

Joint Interactive Symposium EBMT-NG/EONS

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A nurse led out patient clinic for patients after stemcell transplantation

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Background: The role of nurses in managing patients with hematological diseases at the outpatient clinic is evolving. In 1998 we started a nurse led outpatient clinic for patients after stem cell transplantation. Before and after transplantation the patient visits the doctor and the nurse at the outpatient clinic. We are using a guidance program for these patients that is systematically used during the care process which include the following five key nursing areas: patient assessment, monitoring, teaching, patient support and quality of life.

The responsibilities of the nurse providing care at the outpatient clinic are varied and include: obtaining a thorough physical and psychosocial history, formulating a nursing diagnosis with appropriate nursing interventions, teaching patients about their disease and treatments and providing a supportive environment with counselling skills to reduce stress and anxiety.

By using a checklist and an information booklet the nurses guarantee that patients will get all the needed information regarding pre-treatment, transfusion of stem cells, post-treatment and the period of rehabilitation. Patients are confronted with several physical, psychosocial and emotional aspects after stem cell transplantation: the impact on social life, changes in nutritional status, how to deal with fatigue, changed sexuality and the return to activities of daily life and employment. For example, one of the major concerns is fatigue after stem cell transplantation. The nurse follows the patient at fixed moments in order to determine fatigue and to identify fatigue risk factors. The patients are then educated by the nurse to manage their fatigue by means of a standardized oncological guideline concerning fatigue.

Conclusion: Nurses at the outpatient clinic can play an important role in follow-up care, treatment and control of symptoms, through assessment, close monitoring and evaluation of the patients' experience and effectiveness of the intervention. It is necessary that these nurses are specifically trained and have good communication skills. Support of the patient and the reduction of the distressing experience of psychosocial problems and also providing a better quality of life is paramount. The next step is to evaluate the effect of providing nursing care in the outpatient setting.

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Quality of life after stemcell transplantation - a qualitative study

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This study sought to understand the lived experience of people post autologous transplant for a haematological malignancy. For nurses and other health care professionals to improve practice it is imperative that they understand the lived experience their patients have undergone.

High dose chemo/radiotherapy and autologous haemopoietic transplant is an established therapeutic modality for haematological malignancies. Autologous transplant has a relatively low mortality rate yet has high physical and emotional morbidity with physical and psychological sequelae lasting for many months, and sometimes years or permanently, after the event. Research studies have attempted to quantify quality of life post transplant but have failed to explore the phenomena of the lived experience following this physical and psychologically stressful event and the lasting impact the experience of transplant may have on the individual.

A study using Husserlian phenomenological methodology and using Giorgi's (1985) method of analysis was undertaken to attempt to gain some understanding of the patient's experience. Five adult patients who had undergone autologous transplantation for a haematological malignancy at least 6 months previously participated in the study. Interviews with the participants were audio taped and then transcribed verbatim. The data were then analysed using Giorgi's (1985) framework.

Sixteen themes emerged from the participants' stories and included psychological cost, physical and psychological adaptation, reprioritisation and a sense of isolation.

By better understanding the experience through the descriptions of the participants, nursing and other healthcare staff will be better informed to prepare patients and help them make choices prior to transplant. With this greater insight, they may also be able to provide more sensitive, holistic care in the follow-up of these patients.

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Non-adherence in hematology and stemcell transplant patients – is it worth worrying about?

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More and more shared responsibility between caregivers and patients regarding the treatment, or the part which they can handle, is implemented into practice. Among other consequences, this results in a growing number of treatments on an outpatient basis like chemotherapy courses and even allogeneic stemcell transplantations (SCT). Therefore, patients, together with their primary caregiver, have to carry the responsibility for a substantial part of their treatment. This responsibility usually covers not only a complex medication regimen (oral and subcutaneous) that needs to be followed but also a combination of special hygiene regimens together with food restrictions, self-assessment measures and others. Usually the treatment is based on a constructive collaboration and communication between the patient, his significant others and the multidisciplinary healthcare team. It is known that patients want to stay at home as long as possible even during high-dose chemotherapies and SCT. In this situation the question rises whether non-adherence has any significant consequences like early infection, higher costs, earlier relapse or even death – so, do we need to worry? A thorough research study regarding the adherence of patients to the treatment as scheduled has not yet been conducted, but literature is available. Within the oncology literature evidence can be found that between 20 and 70% of the patients are non-adherent, depending on what and how it has been measured. Consequences can be found in the area of infections, costs and quality of life. From studies within the chronic disease management area we know that several factors can play a role in the behavior of the patient and how he/she adheres to the intended treatment. These factors include e.g. prognosis, believe in therapy, personality traits and complexity of treatment. For the team the question might rise how much the patient adheres, and whether the patient can or wants to adhere to the treatment as planned. Nurses need to know the influencing factors and will have to assess them thoroughly to be able to support the patient according to the best available evidence. Next to screening of the risk factors, interventions should include educational and behavioral strategies as well as support through the social network. For the future, it will be important to pay attention to adherence of the oncology patient and therefore increase the possibility to adjust the treatment to the lifestyle of the patient. This presentation will focus on adherence in hemato-oncological patients throughout their course of treatment, influencing factors and possible interventions. Gaps that will need to be filled in the near future will be elaborated.

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Bone Marrow Transplant (BMT) - Nursing in Germany: where are we and where are we going?

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The public health care system in Germany is confronted with its biggest challenge since its existence. The problem of constantly raising costs with at the same time a decline in income is well-known. To get a better influence over the expenses the introduction of a payment system which is referring to diagnosis related groups (DRG) was decided in Germany in 2000.

One can not evaluate completely the effects of this system on nursing and the German hospital yet. But fact is that the competition and the pressure on

costs is increasing for each hospitals. A reduction in hospital beds between 25 and 30 percent of all beds in Germany is expected.

For sure the length of stay of patients in the hospital will decrease.

The following consequences for the nursing are a result of these developments:

Due to a reduction of the duration of a hospitalisation more patients will have to be cared for within the same timeframe.

The relative proportion of severely ill patients in the hospital will rise.

Patients without complications will be sent to outpatient settings more frequently.

Patients will stay a shorter period time on cost-intensive intensive care units.

Cost pressure will rise for the nursing staff.

Due to these changes the management team of BMT units face new challenges. Patients after BMT will be transferred much earlier from the "high-intensity-care" BMT unit to a lower intensity care unit for rehabilitation. This means that the number of patients on BMT units needing highly professional care is increasing but loss of quality can not be permitted. Nurses who care for the BMT patient in the rehabilitation phase these shifts of the patient population in a different way. They are confronted with problems which they have no experience in yet. The constructual requirements as

well as professional level of care for highly immunocompromised patients need to be investigated. At the University Hospital Marburg (Germany) we looked more in detail into these changes and reconstructed a unit for these purposes. The nursing Team received special training to be able to meet these challenges in the near future.

The nursing staff in Germany can not avoid to face their role in the health care system and an active planning of the future of the nursing is mandatory. An open discussion and establishment of a newly defined role and core tasks of nursing is important. Because of an increase in outpatient care and treatment of the patients the demand of advice through nursing staff will rise. Evidence Based Nursing, Primary Nursing and Case Management will become increasingly important. Because of an earlier transfer of patients from cost intensive ICU's to other care units it is necessary to transfer them to an IMC very often.

Just as much as we have to think about for which jobs highly qualified nurses are needed. We need to think about which jobs can be performed by less qualified staff.

The nursing management on all levels is challenged to find practicable and professional solutions. Germany is able to manage its crisis of the health care system only if everybody co-operates constructively.

Workshops

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Generating questions for nursing research

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Conduct of research is a process yielding knowledge that will contribute to practice and cancer care. Opportunities for investigating problems that impact on nurses practising in, and on people who use, cancer nursing services, are diverse and numerous. Identifying a problem is the initial and one of the most significant steps in conducting research. The research purpose evolves from the problem and provides direction for the subsequent steps of the research process. This workshop will provide participants with an opportunity to reflect on the different approaches, both formal and informal that might be used to identify areas that merit research. Sources of research problems including nursing practice, researcher and clinician interaction, systematic review, theory and research priority setting exercises will be reviewed. Research priorities need to reflect the needs of different groups and stakeholders and the role of users of research in this process – patients and clinicians – will be highlighted. Research objectives, questions, or hypotheses are formulated to bridge the gap between the more abstractly stated research problem and purpose and the detailed design and plan for data collection and analysis. Using worked examples it will explore the process of turning an area of interest into a question amenable to research and highlight factors that might influence this. Research should provide answers to significant clinical questions with a sequence of activities generating a continuous flow of questions and answers relevant to practice.

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Chemotherapy and safety aspects for oncology nurses

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In the treatment of cancer patients is cytostatica een important medicijn.

Cytostatica are medicines that has his impact on the cell growth and other biochemical processes in the tumour cells. There is an eliminating effect on the tumour cells but also on the good cells in the body. Cytostatica have also a carcinogenic, mutagenic en teratogenic effect on the healthy person

who works with this medicine by cancer patients. The health risks of nurses en other employers in hospitals depends on the risk of contamination or on the moment of exposure. Important also is the nature of the cytostaticum. Research shows that de health risks are not easy to interpreted. It is also not easy to say something about the risk that an individual has when they work with cytostaticum every day/week. De relation between a high dose and low dose are not clearly understood. By cleaning tests we see that an higher dosis gives more exposure on the floors, toilets etc. This is proven in a monitoring project in two hospitals.

In the treatment of chemotherapy are de safety aspects extremely important, otherwise you get contaminated by cytostatica. The exposure-risk is expected:

- When you give patients chemotherapy, oraal, intravenous, intramuscularly, intravisciaal, intrapleuraal, intrathecaal
- When you work with excreta of patients who received chemotherapie, there is a special riskperiod for each cytostaticum
- In the environment of the patients, the bed, toilets or shower is contaminated with cytostatica
- When there is a incident with cytostaticum or with contaminated excreta.

Researchers expects that cytostatica comes into our body by skincontact. When you touch the patient with chemotherapy and you will not clean your hands, you will be contaminated with cytostatica. And when you do not work with the right safety tools en the right werkmethode. The skin exposure is the most expected, nurses still not make the right decisions. Putting on a hand glove is not difficult but we do we take them off, and when do we wash our hands. Clean working is the best advice but also work critical with protection tools. Using a protocol so that everyone knows what he has to do at special moments of contamination. Safety aspects are not an individual matter, it is a problem for every nurse, doctor or cleaner that works on a ward with patients treated with chemotherapy. Nurses most learn to work with safety protocols. The aspects of why nurses are not working with safety aspects in the first place is because the needs of a patient are more important, not enough knowledge, or not know how.

In this workshop the goals are:

1. Understanding about the best strategy on a ward when you work with patients who will be treated with chemotherapy.
2. You can explain too other colleagues about the safety aspects and when to use personal protection tools.
3. Understanding about an implementation strategy for a safe workmethod how you can change a behaviour by nurses and other disciplines