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ABSTRACTS COLLECTION

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Patient Advocacy Poster Session

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SOCIAL FUNCTIONING AFTER TRANSPLANTATION AND CELLULAR THERAPY: INITIAL PATIENT-REPORTED OUTCOMES RESULTS FROM THE CIBMTR

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Background: The Center for International Blood and Marrow Transplant Research (CIBMTR) built a patient-reported outcomes (PRO) data collection system to directly engage patients and enhance its research. In this first analysis of CIBMTR PRO data, we describe patient-reported social functioning in the first year after hematopoietic cell transplant/cellular therapy (HCT/CT). Social functioning includes social role participation, recreation, leisure and community, and interpersonal communication. Previous studies of show variation in experiences among HCT patients, with some showing declines in ability to engage in social activities while others report interpersonal growth with caregivers. These studies are limited in sample size and small site studies. Little is known of social functioning among CT patients.

Methods: Data are patient-reported through the CIBMTR's electronic PRO (ePRO) system, under a centralized protocol with all enrollment and data collection activities performed by CIBMTR. Social functioning was measured using the Patient Reported Outcomes Measurement Information System (PROMIS) Ability to Participate in Social Roles and Activities computer adaptive test, for which a score of 50 (SD of 10) corresponds to the US general population average and higher scores represent better functioning. We used counts and percentages to describe the transplant, clinical, and patient characteristics of those enrolled in the PRO data collection by type of CT. Means and standard deviations were used to describe social functioning by patient characteristics and timepoint. Kruskal Wallis statistics were used to test for differences in scores by patient characteristics at baseline and 1 year.

Results: Of the 440 patients enrolled in PRO data collection from 17 US centers from 08/2020-10/2022, 39% ($n = 172$) received allogeneic HCT, 58% ($n = 257$) received autologous HCT, and 2.5% ($n = 11$) received CT. Average age at time of treatment was 62; 61% were male. The majority of alloHCT and autoHCT patients had Karnofsky scores 90% or higher (60% and 55%, respectively), while the opposite was true for CT (64% < 90%). In general, average social functioning scores increased over time. Older patients (65+) began with lower social functioning at baseline compared to younger counterparts. The youngest patients (18–39) reported higher average functioning at 1 year compared to older patients. Social function trends were similar for men and women. Participants with lower Karnofsky scores had about ½ standard deviation lower social function scores at baseline compared to those with higher Karnofsky scores ($p < 0.01$), a significant difference that persisted at 1 year.

Conclusions: Social functioning scores among patients receiving HCT and CT increased in the first year after treatment, with scores that were comparable to the US general population. Integration of PROs into the CIBMTR research database provides novel information about the HCT/CT experience to complement clinical outcomes.

Disclosure: Nothing to declare.

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THE PREDICTIVE VALUE OF PATIENT-REPORTED OUTCOMES IN ALLOGENEIC HEMATOPOIETIC STEM CELL TRANSPLANTATION: EXPLORATORY SECONDARY ANALYSIS OF A RANDOMIZED NUTRITION INTERVENTION TRIAL

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Background: Patients undergoing allogeneic hematopoietic stem cell transplantation (allo-HSCT) have a high risk of transplant-related complications. To predict mortality and transplant-related side effects, patients are evaluated according to standard clinical prognostic scoring systems prior to allo-HSCT, such as the Hematopoietic Cell Transplantation Comorbidity Index (HCT-CI) and the European Bone Marrow Transplantation (EBMT) risk score. However, these scoring systems do not include patient-reported outcomes (PROs). Notably, PRO- data provides important information and research evidence suggests that they may have more prognostic overall survival accuracy when combined with clinical data. To clarify if PROs can predict overall survival (OS) and non-relapse mortality (NRM) in allo-HSCT, we performed a secondary analysis of of PROs among recipients of allo-HSCT who participated in a randomized controlled, nutrition intervention trial (RCT).

Methods: The aims of the original RCT were to examine the effect of optimized energy and protein intake compared to routine nutrition support on global quality of life (QoL) and clinical outcomes three months after allo-HSCT. We found no significant differences between the intervention and the control groups on any of the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire (QLQ-C30) scales or items.

One hundred and seventeen patients ≥18 years (intervention $n = 57$, control $n = 60$) were included in the RCT conducted at the Oslo University Hospital from August 2010 to February 2017. QLQ-C30) was used to assess QoL at baseline (i.e. on day -8 or -7 before allo-HSCT). Clinical and transplant–related data were registered daily during hospitalization and later retrieved from the medical records. This included diagnosis, progression of disease, conditioning regime, donor information, stem cell-source, and the HCT-CI and EBMT scores.

Cox proportional hazards models were used to investigate possible associations between the QLQ-C30 scores collected pre-allo-HSCT (baseline) and 1-year OS, whereas logistic regression was used to study associations between these PROs and 1-year NRM.

Results: Data from 119 patients was available for analyses. Two patients in the intervention group were excluded from further analysis, leaving 117 patients for the intention-to-treat analysis (intervention $n = 57$, control $n = 60$).

Most patients (74%) were categorized as low risk according to the HCT-CI score, and acute myeloid leukemia was the predominant diagnosis. Baseline characteristics were evenly distributed between the two study groups. Thirty-five (30%) patients died during the first year, 15 patients of these due to relapse. There was no significant difference in 1-year survival between the two study groups.

Multivariable analyses showed that only the HCT-CI and EBMT risk scores were significantly associated with 1-year OS. In the multivariable model including clinical-sociodemographic factors for 1-year NRM, living alone ($p = 0.009$), HCT-CI ($p = 0.016$), EBMT risk score ($p = 0.002$) and stem cell source ($p = 0.046$) were of predictive significance. Moreover, in the multivariable model, only appetite loss from the QLQ-C30 was significantly associated inversely with 1-year NRM ($p = 0.026$).

Conclusions: In conclusion, we found that HCT-CI and EBMT risk scores were predictive for both 1-year OS and 1-year NRM. Except for appetite loss, none of the studied PROs variables showed predictive values of mortality.

Clinical Trial Registry: The original RCT is registered in ClinicalTrials.gov, ID NCT01181076.

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Fabio Efficace: consultancy or advisory role for AbbVie, Janssen, and Novartis and received research funding (institutional) from AbbVie, Amgen and Novartis; outside the submitted work.

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NEWSPRINGFORME, THE FIRST FRENCH COMPREHENSIVE COMPANION SOLUTION TO IMPROVE TRANSPLANTED PATIENTS SUPPORT

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Background: Nearly 24,000 patients, adults and children, are transplanted yearly in Europe, the last resort to treat and potentially cure serious blood diseases. While this intervention is saving more and more lives, it can lead to early or late complications in 50% of patients, impacting their daily life and fatal in 25% of cases. Therefore, chances of a successful transplant for these patients correlate directly with the non-occurrence of these complications.

Recently, research in the fields of transplantation and psycho-neuro-immunology has highlighted the mutual influence of psychological and physical health on the chances of successful transplantation. Indeed, the simultaneous management of mind and body of the patient would ensure better preparation for the process to foster recovery after transplantation by limiting the occurrence of complications. The establishment of an overall well-being throughout the transplant process, based on three inseparable pillars - nutritional, physical and psychological - would contribute hopefully to very significantly increase the success of the transplant and the chances to come back to a normal life.

Currently, there is limited comprehensive support program in the transplantation field, based on clinical data and patient quality of life that can help them to overcome notably the period of hospitalization in a protected environment as well as that related to the return to a social and professional life as normal as possible.

Methods: To answer patients'needs in terms of health support and quality of life improvement, the HTC Project has developed, in collaboration with experts, NewSpringForMe, the first global digital solution. This tool intends to bring complementary information and intervention support for care.

NewSpringForMe innovation lies in the simultaneous management of transplanted patients in psychology, nutrition and adapted physical activity. Designed around interconnected spaces, NewSpringForMe deploys recommendations, interactive tools and exercises adapted to respond to 1) each patient and his specific situation, 2) the transplant protocol different steps.

Results: Following regulatory authorizations, a clinical study, in collaboration with the St Louis Hospital (AP-HP), has begun in September 2022 in order to measure the impact of NewSpringForMe use on the psychological, nutritional and physical parameters of almost 170 patients during one year starting from the transplant announcement. This study would also evaluate the impact on the post-transplant complications onset and overall recovery.

In 2 months, 10 patients have been already included in the protocol. Their connexions at the platform, according to a defined kinetics, are instantly recorded ; the generated data are collected and monitored in order to verify the achievement of the patient experience throughout the transplantation process.

Conclusions: The data collected during the clinical protocol will help evaluating NewSpringForMe as a global support tool. A positive impact should be expected on patients daily quality of life, on the appearance of the post-transplant complications. In case of success, NewSpringForMe could be proposed to all French transplant centers in order to lead a large-scale randomized study with the objective to include NewSpringForMe as a medical device for psychological, nutritional and physical support to the classical management of transplanted patients.

Disclosure: No disclosure.

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A CROSS-SECTIONAL STUDY EXAMINING POTENTIAL DEMOGRAPHIC BARRIERS TO RECEIVING INFORMATION ON CLINICAL TRIALS IN RELAPSED/REFRACTORY PATIENTS WHO HAVE RECEIVED STEM CELL TRANSPLANTS (SCT)

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Background: Stem Cell Transplant (SCT) and clinical trials involving new treatments provide increased opportunities to longer lasting remission in lymphoma patients with relapsed or refractory settings. However, not all patients are given information or the opportunity to access clinical trials. This study investigates the potential socioeconomic barriers to receiving information on clinical trials or the opportunity to participate in lymphoma patients who have received SCT.

Methods: Globally, 8637 respondents, comprising 7,113 patients and 1,524 caregivers from 84 countries, completed the 2022 Lymphoma Coalition (LC) Global Patient Survey (GPS). The study cohort reflected lymphoma patients with >1 relapse or refractory disease and received SCT. Cross tabulations across age, gender, ethnicity, education, residential area, and those classified as having a partner relative to those reported as single were analysed. Differences found in cross-tabulations were assessed using the likelihood ratio Chi-Square or Fisher's Exact test as appropriate.

Results: After exclusion criteria were applied, 137 respondents remained (Figure 1). Amongst the regions with the most significant response rates (APAC, Europe and North America), approximately 65–75% of respondents reported being provided information on a clinical trial. Interestingly, patients who had a partner were provided with more information on clinical trials and 38.9% ($p = 1.0$) participated in a clinical trial compared to those who classified themselves as being single ($p = 0.06$).

Variable	Levels	Received Clinical Trial Information	*P*-value
Age	18–34	11/17 (64.7%)	0.8
	35–45	22/35 (62.9%)	
	55–64	29/44 (65.9%)	
	>= 65	29/40 (72.5%)	
Gender*	Female	47/73 (66.0%)	0.5
	Male	45/64 (65.5%)	
Education Level	Primary or less	2/2 (100.0%)	0.9
	Secondary	33/52 (63.5%)	
	Post-Secondary	54/80 (67.5%)	
Household Status	With partner	72/101 (71.3%)	0.06
	Single	17/32 (53.1%)	
Ethnicity	Caucasian	62/90 (68.9%)	0.1
	Asian (East & South)	15/21 (71.4%)	
	Latin	4/4 (100%)	
	Others	8/18 (60.0%)	
Residential Area	Rural	21/33 (63.6%)	0.5
	Suburban	35/48 (73.0%)	
	Urban	33/52 (63.5%)	

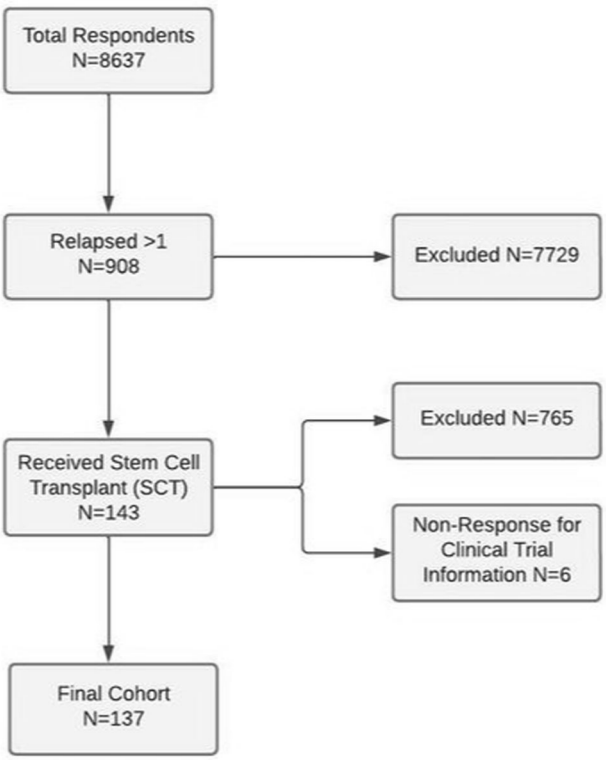

Fig. 1 Inclusion/Exclusion

Conclusions: Thirty percent of respondents with relapsed/refractory disease who have received SCT had never been provided information or presented an opportunity to participate in a clinical trial from their doctor. The data does not reflect a significant cause in the survey using our core demographics apart from a trend in household status. We suspect that those with a partner are, in part, advocating for more information or encouraged by their family members to seek additional options for increased quality of life and life extension. We are encouraged that we were unable to find significant differences amongst most of our core demographics. Interpretation of this data indicates that inequities in access to clinical trials are unlikely to be ascribed to common causes of discrimination based on patients described in this cohort. The implications of this study indicate that further efforts are needed to improve access to clinical trials for all patients, starting with improved communication between patients, caregivers and their doctors. Improved communication will yield a collaborative approach to shared decision-making, empowering patients with relapsed and refractory lymphoma.

Disclosure:

The study was sponsored by AbbVie, BMS, Pharmacyclics and Roche. None of the authors benefited personally from the research.

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PREQOL: A PILOT STUDY TO EVALUATE THE COLLECTION OF SOCIOECONOMIC AND QUALITY OF LIFE DATA FROM PATIENTS UNDERGOING ALLOGENEIC HAEMATOPOIETIC CELL TRANSPLANTATION IN THE UK

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Background: There is growing recognition that inequities in patient outcome and quality of life following haematopoietic cell transplant (HCT) may be due to social and demographic factors. To improve understanding about the impact of social determinants of health on patient outcomes, routine collection of patient demographic status (including age, gender, race, ethnicity, socioeconomic status) and patient-reported outcomes is required. These data will inform strategies to reduce inequity.

The purpose of this project (PrEQoL) is to pilot the collection of demographic (namely ethnicity and socioeconomic status, SES) and Quality of Life (QoL) data among allogeneic HCT recipients using a digital web-based tool hosted by Anthony Nolan.

Methods: Sixty adult (>18 years) allogeneic HCT patients will be invited to complete a brief demographic and QoL questionnaire at four timepoints: before transplant conditioning, on the day of their transplant, 28 days post-transplant and 100 days post-transplant. Participants will be asked to report their age, sex, marital status, living arrangements, and ethnicity. Data on individual socio-economic position. Housing tenure, income, education and occupational status will also be collected using items adapted from the UK Office of National Statistics (ONS) census. Individual postcode data will be collected to obtain the Index of Multiple Deprivation (IMD) score, a relative deprivation score based on residential location. It ranks every small area according to income, employment, health, education, housing, access and child poverty. Higher scores of IMD indicate higher SES. Subjective socioeconomic status data will be collected using the MacArthur Ladder, a two-item questionnaire which asks participants to rank their standing within a) UK Society and b) their own community. Quality of Life (QoL) data will be gathered using the PROMIS-29 a 29-item questionnaire consisting of 7 domains; anxiety, depression, fatigue, pain, physical function, sleep disturbance, satisfaction with participation in social roles.

Results: Data from PrEQoL will provide insight on the feasibility of undertaking prospective demographic and QoL data collection among allogeneic HCT patients. The primary outcome of PrEQoL is percentage uptake (recruitment rate) at baseline and percentage drop-out (participant retention) at each data collection interval (Day 0, Day 28, and Day 100). Secondary outcomes include completion rates of outcome measures, patterns of missing data, and participant experience and satisfaction with participation within the study (collected via feedback forms).

Conclusions: The PrEQoL study will inform a subsequent study tilted SEQoL 'Scaled collection of socioEconomic and Quality of Life data from patients undergoing allogeneic haematopoietic cell transplantation in the UK' which will aim to recruit 1077 patients over an 18 month period. We anticipate the findings from PrEQoL and SEQoL will influence planning and provision of future HCT services. Specifically, these studies will inform targeted service improvements to address inequity at both the individual patient level and the system level across NHS transplant services. The findings from this research will be particularly relevant to NHS commissioning and providers of transplant services.

Disclosure: Nothing to declare.