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Access to Linguistically Appropriate Information for Blood and Marrow Transplant Patients: Results from Transplant Center Staff Survey

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Abstract

Blood or marrow transplant (BMT) is a potentially curative treatment for numerous cancers and non-malignant disorders. BMT is a resource-intense treatment process, requiring patients to comprehend difficult health information and navigate a complex healthcare system. Linguistic and cultural barriers create additional challenges for patients with limited English proficiency (LEP) who may need translated information and interpretive services to make an informed decision about treatment. To identify information needs and gaps in language services for BMT patients with LEP, the National Marrow Donor Program® (NMDP)/Be The Match® administered a cross-sectional, web-based survey to 139 transplant centers (TCs) across the United States (U.S.). The survey yielded a 59% response rate. Findings show a significant need for translated patient education materials, especially in Spanish, Chinese, and Arabic, and practice gaps in the use of appropriate interpreters. Nearly one third of respondents indicated using family and friends to interpret for patients. The inability to locate educational resources in a specific language, lack of available bilingual staff, lack of a formal, centralized tracking system, and outdated tracking systems also pose significant barriers to meeting the language needs of BMT patients with LEP.

Keywords Limited english proficient · Language access · Blood and marrow transplant · Bone marrow transplant · Blood disorders

Background

More than 25 million individuals in the United States (U.S.) are considered to have limited English proficiency (LEP), for whom access to and comprehension of healthcare information is a significant challenge [1]. For these individuals, linguistic barriers contribute to disparities in healthcare and outcomes [2–4]. Numerous studies illustrate that individuals with LEP experience worse access to care, low quality of care, limited comprehension of medication instruction, non-adherence to treatment regimen(s), fewer follow-up visits, poor health outcomes, and difficulty communicating with providers [4–9]. Furthermore, the lack of appropriate language services, such as oral interpretation and translation, prevents individuals with LEP from accessing primary and preventative care, which in turn contributes to the rising cost of healthcare [10]. Literature cites that fewer than 20% of patients with LEP were consistently provided certified medical interpreter (CMI) services due to various reasons including time constraints, and lack of available and accessible interpreters [11]. Studies have also found that communication problems are more likely to result in serious harm more frequently for individuals with LEP [8].

To address these challenges and improve communication between individuals with LEP and healthcare providers, a number of federal policies and guidelines have been issued. Title VI of the Civil Rights Act of 1964 and Executive Order 131669 require recipients of federal funds to take reasonable steps to ensure meaningful access to their programs, services, and activities by eligible groups with LEP [12]. Furthermore, the National Standards for Culturally and Linguistically Appropriate Services (CLAS) mandate language access services for all recipients of federal funds [13]. In addition, the Joint Commission developed new standards on patient-centered communication stressing the importance of language service, cultural competence, and patient-centered care [14]. The Institute of Medicine (IOM) report, *Crossing the Quality*

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Chasm, also emphasizes patient safety and clear communication as important components of patient-centered care [15].

The 2014 National Healthcare Quality and Disparities Report identified effective patient-provider communication, as a mitigating factor in health disparities, promoting comprehension and follow-up versus confusion and non-adherence [16]. It is also an optimal approach to patient-centered care [17]. This is especially true in the treatment of life-threatening diagnoses such as cancer where patient-provider conversations often involve complex, confusing, and emotional discussions [18], even more so when placed in the context of conceptually abstract treatments such as blood and marrow transplant (BMT) [19].

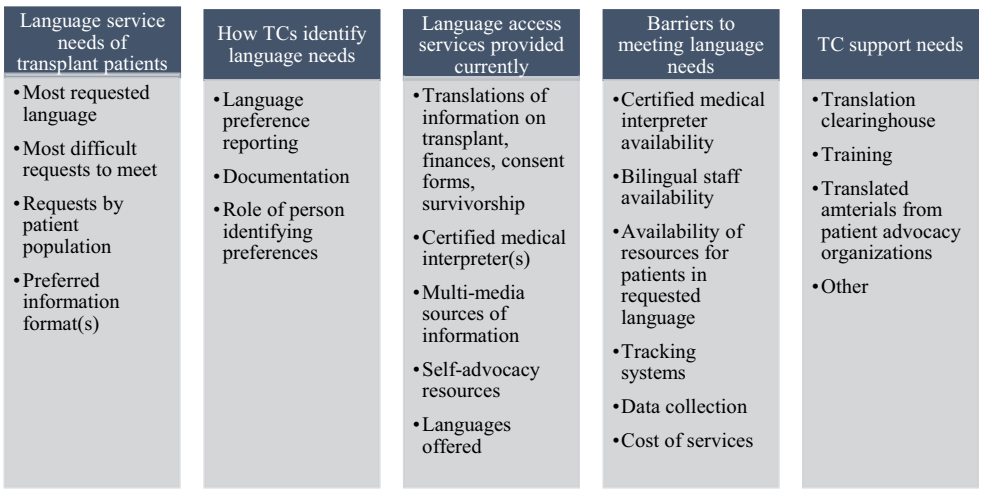
BMT is a potentially curative treatment for numerous cancers and genetic or immune disorders [17]. An estimated 17,500 people need an allogeneic BMT each year in the U.S. [20]. Patients considering this complex therapy face a steep learning curve with an overwhelming amount of information, much of which is provided using clinical language that is difficult to comprehend, even for proficient English speakers. This is often coupled with an urgent need to start the treatment. Understanding the language access and information needs of BMT patients and their families is critical to facilitating informed treatment decisions and reducing the risk of negative outcomes [21, 22].

The National Marrow Donor Program® (NMDP)/Be The Match® supports patients, families, and healthcare professionals throughout the BMT process, providing free, culturally and linguistically appropriate educational resources. The NMDP has a network of transplant centers (TCs) in the U.S. One aim of the NMDP is to support TCs in meeting the language access needs of their BMT patients. To help accomplish this, a comprehensive assessment was conducted with network TCs to characterize and identify language access needs and practice gaps in language services for BMT patients with LEP.

Methods

A national cross-sectional, web-based survey was administered by email to healthcare professionals and staff identified as the "primary contact" at NMDP/Be The Match network TCs in the U.S. ($N = 139$) through email. Eligibility criteria included (1) work directly or indirectly with BMT patients with LEP; (2) have knowledge on the language access needs of patients with LEP at the TC; (3) be familiar with language access resources and services (interpreting, translation, etc.); and (4) the frequency of language service/resource utilization at the TC. If the participant did not meet the eligibility criteria, they were asked to forward the survey to the most appropriate person at the TC. Non-respondents received two reminder emails at 2-week intervals. A final reminder was made by phone to individuals who did not respond to the email invitations. Each TC was allowed one survey response. Respondents were provided a $25 Visa gift card as honoraria. Funding for the honoraria was provided by NMDP/Be The Match. The study was determined by the NMDP Institutional Review Board not to be a human subjects research.

The Language Access Survey instrument was investigator designed and assessed for face validity by patient education, program evaluation, and social work subject matter experts. This cross-sectional, web-based survey was comprised of 30 items within five domains (Fig. 1): (1) language service and resource needs among patients with LEP; (2) how TCs identify language needs; (3) language access services currently provided by TCs; (4) TC barriers to meeting language needs; and (5) TC language support needs from the NMDP. The full survey instrument is provided for further information (Online Resource 1). Five-point Likert scales were used to measure frequency of language service and resource needs,



*LEP=limited English proficiency; TC=transplant center

Fig. 1 Language access survey domains. LEP, limited English proficiency; TC, transplant center

as well as the frequency of provider-level (e.g., inability to locate interpreters for a specific language and time) and system-level barriers (e.g., lack a language tracking system, outdated tracking system, inadequate training on collecting patient's preferred language, and staff unavailability to consistently collect and document language needs). Likert scales were also used to measure frequency of language service requests by patients (such as telephone and in-person interpreting, and translated materials in a variety of formats).

TC patient volume (number of BMTs performed annually) and geographic location were extracted from the Stem Cell Therapeutic Outcomes Database with the Center for International Blood and Marrow Transplant Research (CIBMTR). Geographic regions were determined per U.S. census standards (Midwest, Northeast, South, West) [23].

Descriptive statistics were used to illustrate the distribution of respondent characteristics and examine frequency of key questions related to language access needs and barriers by TC patient volume (small, 1–100; medium, 101–300; large, more than 300). In order to meet Chi-square test assumptions, Likert scales were collapsed into two categories, "often" and "not often," for comparison of language service requests and provider-level/system-level barriers by geographic region and patient population. Respondents with missing geographic region and/or center volume ($N = 5$) were excluded from Chi-square or Fisher's exact tests. Age ranges for the adult and pediatric patient population groups were deliberately undefined, as definitions vary across TCs. Data was collected using SurveyGizmo and analyzed in the statistical software programs SPSS Statistics version 10.0 and SAS Enterprise Guide version 6.1.

Results

The survey yielded a 59% response rate ($N = 82$). Most respondents were social workers (76%) who provided care at medium-volume TCs (35%) or large TCs (29%). Nearly 40% of respondents worked with both pediatric and adult patient populations. One third had more than 10 years of experience in BMT (34%). Respondents were geographically representative of the U.S. Across all geographic regions, respondents indicated that preferred language is self-reported by the patient (68%). A complete demographic profile is provided in Table 1.

Table 1 Language access survey respondent demographics

Demographics	Small (1–100) $n = 18$	Medium (101–300) $n = 29$	Large (> 300) $n = 24$	Transplant center unknown $n = 11$	Total $N = 82$
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Years in BMT					
0–2	2 (11.1)	2 (6.9)	2 (8.3)	–	6 (7.3)
3–5	3 (16.7)	5 (17.2)	4 (16.7)	1 (9.1)	13 (15.9)
6–10	3 (16.7)	4 (13.8)	3 (12.5)	–	10 (12.2)
More than 10	3 (16.7)	15 (51.7)	9 (37.5)	1 (9.1)	28 (34.1)
Missing	7 (38.9)	3 (10.3)	6 (25)	9 (81.8)	25 (30.5)
Role in BMT					
Social Worker	14 (77.8)	27 (93.1)	19 (79.2)	2 (18.2)	62 (75.6)
Patient Educator/Advocate	1 (5.6)	–	–	–	1 (1.2)
Transplant Coordinator	–	1 (3.4)	–	–	1 (1.2)
Missing	3 (16.7)	1 (3.4)	5 (20.8)	9 (81.8)	18 (22)
Patient population					
Pediatric	12 (66.7)	5 (17.2)	2 (8.3)	–	19 (23.2)
Adult	4 (22.2)	14 (48.3)	4 (16.7)	–	22 (26.8)
Both	2 (11.1)	10 (34.5)	18 (75)	–	30 (36.6)
Missing	–	–	–	11 (100)	11 (13.4)
U.S. region					
Midwest	7 (38.9)	5 (17.2)	8 (33.3)	2 (18.2)	22 (26.8)
Northeast	2 (11.1)	8 (27.6)	6 (25)	1 (9.1)	17 (20.7)
South	3 (16.7)	10 (34.5)	4 (16.7)	5 (45.5)	22 (26.8)
West	4 (22.2)	6 (20.7)	6 (25)	–	16 (19.5)
Missing	2 (11.1)	–	–	3 (27.3)	5 (6.1)

Most Requested and Difficult Language Needs To Meet

More than 90% of respondents indicated that Spanish was the most frequently requested non-English language across all geographic regions, followed by Chinese (29.3%), Arabic (23.2%), Vietnamese (11.0%), and Portuguese (8.5%) (Table 2). Chinese was more frequently requested in the Northeast and West regions; Vietnamese more frequently in the West, and Portuguese was requested most often in the Northeast ($P < 0.05$, respectively). Other languages did not see significant variation in requests by region. Respondents were asked to report the "top 3" most difficult language needs to meet. Chinese (19.5%), Arabic (13.4%), and Vietnamese and Creole (9.8% each) were most often included in the top 3. The other three most difficult language needs that were also included as top 3 most difficult language needs to meet were American Sign Language (9%), and Burmese and Russian (6.1% each), and Portuguese and Chuukese (3.7% each). The most difficult language needs to meet significantly varied by region, including Creole in the South, Burmese in the Midwest, Portuguese in the Northeast, and Chuukese in the West ($P < 0.05$, respectively).

Language Service and Resource Availability and Utilization

The most often-needed resources included: translated information on the transplant process (51.9%), telephone-based interpreter (49.4%), translated information for caregivers (46.8%), in-person interpreters and translated information on emotional/mental health issues related to HCT (45.6%) (Table 3). The need for in-person interpreters and translated information for caregivers was significantly associated with TCs serving the pediatric patient population ($P < 0.05$). In-house full-time (39%) and part-time (23%) interpreter staff were available resources. The need for in-house full-time and part-time interpreter staff was significantly associated with the pediatric patient population only ($P < 0.05$). Nearly 43% of respondents indicated that their TC did not develop its own educational resources in a language other than English. From respondents that indicated that their centers developed its own educational resources, about 27% did so in Spanish. Across all geographic regions, respondents indicated that preferred language is self-reported by the patient (68%) but nearly one third reported that they rely on family and friends to interpret for patients with LEP.

Table 2 Regional variation in requests and difficulty in meeting needs by language ($N = 77$)

Demographics	Midwest $n = 22$ n (%)	Northeast $n = 17$ n (%)	South $n = 22$ n (%)	West $n = 16$ n (%)	Total $N = 77$ n (%)	χ^2 or Fisher's exact P value
Most often requested languages (in general)						
Spanish	20 (90.9)	17 (100)	22 (100)	16 (100)	75 (91.5)	0.2454
Chinese	3 (13.6)	7 (41.2)	5 (22.7)	9 (56.3)	24 (29.3)	0.0245
Arabic	10 (45.5)	3 (17.6)	4 (18.2)	2 (12.5)	19 (23.2)	0.0832
Vietnamese	1 (4.5)	–	3 (13.6)	5 (31.3)	9 (11.0)	0.0211
Portuguese	–	6 (35.3)	1 (4.5)	–	7 (8.5)	0.0007
Most difficult language needs to meet (in general)						
Chinese	3 (13.6)	4 (23.5)	4 (18.2)	5 (31.3)	16 (19.5)	0.5742
Arabic	6 (27.3)	1 (5.9)	3 (13.6)	1 (6.3)	11 (13.4)	0.2498
Creole	–	3 (17.6)	5 (22.7)	–	8 (9.8)	0.0187
Vietnamese	–	1 (5.9)	5 (22.7)	2 (12.5)	8 (9.8)	0.0585
ASL	1 (4.5)	2 (11.8)	1 (4.5)	3 (18.8)	7 (8.5)	0.3909
Burmese	4 (18.2)	1 (5.9)	–	–	5 (6.1)	0.0485
Russian	4 (18.2)	–	1 (4.5)	–	5 (6.1)	0.0938
Portuguese	–	3 (17.6)	–	–	3 (3.7)	0.0170
Chuukese	–	–	–	3 (18.8)	3 (3.7)	0.0077

Respondents with missing geographic region and/or center volume ($n = 5$) were excluded from Chi-square or Fisher's exact tests

ASL American Sign Language

Table 3 Frequency of language services and resources needs and barriers at transplant centers in U.S. ($N = 79$)

Needs	Often *n* (%)	Not Often *n* (%)	Missing responses[+] *n* (%)
Resources/services			
In-person interpreter*	36 (45.6)	26 (32.9)	17 (21.5)
Telephone-based interpreter	39 (49.4)	24 (30.4)	16 (20.3)
Translated information on the transplant process	41 (51.9)	22 (27.8)	16 (20.3)
Translated information on emotional/mental health issues related to HCT	36 (45.6)	27 (34.2)	16 (20.3)
Translated information on insurance/financial issues	35 (44.3)	28 (35.4)	16 (20.3)
Translated information on GVHD	35 (44.3)	27 (34.2)	17 (21.5)
Translated information for caregivers*	37 (46.8)	25 (31.6)	17 (21.5)
Translated information on survivorship issues	27 (34.2)	35 (44.3)	17 (21.5)
Translated self-advocacy fact sheets	27 (34.2)	34 (43.0)	18 (22.8)
Barriers			
Provider-level factors			
Unable to locate patient education resources for a specific language	34 (43.0)	38 (48.1)	7 (8.9)
Bilingual staff unavailable	30 (38.0)	44 (55.7)	5 (6.3)
Unable to locate specific interpreter requested by a patient/provider (previously worked with patient)	16 (20.3)	58 (73.4)	5 (6.3)
Unable to locate an interpreter for the time needed	15 (19.0)	59 (74.7)	5 (6.3)
Unable to locate an interpreter for a specific language	7 (8.9)	67 (84.8)	5 (6.3)
Request for interpreter not submitted in a timely manner	5 (6.3)	68 (86.1)	6 (7.6)
System-level factors			
Formal, centralized tracking system unavailable (i.e., varies by department)	16 (20.3)	50 (63.3)	13 (16.5)
Outdated tracking system (i.e., not per current language access standards)	13 (16.5)	52 (65.8)	14 (17.7)
Staff unavailable to consistently collect and document language needs	7 (8.9)	57 (72.2)	15 (19.0)
Inadequate training on collecting patient's preferred language	6 (7.6)	59 (74.7)	14 (17.7)

Often very often/often; *Not often* occasionally/rarely/never

[+] Missing responses to listed questions only, which might be due to services/resources not applicable for the center or unknown to the respondent

*P value < 0.05

Barriers to Meeting Language Access Needs

Barriers to meeting language access needs were evaluated for provider-level and system-level factors (Table 3). Of the provider-level factors, the inability to locate patient education resources for a specific language occurred most often (43.0%), followed by unavailability of bilingual staff (38.0%), inability to locate a specific interpreter requested by a patient or provider (20.3%), and inability to locate an interpreter for the time needed (19.0%) were experienced very often/often. The inability to locate an interpreter for the time needed was significantly associated with the pediatric patient populations ($P < 0.05$). The most common system-level factors that present challenges in serving patients with LEP included lack of a formal, centralized tracking system (20.3%), outdated tracking system (16.5%), unavailability of staff consistently collecting and documenting language needs (8.9%), and inadequate training on collecting patient's preferred language (7.6%). Inadequate training on collecting the patient's preferred language was significantly associated with the adult patient only TCs ($P < 0.05$).

Discussion

The findings presented in this paper are from the first comprehensive assessment of language access needs among BMT patients with LEP to date. The survey results confirmed the need for customized language resources and services to support patients with LEP as they navigate treatment decisions and BMT treatment trajectory. The results are also consistent with anecdotal evidence from TC staff. Since TCs typically operate within a larger cancer center and/or hospital system,

these results may also reflect the language access needs and gaps within the larger system.

Educational resources translated into Spanish, Chinese, and Arabic are most needed by the BMT patient population. While all age groups require translated educational resources, they are needed most often for adults. Brochures and booklets are the preferred format with content focused on the BMT process. Telephone-based services are the most commonly used interpreter resource although previous research suggests in-person interpretation may be more effective for clinical scenarios with complex medical procedures and psychosocial components [24]. While there is not one single model of interpretive services and systems that can be recommended across all TCs, best practices include access to 24-h oral language assistance, delivery of timely interpretive services, and competent interpretation through standardized interpreter training and evaluation [25]. Despite recommendations against the practice, non-qualified "ad hoc" interpreters, such as family members and friends, are still used.

Geographic variation in language requests can pose additional challenges for some TCs in meeting language access needs. For example, Chinese and Arabic are in the "top 3" most common requests along with Spanish, but also in the "top 3" most difficult language requests to meet across the U.S. Areas that have not historically had large settlements of Chinese and/or Arabic speakers may not be equipped to provide interpretive services and educational materials in these languages. Furthermore, smaller TCs that may have limited resources may not be able to provide additional support for patients with LEP. These smaller centers must rely on external advocacy organizations to be able to provide culturally and linguistically appropriate services to meet the needs of their growing LEP populations.

Additionally, time constraints and lack of awareness of existing resources affect providers' ability to locate educational resources in a specific language. The lack of available bilingual staff to provide interpretation and consistently collect and document language needs per standardized data collection practices also exacerbate the difficulties in meeting language access needs.

While this survey did not determine the exact number of patients with LEP each participating TC serves, it is evident from the responses that nearly all U.S. TCs care for patients who have LEP and require some form of customized language service or resource. Results also indicate that a standardized provider- and system-level approach are needed to ensure that providers can easily and efficiently access language services and resources to optimize care for BMT patients with LEP.

To identify and address the need for resources for BMT patients with LEP, we recommend TCs implement several practices. First, TC staff regularly and consistently assess patients' language preferences. We also recommend providing translated brochures and booklets on the BMT process and tailoring the content and formatting to address the unique learning needs of each age group—pediatrics, AYAs, adults, and seniors. To communicate the availability of translated educational resources, TCs are encouraged to share information regarding where and from whom materials can be accessed. Last, to improve competency and ensure quality interpretive services for patients, we recommend providing training to in-house interpreters on BMT and language access laws and policies. TCs should discontinue the use of unqualified interpreters, as this could result in misinterpretations and lead to patient safety concerns and liability issues for providers.

There are a few limitations of our study to consider. First, while we achieved a 59% response, not every TC provided input and patient educators/advocates and TC coordinators are not well represented in the results. TCs with small patient volumes (fewer than 100 patients annually) are not as well represented as centers with medium and large patient volumes. Additionally, we do not have data on the number of patients with LEP who do not access BMT. However, the responses are representative of all U.S. census regions as well as both adult and pediatric patient populations. Furthermore, there was a relatively high percentage of missing data which might be due to the respondent not knowing or the needs/barriers not being applicable to the responding center. Despite these limitations, the descriptive findings provide valuable information for TCs on language access needs and barriers. Of note, the data did not disaggregate differences in dialects within the same language (for example, Mandarin or Cantonese) or preference for the written form (for example, formal or simplified Chinese).

Despite efforts across TCs in the U.S., there remain persistent unmet language access needs for BMT patients with LEP, practice gaps among providers, and system barriers. As more patients with LEP seek access to this complex treatment in a predominantly English-speaking healthcare system, it is imperative for health organizations to identify and meet language needs.

The availability of curative therapies such as HCT offers a second chance at life for many patients. By addressing issues of language access and creating information most relevant for patients with LEP, the BMT community will ensure that underserved patients make truly informed healthcare decisions. The present findings can be used by TC leaders and educators to develop interventions that mitigate barriers to meeting language access needs for patients with LEP.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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