

BACKGROUND

- Clinical management of chronic lymphocytic leukemia (CLL) has changed considerably in recent years. New prognostic factors and highly active regimens have led to improvements in both progression-free and overall survival¹
- Despite these improvements, many hematology/oncology (hem/onc) physicians are challenged to stay current with the latest advances and many lack confidence in their ability to tailor therapy in newly diagnosed and relapsed/refractory patients
- Patients with CLL have been shown to exhibit clinically significant levels of distress.^{2,3} The quality of patient-physician communication affects patients' quality of life, and while patients may be comfortable discussing treatment options with their physicians, they are often less at ease discussing quality of life concerns²
- Medscape Education has collaborated with the University of Alabama at Birmingham (UAB) Health System Cancer Community Network (UABHS CCN) to assess the effectiveness of educational interventions directed to physicians, nurses, navigators, as well as patients

The goals of this initiative included:

- Educating healthcare teams (physicians, nurses, and navigators) about CLL treatment options and the potential impact on emotional, social, spiritual, and occupational health of patients and their family members
- Empowering patients by linking them to educational materials on CLL treatment options and tools to facilitate shared decision making
- Evaluating the impact of implementing a multilevel educational effort targeting patient activation, patient preference and perception of decision making, and patient distress
- Evaluating the impact of a multilevel educational effort targeting providers' knowledge of CLL treatment, perspectives on shared decision making, and self-reported use of educational materials

Learner	Pre-Assessment	Intervention	Post-Assessment
UABHS CCN Network Patients	Survey	Referral to educational materials*	Survey
UABHS CCN Lay Navigators	Survey	Webinar + access to patient education materials*	Survey
Healthcare Providers (UABHS CCN Local participants)	Survey	Live expert lecture and referral to online CME/CE certified program**	Survey
Healthcare providers (HCPs, Medscape National participants)	CME/CE Pre-test questions	CME/CE certified program online**	CME/CE post-test questions***

*Module titled *How to Talk With Your Healthcare Team About Chronic Lymphocytic Leukemia*
**Collection of 3 brief educational articles: *Expanding Treatment Options for Chronic Lymphocytic Leukemia*; *Quality of Life in Patients With Chronic Lymphocytic Leukemia*; and *Improving Communication in Patients With Chronic Lymphocytic Leukemia*
*** Linked pre-/post-assessment study design allowed baseline answers of each learner to be compared with that same learner's responses after exposure to the education. In this way, learners act as their own controls, thus avoiding errors potentially introduced by aggregation of data.



RESULTS

TELMS MODEL: ACTIVATE (Understand the Gap)

Healthcare professionals were not confident in their ability to select and tailor therapies for patients with CLL, as evidenced by HCPs' performance in relevant educational activities. Patients reported feeling stress related to their disease and, often, to the "watch and wait" approach to therapy. In addition, patients were often not comfortable discussing quality of life issues with their care team. MDs, nurses, and navigators became aware of the need to ascertain the patient's understanding of the disease as well as the need for better communication to facilitate engagement from the patients for shared decision making.

ACTIVATE

TELMS MODEL: ADVANCE (Convert Information)

Patients
Although the PAM score was largely unchanged for patients with CLL following the local interventions at UABHS CCN, increases were observed in:

- Understanding the signs and symptoms of worsening disease
- Confidence in responding to those signs and symptoms

Importantly, patients were able to convert new information into practical actions relevant to their individual needs and demonstrated:

- Decrease in distress related to knowledge or psychosocial concerns (Figure 1)
- Improved disease understanding
- Increased confidence in their ability to identify signs and symptoms indicating a worsening of their disease (Figure 2)
- Greater satisfaction with physician's explanation (Figure 2)
- Increased preference for shared decision making (Figure 3)

HCPs

- Providers and navigators reported an increase in comfort with their knowledge of current CLL treatment options after participating in the educational intervention
- Providers and navigators indicated increased perception of shared decision making from pre- to post-assessment

Assessment of knowledge and competence of physician learners from the CME/CE activity distributed nationally on Medscape showed improvement in knowledge and competence. Linked learners demonstrated a:

- 13% improvement in knowledge as it relates to effective physician-patient communications to empower patients (42% of learners had reinforcement of this educational theme)
- 27% increase in competence of hem/onc MD learners in selecting an evidence-based approach to treatment in first-line setting (Figure 4)

ADVANCE

TELMS MODEL: ASPIRE (Demonstrate Engagement)

This initiative was able to demonstrate engagement in practices as patients reported increased perception of shared decision making (Figure 5). Patient and provider perceptions regarding decision making were more aligned at the post-assessment compared with the pre-assessment (Figure 6).

ASPIRE

Survey Tools and Data Collection for Patients and Lay Navigators

- Patient Activation Measure (PAM) survey: Assesses patient knowledge, skills, and confidence in managing their own health and health care
- Control Preferences Scale: Evaluates patient preferences and patient and provider perceptions of decision making
- Distress Thermometer: Calculates an overall distress score and identifies distress related to the following domains: Practical, Family, Emotional, Spiritual, Financial, Knowledge, and Physical Problems; for this initiative, knowledge concerns were characterized to identify the percentage of patients with concerns pertaining to diagnosis, prognosis, treatment, or palliative/supportive care
- Demographics and Illness Understanding: Questions were included to assess patients' understanding of the incurable nature of their cancer, warning signs of progression, and satisfaction with explanations of therapy
- Healthcare Provider Perception Survey: Evaluates HCP perception of patient knowledge and participation in decision making
- Navigator Survey: Identical to the HCP survey, although the wording was modified to reflect the difference between the roles of the navigator vs the HCP

Outcomes Measures UABHS CCN Intervention for Patients

- Primary outcome measure
 - Change in patient activation as measured by PAM survey score
- Secondary outcome measures
 - Percentage of patients with a reduction in distress score
 - Percentage of patients reporting distress related to psychosocial concerns
 - Disease understanding
 - Patient preference for decision making

Outcomes Measures for HCPs and Navigators

UABHS CCN HCPs/Navigators

- Evaluate the impact of the educational initiative on:
 - Provider perception of shared decision making
 - Provider and patient concordance on perception of shared decision making
 - Provider perception of patient knowledge about CLL

National level

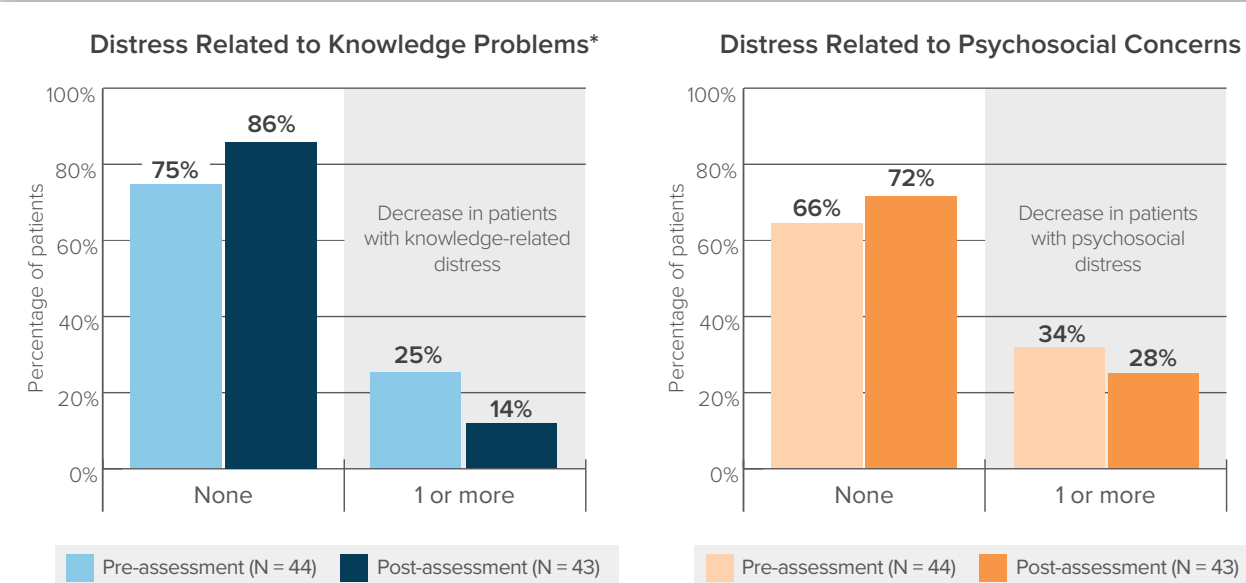
- Analysis: A paired, 2-tailed t-test assessed whether the mean pre-assessment score was different from the mean post-assessment score. *P* values are shown as a measure of significance; *P* values <.05 are considered statistically significant

CONCLUSIONS

- This educational intervention was effective in improving patient knowledge regarding CLL and in increasing patient activation, as demonstrated by a greater desire for shared healthcare decision making, as well as by the noted increase in their perception of their involvement in decision making
- Changes in navigator and provider perceptions reflected the increase in shared decision making reported by patients. Although there was an overall increase in patient distress (the source of which requires further study), a decrease was observed in the specific areas of patient distress related to knowledge gaps and psychosocial concerns
- The online CME activity demonstrated an increase in HCP knowledge and competence regarding CLL management. This improvement is consistent with the increase in comfort with their knowledge of CLL treatment options that was reported by HCPs in the UAB survey

FIGURE 1. Outcome Measures: Distress Related To Knowledge Problems or Psychosocial Concerns

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*Knowledge problems include diagnosis, prognosis, treatment, and side effects

FIGURE 4. What treatment would you select for a 71-year-old patient with multiple comorbidities?

Hematology/Oncology Specialists (n = 52), P <.05	Pre-assessment % (n)	Post-assessment % (n)
A Chlorambucil/obinutuzumab	44% (23)	69% (36)
B Fludarabine/cyclophosphamide/rituximab (FCR)	13% (7)	8% (4)
C Bendamustine/rituximab (BR)	37% (19)	17% (9)
D Chlorambucil	6% (3)	6% (3)

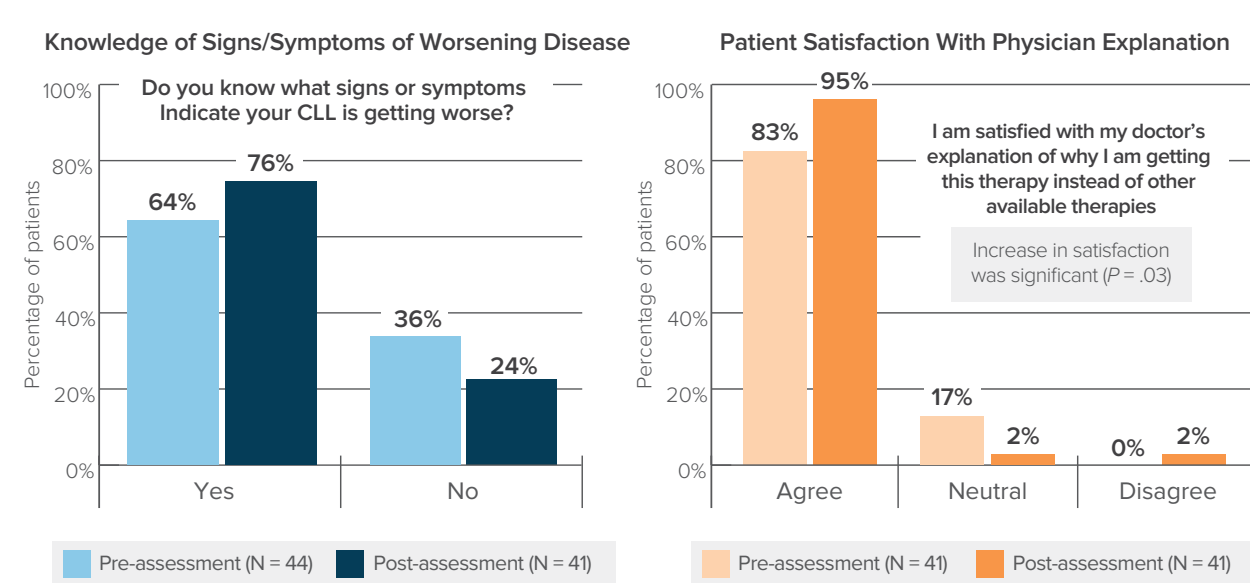
Unaffected Learners: 31%
Improved Learners: 27%
Reinforced Learners: 42%

Impact on Supporter's Goals

This initiative helped demonstrate the importance of education in delivering improved knowledge and competence for clinicians to apply the latest evidence-based treatments for patients with CLL. In addition, this initiative demonstrated the efficacy of engaging patients in their own care through education. In doing so, patients are more likely to participate in shared decision making that, in turn, has been shown to result in better patient outcomes. This initiative provided the supporter with outcomes data that demonstrated education can have an impact on shared decision making for patients and provides confidence in recommending independent medical education (IME) for future educational needs that may arise in the treatment of hematologic malignancies when greater patient engagement is needed.

FIGURE 2. Patient Knowledge of Symptoms and Satisfaction with MD Explanation

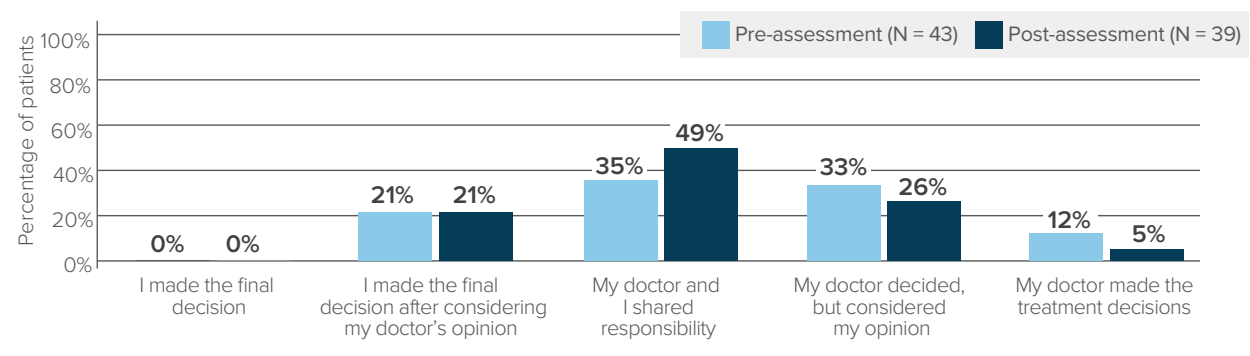
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- Following the educational intervention, patients were more confident in their ability to identify signs symptoms indicating a worsening of their disease
- Clinical trial participation increased post-educational intervention

FIGURE 5. Outcome Measures: Patient Perception of Decision-Making Preference

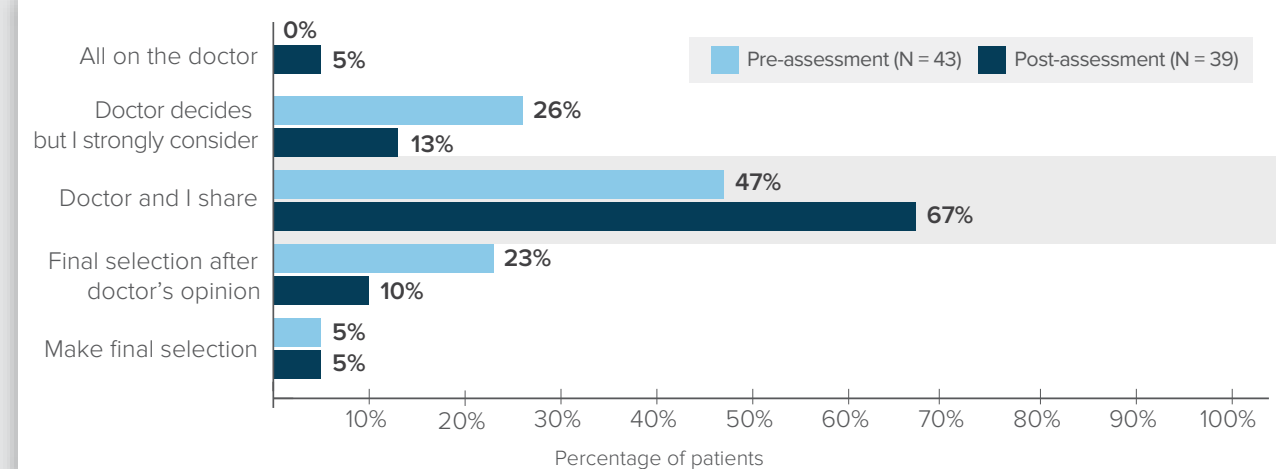
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- Patients reported always at least considering the doctor's opinion when determining a course of treatment
- At the post-assessment, an increase was observed in patient perception of shared decision-making between themselves and their doctor

FIGURE 3. Outcome Measures: Patient Preference for Making Treatment Decisions

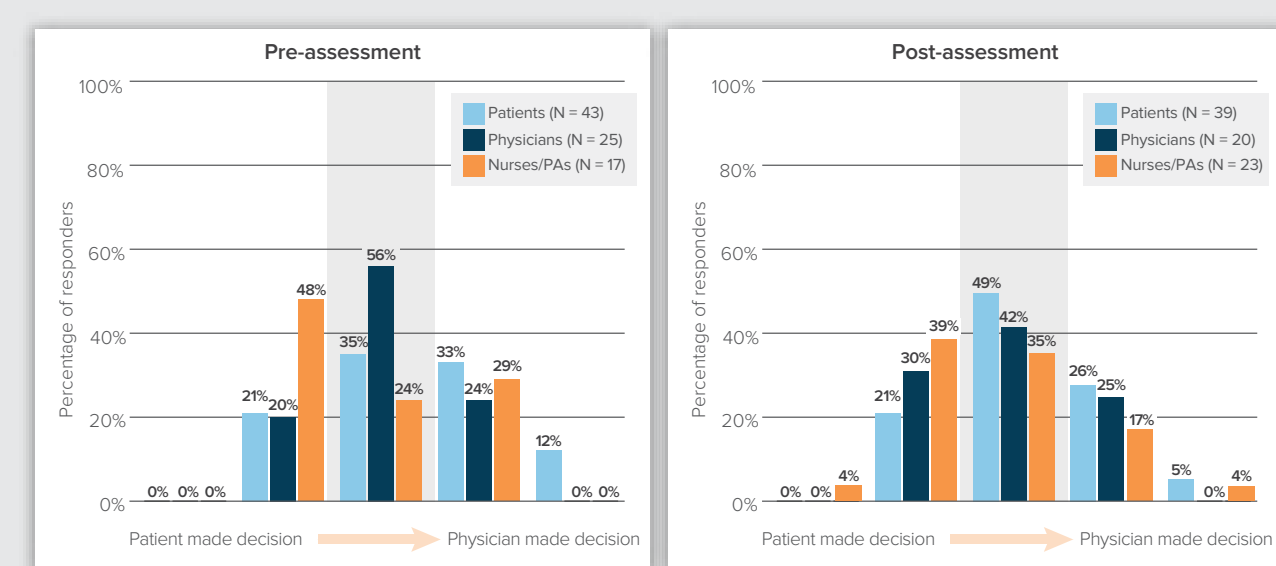
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- Patients increased in preference for shared decision-making after viewing the educational material
- Patients were less likely to ultimately rely on the doctor's decision

FIGURE 6. Alignment of Patient and Provider Perceptions of Decision-Making

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- Patient and provider perceptions regarding decision making were more aligned at the post-assessment compared with the pre-assessment

References

1. Jain N, O'Brien S. Targeted therapies for CLL: Practical issues with the changing treatment paradigm. *Blood Rev.* 2016;30:233-244.
2. Shanafelt TD, Bowen D, Venkat C, et al. Quality of life in chronic lymphocytic leukemia: an international survey of 1482 patients. *Br J Haematol.* 2007;139(2):255-264.
3. Shanafelt TD, et al. The physician-patient relationship and quality of life: lessons from chronic lymphocytic leukemia. *Leuk Res.* 2009; 33(2):263-270.

Note: UABHS CCN includes 12 cancer centers across Alabama, Georgia, Mississippi, Florida, and Tennessee

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