

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.

Materials and Methods: The objective of our study was to evaluate the impact of HPCT in sexuality in autologous, allogeneic and singeneic HPCT patients aged 18–60 yr, with a minimal survival of 1 year. Data were obtained through a personal or phone interview based on the EORTC QLQ-C30 and Molassiotis and Morris questionnaire.

Our questionnaire asked about the meaning of sexuality and changes in this issue before and after transplant. Exclusion criteria were lack of collaboration disease relapse, lack of administrative data and death.

Results: 90% of the interviewed answer the questionnaire. Psychological sequelae were seen in 50% of patients, including fear (30%) and anxiety (25%). 50% of patients had sexual life alterations, mainly dyspareunia (25%) and inappetence (20%). 15% of patients related less sexual activity due to their physical aspect.

Conclusions: A great part of the patients assured that nobody asked them about their sexual life before and after transplant. They didn't know how transplant was going to change their sexuality and missed information in this issue. Although 50% of the interviewed presented sexual life alterations, quality of life and health perception were well punctuated.

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POSTER

Prevention of vaginal agglutination by women treated with radiotherapy for cervical cancer

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Background: A large number of women get agglutination of the vaginal mucosa after radiotherapy. This results in the vaginal walls paste to each other. This is a contributory factor to sexual dysfunction.

Aim: To investigate how the use of dispence aid appliances can decrease the number of women with vaginal agglutination.

Design: Dispense sponge bag with aid appliances in the form of a dilator and exploration lotion together with a verbal as well as a written patient information. The women will be followed for six months, one year and two years after completing the radiotherapy.

Conclusion: Due to very positive feed back from the participants we made the initiative permanent. We didn't quite full fill our aim but we estimate this change of procedure as being beneficial for the entire group of women treated with radiotherapy for cervical cancer.

Needs of children with cancer

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POSTER

Young cancer patients between 15-20 years get the own youth section at an adult hospital department. The first in Denmark

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Background: The background for the pilot project "Young People With Cancer" takes its starting point in the nursing and treatment of the young cancer patients and their relatives. Department D1 at Aarhus University Hospital has treated this group of young patients since 1995. The nurse Nuka Hove worked with the problem "Care for the Young Cancer Patient at an Adult Hospital Department" at the Further Education in Oncology (West) in Denmark in 1997/1998. The implementation of her work put focus on the 15 to 20-year-olds and their relatives. A television documentary in the autumn 1999 where young cancer patients and staff from the Department of Oncology D1 participated also put focus on this patient group. In connection with the budget for the year 2000 Aarhus County decided to spend 0.5 mio. DKK a year for 2 years to improve conditions for young patients with cancer.

Methods: To create an environment for the young patients based on wishes and needs expressed by the young patients themselves. To educate relevant groups of staff to manage treatment and nursing of the young cancer patients considering that this patient group has specific needs concerning care, information and possibilities of action. To develop communication tools in connection with treatment and nursing of the young patients, their parents and other members of their network. To prepare the young people for the changes in life after the treatment period. To offer out-patient nurse consultations in connection with control visits. To develop education material for the young patients. To communicate the methods developed to a broader group of health staff.

Conclusion: The first year has been very successfully. First of all we have organized 2 patientsrooms and a youth section in co-operation with our patients. The education of the staff is an ongoing process, but we can see the results of our work in the better and different care we give our patients and their family. Besides we have successfully developed communication tools, such as network talks and structured meetings, which has upgreated our care.

Needs of relatives and care givers

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POSTER

Participation of relatives in the care of cancer patients and support received from health care professionals

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This study aims to see to what extent relatives do take part in the care of cancer patients and to find out how relatives have been supported by health care professionals before and after the patient's death.

The data were collected with a structured questionnaire administered to relatives of cancer patients who had died in a hospice in southwestern Finland in 1998 and 1999. The final sample comprised 258 family members, most of whom were the deceased patient's spouses. The data were described by percentage, frequency, mean, and standard deviation. For the analysis of statistical significance we used the Mann-Whitney U-test and the Kruskal-Wallis test. Instrument reliability was ascertained by the Cronbach alpha coefficient.

The most central aspect of relatives participating was supporting the patient emotionally. Most of the relatives reported that they supported by visiting the patient in the hospital, being near the patient when he/she desires it, and being careful not to hurt the patients feelings.

Relatives felt that they had received a moderate amount of support from health care professionals. Before the patient's death they received more emotional than informational support. Relatives were informed most about patient's illness and treatment and daily condition. Over three-quarters of them said they had received a lot or a fair amount of information about them. Communication had been honest and based on the relatives needs. Emotional support before and after patient's death consisted mainly of acceptance of the relative and listening to what relatives had to say. Over half of them reported that staff did not talk with them at all or only rarely talked with them about their difficulties in everyday life. Among both patients and relatives some background variables were associated with the relatives participation in the patient's care and with the support received by the relative before the patient's death.

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POSTER

A reference book

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In 1995 we developed in the Netherlands Cancer Institute a computer system for nursing guidelines. Now six years later the system contains not only 500 nursing guidelines but also guidelines for physiotherapists, dieticians and doctors in training as well as information for patients.

The new developments in the treatment of cancer made us realise that multidisciplinary guidelines are essential to ensure continuity and quality of care.

To make this possible we started a project in January 2001, funded by the European Commission. The goal of the project is to evaluate an XML application within the reference book, which will enable us to develop guidelines for all the different professionals with different roles during the route the patient is following when coming to the hospital, so called patient centred guidelines.

We would like to share our experiences and the preliminary results of this project especially because XML gives us the possibility to exchange guidelines with others.