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Chronic Lymphocytic Leukemia Patient Reported Outcomes and Quality of Life: Findings from the Cancer Experience Registry

Joanne S Buzaglo, PhD[1], Melissa F Miller, PhD, MPH[1], Alexandra K Zaleta, PhD[1], Jamese Johnson, MPH[1], Shauna McManus, BS[1], Clare Karten, MS[1], Christopher R Flowers, MD, MS[2]

[1]Cancer Support Community, Research and Training Institute, Philadelphia PA; [2]Department of Hematology and Medical Oncology, Emory University School of Medicine, Atlanta, GA

Background

- Over 20,000 new cases of chronic lymphocytic leukemia (CLL) are expected in the US in 2017, yet understanding of the psychosocial consequences of CLL is inadequate
- Treatment options vary, and many people live a long time with CLL, yet early treatment has not been shown to help people live longer
- Consequently, many people undergo a period of active surveillance ("watch and wait") until symptoms appear before starting treatment

Aims

- The study objectives were to 1) compare how CLL patients describe their quality of life compared to other US population groups, 2) describe how CLL affects daily life, finances, and relationships, and 3) examine the association between quality of life and CLL course

Methods

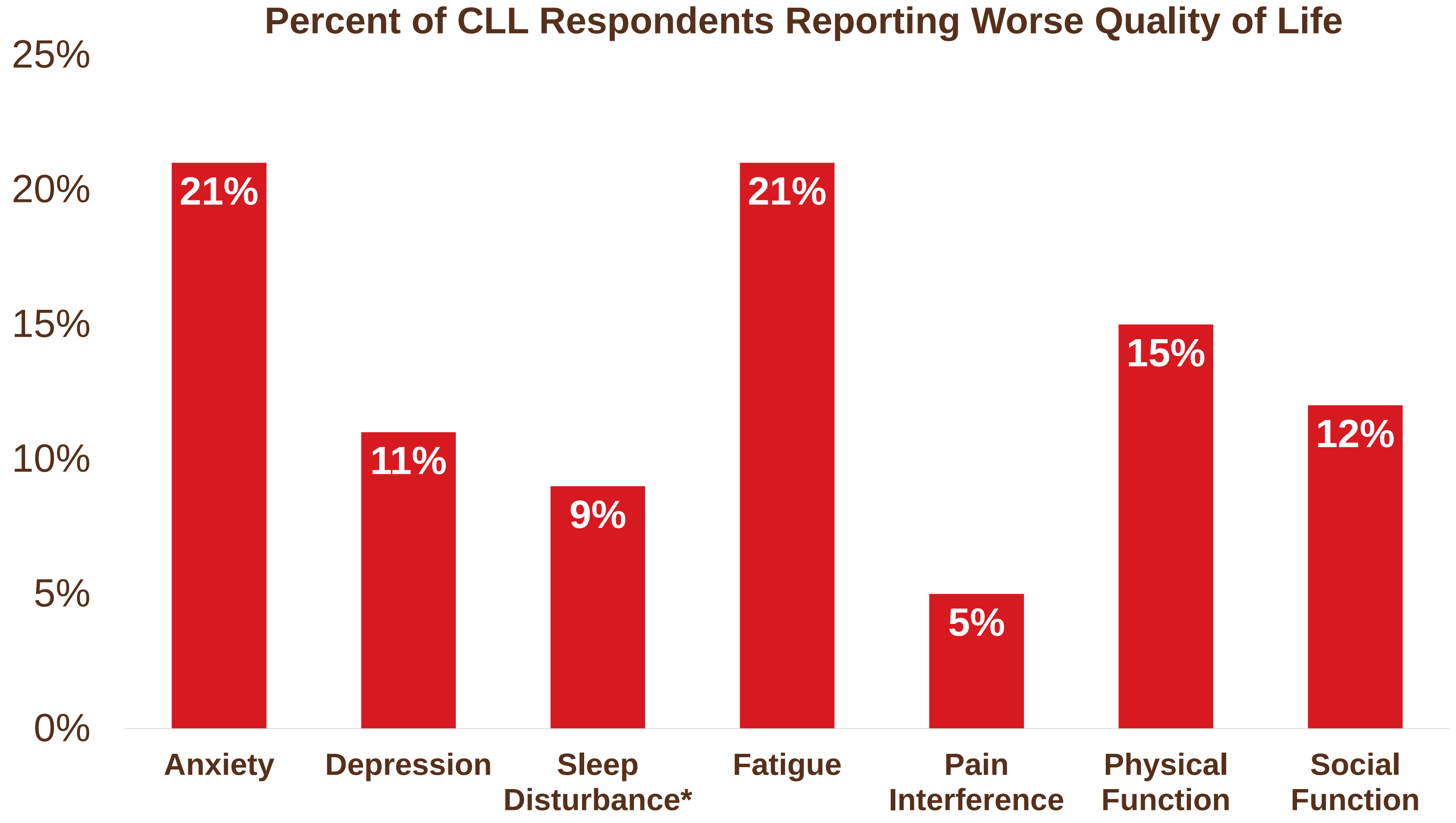
- 134 individuals with CLL enrolled in the Cancer Support Community's online Cancer Experience Registry, provided sociodemographic information and clinical history, and completed surveys including the Patient-Reported Outcomes Measurement Information System (PROMIS-29v2.0), which assesses seven health-related quality of life domains
- After adjusting for sociodemographic variables, associations between course of CLL (undergoing observation, currently receiving first treatment, currently receiving second or subsequent treatment, in remission or maintenance therapy) and PROMIS subscale T-scores were examined with Pearson correlations and multiple linear regression analysis

Participants

N = 134	*M/n*	*SD/%*
Age (years)	61 *Range: 36 – 85*	9
Non-Hispanic White	127	95%
Female	63	47%
Current Treatment Status		
Undergoing observation ("watch and wait")	49	37%
First line treatment	8	6%
Active second or subsequent treatment	16	12%
Remission	52	39%
General Health (*n* = 130)		
Excellent	11	9%
Very good	38	29%
Good	59	45%
Fair	17	13%
Poor	5	4%

Results

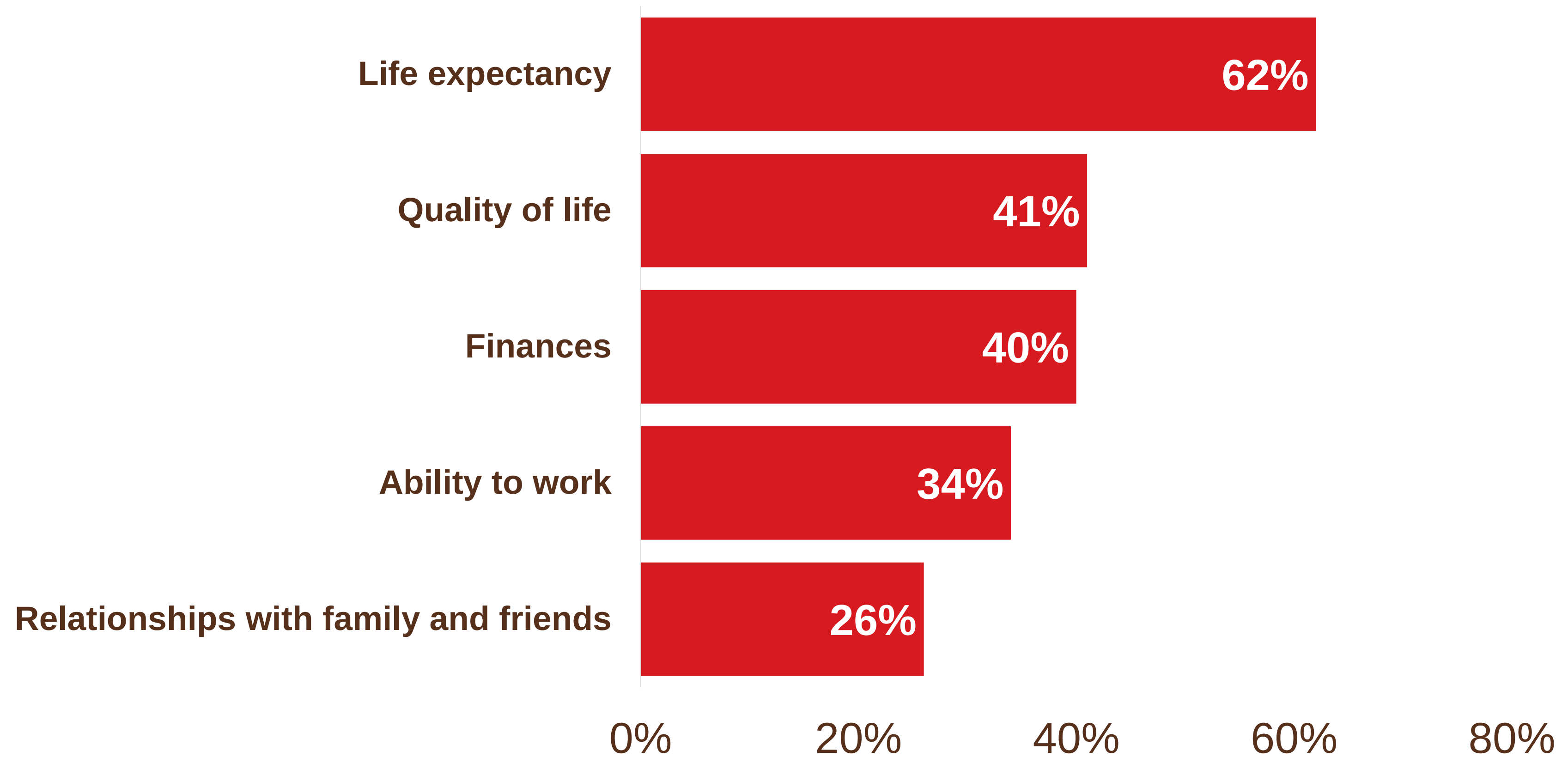
Percent of CLL Respondents Reporting Worse Quality of Life



*Note: Relative to PROMIS-29 US population norms, except where * denotes US population group balanced to include more people with chronic illness; worse denoted as +1SD for symptom scales and -1SD for function scale*

- Many CLL respondents reported substantially worse quality of life as compared to the general U.S. population, especially with respect to anxiety and fatigue (21% of respondents)

Practical and Functional Impact of CLL



- Many respondents indicated that CLL "somewhat to very much" affected their views on life expectancy (62%), quality of life (41%), finances (40%), ability to work (34%), and relationships with friends and family (26%)

Quality of Life Factors Associated with CLL Course (Lines of Therapy)

	Semipartial *r*	*p*
Anxiety (R^2 = .16, *F*(6,122) = 3.79, *p*<.005)		
First line treatment	.20	<.05
Second or subsequent treatment	.20	<.05
Physical Function (R^2 = .18, *F*(5,121) = 5.27, *p*<.001)		
Second or subsequent treatment	-.20	<.05
Social Functioning (R^2 = .17, *F*(5,122) = 5.12, *p*<.001)		
Second or subsequent treatment	-.21	<.05
Depression (R^2 = .11, *F*(5,121) = 3.03, *p*<.05)		
Second or subsequent treatment	.20	<.05
Fatigue (R^2 = .19, *F*(5,122) = 5.65, *p*<.001)		
Second or subsequent treatment	.23	<.01
Sleep Disturbance (R^2 = .13, *F*(6,118) = 2.80, *p*<.05)		
Second or subsequent treatment	.24	<.01

*Controlled for age, gender, education, and income
**Significant associations only are displayed

- With respect to CLL lines of therapy, worse anxiety was significantly associated with active treatment, whether first line of therapy or subsequent therapy
- Currently receiving second or subsequent line of therapy was significantly associated with worse physical and social functioning, greater levels of fatigue and depression, and increased sleep disturbance
- No significant associations were found between active surveillance ("watch and wait") status or disease remission and quality of life outcomes

Implications and Conclusions

- Over one-fifth (21%) of CLL survivors are experiencing substantial levels of anxiety and fatigue, compared to the general U.S. population
- Poorer health-related quality of life was associated with active treatment but not active surveillance ("watch and wait") or when disease was in remission
- It remains unclear the extent to which advancing disease versus treatment itself contributes to poorer quality of life
- Next steps include further examination of factors that place CLL patients at greater risk for poorer outcomes and the evaluation of interventions designed to address emotional distress and quality of life concerns, especially among people with progressing disease

Acknowledgments

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References

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CANCER EXPERIENCE REGISTRY.
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The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers, but also includes 10 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 12,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org

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Contact: Joanne Buzaglo, PhD: joanne@cancersupportcommunity.org