Factors That Influence Patient Treatment Decision Making in the Era of Novel Agents:
An Internet-Based Survey of 281 Patients with Chronic Lymphocytic Leukemia (CLL)

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BACKGROUND ABOUT CLL IN 2016

Chronic Lymphocytic Leukemia (CLL) may be the most common blood cancer in adults in the Western world (37%)[1], but it is still a relatively rare malignancy. Its treatment is further complicated by the wide heterogeneity of its clinical course with some patients never needing treatment and having similar life expectancies as those without CLL and others having rapidly progressive disease.

The recent approval of five novel agents with more in late stage clinical trials, as well as better prognostication of CLL have transformed the therapeutic landscape.

These realities have pushed some patients to become more expert in their disease and more involved in their care and treatment decisions.

OBJECTIVES

- To identify the clinical factors that drive patient's decision-making in treatment selection
- To understand the role of the patient, physician and others in making treatment decisions.
- To identify where patients gather information to inform their decisions

METHODS

Study Design
- This was an online survey of patients with CLL over a 4 week period from Mar 30-Apr 27, 2016.

Patients
- Patients were registered to receive the CLL Society newsletter, *The CLL Tribune*, or registered with the online CLL-specific patient forums hosted by ACOR (Association of Cancer Online Resources) and groups.IO. Only the subset of 281 patients residing in the USA were included in this analysis.

Questionnaire
- A survey containing 11 multi-part questions consisting of demographics, treatment status, factors that drive treatment decision-making, and sources of information.

Statistical Analysis:
- Data were analyzed using descriptive methods. Chi-square was used to evaluate statistical significance.
- Analyses and comparisons were made between the following subgroups:
  - Low-risk or unknown risk versus high-risk
  - Untreated versus treated patients
  - Untreated patients versus those who have received 1 treatment versus received 2 or more treatments
  - Male versus female
  - ≥65 year old treated patients versus <65 year old treated patients
 - Unless mentioned, subgroup analyses were not statistically significant.

RESULTS

Table 1. Patient Characteristics

Median age, years (range)	64 (38-84)
Males, %	46
Median time from diagnosis, years (range)	7 (0-27)
Self-identified Risk Level, %	
High-risk (del 17p, p53 mutated, del 11q, or IGVH unmutated)	40
Unaware of risk level	13
Treatment status, %	
Watch & Wait	31
Considering or receiving 1st treatment	37
Males (51%); ≥65 years old (52%)	
Considering or receiving 2nd or later treatment	32
Males (49%); ≥65 years old (48%)	

RESULTS (continued)

Figure 1. Most Important Criteria When Considering Treatment (% rated 1, 2 or 3)
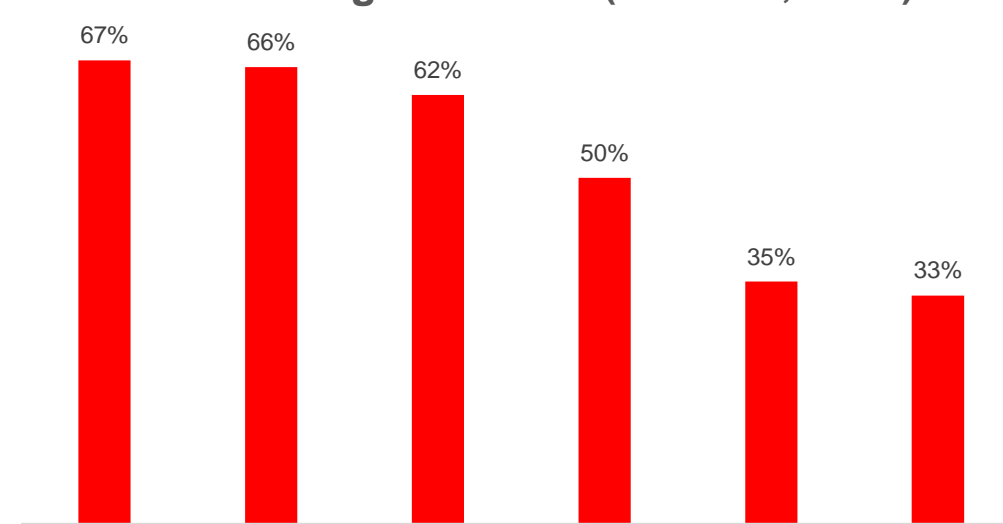

Important Criteria for Treatment Selection

Respondents were asked to rate treatment-related criteria from 1-10, with 1=most important and 10=least important. [Figure 1]

Cost (30%), ability to take treatment orally (23%), participation in a clinical trial (20%), location of treatment administration (19%) and ability to stop treatment after a defined period of time (16%) were of lower importance to patients.

**Role of the Patient, Physician and Others in Making Treatment Decisions**

- 14% allow the physician to make the treatment decision without patient input.
  - Reasons included trust in their doctor or lack of understanding enough to contribute their opinion
- 44% listen to the options their doctor presents, but primarily make their own decision
- 43% proactively research treatment options and the currently available clinical trials and also suggest treatments to their physician

Figure 2. Influence on Decisions Related to Treatment for CLL
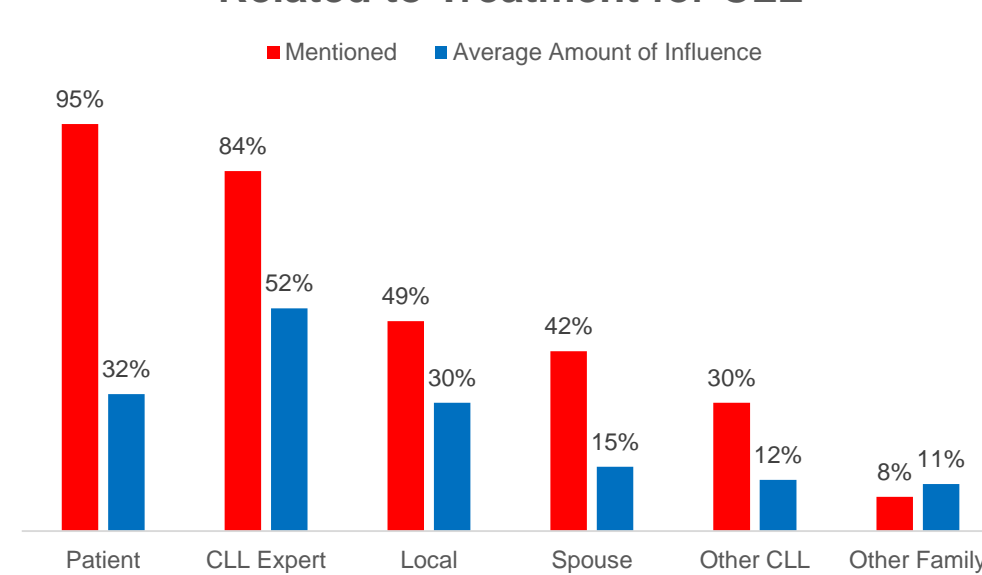
Survey respondents that were actively involved in the decision-making process were asked to indicate who influenced their decisions related to treatment, as well as the percentage of influence provided towards that decision. 95% of respondents stated their own involvement in the treatment decision: 84% involved a CLL expert and 49%, a local hematologist. The average amount of influence for each was 32%, 52% and 30%, respectively. [Figure 2]

Figure 3. Willingness to Take Therapy with Higher Risks but Potential for Cure
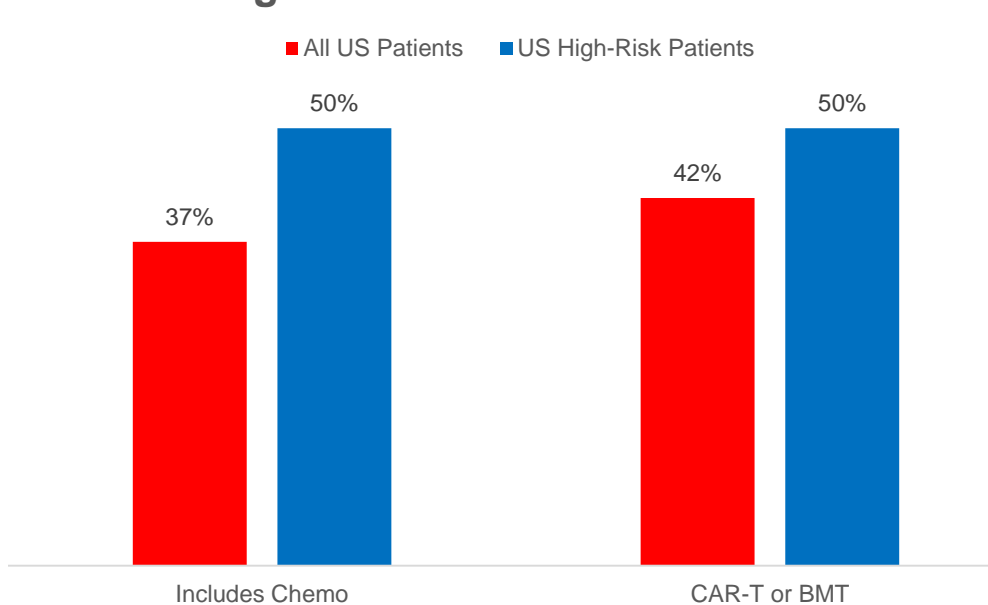
Only 37% of respondents would be willing to take a treatment that included chemotherapy despite higher risks, but a potential for cure.

Similarly, 42% would be willing to consider "CAR-T" or "bone marrow transplant" if it offered a chance of cure. [Figure 3]. Differences between treated patients that were ≥65 and <65 were statistically significant (34%/55%, P=.003), but may represent knowledge that BMT may not be offered to patients ≥65. Future surveys would separate these treatment options.

96% of respondents would be willing to take life-long therapy. [Figure 4].

Figure 4. Willingness to Take Life-long Therapy for Long-term Control Without Potential for Cure
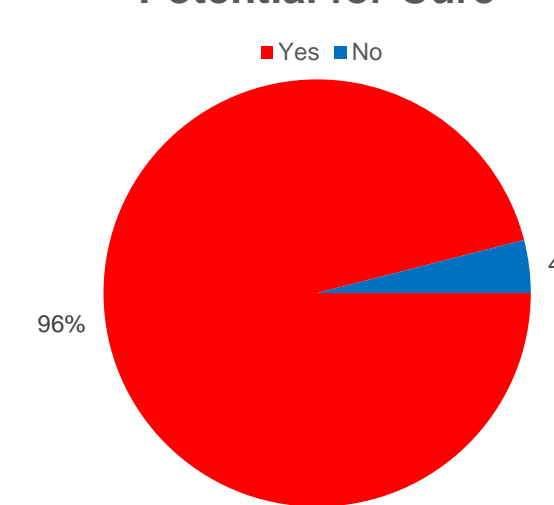
Main Sources of Information About CLL

CLL websites were listed most often (87%) as a source of information about CLL, followed by healthcare providers (HCP) (74%), web-based blogs (72%), patient forums (68%) and webcasts (47%). HCPs and webcasts were less frequently mentioned by untreated patients and may reflect the less frequent contact with HCPs and less interest in webcasts. The difference between responses of treated and untreated patients was statistically significant for mentioning HCPs (P=.001) and webcasts (P=.032) as a source of information about CLL.

CONCLUSIONS

In the era of modern therapies, these data provide insight as to what criteria are important to patients when making treatment decisions, who influences patients in their CLL treatment decision-making process and what resources patients use to gain information about CLL.

In summary:
- 87% of patients reported that they are actively involved in treatment decision-making.
- PFS and OS were mentioned as the most important factors driving their treatment choices.
- Patients rely on multiple sources of information beyond their physician, with online sources mentioned more frequently, perhaps related to the constant availability of the internet compared to infrequent doctor visits.
- There is broad patient acceptance of long-term non-curative treatment.
- There is significant patient hesitancy for chemotherapy, CAR-T therapy and stem cell transplantation despite the possibility of cure.

Recommendations
- All medical decisions should be shared between the patient and the doctor.
- Educated patients are more likely to participate in shared decision-making.
- Encourage and accept patient involvement in their care.
- Be prepared for second opinions – and they may not be from a colleague.
- Don't assume patients are unwilling to consider long-term non-curative but lower-risk therapies.

Limitations
- Our patient respondents were younger (median age 64 years old) compared to the median age of 71 in SEER data[2]. There were also more females (54%) than generally reported (43%)[1]. This likely reflects a selection bias of those completing the survey. Information provided were based on patients' answers and could not be independently verified.
- The survey was only available online, hence the results are obviously influenced by the self-selection of those who use the Internet and access the sources mentioned above and may reflect a group of patients who may be more sophisticated and involved in their care.

Response to Limitations

While we recognize the limits imposed by a survey that was only available online, we believe these data are a true reflection of a growing number of CLL patients who are web savvy and knowledgeable about their disease.

We hope to offer a paper version of a similar survey in 2017 in order to address these concerns.

About The CLL Society Inc.

The CLL Society Inc. is a 501(c)3 nonprofit that focuses on patient education and patient support to address the unmet needs of the CLL community.
- The CLL Society website http://cllsociety.org which contains the most up-to-date, accurate and patient-friendly information on CLL.
- *The CLL Tribune*, a quarterly online newsletter with both patient and physician authors
- CLL-specific patient support groups and educational forums
- CLL Patient peer to peer counseling efforts

The CLL Society wishes to thank the patients who participated in this important research.

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