" doctor and (6) the empathic professional. The relationship was described as very important to the patients' capacity to handle the information and was felt to have been built up during earlier meetings. The relationship was described in four subcategories: personal between well-acquainted individuals, impersonal between unacquainted individuals, personal between unacquainted individuals and impersonal between well-acquainted individuals. Both the character of the physician and his or her ability to create personal relationships influence patients' capacity to cope with this specific situation. Education and guidance are needed both in clinical practice and in medical schools.

**Halldorsdottir, S. & Hamrin, E. (1997). Caring and uncaring encounters within nursing and health care from the cancer patient's perspective. *Cancer Nursing*. 20(2):120-128.**

The aim of this phenomenological study was to explore caring and uncaring encounters with nurses and other health professionals from the perspective of the person who has been diagnosed and treated for cancer. Through thematic analysis of in-depth dialogues with five women and four men in the remission or recovery phase of cancer, three major categories regarding caring

and uncaring encounters were identified: 1. the nurse/health professional perceived as caring: an indispensable companion on the cancer trajectory; 2. the resulting mutual trust and caring connection; and 3. the perceived effect of the caring encounter: a sense of solidarity, empowerment, well-being, and healing. The essential structure of uncaring encounter is also threefold: 1. the nurse/health professional perceived as uncaring: an unfortunate hindrance to the perception of well-being and healing; 2. the resulting sense of mistrust and disconnection; and 3. the perceived effect of the uncaring encounter: a sense of uneasiness, discouragement, and a sense of being broken down. The findings emphasize the primacy of competence in professional caring, as well as that of genuine concern, openness and a willingness to connect with others. The often devastating effects of uncaring encounters on the recipient of nursing and health care raises the question whether uncaring as an ethical and a professional problem should perhaps be dealt with as malpractice in nursing and health care.

**Hansson, L., Björkman, T. & Berglund, I. (1993). What is important in psychiatric inpatient care? Quality of care from the patient's perspective. *Qual Assur Health Care*. 5(1):41-7.**

The development of quality assurance programs for psychiatric care has increased the interest in quality of care and accountability from the patient's perspective. However, most investigations of patient satisfaction use instruments which rate aspects of care defined and held to be important by professionals and care givers. The aims of this study were 2-fold. To map descriptive characteristics of ideal inpatient psychiatric care through open patient interviews, using a sample of 78 hospitalized patients and, secondly, based on a content analysis of these interviews, to have another sample of 77 hospitalized patients rank the importance of 48 treatment characteristics extracted from the qualitative analysis. Results of the content analysis showed that characteristics of ideal inpatient treatment could be classified in six categories: staff-patient relationship, patient co-influence, treatment content, activities, ward atmosphere and staff competence. Results from the patients' rating of the importance of treatment characteristics showed that patients put the highest emphasis on staff empathic qualities: being caring, interested and understanding, respecting patients, devoting time to patients, and creating a safe treatment environment. The least importance was ascribed to characteristics of the physical environment and daily routines on the ward. It is concluded that in order to secure content validity of investigations of the quality of psychiatric inpatient care from the patient's perspective, effort should be put into including the areas of staff-patient relationship and patient information and co-influence.

**Hedström, M., Skolin, I. & von Essen, L. (2004). Distressing and positive experiences and important aspects of care for adolescents treated for cancer. Adolescent and nurse perceptions. *European Journal of Oncology Nursing*. 8(1):6-17.**

Distressing and positive experiences for adolescents with cancer with regard to being told the diagnosis, receiving chemotherapy and being admitted to the ward, and important aspects of care for adolescents with cancer was investigated. Data were gathered through semi-structured interviews with 23 adolescents and 21 nurses, and analysed by content analysis. The findings indicate that cancer during adolescence is connected with a range of negative experiences such as fears of alienation, fears of altered appearance, fears of dying, and various physical concerns. Positive experiences include positive relations to staff and being well cared for. Important care for

adolescents treated for cancer consists mainly of meeting nice, friendly, supportive and competent staff, who provide them with age-appropriate information. The findings indicate that adolescents with cancer experience a range of negative and positive experiences related to disease and treatment and that good care for adolescents with cancer is a broad, complex and multidimensional phenomenon.

**Henriksen, E. & Rosenqvist, U. (2003). Understanding cardiac follow-up services – a qualitative study of patients, healthcare professionals and managers. *European Journal of Cardiovascular Nursing*. 2(2):95-104.**

The study explores the experience and understanding of stakeholders involved in follow-up services after a cardiovascular event. A multi-method approach was used consisting of questionnaires, telephone surveys, and in-depth, face-to-face interviews. Five themes were identified: patients wished to be seen in their total context; patients should do as told; healthcare professionals are in charge of the care processes; and the structure and processes of the healthcare organization. Results indicate that healthcare professionals have considerable difficulty in understanding the patient's situation and to collaborate between different levels of care. Furthermore, the total healthcare organization lacked comprehensive and practical structures in the follow-up process, rehabilitation and secondary preventive services.

**Ivarsson, B. Larsson, S. & Sjöberg, T. (2004). Postponed or cancelled heart operations from the patient's perspective. *Journal of Nursing Management*. 12(1):28-36.**

*Objectives:* The aim was to describe postponements or complete cancellations of planned cardiac operations as a Swedish hospital during 1999 and the reception the patients received from the staff in connection with this, from the inpatient's perspective.

*Design:* A qualitative descriptive design inspired by content analysis was used. Data were collected through questionnaires distributed to all 74 patients who had their heart operation cancelled.

*Results:* During analysis of the questionnaires, five categories of answers emerged describing the patients' perception of: organization, medical aspects, information, waiting time and staff reception. Overall, the patients reacted negatively to the postponement/cancellation in the form of anxiety and disappointment and fear of being affected by cardiovascular problems, but were generally satisfied with reception received from hospital staff. A number of concerns were revealed, however, with possible practical implications for the health-care system.

*Conclusion:* An understanding of the disappointment and anxiety felt by patients because of the postponement/cancellation of heart surgery can help medical staff to improve the situation. An intervention program is suggested that includes a pre-admission clinic, a change in the planning and waiting list system and support via follow-up telephone calls or internet-based support system.

**Ivarsson, B., Larsson, S. & Sjöberg, T. (2004). Patients' experiences of support while waiting for cardiac surgery. A critical incident technique analysis. *European Journal of Cardiovascular Nursing*. 3(2):183-91.**

*Background:* Patients waiting for cardiac surgery experience the period from decision about surgery to the operation as long, heavy and dreary.

*Aims:* The aim was to describe patients' experiences of support in the form of important events during the waiting period.

*Methods:* The design was qualitative and the 'critical incident' technique was used. Incidents were collected via interviews with 26 patients waiting for heart surgery. The selection of patients was strategic.

*Results:* In all, 223 important events, both positive and negative, were identified in the interviews and two main areas emerged in the analysis: internal factors and external factors. Internal factors describe how an experience of support was influenced by changes in life style and by finding strength from within. External factors describe how experiences of support was influenced by being allowed to participate in care management, by receiving attention, as well as by the health care organisation and the social network.

*Conclusion:* By identifying factors that influence patients' experiences of support while they wait for heart surgery, institutional and non-institutional health-care services can improve the organisation of the entire health care process, and develop patient-focused support programmes.

**Johansson, G. & Fridlund, B. (1996). Young adults' views on dental care – a qualitative analysis. *Scandinavian Journal of Caring Sciences*. 10(4):197-204.**

The aim of the present study was to determine young adults' views on dental care. The gathered data were gleaned from interviews and analysed in accordance with comparative method. It was possible to discern the views from two perspectives: the patients' opinions regarding costs in relation to given functions within dental care, and the attitudes to given functions in dental care per se. Costs for information and service were deemed questionable, whereas the costs for examination and treatment were accepted. The patients' stance was active with respect to information and treatment, whereas a greater degree of passivity prevailed within the areas of examination and service. According to this report, maintaining cheap dental care rates was deemed important. The patients questioned having to pay for information perceived as irrelevant to dental care. They expressed a hidden wish to assume an active role while being given more information, and to exercise greater influence with reference to own dental care, but were not in the habit of stating their views to dental staff. Thus, continuous patient satisfaction studies are vital in order to meet this group's needs. One suggestion for further research is to study how young adults regard dental care based on the theory presented.

**Johansson, P., Oleni, M. & Fridlund, B. (2002). Patient satisfaction with nursing care in the context of health care: a literature study. *Scandinavian journal of Caring Sciences*. 16(4):337-44.**

To evaluate and improve the quality of care provided, it is of vital importance to investigate the quality of care in the context of health care. Patient satisfaction is a significant indicator of the quality of care. Consequently, quality work includes investigations that map out patient satisfaction with nursing care. To improve the quality of nursing care, the nurse needs to know what factors influence patient satisfaction. The aim of this literature study was to describe the influences on patient satisfaction with regard to nursing care in the context of health care. In the description of nursing care, we have used Henderson's nursing care model. The results describe eight domains that have an influence on patient satisfaction with nursing care: the socio-demographic background of the patients; patients' expectations regarding nursing care, the physical environment, communication and information, participation and involvement, interpersonal relations between nurse and patient, nurses' medical-technical competence, and the

influence of the health care organization on both patients and nurses. The bulk of the literature included in the study came from the UK, Sweden and the USA. This means that the results should be applicable to health care in the western world. An important implication for future research is to continue to elucidate the factors that influence satisfaction with nursing care, as seen from the patient's perspective.

**Klanghed, U., Svensson, T. & Alexanderson, K. (2004). Positive encounters with rehabilitation professionals reported by persons with experience of sickness absence. *WORK: A Journal of Prevention Assessment and Rehabilitation*. 22(3):247-54.**

More knowledge is needed on different factors that can promote return to work among sick-listed persons. One such factor might be by their interactions with the rehabilitation professionals they encounter. The aim of the present study was to identify and analyze statements about positive encounters with rehabilitation staff, reported by persons who had been absent from work with back, neck or shoulder diagnoses. A descriptive and explorative qualitative approach was used to analyze data from five focus-group interviews. There were few statements on positive encounters, and they were frequently attributed to sheer luck. Experiences of positive encounters were assigned to two major categories: respectful treatment and supportive treatment. Receiving adequate medical examination or treatment was also mentioned as being positive. Further efforts are needed to study and develop methods for investigating interactions with rehabilitation professionals that laypersons experience as positive and that may contribute to empowerment and influence return to work when sickness absent.

**Krevers, B. & Öberg, B. (2002). Development of the "Patient perspective On Care and Rehabilitation process" instrument (POCR). *Aging Clin Exp Res*. 14(5):402-11.**

There is a lack of instruments for assessing patient-perceived quality of care developed from a process perspective and also from theoretical concepts based on a patient perspective. The objective was to develop an instrument for following-up the care and rehabilitation process of the elderly from the patients' perspective. The present instrument, the "Patient perspective On Care and Rehabilitation process" (POCR), is based on a theoretical framework for the patients' evaluation of the care process, i.e., an instrument-construction reflecting that the patients' needs differed during the care process. The POCR contains two scales; one measures the fulfilment of needs and the other the importance of the fulfilment of needs. Data collection took place via telephone interviews. A factor analysis based on 306 cases resulted in seven factors reflecting the different phases in the care process and with an explained variance of 60.8. Conclusions: the POCR is a valid, reliable and useful multi-dimensional instrument for measuring patient-perceived outcome of the care and rehabilitation process in the elderly.

**Lindberg, M., Ekström, T., Möller, M., & Ahlner, J. (2001). Asthma care and factors affecting medication compliance: the patient's point of view. *International Society for Quality in Health care*. 13(5):375-383.**

*Objective:* To identify important factors that can influence patient compliance with prescribed medication and to elucidate aspects of asthma care from the patient's point of view.

*Design:* Field investigation; the interviewer used a semi-structured questionnaire.

*Setting:* Patients with asthma in primary health care settings in Sweden.

*Conclusion:* The factors of importance for self-reported compliance with prescribed medication were age, gender, duration of the disease, the attitude of the staff and information/education about asthma. The patients expressed important aspects of care, and these are in accordance with how an asthma nurse practice functions in Sweden.

**Lindvall, L., von Post, I. & Bergbom, I. (2003). Issues and Innovations in Nursing Practice. Patients' and nurses' experiences of perioperative dialogues. *Journal of Advanced Nursing*. 43(3):246.**

*Background:* Previous research has shown that perioperative visiting can aid the planning and implementation of nursing care by giving patients an opportunity to express their expectation and to receive information. This in turn can reduce anxiety and stress. However, patients' and nurses' experiences of this process have not been studied before.

*Aim:* The aim of the research was to describe and interpret the meaning of nursing care experienced by patients and nurse anaesthetists or operating-room nurses (referred to as preoperative nurses) through the pre-, intra- and postoperative dialogues.

*Methods:* A hermeneutic approach was used when interpreting text from interviews with 10 patients after the operation and 10 nurses who were asked to write down their experiences after having conducted pre-, intra- and postoperative dialogues with their patients. The interpretations of the whole were: the common quality of the pre-, intra- and postoperative dialogues was continuity and the distinguishing quality was how the patient and nurse experienced continuity.

*Findings:* Continuity in 'the perioperative dialogue' from the patients' point of view is expressed as sharing a story and the body is in safe hands. From the nurses' point of view continuity means that professional nursing care becomes visible and that continuity gives meaning to the work.

*Conclusion:* If perioperative nurses used the perioperative dialogue they could create continuity for patients and for themselves in the pre-, intra- and postoperative phases. The nurse is, in this context, the continuity and continuity gives the possibility of establishing a caring relationship and caring for the patient in a dignified way.

**Lundgren, I. (2004). Releasing and relieving encounters: experiences of pregnancy and childbirth. *Scandinavian Journal of Caring Sciences*. 18(4):368-75.**

The experience of childbirth is an important life event for women, memories of which may follow them throughout life. The aim of the study reported here was to synthesize the results from four selected studies describing these experiences by focusing on women's and midwives' experiences of pregnancy from the women's perspective. The setting was the Alternative Birth Care Centre (Sahlgrenska University Hospital, Göteborg) and Karolinska Hospital (Stockholm). A qualitative method grounded in phenomenology and hermeneutics was used as a basis for the studies and synthesis. The essential structure may be conceptualized under the heading 'releasing and relieving encounters', which, for the woman, constitutes an encounter with herself as well as with the midwife, and includes stillness as well as change. Stillness is expressed as transition to the unknown and to motherhood. In the releasing and relieving encounter, for the midwife stillness and change equals being both anchored and a companion. To be a companion is to be an available person who listens to and follows the woman through the process of childbirth. To be

anchored is to be the person who respects the limits of the woman's ability as well as her own professional limits in the transition process. A releasing and relieving encounter implies a sharing of responsibility and participation for women. This may be understood as a unique feature, which differs from other caring encounters and should be further studied.

**Lundqvist, A., Nilstun, T. & Dykes, A. (2002). Both empowered and powerless: mothers' experiences of professional care when their newborn dies. *Birth*. 29(3):192-9.**

The death of a newborn is a complex and tragic situation, the uncertain and stressful nature of which places emotional burdens on the parents. The aim of this study was to examine and illuminate mothers' experiences and perceptions of the care given to them at neonatal clinics while facing the threat and the reality of losing their baby. Interviews were performed, in the form of conversations, with 16 mothers approximately 2 years after the death of their newborns. The interviews were analyzed using a hermeneutic phenomenological method. The primary themes identified were feeling empowered and feeling powerless. Three related themes to feeling empowered were a sense of nearness-supporting confidence; a sense of encouragement-supporting self-esteem; and a sense of empathy-supporting comfort. Three related themes to feeling powerless were a sense of distance-leading to strength or adjustment; a sense of violation-leading to helplessness and despondency; and a sense of disconnection-leading to insecurity and discouragement. All mothers felt both empowered and powerless. When experiencing empowering care, they had a feeling of encountering benevolence, with respect to their individual desires. Experiencing competent care without humane treatment made them feel powerless, and they were neither respected as a mother nor a person. Feelings of empowerment emerged when the health care professionals not only saw the mother as an individual but also "saw through the mothers' eyes" and "felt with the mother's feelings". Feelings of powerlessness emerged when the similarity in the lifeworld (i.e., the world of lived experiences) differed, and the perspectives of the mothers and the health care professionals did not correspond.

**Lövgren, G., Engström, B & Norberg, A. (1996). Patients' narratives concerning good and bad caring. *Scandinavian Journal of Caring Sciences*. 10(3):151-6.**

Narratives from patients (n=80) and patients' relatives (n=12) were collected in order to illuminate experiences of good and bad caring episodes and to obtain descriptions of good caring. Narratives describing good caring included such task aspects as swift and correct assessment and access to information. Aspects less frequently mentioned were, for example, being given time, receiving pain relief and good food. Relationship aspects mentioned: having an interest shown in the care; being taken seriously and being cared about. There are parallels regarding relationship aspects between the narratives concerning good and bad caring episodes; for example what was praised in the good caring narratives was criticized in those describing bad caring. Such parallels were being/not being trusted, being/not being believed and being/not being respected. The narrations concerning bad caring were more specific and more vivid than those about good caring. The authors' interpretation was that the bad episodes were unexpected and very painful and therefore remained imprinted in the patients' memories. The descriptions of good caring included relationship aspects in only 34 cases, task aspects in only five cases and a combination of both in 50 cases. The ultimate purpose of the study was to obtain a basis for the development of a

policy for good caring founded on patients' experiences. It is desirable that further studies be undertaken within various clinical specialities which would also take into consideration medical, social and cultural perspectives.

**Lövgren, G., Sandman, P.-O., Engström, B., Norberg, A. & Eriksson, S. (1998). The View of Caring among Patients and Personnel. *Scandinavian Journal of Caring Sciences*. 12(1):33-41.**

All patients in hospital care and primary health care in the county of Västerbotten, Sweden (n=5158) were asked to express their level of satisfaction with the quality of care. The study was carried out on one specific day. All personnel on duty that day (n=2824) were also included and asked to give their interpretation of their patients' experiences. A questionnaire containing positive and negative statements concerning both the relationship and the task aspects of care was used. The results showed that the youngest and oldest patients expressed the highest degree of satisfaction, while young and middle-aged patients expressed a more restrained view. The least satisfactory aspects concerned the opportunities to express criticism and the possibilities of receiving information about access to help outside the health care organisation. The personnel's responses agreed with those of the patients, but fewer personnel thought that their patients were satisfied than was in fact the case.

**Persson, E., Gustavsson, B., Hellström, A-L., Lappas, G. & Hulten, L. (2005). Ostomy patients' perceptions of quality of care. *Journal of Advanced Nursing*. 49(1):51.**

*Aim:* This paper reports a study whose aim was to assess the quality of care in ostomy patients seen from a patient perspective.

*Background:* A stoma operation causes profound changes in a patient's life because of resulting physical damage, disfigurement, loss of bodily function, and change in personal hygiene. Such changes are a cause of major concern for patients and raise important issue for the quality of care.

*Methods:* The study group comprised patients who had undergone a colostomy for rectal cancer or an ileostomy for ulcerative colitis, all attending a stoma outpatient clinic. Quality of care was assessed using the identity-oriented dimension of the validated questionnaire 'Quality of Care from the Patient's Perspective'. Forty-two ileostomy and 49 colostomy patients completed the questionnaire.

*Result:* While the vast majority of patients in both groups thought that most topics in the questionnaire were important, most rated many aspects of the quality of care as unsatisfactory. One-third of the colostomy patients and one-half of the ileostomy patients were dissatisfied with the information they received about the results of medical examinations and laboratory tests, and an even higher proportion was dissatisfied with their opportunities to participate in the decision-making process or to discuss sexual matters. Stoma-related complications, which occurred in 71% of the ileostomy patients and in 43% of the colostomy patients, had no impact on these results.

*Conclusion:* Information and counselling for patients having ostomies, both on the part of specialist nurses and colorectal surgeons, appeared to deficient, suggesting that standards for quality of care require continuous evaluation and revision.

**Petzäll, K, Berglund, B. & Lundberg, C. (2001). Patients' opinions and experiences regarding the hospital bed and the bedside equipment: an interview study. *Scandinavian Journal of Caring Sciences*. 15(1):106.**

As it is important for patients' recovery that hospital beds are comfortable and adapted to patients' needs, 60 adult patients were interviewed during their stay in hospital about the experiences and opinions regarding the hospitals beds, beside equipment and the general milieu in the ward. The patients were recruited from one ear, nose and throat, one general surgery and one internal medicine ward respectively, at the Sahlgrenska University Hospital in Göteborg. A standardized questionnaire containing both open and closed questions concerning bed function and bed comfort was designed and used. The study revealed substantial and serious dissatisfaction among the patients regarding the comfort of beds, bedside equipment and the physical milieu in the wards. Younger patients were more critical than elderly patients. The patients had many relevant suggestions on how to improve the conditions in the wards with respect to the needs they themselves had experienced as patients.

**Randers, I., Olson, T. & Mattiasson, A.-C. (2002). Confirming older adult patients' views of who they are and would like to be. *Nursing Ethics*. 9(4):416-31.**

This article reveals a 91-year-old cognitively intact man's lived experiences of being cared for in a geriatric context in which the majority of the patients were cognitively impaired. A narrative patient story was analysed phenomenologically. The findings indicate that this patient's basic needs for ethical care were not met. The staff did not see him as a unique individual with his own preferences, resources and abilities to master his life. In order to survive this lack of ethical care, he played the role of an 'old cognitively impaired man', which provided him with at least the understanding and attention the cognitively impaired patients received from the staff. The findings also indicate that ethical care is independent of whether or not older cognitively intact and impaired patients stay or live in the same unit, but it is more dependent on a caregiver's ability to respect and confirm each and every patient for who he or she is and would like to be.

**Rasmussen, B.H., Jansson, L. & Norberg, A. (2000). Striving for becoming at-home in the midst of dying. *American Journal of Hospice and Palliative Care*. 17(1):31-43.**

Research interviews with 12 patients at an inpatient, free-standing hospice in Sweden were analyzed, using a phenomenological hermeneutic approach, to show the effects of individual nursing care as experienced by the guests. The findings revealed that the effects of, and reactions to, nursing care were inseparable from the hospice milieu and the patients situation, which was interpreted as including the prospect of becoming homeless. Thus, the effects of hospice spirit (nursing care and milieu) as experienced by these hospice patients represented the contrasting possibilities of hindering – or contributing to – the prospect of becoming homeless. What the patients spoke about was either a consoling or a desolating hospice spirit. A consoling hospice spirit supports experiences of wholeness and communion, i.e., becoming at-home in the midst of dying, while a desolating hospice spirit results in feelings of alienation and fragmentation, i.e., feeling homeless. Considering the dying person to be a guest rather than a patient is an important component of Swedish hospice philosophy and supports the view of the dying person as an autonomous and dignified human being.

**Rosenqvist, U. (1995). Diabetes service management training and the need for a patient perspective: a 10-year evolution of training strategies and goals. *Patient Educ. Couns.* 26(1-3):209-13.**

In 1977, the Swedish National Board of Health and Welfare published guidelines for comprehensive care of patients with diabetes. The Stockholm County responded and opened a Diabetes Education and Training Centre in 1979. The goal was to reduce the impact of long-term complications. The centre should translate available knowledge about diabetes care into clinical practice, promoting a shift of patients and resources to the primary health care sector. Follow-up studies and new knowledge have changed the short-term training strategies; the long-term goal has remained unchanged. Current work is concentrated on training of staff, improving methods to support better patient learning, aiding organisational changes, and supporting large-scale interventions aimed at both patients, staff and the public. The patient can realize the goals. Knowledge and demands expressed by persons with diabetes are necessary for improvements of diabetes care. The skilled patient is also a guarantee for continuity of care. Regular follow up of diabetes services was an important impetus for progressive change of short-term training strategies.

**Salander, P. (2002). Bad news from the patient's perspective: an analysis of the written narratives of newly diagnosed cancer patients. *Soc Sci Med.* 55(5):721-32.**

Papers in clinical journals dealing with how to tell cancer patients bad news rely mostly on the opinion of the physician. The purpose of the present study was to contribute with knowledge from the patient's perspective by analysing how patients with recently diagnosed cancer narrate the manner in which they received their diagnosis. A consecutive series of 187 patients who had received their cancer diagnosis 2-8 months prior to the outset of this study were asked to describe the manner in which they learned of their diagnosis in writing. A crucial finding from the submitted 138 written narratives was that the participants often described experiences from the first contact with hospital staff to the end of their treatment, rather than as a single instance of diagnosis communication. The relational meaning of these experiences was obvious. Information on treatment was of the utmost significance. No one required more prognostic information. From the perspective of the physicians, "bad news" focuses on how to provide information about diagnosis and prognosis in the course of a single diagnostic consultation. From the patient's perspective, "bad news" reflects the process of being diseased by cancer, and how medical services are available when one is in need of establishing a helpful relationship. In this relationship information about diagnosis and treatment is more a means than an end.

**Samuelsson, K., Larsson, H, Thyberg, M. & Gerdle, B. (2001). Wheelchair seating intervention. Results from a client-centred approach. *Disabil Rehabil.* 23(15):677-82.**

*Purpose:* The aim of this study was to analyse the effects of wheelchair intervention from a client-centred perspective.

*Method:* Results from 38 consecutive active wheelchair users visiting the wheelchair-seating department at the University Hospital in Linköping, were analysed and described. All clients had

defined problems related to wheelchair seating. Back pain was estimated before intervention and at follow-up, using a Visual Analogue Scale. The effect of intervention on different aspects of wheelchair functionality, seating and occupational performance was estimated by the clients at follow-up.

*Results:* Two initial main problem areas were identified among the group; seating discomfort (87%) and back pain (63%). Back pain was significantly reduced at follow-up ( $p < 0.001$ ). Problems initially defined by the clients, e.g. seating discomfort, were affected positively, in 79% of all clients, as estimated by the clients at follow-up. No significant correlation was found between the initial cause of intervention or the highest ranked wheelchair functionality aspect and final acceptance of intervention.

*Conclusions:* The results from this study confirm the possibility of reducing, or even eliminating, common secondary problems such as back pain and discomfort, related to wheelchair seating by individually adjusted measures. Further research and development in this field is both necessary and cost-effective.

**Samuelsson, M., Wiklander, M., Asberg, M., et.al. (2000). Psychiatric care as seen by the attempted suicide patient. *Journal of Advanced Nursing*. 32:635-43.**

The main question for this study was: 'What are the experiences of patients during inpatient psychiatric care after a suicide attempt?'. *Design:* Qualitative description using content analysis of interview data. *Main findings:* 3 central categories were identified: (1) being a psychiatric patient, (2) perceptions of the caregivers and the care provided, and (3) important aspects of the psychiatric care received. The patients described mixed feelings about *being a psychiatric patient*. They commonly reported feelings of discomfort, nervousness, failure and shame as well as feelings of relief at being admitted to hospital because they could not cope any longer. Although the patients had difficulties accepting admission to hospital in a psychiatric clinic, they understood the need for it. Patients expressed shock and horror over having tried to kill themselves. The patients described their *perceptions of the caregivers and care provided* in positive and negative ways. Many patients felt that the staff really cared and showed concern. The word "security" was used by more than half the patients. Other patients felt a lack of consideration and that no one seemed to care. These patients perceived the staff as indifferent and uncaring. The importance of being well cared for and experiencing understanding, confirmation, trust, and respect were emphasised. Lack of confirmation sometimes contributed to patients' feelings of being burdensome, demands for discharge, or even another suicide attempt. *Important aspects of the psychiatric care received* included the opportunity to talk to staff members and be understood, the invitation by staff to access the ward after discharge if necessary, and the admission to hospital itself, which patients viewed as life saving. *Conclusion:* Patients who had attempted suicide and were inpatients on a psychiatric ward emphasised that they wanted to be well cared for and receive understanding and confirmation.

**Sjöling, M., Ågren, Y., Olofsson, N., Hellzén, O. & Asplund, K. (2005). Waiting for surgery; living a life on hold – a continuous struggle against a faceless system. *International Journal of Nursing Studies*. 42(5):539-547.**

This interpretive-phenomenological study examined the lived experience of being on the waiting list for arthroplastic surgery of the knee or hip. Interviews reveal that respondents experience

suffering in different ways: illness-, caring- and life-suffering. Suffering leads to a struggle in order to have their caring needs met and the struggle is often fruitless – against a faceless enemy – “the system”. No one is there to answer their plea or the frustration they experience. This in combination with their present life situation may lead to a disrupted self-image. Finding or creating meaning in suffering appears to be a crucial issue in the struggling process. Respondents who are able to preserve or create meaning in life are able to reformulate their life-world and live a full life, in spite of severe pain and disability.

**Svedberg, P., Jormfeldt, H. & Arvidsson, B. (2003). Patients’ conceptions of how health processes are promoted in mental health nursing. A qualitative study. *Journal of Psychiatric and Mental Health Nursing*. 10(4):448-56.**

The most important goal of nursing care is to promote the subjective experience of health. The health promoting efforts of mental health care nurses must be aimed at creating encounters where the patient will be confirmed both existentially and as an individual worthy of dignity. The patient in mental health care is often viewed by the nurse as nothing more than a passive recipient of care and the belief in the patient’s potential is minimal. This can lead to a situation where the patient loses control in the caring situation and feels unable to improve his/her health, which conflicts with the goal of the nursing care. The aim of the study was to describe patients’ conceptions of how health processes are promoted in mental health nursing. Twelve patients with experience of mental health nursing were interviewed, and the data material was analysed using a phenomenographic approach. The results show 13 different conceptions of the phenomenon, and these were summarized into four descriptive categories: interaction, attention, development and dignity. The conceptions described show that the patients need to be treated as equals and that the nurse must trust the patient-s ability to make decisions and to promote his/her health process. It is suggested that mental health nursing should be built on humanistic science and its view that every individual has the ability to grow and develop. This view is one of the most important preconditions for the promotion of health processes in mental health nursing.

**Söderberg, S., Jumisko, E. & Gard, G. (2004). Clients’ experiences of a work rehabilitation process. *Disability & Rehabilitation*. 26(7-8):419-424.**

*Purpose:* The aim of this study was to describe clients’ experiences of a work rehabilitation process.

*Method:* Ten clients who had participated in work-related rehabilitation at a rehabilitation centre in the northern parts of Sweden were interviewed using a narrative approach. The interviews were analysed using qualitative content analysis focusing on clients’ descriptions of the goals, contents and results of the work rehabilitation process.

*Results:* At the beginning of the rehabilitation the goal was often to confirm a diagnosis, to become healthy and able to return to work. It was hard to be forced to change the goals. When fortunate the rehabilitation provided more profound guidance and function assessment. It resulted in changes varying from practical alterations to important insights into life. It was important to get support and understanding. When the rehabilitation was not adjusted to clients’ needs, feelings of disappointment emerged and life became a struggle with various authorities in order to gain understanding and other forms of rehabilitation.

*Conclusions:* This study shows the need to develop truly client-centred practice. Therefore, we emphasized, based on this study, the importance of professionals involved in rehabilitation working on different levels and in various settings having regular discussions about what the term

client-centred practice means to them. Integrating individual perceptions is essential to advancing a multidimensional approach in return-to-work research.

**Tishelman, C., Lundgren, E-L., Skald, A., Törnberg, S. & Wilde Larsson, B. (2002). Quality of Care from a Patient Perspective in Population-based Cervical Cancer Screening. *Acta Oncologica*. 41(3):253-261.**

In Stockholm, population-based cervical cancer screening is offered free of charge to all women between 23 and 60 years of age. A survey to assess satisfaction with care using a previously validated questionnaire was conducted with 73 women receiving abnormal Pap smear results through the screening program. Thirty-seven women received results of screening within a feasibility project, in which they had extra contact with a midwife prior to receiving standard information and medical follow-up by a gynaecologist. The other 36 women were a matched sample receiving standard information. The results indicate generally high perceptions of quality of care, with particularly high ratings of perceived gynaecological knowledge and medical information provision. Low perceptions of quality were found regarding several aspects of psychosocial care. Higher levels of self-reported psychological well-being were found among the women who had extra midwifery contact. The results indicate that more attention to psychosocial aspects might optimize the screening program.

**Wikblad K.F. (1991). Patient perspectives of diabetes care and education. *Journal of advanced Nursing*. 16(7):837-44.**

Educating and supporting patients in managing their daily life with diabetes mellitus are important goals of diabetes care today. These goals demand not only good medical knowledge but also good communication skills in the members of the diabetes care team and in the patients. Continuity and accessibility are naturally factors influencing the communication between the patients and the care team. This study, based on 55 interviews with well-experienced insulin-dependant diabetic patients, shows further that the contacts between the diabetes care system and the patient's metabolic control. Patients with good or acceptable metabolic control experience positive feed-back from the care team, while those with unsatisfactory or unacceptable metabolic control do not receive positive response and support to the same degree. The patients want to be permitted to be responsible for themselves and need support from the care team in order to accomplish this. From the patient's perspective, the diabetes education consists of an overwhelming amount of new information which often is presented on only one occasion. The patients want the education to be on an acceptable but minimum level and to be a continuous process that is applicable in practice.

**Wilde Larsson, B.W. & Bergström, K. (2005). Adolescents' perception of the quality of orthodontic treatment. *Scandinavian Journal of Caring Sciences*. 19(2):95-101.**

The aim was to describe quality of care from a patient perspective among adolescents receiving orthodontic treatment and to assess the relationship between quality of care and outcome-related aspects. The research design was cross-sectional. The sample consisted of 151 young people (mean age 17.1 years; SD 2.2; 53% girls and 47% boys) receiving orthodontic treatment in the Stockholm region in Sweden (response rate 75%). Data were collected using the Quality from the

Patient's Perspective questionnaire. The highest quality of care perceptions were noted on items dealing with receiving the best possible orthodontic treatment and being treated with respect. Less favourable perceptions of the quality of care were found regarding the opportunity to participate in the decisions related to the orthodontic treatment. In order to improve the quality of care a more active involvement of these patients in the decision-making process is suggested. The item 'I received the best possible orthodontic treatment' noted the highest subjective importance rating. The youngest participants reported the most favourable scores and the oldest the least. The majority (74%) reported that they were 'completely satisfied' with the result of the orthodontic treatment. However, 52% claimed that they had not followed all of the advice obtained during the treatment period, and 29% indicated some or more hesitation about attending the same dentist for future treatment.

**Wilde Larsson, B. & Larsson, G. (2002). Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire. *Journal of Clinical Nursing*. 11(5):681.**

Patients' views on the quality of care are important and it is desirable that these can be assessed using short, yet valid and reliable instruments. The aim of the work reported here was to develop and test a short version of an established questionnaire: Quality from the Patient's Perspective (QPP). Patients ( $n=162$ , 79% response rate). Receiving care at medical and surgical departments in two Swedish hospitals responded to the original QPP as well as to a newly developed short version. An ethical research committee approved the study. Pearson correlations were computed between the long and short forms and differences between means were analysed with  $t$ -tests. Reliability was estimated by computing Cronbach alpha coefficients. The strengths of the work are that the items in the short version are derived from a patient perspective and are formulated in words used by patients: the items still have a theoretical foundation, which makes the interpretation of results more meaningful; global formulations such as 'What do you think about your care?' have been avoided; the short format should make the questionnaire more attractive for many patients to respond to. Limitations are that results indicate that the short form does not fully measure what the long form does. Therefore, when the short form is used in practice, a two-step procedure is suggested, where a follow-up is done with a selection of items from the original long form. This selection could be restricted to areas where problems may be suspected, based on the results from the short form.

**Wilde Larsson, B. & Larsson, G. (1999). Patients' views on quality of care: do they merely reflect their sense of coherence? *Journal of Advanced Nursing*. 30(1):33-39.**

The aim was to explore the relationship between patients' perceptions of the quality of care and their sense of coherence. The sample consisted of 782 Swedish in-patients at a gynaecological, a medical, an orthopaedic, and a surgical department. The median age was 59 years, and 55% of the patients were women. Data were collected using the Quality from the Patient's Perspective (QPP) Questionnaire and the Sense of Coherence Questionnaire. The QPP consists of 61 items designed to measure the following four quality dimensions: the medical-technical competence and the degree of identity-orientation in the actions of the caregivers, the physical-technical conditions and the socio-cultural atmosphere of the care organisation. Each question is posed in two different ways in the QPP; one measures perceived reality of the item in question and one the

subjective importance the patient ascribes to it. Results showed that patients' ratings of perceived reality covaried systematically with their sense of coherence. This was particularly the case on questions rated by experts to be more abstract and emotionally loaded. Patients' ratings of the subjective importance of the items were weakly related to their sense of coherence. The results are discussed in terms of negative affectivity and culturally shared ideals regarding quality of care.

**Wilde Larsson, B., Larsson, G. & Starrin, B. (1999). Patients' views on quality of care: a comparison of men and women. *Journal of Nursing Management*. 7(3):133-139.**

*Aim:* This study set out to explore gender differences among medical and surgical acute care inpatients regarding their perceptions of actual care conditions as well as their evaluation of the subjective importance of various care conditions. *Background:* Firstly, the literature reports inconsistent findings regarding male and female patients' views on care. Secondly, the instruments used in most previous research are not derived from a patient perspective. *Methods:* The sample consisted of 831 patients (48% were women and 52% were men) at two Swedish hospitals. Data were collected using the questionnaire "Quality from the Patient's Perspective". *Findings:* Male and female patients tended to evaluate the actual care received similarly. However, women tend to assign the different care aspects higher subjective importance. *Conclusion:* More research is needed to illuminate the reasons why men and women hold these different values. Until these issues are better understood, there is no valid basis on a group (gender) level to give specific practical recommendations to nursing managers.

**Wilde Larsson, B., Starrin, B., Larsson, G. & Larsson, M. (1993). Quality of Care from a Patient Perspective. *Scandinavian Journal of Caring Sciences*. 7:113-120.**

The aim of the present study was to develop a theoretical understanding of quality of care from a patient perspective, using a grounded theory approach. Thirty-five interviews were conducted with a sample of 20 adult hospitalized patients (mean age: 60 years) in a clinic for infectious diseases. Data were analysed according to the constant comparative method. A model was formulated according to which quality of care can be understood in the light of two conditions, the resource structure of the care organization and the patient's preferences. The resource structure of the care organization consists of person-related and physical- and administrative environmental qualities. The patient's preferences have a rational and a human aspect. Within this framework, patients' perceptions of quality of care may be considered from four dimensions: the medical-technical competence of the caregivers; the physical-technical conditions of the care organization; the degree of identity-orientation in the attitudes and actions of the caregivers; and the socio-cultural atmosphere of the care organization. The model is discussed in relation to existing theories in the field.

**Quality of care from the  
patient's/client's perspective  
(Social services setting  
& home care)**



**Appelin, G. & Bertero, C. (2004). Patients' experiences of palliative care in the home: a phenomenological study of a Swedish sample. *Cancer Nursing*. 27(1):65-70.**

In recent times the rapid expansion of interest in palliative care has become a significant feature of health care development. Caring in the palliative way means simultaneous attention to the medical, nursing, spiritual, emotional and social needs of the patient. The main purpose of the present study has been to obtain an understanding of patients' experiences of palliative care at home with service from district nurses. The research design is influenced by Giorgi's phenomenology. Six patients diagnosed with cancer and receiving palliative care at home were interviewed and the transcribed interviews were analyzed. Interviews were conducted in the patients' homes. The findings show that the essential meaning of the patients' experiences of palliative home care can be described as uncertain safety. This meaning of essence is explicated by 4 themes, which are labelled Safe but unsafe at home, A sense of powerlessness, Change of everyday life, and Hope and belief in the future. The findings of the study point out the importance of well functioning teamwork and resources to facilitate patient's experiences of safety in their own homes. It should be noted that the patient and their next of kin are members of the team.

**Efraimsson, E., Höglund, I. & Sandman, P. (2001). 'The everlasting trial of strength and patience': transitions in home care nursing as narrated by patients and family members. *Journal of Clinical Nursing*. 10(6):813-9.**

The aim of this study was to describe and interpret patients' and their family members' lived experiences of caring at home. Twelve tape-recorded narratives, with seven patients and five family members, were interpreted in accordance with a phenomenological-hermeneutic method inspired by Ricoeur. The findings revealed life situations where natural caring was changed into patient-care-giver relations and the home became a public room. The patients had to deal with decreased abilities and the family members with adjusting to caring needs. The changes in the life situations were interpreted as long lasting and trying transitions. Implications for nursing and further research are proposed.

**Nygren, C., Iwarsson, S., Isacsson, Å. & Dehlin, O. (2001). Quality of Care in Geriatric Rehabilitation: Clients' Perceptions, ADL Dependence, and Subjective Well-being in a One-year Perspective. *Scandinavian Journal of Occupational Therapy*. 8(3):148-156.**

World-wide, the development of community-based geriatric rehabilitation has received increased attention. In Sweden, national reforms during the 1990s aimed at improved quality of geriatric rehabilitation. This paper focuses clients' perceptions of the rehabilitation process, dependence in activities of daily living (ADL), and subjective well-being in a one-year perspective. A study-specific questionnaire, a revised version of the ADL Staircase and the Göteborg Quality of Life Instrument were administered, in 1996 ( $n=278$ ) and 1997 ( $n=233$ ). Even if 77% of the clients were content as regards rehabilitation quality, in 1997 contentment diminished among clients in sheltered housing facilities. Most clients also reported a diminished contentment with the training provided during the period investigated. Most clients were dependent in ADL, but in sub-groups independence in some activities diminished over the study period. In contrast, in

some aspects sub-groups scored their subjective well-being lower on the second measurement than on the first. The investigation of clients' perception of quality of care is a multifaceted matter, and the results of this study were partly ambiguous. Still, since valid descriptions of variables at target for rehabilitation is one important key to the continuous process of quality development, this study produced information valuable for further studies following geriatric rehabilitation processes over time. The implementation of this study could be applicable in similar settings.

**Pejlert, A., Asplund, K. & Norberg, A. (1999). Towards recovery: living in a home-like setting after the move from a hospital ward. *Journal of Clinical Nursing*. 8(6):663-74.**

Six clients with a diagnosis of schizophrenia were interviewed about their experiences of their lives in a home-like setting, their key care provider and the care received. Their narratives of lived experiences in care were interpreted as living a process of health in the midst of severe mental illness, involving: 'becoming more', 'being disabled', 'comforting/confirming relationship', 'discomforting/unconfirming relationship' and 'caring about the caring relationship'. Fatigue and lack of strength influenced the lives of most clients considerably, and the stories were about problems and conflicts. Nevertheless, the clients seemed really to struggle to make communal life work, and there were experiences of increased competence and better self-confidence in most of the stories. On the whole care was described as good, and the process of health seemed to be supported by experiences of comfort and being confirmed in the client-care provider relationship.

**Samuelsson, G., Edebalk, P.G., Ingvad, B. (1993). Quality attributes of Swedish home-help services – from a consumer perspective. *Z Gerontol*. May-Jun; 26(3):202-7**

From existing Swedish literature, we examined different possible quality aspects of home-help services. We ordered the quality attributes of home help services under six headings: consumer adjustment of the services; competence of the staff and their attitudes; continuity; staff hours per services input; accessibility; and information and communication. Concerning the relative importance of different quality aspects, our study indicates that the competence/attitudes of staff were clearly the most important quality factor. Within this category, individual qualities and attitudes were regarded as having greater importance than trained professional competence.

**Wilde, B., Larsson, G., Larsson, M., & Starrin, B. (1995). Quality of care from the elderly person's perspective: subjective importance and perceived reality. *Aging*. Apr; 7(2):140-9.**

The aim of this study was to carry out a theoretically-based survey of elderly persons' perceptions of quality of care, in terms of their evaluations of actual care conditions, as well as the subjective importance they ascribe to these. The sample consisted of 428 elderly persons, in four different care environments: a geriatric department; persons receiving home nursing; nursing homes; and service homes in two Swedish cities. The results show that personal characteristics, such as age, sex, and self-rated health, had a limited effect on reports of what were regarded as highly important care characteristics, as well as on ratings of actual care conditions. Psychological well-being was strongly related to perceived reality ratings: a favourable well-being co varied with

favourable ratings and vice versa. Considerable differences were noted in both types of ratings when the four types of care environments were compared. On the subjective importance scales, persons living in service homes reported lower scores, particularly on the scales designed to measure the medical-technical competence of the caregivers. On the perceived reality scales, the participants in service homes and the geriatric department scored lower.



# Patient/client-centered care



**Holmström, I. (2002). *Gaining Professional Competence for Patient Encounters by Means of a New Understanding*. Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine 1145. Uppsala Universitet.**

Swedish health care is currently facing problems, such as lack of financial resources, staff shortage and dissatisfaction among patients and professionals. Patients' dissatisfaction was the point of departure for the present study, and one approach dealing with this problem was investigated. It was hypothesised that a patient-centred perspective could offer a possible solution. The aim of the study was to explore health care professionals' and medical students' understanding of their professional role and the patient encounter. A further goal was to determine whether these understandings could be developed by educational interventions. Students and professionals have been either interviewed or responded to a survey about their professional role and the patient encounter. Qualitative analysis was used. One group- and one individualised intervention were carried out. The participants' understandings of their professional role were taken as the starting point for learning. The results showed that a minority of medical students and professionals in diabetes care had incorporated a patient-centred perspective. Nurses in telephone advisory services recognised the patients' needs, but experienced conflicting demands of being both carer and gatekeeper. A non-optimal match between patients' needs and what professionals understand as their role could cause some of the problems. Competence development could be achieved by taking the participants' understanding of the professionals' role and of the patient encounter as a starting point for reflection. The results have implications for changes in organisation and education in health care, to optimise outcomes of care. Time for reflection, mentoring and professional development is needed

**Holmström, I. & Rosenqvist, U. (2001). A change of the physicians' understanding of the encounter parallels competence development. *Patient Educ Couns.* 42(3):271-8.**

Patients today complain that physicians do not listen. There is a need to improve the professional competence in the patient encounter. According to theory, competence is a result of how people perceive their work. Observation and reflection can improve the competence. The aim of this study was to investigate if physicians can develop a more patient-centred consultation style by an experienced-based specialist course and how such a development is related to the physicians understanding of the task. The physicians video recorded consultations and reflected on these. The video consultations were analysed with a time study and Pendleton et al.'s consultation schedule [Pendleton, D., Schoefield, T., Tate, P., Havelock, P. The consultation: an approach to learning and teaching. Oxford: Oxford University Press, 1984]. Before-after questions were answered. The study indicates that seven out of 10 physicians participating in the course had developed a patient-centred attitude and acted according to it. The time study gave ambiguous results. This study implicates that it is possible to initiate competence development by influencing the understanding of the encounter.

**Kottorp, A., Hällgren, M., Bernspång, B. & Fisher, A.G. (2003). Client-centred occupational therapy for persons with mental retardation: implementation of an intervention programme in activities of daily living tasks. *Scandinavian Journal of Occupational Therapy*. 10(2):51-60.**

The aim of this study was to implement a single-case design to evaluate the outcomes of a specified occupational therapy intervention programme. The intervention programme was based on a client-centred top-down approach and followed the Occupational Therapy Intervention Process Model. The interventions included both restorative and adaptive strategies to improve performance of the activities of daily living (ADL) tasks the participants defined as relevant and meaningful. Three women with moderate mental retardation living alone in apartments with support from professionals were included in the study. The Assessment of Motor and Process Skills was used to evaluate for changes in ADL motor and ADL process ability. The Assessment of Awareness of Disability was used to evaluate changes in the client's awareness of disability. The results showed improvements for all participants but patterns of changes were different between the participants and the outcome variables. ADL process ability was the only outcome variable that improved in all participants. The results are discussed in relation to the design used for evaluating intervention efficacy. Future improvements in the process of evaluating occupational therapy interventions are suggested.

**Lundgren, S.M. & Segesten, K. (2002). Nurses' altered conceptions of work in a ward with all-RN staffing. *Journal of Clinical Nursing*. 11(2):197-204.**

The aim of this study was to investigate how nurses' conceptions of their patients and work changed after reorganization to all RN-staffing and the adoption of a patient-in-focus philosophy on the ward. The study builds on the perspective that the individual's conception of work precedes and forms the basis for the development of knowledge, skills and attributes used in accomplishing work. The findings are based on a secondary analysis of two open interviews with 22 nurses on the ward. These interviews were conducted on two occasions with an interval of 2 years. The third interview was carried out 6 months later, when 10 nurses were asked to talk about a patient's care episode in a narrative form. The nurses' conceptions changed towards a holistic view of the patient, they developed a new approach to work and they used the altered circumstances in their work.

**Samuelsson, K., Larsson, H. Thyberg, M. & Gerdle B. (2001). Wheelchair seating intervention. Results from a client-centred approach. *Disabil Rehabil*. 23(15):677-82.**

The aim of this study was to analyse the effects of wheelchair intervention from a client-centred perspective. Results from 38 consecutive active wheelchair users visiting the wheelchair-seating department at the University Hospital in Linköping, Sweden, were analysed and described. All clients had defined problems related to wheelchair seating. Back pain was estimated before intervention and at follow-up, using a Visual Analogue Scale. The effect of intervention on different aspects of wheelchair functionality, seating and occupational performance was estimated by the clients at follow-up. The results from this study confirm the possibility of reducing, or even eliminating, common secondary problems such as back pain and discomfort, related to

wheelchair seating by individually adjusted measures. Further research and development in this field is both necessary and cost-effective.

**Saveman, B.I. & Benzein, E. (2001). Here Come the Swedes! A Report on the Dramatic and Rapid Evolution of Family-Focused Nursing in Sweden. *Journal of Family Nursing*. 7(3):303-9.**

Examines the rapid evolution of family-focused nursing (FFN) in Sweden. Decrease in health care funding and diminished resources in the country; Processes involved in the development of FFN namely, research, education and clinical work; Focus on family nursing theory and practice; Need for an intervention program to increase cooperation between nurses and families of elderly people in nursing homes.

**Söderberg, S., Jumisko, E. & Gard, G. (2004). Clients' experiences of a work rehabilitation process. *Disability and Rehabilitation*. 26(7):419-24.**

*Purpose:* The aim of this study was to describe clients' experiences of a work rehabilitation process.

*Method:* Ten clients who had participated in work-related rehabilitation at a rehabilitation centre in the northern parts of Sweden were interviewed using a narrative approach. The interviews were analysed using qualitative content analysis focusing on clients' descriptions of the goals, contents and results of the work rehabilitation process.

*Results:* At the beginning of the rehabilitation the goal was often to confirm a diagnosis, to become healthy and able to return to work. It was hard to be forced to change the goals. When fortunate the rehabilitation provided more profound guidance and function assessment. It resulted in changes varying from practical alterations to important insights into life. It was important to get support and understanding. When the rehabilitation was not adjusted to clients' needs, feelings of disappointment merged and life became a struggle with various authorities in order to gain understanding and other forms of rehabilitation.

*Conclusions:* This study shows the need to develop truly client-centred practice. Therefore, we emphasized, based on this study, the importance of professionals involved in rehabilitation working on different levels and in various settings having regular discussions about what the term client-centred practice means to them. Integrating individual perceptions is essential to advancing a multidimensional approach in return-to-work research.

**Timpka, T., Svensson, B. & Molin, B. (1996). Development of community nursing: analysis of the central services and practice dilemmas. *Int J Nurs Stud*. 33(3):297-308.**

As examples of nurse practitioners in primary care, Swedish district nurses have been shown, in several studies, to respond well to the general pressure to achieve higher productivity in health care. Yet they have less frequently been involved in studies of the detailed content of the service they provide. To maintain total service quality, change should not be brought about only for the sake of efficacy. This study is divided into an analysis of the basic service provided in district nursing by identifying a typical interaction with a patient; and an analysis of the daily dilemmas district nurses experience, their consequences, and possible measures for change. For the consultation study, data were collected from 40 videorecordings of office-hour consultations by a

rural district nurse. Regarding the dilemma situations, a critical incident questionnaire was returned by 153 district nurses in a Swedish county. The analyses showed that the district nurse practises in an area between self-care on the one hand, and the intersection of the different specialties in health care, on the other. Both the consultation study and the study of dilemmas in practice showed that the district nurse has to approach the health care organisation from a viewpoint close to that of the patient, which implies that she can, and has to, maintain an overview of the patient's total interaction with social institutions. This focal localisation of the shared care and co-ordination aspects constitutes a critical target for change and development efforts. The conclusions are that, first, the role of the district nurse/nurse practitioner as co-ordinator and advocate in patient-centred care could be considered in central health services policies and planning. Second, the content of the district nurses' daily work would be taken into account in the implementation of quality programs. These measures together can lead to an integration between today's theoretical nursing models and the dynamically changing structures of health care organisations.

**Wressle, E. & Samulesson, K. (2004). Barriers and bridges to client-centred occupational therapy in Sweden. *Scandinavian Journal of Occupational Therapy*. 11(1):12-16.**

This study investigates barriers to client-centred practice and solutions to overcome these barriers as experienced by Swedish occupational therapists. A British questionnaire was translated into Swedish and completed by 97 occupational therapists. The questionnaire consists of three sections: background information; a list of barriers identified in a literature review; and a list of methods to resolve barriers. The results show that the highest ranked barrier was "the therapist does not know enough about client-centred practice". The highest ranked method to resolve barriers was "management and peer support for use of client-centred practice". Introducing client-centred practice takes time, commitment, education, training, interview skills, discussions with colleagues, and reflection on the therapists' own attitudes.

# Client/Patient participation



**Efrainsson, E., Sandman, P.O., Hydén, L.-C. & Rasmussen, B. (2004). Discharge planning: 'fooling ourselves?' - patient participation in conferences. *Journal of Clinical Nursing*. 13(5):562-70.**

*Background:* The aim of discharge planning conferences (DPCs) is to co-ordinate resources and to enhance patient involvement in care in connection with relocation from hospital. DPCs can be characterized as institutional conversations, and are often executed as standard procedures, but the scientific basis for the activity is weak.

*Aims and objectives:* The aim of this study was to illuminate and describe the communication at DPCs.

*Design:* A purposeful and consecutive sample of eight DPCs was collected in which the future care of eight women, aged 70 years or more, was discussed.

*Methods:* Transcribed video recordings were analysed in two steps. "The initial analysis" aimed at describing the structure and content of the communication. This description constituted the basis for an interpretation, leading to "the focused analysis" aiming at finding evidence for the assumptions made in the interpretation.

*Results:* The result revealed that the participation of patients was very less the DPCs. The decisions had often already been made, and the women were expected to be pleased with the decision; institutional representatives (IRs) frequently justified their actions by referring to bureaucratic praxis.

*Conclusions:* The women were both encouraged and excluded from participation by the IRs. This dichotomy occurred because the IRs, as professionals, struggled to simultaneously realize their caring mission and their obligation to enforce the values and rules of the institution, i.e. efficiency and rationality. Thus, IRs and patients were equally imprisoned within the institutional system.

*Relevance to clinical research:* This result illustrates how conflicting paradigms are imbedded and reproduced by healthcare professionals in their communicative praxis. Awareness of this is a prerequisite for improvements in working procedures congruent with a caring paradigm that support patient participation.

**Eldh, A.C., Ehnfors, M. & Ekman. (2004). The phenomena of participation and non-participation in health care – experiences of patients attending a nurse-led clinic for chronic heart failure. *European Journal of Cardiovascular Nursing*. 3(3):239-46.**

*Background:* Patient participation is stressed in the health care acts of many western countries yet a common definition of the concept is lacking. The understanding of experiences of patients with chronic heart failure (CHF) who attend nurse-led specialist clinics, a form of care suggested as beneficiary to this group, may promote a better understanding of participation.

*Aim:* To investigate the meanings of participation and non-participation as experienced by patients living with CHF.

*Methods:* Narrative interviews analysed in the phenomenological hermeneutic tradition inspired by Ricoeur where the interpretation is made in the hermeneutic circle, explaining and understanding the experienced phenomena.

*Findings:* Participation was experienced as to "be confident", "comprehend" and "seek and maintain a sense of control". Non-participation was experienced as to "not understand", "not be in control", "lack of relationship" and "not be accountable". The findings indicate that the

experiences of participation and non-participation can change over time and phases of the disease and treatment.

*Conclusion:* The study suggests an extended view on the concept of participation. Patients' experiences of participation in health care can vary and should therefore be an issue for dialogue between nurses and patients with CHF in nurse-led specialist clinics.

**Larsson, M. (2000). Organising habilitation services: team structures and family participation. *Child Care Health Dev.* 26(6):501-14.**

This study is part of a project focusing on co-operation between receivers of habilitation services (families) and professionals. The study focuses on the organisation and co-ordination of the services, and compares two structures for their accomplishment. The first is the typical multi-professional habilitation team (MHT), and the second is the individualised team (ISP). MHT teams are organised within the habilitation agency, while ISP teams span institutional boundaries. An ISP team is formed around the individual child who receives services from the habilitation centre, and includes parents (sometimes the child), professionals from the habilitation centre, and professionals from other service-providing institutions that are actively involved (for instance pre-school teacher, schoolteacher etc. ). The team maps child and family needs, organises assessments and services and formulates goals that subsequently are monitored and followed up. A questionnaire (Measures of Processes of Care) was used to assess the experiences of 385 service receivers. The questionnaire focuses on service receivers' experiences of the family-centredness of the service, operationalised in 56 items, along with five items concerning perceptions of level of control over service provision. The experiences of families having individualised teams were compared to those not having these teams. Significant differences were obtained, suggesting the impact of the form of service organisation on the content. Families having ISP teams report both more family-centred service, and a greater level of control over service provision. Results are discussed in terms of organising structures and co-ordination of services, and in terms of family participation.

**Larsson Lund, M. (2004). *Living with physical disability. Experiences of the rehabilitation process, occupations and participation in everyday life.* Umeå University Medical Dissertations. New Series No. 901. Umeå Universitet.**

The overall aim of this thesis was to illuminate and enhance the understanding of how persons with acquired physical disabilities experience their rehabilitation process and their possibilities to engage in occupations in everyday life. The thesis comprised of five studies. The planning of clients' rehabilitation at hospital was explored through interviews with the clients ( $n=57$ ) and the professionals ( $n=50$ ). Interviews exploring how persons with physical disabilities experienced their rehabilitation process ( $n=15$ ), their occupational lives in their homes ( $n=13$ ) and the use of assistive devices ( $n=17$ ) were analysed qualitatively. Data was also collected from persons with spinal cord injury ( $n=161$ ) by the Impact on Participation and Autonomy questionnaire. The findings showed that the professionals used different strategies to encourage the clients to participate in the planning of the rehabilitation and that the strategies were based on traditions rather than on the individual clients' desires to participate. The informants' experiences reflected three parallel chains of rehabilitation over a period of time, a medical, a psychological and a social one. The influence of the different rehabilitation chains on how the clients' lives turned out varied over time, and the professionals were predominantly involved in the medical rehabilitation chain. To conclude, the findings indicate that the rehabilitation services need to be better able to

adapt to clients' desires to participate in the planning of their rehabilitation, and designed to satisfy the various needs the clients experience throughout the rehabilitation process.

**Sahlberg-Blom, E., Ternstedt; & Johansson. (2000). Patient Participation in Decision Making at the End of Life as Seen by a Close Relative. *Nursing Ethics*, 7(4):296-313.**

The aim of the study was to describe variations in patient participation in decisions about care planning during the final phase of life for a group of gravely ill patients, and how the different actors' manner of acting promotes or impedes patient participation. Thirty-seven qualitative research interviews were conducted with relatives of the patients. The patients' participation in the decisions could be categorized into four variations: self-determination, co-determination, delegation and non-participation. The manner in which patients, relatives and caregivers acted differed in the respective variations; this seemed either to promote or to impede the patients' opportunities of participating in the decision making. The possibility for participation seems to be context dependent and affected by many factors such as the dying patient's personality, the social network, the availability of different forms of care, cultural values, and the extent to which nurses and other caregivers of the different forms of care can and want to support the wishes of the patients and relatives in the decision-making process.

**Sahlsten, M.J., Larsson, I.E., Lindencrona, C.S. & Plos, K.A. (2005). Swedish participation in nursing care: an interpretation by Swedish registered nurses. *Journal of Clinical Nursing*. 14(1):35-42.**

*Aim:* The aim of this study was to clarify Registered Nurses' understanding of patient participation in nursing care. Objectives were to investigate ward nurses' interpretation of the elements of patient participation and its implementation.

*Background:* One goal of health care is patient participation. Registered Nurses must encourage the participation of their patients in nursing care situations. A right for patients to make their own informed choices is laid down in Swedish laws and national and local directives. The concept of patient participation can be interpreted differently and is thus difficult to implement and evaluate. Current nursing literature provides little clarity of the elements and processes of patient participation and conceptual definitions differ.

*Design and methods:* A qualitative approach was applied and the Grounded Theory method used. Thirty-one Registered Swedish Nurses described the meaning of patient participation and its implementation in nursing care. Seven focus groups interviews with nurses providing inpatient somatic care were carried out in five hospitals in west Sweden.

*Results:* Four properties, describing nurses' approaches and procedures, constitute patient participation. The properties are: interpersonal procedure, therapeutic approach, focus on resources, opportunities for influence. These properties were considered crucial for patient participation in a nursing care context.

*Conclusions:* The results clarify the concept of patient participation from a nursing perspective. A comprehensive description of important factors for patient participation could be made on the basis of nursing experience. This comprehensive description can be used in nursing care practice and its evaluation. The developed categories can be used in nursing care documentation of how patient participation is realized.

**Wilde Larsson, B., Larsson, G. & Rizell Carlsson, S. (2004). Patient involvement in clinical nursing. Advanced home care: patients' opinions on quality compared with those of family members. *Journal of Clinical Nursing*. 13(2):226.**

*Background:* Advanced medical care in the patient's home setting is becoming more common. Many of the patients who receive this kind of care have severe illnesses and are unable to respond to questions about the quality of care. The research question was: are the patients' opinions congruent with those of family members?

*Aim:* To explore and compare the relationship between patients' perceptions of the quality of care and close family members' perception of this care as well as their perception of the patients' perception.

*Methods:* Sixty-seven patients receiving advanced home care, 82 family members (54 matched patient + family member pairs) participated. Data were collected using a short version of the quality from the patient's perspective questionnaire modified to advanced home care.

*Results:* A high degree of perceptual congruence was found between patients and their family members. The similarity was also high between family members' own opinion and their appraisal of how the patient perceived the care. A subgroup of family members who met the patient once a week or less often deviated from this pattern.

*Conclusion:* Patients' views on the quality of care are congruent with the opinions of family members if they meet every day (live together) and share the same everyday and care-related experiences. The results can be understood in the light of empathic accuracy theory.

*Relevance to clinical practice:* The findings of this study have important implications for clinical nursing practice. Family members' perception of the quality of care may be a valuable data source for nurses in the case of advanced home care if the patient and family member share the same everyday, care-related experiences, otherwise family members' perception tend to be more critical than those of the patients themselves.

**Wressle, E., Eeg-Olofsson, A.-M., Marcusson, J. & Henriksson, C. (2002). *Improved client participation in the rehabilitation process using a client-centred goal formulation structure. Journal of Rehabilitation Medicine*. 34(1):5-11.**

The aim was to evaluate whether the use of a client-centred instrument, the Canadian Occupational Performance Measure (COPM), affects the patients' perception of active participation in the rehabilitation process. The study included 155 patients in the experiment group and 55 in the control, within geriatric, stroke, and home rehabilitation. The COPM was used in the the experiment group. A structured interview was performed within 2-4 weeks after discharge with 88 patients in the experiment group and 30 patients in the control group. The results show significant differences between the groups. More patients in the experiment group perceived that treatment goals were identified, were able to recall the goals, felt that they were active participants in the goal formulation process, and perceived themselves better able to manage after complete rehabilitation compared with patients in the control group. The study indicates that the COPM improves client participation in the rehabilitation process.

# **Patient's experiences of his/her illness/disease**



**Arman, M. & Rehnsfeldt, A. (2002). Living with breast cancer – a challenge to expansive and creative forces. *European Journal of Cancer Care*. 11(4):290-6.**

The aim of this qualitative case study is to obtain a deeper and more profound understanding of the world of women living with breast cancer focusing particularly on changes in life perspective. The study is based on a series of interviews carried out within the space of one year and involving four women with breast cancer; each woman was interviewed four times. The participants were between 42 and 54 years of age; three of the four interviewed were in an advanced stage, with metastasis or recurrent breast cancer. There was an increased awareness of the relationship between life and death, which constituted a disclosure rather than an actual change in life perspective. The four women were 'opening up' to the beauty and the essentials in life and experienced an increased desire to live their life in accordance with their own values. Their revitalised view of life increased their desire for authenticity. When it proved impossible to live in accordance with new insights the women were particularly frustrated. From a caring perspective our findings suggest that an awareness of patients' increased openness to their own needs and desires is an important resource in the healing and rehabilitative process of breast cancer patients. The paradoxes and the struggles involved disguise a hidden potential health.

**Boström, B., Sandh, M., Lundberg, D. & Fridlund, B. (2004). Cancer-related pain in palliative care: patients' perceptions of pain management. *Journal of Advanced Nursing*. 45(4):410-9.**

*Background:* Pain is still a significant problem for many patients with cancer, despite numerous, clear and concise guidelines for the treatment of cancer-related pain. The impact of pain cognition on patients' experiences of cancer-related pain remains relatively unexplored.

*Aim:* The aim of this study was to describe how patients with cancer-related pain in palliative care perceive the management of their pain.

*Method:* Thirty patients were strategically selected for interviews with open-ended questions, designed to explore the pain and pain management related to their cancer. The interviews were analysed using a phenomenographic approach.

*Findings:* Patients described 10 different perceptions of pain and pain management summarized in the three categories: communication, planning and trust. In terms of communication, patients expressed a need for an open and honest dialogue with health care professionals about all problems concerning pain. Patients expressed an urgent need for planning of their pain treatment including all caring activities around them. When they felt trust in the health care organization as a whole, and in nurses and physicians in particular, they described improved ability and willingness to participate in pain management. While the findings are limited to patients in palliative care, questions are raised about others with a cancer-related pain without access to a palliative care team.

*Conclusion:* The opportunity for patients to discuss pain and its treatment seems to have occurred late in the course of disease, mostly not until coming in contact with a palliative care team. They expressed a wish to be pain-free, or attain as much pain relief as possible, with as few side effects as possible.

**Broström, A., Strömberg, A., Dahlström, U & Fridlund, B. (2001). Patients with congestive heart failure and their conceptions of their sleep situation. *Journal of Advanced Nursing*. 34(4):520-9.**

*Aim:* To describe, from a nursing perspective, how patients with congestive heart failure (CHF) conceived their sleep situation.

*Background:* Sleep disturbances are very common in patients with CHF. Polysomnographic studies have shown that the total duration of sleep is shorter and the sleep structure disturbed, with frequent arousals and sleep stage changes.

*Methods:* A qualitative descriptive design inspired by a phenomenographic approach was employed. Conceptions were collected through interviews with 20 strategically chosen CHF patients.

*Findings:* The findings showed that the patients' sleep was affected by their daily activities, the disease itself and cardiac symptoms. The sleep disturbances gave effects such as fatigue, listlessness, loss of concentration and loss of temper. These effects led to a need for daytime sleep, seclusion, counselling and information. Patients handled their sleep disturbances through coping mechanisms related to developed patterns of daily life and through support from their psychosocial environment.

*Conclusions:* Through an increased awareness of the causes of sleep disturbances in CHF patients, nurses can more effectively meet their caring needs and reduce the psychological stressors that patients develop. Information and education, both to patients and the next of kin, about the disease and the sleep situation, especially good sleeping habits, can help patients to better cope with sleep disturbances.

**Ebbeskog, B. & Ekman, S.-L. (2001). Elderly persons' experiences of living with venous leg ulcer: living in a dialectal relationship between freedom and imprisonment. *Scandinavian Journal of Caring Sciences*. 15(3):235-43.**

The aim was to illuminate elderly persons' experiences of living with venous leg ulcer. Fifteen persons 74-89 years of age with active leg ulcer were interviewed. Data were analysed utilizing a phenomenological-hermeneutic approach inspired by Ricoeur. The analysis includes dialectic movement between understanding and explanation of the text as a whole and its parts. In the structural analysis four themes were identified: emotional consequences of altered body image, living a restricted life, achievement of well-being in connection with a painful wound and bandage, and struggle between hope and despair with regard to a lengthy healing process. The comprehensive understanding indicated that the meaning of living with venous leg ulcer can be understood as a dialectal relationship between, on the one hand the feeling of being imprisoned in the body, the bandage and the home, and on the other hand, hope of freedom from a burdensome body. The results indicate that the concept, body of image, is vitally relevant to the caring of elderly people with venous leg ulcer. The study shows the importance of recognizing the persons' perceptions on well-being. Nurses can thereby anticipate problems and provide more sensitive care.

**Ekman, I., Bergbom, I., Ekman, T., Berthold, H. & Mahsneh, S.M. (2004). Maintaining normality and support are central issues when receiving chemotherapy for ovarian cancer. *Cancer Nursing*. 27(3):177-82.**

The aim of this study was to enrich the understanding of patients' perspective of being diagnosed and treated for ovarian cancer. A qualitative approach was used to obtain knowledge and insight into patients' experiences and thoughts. Ten Swedish women, diagnosed with ovarian cancer, participated in a total of 23 interviews on 3 occasions: at the time of diagnosis, during chemotherapy, and after completion of chemotherapy. The results of the interpretation of the interviews were formulated in the form of 3 themes: (1) feeling the same despite radical castrating surgery, (2) accepting chemotherapy, and (3) maintaining normality and support. Suggestions of caring implications from our interpretation of the interview data underscore the need to support these women in learning to cope with their feelings of weakness and anxiety. The findings further indicate the potential in narrative methods to identify important issues in comprehensive cancer care.

**Elofsson, L.C. & Öhlen, J. (2004). Meanings of being old and living with chronic obstructive pulmonary disease. *Palliative Medicine*. 18(7):611-8.**

The aim of this study was to achieve a deeper understanding of the meaning of the lived experiences of elderly persons who are severely ill with chronic obstructive pulmonary disease (COPD) and in need of everyday care. Narratives from dialogues with six persons were interpreted using phenomenological-hermeneutic methodology. The structural analyses showed severe problems in daily life due to old age with a decaying body and dialectic experiences of resignation-contentedness, loneliness-connectedness, and being homeless-being at home. The interpreted whole reveals that life, suffering and comfort must be understood as an interlaced experience where ageing is just as important as the experience of illness. These elderly people's concerns and problems due to old age, a decaying body and being severely ill with COPD call for palliative and comfort care and thus challenge all professionals involved in their care.

**Enskär, K., Carlsson, M., Golsäter, M. Hamrin, E. & Kreuger, A. (1997). Life situation and problems as reported by children with cancer and their parents. *Journal Pediatric Oncology Nursing*. 14(1): 18-26.**

In recent years, the intensification of treatment for children with cancer has resulted in a considerable increase in the number of those who are cured. The intensive treatment has, however, led to a number of problems for the children and their families. The aim of this study was to identify children's experience of problems related to their cancer and the disease-effect on the child's life situation. Five children with varying diagnoses and treatment plans and five parents were interviewed separately. The qualitative interview data were compared with a quantitative measurement of problems. The interview data were analyzed by two of the authors according to the qualitative analysis processes. Six categories regarding influencing factors on the children's life situation were found: (1) medical treatment and side effects, (2) isolation, (3) togetherness and support, (4) being in the centre, (5) feelings and reactions, and (6) quality of care. About half of the variables on the list of problems were mentioned in one or more of the ten interviews. Study findings suggest that health care personnel help children with cancer to reduce their fear of painful and frightening procedures by creating a relationship with the child.

**Flensner, G., Ek, A.-C. & Söderhamn, O. (2003). Lived experience of MS-related fatigue – a phenomenological interview study. *International Journal of Nursing Studies*. 40(7):707-17.**

Fatigue is a major problem among individuals diagnosed with multiple sclerosis (MS), but its meaning in daily living is unclear. The aim was to describe MS-related fatigue as lived by a group of individuals diagnosed with MS. Interviews with nine individuals were analysed from a phenomenological perspective. *Main findings:* MS-related fatigue is living with a time-consuming and all absorbing phenomenon, involving the body and whole human being. Fatigue is commonly non-constructively perceived and expressed in terms of energy loss, emotional afflictions, dependency and restrictions of life in general, however, it is also constructively perceived and involves a desire to accept life and strive for a better situation. *Conclusions:* MS-related fatigue is a comprehensive phenomenon and its relationship with self-care requires further investigation.

**Granberg, A., Bergbom Engberg, I. & Lundberg, D. (1999). Acute confusion and unreal experiences in intensive care patients in relation to the ICU syndrome. Part II. *Intensive and Critical Care Nursing*. 15(1):19-33.**

The intensive care unit syndrome (ICU syndrome) is defined as an altered emotional state occurring in a highly stressful environment, which may manifest itself in various forms such as delirium, confusion, crazy dreams or unreal experiences. The purpose of this part of a study of patients' experiences is to describe and illuminate patients' experiences of acute confusion, disorientation, wakefulness, dreams and nightmares during and after their stay in the ICU. The data were obtained from 19 ventilated patients, who were interviewed twice and had stayed at least 36 hours in the ICU, the first interview being about one week after discharge from the ICU, and the second 4-8 weeks later. The hermeneutic approach used when interpreting and analysing the text from the interviews revealed that patients' experiences of unreal experiences were often associated with intense fear. Intense or continuous unbearable fear seems to result in frightening unreal experiences, which further increase the level of fear. Care actions or caring relationships with relatives or nurses can reduce this fear, which can help to prevent the occurrence and/or duration and intensity of the unreal experiences. Trust and confidence in nurses or significant others and feelings of self-control or trust in self-control seemed to reduce the risk of unreal experiences so that adverse stimuli might only trigger a mild confusion.

**Hedelin, B. & Jonsson, I. (2003). Mutuality as background music in women's lived experience of mental health and depression. *Journal of Psychiatric and Mental Health Nursing*. 10(3):317-22.**

Mental health problems, especially depression, have turned into an extensive public health problem, affecting women in particular. The aim of this study was to obtain a deeper understanding of mental health phenomena through elderly women's lived experiences of mental health and depression. The phenomenological approach was chosen for collecting experience-based and person-centred descriptions from 21 women, focusing on mental health and depression. The interviews were analysed using Giorgi's phenomenological descriptive method. Mutuality in their relationships with themselves and others emerged as a major element in the women's experience of mental health and depression. When the women's existence and value were confirmed in relation to themselves and others, mental health appeared as an ascending

spiral. When the women's value and self-esteem in relation to themselves and others were violated, the result was a descending spiral. Metaphorically speaking, 'mutuality' provided the 'background music' to the women's lives. Being a skilled professional psychiatric nurse means making the best use of mutuality as a creative power in the nurse-patient relationship. This means that the nurse must be aware that her/his attitude, appearance and behaviour are interpreted as a confirmation of the patient's worthiness or worthlessness.

**Hedelin, B. & Strandmark, M. (2001). The meaning of depression from the life-world perspective of elderly women. *Issues in Mental Health Nursing*. 22(4):401-20.**

Depression is a serious public health problem that particularly affects women and elderly people. The aim of this phenomenological study was to gain a deeper understanding of depression in elderly women by investigating and describing the meaning of depression from a life-world perspective. Qualitative interviews were conducted with five elderly women suffering from depression: they were transcribed and analysed using the phenomenological method. The essence of depression emerged as 'reexperiencing a severe personal insult' and the perception of 'increased sensitivity and vulnerability'. These two components constituted the breeding ground for an additional five characteristics. Depression was perceived as a severe multidimensional suffering that affected physical, mental, social, and spiritual aspects, where previous experiences merged with the current situation. Thus, the whole life space of these women was affected. In its most severe form, depression and, thereby, life was perceived as unbearable. The meaning that emerged from the women's descriptions can be understood against the background of the aging individual's retrospection and summation of life.

**Hedestig, O., Sandman, P-O., Tomic, R. & Widmark, A. (2005). Living after external beam radiotherapy of localized prostate cancer: a qualitative analysis of patient narratives. *Cancer Nursing*. 28(4):310-7.**

The treatment of prostate cancer induces adverse effects. Although quantitative studies have evaluated the influence of these adverse effects on the quality of life, few studies have tried to gain a deeper understanding of how men live after external beam radiotherapy of localized prostate carcinoma, which is the purpose of this study. Ten men were interviewed in their homes. The narrative interviews were tape recorded and transcribed into a text. To bear the emotional experience of the illness by oneself is a self-chosen strategy. Some men expressed a sense of being exposed in meetings with female caregivers. The treatment induced changes in body functions influencing daily life. In this new life situation these men are striving to reach a sense of having control, which includes control over disease progression and waning body function. Despite the negative influence of the treatment, the men are striving to become reconciled with their new life. The experience of living after external beam radiotherapy of localized prostate carcinoma could be understood as striving to reach a sense of control and becoming reconciled with a new way of life.

**Hedestig, O., Sandman, P. & Widmark, A. (2003). Living with untreated localized prostate cancer: a qualitative analysis of patient narratives. *Cancer Nursing*. 26(1):55-60.**

Few, if any, qualitative studies aimed at gaining an understanding of the experience of patients with prostate cancer have been done. The purpose of this study was to illuminate the meaning of being a patient living with untreated localized prostate cancer. Seven men with untreated localized prostate cancer were interviewed in their homes. The interviews were tape recorded and transcribed into text. The text was analysed using a phenomenologic-hermeneutic approach inspired by Ricoeur's philosophy. The meaning of living with untreated localized prostate could be interpreted as living life under a dark shadow. The disease was described as a threat to the patient's life. When living under this shadow, many of the men studied had an ambivalent wish both to share their experience with others and to be alone with their experiences of the disease. They believed that the disease had changed their lives, and their manhood was restricted by sexual dysfunctions and described as a burden. They used various coping strategies to manage this situation. Despite a positive relationship with their physicians, there is a risk that these patients will not be given the attention they need because of their good prognosis.

**Hörnsten, Å., Sandström, H. & Lundman, B. (2004). Personal understandings of illness among people with type 2 diabetes. *Journal of Advanced Nursing*. 47(2):174-82.**

*Background:* Professionals and patients understand the experience of illness from different worlds. Professionals' explanatory models focus on aetiology, diagnosis, pathophysiology and treatment, while patients' explanatory models are more focused on consequences and influences on daily life. The differences between patients and professionals in their understanding often result in conflicting expectations about treatment, priorities and outcomes of care.

*Aim:* The aim of this study was to describe personal understanding of illness among people with type 2 diabetes in Sweden.

*Method:* A sample of 44 patients, 47-80 years, diagnosed with type 2 diabetes within the last 2 years, was recruited from four health care centres. Narrative thematic interviews were used covering the areas of developing, coping with and living with diabetes. Qualitative content analysis was performed.

*Findings:* The findings were formulated into six categories: image of the disease, meaning of the diagnosis, integration of the illness, space for the illness, responsibility for care and future prospects.

*Conclusions:* The findings demonstrate that patients' personal understanding of illness is an important complement to the traditional professional view of diabetes. They could serve as a foundation for development of health history interviewing, as well as development of systems of documentation. Patients' personal understandings of diabetes in their daily lives are considered to be an important shared source of information for planning meaningful care.

**Carlsson, E., Ehrenberg, A. & Ehnfors, M. (2004). Stroke and eating difficulties: long-term experiences. *Journal of Clinical Nursing*. 13(7):825-34.**

*Background:* Previous studies have shown that eating difficulties after stroke are common and often associated with communication problems. These difficulties, however, have mainly been

studied from a professional perspective. Although numerous aspects of dysfunction have been identified, little knowledge exists about the experiences of living with eating difficulties.

*Aim:* To explore how people affected by stroke experience living with eating difficulties, during a prolonged period.

*Design:* Explorative, qualitative case study.

*Methods:* Repeated interviews and participant observations with three persons 1.5-2 years after their last stroke. Data were analysed using qualitative analysis.

*Results:* Eating difficulties after stroke were experienced as Striving to live a normal life, with the sub-themes Abandoned to learn on one's own, Experiences of losses and Feeling dependent. The process of getting back to a life that resembled life before the stroke was experienced as long-lasting and hard work. The informants felt that they were abandoned to manage eating training on their own. The informants experienced a loss of functional eating ability and the ability to perform activities related to food and meals. Feelings of dependence were experienced in mealtime situations.

*Conclusion:* Living with eating difficulties after stroke is a complex phenomenon. The informants felt abandoned because of lack of support from the nursing staff. They were left on their own to deal with the difficult process of adjusting to a new way of eating and losses regarding mealtime activities. The combination of repeated interviews and participant observations seemed to be an approach that should be tested in larger studies.

*Relevance to clinical practice:* This case study indicates a need for nurses to develop and use evidence-based guidelines for eating training during the continuum of care. Nurses need to assess patient's habits and desires related to eating and to adjust environment according to patient preferences.

**Larsson, M., Hedelin, B. & Athlin, E. (2003). Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *Journal of Clinical Nursing*. 12(4):562-70.**

Only a small proportion of cancer patients undergo radical radiotherapy to the head and neck, but their needs are particularly complex. Although extensive research describes the side-effects of radiotherapy to the head and neck, few studies focus on patients' experiences of eating problems and the impact these have on the patients' daily life. In this study a phenomenological approach was used, as the purpose was to acquire deeper understanding of head and neck cancer patients' lived experiences of eating problems, their consequences in daily life and patients' strategies of coping with these problems. Eight patients from two radiation therapy departments in mid-Sweden were interviewed in an open dialogue. Data analysis was based on Colaizzi's method. Eating problems experienced were captured in two interrelated main themes: 'Ability to chew and swallow' and 'Will and desire to eat'. The eating problems were found to cause a number of severe consequences in daily life. These are incorporated into one main theme: 'The way of life is disturbed'. Ways to cope with this disturbance were captured in one main theme: 'Trying to see the end – To survive'. This study identifies the need to view eating problems as a complex phenomenon in a specific context including the individual patient's life situation. The findings create the opportunity to develop nursing interventions based on patients' own needs. To facilitate this, as specialist nurse should be responsible for reviewing patients regularly throughout radiation therapy. Intervention studies are needed to provide optimal clinical guidelines.

**Magnusson, K., Möller, A., Ekman, T. & Wallgren, A. (1999). A qualitative study to explore the experience of fatigue in cancer patients. *European Journal of Cancer Care*. 8(4): 224-32.**

Fatigue – which is a complex, multi-causal and multidimensional subjective experience – is today the most frequently reported symptom from patients with cancer. The aim of this study was to explore the experience of fatigue in cancer patients and to describe the categories and dimensions of the symptoms. A qualitative method – grounded theory – was used. Unstructured, tape-recorded interviews with 15 patients were used for data collection. The categories found in this study illustrate fatigue as a process. Three major categories were found: (1) experiences (of loss, need, malaise, psychological stress, emotional affection, abnormal weakness, difficulties in taking the initiative); (2) consequences (social limitation, affected self-esteem, affected quality of life); and (3) actions (coping). The categories were constructed on the basis of dimensions with subordinated qualities. Knowledge concerning the different expressions of fatigue is important in caring for patients with cancer. The results from this study may contribute to a better understanding of how a cancer patient can experience and express fatigue and how the symptoms may affect the patient.

**Olsson, M., Lexell, J. & Söderberg, S. (2005). The meaning of fatigue for women with multiple sclerosis. *Journal of Advanced Nursing*. 49(1):7-15.**

*Aim:* This paper reports the findings of a study that aimed to elucidate the meaning of fatigue for women with multiple sclerosis (MS).

*Background:* Living with chronic illness can involve giving up usual activities. MS is a chronic autoimmune disease of the central nervous system. Fatigue is a common experience among people with MS; however, little is known about the meaning of fatigue experienced by women with this condition.

*Method:* Ten women with MS were interviewed about their experience of fatigue. A phenomenological hermeneutic method influenced by Ricoeur was used to interpret the transcribed interviews.

*Findings:* The findings were presented in two major themes with five subthemes; experiencing the body as a barrier and experiencing a different absence. Fatigue seemed to give rise to an experience of being absent and divided into two parts. This also led to a feeling of not being able to participate in the surrounding world. The feeling of being an outsider and lacking the ability as a healthy person is interpreted as a form of suffering. Although the fatigue had a great impact on the women's daily life, the women still hoped for some relief. Fatigue seemed to imply that instead of working as an implement to manage in the world the body has become an enemy of survival.

*Conclusion:* This study highlights the importance for nurses of understanding how women with MS experience fatigue, which is a prerequisite for communication based on a shared understanding. This awareness would enhance nurses' opportunities to alleviate suffering. More research is needed to investigate what kinds of interventions can help these women to manage their everyday lives and to maintain a sense of normality despite their fatigue and illness. Such interventions should be subject to empirical evaluation research.

**Paulson, M., Danielson, E. & Söderberg, S. (2002). Struggling for a tolerable existence: the meaning of men's lived experiences of living with pain of fibromyalgia type. *Qualitative Health Research*. 12(2):238-49.**

Chronic pain is a major health problem in Sweden because of its consequences in daily life. Fourteen men with fibromyalgia-type pain were interviewed regarding their experiences. A phenomenological hermeneutic method was used to interpret the transcribed interviews. Three major themes emerged: experiencing the body as an obstruction, being a different man, and striving to endure. Overall, the meaning of men's lived experience of chronic pain was experienced as change in the body, self and relationships. Striving to live life required achieving balance during both calm and difficult phases of the illness – struggling for a tolerable existence. Information from this study could provide guidelines for health care staff members to give empathic and supportive care to men living with a long-term illness.

**Strandmark, M. (2004). Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering. *Scandinavian Journal of Caring Sciences*. 18(2):135-44.**

The aim of the study was to create an understanding of the different dimensions of subjective ill health through discovering the essence of ill health, based on the individual experience. A philosophical, phenomenological method has been employed, and in-depth interviews were conducted with 25 individuals. The findings showed that the essence of ill health is powerlessness, which is made by a self-image of worthlessness, a sense of being imprisoned in one's life situation, and emotional suffering. The individual views her/himself as worthless, based on societal norms, attitudes and human models. Incapability and a sense of worthlessness cause the individual to distrust her/himself and others. She/he is imprisoned in her/his own life situation due to limited choices and ability. Such a situation gives rise to apathy. Destructive feelings of alienation, anguish, shame and guilt take over, and the individual's autonomy and existence are threatened. Stigmatization results from suffering and a sense of worthlessness. The informants compensated for their vulnerability by means of human support, intimacy with others, a society adapted to disability, living in the present and awareness.

**Svedlund, M. & Axelsson, I. (2000). Acute myocardial infarction in middle-aged women: narrations from the patients and their partners during rehabilitation. *Intensive and Critical Care Nursing*. 16(4):256-65.**

The purpose of this study was to examine the meaning of lived experiences after an acute myocardial infarction (AMI) and being a partner to an afflicted woman, as it is narrated during rehabilitation. Nine women and their partners narrated their experiences three and twelve months after AMI. The interview text were transcribed and then interpreted, using a phenomenological-hermeneutic method inspired by the philosophy of Ricoeur. The result showed that their experiences of the illness contained two themes: 'rehabilitation needed' and 'loss of freedom' which contains eight sub-themes: 'adapting to it', 'struggling against it', 'living as normally as possible', 'having insight into how it can be', 'feeling guilty and ashamed about being weak', 'withholding feelings', 'feeling useless', and 'feeling fatigued and losing strength'. After further interpretation, the themes gave a deeper meaning of living with AMI and how it affects women and their partners. The women conceded that they felt distressed and vulnerable but struggled against the fear the illness means. The partner's role appears to be one of trying to adapt to the

women's experiences of the illness. That the women withheld their feelings and did not talk about them indicates a lack of communication between the couples. As coronary care nurses often come very close both to the afflicted persons and the relatives they fill an important function in each patient's recovery. The nurses could help and prepare the patients and their relatives to understand better such feelings and reactions as could appear after discharge from hospital.

**Svedlund, M. & Danielsson, E. (2004). Myocardial infarction: narrations by afflicted women and their partners of lived experiences in daily life following an acute myocardial infarction. *Journal of Clinical Nursing*. 13(4):438-46.**

*Background:* The review of the literature showed that many people and their family members share feelings of distress after an acute myocardial infarction. Therefore, it is important to show how the illness affects the relationship in the couple's daily life when the closest relatives involved are men.

*Aim:* The aim was to illuminate the meaning of lived experiences in daily life after an acute myocardial infarction, as narrated by afflicted women and their partners.

*Methods:* Nine women and their partners narrated their experiences three and 12 months after an infarction. The interview texts were then interpreted, using a phenomenological hermeneutic method, inspired by the philosophy of Ricoeur. The text was divided into meaning units that were condensed and abstracted. Two themes and eight sub-themes were then extracted from the text.

*Results:* The first theme was 'living in a changed life situation', with the sub-themes: 'showing consideration', 'taking responsibility', 'living side by side' and 'desiring what to do'. The second theme was 'looking to the future' with the sub-themes: 'feeling uncertain', 'feeling powerless', 'feeling limited' and 'feeling hope'.

*Conclusions:* The results revealed that couples lived in a changed life situation, somewhat in 'discordance', and showed consideration to each other in order to protect the partner. There seemed to be a lack of verbal communication, but both women and their partners revealed that they sensed how their partners felt without verbal communication. In this 'discordance', couples may experience loneliness, in that they may not share feelings about the event and the situation it causes.

*Relevance to clinical practice:* Women and their partner have specific needs in daily living following an acute myocardial infarction. Therefore, nurses should acknowledge the specific needs for the female patients and the partner more clearly.

**Söderberg, S. & Lundman, B. (2001). Transitions experienced by women with fibromyalgia. *Health Care for Women International*. 22(7):617-31.**

Fibromyalgia (FM) is a chronic pain syndrome the hallmarks of which are a chronic diffuse musculoskeletal pain, tender points, and fatigue. The majority of those who have FM are middle-aged women. The aim of this study was to illuminate the transitions experienced by women with FM. Twenty-five women with FM were interviewed about living with FM. The interviews were analyzed using thematic content analysis. The analysis revealed five categories: transitions in patterns of daily life; family life; social life; working life; and learning to live with the changes brought about by FM. The categories were subsumed into one theme: FM as the choreographer of activity and relationships. The transitions experienced were illuminated in a core story. The experience of transitions is apparently something that is invisible to almost everyone except the women themselves. Paradoxically, the women described transitions in life due to the illness, but

they felt that other people saw them as healthy. It is like living in two worlds simultaneously, the world of the sick and the world of the healthy.

**Söderberg, S., Lundman, B. & Norberg, A. (2002). The meaning of fatigue and tiredness as narrated by women with fibromyalgia and healthy women. *Journal of Clinical Nursing*. 11(2):247-55.**

The aim of this study was to elucidate the meaning of fatigue and tiredness as narrated by women with fibromyalgia (FM) and healthy women. Twenty-five women with FM were interviewed with a narrative approach about the meaning of the lived experience of fatigue and tiredness. A reference group of 25 healthy women was interviewed about the same topic. A phenomenological-hermeneutic method inspired by the French philosopher Ricoeur was used to interpret the interview text. The meaning of fatigue and tiredness was related differently by women with FM and healthy women. The findings are presented in four major themes for women with FM – the body as a burden, an absent presence, an interfering obstacle and being in hope of alleviation – and in one major theme for healthy women: needing recovery. Women with FM narrated fatigue as making it obvious that I have a body, instead of I am by body; the lived body becomes urgently present, as an 'it'. Healthy women narrated tiredness as a natural phenomenon when they need recovery and time to rest. The findings are interpreted in the light of the phenomenological work on the lived body by Leder, Toombs and Merleau-Ponty.

**Tishelman, C. (1993). Who cares? Patients' descriptions of age-related aspects of cancer and care in Stockholm. *Cancer Nursing*. 16(4):270-82.**

This exploratory study examines the situation of a heterogeneous group of 46 cancer patients from one general hospital in the Stockholm area who were diagnosed with a malignant disease in 1987. Forty-six patients were interviewed to determine how they experience and cope with their sickness. Although age-related issues were not directly addressed by the interviewer, they were frequently commented upon by the respondents. A questionnaire was also used to quantify various psychosocial aspects of the individual's cancer experience. Quantitative and qualitative data were used in a complementary fashion. The patients interviewed ranged in age from 29 to 88 years (median 61). Issues related to age were frequently addressed spontaneously by the interviewed persons, which led to further exploration of age-related aspects of care. Although few age-related differences in symptom distress were found, some differences were seen in patients' perceptions of the response of the professional health-care system. The older patients related that they have less quantitative contact with specialized formal resources, and perceive less sense of engagement and concern from the professional health-care sector. The qualitative analysis suggests that age may be used by patients as an explanatory factor in a variety of situations, functioning as a means of "making sense" of sickness experiences.

**Wenneberg, S. & Ahlström, G. (2000). Illness narrative of persons with post-polio syndrome. *Journal of Advanced Nursing*. 31(2):354-61.**

This qualitative study investigated the lifetime illness experience of individuals with the 'late effects' of polio or post-polio syndrome. Fifteen individuals were interviewed twice about their illness experience and the interviews were transcribed verbatim. The empirical material first underwent a categorization process. The preliminary categories generated through this analysis were then condensed into broader categories which in the final analysis gave rise to the following temporal pattern or stages of the illness experience: (1) the acute phase of polio and subsequent

treatment and care: (2) rehabilitation and care at institutions for the disabled; (3) adaptation to a new life; (4) living with the post-polio syndrome today, and finally, (5) memories of the past and apprehensions concerning the future. In spite of the difficult experiences of falling ill and slowly recovering from a life-threatening disease, these individuals have had a good life and accomplished most of their ambitions in the areas of work and family life. Their present psychosocial situation is complicated by the symptoms of the post-polio syndrome which make them more vulnerable to stress, but they are able to handle this burden except when any added strain makes it overwhelming. This potential vulnerability may sometimes express itself as a sudden flashback to traumatic polio experiences and it is therefore important that nurses are aware of the illness history of this patient group.

**Wentz, K.A.H., Lindberg, C. & Hallberg, L.R. (2004). Psychological functioning in women with fibromyalgia: a grounded theory study. *Health Care for Women International*. 25(8):702-29.**

The aim of this study was to elucidate psychological functioning and psychological processes in women with fibromyalgia. Twenty-one females with fibromyalgia (aged 26-72 years) were interviewed in-depth. The interviews were analysed in line with grounded theory. A core concept, "unprotected self", mirroring childhood conditions and adult psychological functioning, was identified. Intense activity or hypomanic helpfulness often was used as self-regulation in adult life. Later an increased exposure to mental load is accompanied by reduction of cognitive functioning and generalised pain. The phase of persistence of fibromyalgia is marked by reduction of cognitive functions, unprotected psychological functioning, and increased mental load as from crisis and somatic symptoms.

**Winterling, J., Wasteson, E., Glimelius, B., Sjöden, P. & Nordin, K. (2004). Substantial changes in life: perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nursing*: 27(5):381-8.**

There are few studies on patients' perceptions of their situation after being recently diagnosed with an advanced gastrointestinal cancer and those of their spouses. Fourteen patients and their spouses were interviewed separately. The interviews were analyzed using a phenomenographic approach. The analysis indicated that the response categories for patients and spouses were roughly the same, but the number of patients and spouses who made statements differed between categories. All informants perceived substantial changes in life. This included negative physical, mental and practical changes as well as positive changes. Mental changes included 3 categories: despair, why and uncertainty. The informants described several ways of handling these changes in life. The most frequently reported by patients were that "one shouldn't complain" and by spouses to "hope", and by all informants to "make the best of it". Other ways of handling the situation were reconciliation, avoidance, preparation for death, seeking support, and isolation. In conclusion, more patients than spouses seemed to accept their situation because fewer patients complained and instead prepared for death, whereas more spouses felt despair, used hope and avoidance and were preoccupied with practical matters. These findings suggest that spouses are a vulnerable group and healthcare staff should be just as aware of their situation as that of the patients.

**Ågård, A. Bolmsjö, I.A. Hermeren, G. & Wahlstrom, J. (205). Familial hypercholesterolemia: ethical, practical and psychological problems from the perspective of patients. *Patient Educ Couns.* 57(2):162:167.**

The main aim of the study was to explore the extent to which familial hypercholesterolemia (FH) influences the life of the patients affected. The study employed a qualitative analysis of semi-structured interviews with 23 outpatients who were being treated following a diagnosis of heterozygous FH at a tertiary hospital in Göteborg, Sweden. Some interviewees reported concerns related to their medication and feelings of guilt when not complying with treatment recommendations. However, none of the respondents expressed sustained emotional distress or would have preferred to be ignorant of their diagnosis. Apart from being more observant about food intake, their awareness of FH did not appear to have had a substantial impact on their way of life. In fact, those who did not suffer from any other diseases generally regarded themselves as healthy. Discussing the genetic constitution with family members with whom they had close contact was natural, but informing distant family members was not.

**Åsbring, P. & Narvanen, A. (2004). Patient power and control: a study of women with uncertain illness trajectories. *Qualitative Health Research.* 14(2):226-40.**

The authors interviewed 12 women diagnosed with chronic fatigue syndrome and 13 with fibromyalgia with the aim of determining the strategies they perceive themselves as using to gain control over their situation during the health care process. The results highlight various strategies that the women report applying to find a way of managing the illness and to influence caregivers. They describe, for example, how they try to gain control over their situation by acquiring knowledge about the illness. The women also describe various power strategies they use in their interaction with the caregivers to take command of their situation, namely exiting, non-compliance, confrontation, persuasion/insistence, making demands, and demonstrative distancing.

**Åsbring, P. & Narvanen, A. (2002). Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research.* 12(2):148-60.**

Chronic fatigue syndrome and fibromyalgia are characterized by being difficult to diagnose and having an elusive etiology and no clear-cut treatment strategy. The question of whether these illnesses are stigmatizing was investigated through interviews with 25 women with these illnesses. The women experienced stigmatization primarily before receiving a diagnosis, and the diffuse symptomatology associated with the illnesses were significant for stigmatization. Stigma consisted of questioning the veracity, morality and accuracy of patient symptom descriptions and of psychologizing symptoms. Coping with stigma was also explored and found to comprise both withdrawal and approach strategies, depending on the individual's circumstances and goals.

**Ödegaard, G., Lindbladh, E. & Hovellius, B. (2003). Children Who suffer from headaches – a narrative of insecurity in school and family. *British Journal of General Practice*. 53(488): 210-3.**

*Background:* Headaches are common among schoolchildren who seem to be afflicted increasingly.

*Aim:* To analyse children's descriptions of their headaches and their thoughts about them, it being assumed that children have insight into the conditions that affect their health.

*Design of study:* Interview study.

*Method:* Fourteen children aged between ten and 12 years, who had gone to the school nurse more than once during the previous two-month period complaining of a headache, took part in thematically structured interviews. Qualitative analysis was performed, aimed at identifying the basic themes involved.

*Results:* The children were found to consistently associate their headaches with conditions in school, specifically with more theoretically-oriented subjects (maths or Swedish), a noisy and disorderly school environment, and insecure relations with class-mates. The second theme they took up was insecurity or conflict within the family. Reports of this constituted a major part of the children's accounts of their life situation, despite their failing to link such matters with their headaches. Many of the children considered their patterns of reacting, such as feeling unable to cope or becoming angry, as contributing to their getting headaches.

*Conclusions:* The children related their headaches consistently to everyday situations and to their relations with others. This highlights the need for broadening the consultation in terms of including personal and contextual factors.

# Patients' conceptions of their life situation



**Backe, M., Larsson, K. & Fridlund, B. (1996). Patients' conceptions of their life situation within the first week after a stroke event: a qualitative analysis. *Intensive and Critical Care Nursing*. 12(5):285-94.**

The aim of this study was to find out how stroke patients conceived their life situation within the first week of the acute care phase as seen from the nurses' viewpoint. Six patients were interviewed within 3 weeks from their first stroke, using questions based on a holistic philosophy and analysed with the phenomenographic approach. Two main categories emerged from the results: the feeling of unreality and the awareness of a changed role in life, together with six subcategories: feeling of a changed perception of the body; feeling of being confused; loss of capability; awareness of confined life space; the importance of support and encouragement; and the will to look for new opportunities. The study concludes that the body change resulting from a stroke leads to both physical and psychological trauma, in which the psychological crisis can be very deep and best described as a personal catastrophe. The patient's capability to receive and understand information becomes blocked, which influences both the nurse and the patient's next of kin with regard to their care of the patient. Conversations with the patient must be frequent so that acute care can be evaluated and agreement reached between the patient's wishes and the nurses' objectives. The results indicate the significance of intervention programmes based on crisis theory within the first week of a stroke event.

**Benzein, E., Norberg, A. & Saveman, B. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*. 15(2):117-26.**

The aim of this study was to illuminate the meaning of the lived experience of hope in patients with cancer in palliative home care. Narrative interviews with 11 patients were interpreted using a phenomenological-hermeneutic method, inspired by Ricoeur. The findings revealed a tension between *hoping for something*, that is a hop of getting cured, and *living in hope*, that is reconciliation and comfort with life and death. This tension is highlighted, according to the views of the French philosopher Gabriel Marcel, as a state of 'recollection'. The interviewees told of the hope of living as normally as possible and of the experience of confirmative relationships as dimensions of their lived experience of hope. These findings show that hope is a dynamic experience, important to both a meaningful life and a dignified death, for those patients suffering from incurable cancer.

**Berterö, C.-M. (2002). Affected self-respect and self-value: the impact of breast cancer treatment on self-esteem and QoL. *Psychooncology*. 11(4):356-64.**

There is a need to understand and explain the impact of breast cancer on women's self-esteem and quality of life. The purpose of the present study was to identify and describe, from the perspective of the women's lived experiences, the impact of breast cancer on women's self-esteem and elucidate its impact on their quality of life. Thirteen women diagnosed as having breast cancer were interviewed about these phenomena. The narrated interviews, tape-recorded and transcribed verbatim were analysed and interpreted using a qualitative text analysis, based on the following question: What sense of satisfaction and importance is there with respect to the women's value and preferences? The findings were interpreted as affected self-respect and self-value, which were found to be important aspects affecting the quality of life of these women,

within this lies the satisfaction of desire, to be respected and loved as the women they are. Concerns related to their quality of life seemed to heightened when treatment has been completed, i.e. when the psychological effects of the treatment experience becomes a reality. Health professional need to be aware of how to recognize these women, in order to provide them with support to maintain a positive self-esteem to enhance quality of life as a caring outcome.

**Berterö, C., Eriksson, B.-E. & Ek, A.-C. (1997). A substantive theory of quality of life of adults with chronic leukaemia. *International Journal of Nursing Studies*. 34(1):9-16.**

The person with chronic leukaemia is living with a chronic and life-threatening disease. The aims of this study were to gain a deeper understanding of what individuals with chronic leukaemia consider QoL to be and to give the concept of QoL a theoretical and empirical significance relevant to nursing care. Fifteen adults with different forms of diagnosed chronic leukaemia have been interviewed about their experience of QoL. Verbatim transcripts were analysed using constant comparative analysis. The emerging core category was life satisfaction. Under this construct there were four categories, self-esteem, interpersonal relationships, performance ability and social ability. Changed QoL was described in two ways. First, coping was the core category for living with chronic leukaemia. The strategies were action, denial and hope. Second, QoL was seen as individual perception, experience of a positive attitude to life and self-contemplation.

**Ekman, I., Skott, C. & Norberg, A. (2001). A place of one's own. The meaning of lived experience as narrated by an elderly woman with severe chronic heart failure. A case-study. *Scandinavian Journal of Caring Sciences*. 15(1):60-5.**

The condition of chronic heart failure often means an increasing need of institutional care caused by the severity of symptoms as fatigue and breathlessness. In this case-study, two interviews with an elderly woman were made at a 1-yr interval. A phenomenological hermeneutic method was used to interpret the interviews. The first narrative, recorded in the subject's home, showed a feeling of being at home, a feeling of having no at-homeness, neither in the body, the room nor in the relation to the caregivers, was expressed. To deny a patient this place, or to promote a system that does not permit room for patients as whole persons, threatens patients' as well as caregivers' identity by conveying that there is no place for reflection upon the experience of illness.

**Ekstedt, M. & Fagerberg, I. (2005). Lived experiences of the time preceding burnout. *Journal of Advanced Nursing*. 49(1):59-67.**

*Aim:* This paper reports a study to illuminate the complex interaction between person and their life world during the burnout development period.

*Background:* Burnout is a construct describing the psychological state resulting from ineffective strategies for coping with enduring stress in both client and non-client work. Role conflict and role ambiguity, or long-term stress and frustration caused by strain in daily life, promote or exacerbate burnout, indicating that the person's entire life world is involved. There is still a lack of description of lived experiences of the time preceding manifest burnout.

*Method:* Data were collected from interviews with eight people suffering from burnout and analysed using a phenomenological method.

*Findings:* The essential meaning of the phenomenon of burnout is understood as being trapped with stimulating challenges as a self-nourishing drive on one side and with responsibilities and demands on the other. This essence can be illuminated by its eight constituents: inner incentive, feeling responsible, threatened self-image, cutting off, bodily manifestations, psychological manifestations, fatigue and reaching the bottom line.

*Conclusions:* The lived experiences of the time preceding manifest burnout are an ambiguous struggle. Cutting off is understood as a mean to shelter the threatened self-image in a state of vulnerability and weakened strength. Accordingly, a better understanding of how to reach behind the defence of 'cutting off' and thus help to open up for consolation and self-acceptance is an essential skill for nurses, health care professionals and others encountering the burnout sufferers. Furthermore this study illuminates early signs of burnout and an important issue is how to strengthen the individuals' ability to shelter their need for recovery and restitution.

**Forss, A., Tishelman, C., Widmark, C. & Sachs, L. (2004). Women's experiences of cervical cellular changes: an unintentional transition from health to liminality? *Sociology of Health and Illness*. 26(3):306-25.**

Cervical cancer screening is a preventive intervention directed towards women to both detect cervical cancer and identify those at risk for developing this disease. It has been argued that participation in screening programmes and early detection situations may lead to new kinds of sickness experiences. This article is based on qualitative phenomenological hermeneutical analysis of interviews with women who have received abnormal Pap smear test results through a population-based outreach screening programme in urban Sweden. The aim of this article is to illuminate the meaning, for the participating women, of the lived experience of receiving notification about an abnormal Pap smear result. The data are presented in terms of two themes: Pap smear for routine and recurrent confirmation of health and unexpected and ambiguous communication about Pap smear results. The findings are discussed as an unintentional transition from confirmation of health to liminality. Whereas medical diagnosis has been discussed as structuring the inchoate, an abnormal Pap smear did not create order for the interviewed women. On the contrary, the notification of an abnormal Pap smear created disorder as the women had expected to be confirmed as healthy but instead neither health nor disease were confirmed or excluded. Even 'simple' technology is shown to have an ontological dimension, with the ability to transform daily taken-for-grantedness of ourselves as primarily healthy to (potentially) unhealthy.

**Fridlund, B., Lindgren, E., Ivarsson, A., Jinhage, B., Bolse, K., Sandstedt, B. & Mårtensson, J.(2000). Patients with implantable cardioverter-defibrillators and their conceptions of the life situation: a qualitative analysis. *Journal of Clinical Nursing*. 9(1):37-45.**

The implantable cardioverter-defibrillator (ICD) is today widely used for the treatment of sudden cardiac near-death episodes as a result of malignant ventricular dysrhythmia. After examining the literature, only four descriptive studies, all carried out in the USA, with a qualitative analysis based on ICD-patients' own perspectives on their life situation have been found. The aim of this study was to describe how patients' conceptions seen from a holistic perspective, an analysis inspired by phenomenology was employed on a strategic sample of 15 ICD-patients. Sic

categories emerged: a feeling of safety, a feeling of gratitude, a feeling of being, having a network, having a belief in the future, and gaining awareness. Although the findings cannot be generalized because of the descriptive research design, they illuminate the beneficial as well as further education for personnel in hospital and primary care.

**Johansson, A., Dahlberg, K. & Ekebergh, M. (2003). Living with experiences following a myocardial infarction. *European Journal of Cardiovascular Nursing*. 2(3):229-36.**

Coronary heart disease is a major cause of sudden death and morbidity in the developed world, as well as a cause of great suffering. Research within this area has primarily focused on symptoms, risk factors and treatment. The aim of this paper was to explore women's experiences following a myocardial infarction (MI). Eight women were interviewed: the interviews were audiotaped and transcribed into text and analysed using a phenomenological approach. To explore the meaning that is experienced in the lived world of the patient a method of reflective lifeworld research, based upon phenomenological epistemology has been used. The results indicate that the body is vital for the women in their lifeworlds. After a MI the patient's natural and unreflected relationship with the body and the lived world is interrupted. Uncertainty about life and death as well as the body is experienced as a suffering in the women's lifeworlds. In relation to this, the women's existence is characterised by an uncertainty and a loss of context. It is through reconciliation with their bodies and their illness that the women can achieve a sense of well-being and harmony in life. In that process the women can re-establish a natural relationship with their bodies and lifeworlds.

**Mårtensson, J., Karlsson, J.-E. & Fridlund, B. (1998). Female patients with congestive heart failure: how they conceive their life situation. *Journal of Advanced Nursing*. 28(6):1216-1224(9).**

Congestive heart failure (CHF) is a significant health problem for women, particularly elderly women. The risk factors for heart failure appear to be different in women than in men, with hypertension and diabetes playing a greater role in women and ischaemic heart disease a greater role in men. The aim of this study was to describe, from a nurse's perspective, how female patients with CHF conceive their life situation. Interview questions were designed with a focus on five dimensions: biophysical, socio-cultural, emotional, intellectual and spiritual-existential. A qualitative method was used with a phenomenographic approach, as this approach examines aspects of the surroundings as they are conceived.. Five categories emerged in the result: feeling content, feeling a sense of support, feeling a sense of limitation, feeling anxiety and feeling powerless. A sense of limitation regarding working capacity and being able to support those in their surroundings causes patients with CHF to experience anxiety due to feeling insecure about themselves and in relation to their surroundings. This may result in feelings of worthlessness in women with CHF, both concerning their own capacity and the fact that they feel they are a burden to those around them. Through nursing intervention, these patients can receive help to break this vicious circle of feeling limited and powerless. This can be done by encouraging them to verbalize their feelings and set realistic goals and expectations, and by increasing their knowledge and that of their families concerning CHF and its symptoms, with a focus on self-care and existing possibilities. These measures will make it easier for women with CHF to maintain a hopeful perspective and a sense of control, competence, and self-esteem.

**Persson, L. & Hallberg, I.R. (2004). Lived experience of survivors of leukemia or malignant lymphoma. *Cancer Nursing*. 27(4):303-13.**

Individuals (n=18) in remission from acute leukaemia or highly malignant lymphoma were asked to narrate their lived experience of falling ill, of being under treatment and life following this event. The transcribed texts were analyzed from a phenomenological-hermeneutic perspective, expanded by their medical and social history as related in interviews. The analysis revealed 3 themes: (I) Believed in life, fought for it and came through stronger; (II) Life went on, adapted and found a balance in the new life; (III) Life was over, felt out of control and lost belief in life. Participants in the first 2 groups viewed their quality of life as improved and stated that the struggle had been meaningful and that the experience had made them grow, as a person, related to the experience of gaining new insight or strength. The third group of survivors viewed their quality of life as worse. They found no meaning in their experience and evaluated the situation with bitterness. Thus the core of living through having acute leukaemia or highly malignant lymphoma seemed to be to find meaning with it and the profound crisis it meant to them. To help people retell their experiences may be one way of processing this life-threatening disease and treatment and may be one way to developing a sense of meaning and to regain balance in life.



# The perspective of the patient's family



**Ekenberg, L. (2001). The meaning of physiotherapy: experiences of fathers and mothers of young adults with impairment. *Advances in Physiotherapy*. 3(2):76-85.**

The aim of this study was to explore the phenomenon of physiotherapy when fathering and mothering a child with impairment. Parents of 22 young adults aged between 15 and 25 years were interviewed. A hermeneutic phenomenological analysis was carried out in several steps by alternating between individual analysis and reflection, collaborative group analysis and continued reflection. The meaning of physiotherapy could be understood by three relationships: (1) the fathers' and mothers' experiences of their relationship to the child, (2) their relationship to the physiotherapists and (3) their relationship to the physiotherapy practice. Within each relationship a variety of aspects emerged. The parents perceived ???????? as needed, and perceived that the physiotherapy services did not meet the parents' needs. Fathers and mothers experienced the lack of support in different ways and physiotherapy was taken for granted by almost all parents.

**Frid, I., Bergbom, I & Haljamae, H. (2001). No going back: narratives by close relatives of the brain dead patient. *Intensive and Critical Care Nursing*. 17(5):263-78.**

The aim of this narrative study was to illuminate the meaning of being a relative of a patient diagnosed as brain dead. This has so far been explored only to a limited extent. By phenomenological-hermeneutic analysis of 14 narratives, a chronological narrative in 4 steps was identified: the disquieting event; the uncertain vigil; the arduous struggle; and the difficult road ahead. From the analysis, the metaphor of an inner journey emerged, starting from a life situation taken for granted and experienced as safe, and moving towards the unknown, the unfamiliar. During the journey, a series of events of decisive importance in the relative's life were found to take place. Major stages along the road were efforts made to comprehend the reality of death, saying farewell and taking leave of the loved one. The importance of the ICU nurse taking part in the relative's inner journey is discussed in relation to Eriksson's theory of suffering and Martinsen's theory of caring. Implications and suggestions for nursing care activities are discussed.

**Hertzberg, A. & Ekman, S.-L. (2000). 'We, not them and us?' Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of Advanced Nursing*. 31(3):614-22.**

This study describes relatives' and staffs' experiences of each other in their relationship and interactions in connection with the care of old people with dementia living in nursing homes. The aim was to identify obstacles and promoters concerning these interactions. A qualitative method was used. Data were collected from 27 hours of observations of group discussions about relatives' and staffs' communication, interaction and experiences. Three different groups, with eight participants, trust and a group leader in each, met six times during a period of 3 months. Findings indicate that the experiences that relatives and staff have of each other are related to issues about influence, participation, trust and measures to avoid conflicts. These conclusions build on concrete descriptions about care, activities, competence, communication and visits given by research participants. Experiences of situations were sometimes contradictory between relatives

and staff. This implies that the potential for cooperation between relatives and staff in care of the elderly is not fully utilized. Suggestions for enhancing the relationships between relatives and staff are: pre-planned informal, individual conversations between relatives and staff; development of ways to give regular two-way feedback about matters concerning the resident and the relationship between staff and relatives; giving staff credit for measures taken to facilitate relatives' involvement in the nursing home care; measures to improve documentation about families' involvement; and working together with minor practical tasks.

**Hertzberg, A., Ekman, S.-E. & Axelsson, K. (2001). Staff activities and behaviour are the source of many feelings: relatives' interactions and relationships with staff in nursing homes. *Journal of Clinical Nursing*. 10(3):380-8.**

Family members do not give up their involvement in the life of their older relatives when they move to an institution. Relatives feel that it is they who take the initiative to establish a working relationship with the staff at the nursing home. Relatives want more spontaneous information from staff, particularly about residents' daily lives, and there is a need for relatives to have opportunities to talk with staff under relaxed conditions. Staff behaviour and activities towards and relatives are a source of many feelings for relatives. Relatives' understandings of the challenges faced by staff are not communicated to staff, nor are positive or negative experiences explicitly passed on to staff.

**Johansson, I., Hildingh, C. & Fridlund, B. (2002). Coping strategies when an adult next-of-kin/close friend is in critical care: a grounded theory analysis. *Intensive and Critical Care Nursing*. 18:96-108.**

The aim of the study was to generate a theoretical model of how relatives/close friends cope when faced with having an adult next-of-kin/close friend admitted to critical care. Using interviews. Data were collected from 18 relatives/close friends of adult patients in thoracic surgical, neurosurgical, coronary, and general ICUs in south-west Sweden. The design incorporated grounded theory methodology. The results indicate the relatives/close friends tried to make the experience of their situation easier, but that the approaches used differed in accordance with the individual's internal and external resources. Four coping strategies exhibiting different characteristics were identified: the relatives/close friends alleviated, recycled, mastered, or excluded their feelings. Factors determining the choice of coping strategy were social background, previous experience of ICU-care and how the situation was apprehended. The theoretical model described in this article can contribute to expanding nurses' understanding of the coping strategies of relatives/close friends in critical care.

**Jonsén, E., Athlin, E. & Suhr, O.B. (2000). Family members' experience of familial amyloidotic polyneuropathy disease – an infernal struggle and a fact of life. *Journal of Advanced Nursing*. 31(2):347-53.**

Familial amyloidotic polyneuropathy is a fatal, hereditary, systemic, progressive amyloidosis. No previous qualitative study of the family members' experience of the disease has been published. The purpose of this phenomenological study was to understand the lived experience of family members whose nearest and dearest suffered from familial amyloidotic polyneuropathy. In-depth

interviews were conducted with six family members. The analysis of the data was inspired by Colaizzi's method. Two major theme categories, difficult to accept and forced to accept, emerged from the interviews. Implications for nursing practice, such as genetic counselling and support, are discussed.

**Jonsson, L. & Fridlund, B. (2003). Parents' conception of participating in a home care programme from NICU: a qualitative analysis. *Vård i Norden*. 23(4):35-9.**

Research suggests early discharge from neonatal intensive care units (NICU) as advantageous for infants, their families and health care systems. This type of intervention has rarely been described from parents' perspective, therefore the aim of this study was to describe parents' conceptions of participating in a home care programme provided by the NICU. A qualitative descriptive design inspired by phenomenography was chosen for the study. Data was collected through interviews conducted with parents (n=23) enrolled in the unit's home care programme. The programme brought out two description categories: Becoming a family and Feeling security, comprising the conceptions: Being at home, Being reunited, Getting information, Having accessibility and Having support. To feel secure at home means for these parents to have accessibility to the neonatal staff's knowledge and experiences 24 hours per day. In the hospital the parents do not feel like a family, a feeling that gradually changes when they return home with their baby. This is one of the reasons why it is so important that the infant is discharged as early as possible from the hospital.

**Josephsson, S., Bäckman, L., Nygård, L. & Borell, L. (2000). Non-professional Caregivers' Experience of Occupational Performance on the part of Relatives with Dementia: Implications for Caregiver Program in Occupational Therapy. *Scandinavian Journal of Occupational Therapy*. 7:61-66.**

The aim of this study was to describe how non-professional caregivers understood and responded to the problems of everyday life in their interaction with a family member suffering from dementia disease. Data were obtained through interviews. The analysis was performed using a comparative qualitative approach. The findings demonstrated how the caregivers' strategies for handling everyday problems varied and reflected a personal understanding of the relative's life history. On basis of these findings and previous research, the implications for therapeutic interventions by occupational therapists were presented and discussed.

**Kristensson-Hallström, I. & Elander, G. (1997). Parents' experience of hospitalization: different strategies for feeling secure. *Pediatric Nursing*. 23(4):361-7, 376-7.**

Twenty parents of boys (ages 2-14 years) hospitalized for hypospadias repair in a pediatric surgery department in Sweden, were interviewed concerning their experience when their child was hospitalized. A qualitative analysis of the interviews indicated that the most important issue to the parents was finding security at the hospital. Parents manifested one of three different strategies that enabled them to feel secure at the hospital: (a) relinquishing the care of their children to the nursing staff; (b) obtaining a measure of control over their children's care; and (c) relying on knowing their child best. The parental strategy adopted to feel secure was found to correspond

with the way parents' experienced the hospitalization. Differences were found in their children's experiences of pain and the alleviation of the pain during the hospitalization.

**Lawoko, S. & Soares, J.J.F. (2004). Satisfaction with care: a study of parents of children with congenital heart disease and parents of children with other diseases. *Scandinavian Journal of Caring Sciences*. 18(1):90-102.**

*Aim:* We compared parents of children with congenital heart disease (PCCHD, n=1092) with parents of children with other diseases (PCOD, n=112) regarding satisfaction with their children's care (SCC). We also examined the association between parental/patient characteristics and SCC.

*Method:* The parents completed a questionnaire about such areas as satisfaction with care, children's health status and financial situation. The design was cross-sectional and data were gathered over 20 consecutive days.

*Results:* The univariate and multivariate analyses showed that PCCHD were more satisfied with their children's medical care and waiting period for treatment of the ill children than PCOD, although the difference was only modest. Furthermore, mothers were less satisfied with staff attitudes than fathers, with the lowest satisfaction among mothers of children with CHD. However, the multivariate analysis indicated that less satisfaction with care was more associated with decreasing child age, unemployment, financial burden of disease, social isolation and psychological distress than with children's diseases, their severity and parental gender.

*Conclusion:* We corroborated some previous findings and may have provided new insights regarding determinants of SCC among parents. Interventions to improve SCC may need to address issues of parental psychological distress, socialization and financial burden of illness. Possible ways of achieving this are discussed. Finally, research in a longitudinal format is needed to further scrutinize determinants of parental SCC.

**Olsson, M. (1997). Social support in bereavement crisis – a study of interaction in crisis situations. *Social Work in Health Care*. 25(1/2):117-30.**

This article is based on a study of the interaction between relatives of patients who died in Coronary Care Units in Sweden and staff members of these units. The social support concept is used in a qualitative analysis of the narratives of bereaved spouses and adult children in order to learn about the nature of supportive interactions in such crisis situation. Specific needs for support and different patterns in mobilizing support are described as well as obstacles to the supportive process stemming from the nature of the crisis situation and problems in the interaction. The findings indicate reciprocal influences between the individual bereavement process and the interpersonal social support process. The author also suggests ways for medical social workers to use the findings.

**Paulson, M., Norberg, A. & Söderberg, S. (2003). Living in the shadow of fibromyalgic pain: the meaning of female partners' experiences. *Journal of Clinical Nursing*. 12(2):235-43.**

The aim of this study was to elucidate the meaning of being a female partner living with a man with fibromyalgic pain. Fourteen partners were interviewed about the meaning of their experiences, using a narrative approach. A phenomenological hermeneutic method, inspired by

the French philosopher Ricoeur, was used to interpret the interview text. The structural analysis is presented in three major themes: struggling to give support and comfort, struggling to keep going on, and experiencing lack of understanding and support. The findings elucidate that the meaning of living with a man with fibromyalgic pain meant living a life strongly influenced by the man's illness and in the shadow of the man's pain. Taking daily life for granted was interrupted and restricted family and social life. Prominent in this study was the frustration partners felt as a result of men's reluctance to communicate. This led to feelings of being excluded from men's emotions. The responsibility day in and day out meant that women's own caring and tenderness were replaced, which brought about an almost constant sense of fatigue. Women became drained by the long duration of men's illness. This gave them a feeling of being alone, although they were a couple. Gaining comfort outside the family helped partners to reach a new insight and appreciation for life, which was viewed from a renewed perspective. This involved feelings of both togetherness and separateness in the relationship. The findings also consider the lack of support from the health care system for female partners living with men with fibromyalgic pain.

**Sandén, I. & Hydén, L. (2002). How everyday life is affected: an interview study of relatives of men suffering from testicular cancer. *Journal of Psychosocial Oncology*. 20(2):27-44.**

The aim of this study was to describe, by means of explorative interviews, the experiences of relatives of male family members suffering from testicular cancer. The central questions concerned how the disease and its treatment affected the life of the family, how its daily routines were affected, the form of relationships and closeness during the period of the disease, and how the future was given shape. The results revealed four main themes presented by the relatives during the interviews: the disease and its course, normalization, the long-term consequences of the disease, and the social network. The results showed that relatives of men suffering from cancer live in a vulnerable situation characterized by social isolation.

**Svanström, R. & Dahlberg, K. (2004). Living with dementia yields a heteronomous and lost existence. *Western Journal of Nursing Research*. 26(6):671-87.**

The purpose of this study was to investigate the lived experience of dementia for spouses were one of them is diagnosed as having dementia. The study has been conducted using a phenomenological approach. Unstructured interviews were chosen in order to investigate the informants' lived experiences of dementia, both for the person with dementia and for his or her spouse. The essence of the phenomenon, the lived experience of dementia, is that the persons with dementia and their spouses live in a heteronomous existence in which they are lost and are strangers in their own world. The result of this is a life without coherence and a new but unknown meaning that can make them feel uncertain and puts them in a quandary. Whatever those with dementia and their spouses do, they have no real influence over their situation, which leads to feelings of awkwardness, perplexity and futility.

**Söderberg, S., Strand, M, Haapala, M & Lundman, B. (2003). Living with a woman with fibromyalgia from the perspective of the husband. *Journal of Advanced Nursing*. 42(2):143-50.**

*Background:* Fibromyalgia (FM) is a chronic pain syndrome, which affects mostly middle-aged women. The syndrome is poorly understood and treatment is mainly palliative. The diagnosis is established from diagnostic criteria. Living with FM means living a life greatly influenced by the illness in various ways for people affected.

*Aim:* The aim of this study was to describe the experiences of living with a woman with FM from the husbands' perspective.

*Methods:* Five men married to women with FM were interviewed using a narrative approach. The interviews were analysed using qualitative thematic content analysis.

*Findings:* The analysis resulted in the following seven themes: increasing responsibility and work in the home; being an advocate for and supporting the wife; learning to see the woman's changing needs; changing relationship between spouses; changing relationship with friends and relatives; deepening relationship with the children and lacking information and knowledge about FM. The findings show that the women's illness had a great impact on husbands' lives, and that husbands lacked information about the woman's illness.

*Conclusion:* This study shows that it is not only the women with FM who experience a changed life; the whole family life is influenced and limited by FM. The husband's role in the family changes, first and foremost concerning responsibility and workload within the family. This must be taken into consideration in care planning. This study also highlighted the need of information and knowledge about FM expressed by the participants, information that health care personnel have a great responsibility to give.

**Trulsson, U. & Klingberg, G. (2003). Living with a child with a severe orofacial handicap: experiences from the perspectives of parents. *European Journal of Oral Sciences*. 111(1):19.**

Orofacial functions include competences/abilities such as eating, breathing, speech/language, mimicry, as well as oral health, and disturbances are common in children with rare disorders. To describe parental experiences of orofacial function and needs in children with rare disorders, in-depth interviews focusing on orofacial function were carried out with 14 parents. Interviews were transcribed verbatim and analysed in open, axial (theoretical) and selective coding processes according to Grounded Theory. Two core categories emerged from data in the analysis: 'The vulnerable family' and 'support perceived from others'. The data indicated the importance of a balance between these two core categories: the strain caused by living in a family with a child with a severe disability/handicap, and the availability of perceived support from caregivers and significant others. This balance was necessary for the parents in developing self-reliance and in reconciling themselves to their life situations. Parents described orofacial dysfunction in terms of feeding and communication problems, needs for orthodontic treatment to reduce risk of trauma or improve chewing, and drooling. Oral health issues such as dental caries and gingivitis were not mentioned. Five aspects of good professional attitude were recognized: *respect, involvement, continuity, knowledge and availability*.

**Weslien, M. Nilstun, T., Lundqvist, A. & Fridlund, B. (2005). When the unreal becomes real: family members' experiences of cardiac arrest. *Nursing in Critical Care*. 10(1):15-22.**

The aim of this study was to provide insight into family members' experiences related to cardiac arrest. Data were collected through semi-structured interviews with 17 family members approximately 1-3 months after the cardiac arrest of a relative. As the focus was on the family members' experiences seen from a holistic perspective, content analysis was chosen for the study. When the event occurred to the patient, family members realized the need for assistance and managed to initiate first actions. When the emergency medical service arrived, family members responded to stress and forgot their own needs. When the staff took over at the hospital, family members not only received sympathy but also encountered professional distancing. Because their experiences vary widely, the encounter has to be developed through a comforting, sympathetic and respectful dialogue in consideration for individuals' preferences.



# Articles in Swedish



Akner, G. (2005). Analys och handläggning av äldres multisjuklighet måste samordnas. Med DBU-metod tillämpad vid äldrevårdscentral kan behandling utvärderas. (Eng: Analysis and management of comorbidity among the elderly must be coordinated. Treatment can be evaluated with the DBU method implemented at community centers for the aged.) *Läkartidningen*. 102(10):758-65.

Andreen Sachs, M., Svensson, C., Synnerman, J.E. & Olsson, J. (2000). Traditionellt förbättringsarbete räcker inte! Patientfokus kräver modern, lärandestyrd utveckling. (Eng: Traditional quality assurance is not enough! Focusing on the patient demands modern, learning directed development. ). *Läkartidningen*. 97(30-31):3380-3.

Anell, A. (2004). Närsjukvård – nya revirstrider eller patientorienterad vård? (Eng: Primary health care – preserve conflicts or patient-centered care?) *Läkartidningen*. 101(14):1310-5.

Arborelius, E. (1995). Patientcentrerat förhållningssätt i alkoholrådgivning. (Eng: patient centered attitude in alcohol counseling.). *Allmänmedicin*. 16(6):285-7.

Arman, M., Rehnsfeldt, A. & Hamrin, E. (2002). Bröstcancerpatienters upplevelser av komplementär vård vid en antroposofisk klinik – en fallstudie (Eng: Breast cancer patients' lived experiences of complementary care – a case study). *Vård i Norden*. 22(2):4-8.

In focusing on their own life perspective, the aim of this study was to shed light on the experiences breast cancer patients confer to a stay in complementary care at an anthroposophic clinic. From a larger, matched multidisciplinary study on life situation among women with breast cancer in different systems of care, three women with breast cancer in different stages were chosen. The women had a stay for 11-13 days in an anthroposophic hospital in Sweden. Two follow-up interviews with each participant, three and six months after the stay at the clinic was analyzed with interpretive phenomenological case study method. The theoretical framework of the study was Katie Eriksson's theory of caring. In the findings, the three women's experiences are described separately. Their narratives have many differences and some similarities. It seems like the individual oriented, anthroposophic care had been able to offer each of the women something that they in their actual life situation were in need of. One woman experienced the treatment with anthroposophic medicine and the confirming, holistic paradigm as significant. Another woman experienced that, the healing and loving care, had effected a changed and opened view on life. The third woman emphasized that, the experiences of harmony, wholeness and caring

relations had a meaning for her, long time afterwards. Critical aspects of the care were a lack of continuity and an ambivalent feeling about the consequences of the holistic paradigm.

**Bengtsson, G., Wilde Larsson, B. & Udén, G. (1998). Resultatindikatorer att utvärdera, från patientens perspektiv ( Eng: Outcome indicators to evaluate, from a patient's perspective). *J Nurs Care Qual* 18:9-14.**

The aim of this study was to evaluate outcome indicators such as information, continuity, integrity and participation in relation to a standard of nursing care for approach and information. Examined group consisted of 239 patients from five general wards and one gynaecological ward at two hospitals in Sweden. A questionnaire, consisting of 13 items was used for the data collection. The questions were extracted from the questionnaire "Quality from the Patients' Perspective" (QPP). QPP is based on a theory-based model and every question is evaluated in two ways. One corresponds to how the care is a measurement of reality and the other how the content is a measurement of subjective importance. An index is calculated for every question. The questions that got the highest quality-value were dealing with the area of integrity, the perception of being treated with respect and taken seriously. A lower quality index was given to the questions that corresponded to continuity, if the patient knew which nurse was responsible for their planning of care. Elderly patients (older than 61 years) got significant higher rate on quality of care index than younger patients (younger than 60 years) for all 13 questions.

**Bergström, A. (2004). Patientperspektiv med hjälp av ICF. Hur vet vi om rehabiliteringen haft god effekt? Vad är det vi mäter? (Eng: Patient perspective using ICF. How do we know if rehabilitation has been efficient? What do we measure?). *Svensk Rehabilitering*. 6(4):34-6.**

**Björn-Rasmussen, E. & Erixon, D. (2003). Ny struktur krävs för patientfokuserad vård. (Eng: New structure for patient-centred care is required.) *Läkartidningen*. 100(8):634-5.**

**Crafoord, E. (2004). Förbättringsteam – bra för patienterna och roligt för medarbetarna! (eng: Improvement team – good for the patients and fun for the personnel!). *Chefer och Ledare i Vården*. 36(3):8-12.**

**Ehnfors, M. & Söderström, A. (1995). Patienters tillfredsställelse med vård och omvårdnad (Eng: Patients satisfaction with hospital care). *Nurs Sci Res Nordic Count*. 15:19-29.**

The development and use of a patients' satisfaction questionnaire focused on nursing is described. The questionnaire comprised 27 questions in areas which have been emphasized in the literature as significant, together with two questions asking for comments or suggestions. The questionnaire was mailed to the patients' homes by a person outside the hospital unit in accordance with earlier methodological experience. All the patients discharged during one month from a university

hospital were included. There were 2 260 (54%) responses, showing that most of the patients (80%) rated the care as excellent or very good, but 2% rated it as poor or very poor. Items rated positively were the staff's attitude in listening and showing respect, their gentle handling and a good ward atmosphere. The patients' confidence in the staff's knowledge and skills was high. Dissatisfaction was expressed about information given e.g. on future self-care, explanations, discharge planning, the food and the bed. Many made suggestions for improvement, which also are reported.

**Erixon, G., Jerlock, M. & Dahlberg, K. (1997). Upplevelser av att leva med kärlekskramp (Eng: Experiences of living with angina pectoris). *Vård i Norden*. 17(2):34-8.**

The present study is a qualitative description of personal experiences of living with angina pectoris and how it influences daily life. Nine patients, all belonging to a specific heart unit, were interviewed. The interviews were conducted and analyzed within a phenomenological approach. The participants were encouraged to describe freely what it was like for them to live with angina pectoris. All interviews were performed in the participant's home. The subjective consequences of angina could be described as five themes of concern: fear and anxiety; fatigue and pain; grief astonishment and anger; dependence; and hope and hopelessness. Since angina puts a limit on the possibilities for all types of physical activities it tends to affect the whole life situation. Chronic illness, physical incapacity and an increased existential awareness forced the participants into an insoluble circle where fear and anxiety were predominant.

**Erwander, I. & Hallström, I. (2002). Erfarenheter av föräldraskap hos kvinnor och män med Cystisk Fibros (Eng: Experiences of parenthood among women and men with cystic fibrosis). *Vård i Norden*. 22(3):27-31.**

Today most patients with CF reach adulthood and consequently marry and have children. Health care systems are lacking in knowledge of how these adults cope with the strain of having children. Eight patients were interviewed about their experiences of having children. The study was a qualitative descriptive study and the patients were interviewed with open question regarding their experiences of parenthood. The analysis showed that most of them found it natural to become a parent. Despite their chronic disease they had, on the whole, a healthy self-concept. Many of them experienced a strengthening of their relationship with their partner notwithstanding the strain many of them experience when becoming pregnant and then adapting to life with a new baby and its needs. Partners took greater responsibility upon themselves in caring for the children. Most of the CF parents and partners expressed the need for organised daily structuring and planning in order to cope with parenthood and the routines of living with CF and its treatment. In spite of everything the parents felt that the children gave a special meaning to life and that this was something worth fighting and living for.

**Fossum, B., Arborelius, E. & Bremberg, S. 2003. *Rökfri hemmiljö. Utvärdering av en rådgivningsmetod för att förebygga att spädbarn utsätts för tobaksrök: Ett exempel på föräldracentrerad kommunikation.* (Eng: "A home environment without smoke. An evaluation of a counseling method to prevent**

**infants from exposure of tobacco smoke: an example of parent-centred communication”). Statens Folkhälsoinstitut.**

This report describes how a patient-centred method is working in practice.

**Gune, M. (2004). Projekt Vårdavdelningen 2005 både avslutat och utvärderat. (Eng: Project Nursing Care Department 2005 both completed and evaluated.). *Chefer och Ledare i Vården*. 36(1):24-9.**

The aim of this project was to develop a ward in order to meet new and changed demands from patients, families, co-workers and students. Among other things a patient-focus was emphasised. The project was divided into three sub-themes:(1) patient-near care and teamwork, (2) patients' and their families' learning, and (3) competence development and learning among co-workers and students.

**Gäfvert, A.-C. & Ek, A.-C. (1996). Förväntningar och patienttillfredsställelse i hemsjukvård. En kvalitativ studie (Eng: Home nursing patients' expectations and satisfaction). *Nurs Sci Res Nordic Count*. 16:19-24.**

The purpose of this study was to illuminate the following questions: (1) What do the district nurses think about the expectations of the patients during a home-visit? (2) Which are the expectations of the patients concerning the home-visit done by a district nurse?. The district nurses in a primary health care-centre and the patients that received home nursing in the primary health care district constituted the population. Ten nurses and twenty patients participated in the study. The method was qualitative with a hermeneutical approach. The tape-recorded interviews were transcribed verbatim to constitute the empirical material for analysis and interpretation. The theoretical starting point was the concept of patient satisfaction. In the analysis and interpretation the following dimensions appeared: knowledge-professionalism, art of care-patient –district nurse relationship, participation and responsibility, continuity and availability. The result shows that the patients' expectations of the district nurses were extensively met and that they were satisfied with the home nursing care. The patients expected to meet a skilled person whose judgements are correct, who listens, shows respect and keeps her appointments.

**Larsson, S. (2005). Läkekonst. Kunskap, empati och intuition. (Eng: Medicine. Knowledge, empathy and intuition.). *Svensk Rehabilitering*. 7(1):18-21.**

**Lindh, M. (2003). Familjemedicinska principer kan inspirera till bättre vård och arbetsmiljö. Framtidens primärvård mår väl av att sätta patienten i fokus. (Eng: Principles of family practice can be an inspiration improving care and occupational environment. Future primary health care benefits when focusing on the patient.). *Läkartidningen*. 100(36):2778-80.**

Lindh, M. (2000). Synpunkter på svensk läkarutbildning efter fem i Sydafrika: Patientcentrerat arbetssätt kan minska doktors stress. (Eng: Views on Swedish medical education after five years in South Africa: patient-centered work can reduce physician's stress.). *Läkartidningen*. 97(6):612-5.

Norstedt, L. (1999). Silviahemmet satsar på de patientnära vårdarna. (Eng: The Silvia Home concentrates on patient-centered care). *Omvårdaren*. 46(5):22-5.

Orton, M.L. & Gardulf, A. (2000). Nya karriärmöjligheter I den patientnära vården. (Eng: New career possibilities in the patient-centered care.). *Vårdfacket*. 24(1):40-2.

Román, G. (1997). Klinisk revision av psykiatrisk vård. Multiprofessionell ansats med patienten i centrum. (Eng: Clinical revision of psychiatric nursing. Multiprofessional attempts with the patient in the center.). *Vård: Utbildning, Utveckling, Forskning*. (3):118-21.

Rosenqvist, U. (1997). Att ta plats i vården. (Eng: Occupying room in health care). *Socialmedicinsk Tidskrift*. 74(10):435-6

Samuelsson, K. & Wressle, E. (2004). Kan vi med "rätt inställning" bidra till att öka delaktigheten för klienter? (Eng: Can we with "the right attitude" contribute to increase patient participation?) *Arbetsterapeuten*. (10):32-4.

Strandberg, G. (2002). *Beroende av vård. Innebörden av fenomenet som det visar sig genom patienters, deras anhörigas och vårdares berättelser* (Eng: Dependency on Care. The meaning of this phenomenon as it is shown through the stories of patients, their families and care-takers). Thesis. Department of Nursing, Umeå University.

Söderlund, M. (1998). *En mänsklig atmosfär: trygghet, samhörighet och gemenskap: god vård ur ett patientperspektiv*. (Eng: In the atmosphere of humanity: security, solidarity and mutual understanding: a concept of good caring from the patients' perspective).

**Westrin C.-G. (1996). Olika aktörer på olika nivåer – men patientens val är grundläggande. (Eng: Different actors at different levels – but the patient's choice forms the foundation.) *Socialmedicinsk tidskrift*. 73:9-10: 489-91.**

Questions on who should be guiding the health care are difficult to answer without first having discussed what it is that should be guided. On the crucial level, the patient level, it is quite easy to give a short answer. It should be the enlightened patient in partnership with his/her regular physician and with access to a flexible network of other groups of care staff and medical specialists.

# Miscellaneous



**Bendtsen; P. & Timpka, T. (1999). Acceptability of computerized self-report of alcohol habits: A Patient perspective. *Alcohol and Alcoholism*. 34(4):575-580.**

The acceptability of computerized assessment of alcohol habits was explored in 57 consecutive out-patients over a 6-month period. Altogether, 46 men and 11 women agreed to complete a paper and pencil questionnaire exploring their opinion about computerized assessment. The study focused on the patients' acceptance of computerized testing and also on whether some sub-groups had reservations. The participants indicated that they had no general anxiety towards computers and did not mind being assessed by their use. Nearly half of the men were not convinced of the usefulness of computers as a means of asking about alcohol habits. The same level of confidence was recorded with regard to whether doctors would make better assessments using computers. Around one-quarter of both men and women were worried that computers might cause doctors to spend less time with the patients and that staff might lose the personal contact with patients. Because of the small sample size, we conclude tentatively that a computerized lifestyle test appears to be an acceptable method both to men and women with different educational backgrounds. However, two important issues need to be further addressed, namely concerns about confidentiality and loss of personal contact.

**Björkman, T. & Hansson, L. (2001) Client satisfaction with case management: A study of 10 pilot services in Sweden. *Journal of Mental Health*. 10(2):163-174.**

Client satisfaction has become important both as a measure of outcome of psychiatric care and as a measure of the process of care. However, relatively few studies have investigated client satisfaction with case management services. The general aim of the present study was to investigate client satisfaction in 10 new case management services established in Sweden in 1995. The specific research questions were; how satisfied are the clients of case management services? Are there differences in satisfaction with regard to clinical and social characteristics of then client, case manager characteristics, type of case manager intervention, and characteristics of the service? The study comprised 176 clients out of which 154, (88%) responded to an 11-item satisfaction questionnaire administered at an 18-month follow up. The results showed that client satisfaction with the case management services was high. Type of interventions and life area of the client concerned was mainly unrelated to satisfaction. However, it seems that advocacy and case manager time spent on this type of intervention is essential and associated with a better satisfaction with services.

**Browall, M, Carlsson, M. & Horvath, G. (2004). Information needs of women with recently diagnosed ovarian cancer – a longitudinal study. *European Journal of Oncology Nursing*. 8(3):200-7.**

The aim of this study was to investigate the information needs among patients with ovarian cancer and whether these information needs change over time. The information needs were evaluated three times, through structured interviews, and were based on the paired comparison approach developed by Degner and colleagues. A consecutive sample of patients ( $n=82$ ) with recently diagnosed ovarian cancer was asked to participate. Sixty-four patients (78%) chose to participate. The three different measurements of participants' information needs revealed only

small changes in these needs. The three most important information needs, in all measurements, were information about the likelihood of cure, information about the stage and spreading of the disease, and information about different treatment options. Information regarding sexual attractiveness was the lowest ranked item in all measurements. Regarding subgroups (age, education) the only significant difference throughout all measurements was that younger patients rated issues of sexual attractiveness higher than older patients ( $p=0.005$ ). In this longitudinal study patients with ovarian cancer ranked information about the disease and its treatment (i.e. likelihood of cure, stage of disease and treatment options) highest, and information about psychosocial aspects and self-care lowest. These findings are in accordance with the results from studies of women diagnosed with other types of cancer, which used the same methodology.

**Eklund, M. & Hansson, L. (2001). Ward Atmosphere, Client Satisfaction, and Client Motivation in a Psychiatric Work Rehabilitation Unit. *Community Mental Health Journal*. 37(2):169-177.**

This study investigated the ward atmosphere of a psychiatric work rehabilitation unit and its relationships to clients' satisfaction with the unit and client motivation, operationalised as proneness to set personal goals for their rehabilitation. The Community-oriented Programs Environment Scale was used and 52 clients participated. Their report of the ward atmosphere was in accordance with recommended levels on 5 sub-scales out of 10. A regression analysis revealed that optimal levels of order-and-organization and support were of importance for satisfaction with the unit. An optimal level of support was associated with a high rating of personal goals. This study added two therapeutically interesting factors- satisfaction and motivation – to the flora of factors that have been related to perceptions of the ward atmosphere.

**Emtner, M., Hedin, A. & Stålenheim, G. (1998). Asthmatic patients' views of a comprehensive asthma rehabilitation programme: a three-year follow-up. *Physiotherapy Research International*. 3(3):175-93.**

*Background and purpose:* Twenty-one asthmatic patients aged 27-59 years, with mild to moderate asthma, participated in a 10-week group rehabilitation programme covering physical training and theoretical and practical education in medication, self-management strategies and physiotherapy. This study was undertaken retrospectively to investigate (1) the patients' reasons for joining the programme, (2) their experiences of the programme, and (3) their ways of coping with disease-related problems before joining and three years after completion of the programme.

*Method:* Patients were followed up every six months for three years and were interviewed after the three years. The semi-structured interviews were tape-recorded, transcribed and revised.

*Results:* The life-situation of most of the patients before the 10-week programme was characterized by helplessness at exacerbations, anxiety/insecurity about medication and their side-effects, and/or concern about future health. More than half of the subjects felt physical limitations in daily life or when exercising. All wished to increase their knowledge of asthma by joining the programme, but only nine patients expected asthma improvement. The experience that they were able to carry out physical exercise to a maximal intensity and that physical training improved their asthma, with increased knowledge about medications were mentioned by all as the most valuable effects of the programme. Moreover, most patients emphasized their increased ability in self-management strategies (stress reduction and breathing technique). The increased knowledge and improved practical skills contributed to a better life-situation after the

rehabilitation. After the three years virtually all the patients' lives were characterized by improved self-management, increased physical activity and a sense of security. Almost half of them expressed a wish to take responsibility for the disease.

*Conclusions:* In addition to medical therapy and education, physical training and technique for relaxation and breathing should form part of the treatment of asthma.

**Fagerström, L. Eriksson, K. & Bergbom Engberg, I. (1999). The patient's perceived caring needs: Measuring the unmeasurable. *International Journal of Nursing Practice*. 5(4):199.**

The aim of this study is to elucidate the phenomenon of the caring need in the life-world of the patient and, on the basis of this, to compare patients' perceived caring needs with the six areas of need contained in a new instrument for patient classification, the Oulu Patient Classification (OPC). A total of 75 patients were interviewed and the data were analysed by means of phenomenological- hermeneutical method. Seventeen perceived caring needs emerged from the process of interpretation. The patients experienced themselves as an indivisible unit that contained existential/spiritual needs and desires. The patients' caring needs are constituted from their problems, needs and desires, where human desire for life, love and meaningfulness may, express itself as bodily, psychical and existential/spiritual needs. A comparison between the patients' perceived caring needs and the OPC shows that patients' existential/spiritual needs do not emerge clearly enough and that the instrument should be supplemented by a caring perspective.

**Finnbogadóttir, H., Svalenius, E. & Persson, E. (2003). Expectant first-time fathers' experiences of pregnancy. *Midwifery*. 19(2):96-105.**

*Objective:* To describe first-time-expectant fathers' experiences of pregnancy.

*Design:* An inductive method using narrative interview form and qualitative content text analysis. The text of the transcripts was coded and categorised.

*Setting and participants:* Seven first-time-expectant fathers living in a multicultural industrial town in southern Sweden were interviewed individually when their partner was in the 38<sup>th</sup> to 39<sup>th</sup> week of pregnancy.

*Measurements and findings:* All the fathers-to be experienced some psychological, social and/or physical change during pregnancy. The main category was 'time of transition'. Eight categories were found under this. They were: 'feelings of unreality', 'insufficiency and inadequacy', 'exclusion', 'reality', 'social changes', 'physical changes', 'responsibility', and 'development'.

*Key conclusions:* The fathers'-to-be special needs for support and encouragement during pregnancy may be as important as those of the mother's-to-be. The caregiver needs to be as aware of and sensitive to these needs. However, before any interventions can be recommended more research is needed.

**Grahn, G., Danielson, M. & Ulander, K. (1999). Learning to Live With Cancer in European countries. *Cancer Nursing*. 22(1):79-84.**

Patient group education is an evidence-based and powerful intervention for supporting and guiding patients toward an understanding of the cancer experience. An education program for patients and families, entitled Learning to Live With Cancer, has been developed and evaluated

in a Swedish research project, and implemented clinically. The program is a core model with a structure that allows flexibility in addressing learning needs. It has grown into a pan-European program through “training the trainers” courses, and is now available in many countries. This has taken the project into a new phase, since Europe is characterized not only by showing many different countries, but also by showing cultural diversity and variety in ethical norms. The aim of this phase thus was to assess the presence of core-model divergences conditioned by cultural values and norms, and if present, to investigate adjustments proposed to increase the relevance of the program to best suit patient’s learning needs in different cultures. A questionnaire was distributed to former participants in “training the trainers” courses. The findings indicate that only minor divergences are present, and that the core model thus has the potential to meet the learning needs of cancer patients in many cultures.

**Hallgren, A., Kihlgren, M., Norberg, A. & Forslin, L. (1995). Women’s perceptions of childbirth and childbirth education before and after education and birth. *Midwifery*. 11(3):130-7.**

*Objective:* To illuminate women’s perceptions of childbirth and childbirth education before and after education and birth.

*Design:* Qualitative, using tape-recorded interviews to collect data. Interpretation was performed from Antonovsky’s concept sense of coherence.

*Setting:* Childbirth education, a part of parent education in Sweden.

*Participants:* Eleven women expecting their first child, where the pregnancy was planned and normal.

*Measurements and findings:* The development of perceptions of childbirth and childbirth education was described. The women adopted the content of the education in different ways. Fear as well as unreflected knowledge seemed to block acquisition of new knowledge. Factors with contributed to a childbirth experience worse than expected were lack of or inconsistent information. Increased knowledge about childbirth and experiences of confirmation during childbirth contributed to a good or better experience than expected.

*Key conclusion:* Any model of childbirth education which does not take into consideration the individual woman’s perceptions of childbirth and childbirth education seems to be inadequate.

*Implications for practice:* The findings stress the importance of individual assessment of expectations of an experiences of childbirth education. Consistency in information given before and during childbirth supports a sense of comprehensibility, manageability and meaningfulness.

**Hedelin, B. & Strandmark, M. (2001). The meaning of mental health from Elderly Women’s perspectives: A basis for health promotion. *Perspectives in Psychiatric Care*. 37(1):7-14.**

*Problem:* To gain a deeper understanding of the meaning of mental health.

*Methods:* Qualitative interviews with 16 women between the ages of 71 and 92. The data were collected and analyzed using a phenomenological approach.

*Findings:* The essence of mental health is the experience of confirmation, trust and confidence in the future, as well as a zest for life, development and involvement in one’s relationship to oneself and to others.

*Conclusions:* Creating arenas for encounters confirming the individual’s human existence and dignity is an important basis for the psychiatric nurse’s health-promotion work.

**Hildingh, C., Fridlund, B. & Segesten, K. (1995). Social support in self-help groups, as experienced by persons having coronary heart disease and their next of kin. *International Journal of Nursing Studies*. 32(3):224-32.**

Self-help groups related to coronary heart disease constitute a network for support in which the members of the group have the opportunity both to receive and provide social support. The purpose of this study was to reach in-depth information from group members about lived experience of social support in a self-help group. A qualitative research method influenced by phenomenology was used and the findings showed a pattern of social support that can be described as a sharing of experience among confident equals, thanks to mutual feelings of caring and belonging, which in turn strengthens confidence. The group members' experience of social support show that the group constitutes a cornerstone in a network for support and contributes to well-being, coping ability and a build up of confidence at the prospect of a more promising future.

**Johansson, E., Langius-Eklöf, A., Engervall, P. & Wredling, R. (2005). Patients' experience of ambulatory self-administration of pamidronate in multiple myeloma. *Cancer Nursing*. 28(2):158-65.**

The aim was to explore ambulatory self-administration of Pamidronate (Self-A-Pam) from a patient perspective in patients with multiple myeloma. Pamidronate is normally administered once a month as an intravenous infusion over 2 to 4 hours. Twenty-one patients were included, of whom 13 (6 women, 7 men) with a median age of 56 years (range 37-70) completed the educational program and subsequent ambulatory Self-A-Pam. An RN at the hospital initiated the Pamidronate therapy (90 mg). The patients then left hospital and later, on completion, they disconnected the infusion, either alone or with the assistance of a relative or significant other. Interviews were used to collect information about the experiences during the course of the Self-A-Pam. In total, 12 patients were interviewed after 3 doses of Self-A-Pam. One patient declined to participate in the interview. A qualitative analysis of the textual data was performed. Five main categories were identified: decision concerning Self-A-Pam, information and education, sources of practical help or support, effects of Self-A-Pam, and feelings and activities in relation to place (hospital, home or public place). All 13 patients who started on Self-A-Pam went through 3 courses of Self-A-Pam during the study period. Many patients reported a gain in feelings of freedom/independence and time saving. However, some patients reported insufficient education and feelings of anxiety associated with the responsibility of handling the venous access device.

**Lindahl, B., Sandman, P.-O. Rasmussén. (2005). On becoming dependent on home mechanical ventilation. *Journal of Advanced Nursing*. 49(1):33-42.**

*Aim:* The aim of this paper is to illuminate meanings of becoming dependent on home mechanical ventilator treatment.

*Background:* People suffering from chronic alveolar hypoventilation and requiring home mechanical ventilation represent a small but increasing group in society, and are some of the most vulnerable individuals with chronic disabilities.

*Method:* Thirteen people about to begin ventilator treatment at home were interviewed. Data were tape-recorded and analysed according to a phenomenological-hermeneutic method.

*Findings:* Findings revealed two contrasting meanings of being in the process of becoming dependent on a ventilator, interpreted as getting breath or holding breath. This interpretation is presented in two composite stories.

*Conclusions:* The findings imply possibilities and deficiencies in meeting patients' existential needs, such as helping them to breathe spiritually by supporting them as they get their breath after such a life-changing event as becoming dependent on a ventilator.

**Nordgren, S. & Fridlund, B. (2001). Patients' perceptions of self-determination as expressed in the context of care. *Journal of Advanced Nursing*. 35(1):117**

*Aim:* The aim of this study was to describe patients' perceptions of how self-determination finds expression in the context of care. *Background:* Self-determination is an important concept within health care as well as an important patient right. New legislation on patient rights in Sweden and Europe is aimed at increased patient self-determination. *Design and method:* The analysis found three descriptive categories of the informants' perceptions: trusting, accepting and a feeling of powerlessness. The patients expressed a great sense of trust and confidence in the care provided and they accepted the health care procedures. At the same time, they expressed a feeling of powerlessness because of not being part of decision-making, as well as lacking knowledge and information about treatment strategies. The patients wished to have the right of more self-determination but lacked the strength and knowledge to be able to influence their own care.

*Conclusions:* Patients' perceptions of self-determination suggest that, in their encounters with the professional care, knowledge is expressed as power. The feeling of a lack of self-determination can be reduced by help and support from a nurse who allocates time for communication in order to learn the patient's needs and reach a mutual understanding.

**Ockander, M. & Timpka, T. (2001). A female lay perspective on the establishment of long-term sickness absence. *International Journal of Social Welfare*. 10(1):74-79.**

In Sweden women account for about 60% of the long-term cases of sickness absence. The aim of this study was to describe women's explanations as to how long-term sickness absence arises and becomes permanent, with reference to their personal experience. Semi-structured interviews were performed with 82 middle-aged women who have personal experience of long-term sickness absence. Long-term sickness absence can be said to arise in three distinguishable "spaces": the work space, the medico-legal space and the mental space. In the beginning, the women were positive about sick-leave as such, which they saw as an opportunity for physical rest. But as time went on, they came to regard sick-leave as creating a vicious circle and chronic physical impairments, certain conditions at the workplace, at the hospital and the social insurance office transformed seemingly trivial sick-leaves into long-term and irreversible sickness absences.

**Olsson, M. & Hansagi, H. (2001). Repeated use of the emergency department: qualitative study of the patient's perspective. *Emergency Medicine Journal*. 18:430-434.**

*Objective:* To explore what lies behind repeated emergency department (ED) use, from the patients' own perspectives. *Methods:* Qualitative study based on in depth interviews with frequent

users of the ED at the Huddinge University Hospital, Sweden. Ten adult patients having visited the ED 6-17 times in the previous 12 months were interviewed. The personal meetings they attached to the symptoms and their encounters at the ED were inductively analysed, thereby relating patient behaviour to life conditions. *Results:* The frequent ED visitors perceive pain or other symptoms as a threat to life or to personal autonomy. Irrespective of whether or not the patients relate their health problems to a traumatic event, overwhelming anxiety compels them to seek urgent help. Clear cut diagnoses are seldom mentioned. Although none of the patients is homeless or totally lacking in means, the narratives reveal struggles with adverse life circumstances and medical, psychological and/or social problems, including alcohol or other substance misuse. Occasional referrals from the ED to a psychiatrist seem not to lead to any continuous treatment or to a change in the patients' health seeking behaviour. Satisfaction with care becomes adversely affected when the patients perceive that the ED staff classifies their use of the ED as inappropriate or when their symptoms are belittled. *Conclusions:* From their own perspectives frequent ED visitors are in need of urgent care. It is particularly important to these patients that the personal meaning they attach to their symptoms is attended to and respected by the ED staff.

**Strandberg, G., Norberg, A. & Jansson, L. (2003). Meaning of Dependency on Care as Narrated by 10 Patients. *Research and Theory for Nursing Practice: An International Journal*. 17(1):65-84.**

This article is part of an ongoing study that aims to illuminate the meaning of dependency on care. The aim of this particular study is to disclose the meaning of dependency on care as narrated by patients. We conducted interviews with patients (six men and four women) who had been in medical or surgical wards for at least 14 days. Seven of the patients were also interviewed one week after discharge. The participants ranged from 41 to 84 years old. The interviews were tape-recorded and transcribed verbatim. A phenomenological-hermeneutic approach was used to interpret the resulting text. The results show that to be dependent on care is to face the inevitability of not being able to manage by oneself – it is being attached to the nurses and bound to the care they offer. Being dependent on care involves a struggle to get care without treading on the nurses' toes. The nurses are one's lifelines and getting care is essential, no matter what. It is better to receive any form of care, good or bad, than to receive nothing. Being dependent on care is to be exposed and subjected to a nurse's ability and benevolence. One comprehensive understanding of the meaning of dependency on care is simply that "one does not saw off the branch one is sitting on." Furthermore, dependency on care involves a struggle to move forward in a life that hurts. Patients lose much of their freedom of choice in daily life and grieve their loss of ability and value. Patients may be able, however, to see things they would have never noticed earlier in life. Dependency on care is understood as one kind of "limit situation". Patients who are dependent on care may reevaluate their potential in life and gain another perspective on life.

**Strandberg, G., Norberg, A. & Jansson, L. (2001). Being overwhelmed by the feeling of having a home and family. One aspect of the meaning of being dependent on care: a study of one patient and two of his nurses. *Journal of Advanced Nursing*. 35(5):717-27.**

*Rationale:* This article is part of an ongoing study which aims at disclosing the meaning of being dependent on care. From a larger body of data, interviews with one patient and two of his nurses were selected to study.

*Aim:* The aim was to deepen understanding of the meaning of being dependent on care when this appears desirable for the patient.

*Methods:* A phenomenological-hermeneutic approach was used to interpret the material. Interviews were recorded and transcribed verbatim.

*Findings/discussion:* The interpretation discloses the meaning of being dependent on care as an overwhelming, unfamiliar feeling of having a home and family. The patient is beguiled into believing he is the ruler in an established relationship and his dependency on care gives him an opportunity to be surrounded by loving, altruistic, helpful people. Being dependent on care is overwhelming and irresistible, i.e. coveted, but simultaneously it is like walking on thin ice, i.e. treacherous. The irresistible desire concerns being unconditionally cared about. The danger is that this 'family membership' will not last. It is brought to the patient because of his dependency on care and it is based on his terms. There is reflection about the patient being unprepared for dealing with his own world of loneliness.

**Strandberg, G., Norberg, A. & Jansson, L. (2000). An Example of a Positive Perspective of Being Dependent on Care. *Scholarly Inquiry for Nursing Practice: An International Journal*. 14(4):327-346.**

This article is part of an ongoing study which aims at disclosing the meaning of being dependent on care. From a larger data set derived from 10 patients, interviews with one severely ill patient, her daughter and two of her professional nurses were selected to illuminate a "positive" meaning of being dependent on care. The interviews were tape-recorded and transcribed verbatim and followed by interpretation of transcripts using a phenomenological-hermeneutic approach inspired by Paul Ricoeur's philosophy. The interpretation discloses the meaning of being dependent on care as balancing between being free and negotiating when receiving care. Whether or not dependency on care is negotiated about seems to be about how the power that lies in the existing differences in ability is used. When ability, that is, power, is used to compensate inability, the patients appears free to be dependent on care. Dependency on care is accepted for what it is, when it is. When dependency on care is negotiated about, the differences in ability, that is, power, risk setting limits for what dependency on care is to be. There is a risk that dependency on care will be limited within the frame of what is regarded as polite, appealing and pleasing.

**Strandberg, G., Åström, G. & Norberg, A. (2002). Struggling to be/show oneself valuable and worthy to get care. *Scandinavian Journal of Caring Sciences*. 16:43-51.**

Dependency on care has commonly been described negatively and as a problem that needs to be addressed. From a larger data material, interviews with an old, hospitalized man with a chronic disease, his wife and two of his professional nurses was selected to study. The aim was to illuminate the meaning of being dependent on care, when it appears 'negative'. A phenomenological-hermeneutic approach was used to interpret the material. The interpretation shows that dependency on care is reluctantly shown although it is expected to be expressed and/or respected as it is shown. This makes dependency on care camouflaged and the space to be dependent is limited. The meaning of being dependent on care is understood as a two-dimensional struggle for existence. One dimension of the struggles is about to be/show oneself worthy to get care, as dependency on care holds a fear to be abandoned. The other dimension of the struggle is about to be/show oneself valuable as a human being, as identity is built upon being

able to manage oneself and be strong. The interpretation if reflected on can open up possibilities to improve the quality of life for patients who are dependent on care.

**Wenneberg, S., Gunnarsson, L.-G. & Ahlström, G. (2004). Using a novel exercise programme for patients with muscular dystrophy. Part I: a qualitative study. *Disability and Rehabilitation*. 26(10):586-94.**

*Background:* Muscular dystrophy patients have often experimented with different alternative or complementary methods since there is at present no curative medical treatment.

*Purpose:* To evaluate, through qualitative interviews were performed and data were analysed by a method inspired by Grounded Theory. The material was first coded into 119 categories, thereafter condensed to 59 categories through a constant comparison analysis. In the final analysis, six broad categories were formed out of these 59 categories.

*Results:* These broad categories were: (1) experience of health care and alternative methods: (2) expectations, acceptance and compliance: (3) qigong as an adaptable form of exercise: (4) stress reduction and mental effects: (5) increased body awareness and physical effects; (6) psychosocial effects of group training.

*Conclusion:* Qigong was accepted as a novel exercise regimen and there was a wide variation of experience regarding it among the participants. Depending upon factors such as expectation of benefits, time available to do qigong and perceived effects doing it, compliance varied. One major advantage of qigong is the ability to adapt the different exercises to the physical capability of the person practising qigong. There were reports of mental, physical and psychosocial effects of the qigong, which reduced the feeling of stress and improved well-being.

**Wohlin Wottrich, A., Stenström, C., Engardt, M., Tham, K. & Von Koch, L. (2004). Characteristics of physiotherapy sessions from the patient's and therapist's perspective. *Disability and Rehabilitation*. 26(20):1198-1205.**

*Purpose:* The purpose was to explore, describe and compare the characteristics of physiotherapy sessions with patients after stroke from two perspectives: the patients' and the physiotherapists', in relation to observed behaviour.

*Methods:* A qualitative, descriptive, comparative approach was used. Nine patients and 10 physiotherapists participated. Data from observations and semi-structured interviews were used.

*Results:* Six themes were identified: *setting and attaining goals, focusing on motor activity, finding the optimal training strategy, facilitating active patient involvement, making use of environmental factors and adjusting to the structural reorganization of the rehabilitation services.* The physiotherapists and the patients made similar descriptions in some of the themes but differed in some. The physiotherapists expressed what they perceived to be their lack of scientific knowledge, while the patients trusted their physiotherapists' competence. The physiotherapists wanted to take the patients' personal experiences into account in the sessions, which was not obvious to the patients.

*Conclusion:* Differences in physiotherapists' and patients' descriptions of characteristics of physiotherapy sessions have to be taken into consideration in the rehabilitation of stroke patients. In order to empower the patient to take a more active part in the rehabilitation process, there is a need to explore how to incorporate the patients' personal experiences and knowledge into the rehabilitation process.

**Öhlén, J. (2004). Violation of dignity in care-related situations. *Research and Theory for Nursing Practice*. 18(4):371-85.**

This study seeks to explore narratives of care-related violations for patients with life-threatening illness receiving palliative care. Narratives told in dialogues with the researcher were processed phenomenologically hermeneutically. Four structures of meanings are described: focal points in recalling the experiences, experienced consequences of being violated, relationships causing violation, and personal struggling. The phenomenon of care-related violations means a complex experience of suffering as being abandoned, confronted with hopelessness, and further wounded. This experience may be directed toward readiness to share, introspectiveness, willingness to comprehend the incomprehensible, the riskiness of facing others, and attentiveness to acts of caring. It can be experienced in various relationships to professionals, family members and friends, to the mass media, and to welfare systems. Care-related violating episodes reveal the vulnerability of the person who is already suffering and makes him or her still more wounded, when actually comfort is expected. To receive affirmation in the state of fragility with increased suffering provoked by care-related violations can contribute to a transformation from human degradation into dignity, finding meaning or reaching reconciliation in suffering.

**Öhlen, J. (2003). Evocation of Meaning Through Poetic Condensation of Narratives in Empirical Phenomenological Inquiry Into Human Suffering. *Qualitative Health Research*. 13(4):557-566.**

The phenomenological interest to gain insight into the human being with lived experiences characterized as composite, diverse, ambiguous, vague, obvious, and concealed challenged this researcher in the process of doing life-world phenomenology. While researching the phenomenon of suffering, the author sought ways to intensify and evoke the embedded meanings in oral narratives, and he presents a model for poetic condensation of oral narratives to enhance the evocation of the meaning of suffering. Examples of narrated text are compared to the condensed narrative. Reading poetic condensed narratives of suffering has the potential to create a sense of the phenomenon responsive to and shaped by the way suffering is experienced.

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Jonsson, L. & Fridlund, B. (2003). Parents' conception of participating in a home care programme from NICU: a qualitative analysis. *Vård i Norden*. 23(4):35-9.

Research suggests early discharge from neonatal intensive care units (NICU) as advantageous for infants, their families and health care systems. This type of intervention has rarely been described from parents' perspective, therefore the aim of this study was to describe parents' conceptions of participating in a home care programme provided by the NICU. A qualitative descriptive design inspired by phenomenography was chosen for the study. Data was collected through interviews conducted with parents (n=23) enrolled in the unit's home care programme. The programme brought out two description categories: Becoming a family and Feeling security, comprising the

conceptions: Being at home, Being reunited, Getting information, Having accessibility and Having support. To feel secure at home means for these parents to have accessibility to the neonatal staff's knowledge and experiences 24 hours per day. In the hospital the parents do not feel like a family, a feeling that gradually changes when they return home with their baby. This is one of the reasons why it is so important that the infant is discharged as early as possible from the hospital.

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