

Improving shared decision-making in chronic lymphocytic leukemia through multidisciplinary education

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Abstract

New treatments for chronic lymphocytic leukemia (CLL) with excellent response rates and varying toxicity profiles have emerged in recent years, creating an opportunity for a patient's personal preferences to contribute to treatment decisions. We conducted a prospective, quasi-experimental pre- and post-evaluation of a multilevel educational program and its impact on knowledge of CLL and shared decision-making (SDM). We educated patients, lay navigators, nurses/advanced practice providers (APPs), and physicians. Patients were evaluated for change in patient activation, distress, desired role in decision-making, perception of decision-making, satisfaction with oncologist explanation of treatment choice, and knowledge of CLL. Lay navigators, nurses/APPs, and physicians were evaluated for change in CLL knowledge and perception of decision-making. Forty-four patients, 33 lay navigators, 27 nurses/APPs, and 27 physicians participated in the educational program. We observed trends toward improved patient activation, with 68% before education versus 76% after education reporting a Patient Activation Measure (PAM) score of 3 or 4. The percentage of patients *desiring* and *perceiving* SDM trended upward from 47% to 67% and from 35% to 49%, respectively. The percentage of patients understanding that CLL is incurable increased from 80% to 90%, as did reporting awareness of signs of progression (64% to 76%). Patients' satisfaction with their oncologists' explanations of therapy increased significantly from 83% to 95% ($p = .03$). CLL knowledge increased after education for lay navigators (36% vs 63%) and nurses/APPs (35% vs 69%), and remained high for physicians (85% vs 87%). Nurses/APPs and physicians perceived at least some patient involvement in decision-making at baseline, whereas 12% of patients and 23% of lay navigators perceived that physicians made decisions independently. This project demonstrated trends toward improvements in patient engagement, prognostic awareness, knowledge of signs of progression, and SDM. These promising findings should be tested in larger samples. There remains an opportunity for further improvement in SDM.

Keywords

Shared decision-making, Chronic lymphocytic leukemia, Multidisciplinary education, Quality improvement, Cancer network

New treatments for chronic lymphocytic leukemia (CLL) with excellent response rates and varying toxicity profiles have emerged in recent years [1]. This availability of new treatment options

Implications

Practice: This study indicates that a multidisciplinary educational program administered across a network can be used to improve patient activation, prognostic awareness, knowledge of signs of progression, and SDM, and should be tested in longitudinal studies involving larger samples.

Policy: Policymakers who want to improve patient knowledge, outcomes, and SDM in CLL should consider integrating multidisciplinary interactive educational programs into existing QI programs and CME curricula.

Research: Additional research is needed to better understand patient preferences and how to engage both patients and their healthcare providers in SDM.

creates an opportunity for patient preferences to contribute substantially to treatment decisions. Shared decision-making (SDM) occurs when patients are informed of potential treatment options and the risks and benefits associated with treatment options, and are able to partner with their healthcare providers to incorporate their personal preferences and values into decision-making [2, 3]. Surveys of patients with cancer have shown that although a majority of patients wish to play an active role in making treatment decisions, only one in three actually does so [4]. Patients with advanced, incurable cancers are less likely to report patient-driven decision-making [5]. A low level of involvement in decision-making is associated with increased decisional regret and lower satisfaction with physician communication [6, 7].

Patient's desire for SDM varies by cancer type and stage of disease [8]. For example, in early-stage breast cancer, patients reported less-than-desired engagement in decisions about mastectomy versus lumpectomy [9]. In ovarian cancer, 60% of women preferred to share decision-making and over 80%

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wanted detailed information shared about options [10]. In prostate cancer patients deciding between treatment and observation, patients identified the importance of the physician in making this decision [11]. There are few data on decision-making for patients with hematologic cancers. Chawla and Arora [12] evaluated decision-making preferences across disease types and found 61% of patients preferred a shared role; no difference was observed for patients with leukemia compared with colorectal or bladder cancers. However, this study did not specify the type of leukemia included (acute vs chronic); thus, may not reflect the preferences for chronic, incurable leukemia with longer life expectancies, such as CLL. These patients receive multiple treatments, thus have multiple opportunities to participate in decision-making. This represents a missed opportunity to educate and engage patients in decision-making to maximize their quality of life. Education should include information on CLL treatments, as well as emphasis on empowerment and SDM.

Educating patients with CLL about their treatment options is challenging due to the pace at which novel CLL therapies are being developed and the lack of a standard sequencing of treatments. Since 2013, ibrutinib, idelalisib, obinutuzumab, and ofatumumab were approved, adding to the list of at least two dozen therapies recommended by current treatment guidelines [13]. The many choices available, each with specific adverse effects, administration routes, and efficacy in prolonging life, require that physicians account for patient factors, including comorbidities, and take a tailored approach to the treatment of CLL [1]. However, fewer than half of hematologists participating in a Medscape CLL education activity were confident in their ability to select therapy for patients with CLL and high-risk disease or comorbidities (Medscape internal data).

Patient involvement in decision-making may be influenced by their knowledge of CLL and potential treatment options, their underlying distress, and their degree of engagement in their healthcare. Patients with CLL report physical and overall quality of life scores similar to those of the general population, but emotional well-being scores are dramatically lower compared with both the general population and patients with other types of cancer [14]. One study found that more than 30% of patients reported that their physician did not fully comprehend how CLL was affecting their quality of life [15]. Unaddressed emotional distress reduced patients' ability to engage in decision-making [16]. One potential strategy to help patients with distress is the use of navigators (either nurses or trained lay people), who can identify distress and provide educational resources for patients to mitigate its causes [17, 18]. New strategies are needed to educate patients and their healthcare teams about CLL, empower patients to share their

concerns about quality of life, and to engage patients and their healthcare providers in SDM.

These strategies should consider methods to engage patients within community settings. Although 85% of cancer patients receive their care in the community [19], there may be insufficient numbers of providers and patients in individual, small community cancer centers to participate in quality improvement initiatives for less common cancer types, such as CLL. Participation within a regional network can provide a structure for educational and quality improvement opportunities. In addition, aggregation of data across a network allows for evaluation of the experience of patients and providers within smaller community settings. This approach is utilized within the UAB Health System Cancer Community Network (CCN), which includes affiliated cancer centers across the Southeast [17, 18].

We report results of a pilot study testing an educational intervention for patients, lay (nonclinical) navigators, nurses, advanced practice providers (APPs), and physicians within the CCN about CLL and SDM. The goal of the education was to improve patient engagement, patient distress levels, patient and provider knowledge of CLL, and the extent of SDM as perceived by patients and their healthcare providers.

MATERIALS AND METHODS

Overview

Patients, lay navigators, nurses/APPs, and physicians were educated about SDM and CLL treatment approaches (Supplementary Fig. S1). A prospective, quasi-experimental (pre and post) pilot study design was used to evaluate the effects of the education on patient outcomes (activation, distress, desire for and perception of decision-making, and knowledge of CLL) and on lay navigators' nurses'/APPs', and physicians' outcomes (provider knowledge of CLL and perception of decision-making).

Setting

This study was conducted between March and November 2015 within the CCN, which includes 12 cancer centers across Alabama, Georgia, Mississippi, Florida, and Tennessee [17, 18]. The network is led by UAB, which is a large NCI-designated, academic medical center. Other network sites vary in size and practice structure (private practice, hospital-based, academic), ranging from a large, multi-site oncology practice at Northside Hospital in Atlanta, GA to a single community oncologist at Russell Medical Center in Alexander City, AL. All sites within this network implemented a lay navigator program as part of standard of care [18]. The majority of patient/lay navigator encounters occurred outside of the decision-making encounter, either within the clinic setting before or after the patient was seen by the

physician or by telephone. The UAB Institutional Review Board (IRB) reviewed and approved the study protocol.

Patients

Recruitment and retention

All adult patients (18 years and older) with a CLL diagnosis within the CCN were eligible to participate in the education program. Patients who were unable to participate in education or surveys because of language barriers were excluded. Eligible patients were approached and prescreened by the lay navigators or the research coordinator, who explained the intent of the education program and the study. Patients who expressed interest were contacted by trained interviewers who acquired verbal informed consent by telephone prior to the baseline survey. Patients received a \$25 gift card for participating. Patients continued to interact with their clinical team, including lay navigators, as part of standard of care during the study.

Education program

The 10-min online education program was designed by Medscape and investigators from within the CCN and was hosted on the WebMD Education online platform. The education included interactive questions to engage patients. Content for patients and lay navigators addressed CLL biology, treatment options, side effects, and questions to ask the oncologist. Educational materials were provided immediately after completion of the baseline survey. Participants accessed the online education at home; access was not provided within the physician office. Due to the concern that some patients do not have computer access, a print version of the online education was also provided to patients by mail to maximize likelihood of exposure to the education. The trained interviewers asked if patients had reviewed the material (either online or in print) prior to starting the survey. If they had not completed the education, they were asked to complete it and the interviewer called at later date.

Evaluation

Trained interviewers administered both baseline and posteducation surveys to each participant via telephone. Baseline surveys were administered between April 15, 2015 and July 28, 2015; follow-up survey was administered ~3 months later. The primary outcome was patient activation, as assessed by the Patient Activation Measure (PAM), a 13-item questionnaire that assesses the patient's level of engagement in their healthcare [20]. The PAM provides a summary score ranging from 1 to 4, with higher scores indicating increased patient activation. Secondary outcomes included patient preference for SDM, patient perception of SDM, concordance between patient preference and

perception of decision-making (Control Preferences Scale [9, 21]), patient prognostic awareness, patient knowledge of signs/symptoms of worsening disease, satisfaction with physician explanation of treatment, and patient distress levels (modified Distress Thermometer [17]). The Control Preferences Scale assesses the preference for and perception of decision-making, considering five options that range between the patient making choices independently and the physician making choices independently. Minor modifications were made to tailor the survey tool for each group (patient, lay navigators, nurses/APPs, physicians). All participants responded about the role of the patient compared with the physician both "in general" and for specific patients for whom they provided care for within the study. A study-specific survey was used to test patient's knowledge of curability, awareness of signs or symptoms that might suggest progression, and satisfaction with physician explanation of treatment choice (Supplementary Material S1). In addition, patients provided a 1–10 rating of distress level using an assessment based on the National Comprehensive Cancer Network Distress Thermometer [17, 22]. For navigated patients, the modified Distress Thermometer was administered as part of standard clinical care either by telephone or in person by the lay navigators. For non-navigated patients, the same tool was administered by telephone or in person by a research coordinator.

Healthcare providers

Recruitment

All lay navigators within CCN were invited by email to participate. Lay navigators, nurses/APPs, and physicians participating in routine CCN site visits were invited to participate. Additional participants were invited by participating colleagues using respondent-driven sampling in which providers referred interested peers [23]. Lay navigators received \$150 and nurses/APPs, and physicians received \$100 for participation after completing the posteducation survey.

Education program

After completing the baseline survey, lay navigators were invited to complete the patient online education program and a 20-min navigator-specific video lecture on CLL. Nurse/APP and physician education included two components: (i) an in-person or webinar lecture and (ii) an online 1-hr continuing medical education (CME) activity. In-person lectures were conducted at eight sites; four sites declined the in-person lecture, preferring online content only. A video recording of the in-person lecture was also made available to interested nurses/APPs, and physicians who were unable to attend the in-person lecture. The CME activity was composed of three text-based case vignettes with interactive questions.

The vignettes focused on knowledge of new prognostic markers and treatment options as well as on principles of SDM.

Evaluation

Baseline surveys were administered between April 15, 2015 and August 25, 2015; follow-up surveys were administered at study closure. The outcomes for lay navigators, nurses/APPs, and physicians included perception of SDM, concordance with patient perception of SDM, comfort with CLL knowledge, and perception of patient's prognostic awareness (Supplementary Material S1). For decision-making, lay navigators, nurses/APPs, and physicians were asked about their perception of SDM both in general and for specific patients under their care who participated in the study. A 2-question, study-specific survey also evaluated lay navigator, nurse/APP, and physician comfort with CLL knowledge and perception of patient awareness of the incurable nature of CLL (Supplementary Material S1).

Analysis

Summary statistics were calculated for both baseline and posteducation survey results and consisted of means and standard deviations for continuous variables and frequencies (percentages) for categorical variables. Results of the baseline and posteducation surveys were compared using Wilcoxon signed-rank sum tests for continuous measures and McNemar–Bowker tests of symmetry for categorical measures. Lay navigator, nurse/APP, and physician decision-making data were matched to their specific patients' SDM data, and perception of SDM concordance was assessed using McNemar–Bowker tests of symmetry. SAS version 9.4 was used for all analyses (SAS Institute, Inc., Cary, NC).

RESULTS

Patients

Forty-four patients completed baseline surveys, and 43 completed posteducation surveys (Table 1). Thirty percent had high school education or less and 20% did not have computer access. More than half of patients were being observed and were not on active treatment. The mean time between the baseline survey and follow-up survey was 3.0 months (*SD* 0.8).

Outcomes

Patient activation

The percentage of patients with high activation (PAM score of 3 or 4) was 68% at baseline and 76% posteducation (Fig. 1A). The components of the PAM that demonstrated the largest upward trend were “I understand my health problems and what causes them” and “I know what treatments

Table 1 | Baseline demographic data

	Mean (SD) or Frequency (%)
Patient characteristics (N = 44)	
Age	65.4 (14.4)
Race	
White	40 (90.9%)
Black	4 (9.1%)
Sex	
Male	23 (52.3%)
Female	21 (47.7%)
Highest grade level completed	
Elementary	2 (5.4%)
Some high school	2 (5.4%)
High school graduate	7 (18.9%)
Some college or tech school	7 (18.9%)
College graduate	19 (51.3%)
Internet availability	
Via PC, smartphone, or tablet	32 (72.7%)
Via someone else's device	3 (6.8%)
None	9 (20.5%)
Previously researched internet for cancer information	
Yes	30 (68.2%)
No	14 (31.8%)
Current treatment for CLL	
Observation	26 (59.1%)
Chemotherapy or other anti-cancer treatment	17 (38.6%)
Bone marrow transplant	0 (0.0%)
Don't know/not sure	1 (2.3%)
On clinical trial	
Yes	8 (18.6%)
No	35 (81.4%)
Navigator characteristics (N = 33)	
Sex	
Male	6 (18.2%)
Female	27 (81.8%)
Age	43.4 (12.6)
Years since training	1.5 (0.5)
Provider characteristics (N = 54)	
Sex	
Male	21 (38.9%)
Female	33 (61.1%)
Age	
Years since training	15.7 (12.8)

are available for my health problems.” These components improved by 14% and 15%, respectively. In contrast, the components of the PAM that did not change were “Taking an active role in my own health care is the most important thing that affects my health” (100% at both baseline and posteducation) and “I am confident that I can follow through on medical treatments I may need to do at home” (decreased by 0.1%).

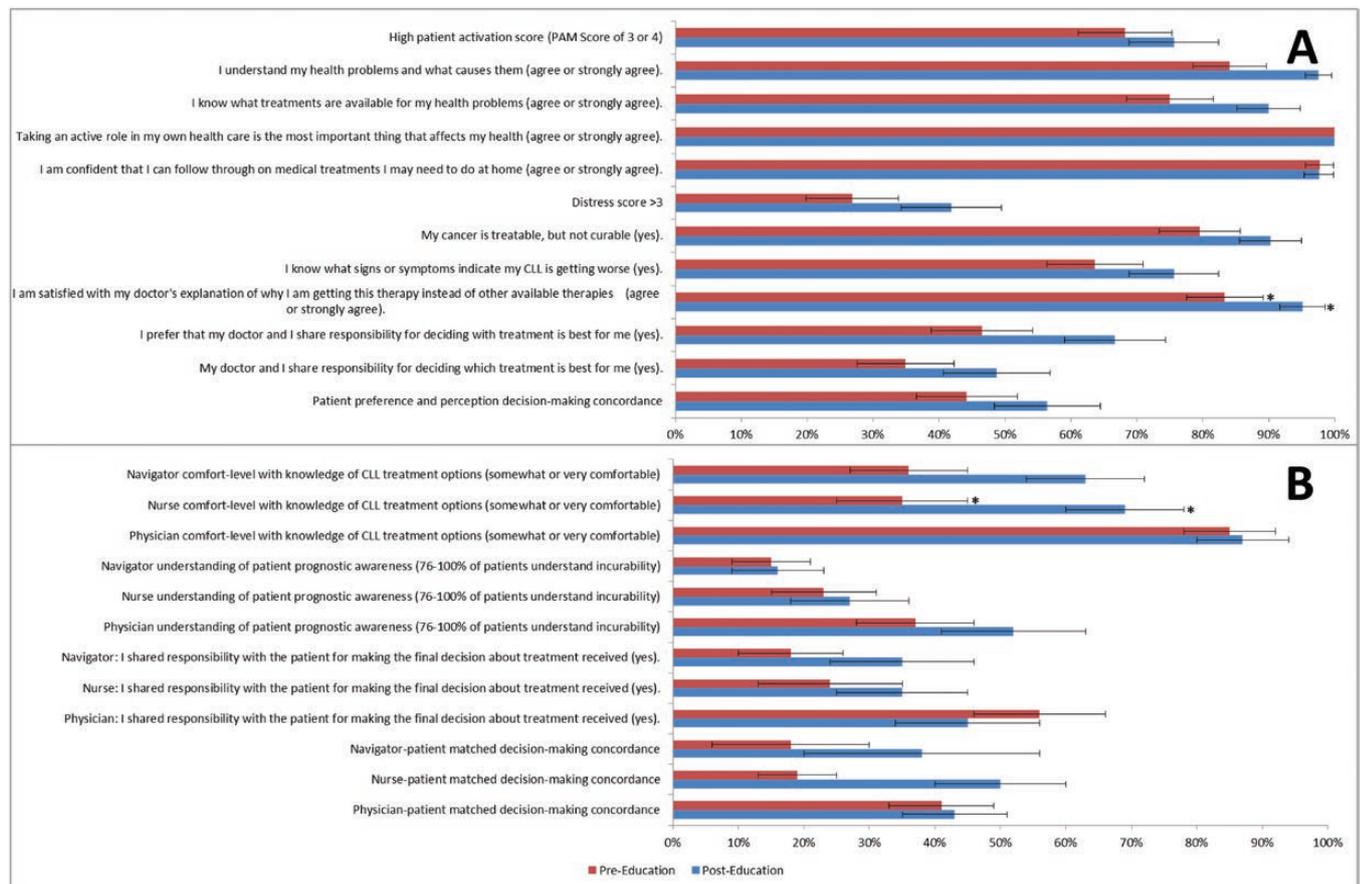


Fig 1 | (A) Patient outcomes. Mean percentage and standard error of patient activation, distress, knowledge, and SDM before and after the education program. **(B) Provider knowledge, prognostic awareness, and perception of decision-making** before and after the education program.

Patient knowledge and distress

Patient awareness of the “treatable, but not curable” nature of CLL rose from 80% to 90% posteducation (Fig. 1A). A greater percentage of patients responded “Yes” to the question “Do you know what signs or symptoms indicate your chronic lymphocytic leukemia (CLL) is getting worse?” posteducation (64% vs 76%; Fig. 1A). A greater percentage of patients responded “Strongly Agree” or “Agree” to the statement “I am satisfied with my doctor’s explanation of why I am getting this therapy instead of other available therapies” after the education compared with before the education (83% vs 95%; Fig. 1A). Despite improved satisfaction with their oncologist’s explanation of why the patient was receiving his or her specific treatment, the median distress level was similar before and after education (1 vs 2).

Shared decision-making

At baseline, 47% of patients preferred SDM and 35% perceived that they had engaged in SDM; posteducation these percentages increased to 67% and 49%, respectively. The rate of concordance between preference and perception trended upward from 44% to 56% (Fig. 1A).

Healthcare providers

All 33 lay navigators invited to participate completed baseline surveys; one lay navigator did not complete the posteducation survey due to leaving the institution. The mean time between baseline and follow-up survey for lay navigators and nurses/APPs/physicians was 4.6 (*SD* 0.5) and 4.0 (*SD* 1.6) months, respectively. The majority (82%) of lay navigators were female. The mean age and time spent as a lay navigator was 43.4 years (*SD* 12.6 years) and 1.5 years (*SD* 0.5 years), respectively (Table 1). Fifty-four nurses/APPs/physicians participated, including 27 physicians and 27 nurses/APPs. Four physicians and one nurse did not complete the follow-up survey. All (100%) nonphysician providers were female and 78% of physicians were male. The mean number of years since training for physicians was 13.6 (*SD* 13.6).

Outcomes

Knowledge

CLL knowledge increased after education for lay navigators (36% vs 63%) and nurses/APPs (35% vs 69%), and remained high for physicians (85% vs 87%). Posteducation, 16% of lay navigators thought that most patients (76% to 100%) understood their

disease was incurable, which was similar to the percentage of lay navigators (15%) who thought this at baseline. Perception of patient prognostic awareness also remained similar before and after education for nurses /APPs (23% and 27%, respectively), and increased for physicians (37% to 52%; Fig. 1B).

Shared decision-making

Forty-three patients completed the baseline decision-making assessment; one patient declined. Physicians, nurses/APPs, lay navigators, and patients perceived different levels of patient involvement in decision-making. At baseline, all (100%) nurses /APPs and physicians perceived at least some patient involvement in decision-making. In contrast, 12% of patients and 23% of lay navigators perceived that physicians made decisions independently. The perception that patients participated in SDM was lower for lay navigators (18%) and nurses/APPs (24%), but increased to 35% and 35%, respectively, following the education (Fig. 2). For the 43 patients who completed baseline assessments, 18% of lay navigators, 41% of physicians, and 19% of nurses/APPs perceived at baseline that patients had the same role in decision-making as reported by that patient. Follow-up assessment was available for 39 of these 43 patients. Posteducation, 38%, 43%, and 50% perceived the same role ($n = 39$; Fig. 1B). For the eight pairs of patients and lay navigators who completed both pre- and posteducation surveys, 38% perceived the same role of the patient in decision-making posteducation, compared with 13% at baseline. Concordance for the 34 physicians and their patients who completed both pre- and postsurveys remained similar (38% and 41%), but there was

a trend towards improvement for concordance between the nurses /APPs and patients who completed both pre- and posteducation surveys ($n = 24$) after the education (25% vs 50%).

Differences in outcomes were not statistically significant, with the exception of satisfaction with oncologists' explanations of therapy (Supplementary Table S1). However, all observed differences were in the expected direction with magnitude of difference ranging from 5% to 20% for patient outcomes.

DISCUSSION

In this pilot study that educated patients with CLL and the oncology care team, patient knowledge, patient empowerment, and SDM improved by ~10% for patients following education. These gains did not reach statistical significance in this pilot study, likely due to the small sample size. The American Statistical Association has recently emphasized that the $p < .05$ does not measure the size of effect or importance of the result [24]. In this study, we observed changes following this multidisciplinary behavioral intervention ranging from 5% to 20% improvement in patient outcomes that may be meaningful to patients.

The education provided to patients, lay navigators, nurses /APPs, and physicians highlighted not only knowledge of CLL, but also how to communicate effectively. We observed a concurrent increase in patients reporting high activation levels and preferring a SDM role, suggesting that education may facilitate SDM through patient activation. Despite the observed moderate increases in patient activation and preferences for SDM, we did not find any differences in distress levels before and after the education, which

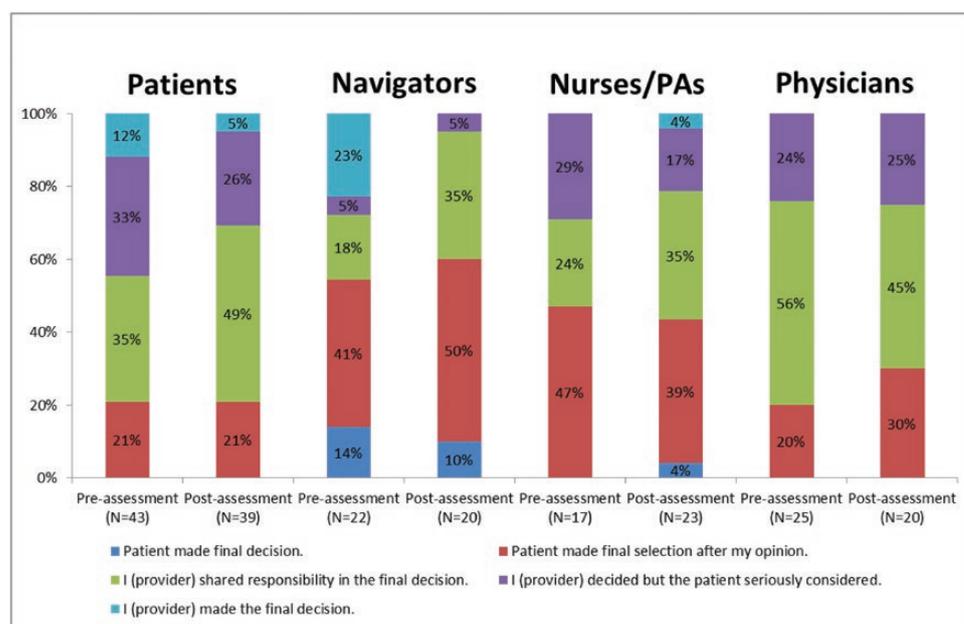


Fig 2 | Perception of decision-making for patients, navigators, nurses, and physicians.

may be due to the overall low levels of reported distress. Nevertheless, this study suggests that education programs may result in improvements in patient experiences of care. In addition, an opportunity exists for further improvement, as less than half of patients identified a shared role in decision-making posteducation. These findings should be confirmed in larger studies.

In this project, we characterized and compared decision-making by different types of healthcare providers, including lay navigators, nurses/APPs, and physicians. To our knowledge, this is the first report of lay navigator perception of decision-making in cancer. We observed varied perspectives on decision-making, with physicians at baseline perceiving that neither the patient nor the physicians make independent decisions. In contrast, both patients and lay navigators at baseline perceived that decisions were made by the physician without patient input in >10% of cases. The observed differences highlight the opportunity to educate the entire care team. The potential impact on patient and physician behaviors is likely enhanced by the multilevel nature of the education, as previous studies targeting behavioral change identified greatest benefit when both patients and care team were engaged [25]. Education delivered within a team-based approach, in which teams who deliver care together learn together, is optimal [26]. This study supports the inclusion of nurses/APPs, and lay navigators in future education initiatives, as they can empower patients to participate in decision-making.

Engaging rural populations in research is challenging [27]. This study was administrated within the real-world setting of a cancer care network, which includes small cancer centers serving patients living in rural communities. This approach may allow for small community sites to participate in a unified quality improvement initiative or multi-site behavioral study despite having relatively few patients in the target study population. Another strength is the engagement of lay navigators as part of the care team in a multidisciplinary quality improvement project. As lay navigators become more prevalent within cancer centers, they are likely to be an important workforce to engage and educate [28].

The study also has limitations that should be considered when interpreting the findings. The small sample size limits the study's statistical power, thus, many findings are only hypothesis-generating and need further testing in a larger sample. In addition, the small sample size did not allow for evaluation of impact of specific treatments on decision-making. We were not able to evaluate whether patients made a new treatment decision within the study period, which may be important for the patients who are being observed and not receiving active treatment. Respondent-driven sampling among providers may have also led to more engaged providers participating and an increase in the perception of SDM.

Minimal change in knowledge of CLL was observed for the participating physicians, which may be due to a ceiling effect, with 85% reporting baseline comfort with CLL knowledge. Although nurses/APPs and physicians were asked in the survey instructions to review both the video/in-person and on-line education, there was not a way to ensure that participants who did not attend in-person sessions reviewed the entire video. In addition, limited measures of knowledge of CLL (subjective single item measure) were used to assess CLL knowledge outcomes. The pilot education was provided online and on paper to reach the 20% of patients who did not have computer access. Although materials can be printed, patients without access to computers may be less likely to utilize this resource. We did not directly observe patient reading information to know how long they spent with the educational materials.

CONCLUSION

This study indicates that a multidisciplinary educational program administered across a network can be used to improve patient activation, prognostic awareness, knowledge of signs of progression, and SDM, and should be tested in longitudinal studies involving larger samples. Additional research is needed to better understand patient preferences and how to engage both patients and their healthcare providers in SDM.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Translational Behavioral Medicine* online.

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Compliance with Ethical Standards

Conflict of Interest: The authors have no conflict of interest to report.

Authors' Contributions: Conceptualization: GR, KH, UB, EV, MP, MS; Methodology: CW, BJ; Data Curation and Analysis: CW, BJ; Investigation: All; Writing—original: GR; Writing—review/edit: All; Supervision, project administration and funding acquisition: GR, EV.

Ethical Approval: The UAB International Review Board (IRB) reviewed and approved the study protocol.

Informed Consent: Informed consent was obtained by telephone prior to the baseline survey.

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