

em um determinado grupo. Um dos maiores estudos sobre as hemoglobinopatias mostrou a presença de 55.217 indivíduos com os genes testados destes o Hb S teve a maior prevalência, estando presente em 60,95% dos 1.703 casos confirmados sendo seguido pelas talassemias alfas e betas que ficaram com 15,56%. Nesse contexto, ao avaliar os registros de óbito por anemia falciforme no Brasil, no período de 2005 a 2010 alertou a incapacidade do sistema de atenção a saúde de detectar a moléstia, que somado a desinformação sobre a doença por parte da população e dos profissionais da saúde, e o baixo nível sócio-econômico serão fatores preponderantes para a deficiência dessa triagem. **Conclusão:** Desse modo, e considerando os dados epidemiológicos, os genes Hb S, Hb C e talassemias beta são considerados como obstáculos para a funcionalidade da saúde pública no Brasil. De tal maneira que é necessário a implementação de estratégias básicas de atenção ao neonato para a prevenção e controle objetivando menor mortalidade e aumento da sobrevivência.

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SATISFACTION AND ADHERENCE TO SICKLE CELL DISEASE TREATMENT IN BRAZIL: CROSS-SECTIONAL ANALYSIS CONSIDERING PATIENTS AND HEALTHCARE PROVIDER PERSPECTIVES

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Background and aims: Sickle cell disease (SCD) treatment may involve several strategies, which is perceived through different ways by patients and healthcare providers (HCPs). This study aims to determine treatment patterns, satisfaction, and adherence of Brazilian SCD patients, considering both patients and HCPs' perspectives. **Material and methods:** Multi-country, cross-sectional analysis, including data from SCD patients and HCPs who actively treat and manage SCD (The SWAY Survey). Herein, data from Brazilian patients aged >6 years old (those aged 6 to 11 years old completed the questionnaire with a caregiver/parent/legal guardian) and HCPs (independently selected from patients) were included. Both questionnaires included variables regarding demographics and treatment characteristics. About treatment goals and satisfaction subjects were asked to classify using a scale ranging from 1 (strongly disagree or very dissatisfied) to 7 (strongly agree or very satisfied).

HCPs were also asked to classify treatment decision factors in a scale ranging from 1 (not important at all) to 7 (the most important). **Results:** A total of 260 patients and 30 HCPs were included. Considering strategies ever used by patients, folic acid (n=252, 96.9%), antibiotics (n=230, 88.5%), anti-inflammatories (n=222, 85.4%), vaccination (n=215, 82.7%), occasional blood transfusion (n=193, 74.2%), HU (n=178, 68.5%) and over the counter pain medication (n=177, 68.1%) were the most frequently reported. The most frequent treatment strategies used at study entry were folic acid (n=239, 91.9%) and hydroxyurea (HU) (n=161, 61.9%). Decision factors classified as most important by HCPs were related to improving patients' survival and improve quality of life (QoL). Despite the survival importance, both HCPs (n=20, 66.7%) and patients (n=154, 59.2%) describe improve on QoL as the main SCD treatment goal. Among HCPs, only 3.3% (n=1) reported to be completely satisfied with treatment options, and for patients 31.9% were very satisfied with the management and treatment of their disease. Regarding treatment adherence, 63% (n=41) of patients reported to never reduce/stop medication without informing doctor and when it happens is due to forgetfulness. HCPs frequently reported that some patients do not take their medication as instructed (n=17, 56.7%) and miss medication doses occasionally (n=12, 40.0%) and all the time (n=17, 56.7%). **Discussion:** This abstract showed the most frequency treatment used by the Brazilian patients and the importance of QoL as the main SCD treatment goal. The treatment satisfaction and adherence results was different between patients and HCPs. Even with the importance of treatment on patients' survival, both patients and HCPs agreed that main treatment goal is to improve QOL. **Conclusion:** In Brazil, SCD patients usually use folic acid and HU. Neither patients nor HCPs were completely satisfied with the SCD treatment and had different opinion about adherence. Treatment options able to improve satisfaction and adherence, especially with impact on QoL, are still needed.

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SÍNDROME DE EVANS COMO MANIFESTAÇÃO INICIAL DE LÚPUS ERITEMATOSO SISTÊMICO

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Introdução: A síndrome de Evans (SE) é uma doença autoimune definida pela primeira vez por Robert Evans em 1951. Apresenta-se como anemia hemolítica autoimune (AHAI) de anticorpos quentes associada à púrpura trombocitopênica imune (PTI). Sua associação ao Lupus Eritematoso Sistêmico é relatada em somente 1,7 a 2,7% dos casos. Relata-