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# The European Blood and Marrow Transplantation Textbook for Nurses

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Editors

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Under the Auspices of EBMT



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## Foreword

Autologous and allogeneic haematopoietic stem cell transplantations (HSCT) are curative procedures for patients with haematological diseases and immune deficiencies.

This textbook is an easy-to-read primer for all those involved in the care of HSCT patients. It offers a solid and comprehensive overview of different nursing methods and requirements and their applications towards improving HSCT patients' outcome.

The book is divided into several chapters which allow reviewing the most important components of nursing and caring after HSCT both in the adult and paediatric patients. It also relies on real-life clinical situations to illustrate the scientific principles and concepts.

Cutting-edge and updated nursing techniques are presented, but the basic principles and general considerations are explained first.

This textbook developed under the auspices of the European Society for Blood and Marrow Transplantation (EBMT) by highly skilled and experienced colleagues in this field represents an invaluable resource that will be highly useful to all professionals involved in the modern management of HSCT patients.

EBMT is very proud of this unique achievement that has been long awaited because nursing science must be continually improved in order to provide the best patient care possible. It will contribute to better patient care and make it visible not only for nurses but also for all other stakeholders. Far from being all-inclusive, it will definitely serve as a catalyst for the interest of the readership.

Mohamad Mohty

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## Preface

### **The EBMT Nurses Group: promoting excellence in patient care through international collaboration, education, research and science**

The EBMT Nurses Group (NG) plays an essential role in haematology and haematological stem cell transplantation nursing. The group was created 33 years ago and now has over 750 members in more than 60 countries worldwide with a principal nurse identified in almost each EBMT centre.

The EBMT NG's mission is to enhance and value the nurses' role all over the world, supporting and sharing knowledge through communication, advocacy, research, training and education. The group is dedicated to improving the care of patients receiving SCT and works towards promoting excellence in care through recognizing, building upon and providing evidence-based practice.

Over the last two decades, BMT nursing has grown rapidly and has acknowledged the need for care of the patients, their families and donors.

Advanced practice nurses have been taking a leading role in the care of patients, providing in holistic care; BMT nurses are involved in the decision-making process about treatment options for their patients, and they evidently contribute to an enhancement in their patients' quality of life. More and more, EBMT NG is conducting a research on topics based within clinical practice and is formulating their own research agenda.

The EBMT NG consists of a board and five committees (paediatric, research, global educational, scientific and communication and networking) and links with national groups/forums.

Recently, we enhanced our collaboration between EBMT and the Haematology Society of Australia and New Zealand (HSANZ) Nurses Group.

<http://www.ebmt.org/Contents/Nursing/WhoWeAre/TheBoard/Pages/TheBoard.aspx>

Bellinzona, Switzerland

Aleksandra Babic

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## About the Author



**Michelle Kenyon** works as Consultant Nurse (BMT Care and Survivorship) at King's College Hospital, London. She has worked for more than 25 years in the field of haemato-oncology and stem cell transplantation. Her interest in improving the patient experience of haematopoietic stem cell transplantation (HSCT) led her to write *The Seven Steps*, a patient information book (2002) and subsequently the *Next Steps* (2012). Around 50,000 copies of these titles have been distributed and are now used as the basis of informed consent for transplant recipients throughout the UK.

She studied her BSc in Cancer Nursing and MSc in Advancing Cancer Nursing Practice at King's College London, and undertook an empirical research study exploring the use of life-coaching in stem cell transplant survivors for her dissertation. She supports patients throughout their post-transplant recovery and has a particular interest in survivorship issues and the effects of treatment. She launched the HSCT long-term follow-up clinic at King's College Hospital in 2014 and has found the patient insights inspiring and the overall experience highly rewarding. She is the nurse representative on the BSBMT executive, Vice Chair EBMT (UK) NAP group and is Secretary of the EBMT NG.

**Aleksandra Babic** is a Nurse Manager, affiliate to Oncology Institute of Southern Switzerland (IOSI), in Bellinzona, as Transplant Unit Coordinator and Quality Manager. She received her nurse diploma from the College Center of Professional Formation in Dubrovnik, Croatia, in 1988, and was



awarded a Master's degree in Nurse Management in 2006. Until 2016 she worked as a nurse manager in apheresis unit at IEO, European Institute of Oncology in Milan, and has published papers on peripheral blood stem cell collection and mobilisation (i.e. R-ESHAP Plus Pegfilgrastim as an Effective Peripheral Stem Cell Mobilization Regimen for Autologous Stem-Cell Transplantation in Patients with Relapsed/Refractory Diffuse Large B-Cell Lymphoma, *Transfus Apher Sci.* 2013; Successful Mobilisation of Peripheral Blood Stem Cells in Children Using Plerixafor: A Case Report and Review of the Literature, *Blood Transfus.* 2013; Who Should Be Really Considered as a Poor Mobilizer in the Plerixafor Era? *Transfus Apher Sci.* 2012) and photopheresis (i.e. Efficacy of Photopheresis Extracorporeal Procedure as Single Treatment for Severe Chronic GVHD: A Case Report, *Transfus Apher Sci.* 2013). In addition, Aleksandra has presented at a number of conferences worldwide, most recently including the GIIMA 3rd National Conference, GITMO and the EBMT 2015 conference: Validation of PBSC collection within JACIE program – A multicenter evaluation. From 2016 she is also a JACIE Quality Manager Inspector.

Aleksandra is the former EBMT NG President (European Blood and Marrow Transplant Society) Nurses Group, which includes more than 800 nurses in 64 countries worldwide. She is a former President of GIIMA, the Italian Nurses Group in Mobilisation and Aphaeresis, and the founder and a board member of the not-for-profit association, Nurses No Frontiers.

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## Brief History of HSCT Nursing: HSCT Nursing Through the Ages and Its Evolution

Since the beginning and progress of stem cell transplantations in the late 1950s/early 1960s, it was clear that nurses play a crucial role within the multiprofessional team caring for patients and their families undergoing this treatment. Nurses as core professionals along physicians and other healthcare workers care for patients and their families around the clock. Continuity of care is vital to patients' satisfaction as well as trust. In the beginning, care was considerably cumbersome with HSCT patients who needed to be treated in a sterile environment such as germ-free tents or bubbles. Being one of the nurses who still remembers how that had to be handled, it is clear that this work was very time consuming and specific material was needed because everything – from the linen and clothes of patients up to every single book, toy or newspaper – is all needed to be wrapped up and sterilized before given to the patient. Next to helping patients deal with the time in the germ-free environment, talking to their beloved ones through a plastic curtain or wearing a mask covering emotions on the face, nurses of course also needed to take care for the physical and psychological challenges patients faced.

- Nurses Field of Competences

To be able to care for patients and families, nurses need to perform duties and responsibilities that often comprise more tasks than the ones taught in nursing schools. Experience and long-term commitment to the care of HSCT patients can be a challenge but also very rewarding. Novices to the field will need to be supervised and supported by expert nurses from the beginning to be able to endure also burdensome situations in a very person-centred care.

- Coordinator, Communicator and Translator

Nurses play an important role as coordinator of all issues including coordinating procedures and care activities within the interprofessional context before, during and after transplantation. This includes organizing all necessary diagnostic tests and checkups prior to transplantation. Sometimes they are responsible also for the donor and his/her health including questions concerning the donation of stem cells and its consequences. The process of transplantation involves many professionals and specialties – therefore, all results need to come back to one single point of coordination. It is important to communicate all diagnostic tests, their results, and what they mean in the situation

of the patient in a language that the patient understands. Often the medical language is difficult to understand by lay people, and therefore nurses play an important role in translating the meaning and consequences to patients and their families.

– Preparer and Educator of Patients for Transplantation and the Period After HSCT

Over the years, every centre developed modules, booklets or information brochures for patients which always supported the educational activities to prepare patients prior transplantation, help them through the phases of transplantation and make them ready for discharge and the time at home when no professional is around, and they have to make important decisions and cope with the situation in their own home environment. Specific attention has developed towards educating the long-term survivors and their next of kin in which nurses can play a prominent role because medical treatment activities are more in the background and day-to-day questions have to be dealt with. Some centres developed classes in which patients and families get together, gain the needed information and share concerns and discuss ways of coping. All this is often done under the auspice of nurses experienced not only in transplant nursing but also in principles of patient education.

– Carer, Administrator and Technician

The administration of chemotherapeutic, immunosuppressive and symptom-control drugs; blood products; and parenteral nutrition through a central venous access device has developed over the years. The accurate handling and care of the central venous catheter and infusion pump systems is vital in the process because the catheter is related to the highest risk of infections. In addition, nurses often need to make important decision when no physician is around to prescribe medication (such as during the night shift) to ease suffering such as pain, mucositis, diarrhoea or nausea.

– Social Supporter and Motivator

The distress during the time prior to undergoing HSCT, during isolation, in the recovery phase and the time after (long-term recovery) is not to be underestimated. Nurses play an important role as part of the interprofessional team in communicating, motivating and supporting patients throughout the entire process including the follow-up time. Connecting patients and family members with other professionals such as social worker, psychologist or spiritual carer whenever emotional distress is overwhelming, other questions arise and encouragement is needed is often considered very helpful.

Being culturally sensitive and meeting the spiritual needs of patients has become a recognized challenge in our often multicultural societies. Because of the 24/7 availability of nurses, they often detect these needs and are able to call for the necessary support that patients and families need.

Although over the years there were tremendous improvements in outcomes, namely, better survival rates, some patients and families need to face limited life expectancy. In this phase, the early support of palliative care in managing symptoms, helping patients in their often difficult and complex decision-making and discussing who of the family can be involved to take care and how to back up the family and look for additional offers to relieve and unburden family members is vital. Advance care planning should be integrated early into the care of stem cell recipients (Button et al. 2014), and nurses can address the above-mentioned topics and help patients and families to find a way in the often overwhelming and complex situation. An interprofessional palliative care service, supposedly even offered pre-transplantation (Loggers et al. 2016), could provide support in helping throughout often complex and instable situations which could lead to a better understanding of the situation, lessen distress and increase hope and quality of life (El-Jawahri et al. 2016) in the unit of care.

- Extended Practice Roles

In the late 1990s during the EBMT conference in Aix-les-Bain (France), nurses performing diagnostic and therapeutic interventions such as bone marrow or lumbar punctures – up to that time executed only by physicians – were strongly discussed and also criticized by the nursing audience. That can probably be considered as the beginning of the development of extended roles that nurses nowadays perform on a regular basis. Importantly, throughout the discussion, the core tasks of nurses remain in the hands of nurses and are not delegated to other professions.

Probably a suitable mix of skills and grades of nurses is the foundation of professional nursing within the interprofessional team. Nurses trained on an academic level and performing tasks as a nurse practitioner or clinical nurse specialist are considered as advanced practice nurses. Several role models exist throughout the European countries. Learning from the highly qualified nurses in the USA and their approach of nursing inspired many European nurses to go beyond what was up to then traditional in their own country. Being academically trained often enabled nurses to argue more based on evidence-reflected practice and led to being accepted by other academic professionals.

Being part of the interprofessional team with a strong shoulder-to-shoulder workforce together with physicians, physiotherapist, dietitians, social workers or chaplains, nurses found their unique role in being present with the patients 24/7 during the treatment but also in the time before and after the treatment. Nurses took over the responsibility to educate patients before the treatment about any aspects that are important to successfully undergo the procedure. Over the past decades, many nurses not only developed clinical skills but are also excellent researchers looking deeper into the phenomena of patients, family members and measuring outcomes based on a reflective way of practising nursing. The field of nursing research in HSCT has evolved from reflecting on symptom management and service development to quality of life and long-term survival topics.

Outcomes of research form the basis of standard operating procedures (SOPs) developed to support clinical practice, guarantee a high level of practice, and audit and accredit the transplant centres on evidence-based practice guidelines. The translation of evidence into clinical practice and taking into consideration the local circumstances is challenging. Still there are varieties among the nursing care in different transplant settings (Bevans et al. 2009). Therefore, networks of nurses in the field in which nurses discuss patient-centred outcomes are vital – not only to prevent the reinvention of the wheel but mainly to establish high-quality standards and data that are comparable in research. Nurses collaborate in local, national and international networks such as the EBMT Nurses Group, the American Society for Blood and Marrow Transplantation (ASBMT), the Special Interest Group of the American Oncology Nursing Society or the Haematology Nurses and Healthcare Allied Professionals Group (HNNHCP). Also nurses reach out to cancer nursing organizations such as the European Oncology Nursing Society (EONS) because issues of haematological patients are not always specific to the stem cell transplant patient population but knowledge from the care for patients with other malignant diseases can be useful in the care.

The shift of the focus towards more educational tasks – especially since the emergence of oral drugs developed to cure haematological malignancies without the necessity of a stem cell transplantation such as tyrosine kinase inhibitors – changed the work of nurses tremendously. Unexpectedly – despite the anticipation that patients with cancer will always take their medication as prescribed by their physician – nurses needed to develop skills and knowledge of adherence. By collaborating together with the industry and patients, educational initiatives were developed to support patients in adhering to the prescribed regimen often over a very long disease and therefore symptom-free time.

- Importance of HSCT Nursing

The best compliment towards nursing was done by Prof. Edward Donnall Thomas (1920–2012), founding medical director of the Fred Hutchinson Cancer Research Center’s Transplant Program who shared the 1990 Noble Prize in Physiology or Medicine with Dr. Joseph E. Murray; he stated that nurses and nursing was his secret weapon without whom he could not have achieved his goals. This acknowledges that nurses play a vital role as part of the interprofessional team in caring for the transplant recipients and their families. The statement of Prof. Thomas should be the basis on which nurses should develop the skills, knowledge and expertise to enhance a reflected care and be alert for any changes in treatments which might influence care. Picking up changes and supporting the developments will become a challenge in the often complex healthcare environment. Nurses will need to understand the challenges and shape the future care for any person trusting in what the interprofessional team has to offer – and maybe unravel the “secrets” of nursing and make it more visible of what nursing has to offer.

## Literature

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