



# The 46<sup>th</sup> Annual Meeting of the European Society for Blood and Marrow Transplantation: Psychiatry and Psychology Group Poster Session (P707-P710)

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## Psychology Poster

P707.

### How Patients' Views are Helping Shape Plans for a New Transplant Psychology Service

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**Background:** The psychological consequences and issues associated with having an allogeneic Haematopoietic Stem Cell Transplant (HSCT) are significant, potentially chronic and less well documented than the physical ones. FACT-JACIE International Standards (7th edition) makes recommendations regarding the inclusion of psychology services staff within transplant centres. Learning from people with lived experience is vital to both increasing our understanding and to developing specialist services to help address patients' psychological needs.

**Methods:** An engagement event was held at St Bartholomew's Hospital to elicit patients' views and ensure they shaped plans for a new Anthony Nolan transplant psychologist post. Twenty five allogeneic HSCT patients (mean time since transplant: 4 years) and 3 family members attended after responding to invitations circulated via post-transplant clinics. Qualitative data from focus group discussions and quantitative data from a dot-voting exercise

and self-report questionnaires was collected. Descriptive statistics and qualitative analysis for service development purposes was used.

**Results:** When asked when they would like to have had additional support and information (before/during/after transplant) most patients voted for the post-transplant stage of the pathway. These quotes highlight some of the reasons for this:

*Would have liked more support after the regular day clinic visits stop. You suddenly feel cast adrift and alone. It took me a long time to realise after the transplant that I needed to take active steps to rebuild myself mentally as well as physically.*

*More support from an emotional point of view with confidence to get back to work, and other personal issues as a result of side effects (being intimate for example)*

Second highest ranked was before transplant with some patients specifying that, for instance, further information during this stage would have been helpful preparation:

*Clear information about how the transplant and treatment will physically and emotionally impact a person*

Exploration of what type of support could be offered to help people with the emotional challenges of having a transplant led to key themes emerging:

- Support with mental/emotional health
- Information and resources
- Issues e.g. managing fatigue, dealing with uncertainty
- Work
- Peer support
- Support for family members, as well as patients

It is important to note that comments were made by several patients suggesting that they did not think that any additional support or information was needed.

**Conclusions:** These findings are guiding the development of a new transplant psychology service with pilot initiatives and ongoing evaluation planned. Some of the support needs expressed by patients can be delivered at Level 2 (NICE Guidance Four-level model of professional psychological assessment and intervention) and therefore close liaison between the transplant centre's psychologist and Clinical Nurse Specialists is important. When appropriate, patients can also be signposted to information and resources provided by charities. Limitations include patients attending the engagement event being a self-selected group and retrospective bias influencing their views. Service development is also being shaped by staff views, through a process of consulting with multi-disciplinary team members, as well as by relevant research and guidelines e.g. Anthony Nolan Post-Transplant Care Pathway.

**Disclosure:** Nothing to declare.

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### Changes in Health-Related Quality of Life in Patients following Hematopoietic Stem Cell Transplantation: Two Different Analytical Approaches

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**Background:** Although hematopoietic stem cell transplantation (HSCT) leads to the improved long-term survival of patients treated by this method, the procedure has an impact on the well-being of patients and their overall short- and long-term health-related quality of life (HRQoL). Prior studies have studied the HRQoL changes after HSCT, however, the majority of them were based on statistical average results for an entire group of patients. Meanwhile, it is unlikely that all post-HSCT patients experience changes in HRQoL in the same manner. Therefore, the study aimed to assess the changes in HRQoL after HSCT using two different statistical approaches and compare the results. Based on average scores, we analyzed the changes in mean scores in all HRQoL domains/scales. For comparison, based on patient individual scores, we identified the subgroups of patients that remain stable, improved or deteriorated in HRQoL domains/scales.

**Methods:** HRQoL were assessed using EORTC QLQ-C30 in 297 patients (mean age = 47.43±13.77 yrs; 43%

females, 57% males; mean time since diagnosis = 21.59 ±25.86 months) a few days after admission to the first autologous (67%) or allogeneic (33%) HSCT, and six months (*N* = 169) and 12 months later (*N* = 145).

**Results:** Based on statistical average scores, significant statistical and clinical (i.e. ≥ 10 points) increase in somatic problems 12 months following HSCT were noted, although only in patients following allogeneic HSCT. There were no statistical changes in global health status and level of functioning (e.g. emotional, role, cognitive, and social) in patients over time. Based on patient individual scores, a large proportion of patients had stable HRQoL (45.2% in global health status, 52.4.6% in somatic problems, and 55.4% in functioning level), however, other patients improved (22% in global health status, 26.8% in functioning level, and 28.6% in somatic problems) or deteriorated (17.9% in functioning level, 19% in somatic problems, and 32.7% in global health status) over one year following HSCT. Allogeneic HSCT was associated with an increased likelihood of belonging to the 'deteriorated group' (as compared to 'improved group') but only concerning somatic problems.

**Conclusions:** Sample of post-HSCT patients appeared to be heterogeneous regarding HRQoL aspects and their course in time. However, only about 25% of patients reported improvement in HRQoL over one year following HSCT. In others, the HRQoL was the same as before HSCT or even deteriorated during this time. An increase in somatic problems was characteristic of patients following allogeneic HSCT. The predictors of patterns of changes in other HRQoL domains require further research.

**Clinical Trial Registry:** not applicable.

**Disclosure:** Nothing to declare.

**P709.**

### 1000 in 10. 10 Years of Clinical Psychology Practice with 1000 Patients in the Same Bmt Unit in Marseille, France

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**Background:** Many international scientific articles discuss and analyze the short and long term psychological impact of HSCT. But most of these studies are based on questionnaires or research interviews with researchers outside the institution and without caring involvement.

This communication aims to report 10 years of psychological interviews (2009 to 2019) with 1000 patients from

the same BMT Unit. To our knowledge, this kind of work has never been proposed to date.

**Methods:** 1000 patients have been recruited and followed for 10 years (2009 to 2019) in the same BMT unit by the same clinical psychologist. Patients and his relatives take systematically part in a psychological interview during the pre-HSCT assessment. Each patient is personally met during his hospitalization for HSCT through in-depth interviews, then when he leaves the BMT Unit and on D100.

**Results:** These 10 years of psychological practice confirm many works in this field but also reveal some original elements of care such as the importance of pre-habilitation (not only pre-transplant exercise but also pre-transplant psychological meeting), the systematic proposal of complementary care such as osteopathy or sophrology. They also show that distress and depression are part of the normal BMT process and have not to be systematically treated with psychotropic drugs. They also taught us that among BMT patients, positive psychological constructs are not systematically associated with improved HRQoL and other health outcomes as previously believed.

**Conclusions:** This clinical psychological work over 10 years should encourage us to develop new and original interventions to promote well-being that are adapted to the needs of BMT patients.

**Disclosure:** nothing to declare.

#### Clinical Abstract

**Keywords:** 1. BMT and HSCT 2. Psychological impact 3. quality of life 4. complementary care

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### Implementation of Psychological Support and Development of Educational Program for Children and Adolescents Undergoing Hsct and their Parents in Russia.

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**Background:** HSCT is one of the most stress-inducing type of treatment both as for patients, their families and as for medical staff at pediatric oncology/hematology. Our previous study allowed to specify the adjustment's complexity of children/adolescents and their families before and during

the HSCT in Russia (Khain A., Kholmogorova A., 2017). This abstract presents an implementation experience of specific program developed for educational and psychological adjustment of children and families to the HSCT in accordance with prior investigated age-related, family-specific aspects. The aims of this program include also the simplification pre-treatment processes for medical staff.

**Methods:** On the basis of analysis of the informational needs, high distress level, adjustment and compliance severities of children and their families during the HSCT the specific integrated program for advanced preparation and psychological support was developed. It proceeded at Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology (Russia) and consisted the following frame. Before the doctor-patient/family HSCT consultation, doctors were familiarized with the results of survey describing the attitudes, worries and questions related to HSCT filled out by families (and patients). The specific inventory and motivation interview were designed to help doctors to discuss these results with patients and families during the appointment. The process of HSCT pre-treatment was supplemented by psychological consultation for children and families. The photo-tour story presenting the HSCT department and steps of the treatment process (where the interdisciplinary medical team explained the HSCT process for children, families and donors) was also created for educational support. The Teddy-bear was a hero of this photo-tour story as a patient. Additionally, the video interview with children overpassed the HSCT and sharing their experience and advises related to coping with different complexity was used.

**Results:** Special survey filled out by families before the doctor consultation allowed to estimate the level of patients and family's knowledgeability, informational needs and preferences, their expectations and level of psychological readiness to HSCT.

Applying the interview by doctors optimized informing process about the treatment.

Inclusion of the psychological consultation to the pre-treatment interview allowed to evaluate children's and families' distress level, to take into the account individual maladjustment factors, children's and families' recourses (previous experience, expectations to HSCT, distress levels and families structure). Photo-tour and video usage facilitated the adaptation to the HSCT complexity, enriched children and families with coping template patterns and provided psychological support.

**Conclusions:** The developed program facilitated and optimized the educational, pre-treatment and treatment adaptation, compliance of children and families, patient/family-medical staff cooperation during the HSCT. It helps also to develop individual program of psychosocial support

during HSCT and propose recommendation for the following treatment periods. A comparison of the obtained data allowed to identify the effective approach to the further development of psychological service to the families.

**Disclosure:** Nothing to declare.

**Clinical Abstract**

**Keywords:** 1. support program 2. educational program 3. children and family 4. HSCT 5. Russia