

Investigating racial disparities in quality of life years after pediatric hematopoietic stem cell transplant

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Abstract

Background While racial disparities in the clinical outcomes of hematopoietic stem cell transplant (HSCT) patients have been explored, racial disparities in quality of life (QoL) during the readjustment phase after transplant has yet to be investigated in pediatric patients. The objective of this study was to examine the role of patient race in QoL at least two years after pediatric HSCT. **Procedure** We conducted a retrospective chart review of patients under 21 years of age at diagnosis that received an allogeneic transplant at our institution between January 2007 and December 2017. Patient QoL was assessed using the PedsQL TM 4.0 at least two years post-transplant. Patient demographic, treatment, and transplant outcome data were obtained for subsequent analysis, where patient race was categorized as either Black, White, Hispanic, or Native American. **Results** Data were collected on 86 pediatric patients who underwent HSCT. Forty patients (46.5%) were non-Hispanic White, 29 (33.7%) Hispanic, 10 (11.6%) Black, and 7 (8.1%) Native American. Where preliminary analyses indicated a difference in QoL by patient race, there were no significant differences in physical, emotional, social, and school functioning by patient race after adjusting for transplant characteristics (age at transplant, sex, diagnosis, donor type and conditioning regimen) and determinants of socioeconomic status (insurance type, estimated household income). **Conclusions** Pediatric patients had comparable QoL, regardless of race, at a median of three years after HSCT in our study cohort.

Title: Investigating racial disparities in quality of life years after pediatric hematopoietic stem cell transplant

Running title: Racial disparity and QoL post pediatric HSCT

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Abstract

Background

While racial disparities in the clinical outcomes of hematopoietic stem cell transplant (HSCT) patients have been explored, racial disparities in quality of life (QoL) during the readjustment phase after transplant has yet to be investigated in pediatric patients. The objective of this study was to examine the role of patient race in QoL at least two years after pediatric HSCT.

Procedure

We conducted a retrospective chart review of patients under 21 years of age at diagnosis that received an allogeneic transplant at our institution between January 2007 and December 2017. Patient QoL was assessed using the PedsQL TM 4.0 at least two years post-transplant. Patient demographic, treatment, and transplant outcome data were obtained for subsequent analysis, where patient race was categorized as either Black, White, Hispanic, or Native American.

Results

Data were collected on 86 pediatric patients who underwent HSCT. Forty patients (46.5%) were non-Hispanic White, 29 (33.7%) Hispanic, 10 (11.6%) Black, and 7 (8.1%) Native American. Where preliminary analyses indicated a difference in QoL by patient race, there were no significant differences in physical, emotional, social, and school functioning by patient race after adjusting for transplant characteristics (age at transplant, sex, diagnosis, donor type and conditioning regimen) and determinants of socioeconomic status (insurance type, estimated household income).

Conclusions

Pediatric patients had comparable QoL, regardless of race, at a median of three years after HSCT in our study cohort.

INTRODUCTION

Hematopoietic stem cell transplant (HSCT) is a widely used treatment for many malignant and non-malignant conditions. However, receiving a transplant can cause significant stress for a patient and their family, and life following transplant can present additional challenges. Children often experience high levels of affective and somatic distress at admission for HSCT that escalates after conditioning. This stress is often compounded by strict long-term adherence to medications, frequent monitoring of physical health and labs, and numerous trips to clinic, culminating in an immense psychological toll. As a result, these patients are at a higher risk for acute distress and lingering adjustment problems in later years, affecting their quality of life (QoL).^{1,2} Poor QoL following HSCT can be related to the psychological outcomes of treatment, impaired social skills due to lack of peer interaction and chronic school absenteeism, cognitive and academic decline, and the stress of loved ones.^{3,4} Studies have generally shown improvements in patient QoL for the years following pediatric HSCT; however, a significant proportion of patients remain at risk for experiencing adjustment difficulties.^{5,6} QoL after HSCT is increasingly being recognized as a major outcome parameter of readjustment.^{7,8} Multiple studies have highlighted key factors that affect readjustment and QoL years after pediatric HSCT.⁹⁻¹³ Pre-transplant family cohesion and adaptive abilities of individual patients,¹⁰ as well as development of long-term complications of HSCT such as graft versus host disease and other comorbidities,⁹ are thought to impact readjustment and thus affect QoL.

Race is a known predictor of health-related outcomes, and racial disparities have been shown to be prevalent in a multitude of diseases, including cancers and blood disorders.¹⁴⁻¹⁷ Racial disparities in the access to and outcomes of HSCT have been explored, with most studies describing inferior clinical outcomes for Hispanic and Black patients as compared to non-Hispanic Whites;¹⁸⁻²² notably, the impact of racial disparities on the QoL of HSCT patients years after treatment has yet to be explored. With the goal of identifying barriers to improved QoL in transplant patients from marginalized and minority populations, we explored the impact of race and ethnicity on QoL two or more years post-transplant in a cohort of pediatric patients undergoing HSCT. We further explored how transplant and socioeconomic variables might serve as modifiers of such relationships. We hypothesized that (1) race and ethnicity affect the readjustment phase and thus impact QoL, (2) minority pediatric patients will experience lower QoL than their white counterparts, and (3) racial differences in QoL will be modified by the inclusion of socioeconomic variables in our analyses.

METHODS

Study population and data source

This study includes patients aged 21 years or younger at the time of diagnosis who received an allogeneic transplant between January 2007 and December 2017 at our 457-bed children's hospital in Phoenix, Arizona. QoL questionnaires that capture patient readjustment were collected longitudinally using the Pediatric Quality of Life Inventory Generic Score Scales (PedsQL TM 4.0) from 2013 to 2017. Patients were excluded if they did not have post-transplant QoL data, as defined by a completed PedsQL TM 4.0, at least two years after HSCT. Considering surveys of patients at least two years after HSCT provided patients with sufficient time to experience adjustments in QoL as expected in early post-HSCT life. For patients with multiple transplants, transplant-specific data from the first transplant was used, but the most recent PedsQL TM 4.0 was used for QoL metrics. A total of 184 patients received HSCT at our hospital between January 2007 and December 2017. Of this, 86 (46.7%) patients completed the PedsQL TM 4.0, and were therefore included in the study. Of these patients, 79 patients (91.86%) received one transplant and 7 patients (8.14%) received two transplants. All patient demographic, treatment, and transplant outcome data were obtained retrospectively through medical chart review. All study procedures were approved by our Institutional Review Board.

Variables

The primary outcome variable was QoL, evaluated at a minimum of two years post-transplant. We assessed this using the PedsQL TM 4.0 questionnaire tool. This tool is reliable and valid in children who are healthy, ethnically diverse, or diagnosed with acute and chronic disease.^{23,24} It is composed of 23 items that gauge function in the following four areas: physical functioning (eight items), emotional functioning (five items),

social functioning (five items), and school functioning (five items). Overall functioning was also recorded as an average of the four individual scores. Patients reported their function using a 5-point Likert scale ranging from 0 (never) to 4 (almost always). These responses were reverse scored and linearly transformed to a 0 to 100 scale, with a higher score indicating higher QoL. The median time between date of transplant and date of most recent PedsQL TM 4.0 completion was 2.98 years (range: 2–15 years). Other variables of interest obtained from medical records included: sex (male or female); race (non-Hispanic White [referred to as White], Hispanic, non-Hispanic Black [referred to as Black], or Native American); and age at transplant.

Patient socioeconomic status was estimated using the following variables: insurance status (state/federally-funded insurance or private insurance) and median household income ($> \$50,000$ or $< \$50,000$, estimated based on median income at patient's billing zip code per the United States Census Bureau).^{25,26}

Transplant-related variables included age and date at first HSCT; type of diagnosis (malignant or non-malignant); conditioning regimen (myeloablative or reduced intensity); donor type (matched related, unmatched related, or mismatched unrelated); donor source (bone marrow, peripheral/circulating blood, or cord blood); and donor and recipient cytomegalovirus (CMV) status (donor/recipient: +/+ , +/- , -/+ , or -/-).

Statistical analysis

Descriptions of continuous variables (time between transplant and QoL survey) were expressed as the means and standard deviations. Discrete qualitative variables (age at transplant, QoL scores via PedsQL TM 4.0) were expressed as numbers and percentages. Characteristics of pediatric HSCT patients were grouped by patient race. Fisher's exact tests were then used to examine potential differences among categorical variables (including sex, type of diagnosis, conditioning regimen, donor type, donor source, CMV status, insurance type, and household income classification) and one way analysis of variance (ANOVA) were used to test for differences in age at transplant and QoL scores. SAS version 9.4 (SAS Institute Inc; Cary, NC) was used for data summary and analysis.

Proc Regression in SAS was used to estimate unadjusted and multivariate adjusted models of the four QoL and overall functioning scores as dependent variables. Independent predictors included patient race, age at the time of transplant, sex, diagnosis (malignant or non-malignant), conditioning regimen, and time since transplant. Models were additionally run assessing the interaction of race and estimated income level (Table 3) and the interaction of race and type of insurance (Table 4).

In multivariate modeling, non-White (including Hispanic, Black, or Native American) patient QoL outcomes were compared to those of non-Hispanic White patients in separate models for each QoL outcome. In these supplementary analyses, multivariate models compared Hispanic, Black, or Native American patient QoL outcomes individually to those of non-Hispanic White patients. For the sets of multivariate analyses in both the manuscript and the supplement, the primary multivariate analysis was adjusted for age, sex, type of disease, and conditioning (Supplemental Table S2) while a secondary analysis further adjusted for insurance type and estimated household income (Supplemental Table S3). An a priori alpha level was set to 0.05.

RESULTS

Demographic and clinical characteristics

Demographic and clinical patient characteristics grouped by race/ethnicity are presented in Table 1. For subsequent analyses, patients were categorized as White (46.5%), Black (11.6%), Hispanic (33.7%), or Native Americans (8.1%). The median follow-up time between HSCT and last follow up was 7.23 years. Of the 86 patients included in the study, an equal number ($n = 43$, 50%) had been diagnosed with malignant and non-malignant conditions. Across racial/ethnic categories, there were no significant differences in the types of conditioning regimen received by the patients, the donor type (match), the donor source, and CMV status of donor and recipient. There were significant differences in the insurance type of patients across racial and ethnic categories. While 86.2% of Hispanic patients, 70% of Black patients, and 71.4% of Native American patients had Medicaid insurance, most White patients (62.5%) had private insurance ($p = 0.0005$).

In addition, there were differences in household income by patient race; most patients receiving transplants lived in areas where the median household income is above \$50,000 (72.4% for Hispanic patients, 82.0% for White patients, and 80.0% for Black patients), where only 28.6% of Native American patients lived in areas with this higher median income ($p = 0.03$).

QoL scores across race and ethnicity

Post-transplant QoL scores across four main domains (physical, work/school, emotional, social) were compared by patient race and ethnicity using ANOVA (Figure 1). Without any adjustments, there were significant differences in all four QoL scores, driving a difference in overall functioning across patients from White, Black, Hispanic, and Native American groups ($p = 0.009$).

QoL scores across diagnosis

Post-transplant QoL scores also were compared between patients with malignant and non-malignant conditions (Supplemental Table S1). Patients receiving HSCT for non-malignant conditions had a significantly higher physical functioning score (80.47) compared to those with malignant conditions (70.34; $p = 0.04$). Similarly, on average patients with non-malignant conditions had a higher work/school functioning score (74.93) compared to those with malignant conditions (64.30; $p = 0.02$).

Multivariate adjusted analyses

After adjusting for transplant-associated variables, race was not found to be associated with patient reports of QoL post-HSCT (Table 2). Inclusion of socioeconomic variables in these analyses, such as income (Table 3) and insurance type (Table 4) did not result in significant associations between patient race and QoL scores.

Unlike patient race, patient diagnosis associated with physical functioning scores, indicating that patients with non-malignant conditions were likely to have greater physical functioning than patients with malignant conditions ($p = 0.039$). This effect persisted when analyses evaluated potential interactions of race and estimated household income (Table 3, $p = 0.04$), but was not significant in analyses highlighting the interaction of race and insurance type (Table 4).

In supplementary analysis, White patients were used as the control group (exponentiated coefficient = 1) to be able to probe more specific two-group analyses. Hispanic, Black, and Native American patients did not have QoL scores that differed from those of White patients across all five types of functioning when controlling for transplant characteristics (Supplemental Table S2) and socioeconomic factors (Supplemental Table S3).

DISCUSSION

We examined potential racial disparities in QoL two or more years post-HSCT in a regional cohort of pediatric patients. Our results demonstrate no significant racial disparities in QoL across a variety of functioning scales during this post-transplant window. Socioeconomic factors did not appear to have any significant impact on this relationship between race and QoL in our patient cohort. However, transplant -related factors did impact certain QoL metrics, even after accounting for certain socioeconomic factors. These findings can provide critical information to providers and patient families concerning potential avenues for growth in managing long-term patient wellbeing following HSCT.

Given multiple reports of racial disparities affecting clinical outcomes related to HSCT.¹⁹⁻²², the current findings of no effect of patient race in long-term QoL scores were surprising. Prior published studies that draw upon much larger databases or registries and include participants from varied socioeconomic backgrounds have found racial and socioeconomic disparities in access to fully-matched unrelated donors for HSCT and in overall completion of HSCT for malignancy.^{18,27,28} There are numerous explanations for the lack of racial disparities in QoL scores post-HSCT within the current study. As a single institution evaluation in a moderately-sized pediatric hospital, the absence of racial disparities in readjustment rates at least two years post-HSCT may not necessarily indicate a lack of racial disparities in transplant outcomes within the

United States. For example, it was noted in this study that a significant majority of patients (74.1%) came from estimated annual income bracket of above \$50,000; this indicates a patient population with a higher socioeconomic status than that of the general population, which had a median income of \$55,000 in 2015.²⁶ Such higher income levels could allow patients and families to better handle post-HSCT life and afford resources to improve their physical and emotional health.²⁹⁻³¹

These findings are potentially attributable to a very organized supportive care program present throughout the transplant process within this institution. During both the immediate and later post-transplant periods, we utilize dedicated mental health specialists, hospital-based schoolteachers, social worker services, inpatient and outpatient pain services, multidisciplinary survivor clinics, and post-HSCT community engagement programs to optimize patient wellbeing; such programs may identify and resolve early declines in physical, emotional, social, and school/work functioning following treatment.³²⁻³⁵ Findings from our institution may be able to provide insight to other transplant centers regarding global changes that can be made to ensure patients from marginalized groups experience optimal outcomes. This includes educating transplant center leadership and staff about racial disparities that may be present in transplant referral, ensuring racial and ethnic minorities have adequate psychosocial support from community and hospital services, and implementing multidisciplinary survivor clinics into other transplant centers to monitor all patients years after transplant.^{36,37}

The results from this study can be contrasted with other work evaluating QoL in healthy controls, cancer patients, and transplant patients via the PedsQL TM 4.0 questionnaire (Table 5). While the QoL scores of patients in this study were still slightly below those of healthy controls,²³ their post-transplant QoL scores were greater than those of pediatric cancer patients across all the categories of readjustment,³⁸ and were higher than cited transplant QoL scores for emotional and work/school functioning.³⁹ The report comprised of healthy controls evaluated a group of patients from California with similar racial and ethnic demographics to the transplant population at our institution, making this a reasonable comparison.^{23,24} The study sample's QoL scores were also comparable to that of pediatric liver transplant recipients 10 years post-transplant³⁹ as well as pediatric HSCT recipients in other published studies.^{40,41} These non-statistical comparisons indicate that patients undergoing HSCT at our institution are adaptive, on average exhibiting nearly healthy functioning two years post-transplant. Further research should examine the role of institution-specific influences, such as effective long-term monitoring of possible complications including heart failure and endocrinopathies and an emphasis on psychosocial readjustment and transition to adult care.

When pediatric patients were divided based on their diagnosis of malignant or non-malignant conditions, regardless of race, patients with malignant conditions reported significantly lower physical and work/school functioning in preliminary analyses. Patients with malignant conditions likely face more physical limitations due to their cancer diagnosis; the physical side effects of cancer therapies and myeloablative conditioning regimens also likely persist for years following transplant, inhibiting long-term improvements in QoL. Those with malignant conditions necessitating HSCT also likely spend a greater amount of time away from school or work due to hospitalizations or treatments related to their diagnosis, impacting their work/school functioning.⁴² The significant relationship between type of diagnosis and physical functioning seen in multivariate regression analysis persisted when estimated household income was factored into the analysis, suggesting that even those with higher income experience lasting physical challenges. Conversely, relationships of diagnosis and school functioning were not present in multivariate analyses. These differences in outcomes highlight a need for provider intervention and follow-up to optimize wellbeing in patients with malignancies. Outside of racial and ethnic groups, particular care and focus should be given to patients with malignant conditions within institutions and transplant centers to improve physical and academic outcomes.

Limitations of this study include retrospective data collection, which precludes inferring causal relationships between covariates. The relationships we describe are based upon the inclusion of self-reported QoL from pediatric patients and estimates of socioeconomic status based upon medical records; it is possible that the nature of these metrics biased subsequent analyses. While there is no gold standard for measuring pediatric QoL, the PedsQL not only has strong psychometric properties,^{23,24} but is also appropriate for use in our

population of interest.³⁸ Nonetheless, there is the potential for differences in self-reporting across race and ethnicity that impact metrics like the PedsQL.⁴³ We have no means of quantifying potential reporting bias, but rely on previous research suggesting the strength of parent-reported health status of children.^{23,44} Lastly, the results of our study should be interpreted in the context of a small sample size (n = 86) as a single center experience. While we had a diverse sample, subsequent work would benefit from exploring the relationships described herein using larger samples sizes and multi-center approaches.

CONCLUSION

Concern over racial and ethnic disparities in QoL following HSCT have become more prevalent with the discovery of racial disparities in health outcomes from numerous other fields of medicine, including transplant medicine.^{18-21,45-48} In this study, we did not find significant differences across racial and ethnic groups in QoL scores of pediatric patients following HSCT after controlling for transplant-associated variables and determinants of socioeconomic status. However, patients with malignant conditions were found to have significantly lower physical and work/school functioning at least two years post-transplant as compared to patients with non-malignant conditions. Such findings underscore the need for careful follow-up with patients undergoing HSCT for malignancy to ensure they can regain physical and mental health to successfully participate in school or work in the years post-transplant.

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References

1. Barrera M, Atenafu E. Cognitive, educational, psychosocial adjustment and quality of life of children who survive hematopoietic SCT and their siblings. *Bone Marrow Transplantation*. 2008;42(1):15-21.
2. Di Giuseppe G, Thacker N, Schechter T, Pole JD. Anxiety, depression, and mental health-related quality of life in survivors of pediatric allogeneic hematopoietic stem cell transplantation: a systematic review. *Bone Marrow Transplantation*. 2020;55(7):1240-1254.
3. Janicsák H, Ungvari GS, Gazdag G. Psychosocial aspects of hematopoietic stem cell transplantation. *World J Transplant*. 2021;11(7):263-276.
4. Mosher CE, Redd WH, Rini CM, Burkhalter JE, DuHamel KN. Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: a review of the literature. *Psychooncology*. 2009;18(2):113-127.
5. Byar KL, Eilers JE, Nuss SL. Quality of life 5 or more years post-autologous hematopoietic stem cell transplant. *Cancer Nurs*. 2005;28(2):148-157.
6. Le RQ, Bevans M, Savani BN, et al. Favorable Outcomes in Patients Surviving 5 or More Years after Allogeneic Hematopoietic Stem Cell Transplantation for Hematologic Malignancies. *Biology of Blood and Marrow Transplantation*. 2010;16(8):1162-1170.
7. Bevans M. Health-related quality of life following allogeneic hematopoietic stem cell transplantation. *Hematology Am Soc Hematol Educ Program*. 2010;2010:248-254.
8. Elwadhi D, Khandelwal SK, Kumar L, Sharma A. Short-Term Impact of Hematopoietic Stem Cell Transplantation on Psychiatric Morbidity and Quality of Life in Hematological Malignancies in Adults. *Indian J Psychol Med*. 2020;42(1):61-68.
9. Liang H, Pan L, Xie Y, et al. Health-related quality of life in pediatric patients with β -thalassemia major after hematopoietic stem cell transplantation. *Bone Marrow Transplantation*. 2022.

10. Barrera M, Boyd-Pringle LA, Sumbler K, Saunders F. Quality of life and behavioral adjustment after pediatric bone marrow transplantation. *Bone Marrow Transplant*. 2000;26(4):427-435.
11. Phipps S, Brenner M, Heslop H, Krance R, Jayawardene D, Mulhern R. Psychological effects of bone marrow transplantation on children and adolescents: preliminary report of a longitudinal study. *Bone marrow transplantation*. 1995;15(6):829-835.
12. Phipps S, Dunavant M, Garvie PA, Lensing S, Rai SN. Acute health-related quality of life in children undergoing stem cell transplant: I. Descriptive outcomes. *Bone Marrow Transplantation*. 2002;29(5):425-434.
13. Phipps S, Peasant C, Barrera M, Alderfer MA, Huang Q, Vannatta K. Resilience in children undergoing stem cell transplantation: results of a complementary intervention trial. *Pediatrics*. 2012;129(3):e762-770.
14. Tammemagi CM, Neslund-Dudas C, Simoff M, Kvale P. In lung cancer patients, age, race-ethnicity, gender and smoking predict adverse comorbidity, which in turn predicts treatment and survival. *Journal of clinical epidemiology*. 2004;57(6):597-609.
15. Kirtane K, Lee SJ. Racial and ethnic disparities in hematologic malignancies. *Blood, The Journal of the American Society of Hematology*. 2017;130(15):1699-1705.
16. Abraham IE, Rauscher GH, Patel AA, et al. Structural racism is a mediator of disparities in acute myeloid leukemia outcomes. *Blood, The Journal of the American Society of Hematology*. 2022;139(14):2212-2226.
17. Fiala MA, Wildes TM. Racial disparities in treatment use for multiple myeloma. *Cancer*. 2017;123(9):1590-1596.
18. Barker JN, Boughan K, Dahi PB, et al. Racial disparities in access to HLA-matched unrelated donor transplants: a prospective 1312-patient analysis. *Blood Advances*. 2019;3(7):939-944.
19. Baker KS, Davies SM, Majhail NS, et al. Race and socioeconomic status influence outcomes of unrelated donor hematopoietic cell transplantation. *Biol Blood Marrow Transplant*. 2009;15(12):1543-1554.
20. Mielcarek M, Gooley T, Martin PJ, et al. Effects of race on survival after stem cell transplantation. *Biol Blood Marrow Transplant*. 2005;11(3):231-239.
21. Eckrich MJ, Ahn KW, Champlin RE, et al. Effect of race on outcomes after allogeneic hematopoietic cell transplantation for severe aplastic anemia. *Am J Hematol*. 2014;89(2):125-129.
22. Ballen KK, Klein JP, Pedersen TL, et al. Relationship of race/ethnicity and survival after single umbilical cord blood transplantation for adults and children with leukemia and myelodysplastic syndromes. *Biol Blood Marrow Transplant*. 2012;18(6):903-912.
23. Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL* 4.0 as a Pediatric Population Health Measure: Feasibility, Reliability, and Validity. *Ambulatory Pediatrics*. 2003;3(6):329-341.
24. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001;39(8):800-812.
25. Zheng DJ, Lu X, Schore RJ, et al. Longitudinal analysis of quality-of-life outcomes in children during treatment for acute lymphoblastic leukemia: A report from the Children's Oncology Group AALL0932 trial. *Cancer*. 2018;124(3):571-579.
26. Bureau UC. American Community Survey Data. 2022; <https://www.census.gov/programs-surveys/acs/data.html>. Accessed June 24, 2022, 2022.
27. Joshua TV, Rizzo JD, Zhang M-J, et al. Access to hematopoietic stem cell transplantation. *Cancer*. 2010;116(14):3469-3476.

28. Paulson K, Brazauskas R, Khera N, et al. Inferior Access to Allogeneic Transplant in Disadvantaged Populations: A Center for International Blood and Marrow Transplant Research Analysis. *Biology of Blood and Marrow Transplantation*. 2019;25(10):2086-2090.
29. Parker C, Berkovic D, Ayton D, Zomer E, Liew D, Wei A. Patient Perceived Financial Burden in Haematological Malignancies: A Systematic Review. *Current Oncology*. 2022;29(6):3807-3824.
30. Bona K, London WB, Guo D, Abel G, Lehmann L, Wolfe J. Prevalence and Impact of Financial Hardship among New England Pediatric Stem Cell Transplantation Families. *Biology of Blood and Marrow Transplantation*. 2015;21(2):312-318.
31. Brown-Iannuzzi JL, Payne BK, Rini C, DuHamel KN, Redd WH. Objective and subjective socioeconomic status and health symptoms in patients following hematopoietic stem cell transplantation. *Psycho-Oncology*. 2014;23(7):740-748.
32. Rove KO, Edney JC, Brockel MA. Enhanced recovery after surgery in children: Promising, evidence-based multidisciplinary care. *Pediatric Anesthesia*. 2018;28(6):482-492.
33. Ajarmeh S, Er L, Brin G, Djurdjev O, Dionne JM. The effect of a multidisciplinary care clinic on the outcomes in pediatric chronic kidney disease. *Pediatric Nephrology*. 2012;27(10):1921-1927.
34. Cantrell MA, Ruble K. Multidisciplinary care in pediatric oncology. *Journal of Multidisciplinary Health-care*. 2011;4:171-181.
35. Hashmi S, Carpenter P, Khera N, Tichelli A, Savani BN. Lost in Transition: The Essential Need for Long-Term Follow-Up Clinic for Blood and Marrow Transplantation Survivors. *Biology of Blood and Marrow Transplantation*. 2015;21(2):225-232.
36. Patzer RE, Paul S, Plantinga L, et al. A Randomized Trial to Reduce Disparities in Referral for Transplant Evaluation. *J Am Soc Nephrol*. 2017;28(3):935-942.
37. Beattie S, Lebel S, Tay J. The influence of social support on hematopoietic stem cell transplantation survival: a systematic review of literature. *PLoS One*. 2013;8(4):e61586.
38. Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer. *Cancer*. 2002;94(7):2090-2106.
39. Ng VL, Alonso EM, Bucuvalas JC, et al. Health status of children alive 10 years after pediatric liver transplantation performed in the US and Canada: report of the studies of pediatric liver transplantation experience. *J Pediatr*. 2012;160(5):820-826.e823.
40. Nuss SL, Wilson ME. Health-Related Quality of Life Following Hematopoietic Stem Cell Transplant During Childhood. *Journal of Pediatric Oncology Nursing*. 2007;24(2):106-115.
41. Bhatia M, Kolva E, Cimini L, et al. Health-Related Quality of Life after Allogeneic Hematopoietic Stem Cell Transplantation for Sickle Cell Disease. *Biology of Blood and Marrow Transplantation*. 2015;21(4):666-672.
42. Oberg JA, Bender JG, Morris E, et al. Pediatric allo-SCT for malignant and non-malignant diseases: impact on health-related quality of life outcomes. *Bone Marrow Transplantation*. 2013;48(6):787-793.
43. Gandhi K, Lim E, Davis J, Chen JJ. Racial-ethnic disparities in self-reported health status among US adults adjusted for sociodemographics and multimorbidities, National Health and Nutrition Examination Survey 2011-2014. *Ethn Health*. 2020;25(1):65-78.
44. Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL Family Impact Module: Preliminary reliability and validity. *Health and Quality of Life Outcomes*. 2004;2(1):55.
45. Ku E, McCulloch CE, Grimes BA, Johansen KL. Racial and Ethnic Disparities in Survival of Children with ESRD. *Journal of the American Society of Nephrology*. 2017;28(5):1584.

46. Majhail NS, Nayyar S, Santibañez ME, Murphy EA, Denzen EM. Racial disparities in hematopoietic cell transplantation in the United States. *Bone Marrow Transplant*. 2012;47(11):1385-1390.
47. Malek SK, Keys BJ, Kumar S, Milford E, Tullius SG. Racial and ethnic disparities in kidney transplantation. *Transplant International*. 2011;24(5):419-424.
48. Warren C, Carpenter A-M, Neal D, Andreoni K, Sarosi G, Zarrinpar A. Racial Disparity in Liver Transplantation Listing. *Journal of the American College of Surgeons*. 2021;232(4):526-534.

Figure Legends

Figure 1: Mean Quality of Life (QoL) scores by function for pediatric bone marrow transplant survivors that had lived more than two years post-transplant, presented by reported ethnicity. Higher scores are associated with better functioning. Provided p values indicate variation in mean scores across ethnicities (One-way ANOVA with a priori 0.05 level of significance).

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Figure 1 QOL scores by ethnicity graph .docx available at <https://authorea.com/users/591537/articles/627448-investigating-racial-disparities-in-quality-of-life-years-after-pediatric-hematopoietic-stem-cell-transplant>

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Tables 1.docx available at <https://authorea.com/users/591537/articles/627448-investigating-racial-disparities-in-quality-of-life-years-after-pediatric-hematopoietic-stem-cell-transplant>

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Tables 2 - 4. new multivariate with interactions .docx available at <https://authorea.com/users/591537/articles/627448-investigating-racial-disparities-in-quality-of-life-years-after-pediatric-hematopoietic-stem-cell-transplant>

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Table 5 .docx available at <https://authorea.com/users/591537/articles/627448-investigating-racial-disparities-in-quality-of-life-years-after-pediatric-hematopoietic-stem-cell-transplant>