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THE CIBMTR HEMATOPOIETIC CELL TRANSPLANT RECIPIENT TRANSFER TOOL FOR FOLLOW UP MAINTENANCE: ADHERENCE ASSESSMENT OF 24 BRAZILIAN CENTERS AND ONE URUGUAYAN

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ABSTRACT

Introduction: Hematopoietic Cell Transplantation (HCT) remains a curative treatment for several malignant and non-malignant hematologic diseases. Despite significant advances in the field, maintaining long-term clinical follow-up continues to be a major challenge. To enhance continuity of care, the Center for International Blood and Marrow Transplant Research (CIBMTR) developed the patient transfer tool within FormsNet3, allowing the transfer of CRID identifiers between affiliated centers. However, little is known about the extent of adherence to this tool among South American centers**. Objective:** To evaluate the adherence of South American centers to the CIBMTR patient transfer tool, aiming to identify gaps and opportunities to improve data completeness and patient monitoring after HCT. **Methods:** An electronic questionnaire was distributed to South American centers actively participating in the CIBMTR, with at least 12 consecutive months of data reporting. The survey collected information on institutional characteristics, transplant volume, and experience with the CRID transfer tool. Data were analyzed using descriptive statistics and visualized through the Power BI platform. **Results:** Twenty-five centers participated in the study, representing 49% of active South American centers in the CIBMTR, of which 96% were Brazilian. Most centers were located in the Southeast region (70.8%) and included a variety of institutional types: private (44%), public (36%), and mixed (20%) hospitals. Regarding experience with the transfer tool, 60% of centers reported transferring patients, accounting for 67 movements (32 sendings and 35 receivings), predominantly involving adult patients undergoing allogeneic transplants. An asymmetric transfer pattern was observed: public centers primarily received transferred patients, whereas private centers were the main origin centers. **Conclusion:** Although the CIBMTR CRID-patient transfer tool represents a significant advancement in promoting long-term follow-up, its adoption remains limited among South American centers. Low adherence could jeopardize continuity of care and data completeness, ultimately impairing surveillance of late complications and hindering the development of effective prevention strategies.

Keywords: Hematopoietic Stem Cell Transplantation. Follow-Up Studies. CIBMTR. Patient Transfer.

INTRODUCTION

Hematopoietic cell transplantation (HCT) is a potentially curative treatment for a wide range of malignant and non-malignant hematological diseases worldwide[1], offering not only survival benefits but also improvements in patients' quality of life[2]. According to the Brazilian Registry of Hematopoietic Cell Transplantation and Cellular Therapy (BRHCT-CT), 12,230 transplants were performed in Brazil from 2012 to 2023, involving 44 centers. In parallel, the number of transplant centers affiliated with the Center for International Blood and Marrow Transplant Research (CIBMTR) increased, with 35 active centers in 2023. This expansion has led to a notable increase in the number of Brazilian transplants registered with the CIBMTR, exceeding 1,900 procedures per year since 2021[3].

Despite significant advances, maintaining long-term follow-up after HCT remains challenging. Factors such as loss of contact with patients, changes in residence or treating physicians, and a lack of structured communication between transplant centers can hinder continuity of follow-up. Buchbinder et al. (2020)[4] demonstrated that loss to follow-up remains a significant challenge. Over a 10-year period, they reported cumulative loss rates of up to 15% in adult populations and 25% in pediatric populations. Key risk factors identified included type of health insurance, diagnosis of non-malignant diseases, and greater distance from transplant centers. These findings underscore the need for targeted follow-up strategies for high-risk groups and the implementation of tools that support

continuity of care across all institutions involved. One of the tools developed to address these challenges is the HCT Patient Transfer Tool, available on the CIBMTR FormsNet3 platform. This functionality allows the transfer of a patient's CRID between participating centers, ensuring continuity of clinical follow-up and data recording. In a previous study[5], we demonstrated the effectiveness of this tool in enabling the transfer of CRIDs between two Brazilian centers, allowing follow-up even after a change of institution. However, the case also highlighted important limitations when the patient was referred to a hospital not affiliated with the CIBMTR, preventing further transfer and highlighting the need for a more unified approach to post-HCT follow-up in regions with partial network coverage. In South America, the use of the CIBMTR Transfer Tool represents a promising strategy to reduce follow-up discontinuity. However, little is known about the extent to which transplant centers in the region have adhered to this tool. Therefore, the objective of this study is to evaluate the adherence to the CIBMTR's HCT Recipient Transfer Tool among South American transplant centers, with a focus on identifying gaps and opportunities to improve long-term patient monitoring and data completeness.

METHODS

Data source

Data were collected through an electronic questionnaire prepared in Google Forms and sent to Brazilian centers and one Uruguayan center, all active in the Center for International Blood and Marrow Transplant Research (CIBMTR). The selection of participating centers followed specific criteria, including being a center formally active in the CIBMTR at the time of the survey, having reported data to the CIBMTR for at least 12 consecutive months, and demonstrating the ability to provide complete responses to the questionnaire.

The questionnaire consisted of 30 questions distributed across three main axes. The first axis addressed the characterization of the centers, collecting information on the type of institution (public, private, or mixed), the population served (pediatric, adult, or both), and the transplant modalities performed (allogeneic and/or autologous). The second axis focused on reporting data to the CIBMTR, investigating the frequency and scope of information submission over the last five years (2018-2022), in addition to the total number of registered patients and transplants performed in that period. The third axis evaluated the centers' experience with the patient transfer tool via CRID in FormsNET3-CIBMTR, including the number of transfers performed and received, the characteristics of these transfers, such as the type of transplant and age group (pediatric vs. adult), and the main difficulties faced in the process.

The questions were previously discussed and approved by the Data Management Group of the Brazilian Society of Bone Marrow Transplantation (SBTMO), ensuring the relevance and adequacy of the instrument before its application. For data analysis, responses from centers that reported information to the CIBMTR in at least one of the five years between 2018 and 2022 were considered.

Statistical analysis

Statistical analysis of the data was performed using descriptive statistics, with categorical variables presented in absolute frequencies (n) and percentages (%). The distribution of responses was categorized and grouped according to the characteristics of the participating institutions, including geographic location, institution category, profile of the transplanted population, type of transplant performed, volume of reported procedures, and frequency of data submission to the CIBMTR. For better visualization of the results, graphs were generated using the Power BI (PBI) platform and later exported to Microsoft PowerPoint for presentation and publication purposes.

Ethical considerations

The study followed current ethical guidelines, ensuring data protection and confidentiality. In compliance with the General Data Protection Law and the Brazilian Resolution on Research Ethics, no personal information was collected from patients or professionals who responded to the questionnaire. The data analyzed are exclusively administrative, related to the use of the patient transfer tool between centers, ensuring the privacy and security of the information.

RESULTS

According to data from CIBMTR, there are currently 51 active centers in South America. Of these, 46 are located in Brazil, while the remaining centers are distributed across Argentina, Colombia, Ecuador, Paraguay, and Uruguay, with one center in each country. In this study, 49% (25/51) of these centers participated in the questionnaire responses, including 24 from Brazil and one from Uruguay. The geographic distribution of the participating units was heterogeneous, with a higher concentration in the Southeast region of Brazil (70.8%), followed by the South (16.7%), Northeast (8.3%), and Central-West (4.2%). Regarding the institutional category, the sample included private (44%), public (36%), and mixed (20%) hospitals, with most centers performing both autologous and allogeneic transplants (Table 1).

Of the 25 participating centers, 10 (40%) did not perform transfers, that is, they neither sent nor received patients. Among the remaining 15 centers (60%), 5 (20%) performed exclusively transfers of received patients, 5 (20%) performed exclusive transfers of sent patients, and 5 (20%) performed both sending and receiving transfers. Regarding the number of patient transfers (CRIDs), 32 sent patient transfers and 35 received patient transfers were documented between the participating institutions.

The distribution of patient transfers between centers followed a well-defined pattern, with most cases involving allogeneic transplants and adult patients, as illustrated in Figure 1. In total, 32 patients were referred to other centers, 81.2% underwent allogeneic transplants and 15.6% autologous transplants. The predominance of transfers of adult patients was evident, representing 87.5% of cases, while only 12.5% of those transferred were pediatric. Regarding the type of destination institution, most transfers occurred to public hospitals (59.4%), while private centers received 40.6% of cases (Figure 1).

The pattern of incoming transfers, detailed in Figure 2, followed a similar trend, with a total of 35 patients received from other units. As with outgoing transfers, 91.4% of the cases involved allogeneic transplants and only 8.6% were autologous. The age distribution maintained a predominance of adults (82.9%), although the proportion of pediatric patients was slightly higher (17.1%). However, unlike outgoing transfers, private hospitals were the main recipients, receiving 82.9% of the transferred patients, while only 17.1% were directed to public institutions (Figure 2).

The results suggest that patient transfers between centers occur predominantly among adults undergoing allogeneic transplants. Furthermore, the discrepancy between institutional profiles indicates an asymmetric pattern in the transplant network, with centers reporting a greater number of patients sent to public hospitals, while incoming transfers were more frequently from private institutions.

The distribution of inter-center transfers varied, as illustrated in Figures 3 and 4. The majority of centers neither performed (14) nor received (13) transfers, while a smaller number actively participated in the process. Only 7 centers transferred one patient, 2 sent two, and 2 recorded three or more transfers. Similarly, 5 centers received one patient, 2 received two, and 5 recorded three or more transfers. These data suggest that patient movement between centers is still limited, with few hospitals playing a more active role in the transfer network.

DISCUSSION

This study assessed the adherence of South American centers to the CIBMTR patient transfer tool, with a greater predominance of Brazilian centers. It was observed that slightly more than half of the centers affiliated with the CIBMTR participated in patient transfers during the period analyzed, mainly in cases of allogeneic transplants and adult patients. The transfers occurred mostly between public and private institutions, evidencing an asymmetric and limited pattern of integration between centers. These findings indicate that, despite the existence of a structured tool to support long-term follow-up, its use is still limited — which reinforces the persistent challenges in ensuring continuity of care and completeness of post-transplant data.

Continuous long-term assessment of HCT survivors is crucial due to the significant impact of late complications, such as cardiovascular, pulmonary, and endocrine diseases, organ dysfunction, and psychosocial effects, as demonstrated in several studies[6-8]. Regular follow-up is essential for the early detection of complications and for the

implementation of interventions that can improve the survival and quality of life of these patients.

On the other hand, low adherence to the CIBMTR handover tool can impact the maintenance of patient follow-up and, consequently, negatively affect long-term surveillance, survival assessment, and identification of post-transplant complications. The lack of complete and updated data can hinder the development of care guidelines, such as the international recommendations published[9]. Continuous updating of long-term follow-up data is an important factor for the creation of preventive and screening strategies targeted at HCT survivors, especially when considering specific subpopulations, such as the Brazilian population, or public and private healthcare system contexts. Stratification of the transplant and patient profile, including factors such as age, disease type, and socioeconomic conditions, is essential to adapt guidelines to the needs of each group.

The analysis of interinstitutional transfers between the centers participating in the study revealed a significant difference in the dynamics of sending and receiving patients between public and private hospitals. When asked about the destination of patients referred from their centers, 59.4% of the centers reported that transfers occur predominantly to public hospitals, while 82.9% of the patients received by the centers came from private hospitals. The higher prevalence of referrals to public hospitals can be justified by the *Ministério da Saúde* program, which allows transplants to be performed in private institutions, with subsequent follow-up of patients in public hospitals. On the other hand, the reception of patients from private institutions can be explained by the fact that most transplant centers are private or mixed[3].

The study allowed us to observe that some centers presented a profile more focused on sending patients, while others stood out for their greater reception profile, reflecting specific characteristics of each center, such as infrastructure, reception capacity, established partnerships, and the origin of the patients. This division may reflect disparities in access to specialized treatments between public and private networks, and it becomes essential to discuss ways to improve collaboration between these networks, ensuring that patients have equitable access to quality care, regardless of the type of hospital.

The geographic distribution of transplant centers in Brazil shows a predominant concentration in the Southeast region, with low representation of the other regions, especially the North, which did not have any participating centers. This inequality in the allocation of services can generate significant impacts on the maintenance of clinical follow-up, especially for patients from more distant areas. International literature corroborates this concern: studies such as those by Buchbinder (2020)[4] and Banerjee (2021)[10] demonstrated that the distance between the patient's home and the transplant center is a significant predictor of loss to follow-up among HCT survivors. Similarly, Loberiza Jr. (2009)[11] identified that the patient's location can negatively influence clinical outcomes, with increased mortality in individuals who live far from specialized centers. These findings reinforce the need for policies that promote greater equity in the distribution of transplant services, considering the logistical and social challenges faced by patients from regions with less access to these services.

Although autologous transplantation is the most frequently performed modality in Brazil[3], the USA[12], and Europe[13], a greater predominance of patients undergoing allogeneic transplantation was observed among the transferred cases. This discrepancy can be attributed to the particularities of allogeneic transplantation, which, due to its greater complexity, requires a longer hospital stay[14], presents a higher risk of complications — such as graft-versus-host disease (GVHD) — and demands more intensive clinical monitoring. These factors contribute to greater clinical vulnerability of allogeneic patients, often leading to the need for transfer to specialized centers with greater support capacity.

Communication between institutions and limited access by some centers to the CIBMTR platform still pose significant obstacles to continued follow-up of transferred patients. Furthermore, communication failures between the care team and the research team during the transfer of care can compromise the accuracy of the registry and the integrity of the follow-up. Although these challenges persist, there has been an increase in the number of Brazilian centers registered with the CIBMTR, and the official adoption of the platform by SBTMO as the national HCT registry represents a substantial

advance. Resolution No. 2,600/2009 of the Brazilian Ministry of Health, which establishes mandatory communication between institutions, reinforces the need for clear and efficient operational guidelines to ensure continuous patient follow-up. Maintaining follow-up, both in the short and long term, is essential for generating high-quality information that supports the formulation of clinical guidelines and drives the improvement of care and surveillance processes in HCT.

Among the limitations of this study is the low representation of South American centers, as most of the data analyzed originate from Brazilian institutions, restricting the generalizability of the findings to other countries in the region. Even among the Brazilian centers registered with the CIBMTR, the participation rate was approximately 50%, with a predominance of institutions from the Southeast region, which may introduce geographic bias. Furthermore, the time gap between the administration of the questionnaires and the publication of results may have affected the timeliness of the information, considering potential changes in the organizational dynamics of the centers. The lack of previous studies with a similar approach limits the possibility of critical comparisons and increases the influence of the researchers' subjective interpretation. Additionally, the analysis of key challenges in the patient transfer process was hindered by the open-ended and qualitative nature of the corresponding survey question, complicating data integration. As a future perspective, it is essential to better understand the barriers to maintaining long-term post-transplant follow-up, including those related to institutional transfer processes and other assistance- or patient-related challenges that may impact continuity of care.

CONCLUSION

This study assessed the adherence of transplant centers in South America to the CIBMTR HCT Recipient Handover Tool, with an emphasis on identifying gaps and maintaining follow-up of patients post-HCT. The results indicated moderate adherence, with 60% of institutions actively participating in handovers. In addition, a higher rate of handovers of adult patients and allogeneic transplants were observed, as well as a disparity in sending and receiving patients between public and private hospitals.

Adherence to this tool by centers is crucial for maintaining follow-up of patient's post-transplant. Although its use is still limited, it represents a significant opportunity to integrate information between institutions, improve communication, and ensure more effective long-term monitoring. This process is essential for early detection of complications, improving patient outcomes, and developing preventive strategies such as creating guidelines based on clinical information and improving post-transplant care management.

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- Dr. Marcelo Pasquini facilitates direct collaboration with the Center for International Blood and Marrow Transplant Research (CIBMTR), ensuring that the latest research updates and best practices are disseminated within the community.

- Monique Ammi has played an active role in facilitating the affiliation of Brazilian centers and has been pivotal in educating and supporting data managers involved in initiatives.

- The multidisciplinary HCT teams across Brazil, through their dedicated efforts, directly contribute to the ongoing development and success of this specialized field of medicine.

- Finally, the invaluable contribution of patients who have undergone HCT cannot be overstated, as their willingness to share data and participate in scientific research is critical to advancing knowledge and improving outcomes in this important area of healthcare.

TABLE 1. Characteristics of participating institutions

	N	(%)
All institutions	25	
South America		
Uruguay	1	(4)
Brazil	24	(96)
Regions		
North	0	
Northeast	2	(8.3)
Central-West	1	(4.2)
Southeast	17	(70.8)
South	4	(16.7)
Category of institution		
Private hospital	11	(44)
Public hospital	9	(36)
Mixed Hospital	5	(20)
Transplant population		
Adult	8	(32)
Pediatric	1	(4)
adult and pediatric	16	(64)
HCT type		
Autologous	1	(4)
autologous and allogeneic	24	(96)
Number HCT (2018-2022)		
0-100	8	(32)
101-300	8	(32)
301-700	7	(28)
701+	2	(8)
Reporting Frequency to CIBMTR (2018-2022)		
5 years (all)	12	(48)
4 years	5	(20)
3 or 2 years	2	(8)
1 year	6	(24)

FIGURE 1. Transfers sent to other centers

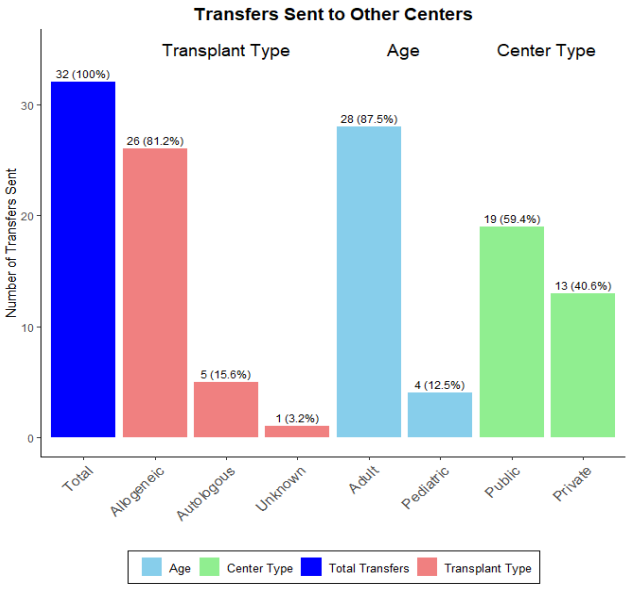


FIGURE 2. Transfers received from other centers

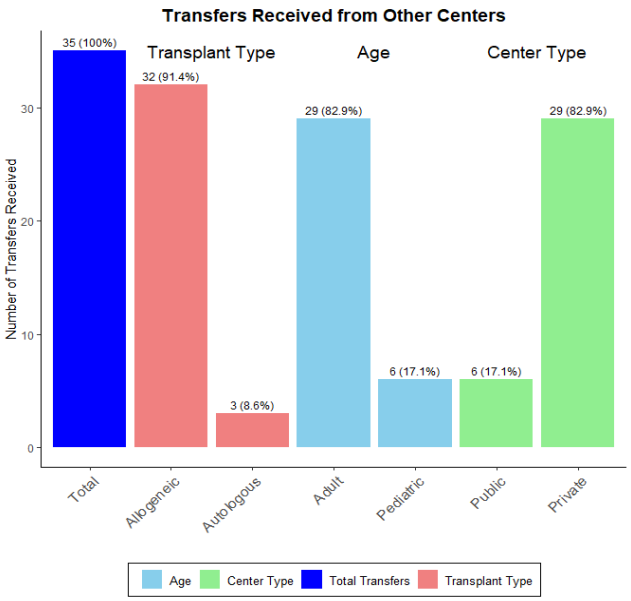


FIGURE 3. Number of transfers sent per HCT center

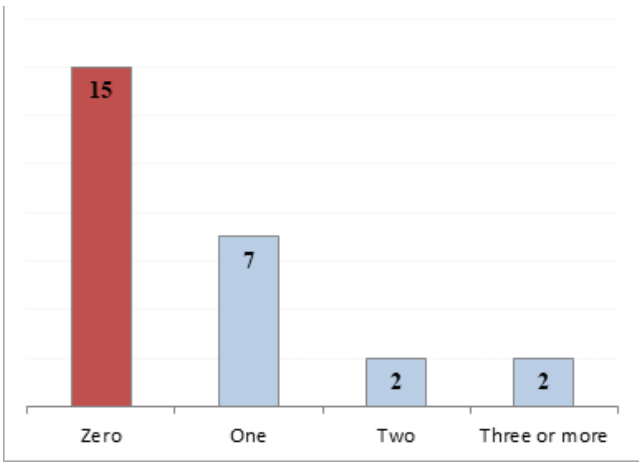
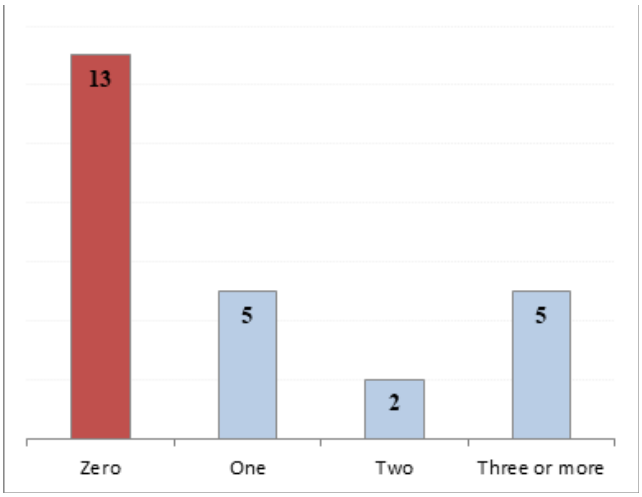


FIGURE 4. Number of transfers received per HCT center



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