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 survival.
- Despite these improvements, many hematologists/oncologists (hem/onc) physicians are challenged to stay current with the latest advances and many lack confidence in their ability to tolerate therapy in newly diagnosed and relapsed/refractory patients.
- Patients with CLL have been shown to exhibit clinically significant levels of distress. 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 concerns.
- Medscape Education has collaborated with the University of Alabama at Birmingham (UABHS Health System-Cancer Community Network [UABHS CCN]) to assess the effectiveness of educational interventions directed to physicians, nurses, navigators, and patients.

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 stressed 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.

TELMS MODEL: ADVANCE (Convert Information)

Patients
- Although the PMM score was largely unchanged for patients with CLL following the local interventions at UABHS CCN, patients were observed to:
  - Increase confidence in their ability to identify signs and symptoms indicating a worsening of their disease (Figure 1).
  - Decrease in distress related to knowledge or psychosocial concerns (Figure 1).
  - Improved disease understanding.
  - Greater satisfaction with physician’s explanation (Figure 2).
- Improved treatment selection as patients reported increased understanding of their disease and the need for better communication to facilitate engagement from the patients for shared decision-making.

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).

METHODS/DESIGN

- **Leamer**
  - Pre-Assessment: Survey
  - Post-Assessment: Survey

- **UABHS CCN Networked Patients**
  - Pre-Assessment: Survey
  - Post-Assessment: Survey

- **UABHS CCN Lay Navigators**
  - Pre-Assessment: Survey
  - Post-Assessment: Survey

- **Healthcare Providers**
  - Pre-Assessment: Survey
  - Post-Assessment: Survey

- **UABHS CCN (Lay participants)**
  - Pre-Assessment: Survey
  - Post-Assessment: Survey

- **UABHS CCN (Medical/Local participants)**
  - Pre-Assessment: Survey
  - Post-Assessment: Survey

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, Relational, Social, Financial, and Physical. 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.
- 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

- **Primary outcome measure**
  - Provider perception of shared decision making.
  - Patient and provider concordance on perception of shared decision making.
  - Provider perception of patient knowledge about CLL.

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 LLL 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 5. Outcome Measures: Pre-Assessment and Post-Assessment for Shared Decision-Making**

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

**FIGURE 7. Outcome Measures: Patient Preference for Making Treatment Decisions**

**FIGURE 8. Outcome Measures: Presence of Distress Related to Knowledge Problems**