

# The Impact of AL Amyloidosis on Absenteeism, Reduced Productivity, and Job Loss

Spencer D. Guthrie,<sup>1</sup> Michelle K. White,<sup>2</sup> Martha Bayliss,<sup>2</sup> Kristen L. McCausland<sup>2</sup>

<sup>1</sup>Prothena Biosciences Inc, South San Francisco, California, United States; <sup>2</sup>Optum, Lincoln, Rhode Island, United States

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## BACKGROUND

- Debilitating chronic conditions and their treatments often negatively affect patients' ability to work, resulting in absenteeism, reduced productivity, and job loss
- Amyloid light chain (AL) amyloidosis is a rare disease in which misfolded light chains are deposited in tissue, possibly leading to organ failure, disability, and death<sup>1,2</sup>
- Current treatments are known to affect patients' functioning and well-being,<sup>1,3</sup> but there is little evidence on the impact of AL amyloidosis on their ability to work
- Mixed-methods research is an important means to investigate complex health-related topics; the use of qualitative and quantitative methods allows for greater understanding of the impact of disease and its treatment and includes the patient's voice<sup>4</sup>

## OBJECTIVE

- To describe the impact of AL amyloidosis on patients' work using data from qualitative and quantitative research

## QUALITATIVE STUDY METHODS

### Patient Population and Study Design

- 10 adults (≥18 years of age) with self-reported AL amyloidosis participated in in-depth, 1-hour long interviews conducted by telephone in 2015
- The purpose of the interviews was to garner information about the patient journey toward the diagnosis of AL amyloidosis and the impact of the disease and its treatment on health-related quality of life (HRQoL),<sup>5</sup> including impact on work, using
  - A concept-elicitation approach
  - A semi-structured interview guide developed for this study
- AL amyloidosis patient advocacy group websites facilitated recruitment and directed interested persons to the Optum Smart Measurement® System (SMS) to complete a screener for study eligibility

### Analysis

- Interviews were audiotaped, transcribed, coded, and analyzed using NVivo (QSR International, Burlington, MA, USA) software and a grounded theory approach,<sup>6</sup> which allows themes to emerge from the data rather than imposing a priori hypotheses to be tested
- Dual coding and review meetings were held to ensure agreement among 4 coders

## QUANTITATIVE STUDY METHODS

### Patient Population and Study Design

- Adults with self-reported AL amyloidosis completed online surveys to assess HRQoL and clinical and sociodemographic characteristics
- 2 patient advocacy groups helped to support recruitment efforts consisting of social media posts and e-mails highlighting the study participation opportunity
- Data were collected online in 2015 using the SMS (Optum)
- Data from the initial (N = 341) survey were used in these analyses; among them were data for a subset (n = 115) of employed patients

### Measure: WPAI

- The Work Productivity and Activity Impairment Questionnaire: Specific Health Problem (WPAI-SHP) is a 6-item, self-report instrument that measures the impact of a patient's health on ability to work during the preceding week<sup>7</sup>
- All scores are expressed as percentages; higher scores indicate worse outcomes (eg, greater impairment, less productivity)
- The instrument yields scores on the following constructs
  - Absenteeism: percentage of time at work missed because of a specific health problem
  - Presenteeism: percentage of time at work negatively impacted by a specific health problem
  - Overall work productivity loss: percentage of productivity lost as a result of both absenteeism and presenteeism
  - Activity impairment: percentage of ability to perform regular activities (outside of work) negatively impacted by a specific health problem
- Because the final score, activity impairment, is not related to work, we report on the first 3 (absenteeism, presenteeism, and overall work productivity loss)

## Statistical Analysis

- The WPAI was scored as described for the subgroup of working patients
- Wilcoxon-Mann-Whitney tests were used to compare mean WPAI scores by 3 subgroups
  - Patients with vs without cardiac involvement
  - Patients diagnosed <12 vs ≥12 months ago
  - Patients with cardiac involvement diagnosed <12 vs ≥12 months ago

## RESULTS

### Patient Characteristics

- Patients' demographic and clinical characteristics varied in both the qualitative and the quantitative studies (Table 1)
- In the quantitative study, 115 (38.3%; n = 300 responses) patients were currently working
- Characteristics in the working subsample did not vary significantly from those in the full quantitative study sample: mean age was 56.1 years, 56% of patients were women, and 10% were nonwhite

**Table 1. Demographic and Disease Characteristics for Qualitative and Quantitative Study Samples**

Characteristics	Qualitative Study Sample N = 10		Quantitative Study Sample N = 341	
	n	%	n	%
Age, years, mean (range)	57 (43–76)		60.6 (23–85)	
Gender <sup>a</sup> (n = 340)				
Male	4	40	160	47.1
Female	6	60	180	52.9
Race/Ethnicity				
White	—	—	304	89.1
Other	—	—	37	10.9
Education <sup>a</sup> (n = 322)				
<4-year college degree	4	40	125	38.8
Bachelor's degree	3	30	109	33.9
Graduate degree	3	30	88	27.3
Employment status <sup>a</sup> (n = 300)				
Currently employed <sup>b</sup>	4	40	115	38.3
Time since diagnosis, years, mean (range)	2.0 (0.25–8.0)		4.5 (0.8–28.0)	
Organs/systems affected <sup>c</sup> (% yes)				
Heart (cardiac)	6	50	178	52.2
Kidney	5	50	214	62.8
Nervous system	2	20	126	37.0
Gastrointestinal	3	30	148	43.4
Number of organs involved				
1	5	50	95	27.9
≥2	5	50	246	75.1
Most recent hematologic response status				
No response to treatment	4	40	23	6.7
Partial hematologic response or partial remission	1	10	126	37.0
Complete hematologic response or complete remission	5	50	141	41.3
Do not know	0	0	51	15.0

<sup>a</sup>Subtotals for the quantitative study do not equal 341 because some data were missing; percentages were based on available data.

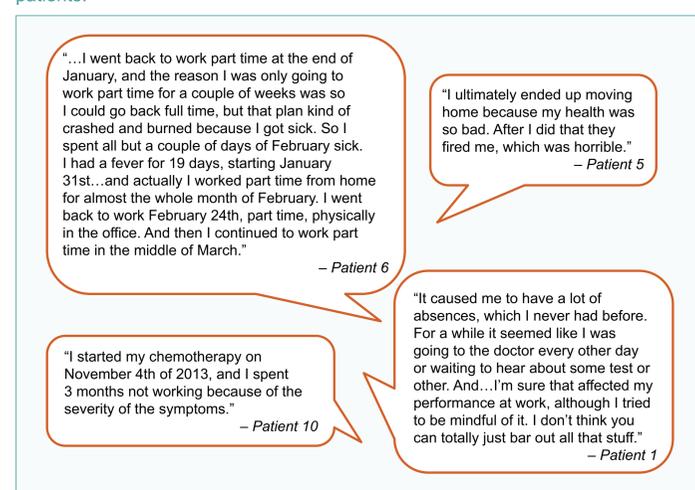
<sup>b</sup>For the qualitative study, 4 patients were employed at the time of the interview, but 7 were employed when symptoms first appeared.

<sup>c</sup>Multiple response options were allowed; only the 4 most reported organs/systems are included in the table.

## Qualitative Findings: Impact of AL Amyloidosis on Ability to Work

- 7 of the 10 patients interviewed were working when AL amyloidosis symptoms started, and all 7 reported that AL amyloidosis significantly impacted their ability to work (Figure 1)
- 3 of the 10 patients interviewed stopped working between the first symptom and early treatment
  - 1 retired because of the condition
  - 1 went on disability
  - 1 was fired after having to move home with parents because of deteriorating health
- 2 additional patients took extended leaves of absence for initial treatment but returned to work after experiencing positive treatment responses
- All employed patients reported many work absences to receive treatment, and all but 1 reported further absences because they felt sick from illness or treatment

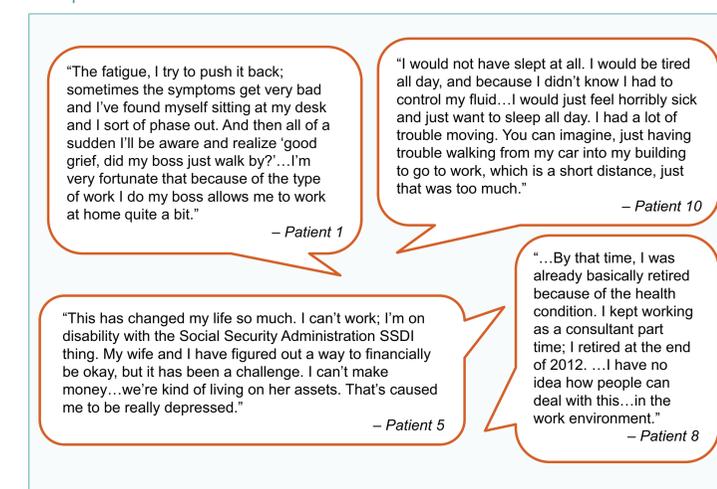
**Figure 1. Impact of AL amyloidosis on ability to work: representative quotes from patients.**



## Qualitative Findings: Impact of AL Amyloidosis on Work

- All employed patients reported work-related problems at the start of the day (Figure 2), such as feeling
  - Too exhausted to get out of bed
  - Too weak to use a hair dryer to get ready for work
  - Too fatigued or dizzy (from treatment side effects) to drive to work independently
- All employed patients reported severe, debilitating effects of fatigue during the workday, including
  - Feeling unable to sit at their desks
  - Needing naps during the day
  - Having trouble walking even short distances in the office
- Many employed patients also reported several non-fatigue problems that affected their ability to work as productively as they used to, including
  - Problems thinking, described as "brain fog," or impaired cognition
  - Pain in legs and other areas from sitting too long in one position at a desk
  - Treatment-related nausea frequently each day
- Patients who continued working found ways to adapt to their symptoms and side effects
  - 2 patients changed to a different position or role at work because they could no longer travel or meet the strenuous hours of their former positions
  - Many changed to more flexible work schedules
  - Most switched from working at the office to working from home
- 1 patient reported feeling trapped in a job she disliked because she feared a new employer would not accommodate her need to leave work for treatment or that new health insurance would not cover her expenses as well as her current health insurance, which led to anxiety
- 1 patient reported experiencing extreme depression because of the inability to work

**Figure 2. Type of impact of AL amyloidosis on work: representative quotes from patients.**



## Quantitative Findings: Impact of AL Amyloidosis on Work

- On average, all employed patients reported
  - Being absent from work 5 hours per week (12% of the workweek)
  - Experiencing impairment while working (presenteeism) 23% of the time because of their disease
  - Losing 28% of their former overall work productivity
- Patients with cardiac involvement did not differ significantly from those without cardiac involvement on any of the 3 WPAI measures
- Patients whose AL amyloidosis was diagnosed <12 months ago differed significantly from patients whose disease was diagnosed ≥12 months ago only in absenteeism (10.5 vs 2.6 hours; P = 0.03)
- Among patients with cardiac involvement, those whose AL amyloidosis was newly diagnosed had worse WPAI scores than those whose disease was diagnosed ≥12 months earlier
  - Absenteeism (15 vs >1.6 hours; P < 0.001)
  - Presenteeism (44.3% vs 23.3%; P = 0.09)
  - Overall work productivity (54.4% vs 25.4%; P = 0.03)

## CONCLUSIONS

- Findings from patient interviews were confirmed in the larger quantitative study. Collectively, these results indicate that AL amyloidosis has a significant impact on patients' work, causing absenteeism, impaired productivity, and job loss
- Patient interviews revealed extreme stress, sadness, and feelings of loss related to the impact of AL amyloidosis on work
- The impact of disease and treatment on work is an added cost not related to medications or procedures that is borne by patients, their employers, and their families
- Advancements in treatment options for patients with AL amyloidosis and increased attention to patients' functioning and well-being could minimize these hidden costs

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