BACKGROUND & INTRODUCTION

Objective(s):
- To assess patient understanding of CLL in terms of symptoms (physical and emotional), diagnosis, prognostic testing to identify specific areas for education and support.
- To assess the experiences of patients in “Watch and Wait” active observation” including psychosocial stresses such as anxiety, depression and fatigue, to identify areas for education and support.
- To assess patient experience related to the option of a clinical trial.

Method(s):

The 2017 CLL diagnosis and Treatment Assessment: The Patient View (2017-CLL-DATA) survey included 64 multi-part questions directed to CLL pts to capture more information on their experience with CLL. The survey, which was available online or on paper, was IRB-approved and took place between October 2017 and 2017. This report will focus on the patient perspective of diagnosis, during the active observation period, prognostic testing, clinical trial participation and sources of information. Data on other topics within the survey will be reported in the future.

Inclusion criteria: Patients must be age 18 or above, have a diagnosis of CLL/SLL, be a United States resident with a working phone, and have a diagnosis of CLL/SLL within the past 5 years.

Survey Recruitment: The survey was administered anonymously using both the CLL Society (CLLS) database, Facebook page, bioinfographic/stream, and online CLL patient forums, as well as information cards distributed in the offices of the principal investigators (PI) and identified physicians that refer to those PIs, as well as attendees at CLL Society patient support groups. A self-selected convenience sample resulted from online methods, as well as informational cards proxided to patients at the offices described above, and CLL Society Patient Support Groups. Patients could participate via an online or a paper survey.

Statistical Analysis:
- Data were analyzed using descriptive methods. Chi-square was used to evaluate statistical significance. Analyses and comparisons were made between the multiple subgroups
- p < .05 was considered to be statistically significant.

A U.S.-Based Survey: The Experience of 1147 Chronic Lymphocytic Leukemia (CLL) Patients

RESULT(S)

Table 1. Patient Characteristics N=1147

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age &gt;65 years old</td>
<td>562 (49%)</td>
</tr>
<tr>
<td>Male</td>
<td>350 (30%)</td>
</tr>
<tr>
<td>Age &lt;65 years old</td>
<td>381 (33%)</td>
</tr>
<tr>
<td>Chromosomal abnormalities</td>
<td>61 (4%)</td>
</tr>
</tbody>
</table>

Table 2. Use of Herbal or Alternative Therapies

<table>
<thead>
<tr>
<th>Use of Herbal or Alternative Therapies</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used before diagnosis</td>
<td>36%</td>
</tr>
<tr>
<td>Used after diagnosis</td>
<td>43%</td>
</tr>
</tbody>
</table>

Table 3. Symptoms Experienced during Active Observation

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>43%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>69%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>49%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>66%</td>
</tr>
</tbody>
</table>

CONCLUSION(S)

In conclusion, this is the largest survey of CLL patients. Much can be learned by detailed surveying of CLL patients throughout their disease. These include previously unreported substantial interrelations between the CLL patient and the HOP. Understanding how patients choose their disease is critical to improve communication between patients and their HOPs, which will ultimately advance CLL outcomes.

REFERENCES


ABOUT THE CLL SOCIETY INC.

The CLL Society Inc. is a three-year-old American-based 501(c)(3) non-profit with a global reach. As its mission states, the CLL Society is focused on educating patients and patient/Family about the needs of the CLL Community through:

- The CLL Society website (https://www.cllsociety.org) which contains up-to-date, accurate and patient-friendly information on CLL.

- The CLL Society Advocate Program (http://www.clladvocate.org) which connects patients and caregivers with trained patient advocates.

- Leading and supporting CLL specific patient support and education groups and hosting educational forums in 4 different continents.

- The CLL Society wishes to thank the patients who participated in this important research and the physicians and support group facilitators that helped create awareness.

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

Figure 1. Statements Provided During Diagnosis of CLL

Figure 2. Emotional Response to Active Observation

Figure 3. Symptoms Experienced during Active Observation

Figure 4. Clinical Trial Consideration

Figure 5. Response to Prognostic Testing

Figure 6. Table 6. Timing of Education

Figure 7. Table 7. Patients’ Report of Good Understanding by Topic

Figure 8. Figure 1.

Figure 9. Figure 2.

Figure 10. Figure 3.