



Challenges in Treating PNH Patients in Brazil's Public Healthcare System Due to the Frequency of Eculizumab Administration and Patients' Distance from Infusion Centers

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OBJECTIVES

The study aimed to describe the commute distances and times for patients to access infusion centers for eculizumab administration in the treatment of paroxysmal nocturnal hemoglobinuria (PNH) within the Brazilian public healthcare system (SUS).

METHODS

Public databases of healthcare facilities (CNES) and patient records (DataSUS) from January 2023 to February 2024 were analyzed to identify PNH patients treated with eculizumab and the centers administering the biweekly infusions. Since only four states specified the centers administering eculizumab, centers were identified based on capabilities, qualifications as blood or rare disease reference centers, and eculizumab dispensation procedure requests. Patients' geolocations were determined by postal codes or municipalities from DataSUS, and infusion centers' geolocations were obtained from CNES data. Distance and time between patients' homes and infusion centers were calculated using a distance matrix API.

RESULTS

Of the 376 PNH patients receiving eculizumab, 55% reside in a different municipality from their infusion center. Patients travel an average of 101 kilometers to reach the infusion center, with an average one-way commute time of 77 minutes (1-711 minutes), implying nearly 2.5 hours of commuting on infusion days. Patients in the Northeast, North, and South regions experience longer commutes averaging about 3 hours on infusion days.

Region	Number of patients	Average driving distance (Km)	Average driving time (min)
North	21	131	104
Northeast	114	118	96
South	75	114	83
Southeast	123	81	60
Midwest	43	71	55
Brazil	376	101	77



CONCLUSIONS

The study shows, with real-world data, the logistical challenges that PNH patients face in accessing their current drug treatment, where one in two patients needs to travel biweekly to different municipalities to receive the treatment, with commutes lasting up to two hours on infusion days. However, the total time spent might be underestimated, as they do not consider variables like traffic conditions, transportation modes, or infusion duration, all of which can impact treatment time, patient quality of life and adherence. These findings underscore the need for more efficient treatment options that offer more convenient posology and sustainable healthcare logistics.

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