

Developing a Patient/Provider Discussion Tool for Chronic Lymphocytic Leukemia (CLL)

Claire Saxton MBA*, Maria Gonzalo MS*, Jenny Karubian MA**, Alex Swales, MSW*, Sheri Walters BSW MPH*, Amelia Robert MPH*, Alexandra K. Zaleta PhD***

*Cancer Support Community, Washington, DC

**Ready To Launch Research, Los Angeles, CA

***Cancer Support Community, Research and Training Institute, Philadelphia, PA

Background

The National Cancer Institute estimates more than 20,000 people will be diagnosed and over 163,000 people will be living with Chronic Lymphocytic Leukemia (CLL) in the US in 2019. In 2017, nearly 40% of CLL patients that participated in the Cancer Support Community (CSC) Cancer Experience Registry® (CER) reported that they were not sufficiently prepared to make treatment decisions and communicate with their health care team. In 2018, CSC developed a patient/provider discussion tool to help patients better communicate with their health care team.

Aims

Develop a patient/provider discussion support tool tailored to CLL patients' specific challenges related to making decisions about the risks vs. benefits of treatment, short and long term side effects of treatment, their stage of life, and the impact on family and friends.

Methods

CSC created the draft tool for CLL patient-provider communication using CSC's discussion tool for CML ((bit.ly/2kiS5Ce) as a template.

The draft tool was tested in focus groups with CLL patients to assess whether it met their needs. The initial draft was shown to the first wave of research participants, who provided qualitative feedback. The CLL tool was then refined and presented as stimuli for the second wave of research.

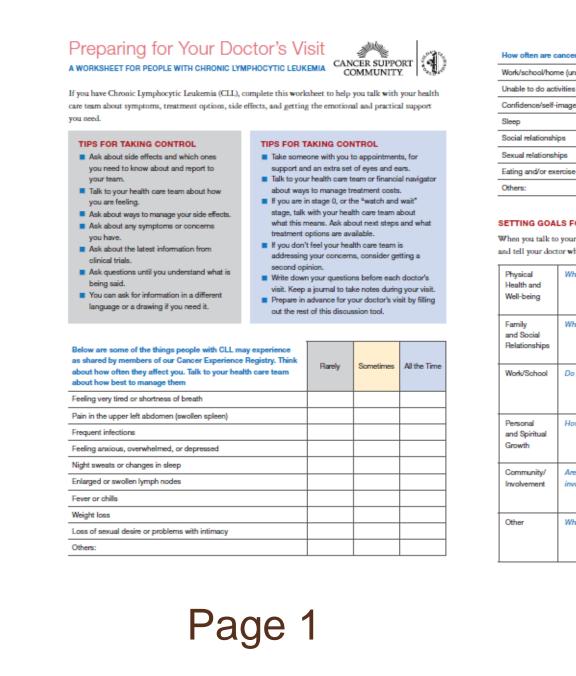
In total, CSC conducted 4 focus groups with 20 CLL patients.

Focus group participants were asked to give feedback about the following:

- Did the tool reflect the top issues CLL patients want to discuss with their providers?
- Was the tool useful for a wide range of CLL patients?
- Did the tool reflect how CLL affects patients' lives?
- Could the tool help patients articulate the broader?

Initial Version of the CLL Discussion Tool

The initial draft was shown to the research participants, who provided qualitative feedback.



nable to do activities I normally enjoy, such a traveling When you talk to your doctor about your treatment options, ask what the goal is. Think about your own values and tell your doctor what is important to you. Also, your goals may change over time. What's going on in the lives of others that is important to you? Work/School Do you want to continue working? Can you adjust your schedule or responsibilities low is your confidence and self-esteem? Are you able to do things you enjoy?

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If you are feeling either better or worse today than at your last appointment, let your health care Write down your questions before each doctor's visit. Below are some suggested questions. The symptoms and side effects that are affecting me the most are: [fill in your answers from page 1 nese are interfering with my life in these ways: [fill in your answers from the top of page 2]. hat can we do to manage these symptoms? My top goals for treatment are: [fill in your answers from page 2]. _

FINANCIAL RESOURCES Think about people in your life who can help (your ven with health insurance, treatment is oup, or co-workers). Make a list of things you whelming. However, there are many ed (childcare, meal prep, laundry, etc.) and w ources that can help. Talk with your an help with each task. Ask your health care to h care team and your pharmacist search for information online, make sure that ker, financial counselor, or to a nonprof organizations, CSC and many of these organizations you can help to reduce unexpecte have helplines, online discussion boards, and more osts. To learn more about ways to ways to seek support from others who have CL nage the cost of treatment, visit:

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Leukemia & Lymphoma Society • 914-949-5213 • www.lls.or

American Cancer Society • 800-227-2345 • www.cancer.org

Financial Support Resources

American Society of Clinical Oncology (ASCO) • 703-299-0158 • www.cancer.net/CI

Patient Access Network Foundation • 866-316-7263 • www.panfoundation.org/assistance-programs/chron

Canoer Support Helpline® Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring

sointments can be made by calling 888-793-9355, visiting www.CancerSupportCommunity.org, or by contacting

Services at Local CSCs and Gilda's Clubs Almost 50 locations plus 120 satellite locations around the country of

The Living Room, Online Here you will find support and connection with others on discussion boards, a special sp

for more information and additional resources, please visit the CSC Leukernia page at http://www.CancerSupportCommunity.org/leukernia

someone with cancer, or a health care professional looking for resources, CSCs toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9am - 9pm ET.

eukemia & Lymphoma Society • 914-949-5213 • www.lls.org/financial-sueeo

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org/help.php

ancerCare • 800-813-4673 • www.cancercare.org/financial_assistan

for teens, and personal web pages to keep your family and friends up-to-date.

ters. www.CancerSupportCommunity.org/join-our- movement

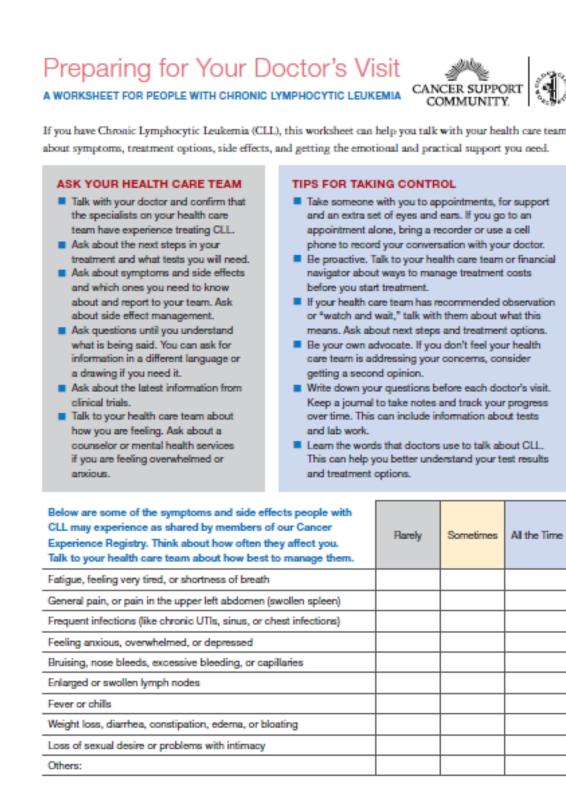
Participants Feedback

Participants suggested adding:

- Language addressing the importance that patients ask questions and communicate with their doctors, take notes and track their progress over time, including test results and lab work.
- Additional side effects, such edema, bone pain, nose bleeds, fatigue, bloating, shingles, bruising, chronic UTIs, weight loss, sinus infections and pneumonia.
- Information about how to be advocates for themselves, resources for managing the cost of care and finding social support.
- Information to help explain CLL and recognition that others may not understand what living with CLL is like.

Final Version of the CLL Discussion Tool

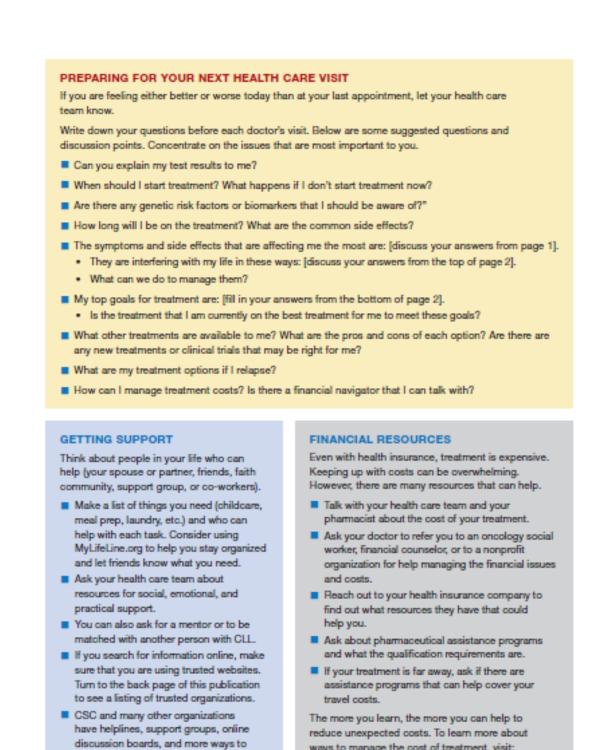
CSC implemented the feedback received by focus groups participants and updated the CLL discussion tool to ensure it meets their communication needs.



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How often are o	ancer or side effects interfering with your life?	Rarely	Sometimes	All the Tir
Work/school/hon	ne (unable to go to work/school or do daily tasks)			
Unable to do act	ivities I normally enjoy, such a traveling			
Confidence/self-	image			
Difficulty thinking	y/brain fog			
Social relationshi	ips			
Sexual relationsh	nips			
Eating and/or ex	ercise			
Difficulty sleeping	g/insomnia			
Others:				
edge treatments.	ate to progress by taking part in research, make it to Let your health care team know about your treatmen hange over time.	_		
		_		
	Let your health care team know about your treatment	_		
edge treatments. your goals may ch Physical	Let your health care team know about your treatment hange over time.	t and personal		
edge treatments. your goals may cl Physical Health and Well-being Family and Social	Let your health care team know about your treatment hange over time. What is most important for you to be able to do?	t and personal	goals. Remer	nber that
edge treatments. your goals may of Physical Health and Well-being Family and Social Relationships	Let your health care team know about your treatmenthange over time. What is most important for you to be able to do? What's going on in the lives of others that is important.	t and personal	goals. Remer	niber that

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seek support from others who have CLL.

ways to manage the cost of treatment, visit:

www.CancerSupportCommunity.org/cost



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Findings

- Most of the top issues patients wanted to address with their providers were captured in the initial version of the CLL-specific tool.
- Additional feedback included adding a system to track side effects and changes in treatment goals over time and suggestions for additional financial and support resources.
- Participants believed this tool would be most useful for newly diagnosed patients with CLL, as well as CLL patients who were deciding whether to switch to a new treatment or provider.
- Patients were concerned about the cost of treatment and highlighted the importance of encouraging others to ask their health care team for referrals to patient advocates or nonprofit organizations for help and guidance.
- Participants reported appreciation for an integrated approach to managing their care in which treatment goals, life goals, and side effects are considered together. They view this tool as a way to empower patients to become active partners in their care and help them find ways to cope with their distress.

Summary

Findings suggest that the CLL discussion tool can help patients communicate with their health care team and lead to fruitful conversations about their treatment goals, treatment decisions, and the impact of CLL on their daily life. Regarding implementation, CSC distributes the tool at no charge to CLL patients and caregivers via its internal network of almost 50 Cancer Support Communities and Gilda's Clubs worldwide, the CancerSupportCommunity.org webpage, the Frankly Speaking About Cancer radio show, and partner patient advocacy groups. We would also like to make patient navigators aware of this tool and allow them to order/download it, at no charge.

Frankly Speaking About Cancer Program

Frankly Speaking About Cancer (FSAC) is CSC's award-winning FREE landmark cancer education series, that provides evidence-based information on a variety of topics important to people affected by cancer. FSAC: Chronic Lymphocytic Leukemia offers a number of publications in both print and electronic formats to help address CLL specific challenges during treatment and survivorship. For more information visit www.CancerSupportCommunity.org.







Acknowledgments

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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 and also includes 12 disease-specific surveys. Findings contribute toward advancing research, health care and policy.
- Over 14,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

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

References

- Cancer Support Community (2017). Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report 2017. Retrieved from
- https://www.cancersupportcommunity.org/sites/default/files/uploads/our-research/2017 Report/the cll specialty report 7-10.pdf • Cancer Support Community (2018) Frankly Speaking About Cancer: Chronic Myeloid Leukemia (CML). Retrieved from: https://www.cancersupportcommunity.org/chronic

• Westbrook T D, Maddocks K, Andersen B L (2016). The relation of illness perceptions to stress, depression, and fatigue in patients with chronic lymphocytic leukaemia.

- Ha, J. F., & Longnecker, N. (2010). Doctor-Patient Communication: A Review. The Ochsner Journal, 10(1), 38–43.

Psychology & health, 31(7), 891–902. doi:10.1080/08870446.2016.1158259

- Shanafelt T D, Bowen D A, Venkat C, et al. (2009). The physician-patient relationship and quality of life: lessons from chronic lymphocytic leukemia. Leukemia research, 33(2), 263–270. doi:10.1016/j.leukres.2008.06.019