ASSOCIATION OF COMMUNITY CANCER CENTERS

MULTIDISCIPLINARY CHRONIC LYMPHOCYTIC LEUKEMIA CARE

MODELS OF EFFECTIVE CARE DELIVERY

ACCC
Association of Community Cancer Centers

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INTRODUCTION

Recognizing that the treatment landscape for patients with chronic lymphocytic leukemia (CLL) has changed considerably in the last several years, the Association of Community Cancer Centers (ACCC) has launched an educational project in partnership with the CLL Society. As a key part of this project, ACCC conducted focus groups with multidisciplinary cancer care teams at two community cancer programs and one academic NCI-designated cancer center to:

- Understand the current multidisciplinary treatment landscape for people living with CLL
- Identify effective practices and potential gaps in provider and patient communication
- Help foster a network of engaged cancer care professionals who are dedicated to the treatment of patients with CLL

About Chronic Lymphocytic Leukemia (CLL)

Chronic lymphocytic leukemia (CLL), a disease of mature, immunologically-deficient lymphocytes that accumulate in blood, marrow, and lymphatic tissue,[1] is the most common leukemia in adults.[2] The average lifetime risk for developing CLL is about 1 in 175, with slightly higher risk for men than women.[3] CLL is rarely diagnosed in people younger than 40 years of age, and the median age at diagnosis is about 70 years.[4] In the United States, the number of estimated CLL new cases and deaths for 2019 is 20,720 and 3,930, respectively.[5]

CLL is heterogeneous, and a number of factors affect a patient's treatment options including age, overall health, whether the disease is high-risk for progression, and what symptom is being treated and why. Diagnostic and prognostic testing for CLL have evolved considerably during the last decade.[6] Several prognostic models incorporating multiple clinical and prognostic markers have been developed to help stratify patients with untreated CLL into low-, intermediate-, and high-risk groups, including a model that may help to identify newly diagnosed patients at high risk for disease progression who may require earlier intervention.

In patients without evidence for progressive or symptomatic disease ("active disease"), active treatment is often not necessary as there is no evidence that early treatment of CLL results in longer survival.[7-9] Thus, physicians often advise observation and that patients wait until the disease progresses or symptoms worsen before starting treatment.[10]

Many patients present asymptomatic, and CLL is commonly diagnosed after a routine blood test shows an elevated lymphocyte count.[11] A recent survey of 1,147 CLL patients conducted by the CLL Society showed that 37 percent of respondents were treated by general hematologists/oncologists, 32 percent were treated by a CLL expert, and 31 percent were treated by a combination of a general hematologist/oncologist and a CLL expert.[12]

Chemoimmunotherapy continues to play a role in CLL management for a few select patients[9,13]; however, the majority of treatment plans now include one of many novel therapies. These agents have improved outcomes for people with CLL, including those with high-risk factors.[14] (See pages 2–3, *Highlights of the Current CLL Treatment Landscape* and *Overview of NCCN Guidelines for CLL Treatment,* for more on CLL therapies.)

For patients diagnosed with CLL, survival may range from several months to normal life expectancy; personalized treatment based on the clinical behavior of the disease is key.[8] CLL treatments that have emerged in recent years have created more opportunity for considering patient preferences in treatment selection. They also underscore the importance of the multidisciplinary team approach to educate patients about treatment options and the important role of the patient in reporting side effects and possible symptoms of disease progression.[15]

Diagnostic and prognostic testing for CLL have evolved considerably during the last decade.[6]

HIGHLIGHTS OF THE CURRENT CLL TREATMENT LANDSCAPE

The management of CLL has changed with the approval of the following novel agents:[16]

- **Duvelisib (Copiktra®)**, a kinase inhibitor indicated for the treatment of adult patients with relapsed or refractory CLL after at least two prior therapies.[17]
- **Ibrutinib (Imbruvica®)**, a Bruton's tyrosine kinase inhibitor indicated for the treatment of CLL with or without 17p deletion.[18]
- **Venetoclax (Venclexta®)**, a BCL-2 inhibitor indicated for the treatment of patients with CLL with or without 17p deletion, who have received at least one prior therapy.[19]
- **Idelalisib (Zydelig®)**, a kinase inhibitor indicated for the treatment of patients with relapsed CLL in combination with rituximab, in patients for whom rituximab alone would be considered appropriate therapy due to other comorbidities.[20] Of note, idelalisib is associated with grade 3 or higher toxicities that include colitis, transaminitis and pneumonitis, as well as infectious complications such as reactivation of cytomegalovirus and P. jirovecii pneumonia.[14] With the approval of newer PI3k inhibitors in which side effects are seen with less frequency, idelalisib has been used less in clinical practice. Recommendations from a multidisciplinary expert panel convened in 2017 and first published in 2018 may help clinicians to minimize these adverse events.[21]

Other recent data of note regarding how novel agents are impacting the treatment of patients with CLL include:

- **Duvelisib** was approved by the FDA in September 2018 for the treatment of patients with relapsed or refractory (R/R) CLL after at least two prior therapies.[17] The approval was based on the phase 3 DUO trial which showed a median progression free survival (PFS) of 13.3 months versus 9.9 months and a 60% reduction in death or progression compared with ofatumumab.[16,22]

- **Ibrutinib** was approved for the treatment of relapsed or refractory (R/R) CLL in February 2014. Based on the Phase 3 RESONATE study of ibrutinib vs. ofatumumab in R/R CLL patients, 88% of patients treated with ibrutinib were still alive with no disease progression at 6 months and the overall survival rate was 90% (hazard ratio for death compared to ofatumumab, 0.43; P=0.005) at 1 year.[23] Updated efficacy results for the RESONATE trial with up to 4 years of follow-up showed that extended treatment with ibrutinib continued to show sustained PFS benefit (median PFS not reached at median follow-up of 44 months) in R/R CLL patients.[24] Ibrutinib was approved as a first-line treatment option for CLL patients in March 2016 based on the results of the randomized phase 3 RESONATE-2 trial, which demonstrated that ibrutinib significantly reduced the risk of progression or death by 84% vs. chlorambucil in treatment-naïve CLL patients without del(17p).[25] Updated efficacy data from the RESONATE-2 study (median follow-up of 48 months), showed ibrutinib to have an 86% reduction in risk of progression or death, with improved quality of responses over time.[26]

- The U.S. Food and Drug Administration (FDA) approval of **venetoclax** in patients with del(17p) was based on a phase 2 trial including 107 patients with relapsed or refractory CLL and del(17p) that showed a 77% objective response rate (ORR) and 20% complete response rate (CRR).[27] The phase 3 MURANO study compared venetoclax for up to 2 years plus rituximab for the first 6 months vs. bendamustine plus rituximab for 6 months in 389 patients with relapsed or refractory CLL. The PFS rates were significantly higher with venetoclax/rituximab than bendamustine/rituximab (2-year PFS rates of 84.9% versus 36.3%, respectively), leading to FDA approval of this combination in all patients with a prior line of therapy.[28,29]

OVERVIEW OF GUIDELINES FOR CLL TREATMENT

Three organizations have developed guidelines for diagnosing and treating CLL: the National Comprehensive Cancer Network (NCCN), the International Workshop on Chronic Lymphocytic Leukemia (iwCLL), and the European Society of Medical Oncology (ESMO).[30]

Across the three guidelines there is consensus that:[30]

- Diagnosis of CLL requires the presence of at least 5000 monoclonal B-cells/mcL (≥5 x 109/L) in the peripheral blood and that the clonality of B-cells should be confirmed by flow cytometry.
- Staging using either the Rai system or the Binet system is recommended.
- Patients with early-stage CLL should not be treated with chemotherapy until symptoms appear or there are indications of rapid disease progression.
- Low- and intermediate-risk patients (Rai stages 0-II) having no indications for treatment should be observed with blood cell counts and clinical exams conducted every 3-12 months.
- Additional tests recommended prior to treatment initiation include: FISH to detect cytogenic abnormalities, such as 17p deletion, 13q deletion, 11q deletion, and trisomy of chromosome 12.

The NCCN Clinical Practice Guidelines in Oncology for Chronic Lymphocytic Leukemia/Small Lymphocytic Leukemia include the following indications for treatment:

- Significant CLL-related symptoms (fatigue, night sweats, weight loss, fever with no infection)
- Threatened end-organ function
- Progressive bulky disease
- Progressive anemia
- Progressive thrombocytopenia

The three ACCC member programs interviewed for this publication all report following the NCCN guidelines for the treatment of CLL. Following is a summary of the NCCN Clinical Practice Guideline for CLL.

Diagnosis. The diagnosis of CLL requires the presence of at least 5000 monoclonal B-cells/mcL (≥5 x 109/L) in the peripheral blood. The clonality of B-cells should be confirmed by flow cytometry. Adequate immunophenotyping using cell surface markers (e.g., kappa/lambda, CD19, CD20, CD5, CD23, and CD10). Bone marrow aspirate with biopsy is not required to diagnose CLL but is useful to evaluate cytopenias.

Prognosis. The Rai and Binet staging systems are used worldwide to determine the extent of CLL. Both systems rely solely on physical examination to assess the extent of tumor burden. The following assessments may provide useful prognostic information beyond clinical staging: Immunoglobulin heavy-chain variable (IGHV) region gene mutational status; cytogenetic abnormalities detected by fluorescence in situ hybridization (FISH) such as del(13q), trisomy 12, del(11q), or del(17p); flow cytometry-based prognostic markers (CD38, CD49d, and ZAP-70); and serum markers (thymidine kinase and beta-2 microglobulin). A recent update in the algorithm for presentation notes IGHV mutation evaluation as necessary for treatment when considering chemoimmunotherapy. Del(17p) reflects the loss of the TP53 gene, is frequently associated with mutations in the remaining TP53 allele, and is associated with worse outcomes. In addition, TP53 mutations can be present without del(17p) and predict poor survival independent of 17p chromosome status.

Treatment. NCCN encourages participation in clinical trials for the best management of any patient with CLL and other types of cancer. The Guidelines recommend ibrutinib as the preferred first-line CLL therapy for patients. For relapsed or refractory therapy, preferred treatments include ibrutinib, venetoclax plus rituximab, duvelisib, and idelalisib plus rituximab (continued on page 4).

As mentioned previously, evaluation of IGHV mutation status was added as necessary for treatment when considering chemoimmunotherapy. Version 3.2019 of the guidelines include the following other treatment updates:

- For CLL without del(17p)/TP53 mutation, first-line therapy for both frail patients with significant comorbidity or patients age ≥65 years and younger patients with significant comorbidities were combined in a single category and these revisions were made: Ibrutinib plus obinutuzumab was added as a category 2B, other recommended regimen; chlorambucil plus obinutuzumab was changed from a category 1 to a category 2A recommendation; chlorambucil plus obinutuzumab, chlorambucil plus ofatumumab, and chlorambucil plus rituximab (now expressed as chlorambucil plus anti-CD20 monoclonal antibody) were moved from preferred regimens to other recommended regimens; bendamustine plus anti-CD20 monoclonal antibody was moved from preferred regimens to other recommended regimens.

- For first-line therapy for patients age <65 years without significant comorbidities, these revisions were made: Ibrutinib was changed from a category 2A to a category 1 preferred regimen; ibrutinib plus rituximab was added as a category 2B, other recommended regimen; bendamustine plus anti-CD20 monoclonal antibody was moved from preferred regimens to other recommended regimens; and FCR (fludarabine, cyclophosphamide, and rituximab) was moved from preferred to other recommended regimens and changed from a category 1 to a category 2A recommendation.

CT scans may be useful to follow and monitor disease progression in patients with new symptoms when peripheral adenopathy is not present. PET scan is generally not useful in CLL but can help to direct nodal biopsy if Richter's transformation is suspected. (With Richter's transformation, the leukemia transforms into a high-grade or aggressive non-Hodgkin lymphoma. This happens in about 2 to 10 percent of CLL cases.)[10]

Newer small molecule inhibitor-based therapy has significantly improved survival outcomes, including for patients with high-risk disease. Evaluating minimal residual disease (MRD) in the peripheral blood after treatment ends has emerged as an important predictor of CLL treatment efficacy. Several studies have shown that among patients who achieved complete response (CR) or partial response (PR), PFS was longer for those with undetectable (<10-4) MRD CR and PR.

NCCN Guidelines include a recommendation to consider lenalidomide maintenance therapy for high-risk patients (blood MRD ≥10-2 or ≥10-4 and <10-2 with unmutated IGHV) or del(17p)/TP53 mutation after first-line therapy. Maintenance therapy is also suggested for CR or PR after relapsed or refractory therapy.

Please see the complete NCCN Guidelines at nccn.org/professionals/physician_gls/default.aspx for other recommended treatments based on age and functional status and for supportive care information.

MODELS OF EFFECTIVE CARE DELIVERY

To understand how patient-focused multidisciplinary care is being effectively delivered across different care settings, ACCC conducted three site-visit focus groups with cancer care teams at the following ACCC-member programs:

Self Regional Healthcare Cancer Center
Greenwood, South Carolina

The University of Kansas Cancer Center
Westwood, Kansas

Sunrise Hospital and Medical Center
Las Vegas, Nevada

SELF REGIONAL HEALTHCARE CANCER CENTER
GREENWOOD, SOUTH CAROLINA

Self Regional Healthcare Cancer Center, Greenwood, S.C., is a not-for-profit, regional referral hospital providing care to Greenwood, Abbeville, Laurens, Saluda, McCormick, Edgefield, and Newberry County residents. The cancer center provides multidisciplinary, individualized, comprehensive care for patients with many types of cancer including CLL.[31] The cancer program is recognized by the Quality Oncology Practice Initiative (QOPI) Certification Program and accredited as a Comprehensive Community Cancer Program by the American College of Surgeons Commission on Cancer (CoC). The multidisciplinary cancer care team follows NCCN guidelines to provide the current standard of care for diagnosis and treatment of CLL. Board-certified oncologists/hematologists, radiation oncologists, and specially trained staff (radiology support team, pharmacists, oncology nurses, and social workers) provide diagnostic and genomic testing, infused and oral chemotherapy, immunotherapy, radiation therapy, surgery, and patient and family support services. Patients have access to clinical trials in the community through the center's partnerships with the National Cancer Institute (NCI) and the Hollings Cancer Center Clinical Trials Network at the Medical University of South Carolina.

Diagnosing and Assessing Risk for People Living With CLL

Typically, the CLL diagnostic process is triggered by an abnormal white blood cell count, and CLL is distinguished from other lymphoproliferative diseases by the clonal B lymphocyte characteristics and confirmed by flow cytometry.[6] A bone marrow biopsy is rarely needed for CLL diagnosis.[31] Self Regional Cancer Center adheres to these guidelines to diagnose CLL. Clinical staging for CLL was introduced in 1975 and over the years, risk assessment has expanded with the addition of IGHV testing and chromosomal analyses with FISH.[32] Accordingly at Self Regional, the next step after diagnosis is staging the disease to identify whether a patient needs observation alone vs. systemic therapy, based on the extent of peripheral blood, lymph nodes, spleen, liver, and bone marrow involvement.[32] Prognostic genetic testing for all CLL patients to help guide treatment decisions is important.[33] In addition to staging, Self Regional does a FISH panel for chromosomal analyses to detect 17p deletion and TP53 sequencing and mutation analysis. If the patient has enlarged lymph nodes based on examination and CT scans, the team biopsies the lymph nodes.[34] They usually perform molecular analysis for IGHV mutation status. Prognostic testing may be done concurrent with staging if the patient needs close observation. The chromosomal analysis is repeated at any point that a patient's clinical status changes because CLL patients may have clonal evolution.[35]

Vaccinations and Other Infection Prophylaxis

Most CLL patients will have infections as a result of their disease and treatment—and infection contributes to a significant proportion of CLL deaths.[36,37] The Self Regional team ensures their patients are up to date with influenza and pneumonia vaccinations and tests them for a number of viruses, as well as educating patients on their role in helping to prevent infection and reporting symptoms of infections.

After CLL is diagnosed, Self Regional's oncologists sit down with patients and their caregivers to explain CLL and its long-term course, as well as treatment needs and options, including clinical trials, based on their stage and prognostic test results.

Multidisciplinary Approach: Educating Patients, Encouraging Treatment Adherence, and Communicating About Side Effects

After CLL is diagnosed, Self Regional's oncologists sit down with patients and their caregivers to explain CLL and its long-term course, as well as treatment needs and options, including clinical trials, based on their stage and prognostic test results. They also discuss how frequently the patient will be monitored. Part of what works well for this team is that the oncologists each partner with their own oncology nurse, who reviews everything with that patient. Throughout the patient's care, the nurse then follows up to make sure the patient understands what has been discussed, including any medical terms that may have been used, knows where they're supposed to be and when for tests and treatment, what their medication is for, and how they will get their medication.

The nursing and pharmacy staff also team up to educate patients about IV and oral medications. Nursing staff takes the lead on patient education for infusion therapy, while pharmacy staff educates patients on oral therapies. The oncology pharmacists discuss the need to take the medication as prescribed and that patients can expect to be on the medication for a prolonged period of time. They explain this in the context of CLL being a chronic disease like high blood pressure or diabetes. They find adherence improves when patients agree with the treatment plan and commit to the lifestyle change of remaining on medication. Initially, the pharmacist follows up with the patient weekly, if needed. The follow-up may be by phone or in person, depending on whether the patient is on site for an appointment or needs an in-person meeting regarding medication adherence. In other instances, for example, those who have been on ibrutinib[18] for two or three years patients may only receive in-person or phone follow-up from the pharmacy staff once a month to make sure that they haven't had any issues or side effects. The aim is to be proactive and have team members available so if there is a problem, patients can present it. Keeping in mind that trust influences patient willingness to disclose information and adhere to treatment,[38] nurses on the team call patients frequently to ask about symptoms and side effects. Some patients will report anything and everything, but others need encouragement from team members to speak up. When a patient is initially reticent, the nurses ask about some common side effects to learn if they can mitigate problems as soon as possible. Self Regional also uses education sheets to teach patients about CLL, treatment, and possible side effects of treatment.

Multidisciplinary Approach: Financial and Psychosocial Support and Referral

The financial impact of CLL is an ongoing concern for many patients, and they need financial assistance programs and advisors.[39] The financial advocate on the Self Regional team receives an electronic health record (EHR) notification to look at the financial aspect of care that is triggered when the oncologist initiates treatment and enters this action into Self Regional's system. In addition, Self Regional's EHR system alerts staff whenever a patient's scheduled test may not be covered. In these cases, as a first step the oncologist appeals any denials. A team member will also inform the patient about discounted self-pay options, if needed.

The team is aware that patients may need assistance with transportation, medications for comorbidities, groceries, utilities, or housing, and these factors are included in the financial assessment along with the cost of treatment. For example, the team will work with the local utility to keep patients' electricity on. Staff are sensitive to the fact that it is not uncommon for patients with CLL, like those with other cancers, to lose income while in treatment and possibly lose their jobs because of extended absences. A diagnosis of CLL (or any cancer) requires psychosocial adjustments that need to be evaluated and addressed along with treatment for the disease. Acknowledging patient stress is often the first step in a therapeutic intervention.[40] The oncology nurse does a psychosocial assessment, one-on-one education, gives patients written materials, answers questions, gets treatment scheduled, and does a complete learning assessment concurrent with the initial financial assessment. A psychosocial assessment is repeated at each visit to capture any significant changes between appointments. Self Regional has a general cancer support group for patients as well as a patient support group for women.

Initiating Treatment

If the patient with CLL is initially recommended for observation rather than treatment, follow-up visits are scheduled at three-month intervals and may extend to visits every six months, depending on patient symptoms, e.g., lymphadenopathy, splenomegaly, fevers, hemolytic anemia, ITP, and the lymphocyte doubling time.

Selecting Treatment and Sharing Decision-Making with Patients and Caregivers

A recent survey of 384 CLL patients' thoughts about treatment selection showed they placed the highest relative importance on longer PFS, but the risk of adverse events also was important. When cost was included in the decision-making, a sizeable proportion of patients changed their choices.[41] Self Regional's oncologists discuss preferences with patients and caregivers, and their practice is to blend guideline-based recommendations with individual preferences. The oncologists review NCCN guidelines when considering first and subsequent lines of treatment. For initial treatment most patients now start with ibrutinib, and chemotherapy is not often used. For patients with lymphadenopathy symptoms, chemoimmunotherapy may be appropriate.[9,42,25] For subsequent lines of treatment, oncologists also search for relevant information in Self Regional's pathway program.

Acknowledging patient stress is often the first step in a therapeutic intervention.[40]

More Opportunities to Help Patients

Self Regional's cancer team is continuously striving to improve care for their patients with CLL. This summary reflects some of their thoughts:

- Communication can always be improved to align all the pieces of patient care. Recently, they put together a core group from each discipline involved in cancer care, and ultimately devised a way to create EMR notifications to update team members on changes to the patient's treatment plan and scheduled appointments.
- A top challenge is getting certain prognostic tests covered by the patients' insurance. For example, IGHV and TP53 tests may not be covered for some patients. More resources, including human resources, are needed to address all types of patient costs associated with a cancer diagnosis.
- The oncologists would like to have a monthly virtual CLL tumor board to make sure they are doing the best for their patients. Education on new data and new drug combinations, comparisons across different guidelines, and helping patients understand the benefits, risks, side effects of various treatments, and self-advocacy, would all be welcome. Finding time for continuing education without compromising excellent patient care is challenging for staff.

THE UNIVERSITY OF KANSAS CANCER CENTER
WESTWOOD, KANSAS

The University of Kansas Cancer Center, in the Kansas City area, is an academic, NCI-designated cancer center providing care to patients across the Kansas City region it continues to expand its reach into the community.[43] The cancer center takes a comprehensive approach to patient care, treats all forms of cancer, and provides personalized treatment for each patient. Services including diagnosis, surgery, radiation and chemotherapy, survivorship care, patient support, and psychological assistance involve the skills and experience of social workers, dietitians, chaplains, and other support staff. In delivery of care, the cancer center's partners include The University of Kansas, Health System, School of Pharmacy, School of Medicine, and the Stowers Institute for Medical Research. Patients have access to multiple locations and specialists, and disease-specific working groups (including hematology/bone marrow transplant) of clinicians and researchers collaborate. The cancer center has a multidisciplinary team approach with weekly conferences to review cases to find the best treatment options.

Diagnosing and Assessing Risk for People Living with CLL

The University of Kansas Cancer Center uses NCCN guidelines for diagnosing CLL: ≥5000 monoclonal B-lymphocytes in the peripheral blood, then confirmed by flow cytometry. Rarely, if ever, is bone marrow biopsy involved in diagnosis. An estimated 70-80 percent of CLL patients have chromosomal abnormalities that can be identified by FISH.[34] Along with staging, the cancer center's team does FISH and IGHV mutation status testing for their patients, usually after the first visit. The FISH panel is performed to detect trisomy 12, and deletions in 11q, 13q, and 17p. The cancer center is not routinely doing TP53 mutation screening at this time because patients often don't have healthcare coverage for this assay. They expect to perform this screening more routinely now that it's part of the recent iwCLL update.[6] A CT scan or PET scan and bone marrow biopsy are needed for all patients prior to initiation of treatment. FISH is repeated whenever the patient's disease stops responding to treatment.

Vaccinations and Other Infection Prophylaxis

The importance of proactive and reactive infection management is a key focus of patient care.[36] At The University of Kansas Cancer Center, infection, prophylaxis, and care start with the oncologist and the nurse practitioner working closely together to verify whether the patient's vaccines are up-to-date or needed, and that all of the patient's immunizations and recent infections are on record. Patients with monoclonal B-cell lymphocytosis have a higher risk of serious infection compared to the general population.[43] Because hypogammaglobulinemia is a known complication of CLL, intravenous immunoglobulin replacement therapy should be limited to CLL patients with hypogammaglobulinemia and repeated infections.[6] At the cancer center, the oncologist checks patients' immunoglobulin levels after the patient's first visit and monitors for any ongoing infections. The oncologist talks with patients and families about preventing infection, what vaccinations are needed, and what to do if they notice any symptoms between appointments and how to contact their oncology nurse if needed. Some patients are given intravenous immunoglobulin (IVIG) based on their immunoglobulin (Ig) levels and their medical history.

Multidisciplinary Approach: Educating Patients, Encouraging Treatment Adherence, and Communicating About Side Effects

After a diagnosis, the oncologist, patient, and caregivers discuss CLL and, in general, its long-term course, risk criteria and testing, and treatment options. They meet again to review the prognostic test results and talk about when treatment may be needed, treatment selection factors, and how they will be monitoring treatment response. Usually the pharmacists will answer questions about potential treatment side effects. The cancer center is flexible about when the pharmacist education about potential side effects is given—and it can be done after treatment selection or at the start of treatment, depending on patient preference. The cancer center also provides written materials about medications and possible side effects. For patients on oral chemotherapy, there are specific check-in points. These include follow-up calls, ongoing education, and toxicity checks every three to six months. At 12 months, the team calls or sees the patient in clinic to monitor adherence.

To provide patients and caregivers with more information about services available from The University of Kansas Cancer Center, including patient support groups, the cancer center provides new patients with a personalized guide specific to their diagnosis that provides disease and treatment resources and information.

> The importance of proactive and reactive infection management is a key focus of patient care.

The multidisciplinary team (MDT) plays a key role in educating and engaging patients, which includes ensuring patients have the information and resources needed to participate in their own care. For those with low health literacy, the teach-back method can help.[44] The cancer center's patient guide features a section on how patients can be an active participant in their care. All team members (including the oncologist, oncology nurse, pharmacy, and palliative care staff) take steps to try to ensure that patients understand the information they are given. For example, they may ask the patient to explain information back to the team member and repeat information as needed at each visit. For patients who need extra help taking their oral medication consistently, the pharmacy team may fill the patients' pill boxes for them. The team is well aware that the physical and psychosocial aspects of CLL and treatment may vary greatly from one person to another. Multiple studies show that offering palliative care early in cancer care may improve quality of life, symptom management, and cost of care.[45] The cancer center has a robust palliative care team which includes physicians, nurse navigators, and dietary counselors who see patients on referral from the oncologist.

Multidisciplinary Approach: Financial and Psychosocial Support and Referral

The University of Kansas Cancer Center's team has found that most of their patients are forthcoming about any collateral problems they are experiencing. Depending on individual needs, one or more of the supportive care staff may meet with the patient. The team includes financial counselors, social workers, and a dedicated oncology psychologist. Financial counselors meet with new patients and provide them with an individual, written breakdown of their healthcare coverage. They identify any financial challenges and work with patients to find solutions, for example, applying for COBRA or Medicaid, accessing assistance to pay bills, arranging transportation to and from medical appointments, and helping them to apply for grants. Patients are given cards with contact information, encouraged to reach out with questions, and assured that the support team is there to help them throughout their treatment. Patients are offered psychological counseling and the referring team member ensures that these appointments are scheduled. The cancer center's palliative care team gets involved as needed. The cancer center has a CLL/lymphoma support group facilitated by nursing and social work staff to discuss patient-selected topics and to answer their questions. The cancer center also offers a mentor program that matches newly diagnosed patients with others who are living with CLL.

> Multiple studies show that offering palliative care early in cancer care may improve quality of life, symptom management, and cost of care.[45]

Initiating Treatment

Patients have follow-up visits every three months during observation, which may be extended to every six months depending on their symptoms. For newly diagnosed patients, the center follows iwCLL guideline criteria[6] for initiating treatment, including these signs and symptoms related to CLL: lymphadenopathy, splenomegaly, fevers, hemolytic anemia, ITP response to steroids, lymphocyte doubling time, and symptoms or cytopenias (anemia or thrombocytopenia). The criteria are similar for relapsed CLL.

Selecting Treatment and Sharing Decision-Making with Patients and Caregivers

Clinical trials are critical to finding new treatments for CLL and other cancers.[46] For treatment selection, The University of Kansas Cancer Center's view is that every CLL patient should be considered for a clinical trial if an appropriate study is available. The cancer center has several studies looking at newer drugs including PI3K inhibitors and other those targeting other tumor pathways.[47] The cancer center is a commercial site for CAR-T49 and also has CLL CAR-T clinical trials.[48,49] For standard of care options, the cancer center applies the iwCLL guidelines based on individual needs and preferences. The oncologist also checks NCCN guidelines[34] thoroughly for the first line and subsequent lines of treatment. For initial treatment, most of the cancer center's patients with CLL start on ibrutinib[18] or a clinical trial. Chemotherapy is not often considered for CLL treatment. Instead, the cancer center uses other novel agents for CLL, including venetoclax for some patients who have had prior therapy. To identify the subsequent optimal approach (either because of the patient's CLL treatment history or because something has changed in their CLL clone), the treating oncologist searches information relevant to the patient in the cancer center's pathway program. Also, in this situation, the team may consult a tumor board or colleagues external to the center. Allogeneic transplant is

another potential option for patients with CLL who have a del(17p) or TP53 mutation.[50] The University of Kansas Cancer Center has a robust blood and marrow transplant program and the transplant team gets involved quickly for del(17p) patients. The transplant coordinators try to identify donors for such patients at the start of treatment so that they are prepared if a transplant is needed.[51]

With shared treatment decision-making (when patients are fully informed of their options, risks, and benefits, and their values and preferences are considered), evidence shows that engaged patients are more likely to consider their treatment options and have better psychosocial and, sometimes, physical outcomes.[52] The team discusses patient treatment preferences with patients and timing for treatment initiation. If the patient needs to start treatment, the team explains why immediate treatment is necessary and reviews the options. This conversation includes a patient-centered discussion of study data and the team's recommendations based on these data, together with the patient's age, overall health, and comorbidities. They review the potential side effects and explain when and why the patient should call the team in between clinic visits.

For treatment selection, The University of Kansas Cancer Center's view is that every CLL patient should be considered for a clinical trial if an appropriate study is available.

More Opportunities to Help Patients

The team shared the following insights on potential for improving care for patients with CLL:

- At present, some insurance companies do not cover the cancer center's specialty pharmacy for oral anti-cancer agents. To improve care, the team would like to be able to fill the prescriptions on-site; otherwise, this lack of coverage often leads to delays and confusion for patients.
- As the CLL treatment landscape evolves, Medicare and Medicaid coverage sometimes lags behind FDA approvals. The cancer center would like to see that gap closed, along with better coverage for prognostic tests from all insurance providers.
- The team hopes to see more resources for the cost of everything treatment related—not just medications but also cost of coming to appointments, etc., so that care is affordable.
- One important piece is to have patients actively engaged in their care. This is not always achievable, even with the entire MDT working toward the same goal. The team would like to see more awareness of how this affects outcomes and perhaps more psychosocial research on how to engage more patients.

SUNRISE HOSPITAL AND MEDICAL CENTER
LAS VEGAS, NEVADA

Sunrise Hospital and Medical Center in Las Vegas is Nevada's largest acute care facility and Level II Trauma Center serving residents and visitors to the area. The center's dedicated adult inpatient oncology unit is one of only five such programs in Nevada. In addition, the cancer center is accredited by the American College of Surgeons Commission on Cancer (CoC). Cancer program services are integrated with care from high-quality, board-certified community medical oncologists/hematologists. Patients with CLL receive care from community oncologists with a special interest and experience in hematologic malignancies, and from clinical research and teaching medical students at Touro University Nevada and the University of Nevada School of Medicine. The hospital's cancer program also offers experienced oncology nurse navigators, a palliative care team, and a cancer resource center to provide patient support and education, and to eliminate barriers to healthcare.

Diagnosing and Assessing Risk for People Living with CLL

The combined team of community oncologists, who see patients both in their clinic practice and with staff at Sunrise Hospital and Medical Center, represent a much needed service.[53] They provide up-to-date clinical practices and patient-centered CLL care to the residents of southern Nevada and its surrounding region who want or need to have treatment close to home. The oncologists follow NCCN guidelines for diagnosis[34] by evaluating the patient's symptoms and then sending blood specimens for flow cytometry to evaluate cell markers that confirm the CLL diagnosis. They sometimes perform a bone marrow biopsy; but in most instances, clinicians obtain the necessary information from blood tests. Their practices for assessing risk are also consistent with current NCCN CLL guidelines. Once the patient's CLL diagnosis is confirmed, the oncologists proceed to staging and prognostic testing to understand more about when and how the patient would benefit from treatment. A FISH panel is done to look for abnormalities of chromosomes 11, 12, 13, and 17. CLL cell expression of ZAP-70 and CD38 correlates with the expression of unmutated IGHV and can be associated with high-risk disease.[6] At Sunrise, for logistical and practical reasons, IGHV studies are not routinely done. The oncologists generally repeat prognostic studies when the patient's disease stops responding to treatment, especially if they are considering

aggressive treatment. That treatment will depend on the patient's comorbid conditions, age, and the biology of their disease.

Vaccinations and Other Infection Prophylaxis

Before treatment begins, CLL patients should be screened for hepatitis B virus (HBV) and hepatitis C virus (HCV) since these viruses may be reactivated after treatment with immunosuppressive or myelosuppressive drugs.[6] As such, the oncologists at Sunrise check for HBV and HBC, and in some cases, they perform HIV testing. They do not usually test for cytomegalovirus (CMV). Patients are encouraged to have influenza, recombinant zoster,[54] and pneumococcal vaccines. Because herpes zoster is more common in patients with compromised immunity,[55] patients are prescribed acyclovir for prophylaxis when indicated. Some CLL patients with low Ig are given IVIG, but in keeping with guidelines, this is not routinely done just because Ig is low.

Multidisciplinary Approach: Educating Patients, Encouraging Treatment Adherence, and Communicating About Side Effects

The initial discussions with patients and caregivers about the CLL diagnosis, prognosis, and treatment are with the oncologist. In talking with patients, the oncologists always explain that CLL is highly treatable although usually not curable. Absorbing and understanding information on multiple effective anticancer therapies and their associated benefits and risks, can be challenging for patients and their families.[52] The oncologists' discussion with patients about what to expect is based on what most patients have experienced with specific treatments. Providers take care to align the details of treatment with the patient's style for receiving information. When patients or caregivers need more information about certain drugs, the availability of support programs and services, or clinical trials, other staff get involved. In the clinic setting, sometimes physician assistants and nurse practitioners also talk to the CLL patients about diagnosis, the treatment, and how their health will be monitored. A social worker is also on hand to meet with patients and caregivers. With the stress of a cancer diagnosis, patients may retain only a portion of the critical information provided to them. Take-home materials combined with discussions with members of the MDT help enhance patient understanding and patients' ability to take part in their own care.[56] With this is mind, the team also provides patients with CLL booklets from patient advocacy organizations. Although Sunrise recognizes that print materials are not always the best way for patients to absorb information; they believe providing these materials can help in furthering discussion and encouraging patients to participate in treatment decisions.

Initiating Treatment

The oncologists follow NCCN guidelines on when to initiate treatment, and they anticipate when the need for CLL treatment is approaching in the three to six-month range—for example, if the patient has a lymphocyte count of 200,000 or a lymphocyte doubling time of six months but is still relatively asymptomatic.

Selecting Treatment and Sharing Decision-Making with Patients and Caregivers

The oncologists on the team believe every patient with CLL who needs treatment should be considered for a clinical trial. They will offer a trial if they have one that fits the patient's disease and individual characteristics. Otherwise they recommend the standard of care based on NCCN guidelines and patient preferences. Their considerations for initial and subsequent lines of therapy are in keeping with treating the whole patient and include personal preferences for shorter-term infused therapy or ongoing oral therapy, tolerability of specific side effects, cost considerations, and treatment goals, age, comorbidities, financial, and psychosocial issues. The effective novel CLL treatments with varying toxicity profiles that have emerged in recent years have amplified the opportunities patients have to contribute to treatment decisions.[15] The team tailors its approach to shared treatment decision-making to the patient's preferences, both for treatment and for involvement in shared decision-making. As an example, some of their patients want minimal treatment or do not want any treatment.

Multidisciplinary Approach: Financial and Psychosocial Support and Referral

Sunrise financial counselors screen uninsured patients at the hospital to determine if they qualify for Medicaid. If patients qualify, the counselors help them apply. In the instances when patients do not qualify, for example, because they are not permanent residents or U.S. citizens, the team looks for alternatives such as referrals to other services and identifying other cancer centers that can help

provide care. The oncologists reach out to various foundations to help pay for molecular testing if the patient is unable to pay. Transportation can be challenging for patients in this area, although there is some help through advocacy organizations, such as American Cancer Society's Road to Recovery program. To help patients keep up with other financial needs, the Sunrise team gives patients the resources to reach out to utilities, including having the oncologists write letters to the utility company on behalf of patients. The social worker sees CLL patients when they are referred or admitted as uninsured. At times, the palliative care team at Sunrise gets involved in supporting CLL patients. Nurses often have more opportunities to obtain information from patients about their health than those afforded to other medical staff.[57] At Sunrise, the staff is aware that many patients, if not most, share different types of information with nurses and social workers than with their oncologist, and they strive to address the patient's physical and psychosocial needs by working as a multidisciplinary team to manage the patient's care.

More Opportunities to Help Patients

The combined community oncology and Sunrise team offered thoughtful perspectives on more ways to help their patients with CLL, including the following:

- Ideally every patient would have the same opportunity for the care that they need. Patients often lack adequate insurance coverage for treatment or resources to pay for nonmedical expenses. More resources are needed for patients to cover the cost of care, for psychosocial needs, transportation, and home care.
- While the explosion of effective treatment options for CLL in recent years is great news, nursing and physician education is a challenge. As a result of these new treatment developments, more community practice sub-specialization may occur (as has been seen in academic settings for many years).
- Increased access to clinical trials would help because almost every CLL patient could benefit from a clinical trial for more efficacy and safety in care.
- Smaller community practices need improved pathways to connect patients with psychosocial services.
- A bone marrow and stem cell transplant center as part of the hospital's services would help because many patients who would benefit from a transplant don't have the resources and support needed to travel a distance for this treatment.

CONCLUSION

As a result of the heterogeneity of the disease, the treatment landscape for CLL has evolved significantly in the last decade. With more options available today, CLL treatment decisions are still shaped by multiple factors including patients' genetics, their overall health (age, fitness, and comorbidities), and prognostic factors for high-risk disease. Novel CLL therapies are offering patients better outcomes, more opportunity to engage in their own care, and the chance to participate in the treatment decision-making process. In the setting of relapsed or refractory CLL, multiple options are available for patients. Clinical trials continue to play an essential role in the ongoing improvement of treatment and quality of life for patients with CLL and their families. With CLL often a chronic disease and our understanding of CLL and treatments continuing to evolve, the multidisciplinary team's role in educating patients about CLL and engaging them as active participants in their own care is an ongoing requirement for quality, patient-centered care delivery. As demonstrated by the three ACCC member programs participating in this project, every member of the multidisciplinary team can play a vital role in helping patients live well with CLL, by engaging patients in shared decision-making, encouraging proactive communication about side effects and symptoms, supporting patient adherence to oral therapy, and offering resources to mitigate associated side effects of living with CLL, such as financial toxicity and psychosocial distress.

ACCC thanks these programs for sharing their experiences in caring for patients with CLL and describing actionable pathways forward for improving care delivery for this patient population. Access additional resources from the ACCC Multidisciplinary Chronic Lymphocytic Leukemia Care project, including an on-demand audiocast series, at **accc-cancer.org/CLL-care**.

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CLL AND SUPPORTIVE CARE RESOURCES LINKS

Please visit **accc-cancer.org/CLL-care** for a listing of CLL education materials, patient advocacy organizations, and financial aid resources. ACCC's Supportive Care Resource Hub at **accc-cancer.org/supportive-care-hub** offers curated resources for providers in the areas of psychosocial distress screening, survivorship care planning, patient navigation, palliative care, and communication.

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ACCC Multidisciplinary Chronic Lymphocytic Leukemia Care Advisory Committee

Beth Marie Faiman, PhD, RN, MSN, ANP-BC, AOCN
Nurse Practitioner, Department of Hematologic Oncology and Blood Disorders
Cleveland Clinic, Taussig Cancer Center
Cleveland, Ohio

Amy Goodrich, RN, MSN, CRNP-AC
Nurse Practitioner
Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University
Baltimore, Maryland

Brian T. Hill, MD, PhD
Medical Oncologist/Director, Lymphoid Malignancies Program
Cleveland Clinic, Taussig Cancer Center
Cleveland, Ohio

Brian Koffman, MD
Physician
St. Jude Heritage Medical Group
Diamond Bar, California

Ben Kosewski, MS, MBA
Executive Director, Cancer Services
Western Maryland Health System, Schwab Family Cancer Center
Cumberland, Maryland

John M. Pagel, MD, PhD
Chief of Hematologic Malignancies; Director, Stem Cell Transplantation
Swedish Cancer Institute
Seattle, Washington

Timothy S. Pardee, MD, PhD
Medical Oncology
Wake Forest Baptist Medical Center
Winston-Salem, North Carolina

Jolynn K. Sessions, PharmD, BCOP
Oncology Clinical Pharmacist
Mission Health, SECU Mission Cancer Center
Asheville, North Carolina

Jennifer Wang, LCSW
Clinical Social Worker
Advocate Lutheran General Hospital
Park Ridge, Illinois

Association of Community Cancer Centers

Christian G. Downs, JD, MHA
Executive Director

Amanda Kramar
Chief Learning Officer

Marianne Gandee, MA
Director, Development and Strategic Alliances

Lorna Lucas, MSM
Director, Provider Education

Leigh M. Boehmer, PharmD, BCOP
Medical Director

Monique Dawkins, EdD, MPA
Assistant Director, Education Programs

Janelle Schrag, MPH
Project Manager, Provider Education

Amanda Patton, MA
Senior Manager, Editorial

Clare Karten, MS
Consultant
CTK Consults

Association of Community Cancer Centers

1801 Research Boulevard, Suite 400
Rockville, MD 20850
301.984.9496
accc-cancer.org

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