Characteristics of Leukocyte Chemotactic Factor 2 (ALect2) Amyloidosis Patients from the Amyloidosis Research Consortium's 2023 Multi-Country Amyloidosis Community Survey

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INTRODUCTION / OBJECTIVES

- Leukocyte Chemotactic Factor 2 (ALECT2) amyloidosis is a common type of renal amyloidosis and hepatic amyloidosis.
- ALECT2 amyloidosis is more prevalent among individuals of Hispanic, Native American, and Middle Eastern ancestry.
- There are currently no effective treatments for ALECT2 amyloidosis.
- This analysis examined the demographic and clinical characteristics of patients with ALECT2 amyloidosis participating in a multi-country survey study.

MATERIAL / METHODS

- The Amyloidosis Research Consortium conducted a cross-sectional study of amyloidosis patients between September and November 2023.
- Patients diagnosed with amyloidosis, or their caregivers, were eligible to participate.
- The online survey was available in six languages: English, French, German, Italian, Portuguese, and Spanish.
- Survey measures included demographics, clinical characteristics, including symptom severity, Eastern Cooperative Oncology Group (ECOG) performance status scale, a measure of the patient's level of functioning, and journey to diagnosis.
- Journey to diagnosis measures were collected on patients recently diagnosed, defined as within 1.5 years of taking the survey.
- Data were summarized and analyzed descriptively in R version 4.3.2.

RESULTS

- Of the 1031 survey respondents, 24 (2.3%) had ALECT2 amyloidosis and were included in this analysis.
- Two-thirds of patients (n=16) were of Hispanic/Latino ancestry, 13 (54%) were female, and mean (Standard Deviation [SD]) age was 66 (7) years (Table 1).
- The mean (SD) time since diagnosis was 5 (4) years and the mean (SD) age at diagnosis was 60 (7) years.
- The majority (96%) reported kidney involvement and 2 (8%) had liver involvement (Figure 1). Heart involvement was reported in 3 (13%).
- Two-thirds (n=16) of patients reported their current symptom severity as moderate, severe or very severe (Figure 2).
- One-fourth (n=6) were recently diagnosed and the mean (SD) time from the onset of initial symptoms to diagnosis was 5 (4) years (Table 2).
- Half (n=3) of recently diagnosed patients saw two or more physicians before being diagnosed with amyloidosis and half (n=3) were diagnosed by a nephrologist.
- A common barrier to receiving a diagnosis reported in half of patients (n=3) was finding a specialist to discuss symptoms.

While ALECT2 amyloidosis primarily presents as a renal amyloidosis, patients reported additional organ involvement, most commonly the heart followed by the liver.

Symptoms are present for several years prior to receiving a formal diagnosis of ALECT2 amyloidosis.

Further studies are needed to understand more about this patient population and address the unmet needs of ALECT2 amyloidosis patients.

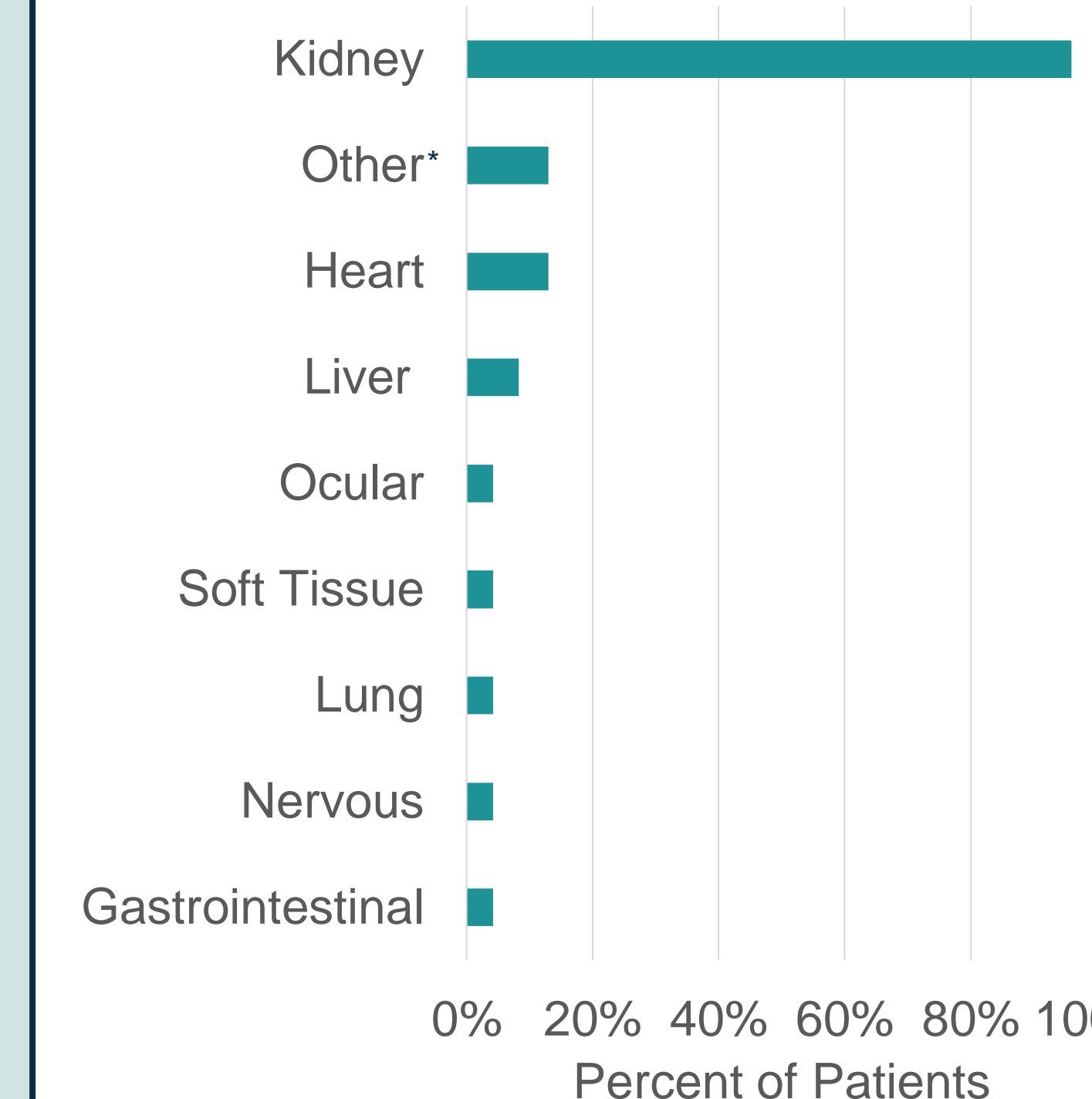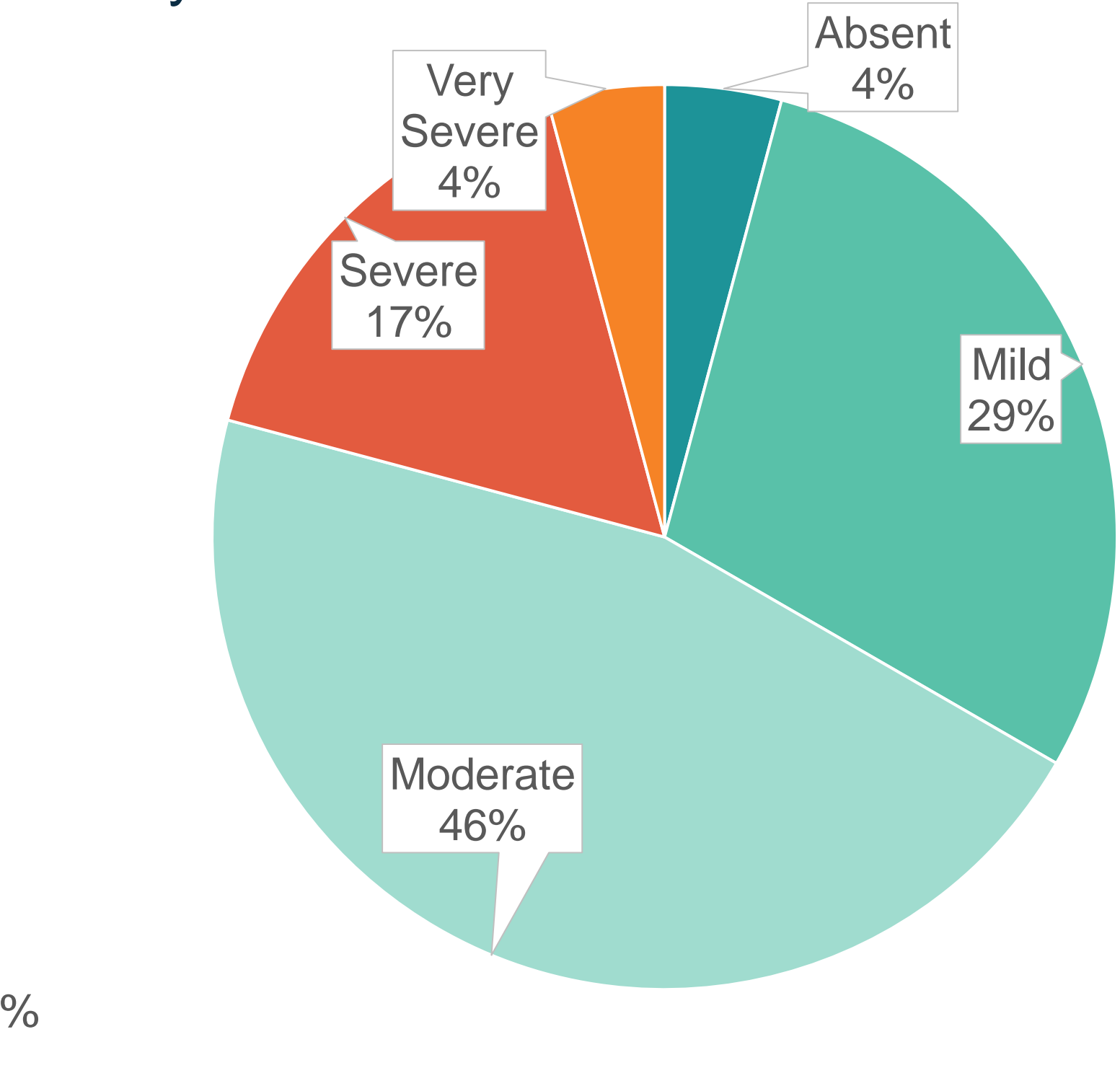**Figure 1:** Organ Involvement of Leukocyte Chemotactic Factor 2 (Alect2) Amyloidosis Patients

*Other organs/organ systems included teeth/gums and spleen/adrenal glands.

Figure 2: Current Symptom Severity of Leukocyte Chemotactic Factor 2 (Alect2) Amyloidosis Patients

Absent 4%
Very Severe 4%
Severe 17%
Mild 29%
Moderate 46%

■ Absent ■ Mild ■ Moderate ■ Severe ■ Very Severe

Table 2: Journey to Diagnosis of Recently Diagnosed Leukocyte Chemotactic Factor 2 (Alect2) Amyloidosis Patients

Journey to Diagnosis	N = 6
Years Since Symptoms Start to Diagnosis, mean (SD)	5.08 (3.65)
Number of MDs Seen Before Diagnosis	
1	3 (50%)
2	1 (17%)
3	1 (17%)
4	1 (17%)
Type of Doctor/Provider Who Made Diagnosis	
Gastroenterologist	1 (17%)
Hematologist/Oncologist	1 (17%)
Nephrologist	3 (50%)
Primary Care Physician	1 (17%)
Barriers to Receiving Diagnosis	
Convincing doctor that symptoms are real and need further testing/diagnosing	2 (33%)
Insurance coverage of visits or tests	1 (17%)
Finding a specialist to discuss symptoms	3 (50%)
Other	1 (17%)
None	1 (17%)

RESULTS (continued)

Table 1: Demographic and Disease Characteristics of Leukocyte Chemotactic Factor 2 (Alect2) Amyloidosis Patients

Characteristics	ALECT2 Patients
Country of Residence	
Jordan	2 (8.3%)
United States of America	22 (92%)
United States Region of Residence	
Northeast	1 (4.5%)
South	4 (18%)
West	17 (77%)
Gender (Male)	11 (46%)
Age, mean (SD)	66.00 (7.34)
Race/Ethnicity	
Hispanic or Latino	16 (67%)
White	19 (79%)
College Education	15 (65%)
Work Status	
Currently employed	4 (17%)
Not able to work because of amyloidosis	1 (4.2%)
Retired	17 (71%)
Not employed for other reasons	2 (8.3%)
Time Since Diagnosis, mean (SD)	5.08 (3.65)
Age at Diagnosis, mean (SD)	60.05 (5.75)
ECOG Performance Status Scale	
0 - Fully active	13 (54%)
1 - Restricted in strenuous physical activity	10 (42%)
2 - Ambulatory and capable of all self-care but unable to carry out any work activities	1 (4.2%)

SUMMARY / CONCLUSION

- The demographics of surveyed patients with ALECT2 amyloidosis are described, and two-thirds of patients may experience moderate/severe symptoms.