

ministradas por especialistas convidados, em formato assíncrono ou síncrono, e têm como temática uma patologia hematológica. Por sua vez, os estágios extracurriculares voluntários possibilitam que os ligantes acompanhem a orientadora da liga, uma hematologista, na prática clínica em um hospital geral de referência. Isso permite que os discentes recebam fundamentação teórica acerca de fisiopatologia, quadro clínico, semiologia e tratamento de diversas doenças hematológicas e procedimentos em hemoterapia. **Discussão:** As contribuições ofertadas por uma liga acadêmica são importantes para a ampliação do conhecimento e para a vivência acadêmica dos estudantes em uma graduação tão complexa e diversa como a medicina. Além disso, a tendência de um perfil de aluno mais proativo na busca do saber enaltece a importância que as atividades extracurriculares promovidas por ligas acadêmicas possuem. Em se tratando do PBL, a liga acadêmica de hematologia e hemoterapia fornece valiosas informações e experiências para preencher muitas lacunas na construção do conhecimento, as quais não são ofertadas aos estudantes desse método pelas atividades curriculares, como acontece no modelo tradicional. A partir do envolvimento com a liga de hematologia e hemoterapia, o estudante apreende e fixa melhor o conteúdo aprendido durante as exposições teóricas e o acompanhamento prático do serviço hematológico, principalmente a respeito de patologias muito prevalentes nessa área, como anemias, leucemias, linfomas e trombocitopenias. Vale ressaltar que são conteúdos relevantes não só para o médico hematologista, como também para o médico generalista. **Conclusão:** Assim, o componente extracurricular desenvolvido pelas ligas acadêmicas possui relevância notória no ensino-aprendizagem nas faculdades que adotam a metodologia ativa de ensino, uma vez que complementam a grade curricular obrigatória. Para além disso, a vivência orientada da rotina hematológica nos serviços de saúde é substrato indispensável para qualificar a formação dos estudantes, os quais serão futuros trabalhadores de saúde.

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EVALUATING THE PATIENT JOURNEY AMONG INDIVIDUALS WITH PAROXYSMAL NOCTURNAL HEMOGLOBINURIA IN BRAZIL: A FOCUS ON DISTANCE TO CARE DISPARITIES

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This study aims to elucidate the patient journey and demographic characteristics for PNH patients in Brazil, focusing on the distance from patients' homes to healthcare facilities as a

proxy for accessibility. **Materials and Methods:** This observational, descriptive, retrospective database study utilized data from January 2010 to December 2023 within the public health system (SUS). Using the Brazilian Informatics Department of the National Health System databases, this study linked inpatient and outpatient data to evaluate the patient journey of PNH patients. Patients of all ages were identified via ICD-10 code D59.5 with minimal exclusion criteria to maximize generalizability. Geospatial analysis was conducted using Google Maps APIs to measure distances from patients' residence to the most frequent health establishments for treatment. **Results:** Among the identified PNH patients (n = 714), the mean age was 44.5 years (IQR: 32-57), 359 (50.3%) were male, and 348 (48.7%) patients presented with comorbidities. Other aplastic anemias accounted for the highest prevalence (29.6%), followed by other anemias (11.5%) and acquired hemolytic anemia (10.1%). Eculizumab was the most frequently administered treatment to 314 patients (44.0%), and treatment for hemolytic anemia was the second most frequently administered treatment to 311 patients (43.6%). Among the total cohort, distance was measure for 376 patients (52.7%). The spatial analysis revealed significant variability in the distance, with a mean distance of 101.1 (IQR: 8.7-62.1) kilometers (km). Patients living in the North and Northeast regions were required to travel 615.9 (IQR: 5.6-224.1) km and 144.4 (10.8-130.9) km, respectively, while those in the Midwest, South, and Southeast regions had to travel 86.4 (13.1-69.3) km, 64.4 (8.1-60.7) km, and 37.1 (9.0-46.6) km, respectively. The total duration of observation was 5,548 patient-years. During the study period, 71 (9.9%) deaths occurred, and PNH was the leading cause of mortality, accounting for 23 (32.4%) of the deaths. Another 11 deaths (15.5%) were associated with unspecified sepsis (A41.9). **Discussion:** Notably, patients living in regions with a lower Human Development Index (HDI) had to travel a longer distance than those living in regions with a higher HDI. Despite its limitations, such as incomplete data, the analysis allowed describing the profile of PNH patients in the Brazilian public healthcare system, as well as the variability in distance highlights potential disparities in access to health care, especially for regions with lower HDI. **Conclusion:** This study provides comprehensive insights into the demographics and clinical characteristics of PNH patients in Brazil. Considering the patient's age, and that the distance traveled to undergo treatment every 15 days may impact their quality of life, it is possible that patients are burdened with unforeseen financial costs. Additionally, the dispensing of Eculizumab and its application site may be different, further affecting this aspect of distance on quality of life. These findings underscore the importance of targeted interventions to improve access and ensure equitable healthcare delivery for all PNH patients. Further research is warranted to explore the impact of distance on treatment adherence, health outcomes, and overall quality of life in this population.

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