Health Services Research Program

Annual Report

2013

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).

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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 improvements, 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, Be The Match 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 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).

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 by:

- Establishing and sustaining partnerships with top-tier academic institutions, research organizations and senior researchers;
- Building a cadre of health services researchers through training/education, mentoring and experience on research and evaluation projects;
- Developing and improving methods and techniques for HSR related to HCT;
- Proactively seeking external contract and grant funding; and
- Communicating 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).
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:

- **Transplant Provider and Center Factors and Outcomes of Allogeneic Hematopoietic Cell Transplantation:** A national survey to capture data on US transplant center characteristics was conducted in 2012. Survey results were merged with HCT survival data from the CIBMTR, and analyzed for association between center factors and allogeneic HCT outcomes (currently in manuscript development).

- **Identifying HCT Patient Housing and Caregiver Challenges and Potential Interventions:** This project was conducted to support efforts of the System Capacity Initiative (see below). Focus groups were conducted to identify barriers and potential interventions to address patient housing and caregiver needs. Results were used to design a national survey, administered to transplant center social workers. The goal was to learn more about barriers and innovative solutions in practice (currently in data analysis).

- **Easy-to-read informed consent for hematopoietic cell transplantation clinical trials:** This randomized controlled trial is being conducted through the Blood and Marrow Transplant Clinical Trials Network (BMT CTN 1205 study) and is evaluating the effectiveness of a novel easy-to-read consent form for multi-center HCT clinical trials (currently in enrollment phase; funded by the National Heart, Lung and Blood Institute).

- **Individualized care plans for HCT survivors:** This study will evaluate a 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 protocol development phase; funded by the Patient-Centered Outcomes Research Institute).

Program Evaluation

The HSR Program is responsible for the evaluation of resources and programs for the Patient and Health Professional Services department. These activities can be categorized into three broad areas: Patient Services Survey (OMB 0915-0212) to assess satisfaction with department services; program-specific process and/or outcomes evaluations, and evaluations of department’s training and education activities. An evidenced-based model based on 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 in evaluation planning to ensure results are translated into practice. Selected utilization-focused evaluations include:
• **Caregiver Companion Program**: This program is a psychosocial health intervention for caregivers of HCT patients. An evaluation project is assessing satisfaction and perceived helpfulness of this program among participants, coaches and transplant centers; and its effect on emotional well-being for caregiver participants (currently in data collection phase).

• **Post-Transplant Care Guides**: Patient-focused post-transplant care guides were developed to facilitate follow-up care for HCT recipients based on preventive care guidelines developed by a CIBMTR Workgroup. To evaluate their effectiveness, a longitudinal, repeat-measures survey was administered at 6, 12 and 24 months post-HCT to a nationally representative cohort of transplant recipients. Results will be used to improve the care guides, precision of information sharing measures and to identify communication barriers (currently in data analysis phase).

**Health Policy**

The HSR program actively works in collaboration with the Be The Match Payor Policy department to inform policy related to HCT at the local, state and federal levels. One study is 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 CIBMTR and administrative claims databases (currently in protocol development).

**System Capacity Initiative**

HCT in 2020: A System Capacity Initiative (SCI) is a multi-year program sponsored by Be The Match 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. Be The Match, in partnership with the ASBMT, convened the Year IV SCI Workforce Summit in November 2013.

**Clinical Trials Support**

Members of the HSR Program team work collaboratively with the BMT CTN to develop easy-to-read consent and assent forms for participants in multi-center HCT clinical trials. In 2013, the HSR team provided technical and plain language writing support to three clinical trials (protocol BMT CTN 1203, 1204, and 1205). To date, we have developed easy-to-read consents, assents and patient materials for more than 13 clinical trials.

**Training, Education and Consultation**

HSR program staff regularly lead training and education opportunities, ensuring that technical skills and knowledge align with current industry standards. Training focuses on implications of research and evaluation results. HSR provides consultation on abstract, presentation and manuscript development as well as survey research design and administration. The HSR Program participates in the University of Minnesota, School of Public Health M.S. Training Program. This training program serves to develop technical and business skills/knowledge among junior health services researchers. To date, 4 Master’s level interns have completed this 2-year training program.
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 2013, 3 manuscripts were published in peer-reviewed journals (Appendix A) and 5 abstracts (research and evaluation) were accepted for presentation at professional conferences. In addition to research abstracts, the HSR Program collaborates with Patient and Health Professional Services staff to develop presentations addressing education needs of patients and healthcare professionals.

![Figure 2. HSR Program publications](image-url)
Appendix-A: HSR Program Publications, 2010-2013

*Not peer-reviewed

Access and Health Care Disparities


Economics of HCT


HCT Capacity and Quality of Care


Clinical Trials Support


Program Evaluation