Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report 2017

What is the CLL Specialty Registry?

Chronic lymphocytic leukemia (CLL) is a cancer of the lymphocytes (white blood cells) in bone marrow and the most common form of adult leukemia, accounting for one quarter of all new cases of leukemias (American Cancer Society, 2017). There are expected to be approximately 20,000 new cases of CLL in 2017.

The Chronic Lymphocytic Leukemia Specialty Registry, which began accepting participants in April 2015, documents the experiences of a cross-section of people living with CLL. The Chronic Lymphocytic Leukemia Advisory Council— made up of CLL specialists and other oncologists, behavioral scientists, patient advocates, and industry representatives—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at **www.cancersupportcommunity.org/RegistryIndexReport2017**).

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KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS INTO THE CLL EXPERIENCE. KEY FINDINGS INCLUDE:

QUALITY OF LIFE

33% ARE AT RISK FOR CLINICAL DEPRESSION AND

21% REPORT WORSE ANXIETY THAN THE NATIONAL AVERAGE

53% ARE CONCERNED ABOUT EATING AND NUTRITION

43% ARE CONCERNED ABOUT BEING PHYSICALLY ACTIVE

ONLY **38%** OF CLL SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT

PSYCHOSOCIAL IMPACT

34% OF SURVIVORS SAY THAT CLL AFFECTS THEIR ABILITY TO WORK

40% OF CLL PATIENTS REPORT THAT CLL AFFECTS THEIR DAY-TO-DAY FINANCES

26% SAY THAT CLL AFFECTS THEIR RELATIONSHIPS WITH FRIENDS AND FAMILY

TREATMENT DECISION-MAKING

67% INDICATED THAT THEY MAKE DECISIONS TOGETHER WITH THEIR HEALTH CARE TEAM

7% LEFT ALL DECISION-MAKING TO THEIR DOCTOR

23% DESCRIBED THEMSELVES AS NOT AT ALL OR SOMEWHAT UNCOMFORTABLE WITH "WATCH AND WAIT"

WHILE **71%** SAID THAT THEY WERE INVOLVED IN TREATMENT DECISION-MAKING

38% SAID THEY WERE NOT SUFFICIENTLY PREPARED TO MAKE A TREATMENT DECISION

FINANCIAL IMPACT

27% OF RESPONDENTS HAD NOT SPOKEN ABOUT COSTS OF CARE WITH A COUNSELOR, PHYSICIAN, OR ANY OTHER MEMBER OF THEIR CARE TEAM

31% ARE REPORTING OVER $250 IN OUT-OF-POCKET COSTS TO COVER CANCER CARE

31% REPORT SIGNIFICANT LEVELS OF INTRUSIVE THOUGHTS ABOUT THEIR ABILITY TO MANAGE THE COSTS OF CANCER CARE

Who is in the Registry?

This 2017 report analyzes survey responses from 302 CLL patients who reside in the United States and completed survey questions from the opening of the Registry in April 2015 to December 31, 2016 (in the tables below, the number of responses is 302 unless otherwise noted).

FIGURE 1 CHRONIC LYMPHOCYTIC LEUKEMIA SPECIALTY REGISTRY SURVEY DEMOGRAPHICS

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
AGE	(n = 241)	
Mean age	61.6 years, SD = 9.8	Range: 26 to 90
18-44	13	6%
45-64	143	59%
>=65	85	35%
GENDER	(n = 168)	
Male	86	51%
Female	82	49%
RACE	(n = 168)	
White	159	95%
NON-HISPANIC ETHNICITY	(n = 168)	
	162	96%
EDUCATION	(n = 168)	
High school or less	14	9%
Associate degree or some college	46	27%
Bachelor degree	46	27%
Graduate degree or higher	60	36%
REGION	(n = 208)	
Urban	50	24%
Suburban	125	60%
Rural	29	14%
EMPLOYMENT STATUS	(n = 162)	
Full-time	70	44%
Part-time	21	13%
Retired	49	30%
Not employed due to disability	14	8%
Not employed (reason not specified)	8	5%
ANNUAL INCOME	(n = 164)	
<$40K	22	13%
$40-59.9K	17	10%
$60-79.9K	11	7%
$80-99.9K	13	8%
$100K+	54	33%
Prefer not to share	46	28%

FIGURE 2 TIME SINCE DIAGNOSIS OF SURVEY PARTICIPANTS

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
TIME SINCE DIAGNOSIS	(n = 149)	
<1 year	8	5%
1–1.9 years	13	9%
2–4.9 years	34	23%
>=5 years	94	63%

What are we learning?

DIAGNOSTIC EXPERIENCE

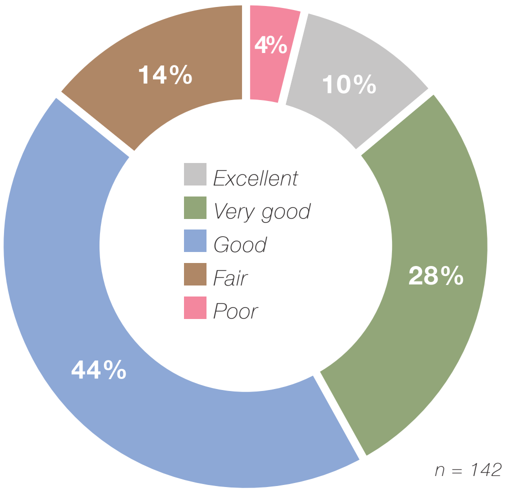
Evidence of CLL is often uncovered from bloodwork during routine check-ups. Forty-one percent of respondents to the CLL Specialty Registry received their diagnosis after a routine annual checkup, compared to the 31% whose symptoms triggered their diagnosis. Risk—how CLL may progress over time—and disease stage are important determinants that health care practitioners use to assess the cancer's progression and develop a treatment plan. More patients (36%) described their risk as intermediate than low (28%) or high (16%). A significant proportion (37%) were at stage 0, the "watch and wait" stage, when patients are not prescribed drugs but instead observed. CLL is sometimes called the "good cancer" because of the many patients on "watch and wait" observation status. In fact, 77% reported they had been told they had "good cancer." One quarter (26%) of respondents reported their status as stage I or II, and 19% as stage III or IV, when the disease has advanced.

There are studies linking leukemias like CLL to chemicals used in warfare—such as Agent Orange during the Vietnam War (Baumann Kreuziger et al, *Leukemia & Lymphoma*, 2014). A small percentage (8%) of respondents described themselves as military veterans. Among them, 9% indicated they were receiving benefits from the Veterans Administration related to either Agent Orange or other military herbicides.

PERCEPTIONS OF HEALTH

In the survey, 38% of CLL respondents described their overall health as very good or excellent, and 44% as good. Just under 20% indicated they were in fair or poor health (Figure 3).

FIGURE 3 SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH

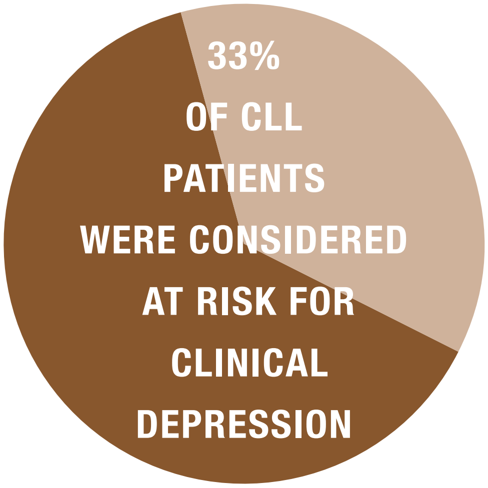


n = 142

CANCER-RELATED DISTRESS

A cancer diagnosis is associated with significant distress, and understanding of the emotional and psychological needs of patients is still inadequate. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to CancerSupportSource®, a validated distress screening instrument.[1]

CancerSupportSource features a depression subscale which demonstrated that one-third (33%) of CLL respondents were at risk for clinical depression.



QUALITY OF LIFE

Patients describe cancer's impact on their quality of life in different ways, and delineating quality of life impairments among CLL patients can go a long way toward addressing their needs. The CLL Specialty Registry incorporates the PROMIS-29, which compares how patients describe their quality of life to other U.S.

FIGURE 4 **TOP 10 CONCERNS OF CLL PARTICIPANTS**

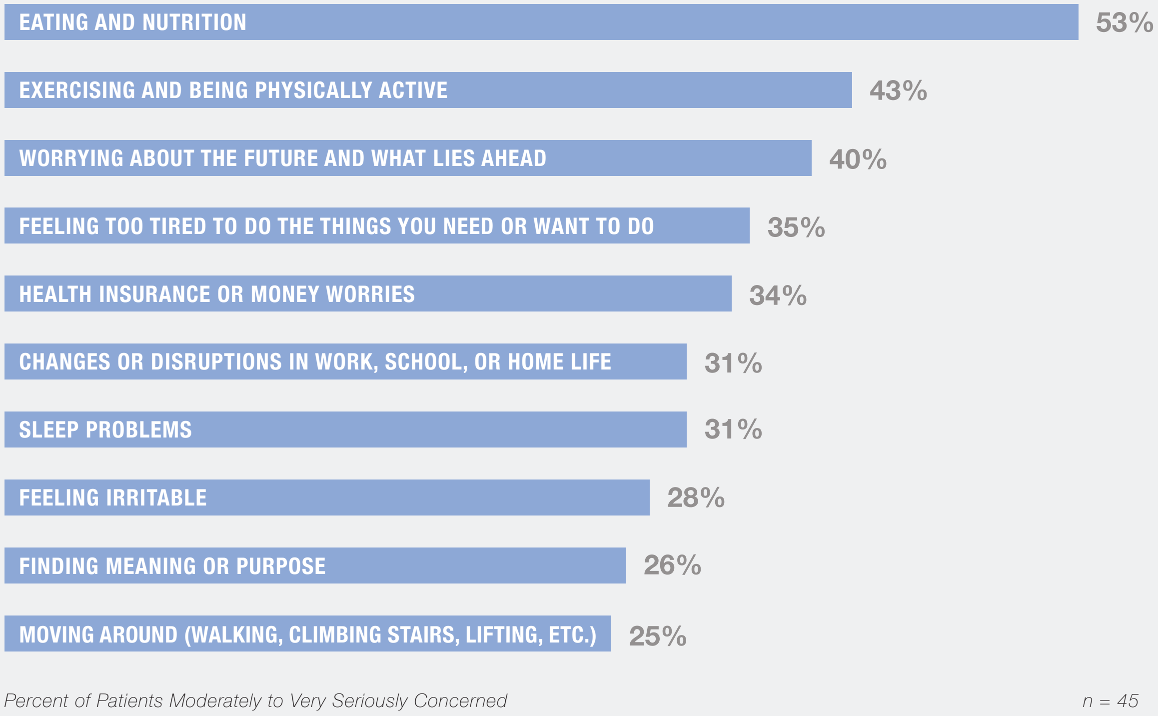
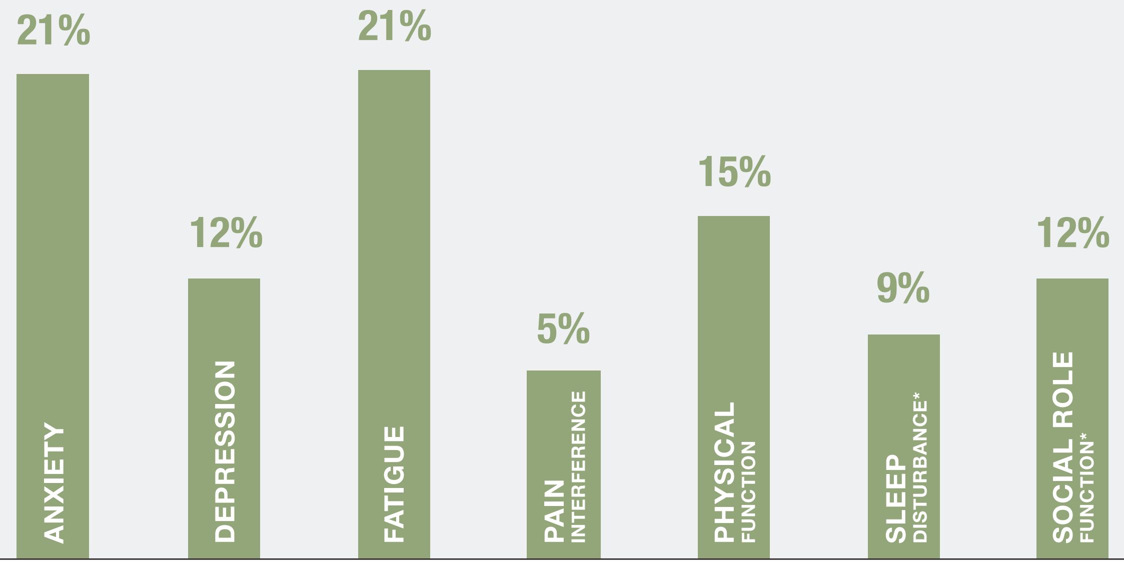


FIGURE 5 **PERCENT OF CLL SURVIVORS REPORTING WORSE QUALITY OF LIFE**

n = 131



*Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.*

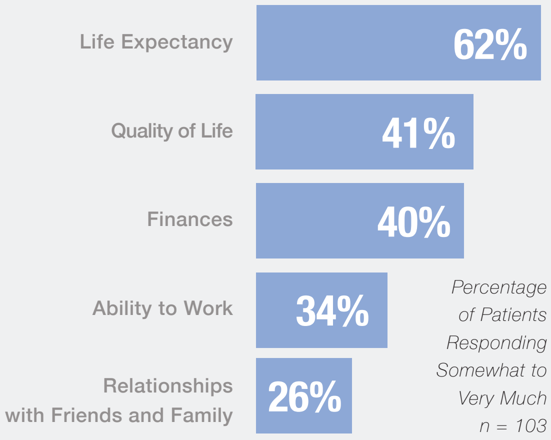
population groups across seven different areas of life.[2] As Figure 5 illustrates, many CLL patients reported substantially worse quality of life than the national average for anxiety (21% of respondents), depression (12%), fatigue (21%), physical functioning (15%), and social functioning (12%). In addition, 9% of respondents reported worse sleep disturbance and 5% reported worse pain interference.

Additionally, Figure 6 presents patients' responses about the extent to which cancer affects CLL patients' day-to-day life, finances, and professional and family relationships.

TREATMENT DECISION-MAKING AND PLANNING

Treatment options for CLL patients may include radiation, chemotherapy, immunotherapy, oral medication, or stem cell transplantation, depending upon disease stage and progress, as well as patient preference. Among CLL respondents to the survey, 18% described their treatment status as in remission after a first treatment with therapy completed, 10% were in their second or subsequent treatment, and 5% were currently in remission after their first treatment

FIGURE 6 **PSYCHOSOCIAL IMPACT OF CLL**



> Respondents indicated that seeking out a community of people affected by CLL was a priority; 72% reported it was at least somewhat important for them to be involved with other CLL patients.

Many choose their treatment facility for a variety of personal, logistical, and financial reasons. An academic or comprehensive cancer center was identified by most respondents (44%) as their main place for treatment decision-making. Nearly one-quarter (24%) reported going to a community cancer center, and 21% frequented a private oncology practice. Most (75%) indicated they had not changed this location as their main point of cancer treatment. Of those who had changed, the majority (62%) transitioned to an academic cancer center, 18% transitioned to a community hospital, and 15% a private oncology practice.

and on maintenance therapy. The largest group (37%), however, described themselves as in "watch and wait"—under doctor observation. This corresponds to the large proportion of stage 0 respondents as described earlier in this report. Only 7% reported they have had a bone marrow stem cell transplant.

Shared decision-making is a critical element of treatment, especially when patients have to make choices between multiple modes of therapy from multiple health care providers at multiple facilities. Although patients are very involved in treatment decision-making (71% quite a bit to very much), they are far less likely to report feeling knowledgeable about treatment options or prepared to discuss treatment options with their doctor (Figure 7).

An overwhelming majority (87%) of respondents reported that they had been under "watch and wait" at some point during their treatment. Over half (52%) were in "watch and wait" for at least three years, and only 9% reported less than six months. Given the extended periods of doctor observation without drug therapies, both health care provider and patient need to build and maintain a considerable level of mutual trust. Most CLL respondents felt high degrees of comfort with their "watch and wait" status: 30% were comfortable from the beginning and 45% became comfortable over time, yet almost one quarter (23%) described themselves as not at all or somewhat uncomfortable.

COST OF CARE

CLL patients have indicated that health insurance and overall cost of care—including health insurance coverage—has been one of their top concerns throughout their cancer experience. Fifty-six percent of respondents had discussed three of the most effective treatments with their doctor, and fewer than half (45%) reported that cost was part of the discussion. More generally, over one quarter (27%) of respondents had not spoken about costs with a counselor, physician, or any other member of their care team.[3]

Thirty-one percent of CLL respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale.[3]

“WATCH AND WAIT” WHAT?

Many patients have expressed discomfort with the term “watch and wait.” Respondents offered alternative terms, some of which reflect their discomfort:

- *Active surveillance*
- *Languishing in limbo*
- *Do nothing ‘til you are really sick*
- *Observational treatment phase*
- *Watch and live*
- *Wait and see*
- *Pre-treatment monitoring*

FIGURE 7 **TREATMENT DECISION-MAKING PROCESS: CLL**

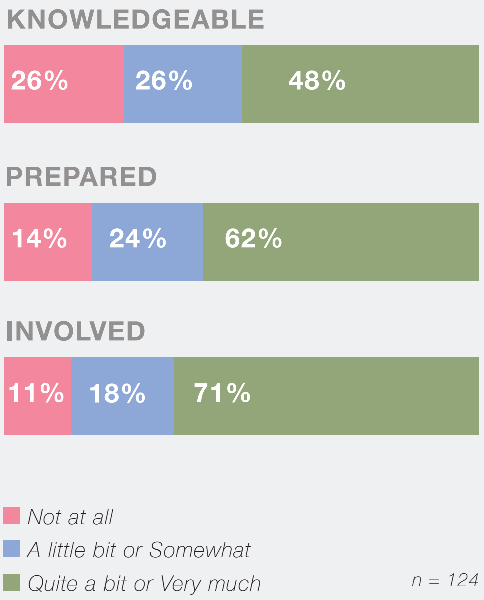
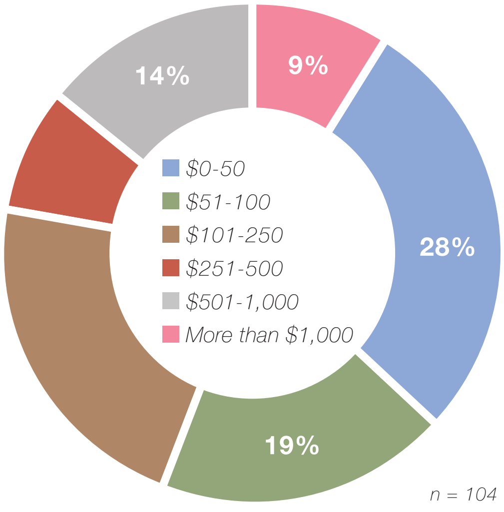


FIGURE 8 **CLL MONTHLY OUT-OF-POCKET COSTS**



KRISTEN, Leukemia Patient

I'm still here because of clinical trials. They are scary, and you don't know what will or will not happen because the treatments are new. But if you are willing to take that chance, there are options. You need to educate yourself, advocate for yourself, and get second opinions.

Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Breast Cancer Specialty Registry Report
- Caregiver Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Lung Cancer Specialty Registry Report
- Melanoma Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report

1. Miller M. F., Mullins, C.D., Onukwugha, E., Golant, M., & Buzaglo, J.S. Discriminatory power of a 25-item distress screening tool: a cross-sectional survey of 251 cancer survivors. *Quality of Life Research*, *23*, 2855-2863.

2. Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S.,…Hays, R. D. on behalf of the PROMIS Cooperative Group. (2010). Initial item banks and first wave testing of the Patient–Reported Outcomes Measurement Information System (PROMIS) network: 2005–2008. *Journal of Clinical Epidemiology*, *63*(11), 1179-94.

3. Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine*, *41*(3), 209-218.

ACKNOWLEDGEMENTS

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