



Moving forward with nurse-led research

An update of the EBMT NG Research Committee Activities

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INTRODUCTION

Specialised nursing care is required to support patients and their carers throughout the transplant trajectory, and includes support from the initial discussion of the transplant procedure itself, conditioning, reinfusion of cells, management during engraftment, follow up after discharge and long term survival. This specialised nursing requires active involvement to promote quality in care provision, and evidence based practice – which unifies best research evidence with clinical expertise (Sackett et al 2000). The lengthy hospital stay and subsequent frequent visits to the hospital following discharge means that nurses are in a key position to observe and critically analyse their practice in relation to HSCT nursing care, and as such be aware of areas of practice where current practice and perceived research evidence are incongruent. The purpose of the EBMT Nurses Group is to promote and develop haematopoietic stem cell transplant (HSCT) nursing in countries throughout Europe, and within this the Research Committee is committed to the development of research activities for nurses and allied healthcare professionals.

An online survey of EBMT Nurses Group Members in 2013 to determine research priorities highlighted a variety of interests. The top 5 research priorities were: post SCT care, symptom management, patient information issues, clinical guidelines and patient & family education.

The EBMT NG Research Committee have encouraged nurse members to bring their research ideas to EBMT and get involved with research activities, and through international collaboration, several projects in these key areas are now being undertaken, see examples below.



RESULTS

CAREGIVERS PERSPECTIVE ON DISCUSSING SEXUAL ISSUES (SI) AFTER STEM CELL TRANSPLANTATION

Background: Although 40-80% of patients experience sexual problems 5-years post stem cell transplantation, health care professionals do not often routinely discuss SI. Therefore (in collaboration with the EBMT Complications and Quality of Life Working Party), we determined the frequency of, perceived barriers and facilitators to, discussing SI with patients.

Methods: Between March 2014 and July 2014, an online survey was sent to all 3127 members (physicians, principal investigators, nurses, and principal nurses of the 193 centres of the EBMT, with the request to disseminate the questionnaire among staff caring for HSCT patients.

Results: The study population consisted of 166 RNs and 126 MDs. In total, 67.5% of the RNs and MDs reported that they never or occasionally discussed SI being related to younger age (MDs; $p=0.001$).

Conclusions: The great majority of RN and MD did not routinely discuss SI but waited for the patient to initiate the topic. The major barrier to discussions for RNs and MDs was the presence of a third party. Manuscript currently under development.

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 results, 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: The survey has now closed and data is being analysed. At the initial findings will be presented during the EBMT Annual Meeting 2016 in Valencia.

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

Background: Every year in Europe, over 30,000 SCTs are performed, including over 13,000 allogeneic SCTs. Consequently there are thousands of new, long-term survivors every year who will face chronic health issues. It is important to increase understanding of all late effects; sexual dysfunction being one recognised to cause significant morbidity. To provide appropriate support it is necessary to fully appreciate the problem and have both quantitative and qualitative data to provide a baseline for any future interventional studies.

Methods: An online survey was developed (in collaboration with the EBMT Complications and Quality of Life Working Party), aiming to explore patients' and their partners' opinions on their sexual functioning 3 and 15 years post allogeneic HSCT. In addition, we are looking at whether discussion, adequate help or counseling with regard to sexual function between the health care provider and the survivor is perceived to have taken place.

Results: 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 COORDINATOR NURSES' (CN's) PERCEPTIONS ON RELATED-DONORS' CARE

Background: This proposal came from 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 (the freedom to give- or not – in an anonymous way) and clinical (the impact of poor receivers' outcomes on donors psychological well-being) issues. HSCT teams have to face the problem of conflict of interest when involved in both receivers and donors' care. Data in this field is scarce and related-donation issues will probably become more significant with the development of haplo-identical transplantation. CN's have a main role in all aspects of donor care, knowing their perceptions can pave the way for future research and recommendations for clinical practice.

Methods: An online survey is under development to provide quantitative and qualitative data exploring the organisation of related-donor care and professionals' perceptions of its specific issues in different centres. The survey is written in English but will have copies in different languages for reference. The only inclusion criteria is to have to role of HSCT CN.

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. Where appropriate we collaborate with other EBMT working parties, encourage and support our members to develop and lead on their own research proposals and develop protocols within the committee. The four studies highlighted here reflect this practice and show the 'Rolling Ball' nature of our programme of work.

REFERENCES

Sackett D, Straus S et al. *Evidence-Based Medicine: How to Practice and Teach EBM*, 2nd edition, 2000. Churchill Livingstone, Edinburgh.

CONTACT

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