**BACKGROUND**
- Cardiac amyloidosis is a severe, progressive, and fatal disease caused by the accumulation of misfolded proteins (amyloid) in cardiac tissue.
- Three main types of amyloidosis can result in cardiac amyloidosis: AL amyloidosis, AL amyloidosis (AL), wildtype ATTR amyloidosis (wtATTR), and hereditary ATTR amyloidosis (hATTR).
- AL is caused by buildup of misfolded immunoglobulin light chains, while hATTR and wtATTR are caused by misfolded transthyretin.
- Delays in diagnosis are frequent due to non-specific initial symptoms and lack of disease awareness.
- Challenges associated with diagnosing amyloidosis were captured in a series of patient-focused survey studies conducted by the Amyloidosis Research Consortium (ARC), which asked questions about the patient and caregiver journey to diagnosis.

**OBJECTIVE**
- To gain insight into patient experiences with delays and errors in the diagnostic pathway for cardiac amyloidosis.

**METHODS**
- Patients and caregiver surveys created by ARC were made available to increase the range of targeted populations.
- Translated surveys were made available to increase the range of targeted populations.

**RESULTS**

**Organ Involvement**
- More than one third of patients with AL and hATTR reported having ≥3 organs involved.
- Most patients had solely cardiac involvement, most commonly in cardiac tissue.

**Diagnosis**
- To gain insight into patient experiences with delays and errors in the diagnostic pathway for cardiac amyloidosis.

**Disease Burden**
- 54% of all patients were hospitalized for their cardiac amyloidosis (54% of AL, 63% of wtATTR, and 50% of hATTR).
- 19% of patients had to travel over 2 hours to their diagnosing physician, and 25% of patients had to have a plane in order to seek treatment.

**Conclusions**
- Patients with cardiac amyloidosis are commonly misdiagnosed, which is frequently associated with their cardiac involvement.
- Misdiagnosing physicians tend to focus on treating presenting symptoms individually, which causes a delay in diagnosis and patients to receive incorrect treatments, that can worsen symptoms and reduce survival.
- The comparison of diagnostic procedures performed shows an underuse of PYP/DPD in the diagnosis of amyloidosis. PYP/DPD scans are non-invasive, inexpensive, and reliable. Increasing the use of PYP/DPD scans may help improve earlier diagnosis among patients.

**References**