

Best Practices and Key Barriers for Amyloidosis Patient Care – a Representative Analysis of Multidisciplinary Amyloidosis Specialists, Referring Physicians, Patients, and Patient Advocacy Groups at US Specialized Amyloidosis Centers

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Abstract

Background: The Amyloidosis Stakeholder Partnerships for Impact, Reach & Equity (ASPIRE), facilitated by Amyloidosis Research Consortium (ARC) brings together biotech and pharmaceutical companies with the shared goal of optimizing amyloidosis patient care. We present our research on current best practices and key barriers to patient-centric amyloidosis care at US Specialized Amyloidosis Centers (SACs).

Method: Teleconference interviews were conducted with 49 healthcare providers (HCPs: cardiologists, neurologists, hematologist-oncologists, nephrologists, advanced practice providers or registered nurses) from 19 SACs, 21 patients, 12 referring physicians and 3 patient advocacy representatives. SACs were selected based on geography, regional demographics, amyloidosis patient volume, years since establishment, and types of amyloidosis treated for a representative view of current amyloidosis care.

Results: We present the interim results of 26/49 HCPs from 13/19 SACs and 19/21 patients (see figure).

SACs prioritize patient-centric multidisciplinary care, ensuring timely intake of new high-risk patients. Expanding local physician education was noted as critical to improving early diagnosis. Barriers to care noted by HCPs include patient distance to SACs, limited medical records and data sharing, and health inequity. From patients' perspectives, travel burden, delayed diagnosis, and insurance hurdles were key challenges. Most SACs utilize metrics - which include but are not limited to internal and external registries, patient volume, and patient demographics - to measure progress in providing quality care.

Conclusions: Our interim results highlight the key barriers to care from amyloidosis HCPs' and patients' perspectives, with time and access to care prioritized by both groups.

Figure.

