i. Title: **"A Perfect Match": How hematologists discuss donor options and risks with Black and white patients considering allogeneic stem cell transplant**

ii. Authors: Thorunn H. Thordardottir MD[1]; Rachel A. Rodenbach MD, MS[1,2]; Markus Brauer, PhD[3]; Aric C. Hall, MD[1]; Earlise Ward PhD[1,4]; Cardinale B. Smith, MD, PhD[5]; and Toby C. Campbell, MD, MSCI[1].

iii. Affiliations: [1]Carbone Cancer Center, University of Wisconsin, Madison, WI; [2]James P. Wilmot Cancer Center, University of Rochester Medical Center, Rochester, NY; [3]Department of Psychology, University of Wisconsin, Madison, WI; [4]Department of Family Medicine and Community Health, University of Wisconsin School of Medicine and Public Health, Madison, WI; [5]Icahn School of Medicine at Mount Sinai, New York, NY.

iv. Corresponding author:
Thorunn H. Thordardottir
Carbone Cancer Center, University of Wisconsin Madison
600 Highland Avenue, Madison, WI 53792
email: tthordardott@wisc.edu

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Abstract

Patients of racial minorities have lower chance of securing a suitable donor, essential part of successful allogeneic stem cell transplant. In this simulated interview study, we sought to examine how hematologists discuss donor options and risks with patients with high-risk myeloid neoplasm considering transplant. Thirty-seven US hematologists participated (65% male; 65% white, 24% Asian, none Black), randomly assigned to meet with a Black or white patient actor. The hematologists emphasized the benefits of a full match with the white patient and high chance of securing a donor. Conversely, with the Black patient, they tended not to ask about ancestry, discuss the donor registry, race implications or challenges with donor search. Knowing the patient had children, many recommended haploidentical transplant. The unique circumstances of transplant argue for a focused communication including discussing race. While conversations should be tailored to each patient, limiting essential information on donor options may contribute to disparities.

Keywords: Allogeneic stem cell transplant, donor sources, communication practices.

Introduction

The availability of a suitable donor plays an integral part in the success of allogeneic stem cell transplant (alloSCT).[1,2] Historically, the preferred donor source has been a fully matched related donor (MRD), with a matched unrelated donor (MUD) being a viable second option. Still, only about a third of patients have a suitable sibling donor[3] and preference for MRDs over MUDs is diminishing due, in part, to superior outcomes with younger unrelated donors in some cases.[4-6] While white patients of European descent have about 75% chance of finding MUD through the international donor registry, patients of racial and ethnic minorities have a lower chance, with Black patients having among the lowest at around 20%.[3,7] Reasons for this are multifactorial, including increased variability in HLA polymorphisms, lower registry representation overall and scarcity of registered donors who ultimately donate upon request.[8-12] Black patients are therefore far more dependent on alternative donors, including haploidentical (haplo), cord blood (CB) and mismatched unrelated donors (MMUD).

AlloSCT is the only treatment associated with cure across many myeloid malignancies, including high-risk myelodysplastic neoplasm (MDS), a disease of older adults associated with particularly poor prognosis and potential for leukemic transformation.[13,14] Survival outcomes of patients with high-risk MDS who undergo alloSCT based on availability of a fully human leukocyte antigen (HLA)-matched donor, related or unrelated, are better when compared to those who do not have a donor and do not undergo transplant.[15-17] However, alloSCT comes with uncertainty and risks, including early treatment-related mortality, graft rejection, and graft versus host disease (GVHD).[18-

[21] AlloSCT from mismatched donors have been associated with worse outcomes,[1,22-24] but recent advances, particularly the use of post-transplant cyclophosphamide, have markedly improved their safety.[25-27] This has reduced barriers to access of alloSCT, particularly for minorities, and most patients will eventually find a donor[28,29], though patients of African ancestry still have the lowest availability, even of alternative donors[30]. Furthermore, due to heterogeneity and the relatively rare nature of performing alloSCT, uncertainty remains about true equivalence with mismatched donors and the historic strong preference for matched donors still influences many providers.

Beyond donor availability, alloSCT remains a highly complex and costly procedure that tends to magnify other disparities in the health care system.[31,32] Disparities in doctor-patient communication contribute to healthcare inequities[33] which can be further amplified by the complexity of the subject[34], such as when discussing alloSCT. As donor availability is affected by race, studying how hematologists discuss donor options and their impact on decision making is of particular interest. To our knowledge, no prior studies have explored how hematologists engage patients of different race/ethnicities in conversations about donor-related issues during the transplant consultation. In this study evaluating communication practices of transplant hematologists with patients with high-risk MDS considering alloSCT, we compared how hematologists discuss donor options and risks with Black versus white patients.

Materials and methods

Study design

This is an observational study of video-recorded virtual encounters. We recruited fellowship-trained transplant hematologists in the United States and randomly assigned them to meet with either a Black or white actor similar in all physical and clinical characteristics, except for apparent race and trained to portray the same 67-year-old man with newly diagnosed high-risk MDS sent for specialty consultation. The encounters were with simulated patients to control for differences in patient factors and isolate hematologists' behavior. The patients were similar in all features except for their apparent race and trained to mirror each other to have consistent performances across encounters. The case represented a realistic alloSCT candidate with potential sibling/children donors and was designed so that hematologists could focus on treatment decision making. The hematologists were informed that the study's purpose was to analyze how hematologists approach a consultation with different patients with high-risk MDS and discuss treatment options. They were told they would meet with a simulated patient but not that they would be randomized to meet with either a Black or white patient or that we would be comparing the interactions based on race of the patient. The hematologists answered a demographic survey prior to participating, which included information on their clinic practice. The encounters mimicked a telemedicine visit using video conferencing software, with each visit lasting up to an hour. Further details about the patient case, participants and recruitment, actor hiring and training, encounters, and qualitative analysis have been described elsewhere.[35,36] All the hematologists who were contacted, met eligibility criteria and agreed to participate were included in the study. We obtained approval to conduct

this study from the University of Wisconsin Minimal Risk Research Institutional Review Board.

Results

We contacted over 200 hematologists from 85 US academic centers, of which 37 from 25 centers consented and participated in the study. Their self-reported demographic and clinical characteristics are listed in **Table 1**. Seventeen hematologists met with the Black patient, and 20 with the white patient. Of the 37 participants, 24 (65%) were white, 9 (24%) were Asian, and none was Black.

A. General observations

All but one of the hematologists discussed donor-related issues during the visit. Seven (19%) limited their discussion to brief review of the process of finding either a related donor or an unrelated donor through the registry. The majority (73%, n=27) provided numerous details about the donor process:

1. **The need for a suitable donor based on matching.** Most hematologists explained that finding an appropriate donor is a major early step in undergoing transplant and inquired about the patient's siblings and/or children very early in the visit. Most expressed a preference for a fully matched donor but many acknowledged recent advances allowing safer use of haplo.
2. **The unrelated donor registry.** Many (86%, n=32) introduced the international donor registry as an additional source.

3. **The need to start the donor search early**. They consistently recommended to start the search to avoid delays later, regardless of whether transplant would ultimately happen or not.
4. **Reassurance that a donor would be found.** Most expressed hope of finding a donor and that it should not be a barrier to undergo transplant.
5. **Lack of pressure to make a decision during the first visit.** Many emphasized that the search would not commit the patient to undergo transplant, but some reasoned that the outcome of the search could help them make a decision.

Rarely (8%, n=3, all with the white patient), hematologists provided even greater details about the donor selection process and risks associated with specific sources.

B. Observations specific to patient race

1. **The role of matching, the risks of mismatching and the use of haplo and alternative transplants.**

Most hematologists who met with the white patient emphasized finding "a perfect match" to optimize transplant outcomes and minimize risks. They expressed a preference for MUD, after a sibling donor, explained the benefits of full match and outlined the risks of mismatching, including GVHD and rejection (**Box 1**). Most (65%, n=13) reviewed the option of haplo and that its outcomes have improved, but given risks involved and less experience this would be less preferred and unlikely needed. Some (25%, n=5) mentioned the option of using CB, though generally not in an older patient. Two hematologists (10%) additionally mentioned the possibility of using MMUD if all other options were unavailable.

Hematologists who met with the Black patient did not discuss the benefits of a close match to the same extent as with the white patient. While many expressed that MRD or MUD would be optimal, after knowing the patient had children, they focused on reassurance that recent advances have enabled the use of haplo (**Box 1**). They gave variable estimates of overall outcomes from haplo, without providing specific details. Some stated that haplo transplants are superior to other donor sources, whereas others acknowledged that variability in outcomes reported in studies has caused debate and uncertainty, but reassured that adjustments could be made to achieve more favorable outcomes. Only two hematologists (12%) mentioned CB as an option, and none discussed the possibility of using MMUD. Hematologists generally discussed differences in risks from alternative donor sources to less extent with the Black patient.

2. Ancestry history taking and the role of race/ethnicity in finding a match.

All but one of the 20 hematologists (95%) who met with the white patient discussed the donor registry whereas 13 of the 17 hematologists (76%) who met with the Black patient mentioned the donor registry. Four hematologists (20%) asked the white patient about his ancestry, whereas none asked the Black patient about his ancestry. Six (30%) explained to the white patient that ethnicity impacted the probability of finding MUD, whereas 3 (18%) explained the same to the Black patient (**Box 2**). Of these hematologists, two were non-white themselves which one explicitly referenced. One hematologist did not explain ethnic differences but markedly overestimated the odds of finding MUD for the Black patient.

3. The assurance of having a donor.

Overall, hematologists expressed optimism that with adequate family members, donor availability should not be a barrier to transplant. They frequently reassured the white patient he would have many options to choose from to find the best donor (**Box 3**).

In comparison, they reassured the Black patient he would find a donor. Several stated that haplo would be a likely source for the Black patient. Some expressed a preference for using one of the patient's children as a donor, inquired about his children before his siblings, and used declarative statements that one of his children would ultimately be the donor. A few explained that haplo would be their first choice based on their institution's preference.

4. Deferring the discussion of donor options.

Notably, some hematologists postponed discussions of donor issues at this first visit, either explicitly or implicitly deferring this to after a first registry search. Some who met the white patient minimized donor-related issues stating it wouldn't pose a problem (**Box 4**). Some mentioned to the Black patient the possibility of not being able to find a donor, or that other barriers such as lack of social support could prevent the patient from undergoing transplant, and consequently deferred recommending for/against it (**Box 4**). The single encounter where donor options were not reviewed at all was with a Black patient where chemotherapy was recommended over transplant after the patient expressed valuing quality of life and time spent with family.

Overall, the differences we observed in communications on donor issues did not result in significantly different recommendations to the Black versus white patient on whether to proceed with alloSCT work-up.

Discussion

This qualitative analysis sheds light on how hematologists explain donor options and their influence on outcomes with Black and white patients considering alloSCT. Despite qualifying statements, most hematologists expressed a preference for a fully matched donor and variably implied their association with the best outcomes. However, this study underscores important differences in discussions dependent on the patient's race.

Conversations with the white patient highlighted ethnicity as a reassuring characteristic that meant a better chance of finding a good donor and achieving a successful transplant. Hematologists more often asked about ancestry and discussed the high likelihood of finding MUD through a donor registry if MRD wasn't available, emphasizing a "perfect match," to minimize risks and increase the success of transplant. They explained that haplo would neither be likely nor preferred and only serve as a back-up option. In contrast, hematologists seemed to shy away from discussing race with the Black patient. They did not ask about ancestry, rarely discussed the donor registry and were guarded in their discussion of finding a fully matched donor. In fact, despite lower likelihood of being needed,[10] there were more discussions about the breadth of alternative donor options including CB and MMUD with the white patient.

Donor concerns were a limited part of the transplant conversation in this single visit making it difficult to infer intent or fully appreciate why the interactions with the Black patient took the directions they did. The patient's male gender (decreasing probability of anti-child HLA antibodies) and presence of multiple young children (features we included to remove a barrier of potentially not having a donor in a Black patient) may have minimized discussions of alternative donor sources. Still, the differences we observed raise some concerns. Hematologists may have avoided discussing race with the Black patient out of concern for the sensitive nature or unfamiliarity with the topic, to preserve hope or avoid eliciting a negative emotional reaction while working to build rapport with a new patient.[37-39] The lack of Black hematologists may have been significant and doctor-patient race concordance could have altered the results.[33] As the overall message about transplant for both patients was positive, this may have been an effort to not dissuade from alloSCT with discouraging statistics surrounding fully matched donor availability.[40] Encouragingly, the conversations centered on optimism around finding a donor and recommendations on pursuing alloSCT did not depend on race. Early donor search is medically appropriate and confirming an appropriate donor can help reduce apprehensions patients with serious illness have about proceeding with alloSCT.[41] Still extremely affirmative statements about the use of one of the Black patient's children as a donor, or about the easy availability of MUD for the white patient, may presuppose the patient had already decided to pursue alloSCT and may bias the decision, highlighting the importance of engaging patients in discussions about their preferences and values at the initial visit.

The complexity and cost of alloSCT add barriers that magnify disparities.[10,31,42,43] Socioeconomic factors including lack of health insurance, employment security and caregiver support are important contributors,[29,32,44-46] and may drive lower referral rates to transplant centers and inclusion of ethnic/racial minorities in clinical trials.[45-48] Historically, donor availability and worse outcomes with mismatched transplants almost certainly contributed to lack of access for racial/ethnic minorities. Medical progress has significantly reduced this gap by allowing safer mismatched transplants and enabled more patients to undergo alloSCT.[28,29,49] Unfortunately, patients of African descent have the lowest donor availability, not only of MUD but also of haplo which cannot be presumed as an option.[12,30] The patient's age was higher than would generally be considered for CB[50], but younger patients should be informed about this option. While the hematologists acknowledged donor search could take time, they did not review expected challenges of securing a donor for the minority patient. Instead, they referred to haplo as a likely source, emphasizing evolution of the field towards its use. While this may reflect recent advances and appropriate clinical reasoning, they did not explicitly state whether the critical lack of fully matched donors was driving their preference for haplo, especially considering the conversations with the white patient where a full match was considered optimal.

Not asking about ancestry suggests assumptions may have been made which is problematic as medical charts commonly have incomplete or inaccurate information on patients' race/ethnicity.[51] Program initiatives to improve collection of race/ethnicity data in healthcare have demonstrated that patients are willing to answer such questions.[52] As racial minorities less often have access to fully matched donors this is critical information

to guide discussions, to identify patients who are unlikely to have an unrelated matched donor and enable use of unrelated donor search prognosis tools to triage them to an alternative donor search in a timely manner.[53]

Regardless of hematologists' perceived risks of mismatched transplants, this study suggests possible contradictory messaging where the benefits of a fully matched donor were emphasized with the white patient but donor-related issues minimized with the Black patient. Black patients with serious illness report poorer communication and perceive greater physician bias, both well-established disparities.[54,55] Clinic visits with Black patients are shorter with less information giving.[56,57] Obscuring a possible differential risk could foster patient distrust and affect treatment decisions.[58] The complexity and high-risk, high-reward nature of alloSCT make shared decision making particularly delicate.[36] Hematologists' approach to the conversation may impact patients' understanding, perceptions and ultimately decision to proceed with a high-stakes treatment.[55] Better communication is associated with greater trust and satisfaction with the care provided.[59,60] To allow patients the most ethical informed consent and build trust, providers should be upfront about uncertainties in transplant practice and donor availability.

This study has limitations. Each hematologist only met one patient and the sample size was relatively small, therefore variation in communication style may have more effect than patient race. Despite a broad recruitment strategy, no Black hematologists participated in the study and the participants primarily treat white patients which may reflect comfort levels and communication practices with the Black patient. The actors were not interviewed post-encounter on their impression of the doctor-patient

communication, which could have supported or undermined the conclusions drawn. More studies are needed examining patients´ perspectives of discussions on impact of race in transplant conversations. While a strength of this study is that participants came from different centers across the US, we acknowledge that centers may have preferences towards specific donor sources.

Our future work will build on results of this study and our prior observations[35] to develop a communication tool aimed to guide shared decision-making, facilitate dialogue engagement with patients of different race/ethnicities and reduce disparities in information- exchange with patients considering alloSCT.

In conclusion, conversations between hematologists and Black and white patients considering alloSCT reflect optimism that donor availability should not be a barrier, and recommendations whether to pursue transplant did not depend on race. Hematologists seemed more comfortable discussing the role of race/ ethnicity in donor search with the white patient. They gave the impression of emphasizing the benefits of a full match and white ethnicity was considered a positive characteristic in securing an optimal donor, whereas haplo was less preferred. Conversely, they seemed to shy away from discussing race with the Black patient and were less upfront about expected challenges of securing a donor. The unique circumstances of transplant as a treatment argue for a focused communication strategy. Given the impact of race on donor availability, discussing race is an imperative part of the conversation. Discussions need to be tailored to each patient, where transparency about potential uncertainties is important so that each patient has realistic expectations about donor availability and outcomes. Limiting such essential

information for racial minority patients may contribute to communication disparities and affect trust building and treatment decision making.

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References

1. Kollman C, Spellman SR, Zhang MJ, et al. The effect of donor characteristics on survival after unrelated donor transplantation for hematologic malignancy. Blood 2016;127(2):260-7. (In eng). DOI: 10.1182/blood-2015-08-663823.
2. Timofeeva OA, Philogene MC, Zhang QJ. Current donor selection strategies for allogeneic hematopoietic cell transplantation. Hum Immunol 2022;83(10):674-686. DOI: 10.1016/j.humimm.2022.08.007.
3. Gragert L, Eapen M, Williams E, et al. HLA match likelihoods for hematopoietic stem-cell grafts in the U.S. registry. N Engl J Med 2014;371(4):339-48. (In eng). DOI: 10.1056/NEJMsa1311707.
4. Guru Murthy GS, Kim S, Hu ZH, et al. Relapse and Disease-Free Survival in Patients With Myelodysplastic Syndrome Undergoing Allogeneic Hematopoietic Cell Transplantation Using Older Matched Sibling Donors vs Younger Matched Unrelated Donors. JAMA Oncol 2022;8(3):404-411. (In eng). DOI: 10.1001/jamaoncol.2021.6846.
5. Pereira MP, Remberger M, Chen CR, et al. Choosing Between Older Matched Sibling Donor and Younger Matched Unrelated Donor in Allogeneic Hematopoietic Cell Transplantation: Comparison of Clinical Outcomes in Acute Myeloid Leukemia and Myelodysplastic Syndrome. Transpl Cell Ther 2023;29(11) (In English). DOI: 10.1016/j.jtct.2023.08.009.
6. Ramdial J, Kebriaei P, Champlin RE, et al. Improved survival with younger HLA-matched unrelated donors versus older matched sibling donor HCT with PTCy-prophylaxis. Leukemia 2024 (In English). DOI: 10.1038/s41375-024-02256-0.
7. Dehn J, Buck K, Maiers M, et al. 8/8 and 10/10 high-resolution match rate for the be the match unrelated donor registry. Biol Blood Marrow Transplant 2015;21(1):137-41. (In eng). DOI: 10.1016/j.bbmt.2014.10.002.
8. Cao K, Moormann AM, Lyke KE, et al. Differentiation between African populations is evidenced by the diversity of alleles and haplotypes of HLA class I loci. Tissue Antigens 2004;63(4):293-325. (In eng). DOI: 10.1111/j.0001-2815.2004.00192.x.
9. Meyer D, Single RM, Mack SJ, Erlich HA, Thomson G. Signatures of demographic history and natural selection in the human major histocompatibility complex Loci. Genetics 2006;173(4):2121-42. (In eng). DOI: 10.1534/genetics.105.052837.
10. Barker JN, Boughan K, Dahi PB, et al. Racial disparities in access to HLA-matched unrelated donor transplants: a prospective 1312-patient analysis. Blood Adv 2019;3(7):939-944. (In eng). DOI: 10.1182/bloodadvances.2018028662.
11. Anthias C, Shaw BE, Bruce JG, et al. Role of Race/Ethnicity in Donor Decisions about Unrelated Hematopoietic Progenitor Cell Donation: Exploring Reasons for Higher Attrition among Racial/Ethnic Minorities. Biol Blood Marrow Transplant 2020;26(3):593-599. DOI: 10.1016/j.bbmt.2019.10.012.
12. Fingrut WB, Gyurkocza B, Davis E, et al. Racial disparities in access to alternative donor allografts persist in the era of "donors for all". Blood Adv 2022;6(20):5625-5629. DOI: 10.1182/bloodadvances.2022007814.
13. Garcia-Manero G. Myelodysplastic syndromes: 2023 update on diagnosis, risk-stratification, and management. Am J Hematol 2023;98(8):1307-1325. (In eng). DOI: 10.1002/ajh.26984.
14. Li H, Hu F, Gale RP, Sekeres MA, Liang Y. Myelodysplastic syndromes. Nat Rev Dis Primers 2022;8(1):74. DOI: 10.1038/s41572-022-00402-5.
15. Nakamura R, Saber W, Martens MJ, et al. Biologic Assignment Trial of Reduced-Intensity Hematopoietic Cell Transplantation Based on Donor Availability in Patients 50-75 Years of

Age With Advanced Myelodysplastic Syndrome. J Clin Oncol 2021;39(30):3328-3339. (In eng). DOI: 10.1200/JCO.20.03380.
16. Kröger N, Sockel K, Wolschke C, et al. Comparison Between 5-Azacytidine Treatment and Allogeneic Stem-Cell Transplantation in Elderly Patients With Advanced MDS According to Donor Availability (VidazaAllo Study). J Clin Oncol 2021;39(30):3318-3327. (In eng). DOI: 10.1200/JCO.20.02724.
17. Robin M, Porcher R, Adès L, et al. HLA-matched allogeneic stem cell transplantation improves outcome of higher risk myelodysplastic syndrome A prospective study on behalf of SFGM-TC and GFM. Leukemia 2015;29(7):1496-501. (In eng). DOI: 10.1038/leu.2015.37.
18. Akahoshi Y, Spyrou N, Hogan WJ, et al. Incidence, clinical presentation, risk factors, outcomes, and biomarkers in de novo late acute GVHD. Blood Adv 2023;7(16):4479-4491. DOI: 10.1182/bloodadvances.2023009885.
19. Arora M, Cutler CS, Jagasia MH, et al. Late Acute and Chronic Graft-versus-Host Disease after Allogeneic Hematopoietic Cell Transplantation. Biol Blood Marrow Transplant 2016;22(3):449-55. DOI: 10.1016/j.bbmt.2015.10.018.
20. Arai S, Arora M, Wang T, et al. Increasing incidence of chronic graft-versus-host disease in allogeneic transplantation: a report from the Center for International Blood and Marrow Transplant Research. Biol Blood Marrow Transplant 2015;21(2):266-74. DOI: 10.1016/j.bbmt.2014.10.021.
21. Hsu J, Chen Z, Shore T, et al. Outcomes of Allogeneic Stem Cell Transplant for Elderly Patients with Hematologic Malignancies. Biol Blood Marrow Transplant 2020;26(4):789-797. DOI: 10.1016/j.bbmt.2019.12.766.
22. Flowers ME, Inamoto Y, Carpenter PA, et al. Comparative analysis of risk factors for acute graft-versus-host disease and for chronic graft-versus-host disease according to National Institutes of Health consensus criteria. Blood 2011;117(11):3214-9. DOI: 10.1182/blood-2010-08-302109.
23. Verneris MR, Lee SJ, Ahn KW, et al. HLA Mismatch Is Associated with Worse Outcomes after Unrelated Donor Reduced-Intensity Conditioning Hematopoietic Cell Transplantation: An Analysis from the Center for International Blood and Marrow Transplant Research. Biol Blood Marrow Transplant 2015;21(10):1783-9. DOI: 10.1016/j.bbmt.2015.05.028.
24. Saber W, Opie S, Rizzo JD, Zhang MJ, Horowitz MM, Schriber J. Outcomes after matched unrelated donor versus identical sibling hematopoietic cell transplantation in adults with acute myelogenous leukemia. Blood 2012;119(17):3908-16. DOI: 10.1182/blood-2011-09-381699.
25. Robin M, Porcher R, Ciceri F, et al. Haploidentical transplant in patients with myelodysplastic syndrome. Blood Adv 2017;1(22):1876-1883. (In eng). DOI: 10.1182/bloodadvances.2017007146.
26. Grunwald MR, Zhang MJ, Elmariah H, et al. Alternative donor transplantation for myelodysplastic syndromes: haploidentical relative and matched unrelated donors. Blood Adv 2021;5(4):975-983. (In eng). DOI: 10.1182/bloodadvances.2020003654.
27. Michel C, Robin M, Morisset S, et al. Outcome after allogeneic stem cell transplantation with haploidentical versus HLA-matched donors in patients with higher-risk MDS. Bone Marrow Transplant 2023;58(5):534-543. (In eng). DOI: 10.1038/s41409-023-01931-7.
28. Auletta JJ, Kou J, Chen M, et al. Real-World Data Showing Trends and Outcomes by Race and Ethnicity in Allogeneic Hematopoietic Cell Transplantation: A Report from the Center for International Blood and Marrow Transplant Research. Transplant Cell Ther 2023;29(6):346.e1-346.e10. (In eng). DOI: 10.1016/j.jtct.2023.03.007.

29. Bashey A, Zhang X, Morris LE, et al. Improved access to HCT with reduced racial disparities through integration with leukemia care and haploidentical donors. Blood Adv 2023;7(15):3816-3823. DOI: 10.1182/bloodadvances.2023009765.
30. Kosuri S, Wolff T, Devlin SM, et al. Prospective Evaluation of Unrelated Donor Cord Blood and Haploidentical Donor Access Reveals Graft Availability Varies by Patient Ancestry: Practical Implications for Donor Selection. Biol Blood Marrow Transplant 2017;23(6):965-970. DOI: 10.1016/j.bbmt.2017.03.001.
31. Ashok Kumar P, Ghimire K, Haroun E, et al. Utilization and outcome disparities in allogeneic hematopoietic stem cell transplant in the United States. Eur J Haematol 2024;112(3):328-338. DOI: 10.1111/ejh.14129.
32. Hong S, Majhail NS. Increasing access to allotransplants in the United States: the impact of race, geography, and socioeconomics. Hematology Am Soc Hematol Educ Program 2021;2021(1):275-280. (In eng). DOI: 10.1182/hematology.2021000259.
33. Shen MJ, Peterson EB, Costas-Muniz R, et al. The Effects of Race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the Literature. J Racial Ethn Health Disparities 2018;5(1):117-140. DOI: 10.1007/s40615-017-0350-4.
34. Penner LA, Eggly S, Griggs JJ, Underwood W, 3rd, Orom H, Albrecht TL. Life-Threatening Disparities: The Treatment of Black and White Cancer Patients. J Soc Issues 2012;68(2). DOI: 10.1111/j.1540-4560.2012.01751.x.
35. Rodenbach RA, Thordardottir T, Brauer M, et al. Communication Strategies of Transplant Hematologists in High-Risk Decision-Making Conversations. JCO Oncol Pract 2024;20(4):538-548. DOI: 10.1200/OP.23.00574.
36. Rodenbach RA, Thordardottir T, Brauer M, et al. Balancing risks and rewards: How hematologists discuss uncertainty in allogeneic hematopoietic cell transplantation outcomes. Patient Educ Couns 2024;123:108177. DOI: 10.1016/j.pec.2024.108177.
37. Alexander SC, Sullivan AM, Back AL, et al. Information giving and receiving in hematological malignancy consultations. Psychooncology 2012;21(3):297-306. DOI: 10.1002/pon.1891.
38. Mack JW, Smith TJ. Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. J Clin Oncol 2012;30(22):2715-7. DOI: 10.1200/JCO.2012.42.4564.
39. Studer RK, Danuser B, Gomez P. Physicians' psychophysiological stress reaction in medical communication of bad news: A critical literature review. Int J Psychophysiol 2017;120:14-22. DOI: 10.1016/j.ijpsycho.2017.06.006.
40. Lee SJ, Fairclough D, Antin JH, Weeks JC. Discrepancies between patient and physician estimates for the success of stem cell transplantation. JAMA 2001;285(8):1034-8. DOI: 10.1001/jama.285.8.1034.
41. Khemani K, Ross D, Sinha C, Haight A, Bakshi N, Krishnamurti L. Experiences and Decision Making in Hematopoietic Stem Cell Transplant in Sickle Cell Disease: Patients' and Caregivers' Perspectives. Biol Blood Marrow Transplant 2018;24(5):1041-1048. DOI: 10.1016/j.bbmt.2017.11.018.
42. Crockett DG, Loberiza FR, Jr. Persistent Disparities in Adult Hematopoietic Cell Transplantation. Curr Hematol Malig Rep 2015;10(3):192-8. DOI: 10.1007/s11899-015-0268-z.
43. Fingrut WB, Gyurkocza B, Flynn J, et al. Analysis of disparities in time to allogeneic transplantation in adults with acute myelogenous leukemia. Blood Adv 2023;7(15):3824-3833. DOI: 10.1182/bloodadvances.2022008572.

44. 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):1385-90. (In eng). DOI: 10.1038/bmt.2011.214.
45. Kirtane K, Lee SJ. Racial and ethnic disparities in hematologic malignancies. Blood 2017;130(15):1699-1705. (In eng). DOI: 10.1182/blood-2017-04-778225.
46. Bierenbaum J, Davidoff AJ, Ning Y, Tidwell ML, Gojo I, Baer MR. Racial differences in presentation, referral and treatment patterns and survival in adult patients with acute myeloid leukemia: a single-institution experience. Leuk Res 2012;36(2):140-5. (In eng). DOI: 10.1016/j.leukres.2011.10.018.
47. Patel MI, Ma Y, Mitchell B, Rhoads KF. How do differences in treatment impact racial and ethnic disparities in acute myeloid leukemia? Cancer Epidemiol Biomarkers Prev 2015;24(2):344-9. (In eng). DOI: 10.1158/1055-9965.EPI-14-0963.
48. Pidala J, Craig BM, Lee SJ, Majhail N, Quinn G, Anasetti C. Practice variation in physician referral for allogeneic hematopoietic cell transplantation. Bone Marrow Transplant 2013;48(1):63-7. DOI: 10.1038/bmt.2012.95.
49. Chowdhury AS, Maiers M, Spellman SR, Deshpande T, Bolon YT, Devine SM. Existence of HLA-Mismatched Unrelated Donors Closes the Gap in Donor Availability Regardless of Recipient Ancestry. Transplant Cell Ther 2023;29(11):686 e1-686 e8. DOI: 10.1016/j.jtct.2023.08.014.
50. Barker JN, Kurtzberg J, Ballen K, et al. Optimal Practices in Unrelated Donor Cord Blood Transplantation for Hematologic Malignancies. Biol Blood Marrow Transplant 2017;23(6):882-896. DOI: 10.1016/j.bbmt.2017.03.006.
51. Fingrut WB, Davis E, Chinapen S, et al. Inaccuracies in assignment of patient race and ethnicity: implications for unrelated donor searches and health care delivery. Blood Adv 2023;7(10):1996-1999. DOI: 10.1182/bloodadvances.2022008526.
52. Shapiro A MD, Riley L, Kurtz B, Barchi D. . Building the Foundations for Equitable Care. NEJM Catalyst 2021 (Commentary). DOI: 10.1056/CAT.21.0256.
53. Davis E, Archer A, Flynn J, et al. An Optimized Search Prognosis Tool to Predict 8/8 HLA Allele-Matched Unrelated Donor Procurement. Transplant Cell Ther 2023;29(5):312 e1-312 e5. DOI: 10.1016/j.jtct.2023.02.016.
54. Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. JAMA 1999;282(6):583-9. DOI: 10.1001/jama.282.6.583.
55. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. Am J Public Health 2004;94(12):2084-90. DOI: 10.2105/ajph.94.12.2084.
56. Smith CB, Pintova S, Adelson KB, Gonsky JP, Egorova N, Bickell NA. Disparities in length of goals of care conversations between oncologists and patients with advanced cancer. Journal of Clinical Oncology 2018;36(34) (In English). DOI: 10.1200/JCO.2018.36.34_suppl.19.
57. Gedeon C, Rodenbach R, Campbell TC, Thordardottir TH, Brauer M. Racial Disparities in Doctor-Patient Communication: Examining Doctors' Encounters with Black and White Patients. J Racial Ethn Health 2025 (In English). DOI: 10.1007/s40615-025-02374-0.
58. Brown CE, Marshall AR, Snyder CR, et al. Perspectives About Racism and Patient-Clinician Communication Among Black Adults With Serious Illness. JAMA Netw Open 2023;6(7):e2321746. (In eng). DOI: 10.1001/jamanetworkopen.2023.21746.
59. Herrmann A, Holler E, Edinger M, Eickmann S, Wolff D. A qualitative study on patients' and their support persons' preferences for receiving one longer consultation or two shorter

consultations when being informed about allogeneic hematopoietic stem cell transplantation. BMC Health Serv Res 2021;21(1):623. DOI: 10.1186/s12913-021-06632-9.
60. Siebinga VY, Driever EM, Stiggelbout AM, Brand PLP. Shared decision making, patient-centered communication and patient satisfaction - A cross-sectional analysis. Patient Educ Couns 2022;105(7):2145-2150. DOI: 10.1016/j.pec.2022.03.012.

Tables and figures

Table 1. Demographic and clinical characteristics of hematologists (n= 37).

Characteristics	**n (%)**
Age	
Years (median, range)	44 (33-73)
Sex	
Male	24 (65%)
Female	13 (35%)
Race	
Asian	9 (24%)
White	24 (65%)
Black or African American	0 (0%)
Latinx or Hispanic	0 (0%)
Other	4 (11%)
Formal communication training	
Workshop, didactics, and/or palliative care rotation	27 (73%)
Estimated number of patients treated with alloSCT annually	
<25	5 (14%)
25-50	19 (51%)
51-75	6 (16%)
76-100	3 (8%)
>100	4 (11%)
Estimated clinical time devoted to alloSCT annually	
Less than 25%	3 (8%)
25-50%	14 (38%)
51-75%	13 (35%)
76-100%	7 (19)
Estimated percentage of transplants using alternative donors (mismatched unrelated, haploidentical, or umbilical cord stem cells)	
10-30%	16 (43%)
31-50%	14 (38%)
>50%	7 (19%)
Estimated percentage of their patients who identify as white	

<10%	0 (0%)
10-25%	1 (3%)
26-50%	4 (11%)
51-75%	16 (43%)
>75%	16 (43%)
Estimated percentage of their patients who identify as Black	
<10%	14 (38%)
10-25%	23 (62%)
26-50%	0 (0%)
31-50%	0 (0%)
>75%	0 (0%)
Location of medical center/place of employment	
Large urban area	24 (65%)
Moderate size city that draws from a rural state	13 (35%)

Box 1: The role of matching, risks of mismatching and the use of haploidentical transplants

With the white patient (n=20) -The hematologists expressed preference for a full match in terms of risks and experience, whereas haploidentical match was considered unlikely and less preferred.

"The closer of a match, the easier parts of the treatment and more successful the outcomes of the transplant can be." Hematologist #2

"We prefer a full match because there's less rejection, right? If you have a full match, then your body will accept the new cells and vice versa. So, with a half match, there's a higher risk of rejection. So, that's why they're not our first choice, but it is feasible to do that type of transplant […] That risk of what I would call rejection, graft rejection, varies depending on how well matched the donor is. If we have what we would consider a perfectly matched donor, that risk is less than 10%. If we don't have a match donor and we have to use, say, a son or a daughter or cord blood, the risk of rejection in the cells not taking could be up to 25%. So, we stack the odds in our favor by searching for a fully matched donor […] Similar to the graft rejection problem, we minimize our graft versus host disease risk by finding a perfect match. And so, if we're using a donor source where we don't have that perfect match, we have a higher risk of this problem as well." Hematologist #7

"So, this is a type of transplant in which we have to find someone whose DNA matches as closely as possible to your DNA so that when we give you the cells, your body does not reject them. When we give you the cells, they do their job, and they keep the MDS under control. And lastly, to minimize the risk of something we call graft versus host disease or GVHD, it's a complication of transplant […] I would still prefer right now just as a personal preference to still explore fully matched donor options first before using the haplo option." Hematologist #13

"That goes back to the initial discussion about how similar or different the donor and the recipient are with relation to the immune system. Definitely, the more different they are, the higher the risk of graft versus host disease." Hematologist #15

"If we had a choice between a matched donor outside of your family and a half-matched donor inside your family? We would actually take the outside of the family donor. We think that's preferable. So that's one part of this in terms of risk." Hematologist #18

"The most important in our eyes are, you know, how closely related, how similar their immune system is to yours and their age. And so, we will ultimately select a donor who is going to give us, we hope, a good chance of curing your MDS, but without

causing you lots of complications and side effects from the transplant itself." Hematologist #25

"There's one backup option of donors, which I don't think we'll go to, but it's good to know there's a backup option. The backup option in this case are your children […] We haven't used that predominantly as the first try yet because half matched transplant is a relatively new phenomenon. We don't have as much experience as using the completely matched donor yet, even though the preliminary result is quite similar. So that's why if you have matched unrelated donor from the registry, we'll still go to them first before using your children." Hematologist #6

With the Black patient (n=17) -The hematologists explained haploidentical transplant would be a likely and reasonable choice emphasizing recent advances with its' use.

"So, if one of your children were your donor, and that's something we do routinely, we would change the recipe for the conditioning therapy a little bit and change some of the medicines we use to prevent graft versus host disease. But we have been successful at getting patients through." Hematologist #33

"Now the field is evolving into using half match because if you have three children and each one of them is actually half your match and the other half is from their mothers. […] So, in the last few years, we've been doing a lot of what we call half-blood transplants, means half match. And we've been getting some good results with that." Hematologist #1

"Our preference would be to first see if one of your siblings or an unrelated donor was a complete match for you. And if that weren't the case, then you know, all of your children are going to be half matches for you. So, we can also consider using them as donors for the transplant. It just changes a little bit how we do the transplant, but the outcomes can be as favorable as if we're using a completely matched donor. So, that would be our, kind of our, I guess, our next level in this hierarchy." Hematologist #17

"Considering that you have three siblings and you have three kids, the chances of one of them being a donor for you is quite high. OK? Children are half donors. They have half the genes of you. And with the way we do transplants these days, they're sometimes just as good as a full matched sibling donor." Hematologist #3

"With recent advances in the technology of transplant, we're able to allow the use of a so-called half-matched or haploidentical donor and achieve outcomes which are equal or sometimes even better than other donor sources." Hematologist #19

Box 2: Ancestry history taking and the role of race/ethnicity in finding a match

With the white patient (n=20) -Hematologists often asked the white patient about his ancestry and frequently discussed the high chance of finding an unrelated donor in the donor registry compared to patients of racial minorities.

"Now we're going back to why I ask you about your ethnic background. The worldwide registry actually has an overabundance of western, of Europeans, white Europeans, and that's partially German Polish background, so you probably will have a lot of potentially matched unrelated donors in the registry. This will also give us the chance to pick the youngest or the healthiest donor if you have more than one donor available." Hematologist #6

"What is your ancestry? […] The reason I ask, and it is an odd question I know to ask in the consultation, is that the majority of donors in the unrelated donor database are of European ancestry. So, individuals of that type of ancestry actually have a very good chance of finding a match in the unrelated donor database." Hematologist #9

"The chances of finding a donor are higher for Caucasians. And as you go down the racial and ethnic minority spectrum, it becomes harder and harder. It's the hardest for African-American patients. For you, I'd say, 60 to 80 percent chance we'd be able to find a donor through the registry." Hematologist #13

"People who have a northern European background have a higher likelihood of finding a donor than people who do not […] We also don't have very good representation in the National Marrow Donor Program for people who are African-American or people who are Hispanic, so they have a lower likelihood of finding a donor." Hematologist #18

With the Black patient (n=17) -The hematologists never asked about ancestry. The patient was less likely to receive information about the international donor registry and some overestimated the odds for him of finding an unrelated donor.

"We can look in the registry. There are people who have registered themselves to be bone marrow donors but most of those persons are from Europe. So, if you're Caucasian, your chances of finding a donor are pretty good, but like 70 percent. But for, for me or for an African American or Hispanic, those chances are like maybe 20, 30 percent." Hematologist #21

"The registry has 10 million people. There is a possibility that we will find somebody. As an African-American there's probably a 60 percent chance that somebody out there has your same tissue type." Hematologist #14

Box 3: The assurance of having a donor

With the white patient (n=20) -The hematologists frequently reassured the white patient that he would have multiple donors to choose from to find the best one.

"I think you will have an adequate donor or for the transplant. You have a couple siblings who are young enough, you know, 60 and under is our ideal age for a transplant donor. You have some children and children can be used as transplant donors. Every child is a half match. And you potentially have some unrelated donors who would be a perfect match in the registry. I suspect in your case, it would be a matter of choosing the best donor for you, rather than whether you would have a donor or not." Hematologist #28

"For people who end up not having a match, there are other options, but I think that is something we can leave for another day because I think you have, you have a good chance of having an unrelated donor." Hematologist #9

With the Black patient (n=17) -The hematologists frequently reassured the Black patient he would have a donor. Many expressed that one of the patient's children would be a donor.

"When people have children, that almost assures us that they have a match. […] I think you have one good thing, which is you've got, I'm pretty confident you have a donor. One of your three children will be a donor." Hematologist #23

"I think for you, your situation, you have good odds, both because you have several siblings and then your children are guaranteed to be half matches. So, if nothing else, one of your children would be a good donor." Hematologist #34

"And your donor, whoever we chose, one of your children, would also have a couple visits where they have their own doctor to make sure that they're healthy enough to be the donor for you." Hematologist #36

"So, we're going to type your kids. And so, one of your kids will be our donor if we don't find a sibling or an unrelated donor." Hematologist #21

"These days, that's usually not the limiting factor and we can usually find a match, being through this registry or in the family, now that we're accepting donors who are not completely matched as well. So, I don't think that's going to be a limiting factor. That's really pretty unusual now that we can't find a good, good donor." Hematologist #5

Box 4: Deferring the discussion of donor options at the first visit
With the white patient (n=20) -Some hematologists deferred discussing donor options as finding a donor would be unlikely to pose a problem. “The bone marrow transplant option involves, first off, finding a donor. I won't talk in more detail about that because we can almost sort, almost always sort that out.” Hematologist #27
With the Black patient (n=17) -Some hematologists deferred discussing donor options out of concern for other barriers. “But we are kind of jumping ahead. I mean, it's important that we assess what donors you have and that you have donors available to you because we can't do the transplant without that. But I need you to be focused on, you know, one if you want to move forward with it after doing all the side effects.” Hematologist #3 “So, I put off the decision until we have all the pieces of information. Because then, you know, because then sometimes there's something that doesn't work out. You know, we can't find a donor or social environment is not supportive of the intensive need for supportive care, transportation, whatever it is. I mean, sometimes it just is not going to be a good idea.” Hematologist #30