Recognition of the non-cardiac (orthopedic, neurologic, renal, and gastrointestinal) manifestations of systemic amyloidosis is essential to facilitate early and accurate diagnosis. Educational initiatives that reach specialists of a variety of different clinical disciplines will be important to raise the index of suspicion and trigger appropriate steps in the diagnostic pathway.

The principal errors in the diagnosis of transthyretin cardiac amyloidosis (ATTR) involve the inappropriate application of bone avid tracer cardiac scintigraphy without testing for a plasma cell disorder, failure to accurately interpret plasma cell disorder testing in the clinical context, or failure to proceed to invasive cardiac biopsy when appropriate. In addition, bone avid tracer cardiac scintigraphy must be performed with single photon emission computed tomography (SPECT) and ideally SPECT/computed tomography (CT) imaging to distinguish blood pool activity from myocardial activity and avoid false-positive scans as has been observed with planar imaging only.

Prospective multicenter collaborations are essential to define the role of biomarker and imaging surveillance in patients with ATTR receiving therapy to determine treatment efficacy.

Further guidance is needed for advanced HF transplant management. The indications and contraindications for heart transplantation in patients with cardiac amyloidosis are not clear and vary by center. Though most consider symptomatic gastrointestinal involvement and autonomic dysfunction, as indicated by orthostatic hypotension, contraindications to transplantation. Guidance formulating the listing criteria would be useful.

Given the multisystem impact of cardiac amyloidosis, multidisciplinary amyloidosis clinics comprising specialists from cardiology, neurology, orthopedic surgery, hematology/oncology, gastroenterology, nephrology, as well as pharmacists and advanced practice providers would improve the evaluation and management of these patients. Access to appropriately skilled pathology and cardiac imaging support is essential. Accreditation criteria or competency designations would be helpful to facilitate patients navigating to qualified centers for care and establish networks of high-quality programs that can collaborate.

The care of the amyloidosis patient is challenging owing to clinical complexity and time required for optimal care. These features are not favorable in a fee-for-service payment model that emphasizes volume. Alternative payment models that explore bundled or value-based compensation may better align with actual care delivery and support the development of clinical programs in non-tertiary care centers.

Cardiac amyloidosis care is frequently administered at select centers of excellence thereby creating a disparate system of access. Telehealth has the potential to overcome disparities by permitting consultations from experienced providers. Federal and state oversight agencies can assist by removing barriers to permit billable interstate telehealth referrals.