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

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BACKGROUND & INTRODUCTION

Background about CLL in 2018

The CLL literature focuses largely on the objective aspects of diagnosis, active observation, prognosis and management. While health care providers (HCPs) try to effectively educate and reassure patients, the literature on patients' subjective experience through the continuum of care is limited.

Introduction

The CLL Society Inc., a patient-driven, physician-curated nonprofit organization focusing on the unmet needs of the CLL community, sought to understand how CLL and its management, including the healthcare team, diagnosis, education, active observation, prognostic testing, and the options of clinical trial affect the lives of those with CLL and what was important to patients. The goal was to better understand CLL from the patient's perspective to inform HCPs in best meeting their patients' needs.

OBJECTIVES

- 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.

METHODS

Study Design

The 2017 CLL Diagnosis and Treatment Assessment: The Patient View (2017 CLLDATA) 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-December 2017. This report will focus on the patient perspective at diagnosis, during the active observation (AO) period, prognostic testing, clinical trial participation and sources of information. Data on other topics within the survey will be reported in the future.

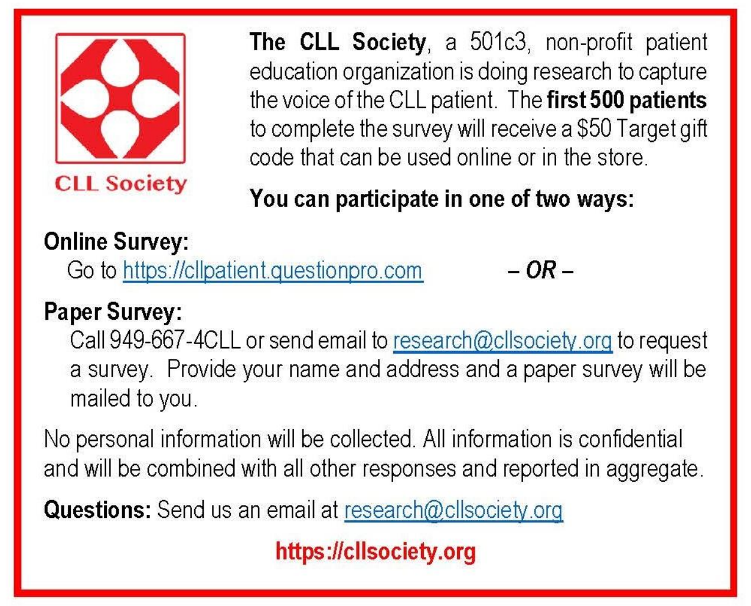
Inclusion criteria: Patients must be age 18 or above, have a diagnosis of CLL/SLL, be a United States resident with a working knowledge of English and be able to provide informed on-line or paper consent for study participation

Survey Recruitment: This survey was administered anonymously using both the CLL Society (CLLS) database, Facebook page, bkoffman.blogspot.com, and online CLL patient forums, as well as information cards distributed in the offices of the principal investigators (PIs) 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 provided to CLL patients within 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

- <65 year old patients versus ≥65 year old patients
- Untreated versus treated patients
- Male versus female
- High-risk versus low-risk
- Patients treated by a general hematologist/oncologist only, a CLL expert only, or both

For the purposes of this research, we used the following definitions:



The CLL Society, a 501c3, non-profit patient education organization is doing research to capture the voice of the CLL patient. The **first 500 patients** to complete the survey will receive a $50 Target gift code that can be used online or in the store.

You can participate in one of two ways:

Online Survey:
Go to https://cllpatient.questionpro.com *– OR –*

Paper Survey:
Call 949-667-4CLL or send email to research@cllsociety.org to request a survey. Provide your name and address and a paper survey will be mailed to you.

No personal information will be collected. All information is confidential and will be combined with all other responses and reported in aggregate.

Questions: Send us an email at research@cllsociety.org

https://cllsociety.org

Definitions	
General hematologist/oncologist	Sees all types of cancer patients
CLL Expert	A hematologist/oncologist who primarily focuses on CLL and works at an academic or research center
High-risk	17p del, 11q del, unmutated IGHV
Low-risk	Trisomy 12, 13q, IGHV mutated with no 17p del or 11q del

RESULTS

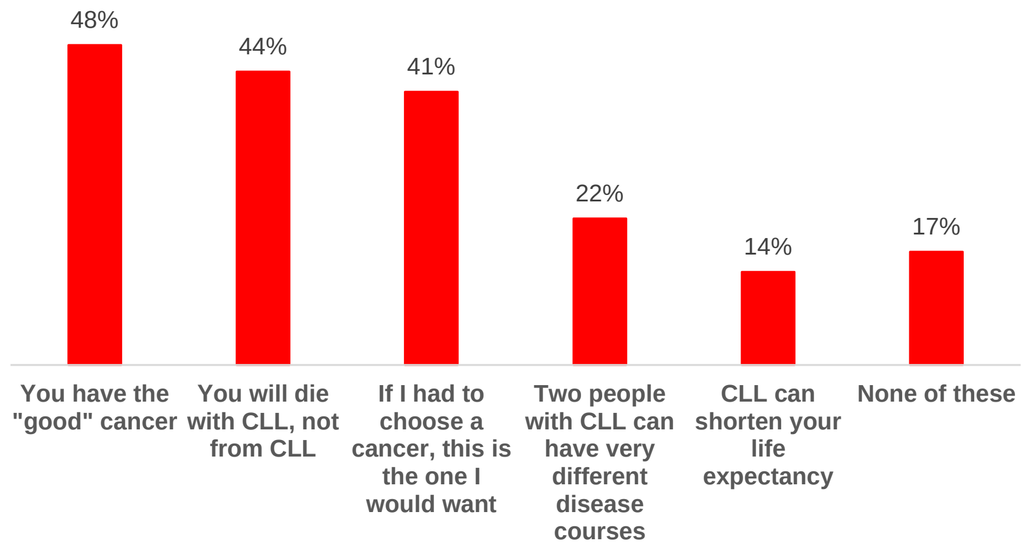
Table 1. Patient Characteristics N=1147

Median age, years % (range)	65 (28-86)
≥65 years old (%)	54
Males (%)	46
Caucasian (%)	96
Median time from diagnosis, years (range)	5 (0-29)
Physician type (%)	
General hematologist/oncologist	**37**
CLL expert	**32**
Both general hematologist/oncologist & CLL expert	**31**
Treatment status (%)	
Watch & Wait	43
Males (37%); ≥65 years old (36%)	
Receiving or completed 1st treatment	25
Males (27%); ≥65 years old (28%)	
Receiving or completed 2nd or later treatment	32
Males (36%); ≥65 years old (36%)	

Diagnosis

At diagnosis, 48% of patients were told they had the "good" cancer by their HCP. This statement, as well as others were reported equally by patients regardless of the type of physician managing/treating their CLL. [Figure 1]

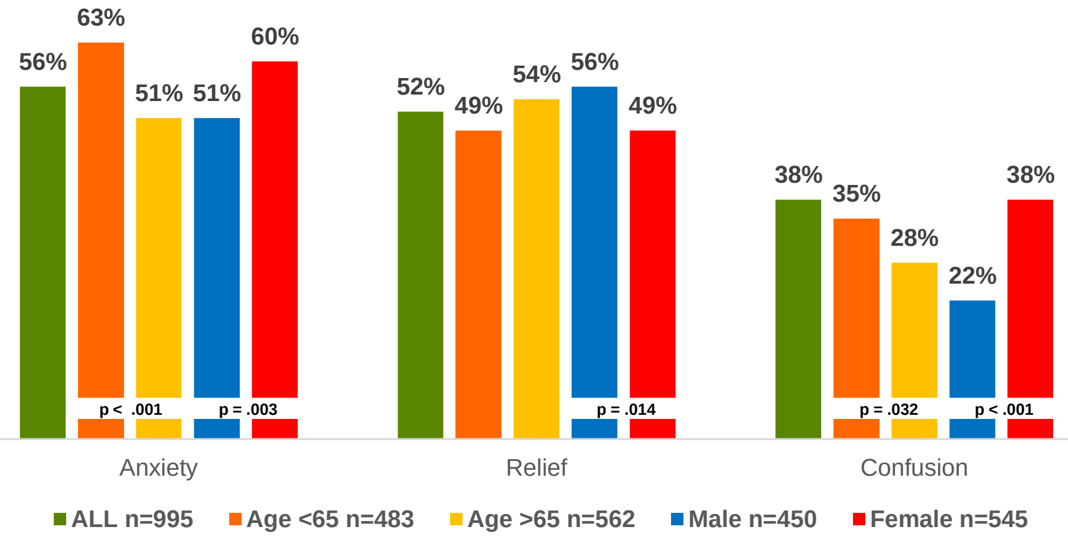
Figure 1. Statements Provided During Diagnosis of CLL



Active Observation

Only 13% of patients reported needing treatment within 3 months of diagnosis. For those managed with active observation (87%), 91% stated that their doctor explained why therapy was not warranted [Figure 2.]

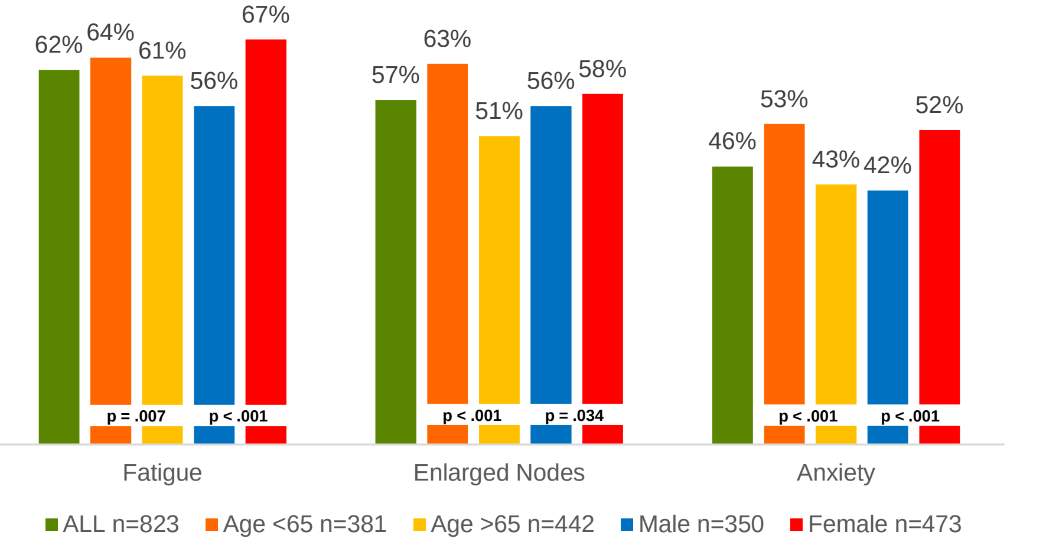
Figure 2. Emotional Response to Active Observation



Symptoms Reported During Active Observation

During active observation, 17% of patients reported experiencing no disease-related symptoms. Men were more commonly asymptomatic (22% vs. 13%), as were those 65 years or older, compared to those under 65 (21% vs. 12%) [Figure 3.]

Figure 3. Symptoms Experienced during Active Observation



Alternative Treatments during Active Observation

Respondents were asked to report on their use of herbal and other non-traditional interventions for managing their CLL during the active observation period, and 66% reported doing so. (Table 2). Fifty-nine percent of patients aged 65 or older reported use of herbal or alternative therapies compared to 75% of patients younger than 65 (p<.001). There was no difference in use of specific herbal or alternative therapies between age groups. Between genders, utilization of herbal or alternative therapies was equal with the exception that women more often use Vitamin D and prayer.

Table 2. Use of Herbal or Alternative Therapies

	ALL n=653	Male n=282	Female n=371	p-value
Green tea or derivatives, %	60	67	55	NS
Vitamin D, %	56	49	61	p<.001
Prayer, %	36	29	41	p<.001

Response to Prognostic Testing

Ninety-two percent of respondents report having had some type of prognostic testing, although 9% were not aware of what specific testing was performed. Two-thirds reported testing at the time, or soon after diagnosis, 33% prior to their first treatments and 7% before 2nd or later treatment [Table 3.]

Table 3. Emotions after Receiving Prognostic Testing Results

	ALL n=804	17p deletion n=121	11q deletion n=140	Unmutated n=247	Low-Risk n=544
More anxious	34%	52%	54%	54%	28%
More depressed	13%	26%	24%	17%	11%
Relieved	17%	7%	7%	7%	20%

Clinical Trial Consideration

Table 4. Invited to Participate in Clinical Trial by Treatment Setting and Age

ALL n=1147		Tx by General Hem/Onc n=426		Tx by CLL Expert n=367		Tx by both n=354		Age <65 n=527		Age ≥65 n=620	
Asked	Agreed	Asked	Agreed	Asked	Agreed	Asked	Agreed	Asked	Agreed	Asked	Agreed
33%	25%	9%	5%	51%	43%	44%	32%	28%	20%	37%	30%

Respondents that were invited but declined participation in a clinical trial, or reported that they would decline participation if asked, reported reasons such as: Preference for a proven treatment (38%), distance from the trial site (29%), fear (20%), and frequent imaging (20%).

Respondents that agreed to participate in a clinical trial cited the following reasons: My healthcare team suggested a trial as a good treatment option for me (71%), access to the latest treatments (69%), close monitoring of my CLL (67%), confidence in the trial team (65%), I wanted to help others (56%) and medications provided for free (54%)

RESULTS (continued)

Education

Respondents were asked to report about the format in which they received education from their healthcare team, when they received this education, their level of understanding after receiving education, whether they sought information for themselves and its impact [Tables 5-7].

Table 5. Sources of Information

	Conversation with MD	Links to CLL-specific websites	General blood cancer websites	Printed materials
ALL (n=1147)	88%	67%	55%	52%
Treated patients (n=656)	92%	70%	58%	59%
Untreated patients (n=491)	83%	64%	52%	43%

Table 6. Timing of Education

	At diagnosis	At each appointment	Upon request	At disease progression
ALL (n=1147)	67%	46%	38%	23%
Treated patients (n=656)	70%	48%	42%	38%
Untreated patients (n=491)	67%	42%	31%	3%

Ninety-eight percent of respondents reported looking for additional information after education received from their healthcare team, most often using an online resource, specifically a CLL-specific website (90%), online CLL patient blog or forum (69%) and general blood cancer websites (64%).

Table 7. Patients' Report of Good Understanding by Topic

	Education from HCP	Self-directed Education
Sources of Information about CLL	66%	72%
Disease Characteristics	64%	87%
Therapy Indications	62%	64%
Prognostic Testing	53%	66%
Progression & Complications	49%	68%

CONCLUSIONS

To our knowledge, this is the largest survey of CLL patients. Much can be learned by detailed surveying of CLL patients throughout their disease. These include previously unrecognized suboptimal interactions between the CLL patient and the HCP. Understanding how patients experience their disease is critical to improve communication between patients and their HCPs, which will ultimately advance CLL outcomes.

Summary and Recommendations:

- 72% of patients reported being offered language similar to "CLL is the good cancer" at the time of diagnosis. This might be better replaced with the facts that CLL is a variable disease, with some patients never needing treatment and others experiencing more aggressive disease.
- AO is an active and symptomatic time for patients with 2/3 using alternative therapies. Patients need more support during active observation.
- Prognostic testing led to increased anxiety in 1/3 of patients, including in 28% who had low-risk disease suggesting a need for improved education.
- Only 7% of patients recall prognostic testing before 2nd or later therapy indicating an unmet need to ensure both patients and providers understand the importance of prognostics when re-treating.
- 9% of patients seeing a general hematologist were asked to consider a clinical trial compared to 51% seeing a CLL expert. Clinical trials should be an option for appropriate patients regardless of where they are treated.
- 33% of patients at time of diagnosis and 77% at progression do not recall receiving education from their HCP. Education should be offered at all stages and perhaps supplemented with durable materials for re-enforcement.
- 98% of respondents reported looking for additional information after receiving education from their healthcare team, most often using an online resource, specifically a CLL-specific website (90%). Anticipating this provides the opportunity to counsel patients about reliable online sources of information.

Limitations

Our patient respondents were younger (median age 65 years old) compared to the median age of 70 in SEER data[1]. They were also more female (54%) than generally reported (38%)[2]. This likely reflects a selection bias of those completing the survey.

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ABOUT THE CLL SOCIETY INC.

The CLL Society Inc. is a three-year old American-based 501(c)3 nonprofit with a global reach. As its mission states, the CLL Society is focused on patient education and patient support in order to address the unmet needs of the CLL community through:

- The CLL Society website https://cllsociety.org which contains up-to-date, accurate and patient-friendly information on CLL.
- The CLL Tribune, a quarterly online newsletter with both patient and physician authors
- Launching and supporting CLL-specific patient support and education groups and hosting educational forums on 3 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

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