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Patient, caregiver, and provider perspectives on the burden of side effects in chronic lymphocytic leukemia

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Introduction: The therapeutic landscape for chronic lymphocytic leukemia (CLL) has evolved substantially, with multiple established and emerging treatment options demonstrating varying efficacy and safety outcomes. As outcomes continue to improve and treatment choices expand, understanding the impact of treatment-related side effects (SEs) on patients and caregivers has become increasingly important. This study assessed patient, caregiver, and healthcare provider perspectives on the burden of SEs and their influence on treatment decisions in CLL.

Methods: Three online cross-sectional, pretested, and custom surveys were conducted from March to June 2026. Eligible respondents included US adults diagnosed with CLL who had experienced ≥1 SE from CLL treatment; unpaid adult caregivers of such patients; and healthcare providers involved in CLL management who had treated ≥5 patients with CLL in the prior 12 months. Survey domains included SE experiences; impacts on physical, emotional, mental, and social functioning; and the role of SEs in treatment decision-making. Survey domains were assessed across first-line (1L), second-line (2L), and third-line or later (3L+) therapies.

Results: The study included 200 patients with CLL (mean age, 64 years; 50% male; 75% White; 50% retired; 1L/2L/3L+: 43%/31%/26% respectively), 200 caregivers (mean age, 51 years; 61% female; 69% White; 60% employed; 82% caring for a family member), and 200 healthcare providers (100 physicians, 42 nurse practitioners, 33 nurses, and 25 physician assistants). The providers had a mean of 16 years in clinical practice and cared for an average of 73 patients with CLL annually; 45% practiced in academic hospitals.

About 60% of patients said providers usually initiated SE discussions, and 90% learned SE management from providers. For their most recent treatment, 38% of patients participated in shared decision-making after multiple options were presented, while 35% were offered only 1 option. Some patients (73%) had regular caregiver help; these caregivers joined treatment discussions in 66% of cases, and 60% of them independently researched disease and treatment information.

In 1L, fatigue mainly affected physical and social functioning, including frequent sitting/lying down (72%), cancelled/declined social events (61%), and loss of interest in hobbies (48%). Diarrhea limited mobility and public activities, including avoiding time away from home (64%), feeling embarrassed/self-conscious in public (63%), and cancelled/declined social events (55%). Headache was associated with cancelled/declined social events (52%), worrying about serious complications (44%), sleep problems (35%), and difficulty concentrating/thinking clearly (32%). Nausea/vomiting affected social participation and mobility, including cancelled/declined social events (58%), avoiding time away from home (54%), and worrying about serious complications (40%). Joint/muscle pain affected physical functioning, including frequent sitting/lying down (42%), sleep problems (42%), and worrying about serious complications (38%). In 2L and 3L+, SE impacts were generally similar to those in 1L.

Across those most common SEs, caregivers often reported taking on more household responsibilities, driving patients to appointments, providing physical support, and getting less sleep or rest.

Providers most frequently discussed the impact of SEs on physical functioning, with more than 60% discussing fatigue in detail, followed by nausea/vomiting (52%), diarrhea (51%), and headache (49%). Discussions of the mental/emotional and social impacts were generally less frequent. Detailed discussions of mental/emotional functioning ranged from 37% (headache) to 54% (nausea/vomiting), while detailed discussions of social functioning ranged from 21% (headache) to 44% (nausea/vomiting).

Conclusions: Treatment-related SEs in CLL impose meaningful physical, emotional, and social burden on patients and caregivers. Although treatment decisions were predominantly provider-directed, caregivers were actively involved in supporting decision-making. Discussions between providers and patients focused primarily on physical functioning, suggesting potential gaps in addressing emotional and social concerns. These findings suggest that incorporating patient preference assessments into routine CLL care may facilitate more comprehensive patient-provider communication, better integrate caregiver perspectives, and support shared decision-making.