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POSTER

A National Oncology Nursing Society as a part of development in cancer care

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Background: The Swedish Oncology Nursing Society was established in 1988 because the need of a forum for nurses in cancer care, this is a voluntary membership organization, exists to promote and develop excellence in oncology nursing and quality cancer care. The society is a national organisation of more than 700 registered nurses dedicated to excellence in patient care, research, teaching, administration and education in the field of oncology.

Method: Through the society nurses can interchange experience and knowledge, there is a collaborating with other associations in the area of care, both national and international.

Results: During 13 years of work this organisation is well known in Swedish cancer care, publish its own magazine (4 No. each year), arranges a national conference every other year (with about 250–300 participants), participate to create national guidelines for care within the area of radiation treatment for cancer. The organisation also have stipends announced for members for further development of care made by nurses. There are also an increased collaboration in the work with European and international nurses organisations. The organisations course of action and ways for collaborations will be presented.

Conclusion: This kind of voluntary organisation can affect the care of patients in a positive way and it is shown that knowledge within nurses organisations are asked for to create guidelines on national levels.

Ethics and values

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POSTER

"I wish I could manage with my cancer" - the right of the cancer patient to get good and high quality nursing care: the development program for nursing of cancer patient in the central hospital of Kokkola

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Background: A development program for treatment of cancer was started in the Central Hospital of Kokkola in 1995. At the same time a subprogram for the development of nursing of cancer patients. At that time there was not an outpatient clinic for cancer diseases. Each medical specialty took care of its own cancer patients. An outpatient clinic for cancer diseases was founded in 2000.

Purpose: The purpose of the development program for the nursing of cancer diseases was to increase the capabilities of the nurses to identify the special features of the nursing and increase the capabilities and possibilities to help and support cancer patients and their relatives in the different phases of the disease. There was an additional purpose in the program to make sure that the patients receive sufficient information concerning their disease and treatment. Finally, the purpose also was to arrange better exchange of information between different care units.

Implementation: The program was started by surveying the quality of nursing by a questionnaire given to cancer patients. Quality standards and criteria for nursing of cancer patients were defined. An operational network was constructed between the Central Hospital and the health centers: A nurse for cancer patients was nominated in every health center. Information booklets were made for the use of cancer patients and their relatives. Training of nursing the cancer patients was given to the nurses. Shortly after the outpatient clinic for cancer patients started, also the philosophy of the nursing was created. The aim of the nursing is the well-being of the cancer patient and their relatives. The patient's idea of health and good life forms the basis for nursing. The task of the nursing is to support the patient and his/her relatives to manage with the disease noticing their resources. The guiding principles of the nursing practise are the patient's individuality, autonomy and feeling of safety. The nurses' task is to take care of the continuity of care and nursing.

The present phase: The nursing of cancer patients is being developed by training and by participating in nursing projects and nursing research.

The patients view of the attainment of the results of the program will be asked by delivering the questionnaire for the second time.

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POSTER

Decision-making on starting terminal care

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Purpose: To describe the provision of decision-making on starting terminal care in the light of a law of patient's position and rights (1992).

Methods: The data were collected by a structured questionnaire. The sample consisted of 328 nurses working on the in-patient wards of 32 community health centres. The data were processed with SPSS statistical software.

Results: The nurses found the decision-making on starting terminal care very important, but the study brought up some shortages in the provision of decision-making. The study brought up also some factors which were associated with decision making.

Conclusion: There is need to start or continue the discussion concerning the principles of the care for terminally ill patients in health centres.

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POSTER

Palliative chemotherapy in advanced cancer: Is it time to abandon the concept of futility?

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Purpose: The aims of this presentation are two-fold. First to question the concept and definition of futility in the context of palliative care and second to determine its place in palliative treatment decisions, particularly in the light of the patient's total good.

Exactly what constitutes futile treatment has evoked significant controversy in the medical literature and in clinical practice. As a result of the ongoing efforts to justify the use of the term futility in medical practice, definitions of futility have been proposed on a range of possible approaches. Also there are occasions when the concept of futility is applied while the explicit term itself is rejected. This is an important point because it leads to doubt over what the real reason is for disputing treatment. The range of approaches may well, in their own right, be justification for a treatment decision. However, if that is the case then futility is not the reason, for the basis on which the decision is made lies elsewhere.

The main approaches are:

- * physiological futility
- * qualitative futility
- * burdens of treatment outweighs benefits
- * resources required outweigh the benefits.

Such a variety of definitions have led to the term futile being labelled as ambiguous. This presentation will review the latter 4 approaches and their relevance to palliative chemotherapy treatment decisions.

Conclusion: Futility is a confusing and contentious term. The issues at stake, including rationing, cannot be rejected and must be brought into an open forum for discussion. What is then seen to emerge is concern for dialogue that establishes appropriate treatment to meet the goals of patients without compromising the professional autonomy of the team. Acknowledgement of such an essential process is integral to the palliative care approach.

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POSTER

Culturally competent nursing care in a group of cancer patients in Iran

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Purpose: Culturally congruent care means to provide care that is meaningful and fit with cultural beliefs and life ways. The purpose of this study was to describe and explicate the meaning of nursing care within a group of cancer patients in Iran. The goal of the study was to discover knowledge to guide nurses in providing culturally congruent care for cancer patients.

Methods: This qualitative study used a phenomenological approach as it focused on individuals lived experiences within their socio-cultural setting. The setting for this study was a general hospital in Tehran. Face

to face in-depth, interactive interview was chosen as a method for data collection.

Results: Findings from interviews with 22 male and female participants reflect the wide variety of expression according to cultural differences in patients. Cultural beliefs, values, and meanings associated with expression on health and illnesses are central prerequisites of culturally specific and meaningful care.

Conclusion: It is imperative that nurses be aware of broad socio-cultural differences issues that influence the health and the well being of the cancer patients.

By focus on a specific culture, it has highlighted relevant areas for change in nursing practice, management, and education.

Nursing, as a profession needs to address the issue of culture and the impact this can have on their practice.

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POSTER

Privacy: a nursing key concept

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Purpose: Privacy is a basic right of any individual. Each human being has a lot of lived personal experiences which represents its references and to which only oneself has access. As a more qualified person to deal with this, the nurse has the obligation to understand the patient as a whole, and therefore to ensure that he is given all the conditions to keep his privacy up to what it's possible and, so, his dignity.

The nurse should help the patient, not only to protect his privacy, but also in order to help him deal with the loss of some privacy which is inevitable in a hospital stay, but that can be minimized.

Our goal is to study how privacy is dealt with and respected in hospital environment, considering privacy as one of the first ethical principles in nursing and that one should have it in mind whenever doing any nursing care. Privacy is essential so the patient can get used to its new life style in hospital and afterwards when recovering.

Our purpose was to answer the question: Is the right to privacy, in patient perspective, taken into account by the nursing team in the Bone Marrow Transplantation Unit?

Methods: Our methodology was a qualitative one. The study was made on six patients (3 males, 3 females; max. age: 58; min. age: 19; median: 42) submitted to stem cell transplantation and in a six month Follow-Up situation. These 6 patients were interviewed from September to November 2000.

Results: Four categories were found referring the meaning of privacy: the right to have one's own space; the right to share a space with meaningful persons; a citizen's right; a citizen's duty and right.

Regarding the importance given to privacy we found only one category, which acknowledged its fundamental role.

In the degree of satisfaction with the relationship between privacy and nursing care, two categories were identified: pleased/not pleased.

Analysing the suggestions to improve privacy, one can find a single category: to make changes in the therapeutic environment.

Conclusion: We can find two levels of interest and feasibility in our work. On the one hand, in a more theoretical and methodological approach, it can add to some reflection on concepts and methods of research. On the other hand, this study can be seen as a case study and therefore in a more applied perspective.

Fertility and sexuality

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POSTER

Breast cancer, sexuality and relationship

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Purpose: Sexuality is an intrinsic part of human nature, which plays an important role in psycho-emotional support in cancer. The purpose of the study to evaluate the impact of breast cancer (BC) on sexuality and relationship.

Methods: The Relationship Questionnaire was developed and used to determine the influence of mastectomy and chemotherapy on sexual functioning, social and family relationship, and quality of life.

Results: 176 women (28–45 y.o.) participated, with lack of sexual interest (24.7%), inorgasmia (18.5%), poor lubrication (34.8%), reduced satisfaction with masturbation (12.2%), reduced frequency of masturbation (11.9%), painful intercourse (15.7%), vaginismus (2.5%). 85.4% reported at least one sexual problem, although 30, 8 reported either no or slight concerns about their sexual difficulties. It was found that one of the most commonly occurring secondary sexual symptom among women with BC is fatigue (89.7%). Fatigue greatly interferes with sexual desire and the physical ability to initiate and sustain sexual activity. The physical changes (mastectomy, hair loss) due to BC and chemotherapy can also negatively affect body image. 75.6% of women might have difficulty feeling physically appealing or "sexy". Some of them (44.2%) may fear they are no longer sexually desirable to their partner. Additional problems may occur in the relationship when the partner assumes the role of caretaker (8.5%).

Conclusion: Obtained information about BC and sexuality makes possible to develop clinical guidelines to modify treatment regimens to best accommodate sexual needs.

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POSTER

Sexuality/fertility issues and the nurses' role in cancer care

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Aim: Clinical practice developments were initiated following two studies among nurses, fertility staff and doctors in a London Teaching Hospital concerning the nurses' role in supporting clients with cancer facing fertility/sexuality concerns. **Methods:** The first study based on a Medical Oncology Unit focussed on finding out what was available to clients, who addressed fertility issues and particularly nurses' experiences and suggestions. Nurses were invited to describe their role in supporting a client who may be considering fertility treatment. The second study took place a year later and was carried out on a Bone Marrow Transplant Unit. This study involved nurses answering a questionnaire about their role in addressing clients' sexual and fertility needs, medical staff were asked to describe their clinical practice. **FINDINGS:** In both studies the findings were similar. Medical staff and staff at the fertility clinic believed nurses had an important role in supporting clients facing infertility concerns. Nurses recognised their role in supporting clients with sexual and fertility concerns. Nurses wanted to address the issue but often avoided fertility/sexual issues, hoping someone else would address clients' concerns.

The reasons cited for not addressing the issues were:

- Lack of experience and knowledge.
- Lack of time and privacy.
- Patients' and nurses' embarrassment.
- Fear of making mistakes.
- Cultural, gender and age differences.
- Myths/prejudices.
- Opening up more than you can handle.

Nurses asked for support in order to address this issue. The following clinical practice developments were initiated: A working party now addresses sexuality/fertility practice development in cancer care. New cancer nursing staff are made aware of sexuality/infertility issues at orientation. All nurses are supported and expected to address sexuality/fertility issues appropriately, related to disease, treatment and hospital stay. Clinical guidelines have been drawn up. Two hospital wide study days have taken place and were well attended, addressing male fertility issues in cancer care, others are planned. Regular Unit based teaching sessions address ongoing concerns. **Conclusion:** In keeping with any practice development, reflection and learning continue. Having begun to change practice following the findings I believe nurses are being better supported in their ongoing commitment to patients with cancer.

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POSTER

Sexuality after hematopoietic progenitor cell transplantation (HPCT). Where is it?

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Introduction: A 15% of the admissions in our centre are HPCT patients. This aggressive therapy alters the individual biopsychological needs. Survival is the main objective of the patients but once the HPCT is overcome they must reorganise their life and the concept of quality of life and sexuality gains new dimensions. Sexual dysfunctions can be produced by physical, psychological and cultural aspects. Studies on this subject in HPCT are few.