

Social Determinants Working Group

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Working Group Approach

- Are there new approaches to account for social determinants of health beyond those currently assessed in risk adjustment model?
- Outline:
 - Review deliberations on this topic from 2014 Center Outcomes Forum
 - Review currently available socio-demographic data from CIBMTR
 - Review work done by CIBMTR to account for socio-demographic variables
 - Review working group discussion
 - Review working group recommendations
 - Open discussion

Socio-demographic Factors Currently Considered In Center Survival Analysis

- Data collected on all US HCT recipients
 - Recipient ethnicity/race (self-reported)
 - Socioeconomic status (median annual household income based on ZIP code of residence)
 - Included as variable starting with 2018 analysis
 - Categorized as deciles (<10th percentile [\$37K] to ≥90th percentile [>\$100K])
 - Well captured overall (2019 analysis: unknown in 2% patients)

2014 Center-Specific Outcomes Forum

- Recommendations around socio-demographic/SES factors
 - Number of factors were discussed (income, education level, insurance status, social support, occupation, employment status, literacy, etc.)
 - Reviewed value of variable vs. difficulty to implement
 - Data fields identified as important and most feasible to consider collecting on all US HCT recipients for inclusion in future risk adjustment models:
 - Insurance status (Medicaid, Medicare, commercial, self-pay, un-insured)
 - Zip Code
 - Race/ethnicity (already collected and included)
 - Level of education
 - Marital status

Recent CIBMTR Studies: Community Health Status and Outcomes After Allogeneic HCT

- Used community health status based on County Health Rankings and Roadmap (collaboration b/w Univ of WI Population Health Institute and RWJC www.countyhealthrankings.org)
 - Annually updated information on county level health factors and outcomes that can serve as surrogate measures of disparities among communities
 - “Health Factors” summary score: weighted composite of four components: health behaviors, clinical care, social and economic environment, and physical environment
 - Macro (county) level indicator of community health status

Recent CIBMTR Studies: Community Health Status and Outcomes After Allogeneic HCT (Cont.)

- 18,544 adult allo HCT recipients at 170 US centers (2014-2016)
- Community risk score assigned to each patient (PCS) and center (CCS)
 - Higher PCS score associated with inferior survival (HR per 1 SD increase: 1.04 [1.00-1.08], P=0.0089)
 - In subset of patients with hematologic malignancies, PCS trended towards inferior survival (1.04 [1.00-1.08], P=0.012) and higher NRM (1.08 [1.02-1.15], P=0.0004)
 - CCS not significantly associated with survival, relapse, or NRM

Recent Studies: Marital Status and Outcomes After Autologous and Allogeneic HCT

- Adult (>40 years) autologous (N=5,714) and allogeneic (N=10,226) HCT recipients (2008-2015)
 - No difference in survival by marital status for autologous and for allogeneic recipients (married vs. single vs. separated/divorced vs. widowed)
 - Compared to married patients, divorced/separated patients had higher risk of grade 2-4 acute GVHD, but not for chronic GVHD
 - No interaction between marital status and recipient sex

Working Group Discussion: Framework

- Considerations regarding inclusion of additional socio-demographic variables in risk adjustment model
 - Parsimony: balance center effort vs. benefit of collecting data
 - Overlap: among variables and their independent contribution to survival
 - Feasibility: of collecting data (completeness, reliability, etc.)
 - Validation: evaluate how much candidate variable enhances model before collecting universally on TED forms
 - Impact: variables that may inform interventions to improve outcomes
- Access to HCT – identified as important issue but beyond scope of this working group

Can Any Variables From CRF Be Moved To TED
To Better Inform Patient Socio-demographic
Characteristics For Center Survival Analysis?

Socio-demographic Variables Collected on CRF

- Evaluate if any high-quality CRF variables are independently associated with center survival and need to be captured on TED
 - Evaluate completeness of data
 - Evaluate contribution of these variables to risk adjustment model (beyond race/ethnicity and ZIP code defined SES)
 - Priority of variables to test: health insurance >>> others
 - Add categories and/or allow variables to capture pediatric specific data (i.e., information on parent/guardian occupation, education, and work status)

Socio-demographic Data Collected By CIBMTR

- TED Forms

- Ethnicity/race
- ZIP code of residence

Already considered in
Center Specific Analysis

Evaluate completeness of
variables and their
contribution to center
survival model

- Comprehensive Report Forms

- Ethnicity/race
- ZIP code of residence

- Marital status
- Occupation
- Work status
- Highest education
- Health insurance
- Gross household income (six categories)

Are There Patient Socio-demographic Variables That Need To be Added To CRF For Future Evaluation In Center Survival Analysis?

Future State: Variables Considered

- Variables to explore in context of socio-demographic status
 - Distance to transplant center (interaction with urban/rural status and SES)
 - Caregiver support
 - Health literacy
 - Poverty (PRO: Food Insecurity Screen)
 - Need for interpreter
 - Use of NMDP grants (e.g., donor search, patient financial assistance)
- Data on some variables already available (distance by ZIP Code of residence) or may be relatively easily derived (NMDP grant use)
- Consider Working Group framework when adding new variables

Future State: Patient Reported Data

- Socio-demographic data are best captured directly from patients
 - Explore possibility of using CIBMTR PRO platform to capture current and new variables that may inform risk adjustment model in the future
 - Explore possibility of capturing data on CIBMTR consent form/process (e.g., add key questions on consent form for patients to complete)
 - Pros: will increase data completeness (given high compliance of consent completion) and reliability (given patient self-report)
 - Cons: consent/survey burden for patients, varying center workflows for consenting patients

Working Group Recommendations: Summary

- Evaluate if any high-quality CRF socio-demographic variables are independently associated with center survival and need to be captured on TED
- No recommendation to add new variables to CRF → prioritize feasibility and contribution of existing socio-demographic variables in refining risk adjustment model
- Consider pilot studies evaluating feasibility of capturing socio-demographic information directly from patients

Questions and Discussion