

## Joint Interactive Symposium EBMT-NG/EONS

1145

### 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.

1146

### 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.

1147

### 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.

1148

### 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