Racial/ethnic minorities comprise small portion of patients referred with AL amyloidosis

November 10 2020

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Despite being theoretically at an increased risk for AL amyloidosis, underrepresented minorities make up only a small percentage of patients

seen at specialized treatment centers for this disease.

AL amyloidosis is caused when a person's antibody-producing white blood cells (i.e. plasma cells) do not function properly and generate abnormal protein fibers made of components of antibodies called light chains, which then deposit in various organs of the body. This severe illness is closely related to, and occasionally overlaps with, multiple myeloma—a cancer of plasma cells. Multiple myeloma is known to be most common hematologic cancer among Black Americans with an incidence rate that is more than two times higher than that observed among White Americans.

To better understand how AL amyloidosis may affect various groups of patients differently, researchers from Boston University School of Medicine (BUSM) examined disease characteristics, treatments, and outcomes according to the self-reported race/ethnicity of patients referred to the Amyloidosis Center from 1990-2020. Among over 2,400 patients with AL amyloidosis seen during this 30-year period, only 14 percent were underrepresented minorities—considerably lower than in the general population. "Systematic underdetection among minorities, along with access barriers to referral centers, may be at the root of this discrepancy," says lead author Andrew Staron, MD, a hematology/oncology fellow at Boston Medical Center.

Despite similarities in disease manifestation, the researchers observed younger age and more severe illness among racial/ethnic minorities. Proportionately, fewer minority patients underwent aggressive treatment with stem cell transplantation as compared to non-Hispanic White patients. The researchers learned that this treatment difference was largely explained by lower educational level and more advanced heart disease among minorities, rather than race/ethnicity itself.

"These findings indicate that, in order to mitigate disparities, earlier

disease detection and efforts to reduce economic and/or language barriers are key. After controlling for disease severity and treatment, race/ethnicity did not independently impact survival," explained corresponding senior author Vaishali Sanchorawala, MD, professor of medicine and director of the Amyloidosis Center at BUSM and Boston Medical Center.

According to the researchers, diagnosing AL amyloidosis can be perplexing and requires awareness by healthcare providers to pursue tissue biopsy. Its manifestations such as structural heart changes, nephrosis (kidney disease), and neuropathy (disease of the peripheral nerves) can mimic common disorders like hypertension and diabetes mellitus. "Because these conditions are more prevalent among certain racial/ethnic minority groups, there is an even greater need for awareness of AL amyloidosis in marginalized communities so that the diagnosis is not missed or delayed," adds Sanchorawala.

More information: Andrew Staron et al, Race/ethnicity in systemic AL amyloidosis: perspectives on disease and outcome disparities, *Blood Cancer Journal* (2020). DOI: 10.1038/s41408-020-00385-0

Provided by Boston University School of Medicine