Patient empowerment is a patient-centered approach to care in which healthcare providers nurture patients’ innate abilities to self-manage and incorporate patient goals for therapy into the overall management plan. Standard care of chronic myeloid leukemia (CML) requires lifelong medication with oral therapy and regular follow-up. The success of CML treatment, therefore, depends on a high degree of patient involvement and motivation, as well as strong collaboration between patients and healthcare providers. Oncology nurses can support patients with CML from the time of diagnosis to the end of treatment to ensure they maintain high levels of involvement in their care. At the author’s center, patients who most actively collaborate with their physicians in treatment decisions take personal responsibility for the quality of their care and show good adherence to treatment. In the current article, the author discusses the potential effect of patient response to cancer diagnosis on clinical outlook and describes strategies in place at the cancer center to ensure that patients diagnosed with CML have the best chance at keeping their cancer under control.

Patient newly diagnosed with cancer often believe the misconception that a cancer diagnosis automatically means a death sentence, but survival after diagnosis depends on many factors, including type of cancer, stage at diagnosis, and response to initial therapy (American Cancer Society, 2013). For example, chronic myeloid leukemia (CML) is a hematologic cancer characterized by the overgrowth of myeloid cells in the bone marrow and their accumulation in the peripheral blood. Most patients with CML are diagnosed in the early chronic phase (CML-CP) of disease (Cortes et al., 2006). With modern therapy, survival rates of patients with CML have improved dramatically since 2001 (Björkholm et al., 2011; Kantarjian, O’Brien, et al., 2012), and CML-CP has been rendered a chronic condition that is manageable with continuous lifelong medication for most patients.

Receiving a diagnosis of CML is an extremely stressful event, after which patients may experience feelings ranging from anger to helplessness (Guilhot et al., 2013). In addition, once patients find their way to a new normal after diagnosis, they must undergo treatment that may last a lifetime. What can be done to encourage a more positive outlook? What can be done to ensure that motivation stays high for patient adherence over the long course of treatment? How can patients be empowered to play a positive role in the management of their disease?

Oncology nurses often are in a position to foster and maintain strong healthcare relationships with their patients. Recognizing the links that connect patient empowerment, patient involvement in care, health-related quality of life (HRQOL), adherence, and clinical outcomes, oncology nurses should seek to empower patients to have greater involvement in their care. The management of patients with CML has become more prevalent because of the extension of life expectancy afforded by modern therapy (Huang, Cortes, & Kantarjian, 2012). As more patients live longer with CML as a chronic condition, healthcare providers and patients must stay involved and motivated for many years.

The current article outlines clinical evidence for standard therapy for CML and summarizes clinical findings that connect the concepts of patient empowerment, patient involvement in...
care, HRQOL, adherence, and clinical outcomes. The article also describes strategies in place at the author’s center that promote empowering patients with CML to take active roles in their care.

**BCR-ABL1 Tyrosine Kinase Inhibitor Therapy**

CML is unusual among cancers because a single molecular defect underlies the disease pathogenesis. The *BCR-ABL1* tyrosine kinase is an aberrant fusion protein generated through a chromosome rearrangement that forms the Philadelphia chromosome (Nowell & Hungerford, 1960), the cytogenic hallmark of CML. Identification of the *BCR-ABL1* gene as the cause of CML has led to the development of tyrosine kinase inhibitors (TKIs) that target *BCR-ABL1* activity.

*BCR-ABL1* TKIs have proven to be highly effective treatments for patients newly diagnosed with CML-CP. In 2001, imatinib was the first *BCR-ABL1* TKI to receive approval by the U.S. Food and Drug Administration for treatment of CML (Deininger et al., 2009; Druker et al., 2006; Hochhaus et al., 2009; Hughes et al., 2003; O’Brien et al., 2003). Long-term treatment with imatinib results in significantly higher rates of cytogenetic and molecular response and significantly lower occurrences of disease progression to advanced CML (accelerated or blast phase), when compared with a control group.

Since the approval of imatinib, four additional *BCR-ABL1* TKIs have become commercially available: nilotinib, dasatinib, bosutinib, and ponatinib. At this time, imatinib, nilotinib, and dasatinib are approved for first- and second-line treatment; bosutinib and ponatinib are approved for second-line or later treatment only (Kantarjian et al., 2010; Kantarjian, Hochhaus, et al., 2011; Kantarjian, Shah, et al., 2012; Larson et al., 2012; Saglio et al., 2010). Treatment with nilotinib and dasatinib has resulted in significantly higher rates of cytogenetic and molecular responses when compared with imatinib. In addition, the rate of disease progression has been lowered with nilotinib and dasatinib, and those drugs have demonstrated manageable toxicity profiles in the first-line setting.

**Empowerment and the Patient Role in Managing Chronic Myeloid Leukemia**

The concept of self-management of patients with cancer was seeded when the delivery of cancer treatment transitioned from the inpatient to the outpatient setting (McCorkle et al., 2011), marking a point when patients needed less intense supervision during treatment. With the increasing use of oral agents in cancer treatment (Given, Spoelstra, & Grant, 2011), responsibility for the delivery of treatment has shifted to patients who must rely on themselves and their support systems to accomplish basic aspects of cancer care (e.g., some adverse events management, treatment adherence, drug storage, drug handling, drug administration) between clinic visits. The role of self-care in the management of cancer is pronounced with CML because the standard of care is continuous dosing of TKI therapy for an indefinite period of time.

For patients to be able to self-manage, they must have the information, skills, and self-assurance to accomplish basic care. The incorporation of patient concerns, goals, and resources in the overall cancer management plan contributes to the empowerment of patients (McCorkle et al., 2011). Focus on patient empowerment in CML has been limited, perhaps because CML only recently could be managed successfully as a chronic condition. Relevant to this topic, however, is an ethnographic study by Guilhot et al. (2013) that supports the principles of patient empowerment in CML. That study qualitatively assessed the effect of CML on patients throughout the course of disease and treatment and found that some patients moved through the psychosocial stages of disease by taking the lead in directing their care, interpreting test results on their own, and developing adaptive behaviors to incorporate medication into their daily routines (Guilhot et al., 2013). These findings highlight the importance of patient-driven care, a concept that is established in other cancers (e.g., breast cancer) (Palmieri & Barton, 2007) and recently has gained attention for CML.

**Patient Involvement, Health-Related Quality of Life, Treatment Adherence, and Clinical Outcomes**

Evidence suggests that actively involved patients may have better HRQOL measures than those who are more passive. In a review of psychological studies of patients with acute and chronic leukemias and lymphomas, those characterized as having a “fighting spirit” and greater self-efficacy and decision-making ability had better HRQOL, and those who reported feeling helpless or hopeless had higher levels of emotional distress and lower HRQOL (Allart, Soubeyran, & Cousson-Gélie, 2013). Other findings from Guilhot et al.’s (2013) study showed that patients felt more hopeful and coped better with uncertainty when they became more knowledgeable and informed about CML and its treatments. Those observations are consistent with ones made in other chronic conditions (i.e., diabetes), showing that the level of patient involvement positively correlates with HRQOL measures, including attitude toward the effect of diabetes on HRQOL (Anderson et al., 1995; Jahng, Martin, Golin, & DiMatteo, 2005), patient satisfaction with medical care, and health perception (Anderson et al., 1995; Jahng et al., 2005).

Recent studies in CML have demonstrated a clear effect of patient HRQOL on treatment adherence. In particular, treatment-related side effects are a major reason cited by patients with CML for not adhering to TKI therapy (Eliasson, Clifford, Barber, & Marin, 2011; Marin et al., 2010). Of note, one study found several HRQOL aspects (i.e., symptom burden, psychosocial functions, and body image) that patients and their healthcare providers valued differently (Efficace et al., 2012). Efficace et al. (2012) emphasized that the effect of CML on patients should be patient-centered assessment and that HRQOL measurement tools also should be reported by the patient. The European Organisation for Research and Treatment of Cancer (2013) Quality of Life Questionnaire-CML24, the MD Anderson Symptom Inventory-CML (Williams et al., 2010), and the Functional Assessment of Cancer Therapy-Leukemia (FACT-Leu) (Cella et al., 2012) measurement tools were developed based on the experiences of patients with CML (and other leukemias, in the case of the FACT-Leu). Assessment of HRQOL will become an increasingly routine practice as patients with CML...
live longer and must maintain TKI therapy for years. Research has shown that low adherence rates to TKI therapy are associated with failure to achieve cytogenetic or molecular response (Marin et al., 2010; Noens et al., 2009), indicating that adherence to TKI therapy is a significant independent factor predicting response to treatment in CML.

Two overarching themes emerge from previously published research: Empowering patients to be more involved in their care can positively affect HRQOL, and improving HRQOL, particularly treatment-related side effects, can lead to better clinical outcomes. Therefore, how can oncology nurses promote the empowerment of patients, increase patient involvement and self-management, and effectively and proactively manage side effects?

Strategies for Patient Empowerment

The empowerment process begins when healthcare providers recognize that patients ultimately are responsible for their own care, and that the purpose of patient education is to enhance the patients’ abilities to think critically and act autonomously with respect to disease management. Empowerment is realized when patients actuate self-efficacy (Anderson et al., 1995).

At the Time of Diagnosis

When patients first receive a cancer diagnosis, healthcare providers should offer support and establish the type of relationship that fosters trust, confidence, and a strong sense of collaboration. A survey of healthcare provider responses to patients at the time of cancer diagnosis found that patients want (a) information on treatments and side effects so that they can make informed treatment decisions; (b) information to be delivered in an understandable written format; (c) to be told the truth, because making intentionally misleading statements undermines patient autonomy and may contribute to a breakdown of the patient/provider relationship; and (d) healthcare providers to encourage patients and demonstrate a sense of partnership with them (e.g., ‘I’ll be here for you’) (Rassin, Levy, Schwartz, & Silner, 2006). Rassin et al.’s (2006) study found that patients wanted written information at the time of diagnosis because the shock can render patients unable

<table>
<thead>
<tr>
<th>Topic</th>
<th>Resource</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease</strong></td>
<td>National CML Society</td>
<td>Website with printable resources available at <a href="http://www.nationalcmlsociety.org">www.nationalcmlsociety.org</a></td>
</tr>
<tr>
<td></td>
<td>Chronic Myeloid Leukemia (2012)</td>
<td>Book by the Leukemia and Lymphoma Society with basic information about CML for patients and their families available at <a href="http://www.lls.org/#/resourcecenter/freeducationmaterials/leukemia/cml">www.lls.org/#/resourcecenter/freeducationmaterials/leukemia/cml</a></td>
</tr>
<tr>
<td><strong>Treatment options</strong></td>
<td>NeedyMeds</td>
<td>Website to help with cost of medicine available at <a href="http://www.needymeds.org">www.needymeds.org</a></td>
</tr>
<tr>
<td><strong>Side effects</strong></td>
<td>Understanding Side Effects of Drug Therapy (2013)</td>
<td>Book by the Leukemia and Lymphoma Society available at <a href="http://www.lls.org/resourcecenter/freeducationmaterials/treatment/drugtherapysideeffects">www.lls.org/resourcecenter/freeducationmaterials/treatment/drugtherapysideeffects</a></td>
</tr>
<tr>
<td><strong>Financial assistance</strong></td>
<td>Bristol-Myers Squibb Access Support</td>
<td>Website with reimbursement support for pharmaceuticals available at <a href="http://www.sprycel.com/consumer/sprycel-reimbursement.aspx">www.sprycel.com/consumer/sprycel-reimbursement.aspx</a></td>
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<td></td>
<td>Bridges to Access®</td>
<td>Website by GlaxoSmithKline available at <a href="http://www.bridgestoaccess.com">www.bridgestoaccess.com</a></td>
</tr>
<tr>
<td></td>
<td>Tasigna® (nilotinib) Financial Assistance</td>
<td>Website by Novartis Pharmaceuticals available at <a href="http://www.us.tasigna.com/patient/financial-assistance.jsp">www.us.tasigna.com/patient/financial-assistance.jsp</a></td>
</tr>
<tr>
<td></td>
<td>Bosulif® (bosutinib) Patient Resource Center</td>
<td>Website by Pfizer, Inc. available at <a href="http://www.bosulif.com/patient-support-resources">www.bosulif.com/patient-support-resources</a></td>
</tr>
<tr>
<td></td>
<td>SeaGen Secure®</td>
<td>Website for reimbursement assistance for ADCETRIS® (brentuximab vedotin) available at <a href="http://www.seagensecure.com/home/patient-assistance/patient-assistance.html">www.seagensecure.com/home/patient-assistance/patient-assistance.html</a></td>
</tr>
<tr>
<td></td>
<td>My CML Circle®</td>
<td>Website with information about the copayment assistance program sponsored by Novartis Pharmaceuticals available at <a href="http://www.mycmlcircle.com">www.mycmlcircle.com</a> or by calling 1-888-625-2333</td>
</tr>
<tr>
<td><strong>Patient support</strong></td>
<td>Cancer Support Community: Central Indiana</td>
<td>Website with cancer support services available at <a href="http://www.cancersupportindy.org">www.cancersupportindy.org</a></td>
</tr>
<tr>
<td></td>
<td>The Empowered Patient</td>
<td>Website on patient empowerment available at <a href="http://www.theempoweredpatient.com">www.theempoweredpatient.com</a></td>
</tr>
</tbody>
</table>
TABLE 2. Adverse Events Related to Tyrosine Kinase Inhibitor Therapy

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Imatinib</th>
<th>Nilotinib</th>
<th>Dasatinib</th>
<th>Bosutinib</th>
<th>Ponatinib</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nonhematologic (All Grades)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Abdominal pain</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
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<tr>
<td>Alopecia</td>
<td>–</td>
<td>VC</td>
<td>–</td>
<td>–</td>
<td>–</td>
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<tr>
<td>Chills</td>
<td>–</td>
<td>–</td>
<td>–</td>
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<td>–</td>
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<tr>
<td>Constipation</td>
<td>VC</td>
<td>VC</td>
<td>–</td>
<td>–</td>
<td>VC</td>
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<tr>
<td>Cough</td>
<td>VC</td>
<td>VC</td>
<td>–</td>
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<td>VC</td>
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<tr>
<td>Diarrhea</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
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<tr>
<td>Dizziness</td>
<td>–</td>
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<td>–</td>
<td>–</td>
<td>VC</td>
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<tr>
<td>Dry skin</td>
<td>–</td>
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<td>–</td>
<td>–</td>
<td>VC</td>
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<tr>
<td>Dyspnea</td>
<td>–</td>
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<td>VC</td>
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<td>VC</td>
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<tr>
<td>Fatigue or asthenia</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
<td>C</td>
<td>VC</td>
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<tr>
<td>Fluid retention</td>
<td>VC</td>
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<td>VC</td>
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<tr>
<td>Headache</td>
<td>VC</td>
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<tr>
<td>Hemorrhage</td>
<td>–</td>
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<tr>
<td>Hepatotoxicity</td>
<td>C</td>
<td>C</td>
<td>–</td>
<td>NC</td>
<td>NC</td>
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<tr>
<td>Hypertension</td>
<td>–</td>
<td>–</td>
<td>VC</td>
<td>–</td>
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</tr>
<tr>
<td>Infections</td>
<td>VC</td>
<td>VC</td>
<td>VC</td>
<td>–</td>
<td>VC</td>
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<tr>
<td>Metabolism or nutrition</td>
<td>VC</td>
<td>–</td>
<td>–</td>
<td>VC</td>
<td>C</td>
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<tr>
<td>Musculoskeletal pain</td>
<td>VC</td>
<td>VC</td>
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<tr>
<td>Nausea</td>
<td>VC</td>
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<tr>
<td>Night sweats</td>
<td>VC</td>
<td>–</td>
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<tr>
<td>Oropharyngeal/pharyngogalyngeal pain</td>
<td>VC</td>
<td>–</td>
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<tr>
<td>Other cardiac or vascular</td>
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<td>C</td>
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</tbody>
</table>

(Continued on the next page)
TABLE 2. Adverse Events Related to Tyrosine Kinase Inhibitor Therapy (Continued)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Estimated Incidence*</th>
<th>Imatinib</th>
<th>Nilotinib</th>
<th>Dasatinib</th>
<th>Bosutinib</th>
<th>Ponatinib</th>
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<tbody>
<tr>
<td>Nonhematologic (All Grades) (continued)</td>
<td></td>
<td>I</td>
<td>I</td>
<td>II</td>
<td>I</td>
<td>II or III</td>
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<td>Other GI disorders</td>
<td>VC – VC C C – VC</td>
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<tr>
<td>Peripheral neuropathy</td>
<td>– – – – – – VC</td>
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<td>PAH</td>
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<td>Pancreatitis</td>
<td>NC C – NC NC NC C</td>
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<tr>
<td>PAOD</td>
<td>– C NK – – – C</td>
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<tr>
<td>Pleural effusion</td>
<td>R NC C VC VC C C</td>
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<td>Pruritus</td>
<td>– VC VC – VC VC – C</td>
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<tr>
<td>Psychiatric disorders</td>
<td>VC – VC – – – C</td>
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<tr>
<td>Pyrexia</td>
<td>VC VC VC – C VC VC</td>
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<tr>
<td>Rash and related conditions</td>
<td>VC VC VC VC VC VC</td>
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<td>QTc prolongation &gt; 500 ms</td>
<td>NC – C NC NC NC –</td>
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<tr>
<td>Rigors</td>
<td>VC – – – – – –</td>
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<tr>
<td>Vomiting</td>
<td>VC VC VC C C VC VC</td>
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<tr>
<td>Laboratory Abnormalities (Grade 3 or 4)</td>
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<tr>
<td>Elevated ALT or AST</td>
<td>C C C NC NC VC VC</td>
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<tr>
<td>Elevated bilirubin</td>
<td>C C C C NC NC C</td>
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<tr>
<td>Elevated glucose</td>
<td>– C VC – – VC C</td>
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<tr>
<td>Elevated lipase</td>
<td>C C VC – – C VC VC</td>
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<tr>
<td>Hypophosphatemia</td>
<td>– C VC C VC C C</td>
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</tbody>
</table>

Note. Based on information from Giles et al., 2013; Kantarjian, Giles, et al., 2011; Larson et al., 2012.

Note. Adverse events that are not known are not possible to reliably estimate the frequency of these adverse events because of postapproval use.

ALT—alanine transaminase; AST—aspartate transaminase; C—common; GI—gastrointestinal; I—first-line therapy; II—second-line therapy; III—third-line therapy; NC—not common; NK—not known; PAH—pulmonary arterial hypertension; PAOD—peripheral arterial occlusive disease; R—rare; VC—very common

*Very common is greater than or equal to 10%; common is 1% to 9.99%; not common is 0.1% to 0.99%; and rare is less than 0.1%.

Elevated ALT or AST ranges from 0%–4% (Cortes et al., 2006; Deininger et al., 2009; Druker et al., 2006; Kantarjian et al., 2010; Kantarjian, (Continued)
Implications for Practice

- Recognize that chronic myeloid leukemia (CML) can be managed like a chronic condition with tyrosine kinase inhibitor (TKI) therapy, and patients are able to live longer.
- Educate patients on the disease and its treatment, as well as on their responsibility to care for themselves because of increasingly longer durations of treatment, heightening the chance of the ultimate success of TKI therapy for CML.
- Empower patients from the time of diagnosis to realize their ability to self-manage, encourage a high level of involvement in self-care, provide emotional support, and integrate patient goals for therapy into overall management.

Hochhaus, et al., 2011; Kantarjian, Shah, et al., 2012; Larson et al., 2012), so patients are more likely to experience a TKI-related side effect than a progression-related symptom. However, patients still should be taught to recognize the signs of progressive disease because they could trigger closer patient evaluation and timely implementation of necessary changes in therapy.

Implications for Nursing Practice

Oncology nurses can be advocates for patient empowerment in several ways. They can provide comfort, encouragement, and emotional support at the time of diagnosis, and give patients information on the disease, its treatments and side effects, resources to facilitate continuing patient self-education, as well as information on financial aid assistance. Oncology nurses also can encourage patients to participate in every aspect of their disease management (e.g., monitoring minimal residual disease, recognizing and self-treating mild side effects, preparing for clinic visits). Working with patients to inspire a stronger sense of personal responsibility for the direction and quality of care builds a solid partnership between the patient and healthcare provider, creating the feeling of a team working together to achieve the best outcomes.

Conclusion

A cancer diagnosis can have a profound effect on patient psychology. The manner in which patients respond to cancer diagnosis and treatment may affect their HRQOL. Patients who feel in control of their care and have the information they need to share in treatment decision making are empowered, and empowerment contributes to improved adherence and greater patient satisfaction with care.

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Given, B.A., Spoestra, S.L., & Grant, M. (2011). The challenges of...
oral agents as antineoplastic treatments. *Seminars in Oncology Nursing*, 27, 93–103. doi:10.1016/j.socn.2011.02.005


