BACKGROUND & INTRODUCTION

• Until the introduction of novel agents, such as Bruton tyrosine kinase inhibitors (BTKi), the management of CLL patients primarily utilized limited duration chemoimmunotherapy (CIT). The use of BTKi significantly changed the CIT treatment paradigm to include continuous single agent (CIT) therapy associated with disease progression or intolerance.

• Now, recently, similar to anti-CD20 protocols, new combinations of non-CIT agents are being used that may be given over a finite duration (aka fixed or limited duration). In addition, measurable (minimal) residual disease (MRD) assessment is emerging as an important clinical tool. Understanding the patient perspective on these needs is critical to providing best care.

• CLL Society, a patient-facing, physician-directed nonprofit organization focused on the unmet needs of the CLL community, sought to understand patient’s self-assessed awareness, understanding, and preferences related to the changing therapeutic landscape with the addition of finite duration non-CIT options and MRD testing, and to research how they influence patient decisions around treatment.

OBJECTIVES

• Understand patient’s self-assessed awareness, understanding and preferences related to finite therapies and MRD testing in the present treatment era.

• Assess how these influence their desires related to therapy.

• Identify gaps and misconceptions in awareness and understanding that can be addressed through improved patient education and shared decision making.

METHODS

Study Design

CLL Society developed a survey instrument to assess patient and caregiver awareness, understanding, and preferences associated with the concepts of MRD and finite duration therapies. The online survey was conducted via a web-based data collection tool.

Inclusion criteria

• Respondents must be age 18 or older.

• Have a diagnosis of CLL/SLL or be caring for someone with CLL/SLL.

• Be an American resident with a working knowledge of English.

Survey Recruitment

Patients and caregivers were invited by CLL Society via message boards, CLL Society website, emails, and multiple online communities. The survey was administered anonymously.

Statistical Analysis

Data were analyzed using descriptive methods. Answers in individual surveys were cross checked for validity.

RESULTS

630 Responses

608 CLL patients

22 CLL Caregivers

5 Months

The survey was administered from SEP-2020 to FEB-2021

2 Formats

Options to respond via PC or mobile device

CONCLUSIONS

• Overall survival (OS) and progression free survival options were the 1st and 2nd very or somewhat important factors respectively in choosing a treatment. Ability to reach uMRD was rated more important than the duration of therapy. When forced to rank treatment preference on a fixed scale, OS was ranked 1st by 35%.

• Despite high levels of self reported confidence in understanding MRD, some patients had preferences for MRD testing when it was not established such as 16% of respondents wanting testing of peripheral blood when routine labs demonstrated persistent CLL. Regarding understanding of which treatments (BCL2, BTKi, Chemomunotherapy) can achieve uMRD about one third of patients were unsure.

• Given its option to select and with nearly 1 in 5 who completed the survey coming from California, the results may not be reflective of all patients and caregivers.

• As the importance of MRD and finite therapy grows in CLL management, it will be incumbent on providers to better understand and communicate their awareness, understanding, and preferences and to help patients become more informed about existing practices so patients can make more informed therapeutic decisions.

ABOUT CLL SOCIETY

CLL Society is a U.S.-based 501(c)3 nonprofit with a global reach. It is focused on patient education, support, advocacy and research to address the unmet needs of the CLL communities.

• CLL Society website (cllsociety.org) which contains up-to-date, accurate and patient-friendly information with >1,000,000 pageviews a year

• The CLL Tribune, quarterly online newsletter with patient, physician and related experts as authors

• 36-CLL specific local patient support and education groups with members in 3 continents

• Online educational forums and webinars present expert speakers and patient advocates.

• Free initial Expert Access™ to CLL experts providing consults to patients who would otherwise have no such access.

• CLL Society wishes to thank the patients and caregivers who participated in this research.

For questions or comments, please contact contact@cllsociety.org