Caring for Patients With Chronic Lymphocytic Leukemia

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Chronic lymphocytic leukemia (CLL) is the most commonly diagnosed form of leukemia in the Western world, accounting for approximately 20%–30% of all cases of leukemia. Despite recent medical and scientific advances, the literature on the subjective experience and nursing care of patients diagnosed with CLL remains scarce and sporadic. This article provides a brief overview on the pathophysiology, clinical characteristics, and treatment options of CLL with focus placed on implications for nursing care. Fatigue, the most common symptom reported by patients, and infection, the leading cause of disease-related deaths, also will be addressed. Emerging data examining quality of life and the incidence of anxiety and depression in this patient population will be reviewed, and strategies aimed at addressing the educational needs of patients and family members will be discussed.

At a Glance

- Chronic lymphocytic leukemia (CLL) is a common and often chronic hematologic malignancy that has undergone major medical and scientific advances since the late 1990s.
- A deeper understanding of the pathology, diagnosing, staging, and treatment of CLL is necessary to provide comprehensive and holistic care.
- Nursing interventions aimed at patient education, symptom management, and quality of life can have a positive effect on the lives of patients and their families.

Hearing the words cancer or leukemia for the first time can be frightening and conjure feelings of uncertainty (Hays & McCartney, 1998). Advances have been made across healthcare disciplines in recent years to gain a greater understanding of how best to diagnose, treat, and predict the prognosis of patients diagnosed with chronic lymphocytic leukemia (CLL). However, despite a plethora of information, the literature does not provide nurses with an adequate guide on how to best care for patients with CLL (Breed, 2003; Hays & McCartney). Knowledge and support from oncology nurses are crucial for patients and their family members as they work through the disease trajectory and transition into a stage of living with an often chronic and incurable illness.

Approximately one-third of patients with CLL are asymptomatic at the time of diagnosis—often found during a routine blood count—and another one-third may not require immediate intervention but, instead, adopt a watchful waiting approach (Dighiero & Binet, 2000). All patients with CLL, regardless of their risk classification, should receive care tailored to meet their specific needs as both patients with cancer and patients living with a chronic illness.

Incidence and Epidemiology

CLL remains the most widely diagnosed type of leukemia in the Western world, accounting for about 20%–50% of all leukemia diagnoses (Redaelli, Laskin, Stephens, Botteman, & Pashos, 2004). The true incidence remains unknown, but recent epidemiology and population studies are shedding new light on the subject. The annual age-adjusted incidence of CLL in the United States is reported as 3 cases per 100,000, whereas a Canadian population-based study, which accounted for cancer registry data as well as centralized flow cytometry data, reported an incidence rate as high as 10.5 cases per 100,000 (Banerji et al., 2006; Yee & O’Brien, 2006). Exact occurrence rates may be difficult to determine because asymptomatic patients with low-risk disease who are diagnosed by family practitioners may not require treatment, negating the need for referral to a specialist and possibly keeping them off of cancer registry databases.

CLL has been referred to as a disease of older adults, and recent statistics continue to confirm this characterization; the median age at diagnosis is approximately 60–68 years in the United States and slightly higher in Canada (72 years) (Banerji et al., 2006; Shanafelt & Call, 2004). Eighty-one percent of patients are...
diagnosed at age 60 or older (Yee & O’Brien, 2006) and men are more likely at a ratio of 1.8:1, but the gap has narrowed in recent years (Shanafelt & Call).

Combined efforts in science and medicine to better understand the action mechanism of CLL and the clinical course of the disease will lead to the development of new treatments and the refinement of existing ones. Access to specialized care, new and expensive drug treatments, and enrolment in clinical trials will become the impetus for patients to be transferred from general practitioner care to regional oncology centers. Consequently, oncology nurses will come into contact with more patients with CLL and their families, necessitating the need for further education.

Etiology

The cause of CLL is unknown. No convincing evidence links the diagnosis to previous chemotherapy or radiation exposure, as seen with acute leukemias, and no clear link to viral exposure, past or current nicotine use, or diet has been noted (Faguet, 1994). Although no clear hereditary pattern has been determined in patients with CLL, it is estimated that 10% of patients also have a family history of CLL or another lymphoproliferative disorder (Houlston, Catovsky, & Yuille, 2002). For those patients, the term “anticipation” is used to refer to a CLL diagnosis that often appears earlier and in a more severe form in successive generations (Yuille, Houlston, & Catovsky, 1998). Nurses should reassure patients and their families of the variable and typically chronic nature of CLL and provide emotional support aimed at minimizing uncertainty. Current practice guidelines do not support routine screening for CLL in family members (Oscier et al., 2004).

Pathophysiology

CLL is a disease characterized by the accumulation of a clonal population of small, morphologically mature but immunologically immature B lymphocytes. Small lymphocytic lymphoma, once classified separately from CLL, is now considered to be the same entity and is treated in a similar manner despite the absence of lymphocytosis (Harris et al., 1999). Both small lymphocytic lymphoma and CLL are marked by an accumulation of lymphocytes within the peripheral blood, bone marrow, lymph nodes or tissue, and spleen. The cells have escaped apoptosis, or programmed cell death, and continue to accumulate at variable rates depending on disease severity (see Figure 1).

On the surface, malignant lymphocytes possess specific antigens that can be detected and identified by flow cytometry. When surface antigens are present in a specific combination, they become characteristic of CLL and help to distinguish CLL from other indolent lymphomas, such as marginal zone or follicular lymphomas, which may present clinically in a similar manner and make an accurate diagnosis difficult. The characteristics surface antigens of the CLL phenotype express include CD5, CD19, CD23, and CD20 (expressed at lower levels). The use of flow cytometry has allowed for accurate classification and treatment of leukemias and lymphomas and has contributed to improved patient outcomes.

Clinical Features

Approximately 70%–80% of patients are diagnosed during a routine blood count (Oscier et al., 2004) and are asymptomatic at the time of diagnosis. One-third of those diagnosed will never require treatment and will die of causes unrelated to CLL; one-third will require treatment at some point in the disease trajectory; and the final one-third will require immediate intervention at the time of diagnosis (Dighiero & Binet, 2000).

The hallmark sign of CLL is lymphocytosis with an absolute lymphocyte count greater than 5 x 10^9/L. All patients with an elevated lymphocyte count should have flow cytometry to confirm the presence of characteristic surface antigens and further rule out other lymphocytosis causes. Patients should be periodically monitored with repeat blood counts if their lymphocyte count is 3 x 10^9/L–5 x 10^9/L, as they may develop CLL in the future (Binet et al., 2006).

Classic signs of CLL include enlarged lymph nodes, hepatomegaly, splenomegaly, anemia, and thrombocytopenia. Cytopenias often occur in more advanced disease stages. Approximately 15% of patients will present with B symptoms, including weight loss of more than 10% total body weight, drenching night sweats, fatigue, and fever (the least likely of systemic symptoms). Fatigue is the most commonly reported symptom and its incidence does not differ between treated and untreated patient groups (Levin, Li, Riskind, & Rai, 2007; Molica, 2005). Patient age does not appear to influence the presence of symptoms, with no difference in clinical findings found between younger (55 years or less) and older patient populations (de Lima, O’Brien, Lerner, & Keating, 1998).

Disease-related complications may be present in advanced cases at the time of diagnosis but can occur at any point in the disease trajectory. Complications include the presence of
autoimmune hemolytic anemia, idiopathic thrombocytopenia purpura, red cell aplasia, infection, and transformation into a more aggressive form of disease (either prolymphocytic leukemia or large cell lymphoma (Richter’s transformation). Approximately 10%–20% of patients with CLL will develop autoimmune complications, and patients treated with purine analogues, such as fludarabine, are at greater risk of developing hemolysis. It is important that nurses are aware of the complications and monitor for symptoms, possibly allowing for early identification and intervention (Palma et al., 2006).

Patients undergoing Richter’s transformation often will present with rapidly enlarging nodes in one area, weight loss, fatigue, elevated lactate dehydrogenase levels, and symptoms of a more aggressive disease. The risk of Richter’s transformation does not increase with time, affecting only 5%–10% of patients; however, when it does occur, the median survival is only five months (Oscier et al., 2004).

### Staging

Two clinic-based staging systems—the Rai and the Binet systems—are widely used to classify patients with CLL. Both are useful in estimating disease prognosis and stratifying treatment populations, with the Rai system more widely used in North America (see Table 1). In addition, both systems correlate patient survival and use the presence or absence of organ infiltration and cytopenias (see Table 2). The Rai system classifies five stages (0 through IV) of CLL but notes that there are only three patterns of survival: low, intermediate, and high. This helps clinicians determine the most appropriate time to commence treatment (Rai et al., 1975).

In addition to these clinical findings, prognostic markers are useful to assess the extent of disease and determine the likelihood of treatment response. Key markers are highlighted in Table 3, along with the clinical significance of each. Surrogate clinical markers also have been identified that are more accessible, less costly, and can assist clinicians in assessing the extent and severity of the disease. Characteristics of aggressive or advanced CLL are outlined in Table 4 and include a lymphocyte doubling time of less than one year; diffuse bone marrow involvement; elevated β2 microglobulin; an elevated lactate dehydrogenase level; and the presence of surface antigens CD23 and CD38, with CD38 being used for prognostic rather than diagnostic purposes (Palma et al., 2006).

Survival times have increased with the addition of effective therapeutic options. Survival times range from less than 2 years in advanced cases to 10 years for patients with low-risk disease. Younger patients often die from disease-related complications, whereas older patients die from causes unrelated to CLL (Oscier et al., 2004).

### Treatment Options

All treatment options for CLL represent an effort to slow disease progression and manage symptoms rather than provide curative therapy. It is crucial that a collaborative approach is carried out, one that includes a discussion of patient values and wishes regarding treatment. Treatments can be complex, and considerable patient counseling by nurses will help to alleviate fears of possible side effects, answer questions about how treatment will impact patients’ lives, reinforce the rationale for initiating treatment, and serve as emotional support along patients’ journeys.

A broad range of treatment options are available today, and it is important that a step-wise progression is implemented to ensure maximum benefit and minimal toxicity. The least invasive management strategy involves careful monitoring of bloodwork and symptoms at regular intervals with the intent to treat when specific clinical parameters have been met. This approach often is labeled watchful waiting, and some patients may feel that nothing is being done. On the contrary, watchful waiting is a dynamic

### Table 1. Rai System for Classifying Chronic Lymphocytic Leukemia

<table>
<thead>
<tr>
<th>RAI STAGE</th>
<th>RISK</th>
<th>CLINICAL FEATURES</th>
<th>MEDIAN SURVIVAL (YEARS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Low</td>
<td>Lymphocytosis greater than 5 x 10⁹/L</td>
<td>&gt; 10</td>
</tr>
<tr>
<td>I–II</td>
<td>Intermediate</td>
<td>Lymphocytosis plus splenomegaly with or without hepatomegaly and with or without lymphadenopathy</td>
<td>7–9</td>
</tr>
<tr>
<td>III–IV</td>
<td>High</td>
<td>Anemia (hemoglobin less than 110 g/l)</td>
<td>1.5–5</td>
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<tr>
<td></td>
<td></td>
<td>Thrombocytopenia (platelet count less than 100 x 10⁹/L)</td>
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### Table 2. Binet System for Classifying Chronic Lymphocytic Leukemia

<table>
<thead>
<tr>
<th>BINET STAGE</th>
<th>RISK</th>
<th>CLINICAL FEATURES</th>
<th>MEDIAN SURVIVAL (YEARS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Low</td>
<td>Hemoglobin greater than 100 g/l and platelet count greater than 100 x 10⁹/L</td>
<td>&gt; 10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than three lymphoid areas</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>Intermediate</td>
<td>Hemoglobin greater than 100 g/l and platelet count greater than 100 x 10⁹/L</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More than three lymphoid areas</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>High</td>
<td>Hemoglobin less than 100 g/l, platelet count less than 100 x 10⁹/L, or both</td>
<td>5</td>
</tr>
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process with considerable dialogue between patients and nurses. Patients often feel anxious and uncertain about the future because this approach defies their instinct to immediately fight the cancer. Patient education about the nature of the disease and the development of a trusting relationship between patients and nurses will facilitate discussion about patients’ priorities and life goals. This helps them adjust to their diagnosis in a healthy manner.

Alkylating agents, such as chlorambucil, were the CLL treatment of choice for decades, but nucleoside analog-based regimens (with fludarabine being the most commonly used) have now become the standard of care (Keating et al., 1991; Rai et al., 2000). Oral preparations of both chlorambucil and fludarabine are convenient, inexpensive, and well-tolerated treatment options that contain minimal side effects of mild nausea, abdominal discomfort, diarrhea, joint discomfort, and cytopenias. The risk of myelosuppression is higher with fludarabine and can persist over time, which can affect future treatment options if not closely monitored (Yee & O’Brien, 2006).

Fludarabine and cyclophosphamide used in combination have shown longer progression-free and treatment-free survival versus single-agent fludarabine and has become the standard first-line therapy despite no difference in overall survival (Palma et al., 2006). Combination regimens with rituximab and/or cyclophosphamide also have been shown to have better response rates (measured by blood counts, lymph nodes, and spleen sizes) than fludarabine alone, with overall response rates of 90% and 73%, respectively (Oscier et al., 2004), but single-agent treatments in either oral or IV form may be more appropriate for older adult patients and patients with multiple comorbidities. IV regimens require greater time spent receiving chemotherapy but generally are well-tolerated.

Alemtuzumab is a monoclonal antibody that may be an appropriate treatment option for patients who are refractory to fludarabine-based regimens (Lynn, Williams, Sickler, & Burgess, 2003). Careful patient selection and close monitoring are imperative because of dose-related side effects, the increased risk of developing a life-threatening infection because of both B- and T-cell depletion, and risk of marrow suppression and associated complications (Lynn et al.). The treatment can be supervised and symptoms managed by knowledgeable nurse clinicians.

Allogeneic stem cell transplantation in patients with CLL is an option that offers patients a possible cure or prolonged disease-free survival (Esteve et al., 2001). However, it comes with considerable risk of mortality and is not an appropriate alternative for all patients. Patients younger than 65 who have not had success with conventional treatments and otherwise have a poor prognosis may be the best candidates for transplantation. Khouri et al. (2002) studied 28 patients with CLL and reported an improved five-year progression-free survival rate in previously untreated patients (78%) compared with chemotherapy-refractory patients (31%), suggesting that treatment with stem cell transplantation should be a consideration earlier than previously thought in the trajectory. Reduced intensity or nonmyeloablative transplants showed good response rates with less patient toxicity (Abbott, 2006).

Clinical trials also are ongoing to evaluate the efficacy of new agents such as flavopiridol, a synthetic flavone with antiproliferation and apoptosis-inducing abilities, and lenalidomide, a thalidomide analog in CLL treatment (Wierda, 2006). In addition to the new agents, drugs such as pentostatin and cladribine also are being studied as possible treatment options (Wierda).

The decision to initiate treatment should be guided by the disease stage, symptom presence, and disease activity. No clear indication shows that early treatment initiation prolongs overall survival, therefore, patients with limited-stage disease should not be treated unless symptomatic. The International Workshop on Chronic Lymphocytic Leukemia composed of an international panel of experts in CLL met and developed guidelines for the initiation of treatment, including Rai stage III or IV disease; early-stage disease with the presence of bothersome symptoms; rapid lymphocyte doubling time; declining bone marrow function as evidenced by progressive anemia and thrombocytopenia; and rapidly enlarging lymph nodes (Binet et al., 2006).

### Table 3. Key Prognostic Markers and Clinical Implications in Chronic Lymphocytic Leukemia

<table>
<thead>
<tr>
<th>CHROMOSOMAL ABNORMALITY</th>
<th>IMPLICATION FOR DISEASE</th>
</tr>
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<tbody>
<tr>
<td>IgVH mutational status</td>
<td>Unmutated status suggests poor outcome.</td>
</tr>
<tr>
<td>Deletion 17p</td>
<td>Aggressive disease progression; drug resistance</td>
</tr>
<tr>
<td>Trisomy 12</td>
<td>Shorter treatment-free survival</td>
</tr>
<tr>
<td>Deletion 11q</td>
<td>Aggressive disease progression; presence of bulky lymphadenopathy</td>
</tr>
<tr>
<td>Deletion 13q</td>
<td>Indolent disease progression; good prognosis</td>
</tr>
<tr>
<td>P53 mutation</td>
<td>Poor response to conventional chemotherapy</td>
</tr>
<tr>
<td>Zap 70</td>
<td>Correlates with unmutated IgVH and associated with poor prognosis</td>
</tr>
</tbody>
</table>

IgVH—immunoglobulin heavy chain variable gene

### Table 4. Surrogate Markers in the Prognosis of Chronic Lymphocytic Leukemia

<table>
<thead>
<tr>
<th>SURROGATE MARKER</th>
<th>INDICATION OF ADVANCED OR AGGRESSIVE DISEASE</th>
</tr>
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<tbody>
<tr>
<td>Lymphocyte doubling time</td>
<td>Less than one year</td>
</tr>
<tr>
<td>Bone marrow</td>
<td>Diffuse involvement with chronic lymphocytic leukemia</td>
</tr>
<tr>
<td>β-2 microglobulin</td>
<td>Elevated</td>
</tr>
<tr>
<td>Lactate dehydrogenase</td>
<td>Elevated</td>
</tr>
<tr>
<td>Surface antigens CD38 and CD23</td>
<td>Present</td>
</tr>
<tr>
<td>Serum thymidine kinase</td>
<td>Elevated</td>
</tr>
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</table>
Surgical intervention, such as the removal of lymph nodes, currently is not an option in CLL treatment outside of the initial disease diagnosis or to rule out Richter’s transformation. Splenectomy may serve as a treatment for steroid resistant idiopathic thrombocytopenic purpura or persistent splenomegaly.

Nursing Care

The earliest case report found in the research literature dates back to 1951 when a nursing student published a report in the American Journal of Nursing detailing the case of a woman diagnosed with CLL who was admitted to a hospital with recurrent infection, ecchymosis, mouth sores, massive splenomegaly, and extensive lymphadenopathy (Yura, 1951). Yura stressed the importance of patient education, frequent bloodwork to monitor disease progression, the importance of guarding against infection, and tailoring nursing care to ensure that the patient was as comfortable and happy as possible. Little has changed in the nursing focus for the past 55 years, but it is important that nursing management strategies are revisited to ensure practice remains current.

Nursing Assessment

Nursing assessment of patients with CLL should start with a head-to-toe physical assessment, with particular attention paid to B symptoms typical of the patient population. Family history of cancer and blood cancers should be determined to rule out any familial patterns. In addition, patients should be asked about their own history of cancer, as there appears to be an increased risk of second malignancy in both treated and untreated patients, and an increased incidence of melanoma and nonmelanomatous skin cancers, cancer of the larynx, lung, brain, stomach, and bladder in the patient group (Oscier et al., 2004; Shanafelt & Call, 2004). Counseling about sun protection, regular skin examinations, and routine cancer screening according to regional and national guidelines should be encouraged and conducted in all CLL patients regardless of the disease extent.

Complete blood counts should be reviewed and interpreted as pieces of a larger puzzle. Elevated blood counts examined alone can cause confusion and frustration, but when connected and viewed as a whole, they may illustrate a very different picture. For example, a lymphocyte count of 20 x 10⁹/L may cause alarm and panic for nurses and patients if considered in isolation. But when the lymphocyte count is trended over time and found to be stable over the past year, coupled with normal platelet and hemoglobin values in asymptomatic patients, there is less cause for concern as little has changed in the patients’ disease status.

A focused assessment should address patients’ energy levels or their degree of fatigue; appetite and current weight; the presence of fever, chills, or recent infection; palpable lymph nodes; and the presence of drenching night sweats (see Table 5). The assessment of fatigue and infection, the most frequently reported physical symptom and most common complication of CLL, will be discussed further.

Fatigue

Fatigue is the most commonly reported symptom, and its action mechanism is poorly understood (Mandrell, 2004). Patients with CLL report more fatigue and lower role performance function than age-matched healthy controls; however, no significant difference was found between previously treated and untreated patients (Holzner, Koppe, Nguyen-Van-Tam, Sperner, & Greil, 2004). Advanced disease and age also are risk factors for fatigue development. Assessment and intervention can help patients better manage their symptoms and improve overall quality of life. Sources of underlying fatigue, including stress, anemia as a result of the disease, treatment or autoimmune complications, infection, dehydration, the presence of comorbid conditions such as diabetes, and insomnia resulting from treatment with corticosteroids should be assessed and addressed.

Patients should plan activities for times when they are rested and attend to one activity at a time. When educating patients, ensure that they are rested and provide information in smaller amounts rather than all at once. Patients also should be encouraged to engage in regular physical activity, eat a well-balanced diet, take naps if necessary, and talk to their healthcare team about management strategies (Graydon, Bubela, Irvine, & Vincent, 1995). For patients interested in more information on diet and exercise, referrals within the multidisciplinary team, such as physiotherapy and nutrition services, can be valuable sources of information.

<table>
<thead>
<tr>
<th>SYSTEM</th>
<th>ASSESSMENT</th>
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<tbody>
<tr>
<td>Cancer risk</td>
<td>Personal cancer history, family history of cancer and chronic lymphocytic leukemia</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>Previous cancer experiences or contacts, presence of anxiety, depression, and overall well-being, presence of uncertainty related to their condition</td>
</tr>
<tr>
<td>Integumentary</td>
<td>Presence of skin rashes, lesions, or moles, abnormal bruising or bleeding, drenching night sweats, fever, enlarged lymph nodes in neck, axilla, and groin</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Persistent or productive cough, signs of sinusitis, adventitia or crickles on auscultation, chest pain</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>Mouth sores, weight loss, appetite, presence of abdominal bloating or discomfort (splenomegaly), dysphagia</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>Urinary frequency or dysuria, symptoms of infection</td>
</tr>
<tr>
<td>Complete blood count</td>
<td>White blood count, lymphocyte count, hemoglobin, platelets, reticulocyte count</td>
</tr>
</tbody>
</table>
Infection

Recurrent infections are another hallmark symptom of CLL. Infection is the leading cause of disease-related deaths, with an estimated 80% of patients developing moderate to life-threatening complications at some point in the course of their illness, and up to 60% of deaths attributed to infection (Morrison, 1998). Mucosal tissue, particularly upper and lower respiratory tract infections, are the most commonly affected sites and pathogens. *Staphylococcus aureus*, *Streptococcus pneumonia*, and *Pneumocystis carinii* are the most common culprits (Chapel & Bunch, 1987; Morrison). Patients also are at risk of developing life-threatening viral and fungal infections as a result of their compromised immunity, which is characteristic of the disease and treatment (Chapel & Bunch, 1987).

Humoral and cellular immunity defects, T-cell dysfunction, and hypogammaglobulinemia make patients with CLL more susceptible to infection. Patients who have received multiple chemotherapy regimens in the past or who have advanced disease are at higher risk of developing severe infectious complications than patients with more indolent disease (Hensel, Kornacker, Yammeni, Egerer, & Ho, 2003). Hypogammaglobulinemia often is a late complication, with 70% of patients developing this condition seven years after diagnosis (Rozman, Montserrat, & Vinolas, 1988). Low dose IV immunoglobulin therapy minimizes the frequency and severity of infections for these patients (Morrison, 1998).

Early symptom recognition and reporting is vital. Patients should be taught to monitor for fevers, persistent cough, and urinary symptoms from the time of diagnosis and report these symptoms. Patients on active treatment with purine analogs and alemtuzumab should have their blood checked regularly for cytomegalovirus reactivation and should receive leukocyte-depleted and irradiated blood products to reduce the incidence of graft-versus-host disease and blood-borne viral infections. Cytomegalovirus reactivation can be life threatening and should be immediately checked if patients become febrile. *Pneumocystis carinii* pneumonia from steroid therapy and herpes infection can occur if medication compliance to prophylactic antibiotics and antivirals for patients with a past history of recurrent infections or on active treatment is not followed.

Quality of Life

Despite the frequency of diagnosis and the chronic nature of CLL, little attention has been paid in the literature to the experience of patients living with CLL (Bertero & Eriksson, 1997; Holzner et al., 2004; Montgomery, Popcock, Titley, & Lloyd, 2002). Clinicians believed for decades that patients on watchful waiting were more anxious than those receiving active treatment, but no research supported this belief. Levin et al. (2007) published results of a cross-sectional study examining depression, anxiety, and quality of life in treated and untreated patients with CLL (N = 105), and no difference was found between the two groups in depression level, anxiety, and mental or physical function. The study supported Holzner's (2004) findings that watchful waiting patients reported similar quality of life and psychosocial morbidity to those who had received chemotherapy in the past. However, patients younger than 60 reported lower levels of emotional and social quality of life and higher levels of anxiety. Older patients with CLL generally do better emotionally than younger patients (Levin et al., 2007), and women generally report lower emotional and social function scores; noteworthy because the prognosis for male patients with CLL is worse than female patients. Nurses can use this information to identify patients at risk for psychological distress and poor diagnosis adaptation. All patient assessments should be individualized and address domains beyond physical characteristics to provide the most comprehensive and holistic nursing care.

Studies examining quality of life, depression, and anxiety in both treated and untreated patients with CLL will change patient care as they validate the importance of nursing assessment and psychosocial interventions on patient outcomes. More attention should be given to the psychosocial needs and coping strategies specific to these patients. Social worker referrals can help patients transition through times of relapse and progression and prevent the development of severe psychological distress.

Nurses should use research findings to identify patients at high risk for psychological distress and poor coping with a chronic illness. Uncertainty, unlike anxiety, is not a medical diagnosis and the presence of uncertainty in patients with cancer can affect psychological adaptation and be a significant source of stress that leads to less optimism and creates adjustment issues for patients and family members (Mishel, Hostetter, King, & Graham, 1984).

Patient Education

Nursing assessment and education should start early in the nurse-patient relationship, enabling them to take control and manage their own health. The provision of information (both one-on-one and in larger group settings) about the natural course of CLL, symptom progression, and treatment side effects is important when addressing patient uncertainties and when bringing patients together to talk with and find support from others in similar situations. Helping patients identify which aspects of their lives are important allows nurses to encourage and facilitate realistic appraisal and adaptation to the illness (Montgomery et al., 2002). Patients should be encouraged to involve their family and friends in their care rather than isolate themselves or keep their diagnosis private. Social support provides patients with an emotional and social network as they cope and make lifestyle changes. Patients who express interest should be encouraged to join support groups and share stories with other patients with CLL.

Conclusion

As new information becomes available on the incidence, diagnosis, treatment, and outcomes of patients with CLL, it is important that oncology nurses review the information and integrate relevant findings into their daily practice. New diagnostic tools and the often indolent nature of the disease mean that more patients will be living with CLL, requiring nursing assessment and intervention at some point in the disease trajectory. Nursing care should be individualized to meet each patient’s unique needs and address their specific questions and concerns. Attention should be paid to disease and treatment side effects, disease complications, symptom management, infection risk, and patient education to help patients adjust and adapt to their diagnosis.
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