



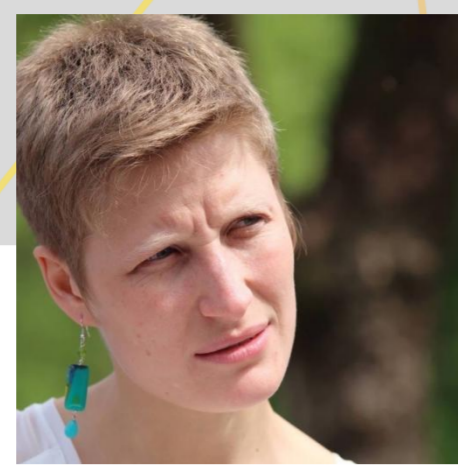
European Society for Blood and Marrow Transplantation

# Nurse –led research activities

An update from the EBMT NG Research Committee

Corien Eeltink<sup>1</sup>, Sarah Liptrott<sup>2</sup>, Marta Canesi<sup>3</sup> Jacqui Stringer<sup>4</sup>

1 – VU University Medical Center, Amsterdam 2 - European Institute of Oncology, Milan (IT),  
3 – Fondazione Mbbm ASST Monza (IT), 4 – The Christie NHS Trust, Manchester, UK



## INTRODUCTION

The Research Committee are clinical and research specialist nurses working to develop research projects, promote awareness of research activities, and facilitate / support active participation in research by EBMT Nurses Group members. In 2013, the group developed and presented the 'Research Proposal Form' as a way to formally encourage EBMT Nurses group members to submit their research ideas and proposals for support and development in collaboration with the Research Committee. Since this time, several projects have been started and some completed, widening the portfolio of nurse based research within the field of stem cell transplantation. Here is an update of the Research Committees activities.

## OUR HEADLINES

### Publications

Watch out for the paper "Healthcare professionals perspective on discussing sexual issues in adult patients after hematopoietic cell transplantation. A study by the Nurses Group and the Complications and Quality of Life Working Party of the European Society for Bone and Marrow Transplantation" which recently been submitted for publication.

### Planned studies in collaboration with various EBMT NG members and Working Parties

- The impact of nursing standards of care and skill-mix of staff in JACIE centres, focusing on patient safety
- Quality of life issues associated with cutaneous GvHD
- The experience of isolation during SCT
- Safe transfer of paediatric patients from the SCT Unit to the Intensive Care Unit
- ATG practice and guideline adherence

### Working Parties Nurse Members

WP's will have a nurse member who will work with the support of the Research committee to facilitate collaborative, nurse-led research relevant to each WP.

### Welcome to Marta - A New Research Committee Member

Marta Canesi is a nurse working in Paediatric Haematology/Paediatric BMT Unit, in Italy and joined the RC in 2015. She is currently involved in research about quality of life in patients living with cGVHD after transplant, skin care during aGVHD, palliative care and quality of life in paediatric patients. Marta is also interested in outreach nursing and programs to implement nursing standards and nursing care in developing countries.

## MULTICENTRE SURVEY REGARDING NUTRITIONAL SUPPORT (NS) IN EBMT TRANSPLANT

**Background:** This proposal came from the Italian National BNT Nurses Group (GITMO), made following their national survey looking at the use of nutritional guidelines, patient screening and assessment practices, and interventions. Findings suggested poor compliance with guidelines and recommendations, variability in nutritional care, a multidisciplinary approach and poor involvement of patients & carers in NS choices. In the light of these result, the group proposed an evaluation of issues surrounding nutritional support in HCT patients in a wider European setting.

**Methods:** An online survey was developed (in collaboration with the EBMT Complications and Quality of Life Working Party), looking at NS in transplant patients. The survey sent to EBMT members (nurses & doctors), focused on dietary practices during SCT, screening & formal assessment for malnutrition, nutritional care planning, monitoring, information & education, methods of providing NS, follow-up and GvHD.

**Results:** For the nurse respondents: 108 transplant programs were represented (64% were adult only). Responses came from Italy (54%), UK (21%) response rates with 14 other countries making up 25%. Whilst nurses felt NS was important, there was a discrepancy in knowing which were the best types of NS for which indications. Over 60% had SOP's in relation to nutritional status screening, but just 45% said they screened patients. During transplant however, >60% formally assessed patients – this was performed by the nutrition team, the nutrition specialist or haematology healthcare professionals equally. Over 60% had SOP's in relation to nutritional support interventions, and decisions were often taken with patients (86%), and with an MDT approach (70%), as many centres reported availability of nutritionists or dieticians etc they could refer to. Over 60% had SOP's in relation to monitoring nutritional status, with similar numbers documenting this in the patient's notes. Nutrition was a part of the pre-transplant discussion for 75% of respondents, with 69% providing both written and verbal information about support. Regarding NS methods, oral supplements were most commonly used as a first line approach followed by parenteral nutrition, with only 35% of centres having access to tube feeding. Only 26% of centres reported nutritional follow up for all patients independent of whether patients had experienced nutritional problems (59%).

**Conclusion:** conclusions to the descriptive data are difficult and may be influenced by results from some countries – both in terms of the number of responses and educational initiatives raising awareness of NS. Initial findings indicate heterogeneity of approaches to NS. These descriptive results were presented at the EBMT 2016 meeting, and are currently being subject to a more in-depth statistical analysis.

## SEXUAL FUNCTIONING IN RECIPIENTS 3 and 15 YEARS AFTER ALLOGENEIC STEM CELL TRANSPLANTATION (SCT)

**Background:** Through the increasing information available in the literature relating to sexual function after cancer, we are aware of the negative impact that cancer and it's treatments can have on sexual functioning (5, 6, 7). Over 30,000 SCT's are performed every year, and as a result there are increasing numbers of patients becoming long-term survivors, amongst which sexual dysfunction has been recognized as a complication impacting on quality of life (7,9,10,11,12).

**Aims:** this study aims to validate and expand on existing published work looking at recovery of patients post transplant with regards to sexual functioning of patients. It will also provide preliminary European wide data on the impact of issues around sexuality for the partners of transplant recipients.

**Methods:** This is a cross-sectional multicentre study among European centres using self-report questionnaires for data collection. The work is a collaborative study between the Complications and Quality of Life Working party and the Nurses Group of the EBMT. All completed questionnaires will be anonymous. Demographic data will be collected and used to correlate with sexual function to explore risk factors for sexual dysfunction. The data will be subject to appropriate statistical analysis.

**The story so far:** 17 centres have opened for recruitment including centres from Belgium, France, Germany, Italy, the Netherlands, Saudi Arabia, Scotland, and the UK. 31 patients and in most cases their partner– CORIEN TO FEEDBACK) have been enrolled. The survey is ongoing. If your centre would like to participate, **please contact us**. There is a fee of €50 for every patient included, up to the number required for the study.

## HSCT NURSE CO-ORDINATORS (HSCT- NC's) PERCEPTIONS OF RELATED DONOR CARE: A EUROPEAN SURVEY

**Background:** This survey was proposed by the French National Nurses Group. Related-donation has been addressed by different authors, who underline: differences in medical management between unrelated and related donors; specific ethical issues (the freedom to give- or not – in an anonymous way) and clinical issues (the impact of poor receivers' outcomes on donors psychological well-being). Both recipients and donors of stem cells are often cared for by the same clinical team, leading to a potential conflict of interest within teams when attempting to ensure confidentiality and protecting the volunteer status of the donor. It was felt that understanding the perceptions and experiences of Nurse Co-ordinators having a key role in the care pathway, would be an important basis for developing further research.

**Methods:** A questionnaire was sent by email to SCT Nurse Co-ordinators registered with the EBMT Nurses Group, and working in adult HSCT Units. The questionnaire collected demographic data of the respondent, donor pathway organisation, and nurses perceptions of donor care. It was available in Dutch, English, French, German, Italian, Portuguese, and Spanish).

**Results:** 101 responses from 20 countries were received. Approximately one third of respondents confirmed that teams were caring for both donors and recipients. With regards to the donor care pathway, haematologists (55%) were the first to approach with recipients the question of related donation, whilst HSCT-NCs were the ones to contact donors (48%). Dedicated interviews with compatible donors were performed either by the transplant physician (31%) or the HSCT-NC (28%), and less often the haematologist (16%). Whilst 76% of HSCT-NCs consider that related donor's needs were addressed, in their opinion the choice to donate (29%), information (33%), financial assistance (45%), psychosocial support (45%) and follow-up (36%) should be improved. Perceptions of conflict of interest had occurred for 30% of HSCT-NCs within the last year, and 47% of respondents thought that the only way to protect related donors' freedom of choice to donate, was to organise their care within a fully independent unit. **The full results will be presented on Monday 27th March at the Abstract finalist's session (NG14) from 16:30-18:00.**

**Conclusion:** The survey showed that related donor care organisation is not standardized and it was felt that many aspects required improvement, in particular ethical aspects. Conflict of interest and the 'choice' of donation by the related donor are main issues to be considered.

## CONCLUSION

The remit of the EBMT NG Research Committee is to lead on nursing research, which reflects the needs of its members in order to facilitate a good basis for evidence based practice within EBMT centres. Efforts are being made to promote greater collaboration with our EBMT Nurses Group members, and other EBMT working parties.

## CONTACTS

For further information please contact the EBMT NG Research Committee  
Chair: Dr Jacqui Stringer - [jacqui.stringer@christie.nhs.uk](mailto:jacqui.stringer@christie.nhs.uk)