



Health Services Research Program

Annual Report

2014

The CIBMTR[®] (Center for International Blood and Marrow Transplant Research), is a research collaboration between the National Marrow Donor Program[®]/Be The Match[®] and Medical College of Wisconsin (MCW).

For more information on the Health Services Research Program, contact:

Linda Burns, MD
Vice President and Medical Director, Health Services Research, NMDP
Member, CIBMTR Executive Committee
Email: lburns2@nmdp.org
Phone: 612-460-4273

Ellen Denzen, MS
Senior Manager, Health Services Research, NMDP
Email: edenzen@nmdp.org
Phone: (612) 884-8562

HEALTH SERVICES RESEARCH PROGRAM

Hematopoietic cell transplantation (HCT) is an established treatment for patients with life threatening hematologic cancers and other diseases. At the same time, it is a highly specialized and resource-intensive medical procedure. Approximately 20,000 HCTs are performed in the United States annually, and that number is expected to increase with technological advances, improved outcomes and the introduction of newer indications and donor sources.

To address the need for more research in health services and health policy issues related to HCT, the National Marrow Donor Program®/Be The Match® (NMDP®) operationalized the Health Services Research (HSR) Program in 2006. The program was formally established in 2008, successfully integrating CIBMTR resources and expertise in HCT-related research with Be the Match Patient and Health Professional Services expertise in HSR, access to networks, and relationships with patients and health care providers.

What is Health Services Research?

HSR studies how social factors, financing systems, organizational structures and processes, health technologies and personal behaviors affect access to health care, the quality and cost of health care, and ultimately patients' health and well-being (AcademyHealth, 2012). Recent HSR focus has been on patient-centered outcomes research, which involves including patients and caregivers in the research process and emphasizes helping patients and their caregivers communicate and make informed healthcare decisions (PCORI, 2013).

HSR Program Goals

The HSR team strives to conduct research that achieves national, peer recognition for its contribution to creating new knowledge and for its value in informing HCT practice and policy. It seeks to accomplish these goals through the following efforts:

- Establish and sustain partnerships with top-tier academic institutions, research organizations and senior researchers;
- Build a cadre of health services researchers through training/education, mentoring and experience on research and evaluation projects;
- Develop and improve methods and techniques for HSR related to HCT;
- Proactively seek external contract and grant funding; and
- Communicate effectively with HSR professionals and the HCT community.

HSR PROGRAM FOCUS AREAS

The HSR program conducts research on several health services and health policy topics related to HCT, including but not limited to: healthcare disparities in access to and outcomes of HCT; characterizing patient barriers; economic aspects of HCT (e.g. costs, cost-effectiveness); patient and population health status and quality of life; practice patterns and their impact on HCT outcomes; quality of care; and survivorship. Its activities complement research conducted using the CIBMTR database by the CIBMTR Health Services and International Issues Working Committee. The Program's agenda is addressed via six major focus areas (**Figure 1**).



Figure 1. HSR Program Focus Areas

Research

The HSR Program conducts research using quantitative and qualitative research methods including focus groups, survey research, secondary data analysis, cost-effectiveness research, and clinical trials.

Selected ongoing research studies include:

- Identifying HCT Patient Housing and Caregiver Challenges and Potential Interventions:* This mixed-method study was conducted to support efforts of the System Capacity Initiative (see below). Focus groups and a national survey of transplant center social workers were conducted to identify barriers and solutions in practice to address patient housing and caregiver needs (currently in manuscript development).
- Easy-To-Read Informed Consent For Hematopoietic Cell Transplantation Clinical Trials:* This NHLBI-funded, randomized-controlled trial evaluates the effectiveness of a novel easy-to-read consent form for Blood and Marrow Transplant Clinical Trial Network (BMT CTN) clinical trials. To date, 36 patients have been enrolled on the trial (projected accrual is 160). The study also includes an evaluation phase, which involved interviews with BMT CTN PIs, IRB staff, and research nurses and coordinators at 9 transplant centers. The goals of the interviews are to elicit feedback on the perceived helpfulness of the ETRIC template and possible barriers to implementing the template at BMT CTN centers. Preliminary findings from the interviews will be available in 2015.
- Individualized care plans for HCT survivors:* This study evaluates a personalized treatment summary and care plan for transplant survivors. Focus groups of patients/caregivers and transplant center and community clinicians were conducted to optimize care plan content, format and delivery. A randomized study conducted in collaboration with the Resource for Clinical Investigation in Blood and Marrow Transplant (RCI BMT) will evaluate whether the care plan can enhance patient knowledge, health behaviors and health care utilization (currently in accrual phase; funded by a Patient-Centered Outcomes Research Institute award #CD-12-11-4062).
- Payer-Partnered Approach to Community-Based Referral for Hematopoietic Cell Transplantation (HCT):* Phase one of this study aims to identify practice gaps associated with referral to HCT consultation among hematologists/oncologists by conducting three surveys (national, provider with an open-network and provider with a closed-network) as well as focus groups. The goal of the needs assessment is to gain a better understanding of referral practice patterns, clinical-decision making and educational preferences. The results of the needs assessment will be used in phase two to create an educational intervention to address practice gaps (currently in protocol development).

Program Evaluation

The HSR Program is responsible for the evaluation of resources and programs for the Patient and Health Professional Services (PHPS) department. These activities include: assessments to determine target populations' unique information needs to inform program development; and program-specific process and/or outcomes evaluations. An evidenced-based model adapted from the Centers for Disease Control and Prevention's Evaluation Framework (Centers for Disease Control and Prevention, 1999) serves as the foundation for all program and evaluation plans. Utilization-Focused Evaluation methods are also incorporated to ensure results are translated into practice. Select utilization-focused evaluations include:

- *Patient and Health Professional Services (PHPS) Navigation Program:* PHPS Patient Services Coordinators (PSCs) provide one-to-one telephone support to patients, caregivers and families, as well as healthcare professionals, who call or email with transplant-related questions. The Patient Services Survey, mandated by Health Resources and Service Administration and approved by the Office of Management and Budget, is administered to patients, family members and caregivers who contact PHPS. This ongoing evaluation enables PHPS program managers to determine level of satisfaction and degree to which information needs are being met, as well as identify any gaps in services.
- *Caregiver Companion Program (CCP):* The CCP is a psychosocial health intervention for caregivers of HCT patients. The program involves 6 individual coaching sessions and a self-care toolkit. A formative evaluation assesses satisfaction and perceived helpfulness of the program among participants, coaches and transplant center referring staff. It also evaluates its effect on the emotional well-being for caregiver participants such as stress levels and coping skills (currently in data collection phase).
- *Language Access Survey:* This needs assessment utilizes a web-based survey of transplant center (TC) staff who provide support directly or indirectly to Limited English Proficient (LEP) patients and caregivers. The goals are to: understand how language needs are identified at TCs; describe language services provided by TCs; and identify barriers to meeting language needs (currently in data analysis phase).
- *Needs Assessment with Adults Who Received a Hematopoietic Cell Transplant (HCT) at Age 65 or Older:* In partnership with three transplant centers a needs assessment is being conducted to: 1) describe the learning needs of older adults who are pre-HCT, 2) understand the decision-making preferences of older adults pre-HCT, and 3) identify optimal ways to provide effective education to older adults pre-HCT. The results will be used to guide the development of new educational resources for older adults planning for HCT (currently in protocol development phase).

Health Policy

The HSR program actively collaborates with the NMDP Payer Policy department to inform policy related to HCT at the local, state and federal levels. Two studies are in progress:

- *Cost-effectiveness of HCT vs. alternative therapy for older AML patients:* This study aims to look at the cost-effectiveness of HCT as compared to chemotherapy in older patients with acute myeloid leukemia using the Truven Health MarketScan Research Database (currently in data analysis).
- *Cost Analysis of hematopoietic cell transplantation in older patients:* This study aims to describe the costs of HCT, billing and coding practice variation among transplant centers, and variation in payment from the Centers for Medicare and Medicaid (currently in data file preparation).

System Capacity Initiative

HCT in 2020: A System Capacity Initiative (SCI) is a multi-year program sponsored by NMDP since 2009 that has engaged professional organizations, experts, transplant centers, payors and other stakeholders. The aim of this collaborative, national effort is to understand the current capacity for performing HCT and to address the

need for future expansion of infrastructure, personnel and resources to meet the anticipated 2- to 3-fold growth in HCT. The HSR program leads the research and evaluation efforts for the SCI and facilitates SCI-related information dissemination activities.

- *Hematopoietic Cell Transplantation Multidisciplinary Care Teams: Burnout, Moral Distress and Career Satisfaction:* One set of challenges for health professionals in HCT involves adverse consequences of caring: compassion fatigue (secondary traumatic stress), burnout and vicarious traumatization. A web-based survey of HCT health professionals will be conducted to characterize the factors that lead to work-related distress. The study will inform research on strategies and interventions to mitigate these issues in order to overcome some of the barriers of recruitment and retention of workforce in HCT (currently in protocol development).

Clinical Trials Support

A cross-functional PHPS team works collaboratively with the CIBMTR and BMT CTN to develop easy-to-read consent and assent forms, as well as supplemental educational materials, for multi-center HCT clinical trial participants. In 2014, the HSR team developed easy-to-read consent forms for 4 clinical trials (BMT CTN protocols 1301, 1302, 1401, and CIBMTR MOXE protocol). To date, HSR has supported 18 clinical trials with consents, assents and patient education materials.

Training, Education and Consultation

In collaboration with the PHPS education and outreach team, HSR program staff play a key role in guiding training and education opportunities for PHPS staff, other NMDP staff members, and external community partners, ensuring that technical skills and knowledge align with current industry standards. HSR leads the PHPS Peer Review Committee as a consultation resource to PHPS staff to support success with peer-review dissemination efforts including development and submission of abstracts, presentations, and manuscripts. HSR also provides consultation on survey research design and administration, on projects such as the Be The Match Registry® Communication Survey, and the World Marrow Donor Association (WMDA) Qualification Training Program. The HSR Program participates in a formal Master's level training program to develop novice researchers. HSR also participated in the University of Minnesota applied health information analysis mentorship project and was awarded the University of Minnesota's 11th Annual Community Partner Star Award.

INFORMATION AND DISSEMINATION ACTIVITIES

Figure 2 illustrates the HSR Program information dissemination efforts including publications and abstracts for presentation at national, professional conferences and meetings. In 2014, 2 manuscripts were published in peer-reviewed journals (Appendix A) and 5 abstracts (research and evaluation) were accepted for presentation at professional conferences.

Number of publications and abstracts accepted 2011--2014

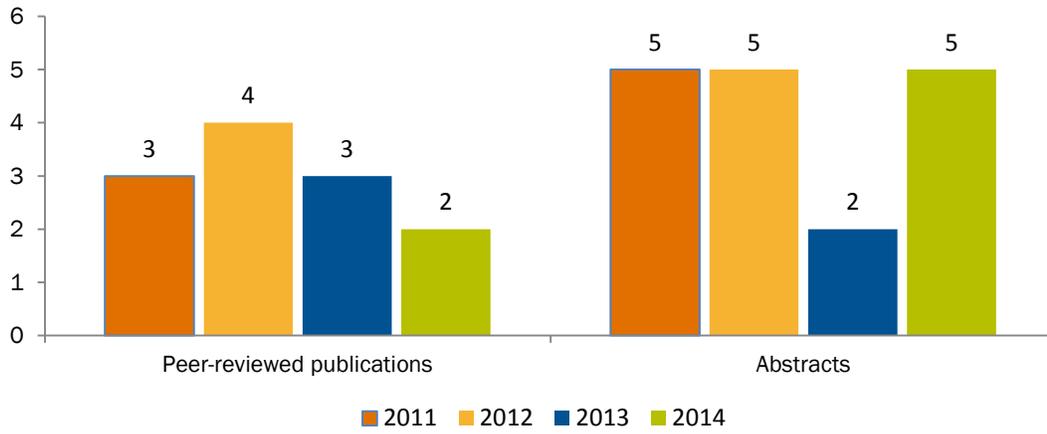


Figure 2. HSR Program publications

Appendix A: HSR Program Publications, 2010-2014

*Not peer-reviewed

Access and Health Care Disparities

1. Majhail NS, Omondi NA, Denzen E, Murphy, E.A., Rizzo, J.D. (2010) Access to hematopoietic cell transplantation in the United States. *Biology of Blood and Marrow Transplant*, 16(8), 1070-1075.
2. Murphy, E., Ferguson, S.S., Omondi, N.A., Getzendaner, L.C., Gajewski, J.L., Goldstein, G.A., Wingard, J.R., Rizzo, J.D., Mahjail, N.S. (2010). National Marrow Donor Program's symposium on patient advocacy in cellular transplant therapy: addressing barriers to hematopoietic cell transplantation. *Biology of Blood and Marrow Transplant*, 16(2), 147-156.
3. Majhail, N.S., Nayyar, S., Burton Santibañez, M.E., Murphy, E.A., Denzen, E.M. (2012). Racial disparities in hematopoietic cell transplantation in the United States. *Bone Marrow Transplantation*, 47(11), 1385-1390.
4. Moore, H. K., Burton Santibañez, M. E., Denzen, E. M., Carr, D. W., Murphy, E. A. (2013). Barriers to accessing healthcare for hematopoietic cell transplant recipients living in rural areas: Perspectives from healthcare providers. *Clinical Journal of Oncology Nursing*, 17(4), 405-411.
5. Omondi, N. A., Stickney Ferguson, S. E. Majhail, N. S., Denzen, E. M., Buchanan, G. R., Haight, A. E., Lobatka, R. J., Rizzo, J. D., Murphy, E. A. (2013). Barriers to Hematopoietic Cell Transplantation Clinical Trial Participation of African-American and Black Youth with Sickle Cell Disease and Their Parents. *Journal of Pediatric Hematology and Oncology*. 35(4), 289-298.

Economics of HCT

6. Preussler, J., Denzen, E.M., Majhail, N.S. (2012). Costs and cost-effectiveness of hematopoietic cell transplantation. *Biology of Blood and Marrow Transplant*, 18(11):1620-1628.
7. Majhail, N. S., Mau, L.W., Denzen, E. M., Arneson, T. J. (2012). Costs of Autologous and Allogeneic Hematopoietic Cell Transplantation in the United States: A Study Using a Large National Private Claims Database. *Bone Marrow Transplantation*, 48, 294–300.
8. Majhail, N. S., Rizzo, J. D., Hahn, T., Lee, S. J., McCarthy, P. L., Ammi, M., Denzen, E. M., Drexler, R., Flesch, S., James, H., Omondi, N., Pedersen, T. L., Murphy, E. A., Pederson, K. (2013). Pilot Study of Patient and Caregiver Out-of-Pocket Costs of Allogeneic Hematopoietic Cell Transplantation. *Bone Marrow Transplant*. 48(6), 865–871.

Health Policy

9. Preussler, J.M., Farnia, S., Denzen, E.M., Majhail, N.S. (2013). The Need for Essential Health Benefits for Complex Medical Procedures: A Case Study of Medicaid Coverage for Transplant. *Journal of Oncology Practice*.

HCT Capacity and Quality of Care

10. Majhail, N.S., Murphy, E.A., Omondi, N.A., Robinett, P., Gajewski, J.L., LeMaistre, C.F., Confer, D., Rizzo, J.D. (2011). Allogeneic transplant physician and center capacity in the United States. *Biology of Blood and Marrow Transplant*, 17(7), 956-961.

11. *Majhail, N.S., Chell, J.W., Snyder, E.L. (2012). Addressing workforce and infrastructure challenges to the growth of hematopoietic cell transplantation: The System Capacity Initiative. *The Hematologist*, 9(3):14.
12. Majhail, N.S., Murphy, E.A., Denzen, E., Stickney Ferguson, S., Anasetti, C., Bracey, A., Burns, L., Champlin, R., Hubbard, N., Markowitz, M., Maziarz, R.T., Medoff, E., Neumann, J., Schmit-Pokorny, K., Weisdorf, D.J., Yolin Raley, D.S., Chell, J., Snyder, E.L. (2012). The National Marrow Donor Program's symposium on hematopoietic cell transplantation in 2020: A health care resource and infrastructure assessment. *Biology of Blood and Marrow Transplant*, 18(2), 172-182.
13. *Murphy, E.A., Sylvanus, T., Tierney, D.K., Denzen, E.M., De Kesel Lofthus, A., Neumann, J. (2012). Addressing workforce and infrastructure challenges to the growth of blood and marrow transplantation: The System Capacity Initiative. *ONS Connect*, November, 20.
14. Denzen, E.M., Majhail, N.S., Stickney Ferguson, S., Anasetti, C., Bracey, A., Burns, L., Champlin, R., Chell, J., Leather, H., Lill, M., Maziarz, R.T., Medoff, E., Neumann, J., Schmit-Pokorny, K., Snyder, E.L., Wiggins, L., Yolin Raley, D.S., Murphy, E.A. (2013). Hematopoietic cell transplantation in 2020: Summary of Year II recommendations from the National Marrow Donor Program's System Capacity Initiative. *Biology of Blood and Marrow Transplant*, 19(1):4-11.

Clinical Trials Support

15. Denzen, E., Burton Santibañez, M., Moore, H., Foley, A., Gersten, I.D., Gurgol, C., Majhail, N.S., Spellecy, R., Horowitz, M.H., Murphy, E.A. (2011). Developing easy-to-read informed consent documents for hematopoietic clinical trials. *Biology of Blood and Marrow Transplant*, 18(2), 183-189.

Program Evaluation

16. Omondi, N.A., Denzen, E., Jacobson, D., Payton, T., Pederson, K., Murphy, E.A. (2010). Evaluating patient satisfaction with the Office of Patient Advocacy. *Journal of Cancer Education*, 26(1), 44-50.
17. Moore, H.K., Preussler, J., Denzen, E.M., Payton, T.J., Thao, V., Murphy, E.A., Harwood, E. (2014). Designing and operationalizing a customized internal evaluation model. *Journal of Cancer Education*, 29(3), 463-472.